



病人互助組織聯盟  
Alliance for Patients'  
Mutual Help Organizations



香港復康會  
The Hong Kong Society  
for Rehabilitation  
社區復康網絡  
Community Rehabilitation Network

# **Patient-Centered Healthcare (PCH) in Hong Kong**

## **- An Exploratory Study Report**

By

Alliance for Patients' Mutual Help Organizations (APMHO)

and

Community Rehabilitation Network of

The Hong Kong Society for Rehabilitation (CRN, HKSR)

December, 2012

# Table of Content

Acknowledgement.....	4
Executive Summary .....	6
Glossary of Terms .....	8
1. Introduction .....	10
1.1 The International Alliance of Patients' Organizations (IAPO).....	10
1.2 IAPO Declaration on PCH in 2006 .....	11
1.3 The Alliance for Patients' Mutual Help Organizations (APMHO) in Hong Kong .	12
1.4 Community Rehabilitation Network of Hong Kong Society for Rehabilitation...	13
1.5 An antecedent of the study .....	14
1.6 The Project.....	15
2. Methodology and Findings.....	17
2.1 Objectives of the Study .....	17
2.2 Phase 1 - Individual Questionnaire and Findings .....	17
2.3 Phase 2 - Telephone Interviews and Findings .....	24
2.4 Phase 3 - Focus Group Meetings and Findings .....	35
2.5 Summary of Findings.....	46
3. Analysis and Discussion on the Findings.....	48
3.1 Prioritization from APMHO's Perspective .....	48
3.2 Prioritization of individual patient organizations .....	49
4. Conclusions and Recommendations .....	51
4.1 Assessing maturity level in PCH .....	51
4.2 Short Term Actions.....	53
4.3 Mid-Term Recommendations .....	55
4.4 Long Term Plan .....	56
4.5 Review of Sections 4.2 to 4.4 in October and November 2012 .....	56

<b>4.6</b>	<b>Limitations</b> .....	61
<b>4.7</b>	<b>Way forward</b> .....	62
	<b>REFERENCE</b> .....	64
	<b>Appendices</b> .....	65
	Appendix 1 - User’s Perspectives on Patient-Centred Care .....	65
	Appendix 2 - Quantitative Survey Questionnaire (Individual) .....	66
	Appendix 3 - Phase 1 with 862 Individual Questionnaires .....	68
	Appendix 4 - Qualitative Survey Telephone Interview Guideline .....	69
	Appendix 5 - Phase 2 Telephone Interviews Summary .....	70
	Appendix 6 - Preliminary Report from Phase 1 and Phase 2 Powerpoint for APMHO on 27 March 2012 .....	71
	Appendix 7 - Revalidation by HKU Excel3 Project in August 2012 .....	71
	Appendix 8 - Phase 3 - Minutes of the two focus group meetings on 14 and 16 June 2012 .....	72
	Appendix 9 - Examples of CRN Research and Project Reports .....	87

## **Acknowledgement**

We are very grateful to the following individuals and collaborative organizations for making this study possible:

- The Alliance for Patients' Mutual Help Organizations (APMHO) and Community Rehabilitation Network (CRN) of the Hong Kong Society for Rehabilitation (HKSR) for co-organizing this exploratory study project.
- The EXCEL3 Project Team of The University of Hong Kong, Dr. Ben Law, Dr. Michelle Xue Bai and Mr. Jason Chan in the revalidation process of Phase 1 and 2; and Professor Cecilia Lai Wan Chan for her insightful review of this report.
- Dr. Leonard S. W. Li, Rehabilitation Consultant from Tung Wah Hospital, for his guidance and comprehensive review of this report.
- Mr. Anthony Wong of Braincare who helped us with the Phase 1 questionnaire design and provision of online input via Internet; and a few Phase 2 telephone interviews.
- Mr. Pun Yau Wai and Ms. Christine Leung of CRN, HKSR who served as the conduit to gather the Phase 1 individual questionnaire informants within 2 months.
- Dr. Edith Mok's MBA classmate Mr. Ezra Lau who tabulated the Phase 1 questionnaire survey results.
- Patient leaders and experts from over twenty Self-Help and Mutual Help Organizations from APMHO representing their own Executive Committees for their participations in the Phase 2 telephone interviews and Phase 3 focus group discussions.
- APMHO Executive Committee members for reviewing the Phase 1 and 2 results.
- Mr. Ng Hang Sau and Mr. Peter Poon of HKSR who reviewed the report and several CRN staff who have assisted to enrich the CRN portions of this report.

- Mr. K. P. Tsang, Chairman of APMHO, who co-authored the report with Dr. Edith Mok, Vice Chairman of HKSR. Dr. Mok, a stroke survivor, is the Project Manager of this study project while Mr. K.P. Tsang also serves as a reviewer of this report.

All the above contributors, named and unnamed, worked in different parts of the project with their own expertise and networks. As a result, we make a bigger whole. Our greatest heart-felt gratitude is extended to all.

## Executive Summary

The concept of patient-centred healthcare (PCH) commenced in 2004 globally through the International Alliance of Patients' Organization (IAPO). In 2005, the Alliance for Patients' Mutual Help Organizations (APMHO) consisting of 44 SHOs and approximately 40,000 members in Hong Kong became a member of IAPO. It is believed that by promoting great patient responsibility and optimal usage, PCH leads to improved health outcomes, quality of life, and optimal value of healthcare investment. In 2006, all IAPO members signed a Declaration on PCH which supports 5 principles: (1) Respect; (2) Choice and empowerment; (3) Patient involvement in healthcare policy; (4) Access and support; and (5) Information.

APMHO has amended its core Vision and Mission to formally adopt PCH in 2009 and has been streamlining its operation to focus on policy advocacy and closer networking with patients' organization. There are more representations of APMHO participating on healthcare issues and related committees and working groups in Hong Kong SAR Government and Hospital Authority.

In February 2012, a project "Patient-Centred Healthcare in Hong Kong – An Exploratory Study" was commissioned to examine the status of PCH in Hong Kong as the 20<sup>th</sup> Anniversary Special Publication of APMHO. This project is supported by APMHO and CRN, HKSR.

The PCH Exploratory Study is substantiated by 3 rounds of data collection:

Phase 1 - Individual Questionnaire to patients and caregivers (862 respondents)

Phase 2 - Telephone Interviews with 20 SHO's Executive Committee representatives

Phase 3 - Two Focus Group Meetings with 18 SHO's representatives from Phase 2

**Phase 1** was using a fixed-format questionnaire to inquire 723 patients and 139 caregivers (with 159 online respondents) about their perception on selective PCH-related questions. The investigation presented 3 major findings – **(a) Patients' involvement in the formulation of healthcare policy is an important part of PCH implementation in Hong Kong; (b) The waiting time and queuing system for the specialist consultation is unacceptable to most patients in the present HA system; (c) Caregivers require training on the caregiving knowledge and skills, and support from caregiving groups.**

**Phase 2** used several open questions to inquire about (1) the top 3 priorities that the current healthcare system has to tackle; (2) the top priority area in their own SHO disease group that has to be dealt with; and (3) the top priority task of their own SHO disease group that can be implemented in the next 5 years. After the revalidation process by the HKU EXCEL3 project team, the results were quite similar. The top priority areas for the healthcare system are: **(a) Lowering the patients' financial burden for medical expenses and other areas; (b) Improving service quality and service types, in particular the quantity and quality of the healthcare professionals; (c) Updating and enhancing the HA Drug Formulary System; (d) Strengthening the existing healthcare system; and (e) Enhancing the QOL for disabled and chronically ill patients.**

**Phase 3** involved 2 interactive discussions from 16 disease groups. The major concerns in the public healthcare system were: **(a) Reducing the financial burden of the chronically ill patients on the drug expenses; (b) Advocating the patients' right to know and make informed choices and to participate in the relevant healthcare policy-making; (c) Increasing the investment in healthcare resources under the appropriate priorities; (4) Enhancing self-management for patients and nursing/caring capabilities of the caregivers.** The SHOs specific needs and common concerns are documented in details in Section 2.4.4 to 2.4.11.

In conclusion, there are **13 Short term actions on Section 4.2** in response to Section 2.4.4 to 2.4.11 and 3.1 and 3.2 that can be worked on in the coming 5 years. There are **5 Mid-term Recommendations on Section 4.3** that will require cross-departmental and cross-bureau communication and agreements before decisions can be made. There are **3 Long Term Plan on Section 4.4** that will require one Bureau to take charge amongst many others.

As part of the review process in October and November, there are **8** clarification, elaboration and updates **to the Action Plan. This is deliberated in Section 4.5.** CRN has future collaboration plan with APMHO that will facilitate the Action Plan.

## Glossary of Terms

<b>A&amp;E</b>	Accidents and Emergency Departments of Hospital Authority
<b>APMHO</b>	The Alliance for Patients' Mutual Help Organizations
<b>CRN</b>	Community Rehabilitation Network, The Hong Kong Society for Rehabilitation
<b>EXCEL3</b>	"Capacity Building for Leaders of Self Help Groups in Hong Kong" Project, part of the Excellence and Capacity Building for Entrepreneurship and Leadership for the Third Sector Meta-Project, The University of Hong Kong. Refer to <a href="http://www.socsc.hku.hk/ExCEL3/project.shtml">http://www.socsc.hku.hk/ExCEL3/project.shtml</a> for more details.
<b>FHB</b>	Food and Health Bureau, Hong Kong SAR
<b>HA</b>	Hospital Authority, Hong Kong SAR
<b>HA Drug Formulary</b>	The HA-wide Standard Drug Formulary is set up to ensure equitable access to cost effective drugs of proven efficacy and safety, through standardization of drug policy and utilization in all HA hospitals and clinics. In this policy, the range, choice, classification and indication for the use of drugs will be clearly defined to ensure uniformity and equity across the settings.
<b>HKSR</b>	The Hong Kong Society for Rehabilitation
<b>IAPO</b>	The International Alliance of Patients' Organizations
<b>LWB</b>	Labor and Welfare Bureau, Hong Kong SAR
<b>PCH</b>	Patient-Centred Healthcare



<b>PwCC</b>	People with Chronic Condition
<b>PwD</b>	People with Disability
<b>QOL</b>	Quality of Life
<b>Samaritan Fund (for Drug Items)</b>	The Funding provides financial assistance to needy patients who require Privately Purchase Medical Items (PPMI) or new technologies in the course of medical treatment which are not covered in hospital maintenance or out-patient consultation fees in public hospitals and clinics.
<b>SHGs</b>	Self Help Groups, synonymous to Self Help Organizations
<b>SHOs</b>	Self Help Organizations
<b>SWD</b>	Social Welfare Department, Hong Kong SAR
<b>WHOCC</b>	World Health Organization Collaboration Centre for Rehabilitation

# 1. Introduction

For decades, healthcare systems have been focused around diseases and acute care. These paradigms are no longer adequate for the changing health problems in today's world. Until recent years, there is a shift towards patients in the healthcare sector in the developed countries of the world. This trend necessitated the set-up of an international organization of patients to join these evolutionary efforts together from the developed and developing countries. Thus the International Alliance of Patients' Organizations was formed.

## 1.1 The International Alliance of Patients' Organizations (IAPO)

IAPO is a patient-led global alliance of over 200 member organizations which span all world regions with over 50 countries and 50 disease areas. Through membership, IAPO represents an estimated 365 million patients. IAPO promotes patient-centred healthcare around the world (<http://www.patientsorganizations.org/>).

IAPO's origins stem from the realization that patients all face some common issues regardless of their country of origin or disease area such as access to treatment and care, the right to care that is safe, and the need for quality health information.

IAPO's role is built around the understanding that patients' voices are amplified and heard effectively when patients' organizations are linked and resources are connected to share best practices and practical strategies.

In 2004, IAPO conducted a consultation with its member patients' organizations investigating which healthcare policy issues were most important. 74% of respondents indicated that defining "patient-centred healthcare" (PCH) was very relevant to their organizations. Henceforth, IAPO developed a review paper on the concept of PCH and its basic principles in 2005.

Five Global Patients Congresses were held in 2005, 2006, 2008, and 2012(twice). Through these congresses, IAPO build up its capacity to enable patients' organizations to exchange their diverse experiences, resources and expertise; and is creating a stronger global support network. In the 2<sup>nd</sup> Global Patients' Congress held February 2006, the IAPO Declaration on PCH of 5 basic principles was launched.

## 1.2 IAPO Declaration on PCH in 2006

Health system requires the involvement of individual patients to adhere to their treatments, make behavioral changes, and self-manage. The essence of PCH is for the healthcare system to address healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective. By promoting greater patient responsibility and optimal usage, PCH leads to improved health outcomes, quality of life, and optimal value for healthcare investment.

To achieve PCH, IAPO believes in the following 5 principles (IAPO, 2012):

- (a) Respect** – Patients and caregivers give a fundamental right to PCH that respects their unique needs, preferences and values, as well as their autonomy and independence.
  
- (b) Choice and empowerment** – Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive healthcare service which provides suitable choices in treatment and management options that fit in with patients’ needs, and encouragement and support for patients and caregivers that direct and manage care to achieve the best possible quality of life. Patients’ organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.
  
- (c) Patient involvement in healthcare policy** – Patients and patients’ organizations deserve to share the responsibility of healthcare policy-making through meaningful supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patients at the centre. This should not be restricted to healthcare policy but include, e.g., social policy that will ultimately impact on patients’ lives.
  
- (d) Access and support** – Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care, and health promotion activities. Provisions should be made to ensure that all patients can access necessary services, regardless of their condition or socio-economic status. For

patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment, and family issues which impact on their approach to healthcare choices and management.

**(e) Information** – Accurate, relevant and comprehensive information is essential to enable patients and caregivers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities, and culture.

These principles encompass some of the same values that are enshrined in international law, based on human rights, participation and empowerment, and access and equity.

### **1.3 The Alliance for Patients' Mutual Help Organizations (APMHO) in Hong Kong**

The Alliance for Patients' Mutual Help Organizations (APMHO) was established in 1992 with the support from key organizations (the Hong Kong Society for Rehabilitation, the Hong Kong Medical Association, the Department of Social Work and Social Administration of the University of Hong Kong, the Hong Kong Joint Council of Rehabilitation, and the Hong Kong Council of Social Services) and 16 patients mutual help organizations serving patients with diabetes, renal failure, cancer, rheumatoid arthritis, lupus, asthma, etc. By 2012, it is a network of 44 patients-led organizations with approximately 40,000 patients in Hong Kong, representing more than 20 disease areas of which most can be classified as chronic illness or currently named under the UN and WHO as Non Communicable Diseases (NCDs). APMHO became a member of IAPO in 2005. Since 2006, APMHO has been promoting the concept of PCH to the government, healthcare sector, media and policy-makers. In 2009, APMHO amended its Constitution to formally adopt PCH as its core Vision and Mission, and has been streamlining its operations to focus on policy advocacy and closer networking of patients' organizations. As a result, there are more patient representatives sitting on advisory committees and working groups of Food and Health Bureau of the Hong Kong SAR Government and a few hospitals, and sporadic improvement in the drug usage through patients' influence.

Some of the major activities of APMHO were available on URL: <http://www.i-patients.org.hk/>. Two recent signature events were held for the

promotion of PCH. On 14 December 2007, a “Conference on People and Patient Centred Care” was organized by the School Of Public Health of the Chinese University of Hong Kong (CUHK), supported by the World Health Organization Collaboration Centre for Rehabilitation (WHOCC), IAPO and APMHO. On 19 October 2010, a “Symposium on Patient Communication” was organized by the School of Public Health of CUHK and APMHO in Prince of Wales Hospital, Shatin, Hong Kong.

The awareness of PCH is brought to certain population of Hong Kong over the last 5 years. However, the challenges remain to be insufficient understanding of PCH among patients and stakeholders, identification and engagement of patient experts, capacity building of patient leaders, and inadequate health literacy among the patients’ organizations.

#### **1.4 Community Rehabilitation Network of Hong Kong Society for Rehabilitation**

Community Rehabilitation Network (CRN), founded in 1994, is one of the key service units of the Hong Kong Society for Rehabilitation (HKSR). CRN has 6 service centres and is subvented by the Social Welfare Department (SWD) to provide community-based rehabilitation service for people with chronic illness and their family members.

CRN operates with two Divisions, namely, the Community Rehabilitation Service Division (CRSD) and the Patient Mutual Help and Support Division (PMSD). The former is to provide community-based rehabilitation programs including self-management courses, health talk and seminars, psycho-therapeutic groups, patient visitation programs, support services to caregivers, and social and recreational activities. The latter is to support and strengthen Self Help Organizations (SHOs) and mutual support groups, volunteer mobilization and promote community education.

CRN is operated by a multi-disciplinary team of professionals including social workers, registered nurses, physiotherapists, and occupational therapists. They liaise with other professionals such as doctors, dietitians, pharmacists, clinical psychologists to provide voluntary social and psychological support for people with chronic illness and caregivers.

The mission of CRN is to foster the spirit of self-help and mutual-support and to provide quality, innovative and diversified service to encourage people with chronic

illness and their families to live positively and to enhance their quality of life. CRN is to build up healthy life style in the community so as to develop a healthy and inclusive society. CRN serves the following chronic disease groups and people with disabilities:

Alzheimer's Disease	Glaucoma
Ankylosing Spondylitis	Haemophilia
Asthma	Parkinson's Disease
Brain Injury	Progressive Neuro-muscular Disease
Chronic Obstructive Pulmonary Disease	End Stage Renal Failure
Cardiac Disease	Rheumatoid Arthritis
Cleft Lip and Palates	Spina Bifida
Cooley Anaemia	Spinal Cord Injury
Diabetes Mellitus	Stroke
Epilepsy	Systemic Lupus Erythematosus
Crohn's & Colitis	Multiple Sclerosis
Mysasthenia Gravis	Mucopolysaccharidoses

The services provided by CRN can be generally classified as follows:

- Patient education and psychosocial support services;
- Patient self-management programs and mobilize peer led initiatives;
- Self-help and mutual aid groups;
- Networking and advocacy;
- Consultancy services for self-help groups;
- Community programs, including public education, indoor and outdoor rehabilitation programs; and
- Information and referral services.

CRN works closely with the SHOs and APMHO to facilitate their start-up, management, and development of functional activities. By 2012, CRN is affiliated with over 80 SHOs. 44 SHOs are being united under the umbrella of APMHO. Some of CRN's research projects are found in the **Appendix 9 – Examples of CRN Research and Project Reports.**

### 1.5 An antecedent of the study

The WHO Collaboration Centre for Rehabilitation organized the "Closer Exchange and

Partnership in the Advancement of Allied Health and Nursing Extended Roles Symposium (CEPA IV)” on 13 January 2012. HKSR is designated as WHOCC for Rehabilitation of West Pacific Region.

The CEPA IV Symposium was held in the Hospital Authority Head Office with an audience of about 200 healthcare professionals in Hong Kong. One of the keynote lectures was “**User’s perspectives on patient-centred care**”. Refer to **Appendix 1** – [http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix1-User's\\_PerspectivesonPatient-CentredCare-CEPASymposiumPowerpointof13Jan2012.ppt.pdf](http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix1-User's_PerspectivesonPatient-CentredCare-CEPASymposiumPowerpointof13Jan2012.ppt.pdf) for the presentation on 13 January 2012.

The speaker Dr. Edith Mok is a stroke survivor for 15 years. Apart from sharing her own illness experience with the audience illustrating how she rehabilitated physiologically and psychosocially, Dr. Mok also presented her recent learning of PCH, APMHO and IAPO. In addition, she exhibited a quick survey in relation to PCH service perceptions from 735 patients from APMHO and CRN, HKSR. The data was collected from 11 SHOs and 159 patients on-line through Internet from mid-December 2011 to early January 2012.

Since more data were coming from the SHOs after the presentation on 13 January, it was decided that the data would be reprocessed to see if the result would be the same.

For 2012-2013, APMHO is celebrating its 20<sup>th</sup> Anniversary. The Chairman of APMHO and Dr. Edith Mok agreed to turn this presentation into a collaborative study project, and make this a signature contribution for the anniversary as joint effort of APMHO and HKSR.

## **1.6 The Project**

The “Patient-Centred Healthcare (PCH) in Hong Kong – An Exploratory Study” project was formulated in early February 2012. An empirical research methodology was introduced to make this project more meaningful. Thus a three-throng approach was adopted:

- Phase 1 – Individual questionnaire were collected from paper and on-line input. This came from patients and caregivers from APMHO and CRN from December

2011 to January 2012.

- Phase 2 – Telephone interviews with representatives from SHOs who were willing to join. 20 SHOs from the 44 SHOs in APMHO showed interest and participated. The interviews were conducted between February and March 2012.
- Phase 3 – Focus Group Discussions from the same SHOs of Phase 2 were invited. 18 of the 20 SHOs participated in the 2 meetings scheduled in June 2012.

The EXCEL3 Project Team of The University of Hong Kong (HKU) was invited to revalidate Phase 1 and 2 for its validity and reliability in April 2012.



## 2. Methodology and Findings

The project was started in February 2012. It was a close collaboration of APMHO and CRN, HKSR with support from the HKU EXCEL3 Project Team.

PCH has been known to the patients' organizations and healthcare professionals to some degree in the last few years. It is a concept being gradually accepted yet it takes time to understand and implement as it is influenced by many factors and a multitude of stakeholders.

To move further down the implementation path, there is a need to develop a comprehensive and deeper understanding of PCH from the patients' perspective and to advocate with a priority in mind to the stakeholders of the healthcare system.

With the above perspective, the aim of this exploratory study is to identify the long term plans and short term measures to accomplish the mission of advocacy to the public healthcare system and other related systems by APMHO.

### 2.1 Objectives of the Study

- (a) To examine and aggregate the existing patients' experience in their disease areas;
- (b) To develop comprehensive and deeper understanding of PCH among patients' organizations; and
- (c) To identify priority areas for APMHO advocacy movements.

### 2.2 Phase 1 - Individual Questionnaire and Findings

2.2.1 There were a total of 862 individual questionnaires collected in mid-December 2011 – mid-January 2012, with 688 (80%) from patients, 139 (16%) caregivers and 35 (4%) unidentified. 703 (82%) questionnaires came through paper and 159 (18%) came from on-line sources. More than half of the questionnaires were collected at the SHO's Christmas parties as this would be the maximum turnout times of the year. The questionnaire is provided in **Appendix 2 – Quantitative Survey Questionnaire (Individual)**.

2.2.2 Among the 862 completed questionnaires, 492 (57%) were under the age

of 60 whereas 339 (39%) aged 60 or above. On the other hand, 355 (41%) were male whereas 498 (58%) were female.

2.2.3 The reported chronic conditions or illness are as follows: brain trauma (24%); neurology (15%); rheumatology (17%); visceral disability (e.g. renal failure, chronic heart disease) (9.3%); spinal injuries (4.3%); visual or hearing impairment (3%); mental illness (4%); oncology (3%); and others (2.6%).

2.2.4 As for their self-care ability level, 36 (4%) rated themselves as dependent; 348 (41%) rated themselves as partially dependent; and 467 (55%) rated themselves as independent. In addition, 9 (1%) participants rated their mobility level as bed-bound; 286 (33%) rated themselves as assistance needed when walking; and more than half (65%) stated that they could walk without any aid.

2.2.5 **Ratings of Patients and Caregivers on PCH services in Hong Kong** - A 6-item form of PCH were used. Informants are requested to rate their subjective experiences of the following items three times, i.e. five years ago, present and future expectation in the next 5 years. The six items are:

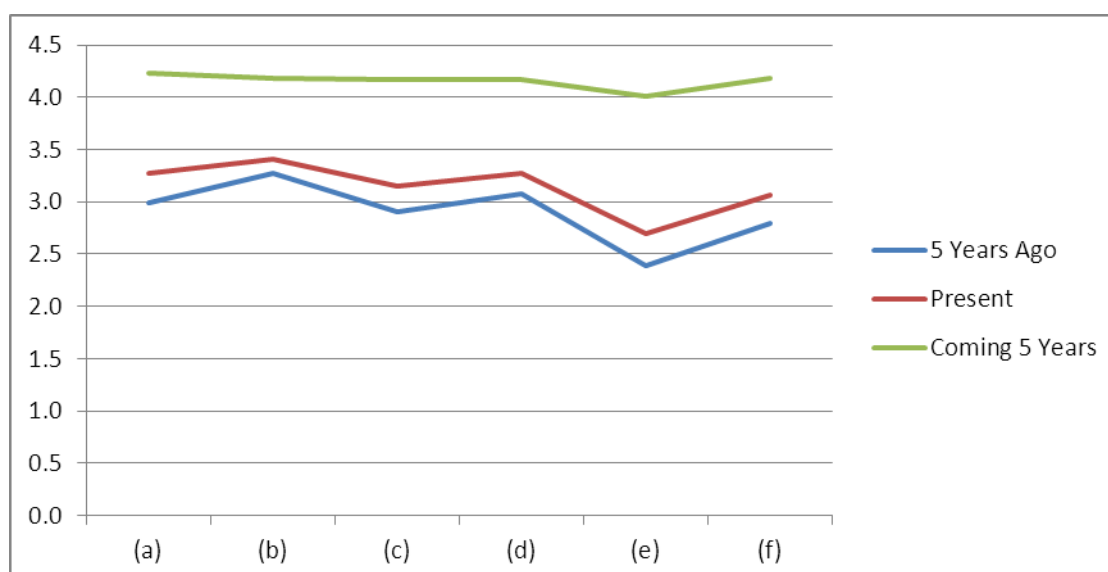
- (a) Patients' right and access to information (disease progress, treatment methods, etc.);
- (b) Healthcare Professionals' (HCP) attitude (respect and courtesy) towards patients and family members;
- (c) Patient and his/her families' right of choices to treatment methods;
- (d) HCP's caring and encouragement to patients;
- (e) Patient involvement in the formulation of healthcare policy; and
- (f) Relevant social resources and information for the Disease Group from HCPs and social workers.

### Average of the 862 informants

Rating is 1 – 5, with 1 being the Worst and 5 being the Best

Chronically ill/Caregiver's rating to PCH services in Hong Kong	5 Years Ago	Present	Coming 5 Years
(a) Patients' right and access to information (disease progress, treatment methods, etc.)	3.0	3.3	4.2
(b) HCP's respect and courtesy towards patients and family members	3.3	3.4	4.2
(c) Patient and their families' right of choices to treatment methods	2.9	3.2	4.2
(d) HCP's caring and encouragement to patients	3.1	3.3	4.2
(e) Patient involvement in the formulation of healthcare policy	2.4	2.7	4.0
(f) Relevant social resources and information for the Disease Group from HCPs and social workers	2.8	3.1	4.2

### Chronically ill/Caregiver's Rating to PCH services in Hong Kong



**Observation 1:** There is an optimistic perspective on the future which will be better than now, and the current situation better than 5 years ago. That is to say, patient leaders in the various patients mutual help organizations are having high expectation for HA and the current leadership of the HKSAR Government to have patients involved in the healthcare policy. The item on (e) Patient involvement in the formulation of healthcare policy is rated 2.4, 2.7, and 4.0 for 5 years ago, present and

in the next 5 years respectively meaning that this may be an area which APMHO has to build up capacity to be able to participate effectively in the healthcare policy formulation.

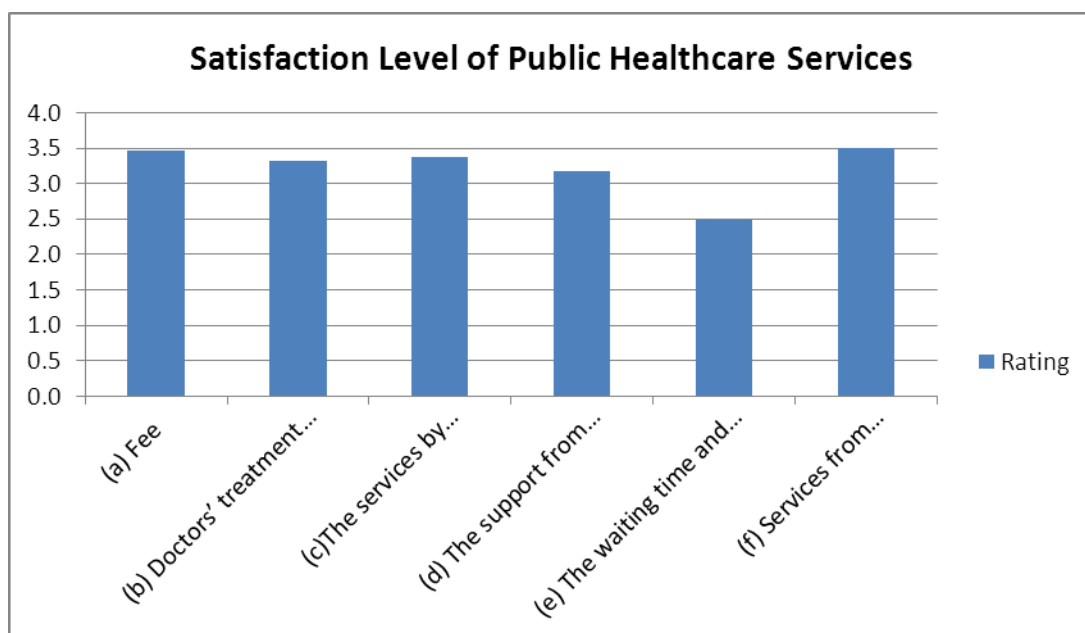
**2.2.6 Satisfaction Level of Public Healthcare Services in Hong Kong** - For the satisfaction level towards current public healthcare services in Hong Kong, informants are requested to rate the current services in terms of:

- (a) Fee;
- (b) Doctors' treatment quality;
- (c) The services by paramedical professionals;
- (d) The support from medical social services;
- (e) The waiting time and queuing system; and
- (f) Services from rehabilitation agencies and self-help groups.

Average of the 862 informants

Rating is 1-5, with 1 being Very Unsatisfied and 5 being Very Satisfied

Satisfaction Levels to Public Healthcare Services in Hong Kong	Average Rating
(a) Fee	3.5
(b) Doctors' treatment quality	3.3
(c) The services by paramedical professionals	3.4
(d) The support from medical social services	3.2
(e) The waiting time for a specialist consultation and queuing system	2.5
(f) Services from rehabilitation agencies and self-help groups	3.5



**Observation 2:** In general, the overall satisfaction level of services that patients rated are high, almost all items except one, obtained an average rating above 3. For the item with an average rating of 2.5, it is indicative that the (e) waiting time and queuing system of the specialist consultancy is much below expectation. This is an area which APMHO should advocate and demand urgently for improvement from Hospital Authority's priority for prompt action.

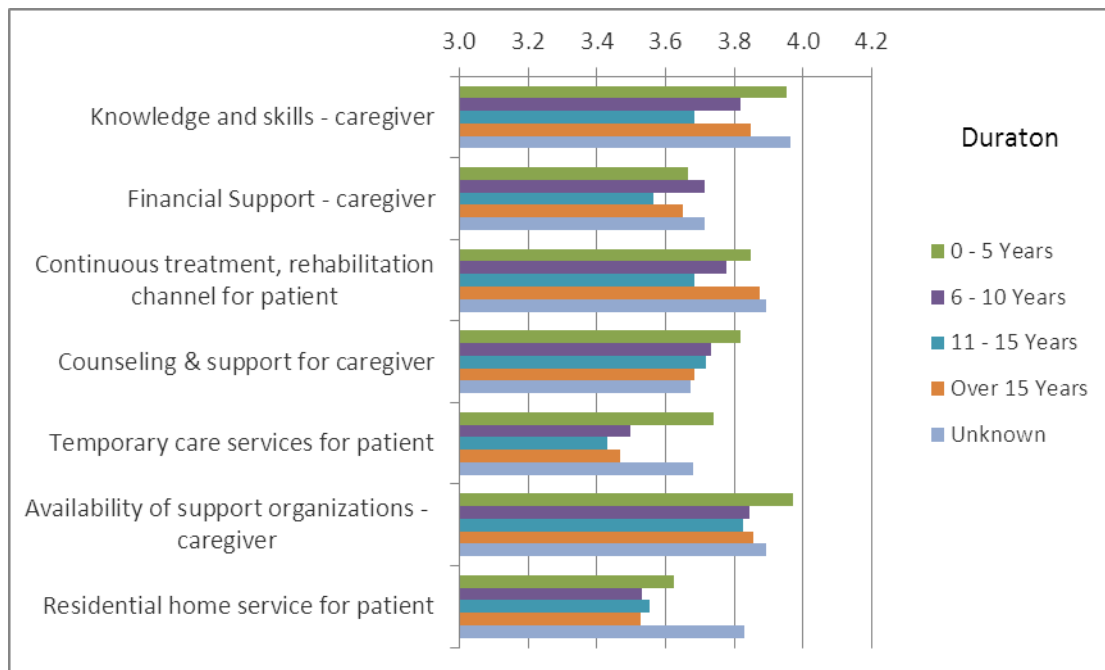
2.2.7 **Caregivers' Desirable Services and Support** - This particular section is on caregiver's needs from their perspective, to be segregated by disease duration of the respective patients.

Average of 139 caregivers

Rating is 1-5, with 1 being no need and 5 being imminent need

Caregiver's Desirable Service & Support / Duration of Patient Since Diagnosis	0 - 5 Years	6 - 10 Years	11 - 15 Years	Over 15 Years	Unknown
Knowledge and skills - caregiver	4.0	3.8	3.7	3.8	4.0
Financial Support - caregiver	3.7	3.7	3.6	3.7	3.7
Continuous treatment, rehabilitation channel for patient	3.8	3.8	3.7	3.9	3.9
Counseling & support for caregiver	3.8	3.7	3.7	3.7	3.7
Temporary care services for patient	3.7	3.5	3.4	3.5	3.7
Availability of support organizations - caregiver	4.0	3.8	3.8	3.9	3.9
Residential home service for patient	3.6	3.5	3.6	3.5	3.8

### Caregivers' Desirable Service and Support



**Observation 3:** Generally, the ratings exceed 3.5 which indicate strong desires from the caregivers to acquire the 7 named services, especially for disease knowledge and skills acquisition for caregivers plus the availability of support organizations. Caregivers of patients who are recently diagnosed (under 5 years) expressed higher level of needs at almost all levels.

#### 2.2.8 Narrative Comments

Nineteen narrative comments were received from the 862 questionnaires. Refer to **Appendix 3 – Phase 1 with 862 Individual Questionnaires** from over 11 Self-Help Organizations from mid-Dec 2011 to mid-Jan 2012, Pages 15-18 of <http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix3-Phase1with862IndividualQuestionnairesfromover11Self-HelpOrganizations-20120916.pdf>. The comments are related to:

- (a) Improvements in quality and cost-effectiveness of the Public Healthcare System;
- (b) Insufficient community resources for the rehabilitants, e.g. rehabilitation centres, treatment options, social support centres, SHO's resource support,

- etc.;
- (c) Insufficient awareness and inadequacy of disabled accessibility options; and
  - (d) Insufficient awareness of patients' and family members' rights on treatment choices.

**Observation 4:** The 3 pages of comments uncovered a variety of spectrums for improvements in the present healthcare system and other related systems such as social welfare, transport, and equal opportunities, etc. Some forms of prioritization in urgency and importance must be recognized to address the issues.

**2.2.8 Summary:** This survey is a quick polling from the patients and caregivers from APMHO and CRN through 11 selected disease groups and randomly from 159 members through on-line Internet survey. As the concept of PCH is relatively shallow among most patients and caregivers, this general survey has served its purpose by educating a wider audience on PCH and identifying some issues for the next step to follow on.

The variations do not show a significant change among the demographics. Details of the demographics and charts can be referred to **Appendix 3:** <http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix3-Phase1with862IndividualQuestionnairesfromover11Self-HelpOrganizations-20120916.pdf>, **Phase 1 with 862 individual questionnaires** from over 11 self-help organizations collected in Dec 2011 to Jan 2012.

The **4 observations** in Sections 2.2.5 – 2.2.8 highlight the following:

- (a) Observation 1 – the patients' involvement in the formulation of healthcare policy is an important part of PCH implementation in Hong Kong;
- (b) Observation 2 – the waiting time and queuing system for the specialist consultation is unacceptable to most patients in the present HA system;
- (c) Observation 3 – caregivers require training on the caring knowledge and skills and support from caring groups;
- (d) Observation 4 - the comments received are diverse and require further understanding by disease groups.

Viewing that there are a mass of spoken and unspoken messages from the patients, Phase 2 and 3 were planned to unveil those issues that deserve action-taking. Besides, this is a good opportunity to learn more about the urgent and important

healthcare issues both in the APMHO and the stakeholders to reach another deeper level of PCH understanding.

### 2.3 Phase 2 - Telephone Interviews and Findings

2.3.1 There were a total of 20 SHO representatives being interviewed by telephone from 22 February – 22 March 2012. Each interview took about 1 – 4 hours based on the **Appendix 4 – Qualitative Survey Telephone Interview Guideline**. Each SHO was asked to nominate a member from their Executive Committee for the interview. This member would represent the SHO's Executive Committee response to the questions being asked. The responses would be documented by the interviewer and returned to the respondent for verification with the SHO's Executive Committee. The verified responses would be the official responses to the questions.

2.3.2 The **20 SHO representatives** interviewed were:

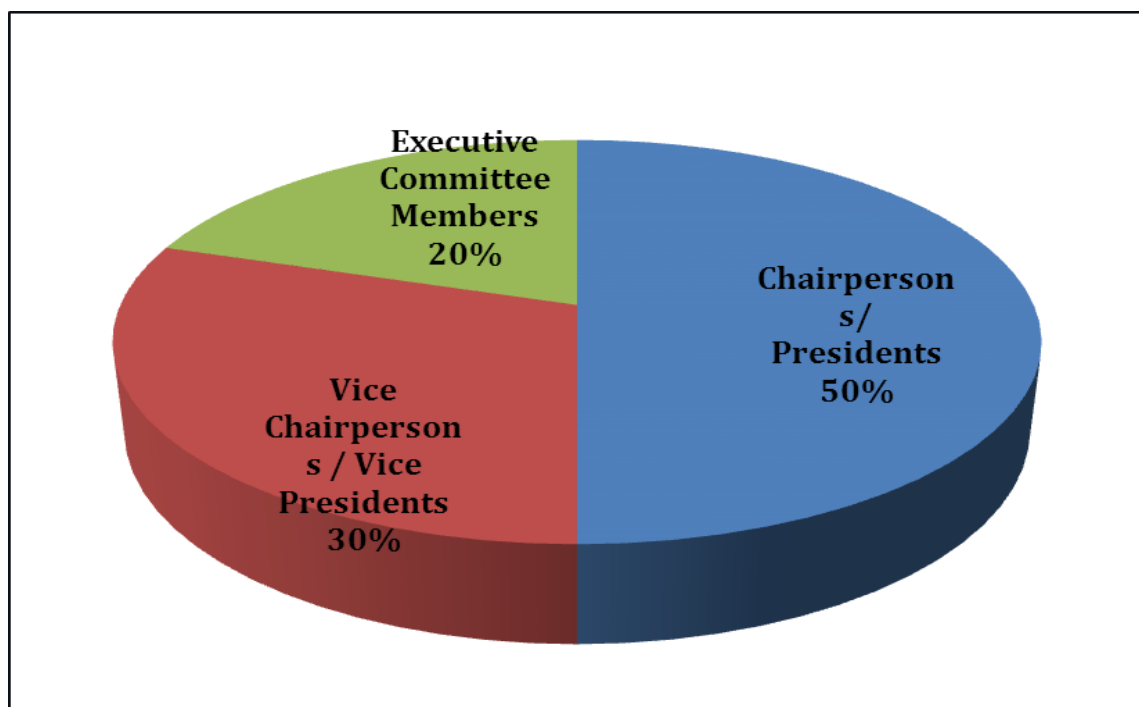
SHO in English	SHO in Chinese	Representative in SHO
1. Amity Mutual-Support Society	恒康互助社	狄國發(執委)
2. B27 Association	B27 協進會	鄺顯強(主席)
3. Direction Association for the Handicapped	路向四肢傷殘人士協會	羅偉祥(副主席)
4. Hong Kong Ankylosing Spondylitis Association	香港強脊會	林韋雄(主席)
5. Hong Kong Association of Squint and Double Vision Sufferers	香港斜視重影病患者協會	朱艷珍(會長)
6. Hong Kong FamilyLink Mental Health	香港家連家精神健康倡導協會	彭淑賢女士(主席)
7. Hong Kong Lupus Association	樂晞會	黃金鳳(主席)
8. Hong Kong Neuro-Muscular Disease Association	香港肌健協會	劉偉明(副主席)
9. Hong Kong Rheumatoid Arthritis Association	毅希會	葉志強(副主席)
10. Hong Kong SARS Mutual Help Association	香港沙士互助會	林志紬(會長)
11. Hong Kong Spinocerebellar Ataxia	香港小腦萎縮症	曹綺雯(副主席)



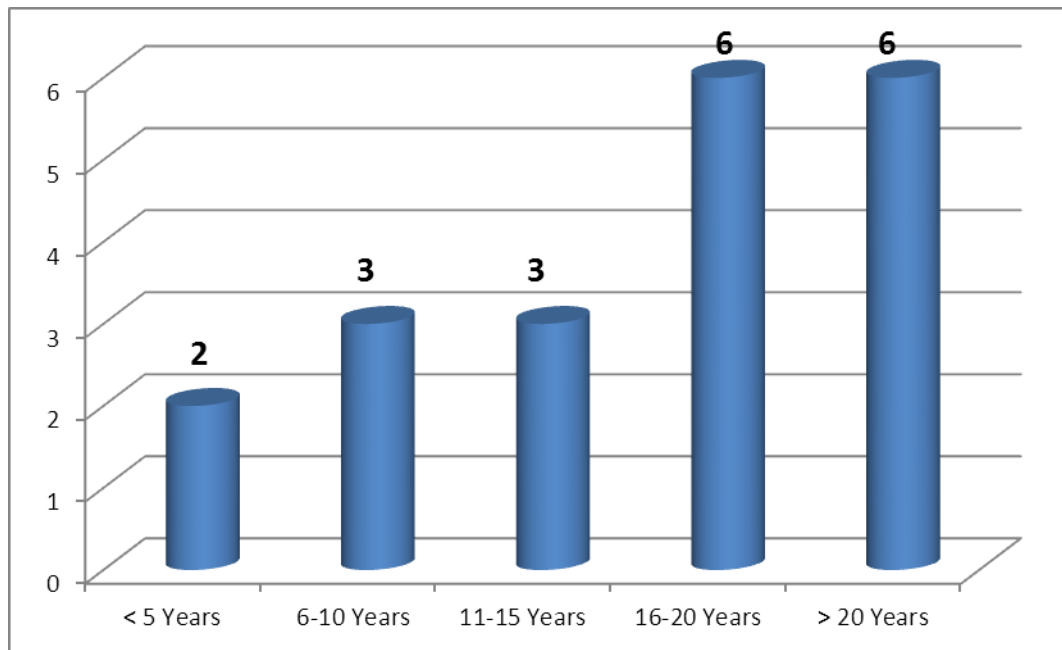
Association	協會	
12. Hong Kong Stroke Association	新健社	劉劍雄(主席)
13. Kin Lok Club	健樂社	梁耀開(外務)
14. Neuro United	腦同盟	周偉良(主席)
15. Renal Companion Association	腎之友	何愛英(主席)
16. Retina Hong Kong	香港視網膜病變協會	譚世鴻(社會政策)
17. Self Help Group for The Brain Damaged	慧進會	袁少林(主席)
18. The Hong Kong Asthma Society	香港哮喘會	陳永佳(義務秘書)
19. The Hong Kong Liver Transplant Patients' Association	香港肝臟移植協會	梁健平(副會長)
20. The New Voice Club of Hong Kong	香港新聲會	鄭植宏(副會長)

The positions represented by the SHO's executive committees and history of the SHO are graphically presented below:

Proportion of SHO's Representation



### Number of SHO's – by Years in Operation



#### 2.3.3 The **Telephone Interview Guideline** had two content sets:

(a) Each SHO was asked about their attributes:

- Patient organization name
- Representative name and role in the Executive Committee
- Disease Group
- Size of the SHO, Size of the Executive Committee
- No. of years – since SHO was established
- Date interviewed

(b) Each SHO was asked the following questions using an open format:

- (1) Do you think Hong Kong has made progress in PCH in the last 5 years from your disease group's perspective? Indicate in a scale of 1 - 5; 1 being no progress, 3 being average, 5 being excellent progress.
- (2) In general, what are the top 3 priority areas that the Healthcare System in Hong Kong must work on in the next 5 years?
- (3) In your disease group, what is the top priority area that the Healthcare System in Hong Kong must work on?
- (4) In your disease group, what is the top priority task (smaller than priority area) that can be implemented?

(5) Other comments for: (a) Healthcare System in Hong Kong; (b) Your specific disease group; (c) Others

(c) The qualitative analysis of questions 1, 2, 5(a) was located at **Appendix 5 – Phase 2 Telephone Interviews Summary** with 20 Self-Help Groups

**[1] Profile of respondents and Analysis of Questions 1, 2, 5(a)**

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix5-Phase2TelephoneInterviewsSummary-ProfileofRespondentswithQ1,2,5a-20120324.pdf>; and

**[2] Analysis of Questions 3, 4, 5(b) and (c)**

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix5-Phase2TelephoneInterviewsSummary-ProfileofRespondentswithQ3,4,5b&c-20120324.pdf>.

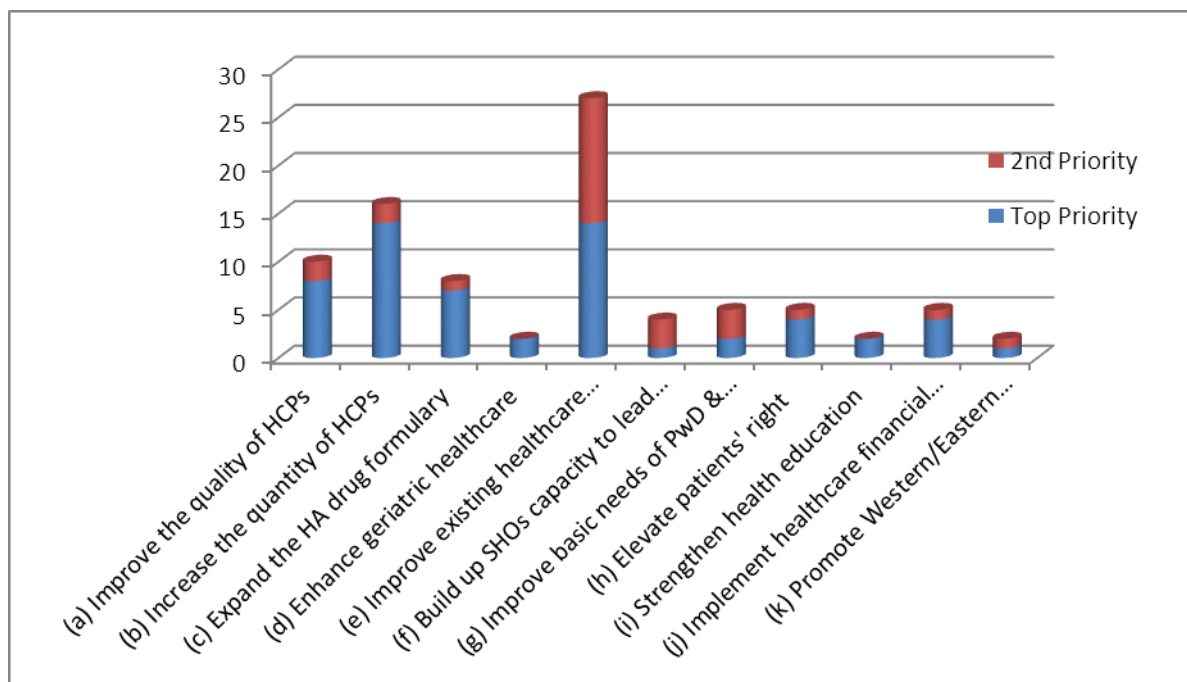
2.3.4 The **3 key questions** were asked in hierarchical order of (1) 3 priority areas in the Hong Kong **Healthcare Service in Q2 and Q5 (a)**; (2) top priority area in the **SHO disease group** that the Healthcare Service must work on in **Q3**; and (3) the **top priority task in the SHO disease group** which are **more implementable within 5 years** in **Q4**. The result was: 59 top priority areas (from Q2), 28 priority areas by individual disease groups (from Q3), 26 priority tasks by individual disease groups (from Q4) were described with duplicating and overlapping meanings in the responses. This is conceivable because the disease groups' concerns are often alike in the healthcare system at different levels and by various disease groups. Nonetheless, these were consolidated and prioritized accordingly to the total frequency mentioned by the SHOs.

Analysis of the quantitative summary of concerns by individual question can be located at **Appendix 5 – Phase 2 Telephone Interviews Summary** with 20 Self-Help Groups from Q2-5 **Quantitative Summary of Concerns by Questions via** <http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix5-Phase2TelephoneInterviewsSummary-QuantitativeSummaryofConcernsbyQuestions-20120324.pdf>

Questions 2 and 5 (a) – 3 Top Priority Areas in the HK Healthcare Service

Priority Areas in Healthcare System	Q2	Q5a
	Top Priority	2nd Priority
(a) Improve the quality of HCPs	8	2
(b) Increase the quantity of HCPs	14	2
(c) Expand the HA drug formulary	7	1
(d) Enhance geriatric healthcare	2	0
(e) Improve existing healthcare system	14	13
(f) Build up SHOs capacity to lead & manage	1	3
(g) Improve basic needs of PwD and PwChronic Conditions	2	3
(h) Elevate patients' right of choice and involvement in Healthcare policy-making	4	1
(i) Strengthen health education	2	0
(j) Implement healthcare financial assistance plan	4	1
(k) Promote Western/Eastern treatment method	1	1

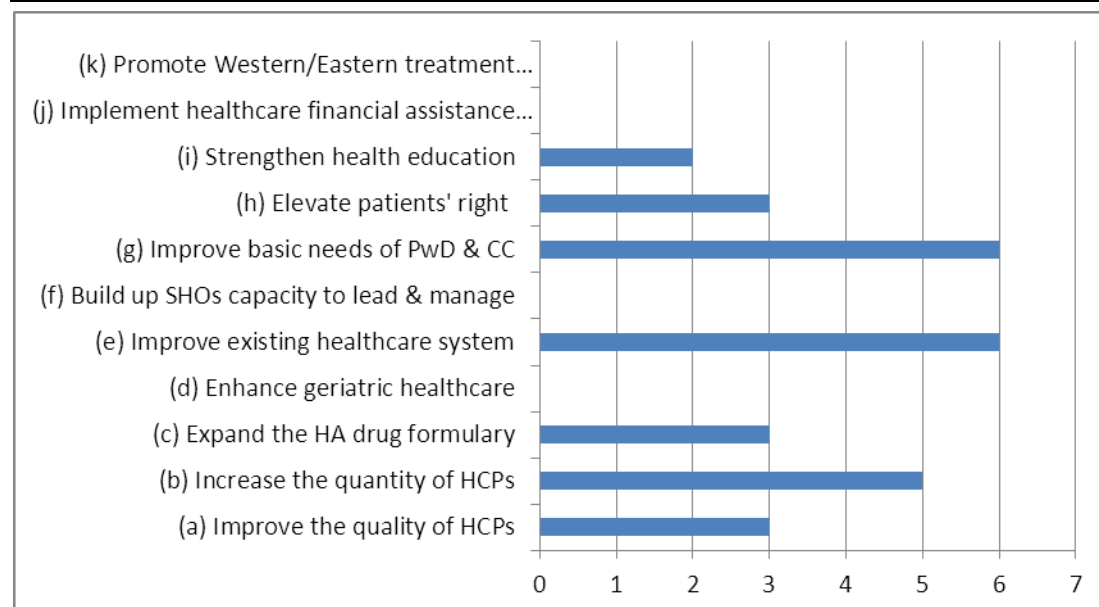
**Blue** being Q2 total top priority total, **RED** being Q5 (a) 2<sup>nd</sup> priority total



**Observation 1** – the top priority areas of the healthcare service are (1) improving the quantity and quality of healthcare professionals; and (2) strengthening of the existing healthcare system.

Question 3 – Top Priority Area by Individual SHOs

Top Priority by individual SHOs	Q3
(a) Improve the quality of HCPs	3
(b) Increase the quantity of HCPs	5
(c) Expand the HA drug formulary	3
(d) Enhance geriatric healthcare	0
(e) Improve existing healthcare system	6
(f) Build up SHOs capacity to lead & manage	0
(g) Improve basic needs of PwD and PwChronic Conditions	6
(h) Elevate patients' right of choice and involvement in Healthcare policy-making	3
(i) Strengthen health education	2
(j) Implement healthcare financial assistance plan	0
(k) Promote Western/Eastern treatment method	0

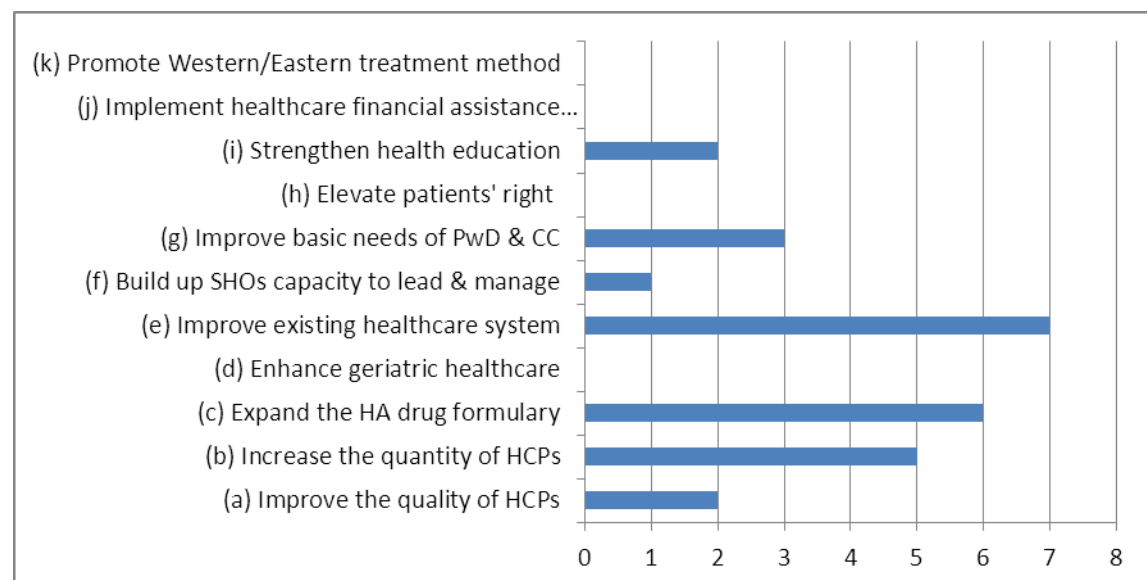


**Observation 2** – The top priority areas of SHOs from various disease groups are (1) enhancing the quality of life (QOL) for persons with disability (PwD) and persons with chronic health conditions; and (2) strengthening the existing healthcare system. A

further observation is that the SHOs view that enhancing the SHOs functions (internal) is less important than the external environment like the QOL of PwD and persons with chronic health conditions and the healthcare system. In fact, the enhancement of SHOs can somehow improve the QOL and is a means to achieve the objective.

Question 4 – Implementable Task within the next 5 years

<b>Implementable Tasks by individual SHOs</b>	<b>Q4</b>
(a) Improve the quality of HCPs	2
(b) Increase the quantity of HCPs	5
(c) Expand the HA drug formulary	6
(d) Enhance geriatric healthcare	0
(e) Improve existing healthcare system	7
(f) Build up SHOs capacity to lead & manage	1
(g) Improve basic needs of PwD & PwCC	3
(h) Elevate patients' right	0
(i) Strengthen health education	2
(j) Implement healthcare financial assistance plan	0
(k) Promote Western/Eastern treatment method	0



**Observation 3** – The implementable tasks within the next 5 years are: (1) improving the quantity and quality of healthcare professionals; (2) enhancing the existing healthcare system; (3) updating and expanding the HA Drug Formulary.

### 2.3.5 Feedback from the Executive Committee Meeting of APMHO

The result of Phase 1 and 2 was presented to the Executive Committee on 27 March 2012. Refer to **Appendix 6 – Preliminary Report from Phase 1 and Phase 2 PPT for APMHO of 27 March 2012:**

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix6-PreliminaryReportfromPhase1andPhase2PowerpointforAPMHO-20120327.pdf>.

A total of 23 SHOs were present. 17 SHOs provided their immediate feedback after the presentation. The comments were summarized as follows:

- (a) The presentation was educational for the SHOs. Unity is power and this was demonstrated in this study;
- (b) The subject of alternative medicine and combination of Eastern and Western medical treatment was brought up. This is a broad subject to be studied and understood;
- (c) Self-management and preventive measures of the diseases are crucial. The Government should allocate more resources to encourage more programs related to these 2 themes to be developed and implemented;
- (d) Hydrotherapy is vital to the Rheumatoid Arthritis (RA) patients. The supply side is only satisfying less than 10% of the demand. There must be measures to bring the supply of facilities closer to the demand;
- (e) The Government should invest more in public health education on various diseases for prevention from young age;
- (f) Different SHOs could have different levels and angles of understanding in PCH. There must be a means to establish targets to measure the outcomes periodically to track its progress;
- (g) Stable mental disease rehabilitants should have certification to be eligible for employment; and

- (h) There are insufficient patient leaders and experts in APMHO members to be distributed in the districts and HA committees. Some patient experts have to cross over other functional areas to serve.

These comments are invaluable to APMHO. Some of them will be put into actions in the next 5 years.

2.3.6 Revalidation by the EXCEL3 Project Team of The University of Hong Kong (HKU) was performed after the presentation of Phase 1 and 2 results in the subsequent Executive Committee Meeting of APMHO on 29 May 2012. The revalidation was reported in August 2012 and can be accessed via **Appendix 7 – Revalidation by HKU EXCEL3 Project Team in August 2012:** <http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix7-RevalidationbyHKU20120824tidy.pdf>.

The summarized responses to the revalidation report are as follows:

- (a) Use of 3 different terms for top priority areas for healthcare system, top priority for disease group, and implementable task within the next 5 years caused some confusion with the interviewees – The 3 terms were translated from English to Chinese for ease of administering the interview as 課題 (major areas in the healthcare system in general)、範疇 (domain in the healthcare system as perceived by the disease group)、項目 (implementable tasks as perceived by the disease group). It was explained to the interviewees over the telephone and should be understood by the interviewees. The reason for duplication in Q2 and Q3 could be arisen from the different views by different disease groups and some of them viewed the same priority areas in both the healthcare system and the SHOs disease groups.
- (b) Use of two interviewers – The interviews of 20 SHOs had to be completed in 1 month. There was limited time to train the interviewers. It is hard to find interviewers who have the knowledge and experience to ask the appropriate questions to prompt the interviewees for open-ended questions. It was agreed that experienced interviewers should be recruited ahead of time for the future.
- (c) Subjective views from interviewees – It was possible that the interviewees could subconsciously give his/her answers accordingly to his/her thinking.



However, the verification process with the Executive Committees could be one way of correcting this from happening.

The Revalidation Team regrouped Q2, 3, and 4 to form an alternative view of the priority areas by renaming them as Major, Domain, and Tasks.

Major areas, domains and tasks that the current Healthcare System should work on in descending order:

	Item	Major area	Domain	Tasks	Total counts
1.	Lower patient's financial burden for medication and other areas	8	9	11	28
2.	Increase the number of medical professionals	15	7	3	25
3.	Ensure and raise the service quality and type of service	8	3	7	18
4.	Reduce the waiting time of follow-up consultation	8	3	3	14
5.	Promote the patient's right in information, participation in policy-making and other related rights	8	2	1	11
6.	Enhance the self-help ability of the patients, and the ability and capacity of their caregivers	5	2	2	9
7.	Settle the Healthcare Financing Reform	4	-	3	7
8.	Implement strategies to promote "Prevention is better than cure" ideology to the Public in a wider scope and scale	4	2	-	6
9.	Seek solutions in healthcare issues related to <b>ageing</b> and address relevant long term healthcare burden	4	-	-	4
10.	Pay attention to some rare disease groups about their needs and difficulties	-	1	1	2
11.	Reactivate the promise of the government for taking care of the HKSAR patients	-	1	1	2
12.	Educate the public on organ donation	-	-	1	1

13. Expand the service types of public healthcare system	-	1	-	1
14. Synchronize the drug labeling system and make it more user-friendly to PwD	-	1	-	1
15. Improve the air quality of hospitals and the environment	-	1	-	1
16. Promote integration of both Chinese and Western medical treatment	1	-	-	1

**Observation 4** – By regrouping the 3 levels of priority areas horizontally (i.e. for healthcare system only), the Revalidation Team came up with: (1) lowering the patients’ financial burden for medication and other areas; (2) increasing the quantity of healthcare professionals; (3) improving the service quality and types of service offered; and (4) reducing the waiting time of follow-up specialist consultation.

2.3.7 **Summary:** This qualitative study was exploratory in nature. According to the 4 observations, the results through hierarchical and horizontal methods did come to identical priority areas.

Using the hierarchical method, the top priority areas for the healthcare system are:

- (a) Improving the quantity and quality of the healthcare professionals;
- (b) Strengthening of the existing healthcare system;
- (c) Enhancing the quality of life for the PwD and persons with chronic health conditions; and
- (d) Updating and expanding the HA Drug Formulary.

Using the horizontal method, the top priority areas for the healthcare system are:

- (a) Lowering the patients’ financial burden for medication and other areas;
- (b) Increasing the quantity of healthcare professionals;
- (c) Improving the service quality and types of services offered; and
- (d) Reducing the waiting time of follow-up specialist consultation.

This interviewing technique was the first encounter with the interviewees. It was a cold start and could serve as an ice-breaker of the PCH study. All in all, this presented the areas of concerns from the SHOs. A more in-depth focus group meeting would give the same group of interviewees a face-to-face meeting to share their concerns together and fill in more contents than the one-to-one telephone

interviews.

## 2.4 Phase 3 - Focus Group Meetings and Findings

2.4.1 Two focus group meetings were held in the evening of 14 June (1) and morning of 16 June 2011 (2), each taking 2 hours. The minutes were taken verbatim. Refer to **Appendix 8 – Phase 3 - Minutes of the two focus group meetings on 14 and 16 June 2012.**

2.4.2 The representatives from **18 SHOs participated:**

Focus Group	SHO in English	SHO in Chinese	Representative in SHO
1	1. Amity Mutual-Support Society	恒康互助社	狄國發(執委)
1	2. Hong Kong Association of Squint and Double Vision Sufferers	香港斜視重影病患者協會	朱艷珍(會長)
1	3. Hong Kong Lupus Association	樂晞會	黃金鳳(主席)
1	4. Hong Kong Neuro-Muscular Disease Association	香港肌健協會	劉偉明(副主席)
1	5. Hong Kong Rheumatoid Arthritis Association	毅希會	葉志強(副主席)
1	6. Hong Kong Spinocerebellar Ataxia Association	香港小腦萎縮症協會	曹綺雯(副主席)
1	7. Hong Kong Stroke Association	新健社	劉劍雄(主席)
1	8. Kin Lok Club	健樂社	梁耀開(外務)
1	9. Neuro United	腦同盟	周偉良(主席)
1	10. Self Help Group for The Brain Damaged	慧進會	袁少林(主席)
1	11. The Hong Kong Liver Transplant Patients' Association	香港肝臟移植協康會	梁健平(副會長)
1	12. The Hong Kong Pioneers Mutual Support Association	香港創域會	伍佩玲女士
1	13. The New Voice Club of Hong Kong	香港新聲會	鄭植宏(副會長)
2	14. Direction Association for the Handicapped	路向四肢傷殘人士協會	羅偉祥(副主席)
2	15. Hong Kong Ankylosing Spondylitis	香港強脊會	林韋雄(主席)

	Association		
2	16. Hong Kong FamilyLink Mental Health	香港家連家精神健康倡導協會	彭淑賢女士(主席)
2	17. Renal Companion Association	腎之友	何愛英(主席)
2	18. Retina Hong Kong	香港視網膜病變協會	譚世鴻(社會政策)

2.4.3 The following **disease groups** are represented in the focus groups:

Disease Groups in English	Disease Groups in Chinese
1. Psychiatric Rehabilitation	精神康復
2. Laryngeal Carcinoma	喉癌
3. Liver transplant	肝臟移植
4. Strabismus ghosting	斜視重影
5. Rheumatoid Arthritis (RA)	類風濕關節炎
6. Stroke	中風
7. Brain Injury	腦損
8. Systemic Lupus Erythematosus (SLE)	系統性紅斑狼瘡
9. Nasopharyngeal Carcinoma	鼻咽癌
10. Cerebellar atrophy	小腦萎縮症
11. Retinopathy	視網膜病變
12. Quadriplegia	四肢傷殘
13. Mental health advocacy	精神健康倡導
14. Nephrology	腎科
15. Ankylosing spondylitis (AS)	強直性脊椎炎
16. Neuromuscular disease	神經肌肉疾病

2.4.4 The focus group meetings were confined to **implementable tasks (Q4 and 5b of the Telephone Interview)** which would be within the direct or indirect reach of APMHO. From data collected in Phase 2 (telephone interviews), the discussions with SHOs in Phase 3 (focus groups) reflected that there are issues relating to:

- (a) The HA Drug Formulary, its operating mechanism and financial assistance to the needed (Section 2.4.5);
- (b) SHOs management and leadership capabilities (Section 2.4.6);
- (c) Community Rehabilitation (Section 2.4.7);
- (d) Support resources to Caregivers (2.4.8);
- (e) Public education programs (2.4.9);
- (f) Choices to patients entering their end of life period (2.4.10); and
- (g) Special conditions requiring attention (2.4.11).

#### 2.4.5 HA Drug Formulary, its operating mechanism and financial assistance to the needed

(a) **Expansion and replacements of the HA Drug Formulary** is demanded, for example:

- The newer generation of inhibitor for Rheumatoid Arthritis (RA) is COX-2 and is well proven to be an effective treatment with fewer side effects in causing GI bleeding than the older generation drug NSAID. Despite the little price difference in the price of the old NSAID drugs and COX-2, HA has retained the older generation drugs under the current Drug Formulary. However, it was common for the doctors to prescribe COX-2 to the patients so that they can purchase it through the private drug dispensary. It was not uncommon to find patients taking the older generation drug for a long period of time suffering from considerable GI bleeding. The reason why the more cost-effective new generation drug is not replacing the old drug is still not fully understood. This is undoubtedly causing more suffering to the patients while there is little cost implications to HA (**RA patients**).
- Lucentis is an effective drug for macular lesions. There are 3,000 new cases per year yet HA is subsidizing only 250 cases. The reasoning for subsidy is less known to the public. The drug is high in demand. (**Retina patients**)
- Biologicals (生物製劑) is the most effective drug than most pain killers. There are only limited Rheumatoid Arthritis and Ankylosing Spondiolitis patients being subsidized by the Samaritan Fund. The rule is relaxed a bit this year hence over 2,000 patients are being subsidized. The main

reason for failing the application of the Samaritan Fund is assessing the family income versus individual income. If this rule can be modified, it will help those in need to pass their application. **(RA and AS patients)**

- Newer generation psychiatric drugs do have fewer side effects as the older generation drugs. Old drugs have been used for a long time on the Drug Formulary without replacement of newer generation drugs. In private practices, the newer generation drugs have proven their value to the patients. Some of the psychiatric patients can go back to work and study with the newer drugs as they are less affected by the side effects. **(Psychiatric patients)**
- Continuous replacements of proven drugs for stroke treatments will bring treatment values and fewer side effects to the patients. **(Stroke patients)**
- For patients who have performed kidney transplant, the anti-resistant and cleansing drugs are self-financed. The older anti-resistant and cleansing drugs on the Drug Formulary can be used but the side effects are intolerable. If the Drug Formulary can be updated or replaced by the newer drugs, it will help the Nephrology patients tremendously. **(Nephrology patients)**

#### **(b) Transparency of operating mechanism of the HA Drug Formulary**

Participants are concerned that the advisory meetings of the HA Drug Formulary are symbolic to most patients. The particular concerns are:

- The Assessment Panels for the HA Drug Formulary are not known to the patient experts;
- The Assessment criteria are less transparent; and
- SHOs Leaders are seldom invited to give comments about their own disease groups before the Assessment, and if invited, they are asked of general comments in a large crowd instead of specific comments within a specific disease group.

#### **(c) Increase financial assistance to the needed**

Repeatedly, the SHOs mentioned the inflexibility in the application of the Samaritan Fund. It is an unfair act for the existing scheme to examine the total income of the family in the household as the eligibility limit. This rule forbids the financially difficult patients to receive the assistance from Samaritan fund. There is a strong plea to change to individual income level for the eligibility limit.

#### 2.4.6 SHOs management and leadership capabilities

- (a) **Need for more patient Leaders and Experts in the patient organizations** - In the past, the healthcare system stresses on the importance of healthcare and paramedical professionals with directions from the Administrative Officers (AOs) of the HKSAR government. Yet without the patients' and patient organizations' feedback, the treatment effectiveness is lessened to a certain extent. The aggregate treatment feedback in the patients' organizations can become a very powerful tool to the medical and pharmaceutical bodies. This brings up the subject of organization development of SHOs, patient leaders and patient experts. These leaders and experts need to be trained on a variety of knowledge and skills to be effective. There is a shortage of patient leaders and experts amongst the SHOs who can take up the existing advocacy work in regard to PCH implementation. This shortage can be fulfilled by expedited training and development programs for selective patient leaders and experts, and identification of potential patient leaders from various sources. Funding from the Government and other public and private funds should be considered to move the SHOs aggregate power to new height in pursuance of PCH.
- (b) **Limited support allowance of SHOs by SWD** - Presently some of the SHOs are financially supported by Social Welfare Department (SWD) but the funding to SHOs is getting smaller because of the increasing number of SHOs. This phenomenon is stifling the development of SHOs. SHOs have to face unceasing turnover of their staff and the challenge of keeping quality staff to enhance their activities.
- (c) **Limitations in the SHOs** – SHOs progress and development are much affected by the functioning of the Executive Committee and their leadership styles. This is further aggravated by the caliber of staff within the SHOs. The Executive

Committee members are all volunteers and the staff is remunerated. Very often, the support allowance can only afford a staff with relative low pay without promotional path. This causes frequent turnover and is crippling the functions of SHOs. Quite a few SHOs are faced with succession planning challenges in their Executive Committees, let alone SHOs development.

#### **2.4.7 Community Rehabilitation**

In many cases, community rehabilitation is a continual and long term process after the patients are released from the acute/rehabilitation hospitals. Appropriate resources and facilities like community rehabilitation centres, community nurses, therapists, and pharmacists in the community rehabilitation centres; and home visits from paramedical professionals and social workers can reduce the length of stay and frequency of hospitalization. Pilot runs have been conducted in selected districts and the result would be announced presumably to the public.

Community rehabilitation will be in greater demand with the ageing population and the increase of prevalence of chronic diseases. Community rehabilitation services are the carry-on aspect of hospital rehabilitation and are contributed by HA and SWD of the LWB. Improvement in Hong Kong requires a radical change from the existing compartmentalization of services to a continuous rehabilitation process. The cost-effectiveness consideration of community rehabilitation services should be in the hands of HA, SWD, FHB, and LWB for cross-functional collaborative discussions and recommendations for improvements to the appropriate authority, e.g. Central Policy Unit of the HKSAR Government, for decision-making.

#### **2.4.8 Support resources to Caregivers**

Grievances from the caregivers have been loud and clear. They are often burdened with the patients' treatment and progress, and are suffering themselves physically and emotionally.

Caregivers of Cerebellar Atrophy, Quadriplegia, RA, and AS patients demand much more support than others. These caregivers plea for the following:

- (a) Some form of financial support/caregivers' allowance should they quit their jobs to look after the patients;



- (b) Half-price on transportation for fulltime caregivers;
- (c) Training and information retrieval on special medical/rehabilitative/side effect knowledge and caring skills;
- (d) SHOs and networks for caregivers; and
- (e) Emotional support and counseling for caregivers.

Learning can be in the form of media like interactive workshops, TV/radio, e-Learning programs, pamphlets, and websites in addition to classroom instructions.

#### 2.4.9 Public education programs

Public Health education is imperative for early understanding of health issues and potential impact to human life. Several SHOs are using their disease experiences as life education to primary and secondary schools for preventive measures. Some SHOs are holding carnivals, symposiums, workshops, seminars, exhibitions, competitions, websites, publications, etc. for their own disease groups. These public education programs also enable the patients to familiarize with their specific diseases within their own SHOs and for other SHOs, thus offering growth in knowledge of diseases and skills on how to deal with groups and individuals.

- (a) Previously, CRN has held a combined carnival for the SHOs together and the experience was very positive. This gave the visitors/participants the understanding of various disease groups in one round, and at the same time pamphlets of numerous disease groups could be distributed. Above all, this provided direct interaction amongst patients, visitors, participants, and other audience which are most meaningful to all. It also offers the opportunity to promote the SHOs. The experience earned should be consolidated and repeated in larger scale and scope;
- (b) The LWD is sponsoring a “Rehabilitation Service Education Fund” of 4-5 million dollars per year. The applications of fund start in February. This is a viable option for funding SHOs public education programs;
- (c) Health Education used to be in the primary school curriculum some 40 years ago but has stopped. There were suggestions to revive this subject in the current education curriculum perhaps in a new form via e-learning and other means for primary, secondary and tertiary school takers.

#### 2.4.10 Choices to patients entering their end of life period

Patients approaching their end of life, e.g. Cerebellar atrophy and neuromuscular disease, may have the desire to spend the rest of their lives at home than hospital. Consideration should be given to release these patients from the hospital (at an estimate cost of \$80,000-\$90,000, assuming the daily hospitalization cost is ~\$3,000 in the HA clusters) and allow them to stay home with medical assistance and nursing financed at an estimate cost of <\$20,000. This is more cost-effective than the HA hospitalization healthcare service.

#### 2.4.11 Special conditions requiring attention

There are specific demands for advocacy from different disease groups:

- (a) The EB virus and ENA semi-annual or annual checking for nasopharyngeal carcinoma (NPC) patients are confined to the Prince of Wales Hospital. This checking is a must for NPC patients, very similar to blood testing for all patients. This is expected to be included in the Drug Formulary or equivalent service. **(NPC patients)**
  
- (b) Stroke SHOs advocate for additional exercise and physiotherapy facilities located in different districts to continue their rehabilitation programs on a regular basis. This is very essential for stroke patients for ongoing self-management and health maintenance; else they will face with deterioration in their physical movements. New updates in medical and rehabilitation are essential from time to time from the Health Bureau and HA. The stroke patients' advocacies are:
  - Having 24-hours emergency stroke centres available in the HA clusters and specialized training program of early stroke diagnostic procedure with the A&E staffing; or better still, establish an acute stroke unit to service stroke patients;
  - Increasing availability of stroke bed provision for hospitalized time, and/or having more community rehabilitation centres in the districts to take over certain loads from the rehabilitation hospitals, particularly for the first 6 months after stroke;

- Avoiding transfer of premature stroke cases from Neurological Units of HA rehabilitation hospitals to community rehabilitation centers or elderly homes;
- Increasing frequency of HA specialist consultancy for stroke patients; and
- Allowing stroke patients from the private hospitals to use the community rehabilitation centres for their post-hospitalization rehabilitation.

**(Stroke patients)**

- (c) There is negligence towards the strabismus ghosting (problem with visual effects) patients who could have no sense in viewing 3-dimensional objects. This type of visual disease cannot be detected externally by other people but the patients are always trapped in their daily life by hitting glass doors, kurbs, staircases, etc. because they fail to see the 3-dimensional objects. The accident rates are very high for such patients. Children with this type of disease are not accepted as the 8 learning disabilities and not as PwD, thus the inconvenience and accidents in schooling are not taken into consideration. These patients suffer life-long with little care from the healthcare and welfare systems. The advocacy is to include strabismus ghosting as a disability in the Rehabilitation Programme Plan of the Government of the HKSAR so that this form of visual disability can be recognized by the Hong Kong Healthcare and Education Systems; and by the World Health Organization (WHO) ultimately.
- (Strabismus ghosting patients [problem with visual effects])**

- (d) Hydrotherapy is very effective for RA, AS, and aged patients with physical pain. The temperature of the pools has to be at least 30° C. The minimum rehabilitation activity of these patients is to slow down the deterioration rate and reduce the level of painfulness by attending regular hydrotherapy. However, hydrotherapy facilities outside the hospitals are very limited. Even the hospital hydrotherapy facilities are limited in use outside of office hours and the users will have to hire a physiotherapist to supervise the sessions. The advocacy is to consider: (1) provision of more supervised sessions in the hospitals with funding support (HA and FHB); (2) provision of more public facilities by renovating the existing community swimming pools and building new pools that can cater for the special needs for the “Old”, “Weak” and People with Special Needs (Leisure and Cultural Services Department). **(RA, AS, and aged patients)**

(e) The introduction of the Medical Voucher System may reduce the attendances to the Accident and Emergency (A&E) Department of HA hospitals and admission to hospital for observation, e.g. RA, AS and SLE patients. The HA average daily expense is about \$3,000. The issuance of medical expenses will replace partly HA expenses while expediting the throughput of patients from the HA systems. With the medical coupons, patients can consult with the private family doctors or community clinics instead. This is more cost-effective to the Government and it can provide more speedy treatment to the patients. The advocacy is to consider: (1) giving medical vouchers to selective disease types e.g. RA, AS, SLS, etc. which require frequent loading of A&E; (2) giving medial vouchers to non-emergent cases to relieve the crowdedness of the A&E; (3) accumulating medical vouchers for a longer period of time where patients can use for other purposes such as dental expenses. **(RA, AS, SLE, general patients)**

(f) The accessibility of healthcare service for patients with visual and auditory impairment, and elderly still needs attention. The following items are the minimum requirements:

- Visually impaired patients – a mechanism to provide drug labels with dosage and drug administration that can be touched by braille displays.
- Hearing impaired patients – not all the HA clinics and hospitals are equipped with display of the numbers in the queues of dispensaries and waiting areas of the medical consultation rooms. The additions of displays are imperative to the life of people with hearing difficulties.
- Patients with physical movement disability – Patients using wheelchairs and walking aids find inaccessible paths in the older HA hospitals for toilets, A&E room (e.g. Kwong Wah Hospital), location (e.g. Prince Margaret Hospital), and the related accessible information for accessing dispensaries and shroff offices.

#### 2.4.12 **Summary:**

The focus group meetings were excellent forums for the patient leaders from the SHOs to share their common concerns and specific needs. 18 SHOs were represented

out of the 44 SHOs in APMHO. 16 disease groups were represented covering roughly 46% of 40,000 patients in APMHO. The discussions were open and candid among the patients organizations. The discussions were rational. Many aspects of the healthcare system were deliberated, ranging from quality of services, operating practices, and unique needs of the disease groups.

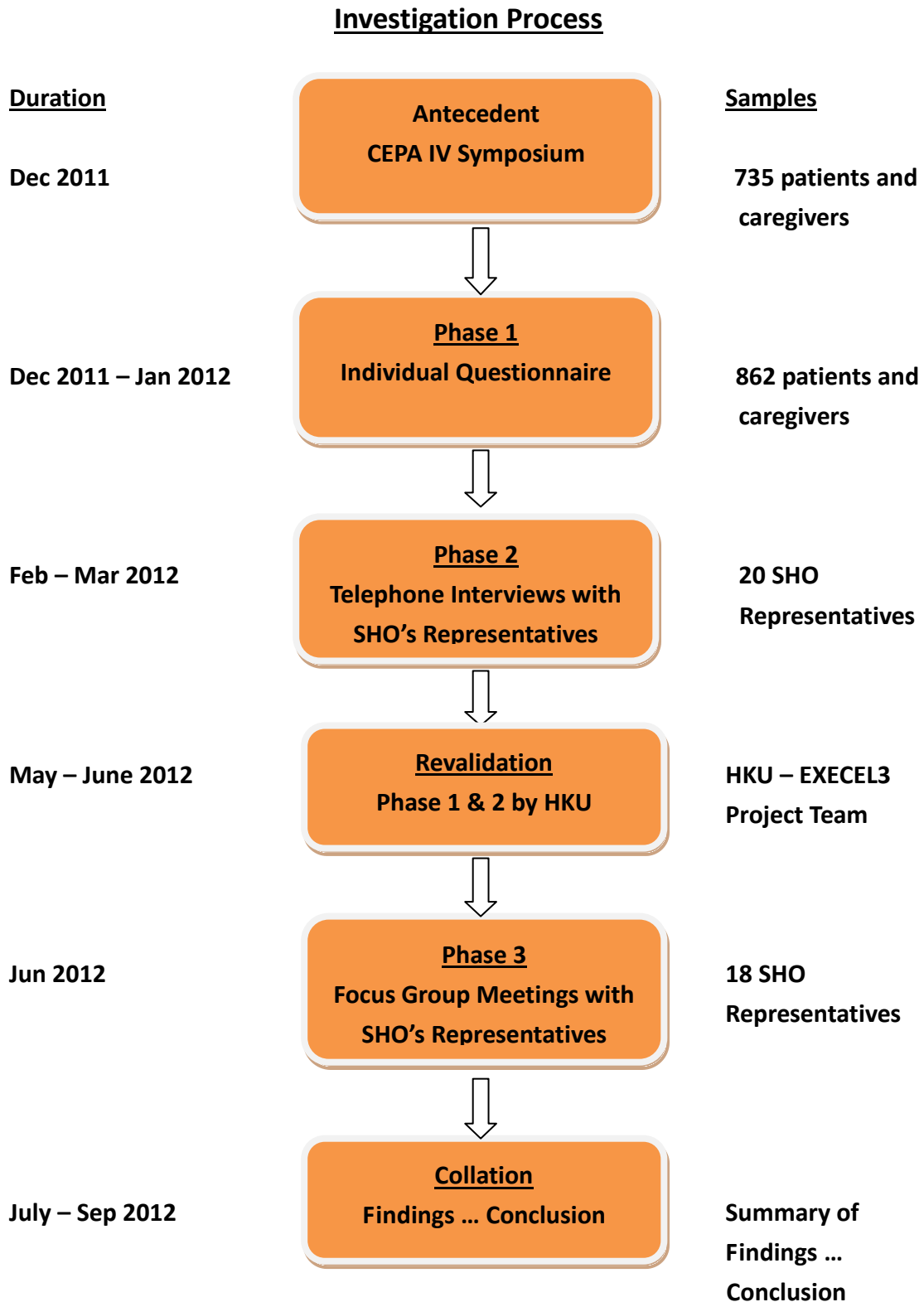
Major areas of concerns in the public healthcare system from the 18 SHOs were prioritized as follows:

- (a) Reduce the financial burden of the chronically ill patients on the drug expenses;
- (b) Advocate for the respect of patients in the right to know and make choices, and to participate in the relevant healthcare policy-making;
- (c) Increase the investment in healthcare resources in the appropriate priority areas; and
- (d) Enhance self-management for patients and nursing/caring capabilities of the caregivers.

The 2 meetings have elevated the understanding of PCH among SHOs. The principles of PCH were illustrated in almost all the key points being made by the SHOs. Undoubtedly, this was an excellent PCH learning opportunity. The **PCH principles applied** were documented in **Appendix 8** which documented the details expressed by the SHOs verbatim in Chinese. These were consolidated and translated to English in Sections 2.4.4 to 2.4.11.

## 2.5 Summary of Findings

This investigation has gone through 3 phases. It can be depicted as follows:



**Phase 1** was a fixed format questionnaire with 862 informants who were mostly patients with some caregivers. It can be condensed to: (1) “Patient involvement in the formulation of healthcare policy” is ranked as the most desirable action in the PCH implementation in Hong Kong in the next 5 years. (2) “Waiting time for the follow-up consultation” is rated as the most imminent improvement from the HA services. (3) “Caregivers’ support system and training of knowledge and skills” are most essential from the standpoint of the caregivers. (4) The 19 comments from the informants were somewhat repeated in Phase 2 and 3 of the investigation.

**Phase 2** was investigating through telephone interviews on the 20 SHOs for their views on the Hong Kong public healthcare system, specific concerns of their disease groups, and what can be perceived as implementable tasks within the next 5 years. The representation was mostly the chairpersons or vice chairpersons of the SHOs. This phase involved a large volume of narratives. The data were categorized into themes for classification. In summation, the top priority areas in the public healthcare system are: (1) Lowering the patients’ financial burden for medical expenses and other areas. (2) Improving service quality and service types, in particular the quantity and quality of the healthcare professionals. (3) Updating and enhancing the HA Drug Formulary System. (4) Strengthening the existing healthcare system; (5) Enhancing the quality of life for the disabled and chronically ill patients.

**Phase 3** was an interactive discussion with the 18 SHOs together. Two sessions were held with 13 and 5 SHOs respectively. This was a voluntary participation scheme from the 20 SHOs in Phase 2. With 16 disease groups joining, there were common concerns and unique concerns expressed. The major concerns in the public healthcare system were prioritized as follows: (1) Reducing the financial burden of the chronically ill patients on the drug expenses. (2) Advocating the patients’ right to know and make informed choices and to participate in the relevant healthcare policy-making. (3) Increase the investment in healthcare resources under the appropriate priorities. (4) Enhance self-management for patients and nursing/caring capabilities of the caregivers. There are immediate needs, mid-term and long term targets being expressed by the discussion groups. The common and unique concerns are documented in **Section 2.4.4 and 2.4.11.**

### **3. Analysis and Discussion on the Findings**

The 3 rounds of data collection have enabled better understanding of the perception of the current public healthcare services as it relates to the compliance of PCH principles from the patients and caregivers at large within the 16 disease groups being represented. The data collection phases have facilitated the project to use both the induction and deduction methods based on 862 – 20 – 18 informants and informant groups to validate and triangulate the input to PCH progress measurement from 3 different angles. The progressive approach of data collection has aided the SHO representatives to understand the concept of PCH with improved breadth and depth. The data collected in Phase 2 were consolidated and prioritized to generate the discussion guideline for Phase 3. Thus, the interactive discussions in Phase 3 were richer and empathetic.

From a data analysis point of view, there are great consistencies in the 3 data sets despite the data from the questionnaires and discussions were at different levels of similar problems and at times identical issues were presented in different dimensions. The delineation of the problem levels was somewhat fuzzy from the patients and caregivers (informants). At the same time, there are distinctive needs from certain SHOs that are legitimate and those needs should be brought to light with the appropriate stakeholders. This is expected from exploratory study where qualitative data are collected for better understanding of the problem. Besides, the scale and scope of PCH implementation is less well-defined at AMPHO and presumably at IAPO at this stage.

This study is intended to kick off the official start of the PCH implementation by defining where we are today. PCH are conceptual in nature and operates on principles. This implies that PCH is an on-going process and improvement from a PCH perspective is required from time to time. In Hong Kong, this study will be the foundation to assist in building up a five-year advocacy framework for the advancement of PCH implementation.

#### **3.1 Prioritization from APMHO's Perspective**

Needs of patients and caregivers have been voiced out by patient leaders and experts from the more mature SHOs to HA and various parties in the healthcare service



supply chain in the past years. However, these voices are in small-groups and rather weak. There have been a few successful cases in the advocacy of drugs and improvement in services. The representation of APMHO-SHO members in various HA and LWD committees are increasing. Nonetheless the scattering of patient leaders and experts in the committees make the advocacy functions less effective. Perhaps the top priority is for APMHO to organize internally to form a Sub-Committee on Advocacy with strong leadership to spearhead the effort to:

- (a) Gather a number of mature SHO representatives with potentially strong leadership and advocacy skills;
- (b) Identify additional patient leaders and experts and caregivers from SHOs;
- (c) Arrange leadership and advocacy training workshops to upgrade management and leadership capability within the Sub-Committee and for the potential leaders from the SHOs (capacity building);
- (d) Form the Sub-Committee which may consist of different advocacy groups for various advocacy themes;
- (e) Arrange sharing sessions for advocacy themes for experience sharing and group brainstorming; and
- (f) Monitor progress of the Sub-Committee periodically, e.g. quarterly, and report in the Executive Committee of APMHO.

While the APMHO members are doing the existing advocacy work, the future has to be planned. The formation of the Sub-Committee first can kick-start the effort to unite the already existed effort with potential leaders to pick out the priority items as stated in 2.4.4 – 2.4.11.

### **3.2 Prioritization of individual patient organizations**

Phase 2 and 3 data collection and analysis indicated that there are succession planning and transition planning difficulties for many SHOs. This is not unusual as the SHOs are formed from patients (and caregivers) who are having some kind of disabilities and/or chronic health conditions. Most of the SHO members are taking health and psychosocial activities as their own priorities and rightly so. Few of them are taking their health burden and are willing to devote their time and energy for the well-being of their peers and others – they are the existing patient leaders and experts.

SHOs often are faced with turnover of the Executive Officer (staff of the SHOs). This

poses replacement issues to the SHOs and training time and effort to the new staff. Some SHOs are facing the dilemma of employing a qualified social worker versus an administrative staff. The SHOs can offer limited career growth to their staff and often this is the reason for staff departure. Also, the allowance given by SWD is not even sufficient to employ a qualified staff to do the daily administrative work and the allowance is getting smaller because the same allowance sum has to be spread to more SHOs.

The SHOs leadership styles and approach often affect the directions taken by the SHOs. The management capabilities of executive committee members vary a great deal between SHOs and within the SHOs. The temporary absence (sometimes permanent) of executive committee members due to relapses or deterioration of the diseases is conventional in the SHOs.

The priority of the SHOs seems to be:

- (a) Invite potential leaders into the SHOs executive committee;
- (b) Assign jobs with more weight to the existing executive committee members who are willing and stable in their chronic health conditions;
- (c) Organize sharing sessions (APMHO and CRN) with experience sharing and themed discussions;
- (d) Coordinate large events (CRN) to motivate the SHOs and their members;
- (e) Organize leadership training sessions for the executive committee members and potential members; and
- (f) Develop more patient experts by assigning them to the HA and FWB committees, working groups and task forces.

The above are just some ways to improve the general capabilities of SHOs. Some SHOs could be more advanced than others. They can also lead by examples and advise the others on possible means to step up their SHOs.

## 4. Conclusions and Recommendations

This exploratory study is the first of its kind in Hong Kong. The PCH concept has been promoted by IAPO since 2005. The level of awareness is getting to be more widespread in the world than ever before. APMHO in Hong Kong has been actively advocating for PCH since 2008. Although the level of awareness is escalating at a steady pace in patients and patient organizations; understanding, acceptance and motivation to implement are still rhetoric among most policy-makers, professionals and service providers in the healthcare sector in Hong Kong. The importance and significance of implementation of PCH have not been recognized. Consequently, institutionalizing as a roadmap towards staged assessment of its progress has not been discussed and adopted. In essence, the desired outcome at a particular period is not measured.

It is increasingly recognized that bringing people and patients to the centre of healthcare with a focus on the whole person, not just the disease, and on the people that deliver healthcare is necessary to align healthcare systems with the needs of patients. Engaging patients and patient organizations in health policy-making helps to ensure that policies reflect patient and caregiver needs, preferences and capabilities.

There are issues with the healthcare system that have to be resolved by constitution and legislation that require a long term view (**4.4 Long Term Plan**). Other specific issues can be resolved over time by administration through major resource allocation across bureaus and upgrading of processes and procedures in HA, SWD, Buildings Department (BD), Transport Department (TD), Food and Health Bureau (FHB), Labor and Welfare Bureau (LWB), Education Bureau (EDB) and other stakeholders (**4.3 Mid-term recommendations**). Yet there are issues that can be dealt with by collaborative effort amongst the patients, caregivers, and the stakeholders such as HA, SWD, FHB, LWB and other professional organizations (**4.2 Short Term Actions**).

### 4.1 Assessing maturity level in PCH

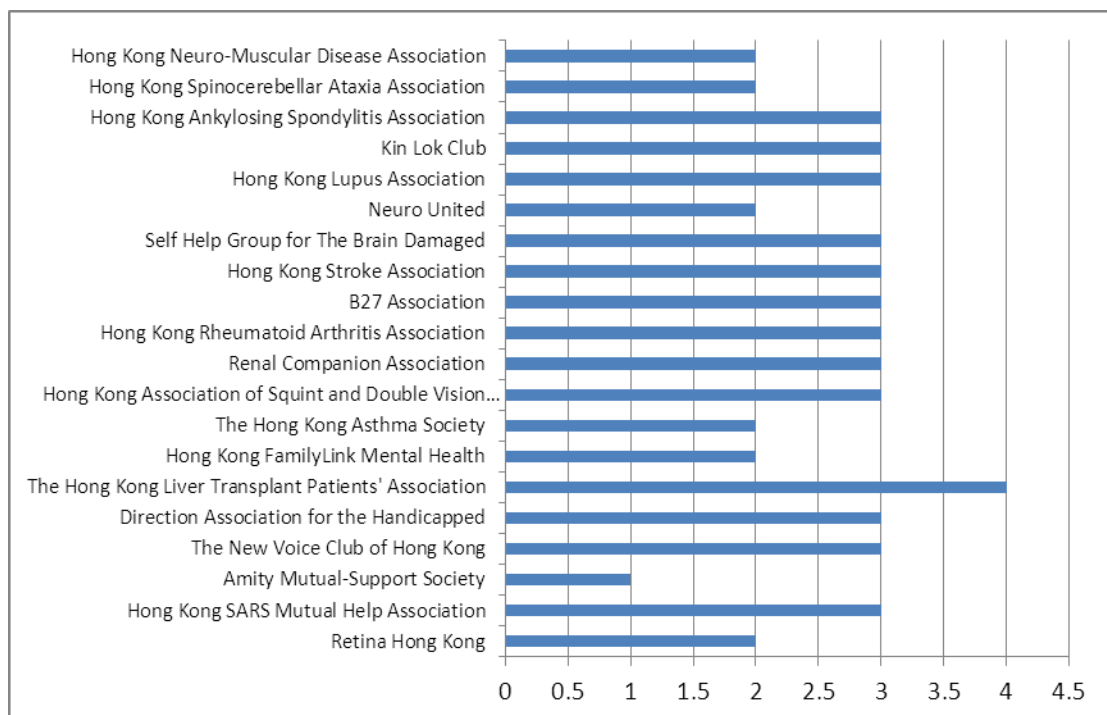
There are many different ways to assess the maturity level of PCH implementation. For the purpose of this study, a self-assessment method on the maturity level is used in Phase 2 with 20 SHOs. The result is exhibited as:

- 1 SHO (5%) rated themselves as no progress;
- 6 SHOs (30%) rated themselves as below average;
- **12 SHO's (60%) rated themselves as average;** and
- 1 SHO rated themselves as above average.

The most dissatisfying SHO is Amity Mutual Support Society which belongs to the mental disease group. The most satisfying group is the Hong Kong Liver Transplant Patients Association. This highlights that specific disease group receives better quality of service than others due to imminent needs but this is only a small minority of patients. The experience of the mental disease SHO, having a large number of patients and caregivers, perceives the quality of service as unsatisfactory. It is expected that those patient groups with life-saving procedures are more satisfied as they receive more health funding hence more attention. Patients with chronic illness and disability without immediate risk of death are likely receiving less attention by the health administration in Hong Kong.

Phase 2 Q1 – Self Assessment of Progress of PCH in the last 5 years

Rating is 1 – 5, with 1 being no progress and 5 being excellent progress



The self assessment is one way of evaluation. It could be influenced by factors such as personal/group bias due to past experiences, partial view of circumstances, and subjective expectations of the evaluators. Nevertheless, this study takes the view

based on the SHO's representatives and can be taken as a point of reference.

#### 4.2 Short Term Actions

By short term actions, it refers to improvements that may be accomplished in 5 years by the stakeholders. According to Sections 2.4.4 – 2.4.11 and 3.1 – 3.2, some items can be acted upon:

Action Plan	Stakeholder	Section
(a) Improve quantity and quality of healthcare professionals	HA	2.2.6; 2.2.8; 2.3.4; 2.3.6; 2.3.7
(b) Lowering the patients' financial burden for drug expenses and other areas via Samaritan Fund with less restriction such as assessing on individual income with family consideration rather than total family income.	HA, SWD; FHB	2.3.6; 2.4.5 (c); 2.4.12 (a)
(c) Updating and enhancing the HA Drug Formulary <ul style="list-style-type: none"> <li>• <b>COX-2</b> replacing old drug (RA patients)</li> <li>• <b>Lucentis</b> (Retina patients)</li> <li>• <b>Biologicals</b> (RA and AS patients)</li> <li>• <b>Newer generation psychiatric drugs</b> (Psychiatric patients)</li> <li>• Continuous <b>replacements of proven drugs</b> for stroke treatments (<b>Stroke</b> patients)</li> <li>• For patients with kidney transplant, the anti-resistant and cleansing drugs are self-financed. The Drug Formulary should be updated the <b>newer drugs</b>. (<b>Nephrology</b> patients)</li> </ul>	HA, FHB, LWB	2.4.5 (a)
(d) Improve on transparency of the HA Drug Formulary – Assessment Panels, criteria, patient experts' participation by disease groups	HA, FHB, LWB	2.4.5 (b)

(e) Enhance self-management for patients and caring and nursing capabilities of the caregivers; strengthen support network for caregivers	CRN, HA, SWD	2.2.8; 2.4.8; 2.5 Phase 3 (4)
(f) Shorten waiting time for follow-up consultation, especially with Specialist with HA services	HA	2.2.6; 2.2.8; 2.5 Phase 1 (2)
(g) Offer more public education to the public by holding a sizeable carnival combining forces from groups of SHO's using the Rehabilitation Service Education Fund from LWD	APHMO, CRN, LWB	2.4.9
(h) Consider organizing a Sub-committee on Advocacy to spearhead the effort to identify patient leaders and experts (and caregivers) of selective disease groups to be trained and practiced on leadership and advocacy skills, upgrade the capacity, and penetrate in the influence of the patients to the Healthcare System (PCH principle 2 and 3)	CRN, APHMO, FHB, LWB	3.1
(i) Advocate the patients' right to know and make informed choices in their own diseases, and to participate in the relevant healthcare policy-making	HA, FHB, APMHO	2.2.5; 2.2.8; 2.3.4; 2.4.12; 2.5
(j) Consider seriously about succession planning of Executive Committees and staff turnover of SHOs	CRN, SHO's, SWD, LWB	3.2; 2.4.6 (a-c)
(k) Stroke services - Improve on the arrangement of the 24-hours emergency centres to be available for the 7 HA clusters; establish more community centres and support resources in the districts as self-management to take over the load from the rehabilitation hospitals; allow stroke patients from the private hospitals to use the community	HA (specific for stroke patients))	2.4.11 (b)

rehabilitation centres for their post-hospitalization rehabilitation		
(l) Increase supply of <u>Hydrotherapy</u> facilities for RA, AS, and elderly patients as the supply is less than 10% of the demand	HA, LCSD, FHB (specific for RA, AS and elderly patients)	2.3.5; 2.4.11 (d)
(m) Take EB virus and ENA checking for nasopharyngeal carcinoma (NPC) as similar procedure to the Drug Formulary or blood test.	HA (specific for NPC patients)	2.4.11 (a)

### 4.3 Mid-Term Recommendations

There are a few pleas from the focus group discussions that may call for actions within the next 5 years and for the medium term. These issues could demand for cross-bureau and cross-department communication and agreement before decisions could be made. Some may be resolved over time by administration through major resource allocation across bureaus, while others may require upgrading of processes and procedures in HA, SWD, BD, TD, FHB, LWD, EDB, and other stakeholders.

Further planning and discussions are essential on the following by the relevant stakeholders:

Action Plan	Stakeholder	Section
(n) Improve quality of service and services types	HA, FHB	2.3.6; 2.3.7
(o) Accept strabismus ghosting (visual problem) formally as visual and learning disability by the Hong Kong Healthcare and Education Systems; and ultimately by WHO as a type of visual disability.	HA, FHB, EDB; WHO (specific for strabismus ghosting patients)	2.4.11 (c)
(p) Consider issuing medical coupons to selective disease groups such as RA, AS, SLE, etc. to off-load the A&E departments and observation in the hospitals	HA, FHB; SWD, LWB	2.4.11 (e)

(q) Improve the accessibility to public healthcare service in the old hospitals and clinics for patients with <u>visual, hearing, and movement difficulties</u>	HA, FHB; BD, TD; LWD	2.4.11 (f)
(r) Give choices to patients entering their end of life period whether they like to spend their time at home or in the hospital at the termination (hospital cost ~ \$80,000-\$90,000 vs home care assistance < \$20,000)	HA, FHB; SWD, LWD	2.4.10

#### 4.4 Long Term Plan

The study revealed the 3 top major areas in the healthcare system to delve into. Each of these areas may warrant an Owner from one of the Bureaus to take leadership to advance the matter further.

Action Plan	Stakeholder	Section
(s) Strength the existing healthcare system	Various with FHB as the chief stakeholder	2.3.4; 2.3.7
(t) Enhance the quality of life for the disabled and chronically ill patients	Various with LWB as the chief stakeholder	2.3.4; 2.3.7
(u) Increase the investment in healthcare resources under the appropriate priorities	Various under the Government	2.3.4

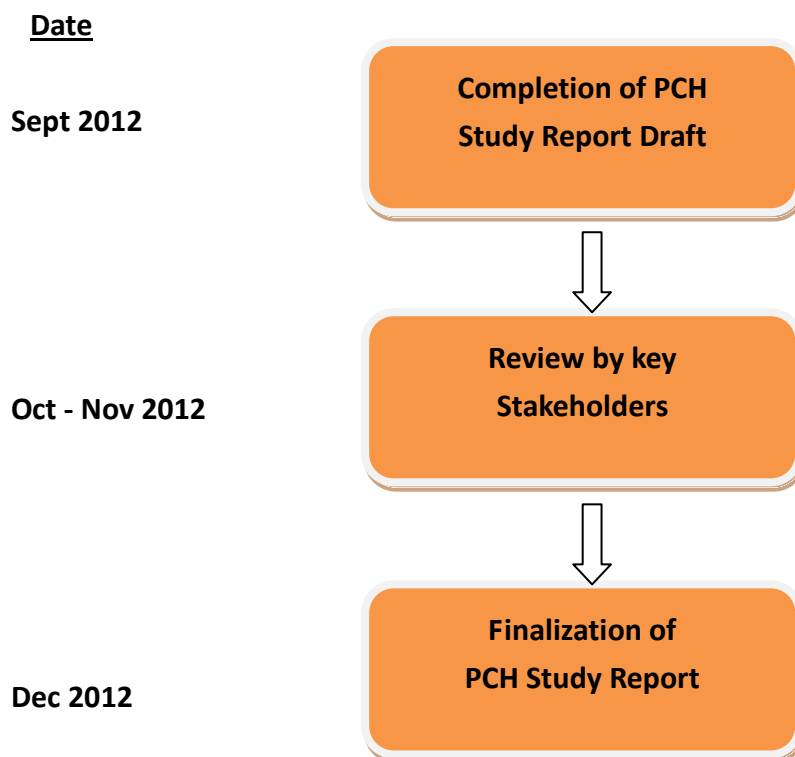
#### 4.5 Review of Sections 4.2 to 4.4 in October and November 2012

The report was drafted by 30 September 2012. The draft was then reviewed by a number of appropriate stakeholders, namely Prof. Ceci Chan (HKU), Dr. Leonard Li (Rehabilitation Consultant), Tsang Kin Ping and others (APMHO), Ng Hang Sau and Peter Poon and others (HKSAR) in October and November 2012. Clarification,



elaboration, and implications were updated in parts of Section 4.2 to 4.4.

#### 4.5.1 Review Process



#### 4.5.2 Clarification, elaboration and implications

Action Plan	Clarification, Elaboration and implications
(c) Updating and enhancing the <u>HA Drug Formulary</u> <ul style="list-style-type: none"> <li>• <b>COX-2</b> replacing old drug NSAID (RA patients)</li> </ul>	<ul style="list-style-type: none"> <li>• COX-2 is successfully placed in the HA Drug Formulary in November 2012. However, it must be understood that COX-2 has the side-effect of increasing cardiovascular risk such as heart attack for which NSAID does not have. The benefit and risk of using COX-2 has to be weighed before its application.</li> <li>• This brings to light that there is <u>no proper channel for patients to be aware of the exact rationale on how HA is working in term of drug formulary.</u> <b>The issue can be resolved by appointing a specialist to the respective</b></li> </ul>

	<p><b>patient groups to listen to the requests and also explain the rationale about drug formulary within HA.</b></p>
<p>(k) <u>Stroke services</u> - Improve on the arrangement of the 24-hours emergency centres to be available for the 7 HA clusters; establish more community centres and support resources in the districts as self-management to take over the load from the rehabilitation hospitals; allow stroke patients from the private hospitals to use the community rehabilitation centres for their post-hospitalization rehabilitation</p>	<ul style="list-style-type: none"> <li>• According to a survey last year, stroke rehabilitation services within the HA hospitals vary significantly in terms of manpower, outcome and length of stay. It was perceived by the stroke SHOs that HA is undermining the essential services for stroke patients from onset of stroke to the rehabilitation stage. In some other developed countries, community rehabilitation is often the carry-on aspect of hospital rehabilitation and is a continuous process with the same funding source. In Hong Kong, <u>hospital and community rehabilitation is funded by 2 sources – community rehabilitation by SWD while hospitalization is funded by HA</u>, thus it is not a natural continuous process. Resource allocation by the Government and related bureaus are critical for community rehabilitation to take place more smoothly and effectively. <u>A fundamental review by the 2 bureaus needs to take place to review how to bridge hospitalization to community rehabilitation as a seamless process with less negative impact to the stroke patients.</u></li> <li>• The long-awaited <b>Centre of Excellence in Neuroscience</b> had been actively planned from 2008 till 2010. Then it was a period of silence till now. This indicates that the <b>project is either on hold, deferred or cancelled.</b> Another indication of negligence in neurological patients is perceived.</li> </ul>

<p>(o) Accept strabismus ghosting (visual problem) formally as visual and learning disability by the Hong Kong Healthcare and Education Systems; and ultimately by WHO as a type of visual disability</p>	<ul style="list-style-type: none"> <li>The strabismus ghosting visual problem was mentioned in the discussion on Classification of Disability for the 10-Year Census of the Rehabilitation Advisory Committee (RAC) Meeting of LWB and placed in the minutes of 12 October 2012. This was the 1<sup>st</sup> time to register such a potential disability by the RAC officially.</li> </ul>
---	---

#### 4.5.3 CRN's Stock-taking of the Action Plan

Stock-taking was completed in November to better understand what CRN's has done in the action plan, as follows:

Action Plan	CRN's stock-taking
<p>(e) Enhance self-management for patients and caring and nursing capabilities of the caregivers; strengthen support network for caregivers</p>	<ul style="list-style-type: none"> <li>Introduction of the self-help concept to serve the chronic illness population since the establishment of <u>CRN in 1994</u>.</li> <li>Formal introduction of the <u>"self-management" definition and program to Hong Kong in 2000</u> and thereafter piloting and evaluating the Stanford Model Chronic Disease Self-management Program (<u>CDSP</u>), further development via set up community-based projects via funding support, <u>revamping of CRN core service in early 2000's</u>, providing sharing and training to the local and regional service providers to advocate the needs and application, publications of manuals and books to support the needs and growth, commissioned by HA to provide <u>community-based Patient Empowerment Program (PEP)</u> and being the largest provider in Hong Kong.</li> </ul>

	<ul style="list-style-type: none"> <li>Finally, with <u>“self-management support and empowerment”</u> as a <u>key strategies</u> of HKSR in service development which further led to the establishment of the <u>“Self-management Training and Development Centre”</u> in 2010 and the <u>“Centre on Research and Advocacy”</u> in 2012. Launching of the new web-based Learning Management System and Diabetes Self-management program as a new innovation in the area took place in November 2012.</li> </ul>
<p>(g) Offer more public education to the public by holding a sizeable carnival combining forces from groups of SHO’s using the Rehabilitation Service Education Fund from LWD</p>	<ul style="list-style-type: none"> <li>Starting <u>from 1998</u>, CRN and SHOs had organized a <u>public education carnival each year</u>. Gradually, the size of carnival was reduced to <u>fewer disease themes and less frequent</u> due to the decreasing participation of SHOs.</li> <li>There are several new SHOs established these few years. <u>In 2013</u>, CRN plans to <u>review</u> the needs and themes in public education programs.</li> </ul>
<p>(h) Consider organizing a Sub-committee on Advocacy to spearhead the effort to identify patient leaders and experts (and caregivers) of selective disease groups to be trained and practiced on leadership and advocacy skills, upgrade the capacity, and penetrate in the influence of the patients to the Healthcare System (PCH principle 2 and 3)</p>	<ul style="list-style-type: none"> <li>An Action Research Group under CRN has completed <u>6 action research projects to promote and advocate for patient needs and rights in the past 3 years</u>.</li> <li>An Advocacy Working Group was set up under the Committee of Rehabilitation of HKSR in 2010 which has formulated a list of recommendations in advocating for barrier-free environment.</li> <li><u>The Centre on Research and Advocacy (CRA) was set up in July 2012</u>. The Action Research</li> </ul>

	<p>Group was re-aligned to operate through CRA's coordination with the aim to put evidence-based research and advocacy under the same umbrella to enhance its growth and effect.</p>
<p>(j) Consider seriously about succession planning of Executive Committees and staff turnover of SHOs</p>	<ul style="list-style-type: none"> <li>• The Patient Mutual Support Division provides leadership training and consultancy support to the executive committees of the Self-help organizations. This is meant to support the SHOs succession, replacement and management.</li> </ul>
<p>(t) Enhance the quality of life for the disabled and chronically ill patients</p>	<ul style="list-style-type: none"> <li>• <u>Funding support and establishment of CRN</u> was supported by the Social Welfare Department <u>since 1997</u> with the aim to support and enhance the QOL for the disabled and chronic disease population.</li> <li>• Funding support and establishment of various <u>community-based services</u> to support the community living and rehabilitation of the target groups such as the enhanced home help services, outreaching rehabilitation services, day rehabilitation centres, meals on wheels, day care centres, etc.</li> </ul>

#### 4.6 Limitations

This study is exploring the understanding of the PCH concept from the patients' and caregivers' perspective while assembling the long standing expectations and hope from them. The scope covers the APMHO which has 44 SHO's of which 20 SHO's were involved in Phase 2 telephone interviews with 18 SHO's in Phase 3 focus group discussions. The total number of SHOs in Hong Kong is estimated to be over 100. Although 16 disease groups participated in this study, it is by no means exhaustive.

Therefore, the review by stakeholders especially the healthcare and rehabilitation service providers to the findings and recommendations are imperative to the appropriateness of the final report.

#### **4.7 Way forward**

As same as in other parts of the world, chronic diseases are exerting an increasing burden on healthcare systems and affecting the health and quality of life of millions of patients in Hong Kong. The World Health Organization (WHO) estimates that non-communicable diseases (NCD's), which WHO defines as four of the chronic disease areas of cancers, diabetes, cardiovascular diseases and respiratory diseases, cause an estimated 60% of all deaths globally. The Department of Health has estimated that NCDs cause over 80% of deaths in Hong Kong. This is placing an ever-increasing burden on healthcare systems which were originally designed to address acute medical conditions. In addition, many people live with a chronic disease, presenting a growing economic and social challenge in this territory alike.

Support for a patient-centred approach is growing globally and there is now a unique opportunity to move from the rhetoric of PCH and its ad-hoc practice to widespread practice. This quote from a WHO advocacy document regarding the additional skills healthcare professionals need in order to deliver PCH exemplifies the shift in focus of healthcare needed – “The essence of care is to centre on the patient. This is a shift from traditional provider-focused practice, and it requires the workforce to develop communication skills that empower patients through seeing health from the patient’s perspective and motivating and training patients in health-related self-management.”

We must not overlook or minimize the importance of patient engagement for initiatives towards healthcare reform to be successful but meaningful patient engagement is still often rhetoric rather than reality. All too often, the users of healthcare are only involved as recipients of care or at the end of initiatives in a cursory way with them having no real impact on the healthcare services available. And yet, people should be involved in the decisions that will affect their lives. In addition, the experience of patients and patient organizations has a lot to contribute. Patients and their families may notice medical errors and question treatment or raise concerns before they cause harm. Patients and their families are there throughout the patient journey and experience, and they see different things or things in a

different way to those working in healthcare who just see brief snapshots of a patient's experience and situation. The patient knows best how the situation and interventions are affecting their lives and can also see when there are positive or negative aspects of treatment, and therefore, they have a valuable role on an individual level.

The collective experiences of patients can also bring valuable insights to the development of quality and safe healthcare. Patient groups bring knowledge of the patient experience from large groups of patient populations with the ability to identify common experiences, different experiences and evidence of trends, and articulate what quality and safety means to them and what balance of benefit versus risk would be acceptable to them.

To conclude, in order to effectively address various healthcare issues and successfully implement healthcare reform in Hong Kong, paradigm shift by policy-makers and other stakeholders in healthcare sector is essentially needed. **Patient-Centered Healthcare and Patient Engagement** must be two core pillars in policy-making, strategy forming, and program planning. To achieve, political will and determination are most important and necessary.

## **REFERENCE**

Community Rehabilitation Network, Hong Kong Society for Rehabilitation (2012). HKSR website: Retrieved in September 2012, from <http://rehabociety.org.hk/e/getContent.asp?contentId=32391&menu=3>.

International Alliance of Patients' Organizations (2012). Declaration on Patient-Centred Healthcare. Web Page Information: Retrieved 19, August, 2012, from <http://www.patientsorganizations.org/showarticle.pl?id=712&n=312>

International Alliance of Patients' Organizations (2012). IAPO Website: retrieved in September 2012, from <http://www.patientsorganizations.org/index.pl>

Alliance of Patient Mutual Help Organizations (2012). APMHO Website: Retrieved in September 2012, from <http://www.i-patients.org.hk/>



## **Appendices**

### **Appendix 1 – User’s Perspectives on Patient-Centred Care**

- CEPA Symposium Powerpoint for 13 January 2012

Refer to URL:

[http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix1-User's PerspectivesonPatient-CentredCare-CEPASymposiumPowerpointof13Jan2012.ppt.pdf](http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix1-User's_PerspectivesonPatient-CentredCare-CEPASymposiumPowerpointof13Jan2012.ppt.pdf)

## Appendix 2 - Quantitative Survey Questionnaire (Individual)

### 「病人為本」醫療及健康護理服務 問卷調查

A. 背景資料：(若填表者為患者家屬或照顧者，請以患者情況填寫問題 5-8)

<b>1. 性別：</b> <input type="checkbox"/> 男 <input type="checkbox"/> 女	<b>2. 類別：</b> i. <input type="checkbox"/> 患者 ii. <input type="checkbox"/> 家屬或照顧者	<b>3. 年齡：</b> _____	<b>4. 患者病發年份</b> _____
<b>5. 病類(患者)：</b> i. <input type="checkbox"/> 腦創傷科 ii. <input type="checkbox"/> 腦神經科 iii. <input type="checkbox"/> 風濕科 iv. <input type="checkbox"/> 器官殘障 v. <input type="checkbox"/> 脊椎神經受損 vi. <input type="checkbox"/> 視障	vii. <input type="checkbox"/> 聽障 viii. <input type="checkbox"/> 精神科 ix. <input type="checkbox"/> 癌症 x. <input type="checkbox"/> 其他 _____	i. 中風/腦腫瘤/意外腦創等 ii. 帕金森症/腦瘤症/肌肉萎縮症/小腦萎縮症/重症肌無力症等 iii. 紅斑狼瘡/類風濕性關節炎/強直性脊椎炎/銀屑病等 iv. 腎病/肝病/心臟病等 v. 兒童脊椎裂/一般脊椎受損引致之癱瘓等 vi. 青光眼/視網膜病變等	
<b>6. 自顧能力(患者)：</b> i. <input type="checkbox"/> 完全自顧 ii. <input type="checkbox"/> 大部份自顧 iii. <input type="checkbox"/> 小部份自顧 iv. <input type="checkbox"/> 完全依賴照顧者		<b>7. 活動能力(患者)：</b> i. <input type="checkbox"/> 健行者 ii. <input type="checkbox"/> 輪椅使用者(手動) iii. <input type="checkbox"/> 輪椅使用者(電動) iv. <input type="checkbox"/> 其他助行器 v. <input type="checkbox"/> 長期卧床	
<b>8. 現在對患者身體之影響 (可選多項)：</b>		i. <input type="checkbox"/> 半身/全身癱瘓 ii. <input type="checkbox"/> 視力障礙 iii. <input type="checkbox"/> 聽力障礙 iv. <input type="checkbox"/> 說話困難	v. <input type="checkbox"/> 吞嚥困難 vi. <input type="checkbox"/> 影響記憶及判斷力 vii. <input type="checkbox"/> 其他

B. 長期病患者/照顧者對香港醫療及健康護理服務的評分：

9. 憶述 5 年或之前對以下服務範疇的評分	評分(1 為最差, 5 為非常好)
i. 病人的知情權(病情進度/藥物及治療方法等資訊)	1□ 2□ 3□ 4□ 5□
ii. 醫護人員尊重及禮貌對待病人及其家屬	1□ 2□ 3□ 4□ 5□
iii. 病人及家屬的選擇權(有不同治療方案供病人選擇)	1□ 2□ 3□ 4□ 5□
iv. 醫護人員的鼓勵(正面鼓勵說話及關懷)	1□ 2□ 3□ 4□ 5□
v. 病人直接參與制定醫療政策的機會	1□ 2□ 3□ 4□ 5□
vi. 提供針對病科的社會資源資訊(社工或醫護人員)	1□ 2□ 3□ 4□ 5□
10. 對現時醫療機構就以下服務範疇的評分	評分(1 為最差, 5 為非常好)
i. 病人的知情權(病情進度/藥物及治療方法資訊等)	1□ 2□ 3□ 4□ 5□
ii. 醫護人員尊重及禮貌對待病人及其家屬	1□ 2□ 3□ 4□ 5□
iii. 病人及家屬的選擇權(有不同治療方案供病人選擇)	1□ 2□ 3□ 4□ 5□
iv. 醫護人員的鼓勵(正面鼓勵說話及關懷)	1□ 2□ 3□ 4□ 5□
v. 病人直接參與制定醫療政策的機會	1□ 2□ 3□ 4□ 5□
vi. 提供針對病科的社會資源資訊(社工或醫護人員)	1□ 2□ 3□ 4□ 5□

Con't

<b>11. 期望(醫療機構於 5 年內最需要改善的範疇)</b>	評分(1 為最不需要, 5 為最需要)
i. 病人的知情權(病情進度/藥物及治療方法資訊等)	1□ 2□ 3□ 4□ 5□
ii. 醫護人員尊重及禮貌對待病人及其家屬	1□ 2□ 3□ 4□ 5□
iii. 病人及家屬的選擇權(有不同治療方案供病人選擇)	1□ 2□ 3□ 4□ 5□
iv. 醫護人員的鼓勵(正面鼓勵說話及關懷)	1□ 2□ 3□ 4□ 5□
v. 病人直接參與制定醫療政策的機會	1□ 2□ 3□ 4□ 5□
vi. 提供針對病科的社會資源資訊(社工或醫護人員)	1□ 2□ 3□ 4□ 5□
<b>C. 其他</b>	
<b>12. 你對現時香港公營醫療服務及健康護理服務的滿意程度</b>	評分(1 為最不滿意, 5 為最滿意)
i. 醫療收費	1□ 2□ 3□ 4□ 5□
ii. 醫生的治療水平	1□ 2□ 3□ 4□ 5□
iii. 輔助醫護人員(護士/各類治療師)的服務	1□ 2□ 3□ 4□ 5□
iv. 醫務社工的服務及支援	1□ 2□ 3□ 4□ 5□
v. 輪候醫療服務的制度	1□ 2□ 3□ 4□ 5□
vi. 病人自助組織/社區復康機構的服務	1□ 2□ 3□ 4□ 5□
<b>13. 照顧者最希望(需要)得到的服務及支援(患者可以不填此項)</b>	評分(1 為最不需要, 5 為最需要)
i. 照顧患者的常識及技巧	1□ 2□ 3□ 4□ 5□
ii. 財務支援	1□ 2□ 3□ 4□ 5□
iii. 持續治療及復康的方法及渠道	1□ 2□ 3□ 4□ 5□
iv. 心理輔導及支援	1□ 2□ 3□ 4□ 5□
v. 暫顧服務(包括日間及短期)	1□ 2□ 3□ 4□ 5□
vi. 院舍服務(包括私營及公營)	1□ 2□ 3□ 4□ 5□
vii. 支援團體(如病人自助組織/ /社區復康機構)	1□ 2□ 3□ 4□ 5□
<b>14. 其他意見</b>	

☺ 謝謝 ☺

## **Appendix 3 – Phase 1 with 862 Individual Questionnaires**

- From over 11 Self-Help Organizations from mid-Dec 2011 to mid-Jan 2012.

Refer to URL:

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix3-Phase1with862IndividualQuestionnairesfromover11Self-HelpOrganizations-20120916.pdf>

## Appendix 4 - Qualitative Survey Telephone Interview Guideline

### APMHO - Survey of Progress on Patient Centered Healthcare (PCH) in HK

#### 病人互助組織聯盟「人本醫療」在香港的進展調查問卷

##### Telephone Interview

Sequence No 編號:

Patient Organization Name 團體名稱:

Representative Name 團體代表姓名:

Role in the ExCom 在團體的職務:

Size of Patient Organization 團體規模:

Size of Patient Organization Executive Committee 團體執委會規模:

Date of Telephone Interview 電話訪問日期:

1. Do you think HK has made progress in PCH in the last 5 years from your disease group's perspective? Indicate in a scale of 1 - 5; 1 being no progress, 3 being average, 5 being excellent progress. 你的團體認為香港在過去五年推行「人本醫療」有進展嗎？(以 1 至 5 表示，1 為沒有進展，3 為一般，5 為進展極佳) □
2. In general, what are the top 3 major *areas* that the Healthcare System in HK must work on in the next 5 years? 總體而言，未來五年內，香港醫療體系必須優先處理的三大課題是什麼？
3. In your disease group, what is the *domain* that the Healthcare System in HK must work on? 你的團體認為，香港的醫療體系必須優先處理的範疇是什麼？
4. In your disease group, what is the top *task* that can be implemented? 你的團體認為，那些優先的具體事項(窄於範疇)可以落實？
5. Other comments for 其他意見
  - (a) Healthcare System in HK 香港的醫療體系
  - (b) Your specific disease group 你所屬的病類
  - (c) Others 其他

## Appendix 5 – Phase 2 Telephone Interviews Summary

With 20 Self-Help Groups represented by a Key Member for each SHG's Executive Committee from 20 Feb – 22 Mar 2012.

### (1) Profile of respondents and Analysis of Questions 1, 2, 5(a)

Refer to URL:

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix5-Phase2TelephoneInterviewsSummary-ProfileofRespondentswithQ1,2,5a-20120324.pdf>

### (2) Analysis of Questions 3, 4, 5(b) and (c)

Refer to URL:

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix5-Phase2TelephoneInterviewsSummary-ProfileofRespondentswithQ3,4,5b&c-20120324.pdf>

### (3) Quantitative Summary of Concerns by Questions

Refer to URL:

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix5-Phase2TelephoneInterviewsSummary-QuantitativeSummaryofConcernsbyQuestions-20120324.pdf>

## **Appendix 6 - Preliminary Report from Phase 1 and Phase 2 Powerpoint for APMHO on 27 March 2012**

Refer to URL:

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix6-PreliminaryReportfromPhase1andPhase2PowerpointforAPMHO-20120327.pdf>

## **Appendix 7 – Revalidation by HKU Excel3 Project in August 2012**

Refer to URL:

<http://braincare.comp.polyu.edu.hk/pch/PCH-Appendix7-RevalidationbyHKU20120824tidy.pdf>

**Appendix 8 – Phase 3 - Minutes of the two focus group meetings on 14 and 16 June 2012**

**擬稿**

**『人本醫療』進度調查聚焦小組(3)會議記錄**

---

**第一組會議**

日期：2012年6月14日（星期四）  
時間：晚上7時30分至9時30分  
地點：九龍橫頭磡邨宏禮樓地下（活動室三）  
主持者：曾建平(聯盟主席)，關雁卿(香港復康會)  
列席者：Jason Chan (香港大學)  
出席者

恒康互助社	狄國發(執委)
香港新聲會	鄭植宏 (副會長)
香港肝臟移植協康會	梁健平 (副會長)
香港斜視重影病患者協會	朱艷珍 (會長)
毅希會	葉志強 (副主席)
新健社	劉劍雄(主席)
慧進會	袁少林(主席)
腦同盟	周偉良(主席)
樂晞會	黃金鳳 (主席)



健樂社	梁耀開 (外務)
香港小腦萎縮症協會	曹綺雯 (副主席)
香港創域會	伍佩玲女士
香港肌健協會	劉偉明 (副主席)

## 第二組會議

日期 : 2012 年 6 月 16 日 (星期六)  
 時間 : 上午 10 時 15 分至 12 時 15 分  
 地點 : 九龍橫頭磡邨宏禮樓地下 (活動室一)  
 主持者 : 曾建平(聯盟主席), 關雁卿(香港復康會)  
 列席者 : Jason Chan (香港大學)  
 出席者 :

香港視網膜病變協會	譚世鴻(社會政策)
路向四肢傷殘人士協會	羅偉祥 (副主席)
香港家連家精神健康倡導協會	彭淑賢女士(主席)
腎之友	何愛英 (主席)
香港強脊會	林韋雄 (主席)

## 兩次會議內容匯總

### 1. 會議目的

- 按著『人本醫療』的五大原則(1)尊重.(2)選擇和自決, (3)病人

參與醫療政策，(4)服務使用權和支援，與(5)資訊；作為進度調查研究。在一月的 862 份個人問卷中取得初步啟示，繼而在三月舉行的 20 個病人自助組織電話訪問調查中，並摘要所得意見及歸納列出病人團體可行的具體事項，以供這次聚焦小組討論。

- 討論的結果將用作草擬紀念聯盟二十週年之『人本醫療』進度報告的出版物，並用作聯盟未來倡導工作之框架，改進及發展倡導工作。
- 透過聚焦小組討論，建立互信、同舟共濟、及同理心；並加深對『人本醫療』的認識。

## 2. 參與聚焦小組的病科

- 精神康復
- 喉癌
- 肝臟移植
- 斜視重影
- 類風濕關節炎
- 中風
- 腦損及中風
- 系統性紅斑狼瘡
- 鼻咽癌
- 小腦萎縮症
- 視網膜病變
- 四肢傷殘
- 精神健康倡導
- 腎科
- 強直性脊椎炎
- 神經肌肉疾病

聚焦小組所談論的具體事項，都是病人自助組織較為有把握操

作的，並希望可在未來五年內於本港醫療體系落實及發展。

### 3. 聚焦小組討論可行的具體事項 (具可操作性)

#### 3.1 擴大及改善醫管局藥物名冊的涵蓋面和運作機制，並增加資助 (『人本醫療』原則 3, 4, 5)

##### 3.1.1 檢討撒瑪利亞基金規則 - 放寬現時的嚴厲限制，把更多有需要的人士納入受惠之列，

進度：香港肌健協會報告在 2012 年 2 月已得到醫管局將干擾素納入專用藥物名冊內，每次藥費\$10。自 2005 年起干擾素被納入藥物名冊自費購買類別，每月病人負擔費用約\$8,000，有需要者可申請撒瑪利亞基金。

##### 3.1.2 增加新一代的精神科藥物

增加精神科藥物的透明度供病人選擇，盡量用較新的藥物，以減少不良副作用及後遺症，間接可減少傷人與傷己的事件。

新一代的精神科藥物顯然比舊一代的優勝，較少副作用及後遺症。有個人經驗的照顧者表示觀察到病人用舊一代藥物的十多年內，全無個人自信及自我形象低落，情況令人擔心；轉用新一代的藥物後精神病不但沒有復發，而且康復進展良好，已從新投入社會。家連家精神健康倡導會的會員因而請求使用新一代藥物，結果令人滿意。但新一代藥物多為自費藥物。

部份精神病患者常因逃避副作用，沒有按時服藥而出亂子。政府應該多撥資源把新一代藥物引進藥物名冊，令部份患者可以控制病情，加速康復，從新投入社會，增加生產力，並減輕家人的擔子。

##### 3.1.3 引進醫治黃斑病變之藥物

現在已經有醫治黃斑病變之藥物 Lucentis，正爭取列入藥物名冊。現在每年有 3,000 新症，但醫管局每年只有 250 個資助名額。

##### 3.1.4 引進較有效及副作用較少的中風藥物 - 查閱 3.8.

##### 3.1.5 鼻咽癌(NPC)每年作 EB 病毒及 ENA 檢查 - 現在香港只有威

爾斯親王醫院可進行此類檢查，NPC 患者需要半年或一年檢驗一次。惟此檢驗並非屬於藥物名冊，建議這項目將放在其他類別之訴求。

### 3.1.6 資助新一代 COX-2 抑制劑

強脊會發言人指出新一代的消炎止痛藥 COX-2 已面世 10 年，可代用於生物製劑，惟現仍未放進藥物名冊的普通科或專用藥物。COX-2 對胃與下腸道具有保護及療效作用，相對醫管局卻將只保障胃的舊藥 PTI(?)，納入藥物名冊，縱使 COX-2 與 PTI 價格相同。近來該會會員長期服用非類固醇的消炎止痛藥的，很多都下腸道大量出血。病友看專科的時候，前線醫生往往樂於將 COX-2 處方到街外購買。該會曾經三番四次向醫管局要求將 COX-2 納入藥物名冊，皆不得要領。

### 3.1.7 資助生物製劑(類風濕性關節炎，強直性脊椎炎)

#### 第一組的關注

強脊會發言人指出現在只有千多名病人獲得撒瑪利亞基金資助生物製劑，其中審查限制甚多；今年限制放寬少許，亦只有二千多人受惠，透明度亦不高。

這十年來，醫管局在更動藥物名冊時並沒有諮詢病人組織，甚至不公開其評審委員會名單，從『人本醫療』的角度來看，藥物名冊應要有適當的透明公開程度，需要有病人的參與和意見。只靠兩小時的病人交流會，就決定百多樣藥物成為藥物名冊之列，這並不是諮詢，只是通知。我們病人組織更應倡導參與製訂藥物名冊。

今後病人組織應該積極地參與藥物名冊之檢討、諮詢、改動及增減名冊上的藥物。醫管局當確立機制以符合『人本醫療』的準則。病人組織個別已吸納病人各種意見，可從各聯盟組織的代表中參與並共同制定主流倡導計劃；包括醫療、藥物處理、制度與政策，根據可行性排列次序，一起策劃倡議行動。

#### 第二組的關注

與會者認為應列明藥物的療效與副作用，讓病人明白及作出選擇；病人有權知道藥物的副作用，而醫生亦可以建議副作用處理之方法。

醫管局處理藥物名冊，好像黑箱作業。

第一：醫管局從未諮詢各病人自助組織，甚至無公佈專家小組名單，免受騷擾，程序鮮有病人參與，缺乏應有之透明度。

第二：醫管局吸納入藥物名冊的藥物需符合下列原則-(1)安全，(2)療效，(3)副作用，(4)成本效益等等。這只是醫管局方面的看法而病人組織無權過問。在西方國家，就有醫療科技採用客觀準則評估各種藥物，包括安全、療效、社會成本、社會經濟學或藥劑經濟學的計算方法；揭示有時雖然藥品是較貴，但對社會的影響卻大。在香港就未有公佈任何客觀準則。

第三：醫生往往替病人決定治療的方法及藥物，而沒有與病人溝通各種選擇，或解釋各樣療法的好壞，共同決定。這正是『人本醫療』五個原則的精髓所在 - 尊重，充權與提供資訊以共同作出決定，病人在各方面的政策參與(如藥物名冊)，使用服務及支援的權利，及獲取各類資訊的渠道皆不足。

藥物名冊、服藥、用藥會於今後幾年成為病人組織的重點倡導。參考英國國民保健服務系統(National Health Service System)，當地已開始製訂決策工具，提供資料予病人參與用藥的選擇。雖然香港與英國稅制與保障制度不同，難以作絕對比較，但鼓勵病人充權及參與決定，依然是香港值得借鏡和推動的方向。

安全用藥：如藥物處理以防療效消失(放於雪櫃)及過期藥物的處理亦是教育的課題。

### 3.1.8 改良腎科藥物

腎科的病人若換腎需用抗排斥劑及洗腎的藥物皆自費，要是負擔不起而改用藥物名冊上的舊藥，又有不良副作用。

## 3.2 提升病人自助組織管理能力 (『人本醫療』原則 2, 3, 4)

以往只靠專業人士，醫療人員或食衛局的 AO，未必能完全的關顧到病人的需要。欠缺病人及病人組織的參與，就欠缺了病人對治療效果的回應，醫療質素難以得到保證。病人雖然不一定受過醫學培訓，但藥物對他們帶來的影響，沒有其他人比他們自己更清楚。這亦是『人本醫療』的第 3 項原則，就是必需有病人與病人組織在不同的層次參與，包括執行和監察等等。

政府協助病人組織發展，倡導病人參與，但若要病人做稱職的持份者，則必須加強病人組織的參與，政府當予以經濟上的支持，提升病人領袖的訓練，增強能力，並加強認識醫療制度與系統，並向各病人組織收集主流意見，。但事實上政府支持卻在減少，原因是病人組織的數目正在增加而社署的資助預算卻

維持不變，尤其是在百物騰貴之下，預算更是捉襟見肘。這對病人組織並不是承擔，而病人自助組織的發展也受到局限，甚至倒退。聯盟主席曾先後向兩屆社署署長反映病人組織的津貼問題，特別是聘請的同事薪酬應按物價上漲幅度調整，但皆得不到回應。除了社署極為有限的津助外，政府從未對自助組織的營運和發展表示關顧。

若是政府真的希望吸納病人加入醫療體系，理應在政策及資源方面加以配合，規劃財政預算以配合政策推行，推行有質量的疾病交流會與研討會，培訓更多的病人領袖，以應付不斷增長的長期病患者及老人，令病人組織的能力及管理質素不斷提升，更趨成熟，並得以應用知識與經驗，參與醫療政策形成及跟進。

在第一次會議中，13 個病人組織用一個自我評核的方法，以看看組織的成熟程度，得到的結果是：

等級	組織成熟程度	數目(#病人組織)
5	最成熟	0
4	成熟	2
3	普通	7
2	不大成熟	1
1	不成熟	2

(謹用以參考資料，並不用作公佈)

一出席者提出病人組織委員會委員有因病情轉變而需要停下職務，留下空缺而待補。另一出席者則認為最重要的是有一個好的制度由人去執行，可減少人為的弱點。另有意見則指出制度是人為的，一旦換了人，制度亦可改變。

一出席者認為提供人力培訓是當務之急，對自助組織提升管治能力是必需的。培訓若是由政府安排，或許會有人用陰謀論看，覺得受到不適當的干預；要是由機構如社聯負責培訓的，又要考慮對方的思維方式是否合適。另外，現時模式由社署資助病人組織來說，有若干問題存在；但若以 NGO(非政府組織機構)的形式，用很高的問責制來管理，到底又有多少個組織能受得起這般考驗呢？

一出席者認為協助提升自助組織管治能力的最實際方法，就是政府給予這方面的特別津貼，訓練在自助組織擔任重要職位的病人(或照顧者)，加強管治及各方面能力，並吸納更多的領袖人材。

一中風自助組織主席認為 3.2 該改為『加強病人自助組織的支援』。原因是：(1) 這是政府對我們的資助；(2) 我們自助組織

還需要很多的支援，作為中風康復者，我們需要很多的運動，物理治療，需要場地與設施，但很多時卻找不到，我們亦需要持續復康治療，如物理治療及其他最新資訊，這是醫管局及食衛局是可以協助的。

## 第二組的關注

自助組織常遇到的挑戰(1)資源有限，請不到有資歷的幹事職員；(2)因病的緣故，時有缺席的執委；(3) 領導能力參差，變成發展的障礙。

另一看法是分 2 個層次來說：(1)執委會 - 自助組織不同商業管理，每自助組織常倚靠主席的管理模式，或民主或賓主或專制或參與管理，各適其式，執委的強弱亦有影響。政府可以給予資源，以訓練執委會的領導才能，怎樣去做個有效的管理人，運用不同的手法及包容的態度，以達致組織的目標。但有些以純義工的心態當執委，有剩餘的時間才做執委的工作，以致部份有心的執委負荷過重。(2) 職員 - 若是社工或專業人士學歷出身的，很容易引起與主席或委員的衝突，個人的體驗就是我們既然同一組織應曉得共融，並以最低成本以達到最高效益，大家服務有需要的人。另外，職員晉升的機會亦有限，通常一兩年就離職，自助組織又要重新訓練新的職員，甚為吃力；主席是否很難兼顧內外的需求呢？

從政策更高的層面來說，假如政府認為醫療體系需要病人參與的話，理應考慮調配一定的資源以支援病人組織的發展。每年在遞減的津貼卻證明政府漠視病人組織的價值，若是政府著意培訓病人組織的能力及重視其發展，在醫療服務上發揮更大的作用，必需投放人與錢培訓一批各類病科的病人領袖，可以領導病人組織參與醫療服務發展。在我們見證的問題中，可見病人與病人組織並未被放進政策中認真考慮，雖然有些病人在工作小組內，但作用不大，此種安排並非制度化而是隨機的，就算病人有合理的建議，亦只是紀錄在案， 有沒有採納是另外一回事，到底病人可否發揮持份者的作用，端看政府的取態以及配合政策的資源投放。病人組織常有困難尋覓繼承人，新的接班人要有心有力，及支援配合。

新的一屆政府需要明白病人與病人組織發展的重要性，提高其功能及結構管治能力，在醫療政策制定方面，刻意培訓病人組織領袖以增強其影響力。病人組織若是連成一氣當可增加影響力，甚至向新的立法局醫療界議員或衛生事務委員會商議，見招拆招，亦未常不可行。

### 3.3 正視斜視重影病患無立體感納入殘疾人士及特殊學障

(『人本醫療』原則 1, 2, 5)

此病患暫時只視為病徵而非病類處理，在政策上的訴求是特定

病類個案，有待醫管局處理。在定義上，此病患非 8 大學障，非傷殘，但常帶來受傷與不便，並令患者長期的心理障礙，家人擔心。

### 3.4 增加暖水療的設施 -水中運動對風濕科病患者有顯注的療效(風濕病科)(『人本醫療』原則 1, 4)

#### 第一組的關注

在電話訪問中，毅希會及強脊會有懇切的需求。公立醫院只可在星期六/日供給水療時間，供給的地方太少及有時間限制，有小部份公眾泳池亦有部份供應，但暖水卻並不乎合溫度的需要。出席者的訴求是在新建或重見的公眾泳池設置合乎醫療的暖水池作為水療，令風濕病科病人、老人家及有需要的人可以使用並從而得到舒緩。另一出席者得悉醫管局曾向外發表聲明表示積極增建水療池，正好用這佈告要求醫管局公開具體計劃及各項設池的落成日期。這建議將在特定病類中出現，如 3.3。

#### 第二組的關注

2012 年 4 月起，醫管局開放轄下的水療設備，供有關組織減費租用，剛收到消息需要有物理治療師在場並負全責，為此我們的組織甚為困惑，因這條件太苛刻。前天有提議在新公眾泳池設立水療池，這安排會將康文署設施與醫療(醫管局)的服務混雜，會有難度。九龍公園泳池也有暖水池的設施；要趕快安排小組開始倡導工作，向政府反映新建及重建的泳池增建水療的需要。

### 3.5 提供醫療券給予長期病患者 (『人本醫療』原則 1, 2, 4)

#### 第一組的關注

現時制度對風濕科及免疫系統病患者造成不便，患者往往在痛症及病徵出現時向急症室求診及入院觀察，浪費資源。若有醫療券，他們便可以向家庭醫生或社區醫生求診，省卻診治時間及減底對公營醫療系統的壓力。會內大部份的組織皆同意，精神科的治療則略有不同。

#### 第二組的關注

醫療券可以轉移一些非急症的病人到社區家庭醫生，減輕急症室的壓力，使公私營醫療系統互相發揮所長，病人也有權選擇醫生。



另有意見是看專科的價錢比較貴，用醫療券，可能無補於事；各病科亦可能有不同的情況。

醫療券現可存留使用，是一個有彈性的設施；盼望將來會覆蓋老人牙科保健。

從另一角度看，公營醫療的成本每天\$3,000 多元，急症室的成本也不菲，若將這些成本部份轉為醫療券，來應付因社會高齡化所增加的醫療負擔，未嘗不可行。

### 3.6 支援照顧者及增加公民教育 (精神康復； 斜視重影病；

系統性紅斑狼瘡，硬皮症， 血管炎， 乾燥綜合症； 小腦萎縮症) 照顧者 (『人本醫療』原則 4，5)

#### 第一組的關注

眾人與主席皆同意支援照顧者比公民教育為先，照顧者正在水深火熱中，每天為看顧患者憂心煩惱，比患者尤甚。

3.2 與 3.6 應放於同等的優先具體事項。有些照顧者甚至放棄工作來照顧患者，犧牲自己，其志可嘉，有的甚至患上情緒病(抑鬱症)。

小腦萎縮症的出席者道出病發後，醫生冷漠地告知此為不治之症，也沒有安排物理治療，亦無心理支援，使患者與照顧者無奈地接受現實。

照顧者對精神康復病人尤其重要，要是照顧不周，隨時會出事，累己累人。

照顧者需要經濟支援如乘車半價證，以及資訊傳達。

嚴重傷殘者的津貼現有患者及需要照顧部份，但沒有為照顧者而設的津貼。

教育照顧者在各自助組織進行是比較理想的選擇，因為可分享類似的病人照顧知識與經驗並組成網絡。3.2 與 3.6 可結合作講座的專題。

#### 第二組的關注

照顧者需要有基本護理知識，嚴重傷殘者(如路向)指出四肢傷殘照顧者需懂得衛生處理如喉管處理及其他維生的設施。除此，照顧者/家人亦需支援，或許是社工或醫務人員，其中包括(1) 經濟 - 除嚴重傷殘四肢傷殘有照顧者津貼外，其他病科還未在考慮之列，(2) 知識的支援 - 怎樣護理病人及其生活上的需要，(3)情緒上的支援，(4) 社區的支援如互助的網絡。

從醫院返家，照顧者/家人成了病人的支柱，他們需要知道病的

知識，醫護人員負責藥物方面，照顧者執行輔助的料理，他們需要明白藥物的副作用及徵兆處理，亦要尋找社區支援，應付危機處理。

媒體如廣播電台電視、網上學習、宣傳單張也是好的渠道，多看及多聽各種病的成因及預防知識，可警惕不同年紀的人對健康的重視。

## 公民教育

### 第一組的關注

公民教育的受眾是一般市民，像路向到學校分享及進行生命教育。以前 CRN 每 2 年有舉辦社區嘉年華會，讓各病人組織擺設攤位向市民介紹各病科、病人及有關的需要；現在好像很久未聽到有這樣的活動，間中也有醫院示範病科。席中人認為踏進社區派單張，接觸人群，是最有效的宣傳方法。

有意見認為讓政府牽頭帶動公民教育，因病人組織沒有能力動員這麼多資源。但實際上，個別也有較大規模的講座及嘉年華，如腦科病友組成的腦友心舉辦的活動。主席報告勞福局每年也有 4-5 百萬元資助公民教育，名為『康復服務工作教育基金』，每年二月開始申請，三月截止申請，四月批出；自助組織可以參與申請。

關於中小學的學科，以前也有『健康教育』，是一般性的層面；不過現在已不存在，看來教育局也是時候再納入學科的時候了。

肝臟移植協會近期在幾間中小學推行『肝康大使』，宣傳肝的健康。

主席以各個病人組織所做的公民教育是件好事，一方面可接觸社區及市民，又可認識病人及病人組織；另外透過這些活動，可以令病人更熟識其病科而令執委及會員能力提升。不過，在資源分配上，就需要動腦筋。

### 第二組的關注

預防勝於治療，教育應該從小開始，剛才的醫療體系圖中，缺少了教育局的參與。從小學開始，就需要灌輸健康教育，以明瞭生理及心理的健康與病之關係，減少、預防、及盡早察覺疾病的發生，間接地成為醫療系統之持份人。

## 3.7 臨終病人的選擇（『人本醫療』原則 1，2）

在香港肌健協會內，有三十多位的臨終病人，希望是能回家渡過餘年，要是醫管局或醫療體系能為他們在家購置醫療設施及安排照顧者，費用每月約 1-2 萬元；這樣比較住院的費用約每月 9 萬元，更見成本效益及合乎病人意願

## 第一組的關注

肌健會出席者指出其它病科也有同樣情況，當病人已近生命最後期，若是有意願返家，醫療系統該安排在家購置醫療設施及安排照顧者，將醫院的費用(9萬元)轉為在家的特種醫療津貼(<2萬元)，以免浪費公帑。這正是『人本醫療』第2原則的精髓，就是醫療體系會因人而施，在體系中照顧個別病人的需要。

其實，很多的長期病患也可以在社區及家居做康復，減少留在醫院的時間，無論經濟及支援配套如社康護士、藥劑師等等，如能在社區配合，比現在有事就入院為佳。這先導計劃側聞已在觀塘區推出兩年，未知結果如何。

這正引出是推動『社區為本』的治療、康復、或照顧。

## 第二組的關注

有些重病不能治愈而每況愈下的病人，既不符合綜緩也得不到關愛基金的幫助，只得留在醫院，插著各類喉管以維生，等待死亡的來臨。若是政府能撥款設立特殊基金給這一群人返家渡過餘生，比較住院的成本每人省卻7-8萬元。

### 3.8 加強對中風病患者的支援（『人本醫療』原則2，4，5）

- 正式設立政府醫院 24 小時中風急救服務
- 增加中風病房床位 - 中風病人一般住院時間太短
- 希望可在復康醫院逗留多一點做物理及復康職業治療
- 過早將未穩定的中風患者由腦神經專科轉至地區診所的普通內科跟進
- 希望院方不要過早將中風患者轉介內科跟進
- 增加覆診次數

現時中風病人在 2-3 星期便要出院，跟著的康復期需要安排到日間康復中心(醫院或社區)繼續康復治療，包括物理治療、職業治療、言語治療、心理治療、護理、及適應中風後的身心靈康復以適應未來的新生活。

中風後首 6 個月是關鍵及最有效的康復期，醫院到日間康復中心的過渡期安排並不一致，從日間康復中心再回社區的編排也不一樣。病人自助組織其實可以在中風後過程中發揮力量，現時有少部份醫院有病人自助組織參與。若是自助組織的工作能夠與各醫院及中風日間康復中心有某程度的配合，相信是對病人幫助更明顯。

中風病人的訴求：在病患者離開公營醫院時，醫療系統可以給

予起碼的使用權到日間康復中心進行康復治療及供給相關的交通配套。相對十年前，中風患者可住院數月，這樣的轉變背後理念相信是財政，治療產量量度相對病人需要的結果。

另有在私營醫院治療的中風患者，出院後很難找到合適的復康配套，加上地點不便，令康復進展受阻。訴求：日間康復中心應分佈各大社區，讓公私營的病人皆可選擇及使用。

因家居無升降機，只能留在復康醫院接受康復治療，期望醫院能體諒個別的情況，允許適當延長住院期。須知道中風者需要長期復康，社區裡面，實在對中風患者的支援不足夠，單單靠在家居簡單的改造，只可以幫助日常生活的必需及基本運作，並不能滿足中風患者所需的運動方式及生活模式；於是，中風患者便留在家『自生自滅』了。我們的訴求是：政府需要給中風患者長期的康復治療，在社區繼續治療，讓我們能達到治療的最大極限。最後，就是政府醫院 24 小時中風急救服務的推行，現在只有伊利沙伯醫院及威爾斯醫院有這樣的服務，但威爾斯醫院只限於星期 1-5，我們幾個中風自助組織正在向醫管局倡議在 7 個醫院聯網，每聯網都要有 24 小時中風急救服務。

補充：增加白車的救護員及急症室護士對中風評估的認知和培訓，將中風病人在最短的時間內送至 24 小時中風急救服務醫院，以減低失救與後遺症的風險。給予 999 接線生指引以辨別中風的徵兆。

設立更多的日間康復中心，以達到持續康復之目標及減低醫院治療師的壓力

總括來說，就是要求(1)在 7 大聯網皆設 24 小時中風急救服務，(2)住院的時間能因應病患者需要而適當地延長，(3)在社區增設地方及設施支援病人康復之需要，(4)加強對前線人員的培訓。

### 3.9 提供視障，聽障及老人的特定醫療配套需要 (後加的事項)

(『人本醫療』原則 1, 4, 5)

視障人士及老人家需要一個容易處理藥物的資料系統(如盲人點字)印在標籤上，讓他們能自己處理藥物。

整個公營醫療服務的無障礙建設 - 包括醫院通道(尤其舊醫院)，廁所，急症室(如廣華醫院)，醫院位置(如瑪加烈醫院)及訊息，應按照聯合國殘疾人士公約的要求而架設。

還有，醫管局普通科門診一定要打電話掛號，傳真亦不能，聽障的朋友並不能處理，有組織就此事曾與醫管局通會惟不得要領。其實醫管局可以考慮以流動電話 SMS 處理。急症室走廊很多也沒設顯示器，以供聽障的朋友方便。

## 4. 在我們可操作範圍外，我們以持份者的身份可擔當的角色

4.1 應該用非激烈的『主動』，以和平的手段，通過建議或研究方式，得到結論，繼而與有關當局磋商。我們病人組織剛才互動的溝通，對政府來說，是節省資源而效果彰顯的討論。

#### 4.2 聚焦小組對香港醫療體系之十大課題的優先次序

原先有 9 大課題，第 7 個課題增加醫療資源投放與處理醫療融資問題將控制範圍內與外放在一起。因此，決定將第 7 個課題分成 2 個課題，變成共有 10 大課題。

(各組織可以投票選擇三個優先的課題)

十大課題	投票次數
1. 減輕長期病患者在藥物上的財政負擔	13
2. 增加醫護人員數目	1
3. 確保並提高醫療服務質素	3
4. 縮短覆診輪候時間	0
5. 提倡尊重病人知情權、參與政策制定等權利	11
6. 提升患者自理及照顧者護理病患者的能力	9
7. 增加醫療資源投放	11
8. 處理醫療融資問題	1
9. 加強有關預防及各類病徵的社區教育	4
10. 應對人口老化，對醫療系統作出籌劃	1

## 5. 結論

經過今年 1 月第一階段向 862 病人/照顧者進行個人問卷調查，及今年 3 月第二階段向 20 個病人自助互助組織的電話訪問，與及今次 6 月中第三階段的聚焦小組，共有 18 個病人自助互助組織參與，我們以互動的形式，令大家對『人本醫療』及病人參與的概念和實踐有進一步的認識。

我們收集了很多的寶貴意見，加深了各組織的互相了解，亦對『人本醫療』有了進一步的認識，從而可以作為一個起點，樹立基線，建立未來 5 年的目標。

報告書將會分別以中文和英文撰寫，由聯盟、復康會、與港大合作，並由各持份者提供意見，於 10 月時會制作為聯盟 20 週年刊

物。

另外，此報告將會成為聯盟今後幾年的政策倡導框架，推動聯盟倡導政策的方向，運用『人本醫療』的概念，爭取病人參與，提升醫療制度和服務。

## Appendix 9 – Examples of CRN Research and Project Reports

<u>Year</u>	<u>Project name</u>
2002	Outcome Study of Community Cardiac Rehabilitation Program
2002	Public Awareness, Attitude, and Understanding of Epilepsy in Hong Kong
2003	An Exploratory Study on the Effectiveness of a Community-based Stroke Prevention Program for Clients with Minor Stroke
2004	An Evaluation of Self-Management Program for People with Ankylosing Spondylitis
2004	Cognitive-Behavioural Treatment Groups for People with Chronic Physical Illness in Hong Kong_ Reflections on a Culturally Attuned Model
2005	A Training Workshop on Late Stage Dementia Care for Family Caregivers
2005	Does Pulmonary Rehabilitation Give Additional benefit over Tiotropium Therapy in Primary Care Management of Chronic Obstructive Pulmonary Disease
2005	The Effects of a Community Based Water Exercise Program on Health Outcomes for Chinese Patient with Rheumatic Disease
2005	中年長病患照顧者壓力調查研究
2005	類風濕性關節炎患者自我管理課程成效評估
2006	Effectiveness of School Education Program on Epilepsy for Primary School Students
2006	Incorporating Family Therapy into Asthma Group Intervention_A Randomized Waitlist- Controlled Trial
2006	The Psychometric Properties of the Diabetes Management Self-efficacy Scale for Patients with Type 2 Diabetes Mellitus in Hong Kong
2006	The ‘Diabetes Mellitus Self-help Course’ Outcome Study
2006	互助小組組長訓練課程成效評估
2006	長期病互助小組成效評估研究
2006	醫務人員如何促進病人管理長期病調查報告
2007	Evaluation of the Chronic Disease Self-management Program in a Chinese Population
2007	Group Process and Outcome of the Chronic Disease Self-Management Program (CDSMP)_A Qualitative Study
2007	Group Psychosocial Program for Enhancing Psychological Well-being of People with Systemic Lupus Erythematosus
2007	Perceived Factors to Group Exercise Adherence in People with Chronic Disease in Hong Kong

- 2007 Pilot Project on Diabetes Self-management Services from General Out-Patient Clinic to Community
- 2007 Skills transfer project in organizing the Community Rehabilitation Program (CRP) for elderly suffering from stroke at a District Elderly Community Center (DECC)
- 2007 長期病患者家庭問題調查
- 2008 Weight Management Factors Affecting Weight Maintenance after Participating in a Weight Loss Program, from the Perspectives of People with Obesity
- 2008 長期病患者對死亡的態度及為後事作準備的情況調查
- 2008 長期病患者腹腔脂肪認知程度調查
- 2009 A survey of public health services in Tuen Mun: Fostering responsive healthcare for patients
- 2010 Evidence-based outcome evaluation of the “Breakthrough from Epilepsy” Self-Management Programme
- 2010 長期病患者對基層醫療服務改革的擔心與期望調查
- 2010 Love life as it is: An evaluation on a life and death educational group for people with chronic diseases in Hong Kong
- 2010 The effect of a Satir-based psychosocial group enhancing self-esteem interpersonal relationships of persons with chronic illness in Hong Kong: A randomized controlled trial
- 2011 長期病患者使用保健食品情況調查
- 2011 Effects of a newly developed community-based stroke rehabilitation programme in Hong Kong
- 2012 The sleep hygiene project: Can you sleep through the night? A new service model to enhance awareness of and coping with insomnia

- End -