

Progress of Patient-Centered Healthcare in Hong Kong  
A survey re-validation report

Alliance for Patients' Mutual Help Organizations (APMHO)  
Community Rehabilitation Network of the Hong Kong Society for Rehabilitation  
(CRN, HKSR)  
Excel3 – The University of Hong Kong (Excel3, HKU)

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# Chapter 1 Introduction

- 1.1 According to the Institute of Medicine (IOM), **patient-centred healthcare (PCH)** is “**care that is respectful of, and responsive to, individual patient preferences, needs and values**”. It is personalized care that provides the chance for patients to choose whether and to what extent to have control over their health care decisions (Cropley, 2012; Hudon et al., 2011). Recently, growing empirical evidence shows that implementation of PCH may contribute to a series of positive outcomes such as improved quality and safety of care (Isaac et al., 2010; Wolf et al., 2008); enhanced emotional health status and life satisfaction (Steward et al., 2000; Wolf et al., 2008); and lower readmission and referral rates (Cropley, 2012). Owing to the positive effects of PCH, an increasing number of healthcare organizations, research institutions, public policymakers, and patients themselves all over the world have been interested in examining PCH. There is an also increasing recognition of the importance of fostering compassionate, respectful and dignified healthcare.
- 1.2 The study, consisting questionnaire surveys in 862 patients with chronic conditions and telephone interviews with 20 self-help organizations (SHO’s), aims to examine the development of PCH in Hong Kong public hospitals by comparing the patients’ subjectively-perceived views towards its past, present, and expectations for future in terms of *right to know, respect, choice, support, involvement in relevant policymaking process and access to information*. In addition, this study attempts to identify the perceptions of PCH in Hong Kong among different disease groups of patients. Findings of this study are of great significance to enable health policy debate and to facilitate evidence-based policymaking.

## Background of the survey

- 1.3 Based on the *Declaration on Patient-Centered Healthcare* (IAPO, 2012) published by the **International Alliance of Patients' Organizations (IAPO)** in 2006, the **Alliance for Patients' Mutual Help Organizations (APMHO)** and the **Community Rehabilitation Network** of the **Hong Kong Society for Rehabilitation (CRN)** had launched a survey project named “*The implantation progress of patient-centered healthcare in Hong Kong*” (「人本醫療」在香港的進展調查) between December 2011 and September 2012. Two surveys were conducted from December 2011 to May 2012 and

re-validated.

- 1.4 The objective of the survey project is to:
- (a) Compare the patients' subjective views towards six critical domains with reference to evaluation of the past situation, present condition and future expectations.
  - (b) Set up a base line for measuring the implantation of patient-centered healthcare in Hong Kong with the effort of patients from different patients' self help organizations.
  - (c) Serve as the protocol for future advocacy work
  - (d) Serve as a significant event celebrating the 20th Anniversary of the APMHO.
- 1.5 In the *Declaration on Patient-Centered Healthcare* published by the IAPO in 2006, it proposed five principles which health care should based on:
- (a) Respect
  - (b) Choice and empowerment
  - (c) Patient involvement in health policy
  - (d) Access and support, and
  - (e) Information provision

### **Research Methodology**

- 1.6 The survey consists of 2 parts: (a) Self-reported questionnaire filled by members of SHO's affiliated to the APMHO (quantitative research), and (b) An in-depth telephone interview with the representative of the executive committee members of SHO's affiliated to the APMHO (qualitative research).
- 1.7 Both the self-reported questionnaire (Chapter 3 Data Analysis for Quantitative Survey
- 3.1 Among the 862 completed questionnaires, 492 (57.1%) were under the age of 60 whereas 339 (39.3%) aged 60 or above. On the other hand, 355 (41.1%)

were male whereas 498 (57.5%) were female.

3.2 They reported chronic conditions or illness as follows: brain trauma (24%); neurology (15%); rheumatology (17%); visceral disability (9.3%); spinal injuries (4.3%); visual or hearing impairment (3%); mental illness (4%); cancer (3%); and others (2.6%).

3.3 As for their self-care ability level, 36 (4.2%) rated themselves as dependent; 348 (40.9%) rated themselves as partially dependent; and 467 (54.9%) rated themselves as independent. In addition, 9 (1.1%) participants rated their mobility level as bed-bound; 286 rated themselves as assistance needed when walking; and more than half (n=555; 65.3%) stated that they could walk without any aid.

3.4 Patients' perception of PCH

(a) Among the six domains for PCH, patients rate the following in the descending order (Table 3.1): (1) HCP's attitudes toward patients and family members; (2) patients' right to know the real situation; (3) HCP support and encouragement; (4) patients and families' right to access different treatment choices; (5) provision of relevant information and resources; and lastly (6) patient involvement in the formulation of health and medical policies.

(b) For all six domains, there is a trend that the patients rate the present situation (total score = 18.85) better than the past situation (total = 17.32), whereas the future situation (total = 24.98) also better than the present one.

(c) With reference to people with different self-care abilities, people with higher self-care ability tend to rate higher than people with lower self-care ability. People with higher activity level also tend to rate higher than people with lower activity level.

(d) People with higher ages tend to rate the current medical system higher. People with the chronic illness earlier than 2002 also rate higher than those who attain the illness after 2002.

(e) As far as the satisfaction is concerned, the highest rating is the service from rehabilitation agencies and self-help organizations (mean = 3.51), followed by fee (3.46), service from paramedical services (3.37),

treatment quality of doctors (3.32), support from medical social services (3.18) and the waiting time (2.49). It shows that patients in general would like to have a shorter waiting time. The total mark for satisfaction is 19.4/30, i.e. 65%, which is not a high satisfaction rate.

Table 3.1

Patients' Perceptions of Various PCH Domains

<b>PCH Domains</b>	<b>Patients' Perceptions of PCH</b>		
	Ratings for the Past ( <i>Mean</i> )	Ratings for Present ( <i>Mean</i> )	Expectations for Future ( <i>Mean</i> )
1. patients' right to know the real situation about their illness	2.99	3.27	4.24
<i>paired sample t-test</i>	0.28***		0.96***
2. HCP's attitude (respect and courtesy) towards patients and their family members	3.27	3.4	4.18
<i>paired sample t-test</i>	0.14***		0.77***
3. patients and their families' right and access to different treatment choices	2.91	3.14	4.17
<i>paired sample t-test</i>	0.23***		1.03***
4. HCP's support and encouragement for patients	3.07	3.27	4.17
<i>paired sample t-test</i>	0.21***		0.91***
5. patient involvement in the formulation of health and medical policies	2.39	2.7	4.02
<i>paired sample t-test</i>	0.31***		1.33***
6. provision of relevant and useful information and social resources	2.79	3.06	4.17
<i>paired sample t-test</i>	0.27***		1.12***

## Chapter 4 Data Analysis for Qualitative Survey

- 4.1 Interviewees were instructed to share four questions (Appendix II for the questions). In question 1, they were required to rate the development of the implantation progress of patient-centered healthcare in Hong Kong with a 5-point scale (1 being no progress whereas 5 being excellent progress). According to Table 4.1, among the 20 interviewees, the average score was 2.65. The mode is 3, maximum is 4 and minimum is 1. There is no 5.
- 4.2 The scores in question 1 reveal that among patients, there was certain improvement in patient-centered healthcare in the past 5 years, but the rate of improvement was not substantial enough. The progress is by and large viewed as fair only from the modal scores. This observation matches with the result showed in the quantitative survey.

Table 4.1

General perceived progress of healthcare system when compared 5 years ago

Score	N	%
1 (no progress)	1	5
2 (little progress)	6	30
3 (fair progress)	12	60
4 (some progress)	1	5
5 (excellent progress)	0	0
Total	20	100

### Principle in counting the responses

- 4.3 It is not easy to differentiate the three hierarchical levels of concerns, i.e. Area (課題)、Domain (範疇)、task (項目) – the same item could be mentioned by the interviewees in all three questions during the interviews. Thus the responses for these three questions are analyzed together.
- 4.4 If the item is mentioned again in more than one question, it will be counted separately.
- 4.5 For questions 3 and 4 (domains and tasks), as the questions are not specific, therefore the number of items raised by different interviewee is different. All the items raised by the interviewees are all counted.

4.6 The statistical result is listed in Table 4.1.

Table 4.1

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 area	8	9	11	28
2.	Increase the number of medical professional	15	7	3	25
3.	Ensure or 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, participating in policy making and other related rights	8	2	1	11
6.	Enhance the self-help ability of the patients, the ability and capacity of their care-taker	5	2	2	9
7.	Settle the Healthcare Financing Reform	4	-	3	7
8.	Educate the public and promote "Prevention is better than cure" ideology	4	2	-	6
9.	Prepare for the ageing problem and long term health care burden	4	-	-	4
10.	Pay attention to some minority illness about their needs and difficulties	-	1	1	2
11.	Reactivate the promise of the government for taking care of the SARS patients	-	1	1	2
12.	Educate the public about organ donation	-	-	1	1
13.	Expand the kind of service of public health care system	-	1	-	1
14.	Synchronize the drug labeling system and make it more disability friendly	-	1	-	1
15.	Improve the air quality	-	1	-	1
16.	Popularize the merge of Chinese and Western medical therapy	1	-	-	1

4.7 Among the 16 mentioned items, 4 out of the top 5 items fall into the principle of “Access and Support”, which include:

- (a) Reducing patient’s financial burden for medication and other area;
- (b) Increasing the number of medical professional;
- (c) Raising the service quality and type of service; and
- (d) Reducing the waiting time for follow-up consultation.

4.8 From the perspective of the interviewees, barriers exist which deter patients from getting quality services. These barriers include:

- (a) Insufficient medical professionals:
  - i. Long waiting time for follow-up consultations. Interviewees were worried that they would miss the golden period for accepting proper treatment. Otherwise, the condition may get deteriorated or even possess other complications; and
  - ii. Short consultation time. Patient may be not able to enquire all the questions they have got. Interviewees felt that their right to know about their own condition and choice for possible treatment options being infringed.
- (b) Different doctors managing the same case at different contact points:
  - i. The doctor may lack the holistic view or fully understanding about their situation. Advice or treatment provided by an individual doctor depends on the current situations. They are often ad-hoc and sometimes not the best option;
  - ii. Advice obtained from different doctors contradicts to each others. Patients are confused;
  - iii. Doctor-patient relationship cannot be strengthened as each time is a new visit; and
  - iv. Doctors in general tend to ignore psychosocial stresses arisen by the illness as they only focus on the medical aspects.
- (c) Patients experience financial difficulties for obtaining better drugs with

fewer side effects or more advance treatment methods

- (d) Patients do not fully understand the treatment modes and treatment direction.

4.9 Besides, the result also reveals that patients in general would like to give a strong voice to the Healthcare System in Hong Kong. They raise several paramount needs:

- (a) Increase the manpower of medical professional by:
  - i. Increasing the number of training quota;
  - ii. Increasing the number of recruitment;
  - iii. Retaining public doctors by various measures;
  - iv. Lowering the criteria for recruiting oversea doctors; and
  - v. Establishing a specific committee for formulating long term medical policy.
- (b) Set up a registered system for community health workers including nurses and social workers.
- (c) Purchase more state-of-the-art medical apparatus and pharmaceutical products vis-à-vis private hospitals.
- (d) Include drugs with less side effect into the HA Drug Formulary.
- (e) Provide financial aid for patients:
  - i. to subsidize medical apparatus and pharmaceutical products;
  - ii. to subsidize private medical service;
  - iii. to provide transportation allowance or discount; and
  - iv. to streamline the application procedure for subsidy.

4.10 Right of the patients is another concern among patients. The rights included:

- (a) Right to know more about the side effects of different kind of medicine.

With the misunderstanding of the medicine, many patients stop taking medicine with their own decision;

- (b) Right to participate in formulating the HA Drug Formulary;
- (c) Right to request the doctor to explain clearly the medical reports to the patients;
- (d) Right to discuss with doctor about the health condition in more details so that the patients can make self-conscious choices about their healthcare; and
- (e) Improve the mechanism in handling complaints.

## **Chapter 5      Discussion**

- 5.1      Patients are positive on all six PCH dimensions, and they felt that the six aspects have all improved in the past five years while their expectations for its improvement in the coming five years are extremely high.
  
- 5.2      The priority of needs is different in people with different self-care abilities, mobility levels, age, and duration of chronic illnesses. When the principle of PCH is observed, the healthcare system should be sensitive to the different needs of different types of patients.
  
- 5.3      The healthcare system is evaluated by and large as “some progress”. The quality of the healthcare system can be improved by a more coherent treatment plan by different professionals, increased medical professionals, more consultation time, financial aids for patients in need and enhanced right to know.

- 1.8 Appendix I) and the individual interview guideline (Appendix II) were prepared by the APMHO.
- 1.9 Both questionnaires and interviews were conducted and completed between December 2011 and March 2012. For the quantitative survey, there were about 1000 distributed questionnaires with the assistance from the CRN, and 862 were completed (Completion rate = 86%) with 158 online input directly through Internet. For the qualitative survey, 20 individual in-depth telephone interviews had been conducted by two interviewers from the APMHO.
- 1.10 For the qualitative survey, participants were selected by APMHO representing 20 SHO's out of 43 SHO's and 18,500 patients out of 40,000 patients of the Alliance in Hong Kong
- 1.11 The inclusion criteria for the qualitative survey are: (a) diagnosed with at least one chronic illness; (b) use services in public medical healthcare system; and (c) cognitive capable to understand the questionnaire.
- 1.12 Ethical consent procedures were carried out by both APMHO and CRN during data collection.
- 1.13 The questionnaires were conveniently distributed to the target participants when they came to the CRN centers for participating activities organized by their affiliated SHO's. Completed questionnaires were collected immediately. APMHO also notified the individual SHO's to encourage their members sending in their input through the Internet Questionnaire.
- 1.14 For the telephone interviews, the target participants were all leaders of the SHO's. Questions were discussed interactively over the phone with the respective leaders and the interviewer was responsible for transcribing the interview on the questionnaire form. The transcribed form was sent via email to the interviewee who would discuss among executive committee members. The result of the discussed form in each SHO was returned to the interviewer v.
- 1.15 Descriptive data of both the quantitative and qualitative parts were generated by the person-in-charge of the survey from the APMHO.

- 1.16 Data had been inputted and analyzed by the APMHO and the CRN between February and March 2012.
- 1.17 The first preliminary survey and the phone interviews results were prepared on 27 March 2012 during the meeting of the APMHO.
- 1.18 The **ExCEL3 project** of the **University of Hong Kong (HKU)** was invited by the APMHO to validate the survey results and prepare the first version of this survey report for the further processing of APMHO and CRN.

### **Measurements for Quantitative Survey**

- 1.19 A six-item form of PCH was used. Informants are requested to rate the subjective experiences of the following items three times, i.e. five years ago, present and future expectation. The six items are:
- (a) Patients' right and access to information;
  - (b) Health Care Professionals' (HCP) attitude (respect and courtesy) towards patients and family members;
  - (c) Patient and their families' right and access to different choices;
  - (d) HCP support and encouragement to patients;
  - (e) Patient involvement in the formulation of health and medical policy;  
and
  - (f) Provision of relevant and useful information and social resources from HCPs and the hospital.
- 1.20 For the satisfaction towards current medical system, informants are requested to rate the current medical system 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

- (f) Services from rehabilitation agencies or self-help groups.

### **Scope of Validation**

- 1.21 The scope of validation conducted by the HKU includes the research methodology and data re-analysis of both qualitative and quantitative studies.

## Chapter 2 Evaluation of the Research Methods

### Self-report questionnaire (Quantitative Survey)

#### Design of the questionnaire and the reliability of the measuring tools selected

- 2.1 Please refer to Appendix I for the questionnaire content.
- 2.2 Questions used in the questionnaire of the survey have high internal consistency (alpha value between 0.84 and 0.93). It shows that the questionnaire has a satisfactory reliability. Besides, the result could be generalized to the populations, which are the people with chronicle illness.
- 2.3 Questions used in the questionnaire are designed base on the *Declaration on Patient-Centered Healthcare*. It provides an evidence base foundation and a framework for the survey. It is suggested that the same framework provide by the literature could be used in the data analysis part.
- 2.4 For the questionnaire, it provides 2 options about the role of the participant: “Patient” or “Care-taker”. In the original data analysis, all 862 completed questionnaires (688 from patients; 139 from care takers; 35 status unknown) are analyzed together. It is suggested that the data could be divided into 2 separate groups, patient group and care-taker group, during data analysis.
- 2.5 For question 9 in the questionnaire, it requires the respondent to score the service level for 5 years ago. It is suggested that those respondent who suffered from the illness for 5 years or less should be eliminated.
- 2.6 For question 9 in the questionnaire, it requires the respondent to score the service level for 5 years ago. The reliability for 5 years of memory of the participants will be in doubt. It is suggested that a longitudinal study should be conducted instead of trajectory or post-hoc evaluations

#### Sampling method of the survey

- 2.7 The questionnaires were distributed to the respondents when they were present in CRN centers for participating event of their self-help groups. The questionnaires were collected immediately afterwards. The result of this sampling method may bias towards those individuals with higher physical mobility, better health situation and higher engagements in self help

organizations. It is suggested that more data collection methods could be used in order to enhance the randomness and thus the finding generalizability. Examples included are mailed questionnaires, data selection by random draws, or online questionnaires, could be used in order to raise the randomness.

### **Respondent rate of the survey**

- 2.8 The sampling size (n=862) of the quantitative survey is satisfactory. The estimated size of the population of each group – Patient and care taker – is suggested to be indicated in the report as well.
- 2.9 The incomplete questionnaires or rejected rate of the surveys have not been recorded.

### **Telephone Survey (Qualitative Survey)**

#### **Design of the questionnaire and the reliability of the measuring tools selected**

- 2.10 For question 1, the 5 point Likert scale ranges from no progress to excellent progress (1 being no progress, 3 being average, 5 being excellent progress). It is recommended that backward or negative progress should also be included in the scale.
- 2.11 The use of the constructs for each level (area, domain, task , i.e. 課題、範疇、項目) was defined but not clearly understood by the interviewees. This results in similar responses in different levels. For a hands-on interview, it is not easy to administer the conceptual differences for three levels. It is suggested that only two levels of constructs would be adopted and the constructs are also well-defined with examples before the commencement of the interview.
- 2.12 The use of the two interviewers with one handling the same disease groups of three to conduct all the telephone interviews is good. This could avoid the error lead by the difference between each interviewer. However, there is also a concern that the same interviewer may pose certain bias or sensitivity towards a particular type of answers. The interview data is suggested to be analyzed by at least by two persons and the inter-rater reliability can be used to enhance the trustworthiness of the result.
- 2.13** The result of the discussion in each SHO is reported by one of the

representative after the discussion of the questions inside the organization. Although it was explained to the person that he or she represents the organizations, he or she may represent himself or herself subconsciously.

#### **Sampling method of the survey**

- 2.14 Organizations with different maturity are included in this study: years of history and number of members. This may raise the reliability of the survey when making comparisons.

#### **Data recording methods**

- 2.15 The conversation of the telephone interview is recorded as summary by the interviewer. The interviews were tape recorded and transcribed on the questionnaire form. The audio-record could allow at least one more person to perform analysis with the same set of data. The conclusion of each analysis could then be compared thus a more objective conclusion could be obtained.

## Chapter 3 Data Analysis for Quantitative Survey

- 3.1 Among the 862 completed questionnaires, 492 (57.1%) were under the age of 60 whereas 339 (39.3%) aged 60 or above. On the other hand, 355 (41.1%) were male whereas 498 (57.5%) were female.
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- 3.4 Patients' perception of PCH
- (f) Among the six domains for PCH, patients rate the following in the descending order (Table 3.1): (1) HCP's attitudes toward patients and family members; (2) patients' right to know the real situation; (3) HCP support and encouragement; (4) patients and families' right to access different treatment choices; (5) provision of relevant information and resources; and lastly (6) patient involvement in the formulation of health and medical policies.
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- 4.2 The scores in question 1 reveal that among patients, there was certain improvement in patient-centered healthcare in the past 5 years, but the rate of improvement was not substantial enough. The progress is by and large viewed as fair only from the modal scores. This observation matches with the result showed in the quantitative survey.

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General perceived progress of healthcare system when compared 5 years ago

Score	N	%
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### Principle in counting the responses

- 4.3 It is not easy to differentiate the three hierarchical levels of concerns, i.e. Area (課題)、Domain (範疇)、task (項目) – the same item could be mentioned by the interviewees in all three questions during the interviews. Thus the responses for these three questions are analyzed together.
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22. Enhance the self-help ability of the patients, the ability and capacity of their care-taker	5	2	2	9
23. Settle the Healthcare Financing Reform	4	-	3	7
24. Educate the public and promote "Prevention is better than cure" ideology	4	2	-	6
25. Prepare for the ageing problem and long term health care burden	4	-	-	4
26. Pay attention to some minority illness about their needs and difficulties	-	1	1	2
27. Reactivate the promise of the government for taking care of the SARS patients	-	1	1	2
28. Educate the public about organ donation	-	-	1	1
29. Expand the kind of service of public health care system	-	1	-	1
30. Synchronize the drug labeling system and make it more disability friendly	-	1	-	1
31. Improve the air quality	-	1	-	1
32. Popularize the merge of Chinese and Western medical therapy	1	-	-	1

4.7 Among the 16 mentioned items, 4 out of the top 5 items fall into the principle of “Access and Support”, which include:

- (a) Reducing patient’s financial burden for medication and other area;
- (b) Increasing the number of medical professional;
- (c) Raising the service quality and type of service; and
- (d) Reducing the waiting time for follow-up consultation.

4.8 From the perspective of the interviewees, barriers exist which deter patients from getting quality services. These barriers include:

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  - ii. Short consultation time. Patient may be not able to enquire all the questions they have got. Interviewees felt that their right to know about their own condition and choice for possible treatment options being infringed.
- (b) Different doctors managing the same case at different contact points:
  - i. The doctor may lack the holistic view or fully understanding about their situation. Advice or treatment provided by an individual doctor depends on the current situations. They are often ad-hoc and sometimes not the best option;
  - ii. Advice obtained from different doctors contradicts to each others. Patients are confused;
  - iii. Doctor-patient relationship cannot be strengthened as each time is a new visit; and
  - iv. Doctors in general tend to ignore psychosocial stresses arisen by the illness as they only focus on the medical aspects.
- (c) Patients experience financial difficulties for obtaining better drugs with

fewer side effects or more advance treatment methods

- (d) Patients do not fully understand the treatment modes and treatment direction.

4.9 Besides, the result also reveals that patients in general would like to give a strong voice to the Healthcare System in Hong Kong. They raise several paramount needs:

- (a) Increase the manpower of medical professional by:
  - i. Increasing the number of training quota;
  - ii. Increasing the number of recruitment;
  - iii. Retaining public doctors by various measures;
  - iv. Lowering the criteria for recruiting oversea doctors; and
  - v. Establishing a specific committee for formulating long term medical policy.
- (b) Set up a registered system for community health workers including nurses and social workers.
- (c) Purchase more state-of-the-art medical apparatus and pharmaceutical products vis-à-vis private hospitals.
- (d) Include drugs with less side effect into the HA Drug Formulary.
- (e) Provide financial aid for patients:
  - i. to subsidize medical apparatus and pharmaceutical products;
  - ii. to subsidize private medical service;
  - iii. to provide transportation allowance or discount; and
  - iv. to streamline the application procedure for subsidy.

4.10 Right of the patients is another concern among patients. The rights included:

- (a) Right to know more about the side effects of different kind of medicine.

With the misunderstanding of the medicine, many patients stop taking medicine with their own decision;

- (b) Right to participate in formulating the HA Drug Formulary;
- (c) Right to request the doctor to explain clearly the medical reports to the patients;
- (d) Right to discuss with doctor about the health condition in more details so that the patients can make self-conscious choices about their healthcare; and
- (e) Improve the mechanism in handling complaints.

## **Chapter 5      Discussion**

- 5.1      Patients are positive on all six PCH dimensions, and they felt that the six aspects have all improved in the past five years while their expectations for its improvement in the coming five years are extremely high.
  
- 5.2      The priority of needs is different in people with different self-care abilities, mobility levels, age, and duration of chronic illnesses. When the principle of PCH is observed, the healthcare system should be sensitive to the different needs of different types of patients.
  
- 5.3      The healthcare system is evaluated by and large as “some progress”. The quality of the healthcare system can be improved by a more coherent treatment plan by different professionals, increased medical professionals, more consultation time, financial aids for patients in need and enhanced right to know.

## Appendix I Quantitative Survey Questionnaire

### 「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/腦癱症/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 為最不满意, 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 II Qualitative Survey 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

**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:**

**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

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