

VALIDATION OF THE PATIENT ACTIVATION MEASURE (PAM-13)  
AMONG ADULTS WITH CARDIAC CONDITIONS IN  
SINGAPORE: A MIXED METHODS STUDY

by

Bi Xia Ngooi

Submitted in partial fulfilment of the requirements for the degree of Master of Science

at

Dalhousie University

Halifax, Nova Scotia

March 2016

© Copyright by Bi Xia Ngooi, 2016

# TABLE OF CONTENTS

LIST OF TABLES.....	v
LIST OF FIGURES.....	vi
ABSTRACT.....	vii
LIST OF ABBREVIATIONS USED.....	viii
ACKNOWLEDGEMENTS.....	ix
CHAPTER 1 INTRODUCTION.....	1
1.1 SECTION A: THE NEED FOR A VALID PATIENT ACTIVATION MEASURE IN SINGAPORE.....	1
1.1.1 Introduction.....	1
1.1.2 Singapore.....	3
1.1.3 Ischemic Heart Diseases (IHD) and Heart Failure (HF).....	5
1.1.4 Self-management.....	8
1.1.5 Patient activation.....	9
1.1.6 Patient Activation Measure (PAM-13).....	11
1.2 SECTION B: METHODS AND RATIONALE FOR VALIDATING THE PAM-13 IN SINGAPORE.....	15
1.2.1 Validity.....	15
1.2.2 Mixed Methods.....	20
1.2.3 Research Objectives.....	22
1.2.4 Thesis Goals.....	25
1.2.5 Ethical Considerations.....	25
CHAPTER 2 VALIDATION OF PATIENT ACTIVATION MEASURE (PAM-13) AMONG ADULTS WITH CARDIAC CONDITIONS IN SINGAPORE.....	27
2.1 INTRODUCTION.....	27
2.2 METHODS.....	30
2.2.1 Participants.....	30
2.2.2 Measures.....	31
2.2.3 Statistical Analysis.....	33
2.2.3.1 Evidence of internal structure.....	33
2.2.3.2 Evidence in response processes.....	34

2.2.3.3	Evidence of relationship to other variables.....	34
2.3	RESULTS.....	35
2.3.1	Evidence in internal structure.....	35
2.3.1.1	Data quality.....	35
2.3.1.2	Internal consistency.....	36
2.3.1.3	Unidimensionality.....	36
2.3.1.4	Differential Item Functioning (DIF).....	37
2.3.2	Evidence in response processes.....	37
2.3.3	Evidence in relations to other variables.....	38
2.4	DISCUSSION AND CONCLUSION.....	38
2.4.1	Discussion.....	38
2.4.2	Conclusion.....	42
2.4.3	Practice and Research Implications.....	43
CHAPTER 3 HOW ADULTS WITH CARDIAC CONDITIONS IN SINGAPORE UNDERSTAND THE PATIENT ACTIVATION MEASURE (PAM-13) ITEMS: A STUDY USING COGNITIVE INTERVIEWING.....		
3.1	INTRODUCTION.....	48
3.2	METHODS.....	51
3.2.1	Design.....	51
3.2.2	Participants and Setting.....	52
3.2.3	Interviews.....	53
3.2.4	Measures.....	54
3.2.5	Analysis.....	55
3.3	RESULTS.....	55
3.3.1	Comprehension.....	56
3.3.2	Decision processes.....	57
3.3.3	Response processes.....	58
3.4	DISCUSSION.....	59
3.4.1	Comprehension.....	59
3.4.2	Decision processes.....	61
3.4.3	Response processes.....	62

3.5	LIMITATIONS.....	62
3.6	IMPLICATIONS AND CONCLUSION.....	63
CHAPTER 4 DISCUSSION.....		83
4.1	DISCUSSION.....	83
4.1.1	The PAM-13 in Singapore.....	83
4.1.2	Response Categories.....	84
4.1.3	Cultural Adaptation of Measures.....	86
4.2	IMPLICATIONS.....	89
4.3	LIMITATIONS.....	90
4.4	CONCLUSIONS.....	91
BIBLIOGRAPHY.....		93
APPENDIX A	Patient Activation Measure (PAM-13).....	106
APPENDIX B	Ethics Approval from Dalhousie University.....	107
APPENDIX C	Ethics Approval from National Healthcare Group, Singapore.....	108
APPENDIX D	Participant Information Sheet and Consent Form.....	111
APPENDIX E	Confirmation of Compensation Received Form.....	116
APPENDIX F	Demographics and Health Characteristics Questionnaire.....	117
APPENDIX G	Patient Health Questionnaire-9 (PHQ-9).....	119
APPENDIX H	Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale (SSE).....	120
APPENDIX I	Semi-structured Cognitive Interview Guide.....	122

## LIST OF TABLES

Table 1	Sources of evidence to be examined for validity.....	24
Table 2	Participant characteristics and PAM-13 scores (n=270).....	44
Table 3	Data quality and internal consistency of the PAM-13 in a population with cardiac conditions (n=270).....	45
Table 4	Results of the Rasch rating scale model of the PAM-13 in a cardiac population with data collapsed to three response categories per item.....	47
Table 5	Characteristics of participants.....	65
Table 6	Main findings with comprehension, decision and response processes of PAM-13 among English speaking adults with cardiac conditions in Singapore.....	66

## **LIST OF FIGURES**

Figure 1     Distribution of responses by PAM-13 item (excluding missing data)....46

## **ABSTRACT**

The purpose of this study was to validate the Patient Activation Measure (PAM-13) among English-speaking cardiac patients in Singapore. A concurrent mixed methods design was utilized. The quantitative approach was conducted in a convenient sample of 270 heart clinic patients. The qualitative approach utilized cognitive interviews in a smaller purposive sample (n=13).

Our results suggest that PAM-13 has good internal consistency and item fit, acceptable unidimensionality and moderate correlation with self-efficacy in this population. However, under-utilization of the 'strongly disagree' response category, poor separation distances and unexpected item difficulty ranking pose potential problems. The interviews offered insights into reasons for these findings. We suggest that PAM-13 can be used in combination with clinical judgement to explore patient activation and self-management practices. To improve clinical usefulness in Singapore, we recommend: 1) culturally adapt instruments even when language translation is not required, and 2) consider response categories with a wider Likert scale.

## **LIST OF ABBREVIATIONS USED**

BMI	Body Mass Index
CCM	Chronic Care Model
CTT	Classical Test Theory
DIF	Differential Item Functioning
eRm	extended Rasch model
FA	Factor Analysis
GDP	Gross Domestic Product
HbA1C	Glycated hemoglobin
HF	Heart Failure
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
IHD	Ischemic Heart Disease
KMO	Kaiser-Meyer-Olkin
LDL	Low-density lipoprotein
MSQ	Mean Square
N/A	Non-applicable
PAM-13	Patient Activation Measure
PCA	Principal Component Analysis
PHQ-9	Patient Health Questionnaire-9
PI	Principal Investigator
SF-8	Short Form (8) Health Survey
SF-12	Short Form (12) Health Survey
SSE	Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale



## **ACKNOWLEDGEMENTS**

Title: Validation of Patient Activation Measure (PAM 13) among adults with cardiac conditions in Singapore: A mixed methods study

Author: Bi Xia Ngooi, B.App.Sc (OT) (University of Sydney)

Supervisor: Dr Tanya L. Packer, Ph.D.

Co-supervisor: Dr George Kephart, Ph.D

Committee member: Dr Grace Warner, Ph.D

Acknowledgement of funding received throughout graduate studies:

- Academic Medicine Development Award (AMDA), National University Health System, Singapore
- Faculty of Graduate Studies Scholarship, Dalhousie University, Canada
- Singapore Association of Occupational Therapists (SAOT) Research Grant, SAOT, Singapore
- Dr Gustave Gingras Award, Dalhousie University, Canada

## **CHAPTER ONE: INTRODUCTION**

### **1.1 SECTION A: THE NEED FOR A VALID PATIENT ACTIVATION MEASURE IN SINGAPORE**

#### **1.1.1 Introduction**

The burden of chronic disease is rapidly increasing worldwide. Ischemic heart disease has remained the top killer during the past decade [137], making a major contribution to hospitalizations and health care expenditure. Similarly, heart diseases are ranked in the top 10 principal causes of death and top 10 causes of hospitalization, with cardiovascular diseases accounting for the top disease burden (20%) in Singapore [81-83].

Given the complex and progressive nature of ischemic heart disease and heart failure, it is important to identify interventions to assist those with these conditions to practice effective self-management [6, 15]. Evidence shows that effective self-management reduces hospitalization costs and complications associated with chronic conditions, helps patients achieve healthier outcomes and enhances overall quality of life [75].

The Chronic Care Model, which is supported by substantial evidence, asserts that an “activated” patient is a key variable in achieving optimal health outcomes for people with chronic conditions [23]. An activated patient is defined as one having knowledge to manage their condition and maintain functioning and prevent health declines; skills and behavioral repertoire to manage their condition, abilities to collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care [42].

Hibbard and colleagues (2005) developed the Patient Activation Measure (PAM-13), a self-rating questionnaire that measures patient activation [43]. It is an interval-level,

uni-dimensional, Guttman-like measure that includes four elements of patient activation (knowledge, skills, confidence, and behaviors) and suggests four levels of activation that patients reach in becoming fully engaged in managing their own health [44]. Higher PAM scores are associated with more satisfactory interactions with providers, more engagement in care and self-management behaviours, more initiative in information seeking and improved health outcomes [45, 85, 100].

Validation studies have been done on the PAM-13 in various countries and population groups. However, findings such as discrepancies in item difficulty ranking and activation score ranges suggested that PAM-13 may be influenced by differences in health beliefs embedded in different cultures and/or different self-management needs of various client groups. These reinforce a need to validate PAM-13 before usage in Singapore. To achieve a culturally relevant tool qualitative methods such as cognitive interviews to investigate reasons behind differences in response processes is indicated.

As of today, there are no published validation studies of the PAM-13 in Singapore. Therefore, the purpose of this study was to validate and assess the properties of the PAM-13 among English speaking cardiac patients in Singapore. The 1999 revised Standards for Education and Psychological Testing advocated for a unitary concept of validity [4]. Under this unitary concept, validation should be demonstrated by examining five types of evidence, which are evidence based on 1) test content, 2) response processes, 3) internal structure, 4) relations to other variables, and 5) consequences of testing [4]. In this study, three sources of evidence, namely response processes, internal structure and relation to other variables, were collected to examine the validity of PAM-13.

This study used a concurrent mixed methods design [22] which collects quantitative and qualitative data concurrently, merging data at interpretation, to provide a comprehensive validation of the PAM-13. The study was done at The National University Heart Centre, Singapore's second national heart center to provide a comprehensive and holistic approach to the treatment of heart problems. The quantitative approach was a cross-sectional study conducted in a convenient sample of heart clinic patients. It collected data on basic demographic and health characteristics variables, PAM-13 and its relation to depression (Patient Health Questionnaire-9) and self-efficacy (Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale). The qualitative approach utilized cognitive interviews in a smaller purposive sample of the same population.

### 1.1.2 Singapore

Singapore is a multiethnic society mainly consisting of ethnic Chinese (74%), Malay (14%), Indian (9%) and others (3%) [109]. In Singapore, English is the working language and about 75% of the residents are literate in English [109].

Since independence in 1965, Singapore has been through rapid urbanization estimated at 59% in the 1960s to 100% since 1980 [56]. Currently, Singapore is one of the more developed countries among Southeast Asia countries, with a gross domestic product (GDP) per capita of \$78,763 international dollars (also known as Geary-Khamis dollars) in 2013 [125].

Parallel to the prospering economy, a rising incidence of ischemic heart disease (IHD) peaked in the 1980s and has been declining since then [56]. However, the age-adjusted mortality for IHD in Singapore remains one of the highest in the world [126].

Heart diseases are ranked in the top 10 principal causes of death and top 10 reasons for hospitalization, with cardiovascular diseases accounting for the top disease burden (20%) [81-83].

Some factors continue to drive the high prevalence of IHD in Singapore. Firstly, Singapore is facing the silver tsunami of an aging population due to a reduction of fertility rates and increased life expectancy. The total fertility rate is 1.19 and life expectancy was estimated at 82.5 years in 2013 [108]. Together, these trends result in a larger proportion of older adults in Singapore, accompanied by an increase in rates of chronic non-communicable diseases.

Secondly, with increasing affluence among the Singapore population, significant changes in lifestyle choices have taken place. The 2010 National Health Survey reported that 39.1% of people do not participate in sufficient physical activity [84]. Chinese ethnicity is associated with lower levels of total physical activity than Malay and Indian ethnicity in Singapore [55]. At the same time, changes in dietary practices have led to nearly half of adult Singaporeans meeting or exceeding the recommended daily caloric intake appropriate for their gender and age [56]. As a consequence, one in nine (10.8%) Singapore residents aged 18 to 69 years are obese ( $BMI \geq 30\text{kg/m}^2$ ) and about 25% of the remaining population overweight ( $BMI \geq 25\text{kg/m}^2$  but  $< 30\text{kg/m}^2$ ) [111]. The prevalence of obesity is highest among the Malays, followed by the Indians and Chinese [111]. These contribute to the risk factors for cardiovascular diseases.

Other medically related risk factors for IHD are also high in Singapore. The prevalence of diabetes mellitus is about 11.3%, with only one in four people achieving good glycemic control ( $HbA1C < 7\%$ ) [111]. Among those aged 60 and above, one in every

two adults is hypertensive [111]. About half of Singaporean adults (48.1%) have elevated LDL-cholesterol levels based on their estimated risk of cardiovascular disease [56].

Although factors such as an aging population and increasing life expectancy cannot be expected to change, there are other individual risk factors that can and should be addressed [67]. Findings have indicated that lifestyle modification has an important role in reducing the risk of cardiovascular disease in individuals, thus interventions can be geared to address these issues.

### 1.1.3 Ischemic Heart Diseases (IHD) and Heart Failure (HF)

ICD-10-AM is the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification, the classification system being used in Singapore. IHD (ICD10AM: I20-I25) accounted for 15.5% of all deaths in 2013, ranking third after cancer and pneumonia [82]. It is the most common type of heart disease, arising from narrowing of the coronary arteries, causing reduced blood flow and oxygen supply to the heart muscles. Characterized by angina, a squeezing chest pain which may spread to the neck, jaw, abdomen and upper left of the body, the narrowing of the coronary arteries is typically caused by atherosclerosis. Other contributory factors include lifestyle and medical factors discussed in the earlier section.

In IHD, prevention initiatives such as healthy lifestyle modifications and adherence to prescribed medications, offer an evidence based approach to reduce cardiac mortality and morbidity [95]. However, despite evidence of the benefits, recommendations have not been translated into significantly improved clinical outcomes as only 50% of individuals adhere to such recommendations [135].

Moreover, attendance for cardiac rehabilitation, an evidence-based secondary prevention intervention, has been sub-optimal worldwide, with less than 50% of people eligible attending [13]. Multiple barriers to attending cardiac rehabilitation have been found. Very often, socioeconomic status, such as employment status, living in remote areas and access to transport, are linked to non-attendance at cardiac rehabilitation [90]. Patients' beliefs about cardiac rehabilitation itself have also been found to be an important factor [90]. Therefore, even though cardiac rehabilitation has been the benchmark intervention, it may only have the ability to cater to a fraction of individuals who are of better socioeconomic status and who understand cardiac conditions.

To date, these interventions have also generally focused on the transference of knowledge from healthcare professionals to patients. Hence, more attention is needed to engage patients with secondary prevention behaviors after a cardiac event [135, 136]. As the World Health Organization stated, health professionals should be equipped with the competencies to provide self-management support [96].

Heart failure (HF) (ICD10AM: I50) is the most common cardiac cause for admission to Singapore hospitals, accounting for approximately 25% of such hospital stays [103]. Heart failure can develop as a result of IHD, a previous heart attack, high blood pressure, damage to the heart valves or cardiomyopathy. It occurs when the heart loses its ability to pump blood within the body effectively, causing backward pooling of blood in vital organs and vessels. It is often characterized by shortness of breath and fluid retention, resulting in symptoms such as abdominal pain, loss of appetite, distension of the veins in the neck and breathing difficulties.

People with HF are plagued by downward erratic patterns of functioning, peppered by acute medical crises that often result in repeated hospitalizations [91]. A sense of helplessness and hopelessness [6], stress [6, 79] and low self-worth linked with physical and role limitations [16] tend to overwhelm people with HF. Fear leads to immobilization as activities previously part of daily life became challenging during early recovery. Individuals need to establish new boundaries to their physical abilities. Some limit their activities for fear of ‘over-doing it’ while others feel that new boundaries can only be found by challenging them [6, 54]. As a result, patients with HF usually are affected not just physically, but also emotionally, and socio-economic concerns impact on overall quality of life [58].

The management of HF is becoming more complex, often requiring multidisciplinary expertise [91]. People with HF have to manage various aspects of the condition, often including treatment implementation (e.g. diuretic titration), energy conservation, symptom monitoring (e.g. daily weights), diet adherence, medication routine, exercise, stress management and fluid restriction [25]. Yet, behavioral factors account for a large number of CHF hospitalizations [91], suggesting a gap in current interventions to support the lifestyle changes needed after diagnosis and consequently reducing unplanned admissions.

In the review of current healthcare provision for people with IHD and HF, both revealed a gap in interventions to support secondary prevention behaviors and lifestyle changes needed to support effective self-management. As a result both IHD and HF remain common cardiac conditions contributing to the disease burden in Singapore. Therefore, these two conditions will be the targeted conditions in this study.



#### 1.1.4 Self-management

To reduce the overall burden of care, cost effective interventions targeting prevention and control of diseases are needed [136]. The most effective interventions for chronic disease management include multi-pronged strategies [102]. The Chronic Care Model (CCM) [129] is an example of such an approach that is widely implemented. In the CCM, improved health outcomes for chronic disease management are the result of productive interactions between informed, activated patients and a prepared, proactive practice team. These take place within the context of the community (resources and policies) and health system (organization of healthcare). Recommended reforms in health systems include self-management support, delivery system design, decision support tools and clinical information systems. Of these, self-management support emphasizes the importance of the central role that patients have in managing their own care, which resonates with the gap in cardiac interventions identified earlier [129].

Self-management, refers to an individual's ability to manage the symptoms, treatment, daily functioning, emotions and changes in interpersonal relationships inherent in living with a chronic condition [64]. It involves three self-management tasks, namely medical management, role management, and emotional management which can serve as a critical link to empower patients with cardiac conditions to maintain their health and wellness. There are specific and universal skills needed for the mastery of self-management across all conditions; problem solving, decision making, action planning, resource utilisation and forming of patient-physician partnership [64]. Specific skills, such as diuretic titration, are related to the cardiac condition specifically.

However, promoting effective self-management can be complex, particularly when transitioning from diagnosis to appropriate self-management [75]. During this shift of self-identity and transition period, individuals have to i) consider connections between the cause of heart disease and lifestyle, ii) access, interpret and integrate advice and information, iii) integrate attributions and information to inform life change and scope of lifestyle changes, iv) make life changes and lifestyle changes, and vi) find new limits and integrate changes [6]. These are often performed against the background of their social contexts and environment. While these self-management tasks require the support of health professionals, there is a stronger need for individuals to implement these changes and integrate them into their respective lifestyle [5]. Therefore, individual characteristics and responsibility play a major role in the quest to achieve successful self-management [88].

### 1.1.5 Patient Activation

As self-management performed by individuals is a crucial part of chronic disease management [5], it has been argued that the lack of patient activation has limited effective management [41]. Patient activation is described as the degree to which one 1) understands his/her own central role in actively taking charge of managing personal health care needs and 2) feels capable of self-management [47]. Importantly, people who actively self-manage report higher quality health care and have better health care outcomes [47, 53, 127].

Hibbard and her colleagues have described the theory and measurement of patient activation [41, 42, 47]. More specifically, they define patient activation as having knowledge to manage one's condition and maintain functioning and prevent health declines; skills and behavioral repertoire to manage their condition, abilities to collaborate with their

health providers, maintain their health functioning, and access appropriate and high-quality care [42].

People who have high levels of activation are more likely to play an active role in staying healthy, seeking help when needed, following a health care treatment plan and maintaining their health when they are no longer being treated [48]. Higher levels of activation have also been associated with better health outcomes [27, 32, 43, 46, 121], adopting healthy behaviors [27, 45], more efficient health services utilization [11, 49], and higher satisfaction with health services [48].

Socio-demographic and other external factors have been found to have an impact on patient activation. Higher education [3, 27, 66] and income [3, 27, 114] tend to have a strong positive association with higher patient activation. It is uncertain if patient activation is associated with age, gender and race as results differed in studies [3, 27, 66, 121]. Levels of patient activation have not been seen to differ according to language (English versus non English) [66]. However, a positive association ( $P < 0.001$ ) was shown with being bilingual in a sample of 1067 Latino patients in United States [3].

Patients with better self-reported health status are also more likely to be more activated [3, 30, 66]. Fowles, Terry & Xi, et al (2009) found that activation in a sample of 625 employees, was directly correlated with both the physical and mental health component summary scales of SF-12 ( $P < 0.0001$ ), as well as directly related to the single item general health status ( $P < 0.0001$ ).

Emotional and psychological factors are also significantly associated with activation levels. Depression has been reported to have a negative correlation with patient activation [70, 114, 121], suggesting that as patient activation increases, severity of

depression symptoms decrease. Skolasky, Mackenzie, Wegener & Riley (2008) reported higher self-efficacy, increasing hopefulness and decreasing externalized control to be significantly associated with higher activation. High self-efficacy has been shown to have a positive correlation with patient activation in multiple studies, across a wide variety of clinical populations [17, 70, 121].

#### 1.1.6 Patient Activation Measure (PAM-13)

The importance of patient activation mandates the need for robust tools to measure and improve care for people with chronic conditions. Hibbard and colleagues (2004) developed the Patient Activation Measure (PAM) (refer to Appendix A) to assess knowledge, skills and confidence in managing health [42, 43]; the most commonly used measure of activation [30, 42, 48].

PAM was originally developed in 2004, as a 22 item scale using a four stage process [28]. A national expert consensus panel and patient focus groups were first formed to define and identify the domains of “activation” [42]. In the second stage, the findings were operationalized by constructing a large item pool which was pilot-tested using a convenience sample of 100 respondents recruited through newspaper advertisements [42].

Initial psychometric analysis was performed using Rasch’s Rating Scale Model, which assumes response categories have uniformity in distance and order for all items [42]. Using rating scale responses to the survey questions, Rasch measurement facilitated the creation of an interval-level, unidimensional, Guttman-like scales which calibrates “difficulty” of items according to response probabilities [42]. A person with lower activation will score lower. Similarly, one who is more activated will score higher. The

location of each individual on the scale therefore indicates activation level. Standard error of measurement allows the calculation of precision in item difficulty estimation [42].

Item selection was based on two item fit statistics; infit and outfit. Both represent how responses to an item deviate from the model's expectations, with infit statistics more sensitive when the item's scale location is close to the respondent's scale location whereas outfit statistics more sensitive for items more distant [42]. A fit value of 1.0 indicates perfect fit to model expectations though fit statistics between 0.6-1.4 usually produce sufficient unidimensionality and response variability [74].

In the third stage, extension and refinement of PAM was done using a convenience mixed sample of 120 cardiac rehabilitation patients and 366 employees of a large health organisation [42]. The final validation was done with a national probability sample of 1515 people, selected via random digit dialing selection and a screening question to determine age eligibility (aged 45 and above) [42]. There was a 48% response rate with a minimum of 12 call-backs [42]. Respondents were aged 45 to 97, with 66% under the age of 65 [42]. Of these, 50% had more than high school education and 68% had a household income of more than \$25,000 [42]. Seventy-nine percent of the sample had at least one chronic disease (angina/heart problem, arthritis, chronic pain, depression, diabetes, hypertension, lung disease, cancer, high cholesterol) [42].

Reliability was assessed using fit statistics, test-retest reliability and Rasch person reliability [42]. Rasch person reliability is the proportion of the total sample variability in measured activation that is not measurement error [42]. It provides upper bounds (model person reliability assuming that data fit model expectations and misfit in data is due to probabilistic nature of the model) and lower bounds (real person reliability assuming that

misfit in responses due to departure of data from model's expectations) [42]. True reliability of the measure lies between the two bounds [42]. For test-retest reliability, 28 out of 30 respondents had a retest activation estimate within 95% confidence interval of their first test activation estimate [42]. Infit values ranged from 0.71 to 1.44 while all but one of the outfit values were between 0.80 and 1.34 [42]. Rasch person reliability ranged from 0.76 to 0.91 [42]. In summary, all the reliability tests indicated a reliable tool.

Validity was assessed using criterion and construct validity by examining PAM's relationship with variables believed to be conceptually related [42]. The following findings indicated a high degree of validity. People with higher activation were found to 1) report significantly better health as measured by SF 8 ( $r=0.38$ ,  $p<0.001$ ), 2) significantly lower rates of doctor office visits, emergency room visits and hospital nights ( $r=0.07$ ,  $p<0.01$ ), 3) significantly more likely to exhibit healthy lifestyle behaviours such as regular exercise, 4) significantly more likely to exhibit self-management behaviours such as keeping a glucose journal, and 5) have a lower degree of fatalism about their health [42].

PAM was later reduced to 13 items (PAM-13) in 2005 using Rasch methodology, and has psychometric properties similar to the original measure [43]. Each item has four response categories with scores from 1 to 4: (1) strongly agree, (2) disagree, (3) agree and (4) agree strongly, and a non-applicable (N/A) category [43]. The raw score is calculated by adding all the responses to the 13 questions [43]. If all questions are answered and no N/A is used, the range of raw scores is 13 to 52 [43]. If there is at least 1 item with a response of N/A, the total is divided by the number of items completed and multiplied by 13 to obtain a total raw score [43]. The sum raw score is converted to a derived score from 0 to 100 using a computer algorithm provided by Insignia Health PAM 13 License [52].

Based on the activation score, patients are placed into 1 of 4 stages of progressive activation: believes active role is important (PAM score  $\leq 47.0$ ), has the confidence and knowledge to take action (PAM score of 47.1 to 55.1), is taking action (PAM score of 55.2 to 67.0), and is able to stay the course under stress (PAM score of  $\leq 67.1$ ) [29]. Further research has demonstrated that higher PAM scores are associated with more satisfaction with services [86], more engagement in care and self-management behaviours [45, 86], and improved health outcomes [86, 100].

These potential clinical benefits and good psychometric properties of PAM have prompted translation and validation into several languages including Korean [2], Hebrew [69, 70], Bengali [105], Dutch [98], Danish [68], German [17, 139] and Spanish [3]. Validation studies have also been completed with various population groups and settings, such as multimorbid older adults [115], elective lumbar spine surgery patients [114], people with multiple sclerosis (MS) [121], employees [27], those with mental health [33] neurological populations [92], and people in rural settings [51].

While all the validation studies agree that PAM is a valid and reliable tool that retains the probabilistic, Guttman-like scale properties, some studies have identified that item difficulty varies from the originally intended ranking. In the Korean version, all items except item #1 and #2 were ranked differently from the original PAM-13, with item #4 “I know most of the whys, whens, and hows of the medications I am taking” being the most difficult to [2]. Similarly, in the Bengali version, only items #17 and #22 matched the item difficulty of the original PAM 22 [105].

Items highlighted by other authors include item #3 “I am confident I can help prevent or reduce problems associated with my health”, being rated as more difficult by

people in Korea [2], Netherlands [139], Germany [98], rural areas [51], and among people with MS [121] and neurological conditions [92]. Another highlighted item was item #7 “I am confident that I can follow through on medical treatments I may need to do at home”, being ranked easier in the neurological [92], MS [121], Dutch [98] and Danish [68] studies. Interestingly, it was ranked as more difficult in Korea [2] and Germany [98]. These discrepancies may be due to differences in health beliefs embedded in different cultural backgrounds of the countries and/or different self-management needs of various client groups.

Activation score ranges also differ in various studies. For example, the range was 38.6-53.0 in the original United States data [43], 33.3-57.5 in the Danish data [68] and 23.9-67.0 in the Korean version [2]. These studies support findings of cultural differences in activation scores.

As there are multiple findings suggesting cultural and diagnostic influences in activation scores, there is a need to validate PAM-13 in Singapore to achieve a culturally relevant tool. As of today, no published validation work on the PAM-13 in Singapore has been found, though usage of PAM-13 in healthcare services has been mentioned [106, 107].

## **1.2 SECTION B: METHODS AND RATIONALE FOR VALIDATING THE PAM-13 IN SINGAPORE**

### **1.2.1 Validity**

With a need to validate a culturally relevant PAM-13 in Singapore, it is crucial to explore suitable validity methods. Important to note is that many of the validation methods currently in use were developed based on psychometric methods of classical test theory (CTT) [9]. PAM, on the other hand was developed based on item response theory and use



of the Rasch model [99] in which there are differences in how instruments are constructed, administered and interpreted. Although many validity analyses such as internal consistency are based on CTT, it is common for authors to utilize and report these methods in combination with Rasch analysis for PAM validation studies. Therefore, for this study, both CTT and Rasch validity analysis will be discussed and utilized concurrently to provide a robust analysis and ease of comparison with past studies.

The concept of validity was first conceptualized as three separate types, namely content, criterion-related and construct validity [59]. This was later considered to be an incomplete interpretation of validity as it did not consider the social consequences of score use [77]. Instead of being a property of an instrument, validity was then defined as a property of scores based on usage of a particular assessment with a particular group of subjects, in a particular setting and under certain conditions [35, 78]. Drawing from Messick's work, the Standards for Education and Psychological Testing were revised and published in 1999, emphasizing omission of the breakdown of validity into three types and advocating for a unitary concept [4]. Under this unitary concept of validity, validation should be demonstrated by examining five types of validity evidence, which are 1) evidence based on test content, 2) internal structure, 3) response pattern, 4) relations to other variables, and 5) consequences of testing [3]. This concept has been widely accepted and used [59]. In a more recent review on validity and reliability by Cook and Beckman (2006), the same validity concept was reinforced.

Evidence based on "test content" examines whether the content of an instrument represents the domain it proposes to measure [47]. This was traditionally termed content validity, which contains content relevance, representativeness, and technical quality [77].

One common way of obtaining this evidence is to engage an expert panel to evaluate these qualities [133]. As this aspect was comprehensively examined during the development of PAM, the first source of validity evidence will not be a focus in this study.

Evidence based on “internal structure” examines whether the internal components of a test match the defined construct [4]. Smith (2001) suggests that this level of evidence can be addressed by the two working assumption of Rasch models. First, persons with greater ability are more likely to answer more items correctly or agree to more difficult questions than persons with lesser ability, and second, items that are easier should be scored better or agreed to more than difficult items by all respondents regardless of their abilities [119]. If these two assumptions are met and unidimensionality of the scale has been shown, the internal structure is satisfactory [117]. Differential item functioning (DIF) is another Rasch analysis that can detect item bias in the internal structure [34]. For example, when respondents of different groups (e.g. male vs female) have the same ability but have different probability of success on an item, DIF is present. If that happens, it may produce consistently biased scores across different sample groups and lead to inaccuracy in interpreting the underlying ability [4].

Evidence based on “response processes” examines the extent to which the types of responses required of respondents fit the defined construct [4]. Using Rasch analysis, whether or not item difficulties agree with the original instrument ranking can be tested [133]. By examining the consistency between the expected and empirical item difficulty, clues regarding whether the responses fit the intended construct can be gained.

Another way to obtain response process evidence is using qualitative methods to explore the cognitive processes involved in perceiving and interpreting how respondents

answer the questions [24, 34]. The most common method by far is cognitive interviewing [122], developed based on cognitive psychology and survey methodology theories to identify problematic questions that may elicit response error [26]. The Tourangeau's cognitive model contributed largely to the background theory underlying cognitive interviewing [132]. It is comprised of comprehension of the question; retrieval from memory of relevant information; decision processes; and response processes. Comprehension of the question referred to what participants believe the question to be asking and the meaning of specific terms. Retrieval from memory of relevant information involves recall ability of information and recall strategies used. Decision processes reflect whether participants possess sufficient motivation to answer the question accurately and thoughtfully, and influences of social desirability/ sensitivity. Lastly, response processes examine if participants are able to match internally generated answers to response categories given by questions. The commonest sample recruitment procedure is to draw a small convenience sample from the entire population [76].

There are two main types of cognitive interview: concurrent and retrospective. Concurrent involves respondents verbalizing their thinking ("think-aloud") at the same time they answer the question [132]. Retrospective involves respondents reporting and debriefing after the completion of questionnaire [132]. There are advantages and disadvantage to each type. Advantages of the concurrent technique include freedom from interviewer bias, minimal interviewer training requirements, and open-ended format allowing the possibility of free articulation from respondents [132]. Disadvantages are the need for respondent training as thinking-aloud is unusual for most people, difficulty in respondent proficiency in the method, tendency for respondents to stray from the focus of

the discussion and bias in respondent information processing as extra mental effort is needed to elicit thinking aloud which may contaminate cognitive processes used in answering the questions [132].

In the retrospective technique, the interviewer asks questions (probes) about the instrument after its completion, thus advantages are that there is less burden for the respondents, ease of respondent training, and control of interview by interviewer [76, 132]. However, disadvantages may involve missing important information due to deficiencies in recall and potential for bias due to leading questions by interviewer [76, 132]. While there are both pros and cons to each technique, retrospective probing after the whole questionnaire is completed can be useful when testing self-administered questionnaires as it also takes into account respondents' ability to complete the instrument unaided, as well as to stimulate a more realistic questionnaire administration [132]. Moreover, in short questionnaires (for example PAM-13), there is lower probability of contamination in recall [132].

Probes can be categories as scripted or spontaneous as the interview progresses [76, 132]. However, the most effective interviews usually involve a combination of both types [85]. The types of probing questions include [132]:

- Comprehension: What does the term “lifestyle changes” mean to you?
- Paraphrasing: Can you repeat the question in your own words?
- Confidence judgment: How sure are you that your home medical treatments include diuretic titration?
- Recall probe: How do you remember that you missed your medication twice in the past month?

- Specific probe: Why do you think stress cause your heart problem?
- General probes: I noticed that you hesitated at question 3 – tell me what you were thinking.

Evidence based on “relations to other variables” examines the extent to which the scores of the tool relate with other measures, reflecting the expected relations based on the theory of the construct being assessed [4]. The most common way of establishing is correlation with scores from another instrument for which correlation would be expected, supporting interpretation consistent with the underlying construct [24].

Lastly, evidence based on consequences of testing examines the anticipated and unanticipated consequences of the measurement [4]. It is related to the implications of score interpretation and consequences of the assessment usage [77]. As Rasch analysis does not directly address the consequences and implications, and traditional validation analysis requires descriptive studies to investigate [59], this last source of evidence will not be an area of focus in this study.

### 1.2.2 Mixed Methods

Mixed methods research can be suitable for exploring variations in how respondents make sense of their experiences and report it in the questionnaire [12]. It is believed that mixed methods will assist in understanding complexities. These studies provide opportunities for integration of a variety of theoretical perspectives, which is suitable for exploring variations in how respondents answer questionnaires and making sense of their experiences [12]. Quantitative research typically focuses on testing theories or hypotheses and examining relationships among variables which can be measured. It

produces numeric data that can be analyzed statistically [22]. The strengths of quantitative approaches include: a) accurate operationalization and measurement, b) capacity to conduct group comparisons, c) the capacity to examine the strength of association between variables of interest, and d) the capacity for model specification and testing of research hypotheses [18]. However, one major limitation is that measurement typically decontextualizes the information, therefore making it impossible to examine the meanings behind information.

On the other hand, qualitative research focuses on understanding processes, context and meaning of participants' experiences to provide a depth of understanding of concepts [22]. The strengths of qualitative approaches include: a) the ability to generate rich detailed accounts of human experiences, and b) narrative accounts examined within the natural context [18]. Limitations include inability to produce generalizable findings and difficulties in assessing associations that occur between observations or cases [18]. One approach to qualitative analysis that is suitable to be used in such mixed methods study design is the Framework Approach [104]. It consists of seven stages: transcription; familiarization; coding; identifying a framework; indexing; charting; and interpretation [104]. This systematic and flexible approach is suitable for studies that are more descriptive than interpretative, with the ability to organize and reduce data on a case-based approach [28].

There are several possible mixed methods study designs that can be used in different combinations to meet study aims [22]. The choice of designs can depend on 1) the time and resources available, 2) study aims, for example if it is crucial for one data to

be collected and analyzed before another, and 3) sampling issues [22]. Some of these designs are [22]:

- Concurrent mixed methods designs: Both quantitative and qualitative data are collected during the same stage, although priority may be given to one form of data over the other. The data is then merged and results compared to address the study aims.
- Sequential mixed methods designs: Either the qualitative or quantitative data are collected in an initial stage, followed by the other during a second stage.
  - Explanatory sequential: Begins with a quantitative phase and analysis, which then inform a qualitative phase to further explain the quantitative results.
  - Exploratory sequential: Begins with a qualitative exploration and analysis, which then inform the design of a quantitative instrument/phase.
- Embedded (or nested): This may be a variation of a convergent or sequential design. Quantitative and qualitative approaches are used in tandem and embed in one another to provide new insights.
- Multiphase: Multiple projects commonly involving both convergent and sequential elements, conducted over time to be linked together by a common aim.

Each type of data is collected independently. When integrated and interpreted, the results will be useful for exploring whether difference sources of evidence provide similar

conclusions to study findings, thus offering stronger evidence for the conclusions [85]. Multiple sources of evidence collected in different ways will help capture a richer understanding of how the questionnaire functions.

### 1.2.3 Research Objectives

The purpose of this study was to validate and assess the properties of the PAM-13 among English speaking cardiac patients in Singapore by examining the three sources of evidence for validity identified earlier.

Specifically, this study aimed to examine whether the PAM-13 is a valid assessment tool by demonstrating evidence in:

1. Internal structure via data quality, unidimensionality, DIF and internal consistency
2. Response processes through cognitive interviewing, item difficulty and item fit
3. Relations to other variables via a negative correlation with depression and positive correlation with self-efficacy



Table 1. Sources of evidence to be examined for validity

	<b>Quantitative</b>	<b>Qualitative</b>
<b>Evidence based on test content</b>	NA	NA
<b>Evidence based on internal structure</b>	<ul style="list-style-type: none"> <li>• Data quality</li> <li>• Unidimensionality</li> <li>• DIF</li> <li>• Internal consistency</li> </ul>	NA
<b>Evidence based on response processes</b>	<ul style="list-style-type: none"> <li>• Item difficulty</li> <li>• Item fit</li> </ul>	Cognitive Interview (retrospective)
<b>Evidence based on relations to other variables</b>	Co-relation with: <ul style="list-style-type: none"> <li>• Depression</li> <li>• Self-efficacy</li> </ul>	NA
<b>Evidence based on the consequences of testing</b>	NA	NA

This study used a concurrent mixed methods design [22] which collected quantitative and qualitative data concurrently, providing a comprehensive validation of the PAM-13. Numerous PAM validation studies had been completed since its introduction. Previous research had identified consistent differences with item difficulty in different cultures and population groups. This had been an issue which past quantitative methods had been unable to examine further. Furthermore, the current review on validity highlighted a need to adopt qualitative methods to gather evidence in the area of response processes. These two points highlighted a need to include qualitative methods alongside traditional quantitative methodology to validate the PAM-13.

In summary, quantitative data assisted in measuring statistical relevance and associations of PAM in particular populations and settings while qualitative data allowed identification of previously unknown processes, explanations of why and how the difficulty

rankings differed, and the range of their effects [65]. Therefore, a mixed method approach which utilized both qualitative and quantitative methods was employed.

#### 1.2.4 Thesis goals

This introductory chapter provides the background and purpose of a thesis that describes the validation of the PAM-13. Chapter 2 detailed the quantitative approach, a cross-sectional study conducted in a convenient sample of heart clinic patients. Quantitative data was used to provide information on 1) internal structure via data quality, unidimensionality, DIF and internal consistency, 2) Response processes through item difficulty and item fit, and 3) relations to other variables by correlating PAM-13 scores with measurement of depression and self-efficacy. Chapter 3 describes the qualitative approach which utilized cognitive interviews in a smaller purposive sample of the same population. Qualitative data served to inform on the response processes. Chapter 4 then brings results of the two approaches together and discusses the possible findings and implications.

#### 1.2.5 Ethical considerations

To conduct the work reported in Chapters 2 and 3 of this thesis, ethical approval was obtained from the Dalhousie University Health Sciences Research Ethics Board (refer to Appendix B) and National Healthcare Group Domain Specific Review Board (refer to Appendix C) in Singapore. For all the work described in Chapters 2 and 3, informed consent (refer to Appendix D) was obtained from all participants. An ID code was assigned to all participant materials to ensure confidentiality. All original hard copies of

questionnaires and demographic information was kept in the hospital's locked cabinets, to which only the principal investigator (PI) has access. For the work reported in Chapter 3, audio-recordings of the interviews were transferred to a password protected computer following the interview. The digital recording was destroyed at that time. During the transcription of interviews, the PI anonymized any names and/or potential personal identifiers mentioned in the interview.

# **CHAPTER TWO: VALIDATION OF THE PATIENT ACTIVATION MEASURE (PAM-13) AMONG ADULTS WITH CARDIAC CONDITIONS IN SINGAPORE**

## **2.1 INTRODUCTION**

Singapore is a multiethnic society consisting of ethnic Chinese (74%), Malay (14%), Indian (9%) and others (3%) [109]. English is the working language and about 75% of residents are literate in English [109]. Singapore is one of the more developed countries in Southeast Asia, with a gross domestic product (GDP) per capita of \$78,763 international dollars (also known as Geary-Khamis dollars) in 2013 [125].

Parallel to the prospering economy, the age-adjusted mortality for ischemic heart disease (IHD) in Singapore is one of the highest in the world [126]. Heart diseases are in the top 10 principal causes of death and top 10 reasons for hospitalization. Cardiovascular diseases account for the greatest disease burden (20%) in Singapore [81-83]. Factors such as an aging population, higher life expectancy and unhealthy lifestyle choices contribute to the high incidence of heart diseases [84].

To reduce the overall burden of care, cost effective interventions targeting prevention and control of diseases are needed [135, 136]. The most effective approaches for chronic disease management are multi-pronged [102] with the Chronic Care Model (CCM) [129] the most widely implemented. In the CCM, improved health outcomes are the result of productive interactions between informed, activated patients and prepared, proactive practice teams. As self-management performed by individuals is a crucial part of chronic disease management [5], it has been argued that low levels of patient activation limits full implementation of the CCM model [32].

Since patient activation is important, a measurement tool is needed to measure and improve care in chronic conditions. Hibbard and colleagues (2004) developed the Patient Activation Measure (PAM) to assess knowledge, skills and confidence for self-management [16, 17], now the most commonly used measure of activation [13, 16, 18]. It was developed using Rasch modelling, first as the 22-item PAM, then reduced to 13-items (PAM-13) [42, 43]. Both are unidimensional, Guttman-like scales with items sequenced by increasing difficulty of “activation”. Each item has five response categories: (1) strongly agree, (2) disagree, (3) agree and (4) agree strongly, and (5) non-applicable (N/A). Raw item scores are converted into activation scores using a computer algorithm. Scores range from 0 to 100; higher scores indicate higher activation. Depending on the scores people are categorized into four progressively higher levels of activation (Level 1 to 4) [52].

Socio-demographic and other external factors have been found to have an impact on patient activation. Higher education [3, 27] and income [3, 27, 114] tend to have a strong positive association while conflicting associations have been found between patient activation and age, gender and race [3, 27, 56]. Emotional and psychological factors are significantly associated with activation levels. Depression is negatively correlated [26, 49, 56], suggesting that as patient activation increases, severity of depressive symptoms decrease. In multiple studies [7, 26, 121] high self-efficacy has also been shown to be positively correlated with patient activation.

The potential clinical benefits and strong psychometric properties of the PAM-13 have prompted translation and validation into several languages including Korean [2], Hebrew [69, 70], Bengali [105], Dutch [98], Danish [68], German [17, 139] and Spanish [3]. Validation studies have also been completed with various population groups and

settings, such as multimorbid older adults [115], patients awaiting elective lumbar spine surgery [116], those with multiple sclerosis (MS) [121], neurological [92], mental health conditions [33], employees [27] and people in rural settings [51]. While confirming unidimensionality and Guttman-like scaling, some studies identified item difficulties that vary from the original ranking. Activation score ranges also differ across studies. These discrepancies may be due to differences in health beliefs embedded within different cultural backgrounds and/or the differing self-management needs of client groups, indicating a need to validate the PAM-13 in Singapore.

Validity and reliability testing is evolving. While many instruments currently in use were developed using the psychometric methods of classical test theory (CTT) [9], PAM-13 was developed based on the Rasch model [99]. Theoretical differences between the two result in differences in how instruments are constructed, administered and interpreted. While many validity analyses such as internal consistency are based on CTT, it is common for authors to utilize and report these methods in combination with Rasch analysis for PAM-13 validation studies [9, 68, 92, 98, 139].

In recent reviews of validity, the breakdown of validity into content, criterion-related and construct validity has been described as an incomplete interpretation and a ‘unitary concept’ of validity is now advocated [4, 24, 78]. Using this concept, validation should be demonstrated by examining five types of evidence; 1) test content, 2) internal structure, 3) response pattern, 4) relationship to other variables, and 5) consequences of testing [4]. Reliability, while necessary, is not sufficient, and should be considered a component of validity, contributing to evidence on internal structure [24]. As evidence based on test content and consequences of testing were beyond the scope of this study, we

aimed to examine whether PAM-13 is a valid and reliable assessment tool by demonstrating evidence of:

4. Internal structure via data quality, unidimensionality, differential item functioning (DIF) and internal consistency,
5. Response processes through item difficulty and item fit, and
6. Relationship to other variables via a negative correlation with depression and positive correlation with self-efficacy.

## **2.2 METHODS**

### **2.2.1 Participants**

Participants were recruited via convenience sampling from ten clinics at an outpatient heart center, based in a tertiary hospital in Singapore. To be eligible for this study, patients had to be: (1) at least 21 years old, (2) residents of Singapore (Citizens or Permanent Residents), (3) diagnosed with ischemic heart diseases (ICD10AM: I20-I25) or heart failure (ICD10AM: I50), (4) have self-reported English proficiency (i.e. able to speak and read English), and (5) willing to give written informed consent. Patients were excluded if (1) they did not have sufficient visual acuity to read the questionnaires, (2) had a formal physician diagnosis of deafness, dementia, brain tumor, brain injury or (3) cognitive impairment that precluded adequate interaction with the interviewer. Patients were screened for eligibility using clinic lists and were approached in the clinic waiting area by the principal investigator (PI) after registration. Patients who agreed to participate were asked to sign an informed consent. Questionnaires were completed in a quiet corner of the clinic waiting room to ensure privacy. Participants were given a SGD\$5 supermarket

voucher upon completion of the questionnaire (refer to Appendix E). Ethics approval from Singapore's National Healthcare Group Domain Specific Review Board and Canada's Dalhousie University Health Sciences Research Ethics Board were obtained prior to participant recruitment and data collection.

The required sample size was determined via multiple methods. Firstly, a power analysis based on a simple correlation model, providing 80% statistical power, with  $\alpha = 0.05$  was calculated for both depression and self-efficacy. An expected correlation of -0.35 for depression [69] indicated a needed sample of 49 patients. For self-efficacy, Magnezi, Glasser & Shaley et al. (2014) reported a correlation of 0.47 while Brenk-Franz, Hibbard & Herrmann, et al (2013) reported a correlation of 0.43, thus an expected average correlation of 0.45 indicated a need for a sample of 29 patients. Secondly, when using Rasch analysis with rating scale tools, Linacre (1999) recommended that there be at least 10 responses for each category label (e.g. sometimes, never). PAM-13 has five category labels, namely disagree strongly, disagree, agree, agree strongly and non-applicable (N/A), indicating a minimum sample size of 50. However, previous research had demonstrated that for polytomous items, large sample sizes of more than 250 subjects may be needed to ensure stable and robust estimates of item parameters [19, 63, 101]. Hence, to ensure robust Rasch analysis results, the minimum number of participants required was set at 250.

### 2.2.2 Measures

Age, race, gender, education level, marital status, employment status, total household income and self-reported health status were collected as demographic and health variables (refer to Appendix F). Total household income was estimated based on each 20<sup>th</sup>



percentile of Singapore's monthly household income [110]. Self-reported health was collected using the first item of the SF 36. This single item general health status is often used as a stand-alone measure and has been found to be directly correlated with activation [27].

Evidence based on relationship to other variables was collected by correlating the PAM-13 with depression, measured by Patient Health Questionnaire-9 (PHQ-9) (refer to Appendix G) [118] and self-efficacy, measured by Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale (SSE) (refer to Appendix H) [68]. PHQ-9 is a self-report questionnaire for screening of depression symptoms based on the Diagnostic and Statistical Manual of Mental Disorders-IV. The 9-item PHQ-9 uses a 2-week recall period and a 4-point response scale to measure symptom severity. PHQ-9 had been validated among 400 English-speaking Singaporean primary care patients. Sensitivity and specificity for diagnosing major depression (cutoff score of 6) were 91.7% and 72.2% respectively [123]. Good internal consistency (Cronbach's alpha: 0.87) have also been reported [123].

The SSE is a 6-item self-report scale measuring patient confidence doing certain activities. The six items, rated on a 10-point scale range from "not at all confident" (1) to "totally confident" (10). Higher total scores indicate higher self-efficacy. Internal consistency reliability of 0.91 and a moderate correlation ( $r=0.58$ ) with the General Self-efficacy Scale have been reported, indicating acceptable validity and reliability [65, 119]. Although no validation of the SSE had been done in Singapore, it is a well-recognized tool [65], disseminated worldwide including Singapore. As no other validated self-efficacy tool could be found for Singapore, the SSE was chosen.

### 2.2.3 Statistical analysis

As noted above, both CTT and Rasch validity analysis have been reported in previous studies of the PAM-13. For this reason both types of analysis were undertaken, in order to provide a robust analysis and for ease of comparison with past studies. Data were first reviewed for completeness prior to statistical analysis. The PAM-13, PHQ-9 and SSE were scored as per standard protocols and missing data were treated as specified. Most of the analyses were performed using Stata 14 [120]. The Rating Scale Model and associated diagnostics were estimated using the statistical program R [97] with the extended Rasch model (eRm) package [71, 72].

#### 2.2.3.1 Evidence of internal structure

Data quality of the PAM-13 was assessed at the item-level via standard deviation, median, percentage of missing data, number of “non-applicable” answers and extent of ceiling and floor effects. Floor and ceiling effects between 1-15% were defined as optimal [74]. To assess unidimensionality, principal component analysis and factor analysis were performed. To assess the internal consistency, Cronbach’s alpha and item-rest correlations (Pearson’s  $r$ ) were calculated. An alpha of 0.80 or higher was defined as the acceptable value [14, 73]. Item-rest correlations are correlations between an item and the scale formed by all other items. Since in a multiple item scale, items should be moderately correlated with each other to capture the breadth of the concept, in this study a correlation  $r \geq 0.50$  was considered strong,  $r \geq 0.30$  moderate and  $r \geq 0.10$  weak [1].

Differential item functioning (DIF) detects item bias in the internal structure. For example, when respondents of different groups have the same ability but a different

probability of success on an item, DIF is present. If that happens, it may produce consistently biased scores across sample groups and inaccuracy in interpreting underlying ability [4]. It was tested using the Anderson LR test, which is a global assessment of the null hypothesis that scaling is equal between two groups. A p-value of less than 0.05 means that there is less than a 5% chance that scaling is equal between the groups.

#### 2.2.3.2 Evidence in response processes

The Rating Scale Model was used to assess whether the sequence of item difficulty matched that of the original PAM-13 [42, 43, 92]. Item difficulties were expected to follow the same sequence as in PAM-13. Location parameters were calculated to estimate the sequence of items from easiest to most difficult, with a separation index of at least 0.15 logits expected. Using the Rating Scale model, item fit was evaluated using infit and outfit mean square (MSQ) statistics. If data fit the Rasch model, the fit statistics should be between 0.6-1.4 [74].

#### 2.2.3.3 Evidence of relationship to other variables

The correlation between PAM-13, self-efficacy and depression was tested using Pearson Product Moment Correlations. Strong correlations were considered to be over 0.60, moderate between 0.30 and 0.60, and low correlations below 0.30 [50]. Moderate correlations with values close to previous studies were expected.

## 2.3 RESULTS

A total of 270 participants completed the questionnaires. Participants in this study were mostly working (59%) adults between the ages of 33 and 86 (Table 2). They were predominantly male (83%) and married (80%). Chinese formed the largest group of participants (50%), followed by Malay (25%), Indian (18%) and other (7%) participants. Fifty-nine percent had secondary school or less, with 39% reporting a monthly household income of below \$1,999. The majority of participants had IHD (79%) and rated their health as “good” (48%).

[Insert Table 2]

### 2.3.1 Evidence of internal structure

#### 2.3.1.1 Data quality

Table 3 describes data quality of the 13 items. The item response was high with only one missing answer on item 12. The response category “not applicable” was used once in seven of the items (3, 4, 5, 7, 8, 9 and 12). All items had a small floor effect (range 0.00-1.48%). In four of the items (9, 11, 12 and 13), there was a ceiling effect less than 15% (range 5.19-12.59%). All other items had a ceiling effect larger than 15% (range 15.19-40.74%). The transformed mean of the PAM-13, on a scale of 0 to 100, was 58.57 (SD: 10.79; range 38.1-100).

[Insert Table 3]

Responses across the four categories (strongly disagree, disagree, agree, strongly agree) were not evenly distributed (Fig. 1). The strongly disagree category was seldom used, accounting for <2% of responses on any item. By contrast, the agree category was

highly selected, representing 59% to 79% of responses, depending on the item. Because of the low frequency of use of the strongly disagree category in this sample, it was combined with the disagree category to create a three-category dataset used in estimating the rating scale model.

[Insert Figure 1]

#### 2.3.1.2 Internal consistency

Cronbach's alpha for the full PAM-13 scale was 0.86, exceeding the minimum criteria of 0.8 and indicating strong internal consistency. The average inter-item correlations for the full scale was 0.324, with individual inter-item correlations ranging between 0.314 and 0.331, falling within the ideal range of 0.15-0.50. With the exception of items 1, 4 and 8, all other items had item-rest correlations ranging from 0.503 to 0.623, above the cutoff for strong correlations ( $\geq 0.50$ ). Item 1, 4 and 8 had item-rest correlations of 0.493, 0.461 and 0.492 respectively, slightly below the cutoff score. Details are reported in Table 3.

#### 2.3.1.3 Unidimensionality

The measure of sampling adequacy showed an adequate correlation of items (KMO criterion = 0.83) which met the requirements for principal component analysis (PCA). The eigenvalue of the first PCA factor was 4.9, which explained 38% of the variance in the data. The second and third components accounted for 11% and 9% of the variance. Factor analysis (FA) (principal axis factoring) was then calculated, and the first factor accounted for 77% of the variance, while the second and third factors accounted for 19% and 12% of

the variance. Scree plots showed that it was reasonable to assume a one-factor solution, but additional factors could be possible.

#### 2.3.1.4 Differential Item Functioning (DIF)

The DIF test examining gender showed statistically significant differences between women and men (LR-value: 23.54,  $df = 12$ ,  $p = 0.023$ ). DIF according to education was tested by comparing the completed secondary school or less group and the post-secondary education group; significant differences were found (LR-value: 75.87,  $df = 12$ ,  $p < 0.001$ ). DIF was also tested for subgroups in self-rated health status and again results showed evidence of DIF (LR-value: 55.526,  $df = 27$ ,  $p = 0.001$ ). No DIF was found for race (LR-value: 34,  $df = 30$ ,  $p = 0.281$ ) or employment status (LR-value: 13.42,  $df = 15$ ,  $p = 0.57$ ).

#### 2.3.2. Evidence in response processes

Table 4 shows that separation distances for five of the 12 items were below 0.15 logits; between items 4 and 7 (0.14 logits), items 7 and 6 (0.12 logits), items 6 and 8 (0.02 logits), items 5 and 10 (0.11 logits), items 10 and 9 (0.03 logits). Separation distances between items 6 and 8, and items 10 and 9 were particularly low at 0.02 and 0.03 logits.

The infit (range from 0.739 to 1.029) and outfit (range from 0.678 to 1.017) MSQ were all within the acceptable range of 0.6 to 1.4. However, the ranking of items by difficulty differed from the original PAM-13 ranking. Items 1, 2, 3, 4, 6 and 11 retained their ranking. Of those items that differed in ranking, most differed by one rank with the exception of items 7 and 5. In particular, item #7 (I am confident that I can follow through on medical treatments I may need to do at home) became the 5th easiest to agree to, while

item #5 (I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself) was ranked as item #8 in this study.

[Insert Table 4]

### 2.3.3 Evidence in relations to other variables

The Pearson correlation coefficient between the mean sum scores of the PAM-13 and the PHQ9 was -0.16 ( $p < 0.05$ ), while with SSE was 0.39 ( $p < 0.05$ ). A correlation of -0.16 between PAM-13 and PHQ9 is considered low [19], falling below the expected correlation of -0.35 [27]. The correlation of 0.39 between PAM-13 and SSE met the expectation of a moderate correlation, but the value was below previous studies of 0.47 [27] and 0.43 [7].

## 2.4 DISCUSSION AND CONCLUSION

### 2.4.1 Discussion

In some aspects, the PAM-13 performed adequately in our sample of adults with cardiac conditions in Singapore. Internal structure was the first characteristic examined. The scale demonstrated good internal consistency (Cronbach's  $\alpha = 0.86$ ). This finding is comparable to other studies done on older adults ( $\alpha = 0.87$ ) [115], persons with neurological conditions ( $\alpha = 0.87$ ) [92], muscular sclerosis ( $\alpha = 0.88$ ) [121] and mental health conditions ( $\alpha = 0.87$ ) [33], and the translated versions in Danish ( $\alpha = 0.89$ ) [68], Dutch ( $\alpha = 0.88$ ) [98], German ( $\alpha = 0.84$ ,  $\alpha = 0.88$ ) [17, 139], and Korean ( $\alpha = 0.88$ ) [2]. Interestingly, in our study, there were 19% of participants who scored all items as "agree" and one percent who used "strongly agree" for all their responses. All items also had more than 50% of the answers in the "agree" response category. The consistent response pattern

might have contributed to a higher alpha than intended due to the low usage of the lower response categories, namely “strongly disagree” and “disagree”, and also participants’ preference not to choose extreme responses such as “strongly agree” [89]. This pattern of response category usage is mirrored in the German version of PAM-13, where the response category “agree” was chosen most [139]. Similarly, in another study, the “agree” and “strongly agree” response categories accounted for 60 to 85% of the responses among participants with neurological conditions [92]. These results can be interpreted as a lack of fit of the response scale.

Problems with ceiling effect were evident as most items demonstrated a ceiling effect. The issue with ceiling effect was also pronounced in the mental health [33], neurological [92], Danish [68], and German studies [17, 139]. However, as per the design and scaling of PAM-13, ceiling effect was most pronounced for the first two items while the rest followed a vague but inconsistent difficulty sequence; participants were more likely to strongly agree with the easier items. The huge ceiling effects and poor differentiation between items 3 - 13 suggest a lack of spread in response categories, resulting in possible inadequacy to cover relevant answers and measure changes over time. Interesting to note is a recent study showed that the scale still demonstrated sufficient sensitivity to change despite having 10 out of 13 items with a ceiling effect [33]. Further studies will be needed to explore the scale’s sensitivity to change in both research and clinical settings.

PCA and FA suggested that PAM-13 may be treated as a unidimensional scale, but also implied the possibility of additional dimensions. This finding is not unique to our study as the neurological conditions study found, using PCA, that 40% of the variance was explained by the 1<sup>st</sup> factor but another 10% and 9% were explained by the 2<sup>nd</sup> and 3<sup>rd</sup> factors



respectively [92]. Through FA, very similar findings were also reported [92]. Likewise, in the Norwegian study, two main components were labelled [33], while the spine surgery study found that a three factor model provided a better fit when using confirmatory factor analysis [116]. These suggest that patient activation may not be a unidimensional concept, and additional dimensions should be considered in future research.

Evidence of response process was also mixed. Although results suggest a good overall fit to a Rasch model, when compared to the original PAM-13, differences in item ranking and separation occurred at seven and five points respectively in the scale. Low separation, particularly between items 6 and 8, and items 10 and 9, demonstrated little to no difference in how participants answered the two items on the scale. Separation distances were only reported in one other study and it too discovered poor separation at three points of the scale, namely between #2 and #3, #10 and #9, and #9 and #5 [68]. This suggests that some items could be omitted without loss of information. Further research is needed to clarify if omission of items is necessary and which items to omit.

In the original PAM-13, items were ranked in order of difficulty according to patient activation in an American population with chronic conditions. However, the items were ranked differently in our sample. In particular, item #7 (I am confident that I can follow through on medical treatments I may need to do at home) became the 5th easiest to agree to, while item #5 (I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself) was ranked as item #8 in this study. This finding is not unique to our study as previous validation studies also identified variation in the same items. Item #7 was ranked easier in the neurological [92], muscular sclerosis [121], Dutch [98] and Danish [68] studies. Interestingly, it was ranked as more

difficult in Korea [2] and Germany [17]. For item #5, it was also ranked more difficult in the neurological [92], muscular [121], Danish [68] studies and Germany [17]. On the other hand, it was ranked easier in Dutch [98] and Korea [2]. The problem with item difficulty ranking was not restricted to these two items as other items were also identified as misfits in these studies.

In the final stage of the original study, PAM was tested with a national sample of 1,515 adults [42]; 21% of the sample did not have any chronic conditions, while the other 79% were divided among nine different chronic conditions. Only 13% of the sample had chronic conditions similar to our study's sample. Among the currently published PAM-13 validation studies, populations and countries vary with few overlaps in sample characteristics. None of the studies have reported the same item difficulty ranking. The variation in scaling across various countries and populations suggests that it may be a generalized problem with PAM-13. This means that people in different populations find some questions easier or more difficult to answer when compared with the American population. This is also reflected in the DIF results, where people of different gender, education levels and self-reported health status performed differently on PAM-13. Therefore, the original PAM model with four stages of activation needs to be used with caution as the algorithm used to set the final score and therefore activation level is based on the original item difficulty.

Lastly, we looked at the evidence in relation to other variables. As expected, PAM-13 was moderately correlated to SSE ( $r=0.39$ ,  $p<0.05$ ), indicating patients with higher activation had higher self-efficacy. This was an expected association; previous studies have shown strong correlations between the two constructs, though they remain conceptually

distinct [121]. Significant correlation between PAM-13 and PHQ9 ( $r=-0.16$ ,  $p<0.05$ ) was also in the anticipated direction, such that higher activation was associated with lower depression. The low correlation is an interesting finding as previous studies consistently report a significant inverse relationship between PAM-13 and depression; people who are depressed are less likely to be highly activated. Among people with MS, significant correlation was found between the PAM-13 and the Beck Depression Inventory ( $r=-0.43$ ,  $p>0.01$ ) [121], while in a primary care setting, PAM-13 scores correlated negatively with PHQ9 ( $r=-0.35$ ,  $p<0.00001$ ) [69]. However, the low correlation could be attributed to the lack of spread in our PHQ9 results as the majority of the participants had low PHQ9 scores. The mean PHQ9 score in the primary care study was  $6.1 \pm 6.1$  [69] while the mean PHQ9 score in our study was only  $3.5 \pm 4.1$ . A possible reason for this distribution is that in Singapore, women typically have a higher prevalence of depression than men [20]. However, in our study, the majority (83%) of the participants were male. The relationship between depression and patient activation in Singapore should be further explored in future research as it can possibly impact on intervention designs.

#### 2.4.2 Conclusion

Overall in our study, the PAM-13 was found to have good internal consistency and item fit, acceptable unidimensionality, and moderate correlation with self-efficacy. However, evidence in all three areas of validity (internal structure, response processes, and relation to other variables) were mixed. Results indicate a need for improvement, especially in the area of item statistics. Future studies are recommended to further validate and tailor the scale to specific diagnostic groups in Singapore.

### 2.4.3 Practice and Research Implications

We suggest that PAM-13 can be used as a tool to introduce discussion of patients' self-management practices. This in combination with clinical interviews may assist practitioners to provide more targeted and individualized treatment. Researchers may use the total score of PAM-13 to measure patient activation and track progress of activation during and post interventions. However, strict reliance on the four levels of activation to inform and guide interventions in both research and clinical settings should be done with caution.

Table 2 Participant characteristics and PAM-13 scores (n = 270)

	<b>Mean</b>	<b>(SD)</b>	
<b>Age in years</b> (range 33 to 86)	58.49	(10.37)	
<b>PAM-13</b> (out of 100)	58.57	(10.79)	
<b>SSE</b> (out of 10)	7.07	(1.89)	
<b>PHQ-9</b> (out of 27)	3.48	(4.10)	
	<b>Number</b>	<b>%</b>	<b>Mean PAM-13</b>
<b>Gender</b> (n = 270)			
Male	225	83.33	58.96
Female	45	16.67	56.65
<b>Race</b> (n = 270)			
Chinese	136	50.37	60.21
Malay	68	25.19	54.90
Indian	48	17.78	59.42
Others	18	6.67	57.86
<b>Education</b> (n = 269)			
Completed secondary school or less	158	58.7	57.39
Post-secondary education	111	41.3	60.29
<b>Marital status</b> (n = 270)			
Single	25	9.26	56.77
Married	215	79.63	59.14
Widowed	17	6.30	54.91
Divorced	13	4.81	57.50
<b>Employment status</b> (n = 270)			
Employed full-time	127	47.04	59.76
Employed part-time	32	11.85	57.86
Unemployed	28	10.37	53.54
Retired	64	23.70	59.30
Full-time student	1	0.37	67.82
Housewife	18	6.67	56.17
<b>Total household income/month (SGD)</b> (n = 255)			
Below \$1,999	100	39.22	56.27
\$2,000 - \$4,999	81	31.76	58.54
\$5,000 - \$7,999	37	14.51	61.84
\$8,000 - \$12,999	19	7.45	59.16
\$13,000 and above	18	7.06	65.06
<b>Type of heart condition</b> (n = 270)			
IHD	148	54.81	59.36
HF	57	21.11	56.87
IHD & HF	65	24.07	58.26
<b>Health status</b> (n = 270)			
Excellent	14	5.19	70.11
Very good	53	19.63	61.39
Good	130	48.15	58.19
Fair	58	21.48	55.12
Poor	14	5.19	54.50
Very poor	1	0.37	55.62

Table 3 Data quality and internal consistency of the PAM-13 in a population with cardiac conditions (n = 270)

<b>I t e m</b>	<b>N</b>	<b>Median</b>	<b>Missing values % of N = 270</b>	<b>“Not applicable” % of N = 270</b>	<b>Floor %</b>	<b>Ceiling %</b>	<b>Item-rest correlation</b>	<b>Average inter-item correlation</b>
1.	270	3	0	0	0.37	40.74	0.493	0.327
2.	270	3	0	0	0.37	40.37	0.550	0.321
3.	270	3	0	0.37	0.00	22.22	0.533	0.323
4.	270	3	0	0.37	0.37	19.26	0.461	0.331
5.	270	3	0	0.37	0.37	15.19	0.527	0.324
6.	270	3	0	0	0.37	15.19	0.503	0.326
7.	270	3	0	0.37	0.74	18.15	0.528	0.324
8.	270	3	0	0.37	0.00	15.93	0.492	0.327
9.	270	3	0	0.37	0.00	10.74	0.518	0.325
10	270	3	0	0	1.11	16.30	0.566	0.320
11	270	3	0	0	0.37	12.22	0.623	0.314
12	269	3	0.37	0.37	0.74	5.19	0.514	0.325
13	270	3	0	0	1.48	12.59	0.524	0.324

Fig.1 Distribution of responses by PAM-13 item  
(excluding missing data)

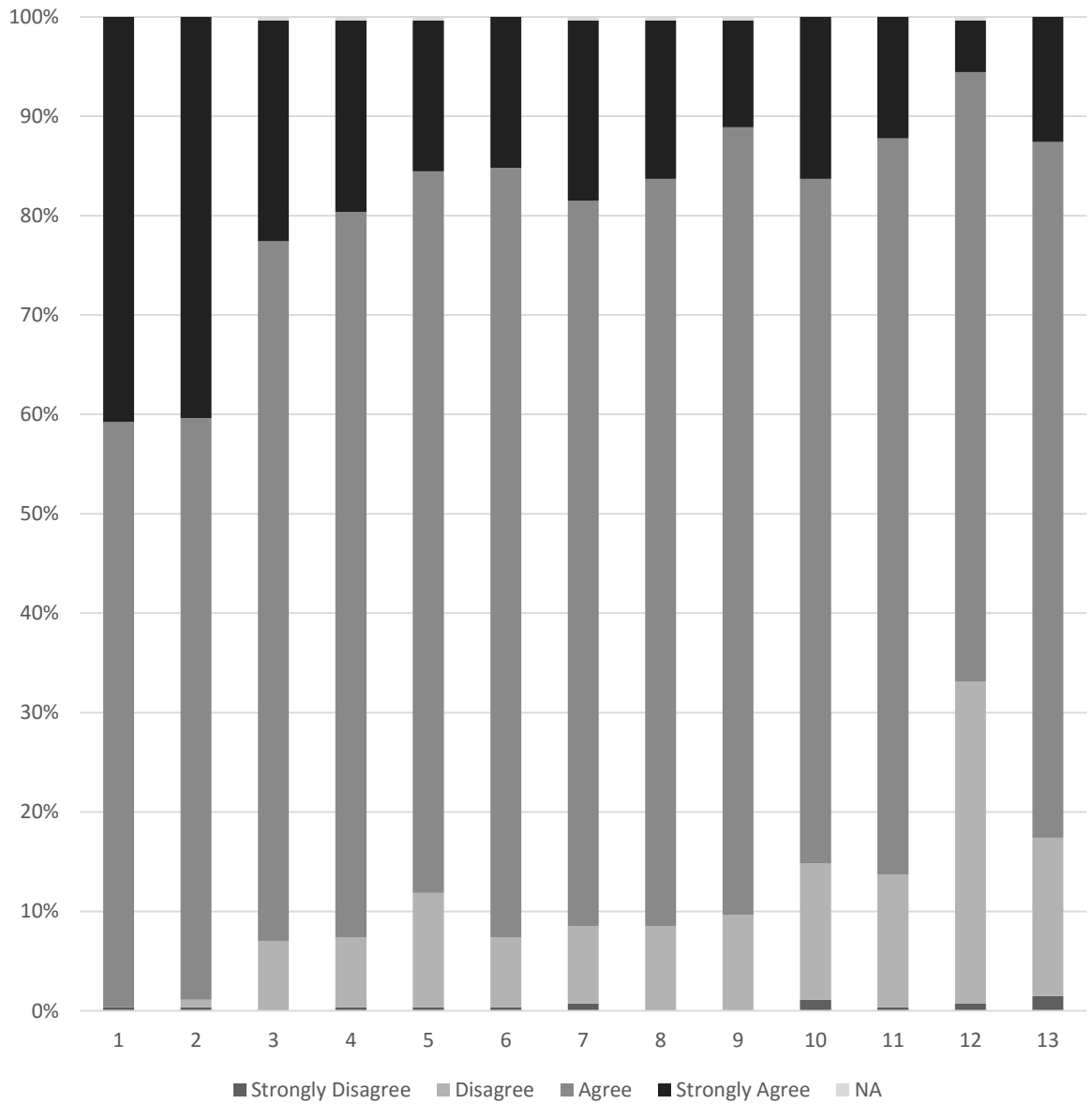


Table 4 Results of the Rasch rating scale model of the PAM-13 in a cardiac population with data collapsed to three response categories per item

<b>Item number based on current study</b>	<b>Original PAM-13 item number</b>	<b>Mean</b>	<b>SD</b>	<b>Difficulty parameter</b>	<b>SE of difficulty parameter</b>	<b>Outfit MSQ</b>	<b>Infit MSQ</b>
1	1	3.40	0.51	Reference		0.913	0.864
2	2	3.39	0.53	-1.904	0.152	0.766	0.787
3	3	3.16	0.53	-0.426	0.148	0.985	0.995
4	4	3.12	0.53	-0.217	0.147	0.948	1.029
5	7	3.10	0.54	-0.082	0.146	0.844	0.937
6	6	3.07	0.48	0.037	0.145	0.751	0.829
7	8	3.08	0.50	0.058	0.145	0.878	0.921
8	5	3.04	0.54	0.310	0.143	0.924	0.945
9	10	3.00	0.59	0.416	0.142	1.017	1.023
10	9	3.02	0.47	0.441	0.143	0.704	0.739
11	11	2.98	0.52	0.588	0.141	0.678	0.746
12	13	2.94	0.58	0.776	0.140	0.949	1.006
13	12	2.72	0.59	1.970	0.139	0.899	0.911



# **CHAPTER THREE: HOW ADULTS WITH CARDIAC CONDITIONS IN SINGAPORE UNDERSTAND THE PATIENT ACTIVATION MEASURE (PAM-13) ITEMS: A COGNITIVE INTERVIEWING STUDY**

## **3.1 INTRODUCTION**

The burden of chronic disease is rapidly increasing worldwide. Ischemic heart disease (IHD) has remained the leading cause of death worldwide for the past decade [137], making it a major contributor to hospitalizations and health care expenditure. In Singapore heart diseases are within the top 10 principal causes of death and hospitalization; cardiovascular diseases account for the top disease burden (20%) in Singapore [81-83].

Given the complex and progressive nature of IHD and heart failure (HF), it is important to identify interventions to assist those with these conditions to practice effective self-management [6, 15]. Self-management refers to an individual's ability to manage the symptoms, treatment, daily functioning, emotions and changes in interpersonal relationships inherent in living with a chronic condition [65]. Evidence shows that effective self-management reduces hospitalization costs and complications associated with chronic conditions, helps patients achieve healthier outcomes and enhances overall quality of life [79]. The Chronic Care Model (CCM) [129] is an example that is widely implemented. In the CCM, improved health outcomes for chronic disease management are the result of productive interactions between informed, activated patients and a prepared, proactive practice team, emphasizing the central role that patients have in managing their own care.

Hibbard and colleagues (2005) developed the 13-item Patient Activation Measure (PAM-13), as a self-report questionnaire to measure patient activation [43]. The most commonly used measure of activation [30, 48], PAM was originally developed as a 22 item scale in 2004 using a four stage process [43]. In stage one, activation was conceptually defined using a literature review, national expert consensus panel and focus group consultations with individuals with chronic diseases. Based on these results, an activated person was defined as: (1) believing the importance of oneself being active in managing care, collaborating with providers, and maintaining their health, (2) having knowledge of condition management, functional maintenance, and prevention of health declines, and (3) having skills and behavioral repertoire to access appropriate and high-quality care, as well as performing those tasks mentioned in points one and two [42].

In stage two, domains of activation identified in stage one were operationalized by creating an 80-item pool of questions from existing instruments and newly created ones. Items were categorized by domain, reviewed by a subset of the expert panel, using cognitive testing with 20 individuals with chronic conditions. A pilot study was then conducted with a convenience sample of 100 participants with a wide range of chronic conditions. Items were selected with Rasch's Rating Scale Model, which facilitated the creation of a unidimensional, Guttman-like scale, calibrating "difficulty" of items according to response probabilities. After the initial study, the domain of accessing appropriate and high-quality care was excluded as analysis revealed that it had a different construct from activation [42]. The authors also concluded that activation appeared to involve four progressive levels: (1) believing the patient role is

important, (2) having the confidence and knowledge necessary to take action, (3) actually taking action to maintain and improve one's health, and (4) staying the course even under stress [42].

In the third stage, extension and refinement of PAM items was done using a convenience sample (n=120 cardiac rehabilitation patients and 366 employees of a large health organisation). Final validation (stage 4) was done with a national probability sample of 1515 people, selected via random digit dial selection [42].

PAM was later reduced to 13 items (PAM-13); this shortened scale has psychometric properties similar to the original measure [43]. More specifically, items #1 and #2 were grouped under level one of activation, item #3 to #8 under level two, item #9 to #11 under level three, and lastly item #12 to #13 under level four [43]. PAM-13 suggested that the four levels of activation are reached progressively before becoming fully engaged in managing their own health [44].

The PAM-13 has been validated with various populations and settings. However, studies have shown that PAM-13 performed differently with different populations and settings as item difficulties vary from the original ranking. For example, item #3, "I am confident I can help prevent or reduce problems associated with my health", has been perceived as more difficult in Korea [2], Netherlands [98], Germany [17], rural areas [51], and among people with muscular sclerosis [121] and neurological conditions [92]. These discrepancies may be due to differences in health beliefs embedded in different cultures/countries and/or the different self-management needs of various client groups.

With the possibility that culture influences participant responses, prior to using the PAM-13 in Singapore there was a need for further validation in order to confirm whether it was a culturally relevant tool. Singapore is an island city-state in Southeast Asia, with a multiethnic society mainly consisting of ethnic Chinese (74%), Malay (14%), Indian (9%) and others (3%) [109]. In Singapore, English is the working language and about 75% of the residents are literate in English [109].

Survey results are known to be compromised when questions are not interpreted in the way researchers expect [29]. Cognitive interviewing is the most common method to detect problems respondents have in understanding and formulating answers to survey items [122]. Cognitive interviewing results can be used to ensure that items and response options are relevant, understood as intended, and whether they differ depending on cultural background. Cognitive interviewing also enhances validity by providing evidence on response processes, defined as the extent to which the types of responses required of respondents fit the defined construct [4].

The purpose of this study was to examine how adults with cardiac conditions in Singapore interpreted and responded to the English version of the PAM-13, thereby providing evidence on responses processes for the validation of PAM-13.

## **3.2 METHODS**

### **3.2.1 Design**

This paper reports the qualitative findings from a larger study that used a concurrent mixed methods design to validate PAM-13 among English speaking adults with cardiac conditions in Singapore. The quantitative, cross-sectional study was

conducted with a convenient sample of heart clinic patients, to examine the validity and reliability of the PAM-13. The qualitative portion of the study recruited a smaller, purposive sample of the larger sample to better understand response processes, contributing to the comprehensive validation study.

This study utilized retrospective cognitive interviews. In the retrospective technique, the interviewer asks questions about the instrument after its completion, rather than during initial completion. Advantages of this method are that there is less burden for the respondents, ease and simplicity of respondent training, and control of the interview by the interviewer [76, 132]. However, disadvantages may involve missing important information due to deficiencies in recall and potential for bias responses due to leading questions by the interviewer [76, 132]. While there are both pros and cons, retrospective probing after completing the whole questionnaire is recommended when testing self-administered questionnaires as it takes into account respondents' ability to complete the instrument unaided, as well as to simulate a more realistic questionnaire administration [132]. Moreover, in short questionnaires, such as the PAM-13, there is a lower probability of contamination in recall.

### 3.2.2 Participants and Setting

Participants were recruited from ten out-patient cardiac clinics in a Singapore tertiary hospital. The inclusion criteria were as follows: at least twenty-one years old, resident of Singapore, diagnosed with IHD or HF, self-reported English proficiency and willingness to give written informed consent. Patients were excluded if (1) they did not have sufficient visual acuity to read the questionnaires, (2) had a formal

physician diagnosis of deafness, dementia, brain tumor, brain injury or (3) other form of cognitive impairment that precluded them from adequately interacting with the interviewer.

A convenience sample of 270 participants was recruited for the full study. A purposive sampling frame was used to recruit a diverse group of 13 participants for the qualitative portion of the study. The use of a maximum variation sampling technique resulted in maximum heterogeneity on specific attributes anticipated to affect the variables of interest. Attributes sampled included 1) PAM-13 levels 1 and 2 versus levels 3 and 4, and 2) HF and IHD. This was to ensure that there was diversity in the PAM-13 scores among the sample and to provide a more holistic picture of how patients with different activation levels and diagnosis interpreted the questions in PAM-13.

Ethics approval from Singapore's National Healthcare Group Domain Specific Review Board and Canada's Dalhousie University Health Sciences Research Ethics Board were obtained prior to participant recruitment and data collection. Suitable patients were approached by the principal investigator (PI) in the clinic waiting room. Informed consent was obtained from all individual participants included in the study. After completion of the surveys, individual interviews were arranged with suitable and agreeable participants.

### 3.2.3 Interviews

With the exception of one participant, face-to-face interviews were conducted, in private, in the tertiary hospital, by the PI. For one of the participants, a telephone

interview was conducted. All interviews were conducted between June 2015 and August 2015.

The cognitive interviews used scripted questions, adding emergent probes as needed (refer to Appendix I). The PAM-13 questions were reviewed item by item with participants, probes were structured according to the four stages of Tourangeau's cognitive model (comprehension of the question; retrieval from memory of relevant information; decision processes; and response processes) [124]. This model was chosen as it has contributed to the background theory underlying cognitive interviewing [132]. Comprehension of the question refers to what participants believe the questions to be asking and the meaning of specific terms within the questions. Retrieval from memory of relevant information involves recall-ability of information and recall strategies used. Decision processes reflect whether participants possess sufficient motivation to answer the question thoughtfully, and the influence of social desirability. Lastly, response processes examine if participants are able to match internally generated answers to response categories given by questions. Sample questions used included: 'Can you explain this question in your own words?' and 'How did you come to your answer?'

Interviews were audio-recorded and each interview took about 30-60 minutes. All participants were given an S\$10 shopping voucher after the interview.

### 3.2.4 Measures

In addition to PAM-13, age, race, gender, education level, marital status, employment status and total household income were also collected as demographics variables.

### 3.2.5 Analysis

The interviews were analyzed using the Framework Approach to qualitative analysis, consisting of seven stages: transcription; familiarization; coding; identifying a framework; indexing; charting; and interpretation [104]. This systematic and flexible approach is suitable for studies that are more descriptive than interpretative, with the ability to organize and reduce data on a case-based approach [28].

In this approach, it was not necessary to transcribe speech disfluency, as the content was of primary interest. Since the intent of the cognitive interviews was to understand how participants interpreted and responded to each of the 13 items on the PAM-13, verbatim transcriptions of participants' responses were grouped by item using tables created in Microsoft Word. Familiarization and coding of the interviews were done, and a research diary was kept. Tourangeau's cognitive model was identified as the framework to index, chart and interpret data of each item [124]. Reflexive notes, impressions of data, coding and thoughts about analysis were recorded throughout the process. This was reviewed by members of the research team and reconciled at multiple touchpoints.

## 3.3 RESULTS

The mean age of participants was 55.2 years (range 35-69 years). Most of the participants were male (92%), married (85%), employed full-time (62%), had completed post-secondary education (69%), and reported good to very good health status (84%). The majority (69%) of the sample's monthly household income was within the bottom 40<sup>th</sup> percentile of the national monthly household income. As



intended with the maximum variation sampling, specific attributes were represented. Seven participants had IHD, with three in the lower PAM-13 levels (levels 1 or 2) and four in the higher levels (level 3 or 4). Six participants had HF, again half were in the lower PAM-13 levels. However, due to difficulty in sampling people with just HF, three participants in the higher levels also had IHD. Characteristics of participants are summarized in Table 5.

[Insert Table 5]

The number of problems identified for each item were summarized according to Tourangeau's cognitive model and are presented in Table 6. The number of people who verbalized each problem was calculated, and quotes identified to illustrate particular problems. As no participants cited problems with retrieval, Tourangeau's category of retrieval was omitted from Table 6. The lack of problems with retrieval was likely because PAM-13 questions did not require participants to recall specific information.

[Insert Table 6]

### 3.3.1 Comprehension

Participants had similar comprehension for 5 out of 13 questions (#1, 2, 6, 8 and 10). However, even when comprehension was similar, participants indicated they attributed different degrees of responsibility to the question. For example, in question 1 'When all is said and done, I am the person who is responsible for my health', all participants viewed the question as asking about being 'responsible for the care of my own health'. However, some attributed less personal responsibility than others: e.g.

*“need to take care of my health”* versus *“I am the only one who can take care of my health”*.

The differences in comprehension were more apparent with certain questions (#3, 4 and 13), such as in question 4 ‘I know what each of my prescribed medications do’. Even though all participants agreed on the overall meaning, there were differences in the extent of knowledge participants felt was implied by the question. Some viewed it as only knowing the purpose of their medication, while others believed it included the need to understand medication side-effects and contra-indications.

For others (#5, 7, 9 11 and 12), there were obvious differences in comprehension. For example, in question 7 ‘I am confident that I can follow through on medical treatments I may need to do at home’, there were differences in the understanding of the term ‘medical treatments’. There were 2 participants who interpreted it as wound dressing, another 2 who were unsure about it, and for the remaining participants, half viewed it as taking medications and the other half viewed it as self-management practices.

Common problems reflected in comprehension were difficulties with specific English terms such as ‘when all is said and done’ and a perception that the words used in the questions were vague.

### 3.3.2 Decision processes

Decision processes involve the influence of motivation or social desirability of participants’ responses. The most common recurring theme was regarding use of the “agree strongly” response. Some participants were explicit in not selecting this

response option due to personal preference for a more neutral answer. Others did not explicitly voice avoidance of the “agree strongly” response category, but gave reasons such as “*there will always be something that I won’t know*” and “*if I choose strongly agree, I am better than the doctor*” as barriers to selecting the “agree strongly” response option. In two instances, Malay participants cited cultural or personal beliefs influencing their decision. For example, one Malay participant reported that thinking about possible problems was not relevant in his culture. Another participant reported that he never believed in ‘stress’, thus making question 13 irrelevant. Participants from other ethnic groups did not explicitly cite such influences.

### 3.3.3 Response processes

Response processes involve matching generated answers to the given response categories. Variation in the comprehension of questions, contributed to variation in selection of response categories. For instance, reasons for choosing “agree strongly” often overlapped with reasons for “agreeing”. Reasons for choosing “agreeing” also overlapped with reasons for disagreeing. For example, in item #11 “I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising”, participants who selected “agree strongly” and “agree” cited similar examples of lifestyle changes to justify their selection. Similarly, participants who selected “agree” and “disagree” cited ‘lack of maintenance’ as reasons for selection.

Understandably, participants who had problems understanding the questions also had difficulties selecting a response. Some chose to randomly select a response, others responded as they understood it.

### 3.4 DISCUSSION

All participants completed the PAM-13 with no missing data. Key problems identified through the cognitive interviews included interpretation of items, social and culture influences in decision processes, and interpretation of response options.

#### 3.4.1 Comprehension

Although English is the primary language in Singapore, variation in comprehension surfaced in this study, highlighting problems with use of certain terms and phraseology that is not common in Singapore. For example, ‘when all is said and done’ was identified as an unfamiliar term in Singapore. Some participants highlighted difficulty in understanding the term while many neglected it when explaining the question in their own words. In another question, a participant highlighted that ‘I am confident that I can tell a doctor my concerns’ made more sense in the Singapore context as compared to the PAM-13 phrasing ‘I am confident that I can tell a doctor concerns I have’.

Participants articulated a desire for more specificity to facilitate understanding of items. For example in item #4, “I know what each of my prescribed medications do”, one participant felt that the question should state that it meant knowledge of “*what it does, how it works, in order to get the best effect out of it*”. Likewise, numerous terms such as, ‘active role’ in item #2, ‘medical treatments’ in item #7, and ‘solutions’ in item #12, were considered ambiguous. This reinforces the importance of establishing cultural equivalence of measures before use in another culture even without translation [10].

As the original meaning of the PAM-13 items is not documented, other than as expressed in the items, it was not possible to compare Singapore participants' comprehension with the original meanings. However, the PAM-13 authors' grouping of questions according to four levels of activation, i.e. believes active role important, confidence and knowledge to take action, taking action, and staying the course under stress, provides some insight into the intended meaning of the questions [43]. One potential discrepancy is question 11 'I know how to prevent problems with my health', which was categorized in the "taking action" level by the PAM-13 authors. Interestingly, many participants in this study interpreted it as asking about their *knowledge* of prevention, a perspective that is more theoretically compatible with Level 1 of the PAM-13. One participant even explicitly questioned whether it was asking about the act of knowing or doing.

Culture can influence approach to a task. This might result in individual items being inherently more or less difficult when compared with other items in PAM-13. For example, in question 12 'I am confident I can figure out solutions when new problems arise with my health', participants cited the need for doctors' help to figure out solutions or that finding a doctor could be the solution itself. Depending on participants' interpretation of the item, difficulty of the item is altered thus affecting the item difficulty ranking of the scale. Since PAM-13 utilized item-level analyses, these differences can change the validity of the measure [8]. It is known that Western and Asian cultures have differences in values, and especially significant is Asian collective autonomy vs. Western individual autonomy in the decision-making process [38, 131]. These differences are also reflected in the structure of health care systems,

where values held to be important in respective societies are embedded [37]. In United States, where PAM-13 was developed, the system values individual freedom and choice [37]. In contrast, Singapore's health care system emphasizes collective responsibility and inter-dependence [80]. These differences are deeply rooted in each society, likely accounting for diversity in health behaviors between countries and influenced participants' views of the questions and their responses [21].

### 3.4.2 Decision processes

The most prominent finding in decision processes was the preference not to select "strongly agree". Collectivistic culture could have influenced why some participants chose not to select strongly agree. Responses to surveys are influenced by more than the meaning of the items. Responses are also influenced by one's response style, which is a tendency to systematically respond to survey items in a particular way regardless of item content [8]. As collectivistic cultures tend to promote harmony and avoidance of confrontations, participants from these cultures tend to give either middle or slightly positive responses [39].

There were two Malay participants who cited influences from cultural or personal beliefs, no other ethnic groups explicitly stated these influences. This highlighted the possibility of differences in cultural influences between ethnic groups in a multi-racial country like Singapore. However, further studies would be needed to draw clearer conclusions of such influences on performance of PAM-13.

### 3.4.3 Response processes

The most notable result in response processes was the inconsistent use of response categories by different participants. The variation in response processes is a known problem with self-rating scales. Participants interpreted and used scales differently, allowing people with the same opinions to rate a different response category due to difference in interpretation of the scale points [7].

One's introspective ability and understanding of questions can also influence the responses. This was also reflected in our findings, where responses were influenced by how participants comprehended the questions. Very often, problems with response processes were a result of varied or poor interpretation of key terms in questions.

## 3.5 LIMITATIONS

A limitation of this study was that the PI conducted the interviews and therefore might have unintentionally influenced the participants' perspectives. Furthermore, due to confidentiality considerations during data collection, member checking was not possible to implement. This would have strengthened the trustworthiness and rigor of the qualitative process. However, to enhance trustworthiness, a research diary where reflexive notes, impressions of the data, coding and thoughts about the analysis were recorded throughout the process. This was reviewed by members of the research team and reconciled at multiple touchpoints to minimize bias of the PI in interpretations of the findings.

Another limitation of the study was that the sample is not representative of the Singapore's general population. In particular, Indian Singaporeans were not

represented in our sample. However, it is important to note that the demographics gathered, education and total household income, are variables known to affect activation. According to Singapore statistics, 66% of Singaporeans have higher than secondary school qualifications [109]. Our sample had comparable percentage of people (69%) with higher than secondary school qualifications. On the other hand, a majority of the sample (69%) had total household income in the bottom 40 percentile of the national total household income per month. This was despite our sample having comparable education status as the national standards. The finding that 23% of the sample was retired could have contributed to the lower household income, as participants typically depend on savings and allowances from children post-retirement, and do not account for them as “income”. However, since it was not possible to sample according to the wide range of national demographics in such a small sample, it was ensured that the sample was purposively sampled according to their diagnosis and PAM-13 levels.

### **3.6 IMPLICATIONS AND CONCLUSION**

To our knowledge, this is the first study using cognitive interviewing to explore the use of PAM-13. Previous studies on the validation of PAM-13 have demonstrated differences in results between different countries and populations. However, the quantitative methodologies have limited ability to provide reasons for the differences. This study elucidates possible reasons for differences and highlights the need for caution when interpreting results in Singapore and perhaps across different countries and populations.



A possible solution to mediate the problems with decision and response processes is to use Likert scales with a larger number of categories, which allow participants to voice a more nuanced position, even without choosing the most extreme answer [39]. Issues with comprehension and decision processes reinforce the need to culturally adapt tools even when a language translation is not necessary. To widen the usage and relevance of PAM-13 in Singapore, translation into the other official languages (Mandarin, Malay and Tamil) of Singapore is encouraged.

The original English PAM-13 can be useful in exploring individuals' self-management habits and whether they are "activated" to perform them. However, due to differences in interpretation of items and response options, social and cultural influences on decision processes, caution must be taken when using PAM-13 scores and levels to decide interventions for each individual. It is therefore recommended that clinical judgement be utilized when designing personalised interventions.

Table 5 Characteristics of participants

	<b>Cognitive interviewees (n=13)</b>	
<b>Age (SD)</b>	55	(2)
	N	%
<b>Diagnosis</b>		
IHD	7	(54)
HF	3	(23)
IHD & HF	3	(23)
<b>Gender</b>		
Male	12	(92)
Female	1	(8)
<b>Race</b>		
Chinese	7	(54)
Malay	4	(31)
Indian	0	
Others	2	(15)
<b>Education</b>		
Completed secondary school or less	4	(31)
Post-secondary education	9	(69)
<b>Marital status</b>		
Single	2	(15)
Married	11	(85)
Widowed	0	
Divorced	0	
<b>Employment status</b>		
Employed full-time	8	(62)
Employed part-time	2	(15)
Unemployed	0	
Retired	3	(23)
Full-time student	0	
Housewife	0	
<b>Household income/month (SGD)</b>		
Below \$1,999	3	(23)
\$2,000 - \$4,999	6	(46)
\$5,000 - \$7,999	1	(8)
\$8,000 - \$12,999	2	(15)
\$13,000 and above	1	(8)
<b>Health status</b>		
Excellent	0	
Very good	4	(30)
Good	7	(54)
Fair	1	(8)
Poor	1	(8)
Very poor	0	

Table 6 Main findings with comprehension, decision and response processes of PAM-13 among English speaking adults with cardiac conditions in Singapore

PAM 13 item	Comprehension	Decision processes	Response processes
<p>1. When all is said and done, I am the person who is responsible for my health</p>	<p>Overall: All participants viewed it as ‘responsible for care of own health’.</p> <p>2 problems identified #1<sup>1</sup>: N<sup>2</sup>=2 – Difficulty with the wording ‘when all is said and done’</p> <p><i>“I think when all is said and done is not the way we normally talk.” (043)</i></p> <p>#2: N=1 – Found question too long</p>	<p>3 problems identified #1: N=1 – Chose agree as he felt he had to be responsible</p> <p><i>“Just choose the answer agree cause I got to do it” (009)</i></p> <p>#2: N=2 – Personal preferences for not choosing agree strongly</p> <p><i>“Normally I wouldn’t choose the strongly” (041)</i></p> <p>#3: N=2 – Possibility of unforeseen and unknown factors as the reason for not choosing agree strongly</p> <p><i>“Sometimes you know, like, some other reason also.” (024)</i></p>	<p>1 problem identified Participants who chose strongly agree and agree gave similar reasons</p> <p>Strongly agree: <i>“It is your life. You have to take care. Nobody can help” (002)</i></p> <p>Agree: <i>“I am the one who will take the responsibility. I can’t depend on anybody.” (124)</i></p>

<sup>1</sup> # = problem number

<sup>2</sup>N = number of participants

<p>2. Taking an active role in my own health care is the most important thing that affects my health</p>	<p>Overall: All participants viewed it as ‘taking actions such as lifestyle changes to manage their health’. However, no participants discussed if it is ‘the most important thing’.</p> <p>2 problems identified #1: N=2 – Queried meaning of ‘active role’</p> <p><i>“Active role... a lot will straightaway connect it to... lifestyle changes mostly. But if you talking about things like you know... going to see a doctor, we may not think of it as an active role in our own health.” (028)</i></p> <p>#2: N=1 – Queried meaning of ‘health care’</p> <p><i>“Except that the word health care not quite the way that we will use. We will probably just say actively taking care of my health.” (043)</i></p>	<p>3 problems identified #1: N=1 – Did not attempt to think further</p> <p><i>“I will say that oh that affects my health, you don’t scrutinize further” (043)</i></p> <p>#2: N=1 - Personal preferences for not choosing agree strongly</p> <p>#3: N=1 - Possibility of unforeseen and unknown factors as reason for not choosing agree strongly</p>	<p>No problems identified</p>
--	--	--	-------------------------------

<p>3. I am confident I can help prevent or reduce problems associated with my health</p>	<p>Overall: N=11 viewed it as ‘taking actions such as following medical treatments or lifestyle changes to reduce problems’.</p> <p>Differing comprehension: #1: N=1 – Helps prevent or reduce by seeing doctor</p> <p><i>“See that means I still can come and take the advice from the doctor. See I can help to prevent.” (002)</i></p> <p>#2: N=1 – Return to pre-morbid status</p> <p><i>“I must have my own confidence la, to have my own confidence to get back to what I doing” (009)</i></p> <p>4 problems identified #1: N=1 – Viewed reduce and prevent as separate questions</p> <p><i>“Reducing will be all right, because “prevent” is, I don’t think anyone can prevent anything that is natural. Nature courses, something. So,</i></p>	<p>2 problems identified #1: N=1 – Chose it because he felt he had to do it</p> <p><i>“I have to agree strongly because there’s no other options for me.” (013)</i></p> <p>#2: N=3 - Possibility of unforeseen and unknown factors as reason for not choosing agree strongly</p> <p><i>“I do not agree strongly as I may not know everything.” (071)</i></p>	<p>5 problems identified #1: N=1 – Comprehension problems (Chose agree strongly as he helped by visiting a doctor)</p> <p>#2: N=1 – Unable to give meaningful reason for answer</p> <p><i>“Agree because your own body?” (021)</i></p> <p>#3: N=1 – Felt that he could reduce but not prevent, thus choose agree (a neutral option)</p> <p>#4: N=2 – Disagreed because of genetics factors though they were confident of lifestyle and medical management</p> <p>#5: N=1 – Disagreed as no matter what actions were taken, the existing conditions would remain.</p>
--	--	--	--

	<p><i>prevent can be a bit ambiguous” (023)</i></p> <p>#2: N=1 – Not sure if actions can actually help prevent or reduce</p> <p><i>“How we feel it has prevent or reduce. It is difficult for us to gauge. Sometimes, we may feel that we are very much better, but in actual fact, we may not be.” (028)</i></p> <p>#3: N=1 – Found associated to be a difficult word</p> <p>#4: N=1 – Unsure of the type of problems</p>		
--	--	--	--

<p>4. I know what each of my prescribed medications do</p>	<p>Overall: Differences in extent of knowledge. Some viewed it as just knowing the purpose of their medication. Some saw the need to understand side-effects and contra-indications.</p> <p>Just knowing purpose: <i>“There is one they giving me for my...urine. One protect my blood. Two protect my blood. Then one protect my... diabetes. And one protect my heart.” (041)</i></p> <p>Understand further knowledge: <i>“you should be able to know, what is happening. So what is the contra-indication all these” (109)</i></p> <p>3 problems identified  #1: N=1 – Did not understand meaning of prescribed  #2: N=1 – Felt that question was not specific enough</p> <p><i>“I mean it will be better to more focus the question. So that</i></p>	<p>1 problem identified  #1: N=3 – Chose agree as need to have a more neutral response</p> <p><i>“So, sometimes, I overlook, that’s why I cannot put (strongly agree). I have to, what you call that, be in the safe place, so...” (024)</i></p>	<p>Overall: Differences in standards for choosing responses</p> <p>N=1 – Disagreed strongly as did not read up further though there is awareness of the general purposes</p> <p><i>“Because I don’t read. So I got 10 medications now which I am taking for my heart right, I roughly know ok, he say this is the heart.” (043)</i></p> <p>N=8 – Chose agree as healthcare providers explained the medications to them</p> <p>N=1 – Chose agree as he read up further</p>
--	--	--	---

	<p><i>people will know that medication... you have to know what it does, how it works, in order to get the best effect out of it.” (028)</i></p> <p>#3: N=1 – Felt the question did not differentiate between people who know because of explanations given to them by others, and people who know because of their personal research</p>		
--	---	--	--



<p>5. I am confident that I can tell whether I need to go to doctor or whether I can take care of a health problem myself</p>	<p>Overall: N=10 viewed it as' judgement on the need to see doctor.</p> <p>Differing comprehension: #1: N=3 – Viewed 'need to go to doctor' and 'take care of a health problem myself' as two separate question.</p> <p><i>"So I confident that I can tell whether I need to go. Hmm, of course when you sick, you go... Whether I can take care of a health problem myself, of course cannot. Right or not. You need a doctor medication."</i> (002)</p> <p>2 problem identified #1: N=3 – Found question complicated as there were two components within the question (same as conflicting comprehension above)</p> <p>#2: N=1 – Unsure of what the question meant</p>	<p>2 problems identified #1: N=3 – Options affected by personal dislike for seeing doctor</p> <p><i>"Some people they ok to see doctor but for me, I don't like to go see doctor, that's why I don't agree"</i> (009)</p> <p>#2: N=1 – Felt that strongly agree meant that he was better than the doctor</p> <p><i>"If I say that strongly agree, that means I know better than the teacher. I know better than the doctor. I cannot do that"</i> (109)</p>	<p>Overall: N=7 chose agree as being confident to take care of themselves if it is a common condition like flu, but there was a need to see a doctor if it is serious like a heart condition.</p> <p>2 problems identified #1: N=2 – comprehension issues (felt that confident to see doctor but not confident to take care of it themselves – 1P chose agree, 1P chose disagree)</p> <p>#2: N=1 – comprehension issues (chose disagree as he did not understand the question)</p>
---	--	---	--

<p>6. I am confident I can tell doctor concerns I have even when he or she does not ask</p>	<p>Overall: All viewed it as ‘telling or asking the doctor about symptoms or concerns’.</p> <p>2 problems identified #1: N=1 – Did not understand question at all</p> <p>#2: N=3 – Felt the sentence structure of ‘I can tell doctor concerns I have’ was difficult to understand</p> <p><i>“It can be placed better... Because when I read it, I wasn’t thinking whether it was a doctor concerns, or the concerns that I had to tell the doctor.” (023)</i></p> <p><i>“I am confident that I can tell a doctor concerns I have, so I don’t know why the English like that. Because I am confident that I can tell a doctor my concerns, even when he or she does not ask.” (043)</i></p>	<p>3 problems identified #1: N=1 – Chose his answer after considering abilities of different age groups</p> <p><i>“Yes and no la, in between. If come to young, yes. If come to old, no. If young, cannot tell.” (002)</i></p> <p>#2: N=4 – Confident to tell the doctor but unsure if knew enough information</p> <p><i>“Not strongly agree, because I can only tell what I know. There could be things I don’t know. That the doctor need to ask.” (071)</i></p> <p>#3: N=2 - Personal preferences for not choosing agree strongly</p> <p><i>“For me, always like to be on the safe side.” (024)</i></p>	<p>3 problems identified #1: N=1 – Did not choose strongly agree as he needed time to fully understand the question (question unclear)</p> <p>#2: N=2 – Felt that answer dependent on rapport with doctor</p> <p><i>“Some doctor is always in a hurry you know, so he keep talking then after that, you forget, you just walk out of the room” (037)</i></p> <p>#3: N=1 – comprehension issues (did not understand question but answered)</p>
---	--	--	---

<p>7. I am confident that I can follow through on medical treatments I may need to do at home</p>	<p>Overall: Differences in meaning of medical treatments. Half viewed it as following up with medications, while half viewed it as doing self-management practices.</p> <p>Differing comprehension: #1: N=2 – Viewed it as wound dressing</p> <p><i>“Sometimes it’s a bit of your own nursing, like wound dressing.” (037)</i></p> <p>2 problems identified #1: N=2 – Unsure about the types of treatment</p> <p><i>“What you mean by may need to do at home? The treatment do at home is it? What kind of treatment?” (002)</i></p> <p>#2: N=1 – Found ‘follow through’ a difficult word</p>	<p>2 problems identified #1: N=3 – Did not strongly agree due to personal preferences for changing prescription by self at times.</p> <p><i>“I cannot say agree strongly because sometimes you can change your prescription.” (021)</i></p> <p>#2: N=2 - Personal preferences for not choosing agree strongly</p>	<p>1 problem identified Participants who chose strongly agree and agree gave similar reasons.</p> <p>Strongly agree: <i>“So far, I don’t have any problem with any of the instruction or any advice” (023)</i></p> <p>Agree: <i>“As long as I can read and understand and I ask whatever relevant questions, there should be no problem in following through.” (013)</i></p>
---	---	---	--

<p>8. I understand my health problems and what causes them</p>	<p>Overall: All viewed it as ‘having knowledge on their conditions and what causes them’.</p> <p>2 problems identified #1: N=1 – Felt that the question is vague</p> <p><i>“This is also very vague in the sense that I understand my health problem. There are some health problems...you know you can understand. There are some complications you don’t understand. So what are you referring to?” (037)</i></p> <p>#2: N=1 – Felt that the question should be split into two</p> <p><i>“Maybe you can split the question into two? Understand the problem, and what causes them.” (043)</i></p>	<p>1 problem identified #1: N=1 - Personal preferences for not choosing agree strongly</p>	<p>2 problems identified #1: N=1 – Felt the question was not applicable if one did not have a condition thus did not strongly agree</p> <p>#2: N=1 – Disagree as one needed a doctor’s diagnosis first</p>
--	---	--	--

<p>9. I know what treatments are available for my health problem</p>	<p>Overall: Differences in interpretation of treatments. Some viewed it as medications, some viewed it as operations, and some viewed it as lifestyle changes.</p>	<p>2 problem identified  #1: N=1 – Felt that he cannot compare to a doctor’s knowledge    <i>“I cannot compare myself to the doctor, you know, if I got a headache I know I can take Panadol. But if persists then I must go and see a doctor.” (009)</i>    #2: N=10 – Did not choose strongly agree as there will always be something they won’t know    <i>“I didn’t put agree strongly because you don’t know everything” (013)</i></p>	<p>1 problem identified  #1: N=3 – Unsure of the reason they chose their options    <i>“Don’t know, I just put only, agree. I don’t really know” (009)</i></p>
--	--	---	--

<p>10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising</p>	<p>Overall: All viewed it as 'healthy lifestyle habits'.</p> <p>No problems identified.</p>	<p>No problems identified</p>	<p>Overall: Similarities in reasons given for strongly agree and agree.</p> <p>Strongly agree: <i>"I have been able to maintain. Like I came down here, I training. Then go back home, I cook myself. I cook potatoes, all boil. All fresh one. Then lifestyle have to change already, no choice. Eating right and exercising. Yea, we have to do."</i> (002)"</p> <p>Agree: <i>"Been able to maintain lifestyle change eat right or exercise"</i> (009)</p> <p>Overall: Similarities in reasons given for agree and disagree</p> <p>Agree: <i>"Agree because not everybody have the time to exercise. Not so much. I think I have to do much more than this."</i> (021)</p> <p>Disagree: <i>"I answer disagree because no discipline. Sometimes can</i></p>
---	---	-------------------------------	--

			<p><i>keep, sometimes cannot keep.” (071)</i></p> <p>1 problem identified #1: N=1 – Described some changes he made yet chose disagree strongly</p>
--	--	--	--

<p>11. I know how to prevent problems with my health</p>	<p>Overall: Majority viewed it as 'lifestyle changes' to prevent problems</p> <p>Differing comprehension: #1: N=1 – Viewed it as seeking alternative treatments</p> <p><i>“Maybe I eat some... alternative treatment medicine like supplement other than eating medicine of doctor. I've been getting some info from the internet like alternative what are the best to eat”</i> (021)</p> <p>#2: N=1 – Viewed it as following through on a medical routine</p> <p><i>“Take medicine, and then take the blood pressure, then monitor. All these are things I can follow through.”</i> (124)</p> <p>1 problem identified #1: N=1 – Question whether it is asking about knowledge or action</p> <p><i>“So this question is a bit fuzzy, in the</i></p>	<p>1 problem identified #1: N=6 – Did not choose strongly agree as there will always be something they won't know</p> <p><i>“I did not put agree strongly because there's always new knowledge that I am not aware of. I cannot know everything.”</i> (013)</p>	<p>No problems identified</p>
--	--	---	-------------------------------



	<p><i>sense that I know how to do. Is it just knowledge or do I actually do it. Right? I know how to, doesn't mean that I do it, you know." (043)</i></p>		
--	---	--	--

<p>12. I am confident I can figure out solutions when new problems arise with my health</p>	<p>Overall: All viewed problems as ‘new symptoms or condition’. However varied interpretation of solutions. Some viewed solutions as seeing doctor while some viewed it as figuring out how to deal with the issue themselves.</p> <p><i>“So when you say solutions, the solution is to see doctor.” (043)</i></p> <p><i>“Means how to cure yourself.” (124)</i></p> <p>2 problems identified #1: N=2 – Queried about the definition of problem</p> <p><i>“What is the definition of problem? Is it very simple problem? Or is it... like...” (043)</i></p> <p>#2: N=1 – Queried about the definition of solution</p>	<p>2 problems identified #1: N=1 – Felt the question was inappropriate in his culture</p> <p><i>“Usually for us, as a Malay and Muslim, we don’t think bad thing. I think other religions also, we don’t want to think about what to come, what form to come you, we don’t expect that also. We just do whatever have now” (009)</i></p> <p>#2: N=1 – Personal belief that there is no solution to every problem</p> <p><i>“I don’t really think that everything there’s some solution.” (109)</i></p>	<p>Overall: Varied reasons for answers. Some similarities between reasons for agree and disagree.</p> <p>Agree: <i>“This one is not true, so I agree only. Not true, maybe simple things we may be able to find solution to things that come up. But when it comes deeper and then becomes prolong, you won’t know. You have to seek medical profession” (028)</i></p> <p>Disagree: <i>“I am not confident, except for common issues like cough, flu. Other than that, I don’t think I know how.” (024)</i></p> <p>1 problem identified #1: N=1 – Explained that he wouldn’t know the solution but chose agree</p>
---	---	--	--

<p>13. I am confident I can maintain lifestyle changes, like eating right and exercising, even during times of stress</p>	<p>1 problem identified #1: N=2 – Did not read the sentence in full</p> <p><i>“Because to me, when I read this, the moment I see “lifestyle change”, I stop here. I don’t have to read the rest. I stop there, and I know what is it and they ask me whether I’m confident, I say “yes”.” (023)</i></p>	<p>1 problem identified #1: N=1 – Did not believe in the notion of stress</p> <p><i>“Personally for me, I keep telling myself, I don’t have stress.” (023)</i></p>	<p>2 problems identified</p> <p>#1: N=3 – Difficulty in deciding answer as it depended on the type and severity of stress</p> <p>#2: N=1 – Unsure of reason for response</p> <p><i>“That’s why I don’t know, I just put” (009)</i></p>
---	---	--	--

## **CHAPTER FOUR: DISCUSSION**

### **4.1 DISCUSSION**

#### **4.1.1 The PAM-13 in Singapore**

This dissertation has examined the validity of PAM-13 among adults with cardiac conditions in Singapore. Evidence in all three areas of validity (internal structure, response processes, and relation to other variables) were mixed. PAM-13 was found to have good internal consistency and item fit, acceptable unidimensionality, and moderate correlation with self-efficacy. However, the other areas demonstrated room for improvement. Large ceiling effects were found for nine out of 13 items, and responses across the four categories (strongly disagree, disagree, agree, strongly agree) were not evenly distributed. DIF test for gender, education and self-rated health status showed statistically significant differences. Five out of the 12 separations between items were poor, and the ranking of items by difficulty differed from the original PAM-13 ranking. A low correlation was also found between patient activation and depression. Key problems identified through the cognitive interviews included interpretation of items, social and culture influences in decision processes, and interpretation of response options.

These findings pointed towards two main areas of concern, (1) response categories, and (2) cultural adaption of measures. The information generated from this dissertation may assist clinicians and researchers in (1) interpretation of PAM-13 results and its usage in a clinical setting, and (2) identification of areas that require further research and improvements.

#### 4.1.2 Response categories

Several sources of evidence highlighted problems with the response scale. First and foremost, in the quantitative analysis, results reflected low usage of the lower response categories, namely “strongly disagree” and “disagree”. This resulted in the need to combine the two categories to create a three-category dataset used for the estimation of the rating scale model. This was further plagued by most items demonstrating a ceiling effect. This combination led to all items with more than 50% of the answers in “agree” response category and a consistent response pattern, with 19% of participants scoring all items as “agree” and one percent of participants scoring all items as “strongly agree”. The cognitive interviews echoed the same sentiments, where the most common recurring theme in decision processes was the avoidance of the “agree strongly” response category. The narrow usage of response categories, exacerbated the poor differentiation between items, reflected by low separation distances between items at five out of 12 points in the scale.

Research has found differences in the use of response categories between different ethnic groups. Studies that include Asians and their western counterparts suggest that Asians are more likely to select the midpoints and avoid extreme responses on Likert scales [60, 130]. This may explain the use of only the mid-range of the response scale in our sample; i.e. due to the dominant collectivistic culture in Singapore. The individualist versus collectivist perspective is the most widely reported explanation for differences in usage of subjective Likert scales [130]. Specifically, Western, particularly North American, cultures typically are rated high in individualism, whereas cultures in other parts of the world, especially in East Asia, usually have strong

collectivistic values [40]. While Singapore is seen as a modern society, with exposure to diverse cultures, Singapore remains largely a country with traditional Asian ideas of morality, duty and society. In fact, the Singaporean Parliament passed a white paper on a set of shared values to build and maintain a cohesive national identity [61]. The five Shared Values are: 1) nation before community and society above self, 2) family as the basic unit of society, 3) community support and respect for the individual, 4) consensus not conflict, and 5) racial and religious harmony [112]. As collectivistic cultures tend to promote harmony and avoidance of confrontations, participants from these cultures tend to give either middle or slightly positive responses [39]. These preferences were also reflected in the cognitive interviews, where some participants were explicit in not selecting this response option due to personal preference for a more neutral answer. Others did not explicitly voice avoidance of the “agree strongly” response category, but gave reasons such as *“if I choose strongly agree, I am better than the doctor”* as barriers to selecting the “agree strongly” response option. These tendencies and preferences suggest that the four-point Likert scales of the PAM-13 may be inadequate in capturing diversity in responses. A possible solution to mediate the problem is to use Likert scales with a larger number of categories, which allow participants to voice a more nuanced position, even without choosing the most extreme answer [39]. Having response categories with a wider Likert scale (e.g. six points) could minimize the pattern seen with the large majority of responses in one category. This would then reduce problems with poor separation distances between items and lend more confidence to the strong internal consistency result.

These differences in use of Likert scales also flag the need for caution when doing cross-cultural comparisons as interpretation of the subjective self-rating scale is likely compromised with different reference groups; people from different cultures adopt different standards. Therefore, for PAM-13 which utilises a standardised algorithm in the interpretation of scores, problems as reflected in our study can surface. In order for the PAM-13 to be effective in different cultures, calibration of scores may have to be performed in different settings and cultures. Another consideration for the development of a future patient activation tool is to explore use of a forced-choice framework that includes items with concrete, objective options, which enhance the validity of comparisons across groups [40, 94].

#### 4.1.3 Cultural adaptation of measures

It has been recognized that for measures to be utilized and compared across countries and cultures, they need to be translated and culturally adapted [10]. However, cross-cultural adaptation guidelines have typically focused on the language translation process, neglecting the cultural adaptation process. The cultural adaptation, if not done, can change the validity of the measure, especially with measures using item-level analyses such as PAM-13 [10]. This is as different cultural beliefs can affect one's thinking and way of approaching a task, altering the interpretation of each item in the scale, making it more or less difficult when compared to other items. Furthermore, under the unitary concept of validity, validity instead of being a property of an instrument, is defined as a property of scores based on usage of a particular assessment with a particular group of subjects, in a particular setting and under certain conditions

[35, 78]. Hence it might be unrealistic to assume that PAM-13 should perform the same with different populations, different settings and conditions, particularly in the area of item difficulty ranking.

These challenges were well-illustrated in our study. Even though both countries (Singapore and United States) share the same language (English), results reflected a need to facilitate cultural adaptation. In the cognitive interviews, multiple issues with comprehension were found. First of all, there was the problem with use of certain terms and phraseology that is not common in Singapore. For example, ‘when all is said and done’ was identified as an unfamiliar term in Singapore. Some participants highlighted difficulty in understanding it while many neglected this term when explaining the question in their own words. In the adaptation of PAM-13 in Korea, “when all is said and done” was also identified as a problematic term, and was instead modified to “regardless of what people say or do” [2]. In another question, a participant highlighted that ‘I am confident that I can tell a doctor my concerns’ made more sense in the Singapore context as compared to the PAM-13 phrasing ‘I am confident that I can tell a doctor concerns I have’. Likewise, numerous terms such as, ‘active role’ in item #2, ‘medical treatments’ in item #7, and ‘solutions’ in item #12, were considered ambiguous.

In addition, participants articulated a desire for more specificity to facilitate understanding of items. For example in item #4, “I know what each of my prescribed medications do”, one participant felt that the question should state that it meant knowledge of “*what it does, how it works, in order to get the best effect out of it*”. Interestingly, in the Korean version, item #4 was changed to “I know most of the whys,



whens, and hows of the medications I am taking” [2]. This may reflect some similarities in challenges with PAM-13 in the Asian context.

Variation in the comprehension of questions, translated to variation in selection of response categories. Different cultural beliefs resulted in differing self-management behaviors of participants, while differing use of the English language affected understanding of questions. For example, in question 12 ‘I am confident I can figure out solutions when new problems arise with my health’, Singaporean participants cited the need for doctors’ help to figure out solutions or that finding a doctor could be the solution itself. Depending on participants’ interpretation of the item, difficulty of the item is altered. This then affects the scoring of items in PAM-13, leading to problems with its quantitative analyses, such as item difficulty ranking. This reinforces the importance of establishing cultural equivalence of measures before use in another culture even without translation [10].

In Singapore, many clinicians use measures developed from Western countries due to a lack of locally developed measures and the common usage of English language. However, this dissertation has shown that it is necessary to undertake cultural adaptation of existing measures developed in other countries, even when the language is common. Singapore clinicians and researchers should invest efforts to ensure that measures are culturally validated and exercise caution when interpreting results of measures developed in other countries. This can potentially affect the design of interventions and development of healthcare programs and policies in Singapore.

## **4.2 IMPLICATIONS**

The validation of PAM-13 among adults with cardiac conditions presented mixed results in this study. Before further work is done with PAM-13 in Singapore, a cultural adaptation should be the priority. As a translation is not necessary, the process can start with the formation of an expert panel. They will need to ensure the achievement of cross-cultural equivalence in four areas: (1) semantic equivalence (do words have the same meaning or whether any term has multiple meanings), (2) idiomatic equivalence (colloquialisms or idioms that are difficult to translate), (3) experiential equivalence (tasks or experiences that may be different or not experienced), and (4) conceptual equivalence (words holding different conceptual meaning being cultures) [10, 36]. After a consensus is reached, cognitive interviews with patients from the target setting should be performed with the new version. If there are concerns that surface from the cognitive interviews, further discussion with the expert panel will be required. After this, testing of the adapted version's statistical or psychometric properties should be done. Ideally, the adapted PAM-13 should retain item characteristics of the original PAM-13.

However, there have been variations in item characteristics among all PAM-13 validation studies, including studies consisting of language translation and cross-cultural adaptation. Therefore, there appears to be a need to examine the Likert scale response categories, to further improve the measure. Further research on the concept of patient activation is indicated to determine if it is indeed a unidimensional concept and whether the PAM-13 measures all aspects of patient activation, is developmental in nature and feasible in different countries and populations.

### **4.3 LIMITATIONS**

A limitation of this study is that the convenience sample is not representative of the general population in terms of ethnicity, income and education. Based on the Singapore population statistics, the ethnicities of Singaporeans are Chinese (74%), Malay (14%), Indian (9%) and others (3%) [109]. In our study, the distribution was Chinese (50%), Malay (25%), Indian (18%) and others (7%). However, the over-representation of Malays and Indians allowed statistical representation and comparison between ethnic groups. Important to note demographics are education and total household income, variables known to impact PAM-13 scores. According to Singapore statistics, only 66% of Singaporeans have higher than secondary school qualifications [108]. In our sample, only 41% had higher than secondary school qualifications. In addition, the majority of the sample (71%) had a total household income in the bottom 40 percentage of the national total household income per month. The lower education status and total household income could be because sampling was done in a public hospital versus in a private hospital where more affluent Singaporeans visit. Retirees, which formed 23% of the sample could have also contributed to the lower household income as participants typically depend on savings and allowances from children post-retirement, and do not account for them as “income”. It is important to note that lower education level and total household income could mean lower activation scores in our sample when compared to the national population. The study could have recruited more participants, recruited from more diverse settings or adopted a stratified sampling approach to ensure that the study population was representative of the national population in terms of education and total household income.

There were two main limitations for the cognitive interviews. Firstly, the interviewees were mainly male, with only one female out of the 13 interviewees. This may have limited the understanding of PAM-13 from a female perspective. However, this limitation in sampling is likely due to the higher prevalence of heart diseases in men. Another limitation was that the principal investigator conducted the interviews and therefore might unintentionally have influenced the participants' perspectives. Furthermore, due to confidentiality considerations during data collection, member checking was not implemented to strengthen the trustworthiness and rigor of the qualitative process. However, to enhance trustworthiness, a research diary with reflexive notes, impressions of the data, coding and thoughts about the analysis were recorded throughout the process. This was reviewed by members of the research team and reconciled at multiple touchpoints to minimize bias of the principal investigator in interpretations of the findings.

#### **4.4 CONCLUSIONS**

Before clinical use, it will be most ideal to do a cultural adaptation of the English PAM-13 to determine if the existing problems still present themselves after ensuring cultural relevancy. In its present form, the original English PAM-13 should be limited to screening out patients with very low activation levels. It can also be used as a tool for clinical exploration of patient activation. This in combination with clinical interviews may assist practitioners to provide more targeted and individualized treatment. However, strict reliance on the four levels of activation to inform and guide interventions should be done with caution. This dissertation also sounds a note of

caution to Singaporean clinicians in the use and interpretation of measures developed in different countries. Cultural relevancy should be ensured even if language translation is not necessary.

## BIBLIOGRAPHY

1. Acock, A.C. (2008). *A gentle introduction to STATA (2nd edition)*. Texas: Stata Press.
2. Ahn, Y-H., Yi, C-H., Ham, O-K. & Kim, B-J. (2014). Psychometric properties of the Korean version of the “Patient Activation Measure 13” (PAM13-K) in patients with osteoarthritis. *Evaluation & the Health Professions*, 1-10. DOI: 10.1177/0163278714540915
3. Alegria, M., Sribney, W., Perez, D., Laderman, M. & Keefe, K. (2009). The role of patient activation on patient-provider communication and quality of care for US and foreign born Latino patients. *Journal of General Internal Medicine*, 24, 534-541.
4. American Educational Research Association (AERA), American Psychological Association (APA), National Council on Measurement in Education (NCME). (1999). *Standards for Education and Psychological Testing*. Washington, DC: American Educational Research Association.
5. Asudulv, A. (2013). The over time development of chronic illness self-management patterns: A longitudinal qualitative study. *BMC Public Health*, 13, 452-467.
6. Astin, F. Horrocks, J. & Closs, S.J. (2014). Managing lifestyle change to reduce coronary risk: A synthesis of qualitative research on peoples’ experiences. *BMC Cardiovascular Disorders*, 14, 96-111.
7. Austin, E.J., Gibson, G.J., Deary, I.J., McGregor, M.J. & Dent, J.B. (1998). Individual response spread in self-report scales: personality correlations and consequences. *Personality and Individual Differences* 24, 421-438.
8. Baumgartner, H. & Steenkamp, J.E.M. (2001). Response styles in marketing research: A cross-national investigation. *Journal of Marketing Research*, 38, 143-156.
9. Baylor, C., Hula, W., Donovan, N.J., Doyle, P.J., Kendall, D. & Yorkston, K. (2011). An introduction to item response theory and Rasch models for Speech-Language Pathologists. *American Journal of Speech-Language Pathology*, 20, 243-259.
10. Beaton, D.E., Bombardier, C. Guillemin, F. & Ferraz, M.B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, 25(24), 3186-3191.

11. Begum, N., Donald, M., Ozolins, I.Z. & Dower, J. (2011). Hospital admissions, emergency department utilisation and patient activation for self-management among people with diabetes. *Diabetes Research and Clinical Practice*, 93(2), 260-267.
12. Bergman, M.M. (2010). On concepts and paradigms in mixed methods research. *Journal of Mixed Methods Research*, 4(3), 171-175.
13. Bjarnason-Wehrens, B., Mcgee, H., Zwisler, A.D., Piepoli, M.F., Benzer, W., Schmid, J.P., Dendale, P., Pogosova, N.G., Zdrenghea, D., Niebauer, J. & Mendes, M. (2010). Cardiac rehabilitation in Europe: results from the European Cardiac Rehabilitation Inventory Survey. *European Journal of Cardiovascular Prevention & Rehabilitation*, 17, 410–418.
14. Bond, T.G. & Fox, C.M. (2007). *Applying the Rasch Model. Fundamental Measurement in the Human Sciences (2nd edition)*. Mahwah, New Jersey: Lawrence Erlbaum Associates.
15. Boren, S.A., Wakefield, B.J., Gunlock, T.L. & Wakefield, D.S. (2009). Heart failure self-management education: A systematic review of the evidence. *International Journal of Evidence-Based Healthcare*, 7, 159-168.
16. Bosworth, H.B., Steinhauer, K.E., Orr, M., Lindquist, J.H., Grambow, S.C. & Oddone, E.Z. (2004). Congestive heart failure patients' perceptions of quality of life: the integration of physical and psychosocial factors. *Aging & Mental Health*, 8(1), 83-91.
17. Brenk-Franz K, Hibbard JH, Herrmann WJ, Freund T, Szecsenyi J, et al. (2013) Validation of the German Version of the Patient Activation Measure 13 (PAM13-D) in an International Multicentre Study of Primary Care Patients. *PLoS ONE*, 8(9): e74786. doi:10.1371/journal.pone.0074786
18. Castro, F.G., Kellison, J.G., Boyd, S.J. & Kopak, A. (2010). A methodology for conducting integrative mixed methods research and data analyses. *Journal of Mixed Methods Research*, 4, 342-360.
19. Chen, W-H., Lenderking, W., Jin, Y., Wyrwich, K.W., Gelhorn, H. & Revicki, D.A. (2014). Is Rasch model analysis applicable in small sample size pilot studies for assessing item characteristics? An example using PROMIS pain behavior item bank data. *Quality of Life Research*, 23, 485-493.
20. Chong, S.A., Abdin, E., Vaingankar, J.A., Heng, D., Sherbourne, C., Yap, M., Lim, Y.W., Wong, H.B., Ghosh-Dastidar, B., Kwok, K.W. & Subramaniam, M. (2012). *A population-based survey of mental disorders in Singapore. ANNALS Academy of Medicine Singapore*, 41, 49-66.

21. Claramita, M., Nugraheni, M.D.F., van Dalen, J. & van der Vleuten, C. (2013). Doctor-patient communication in Southeast Asia: A different culture? *Advances in Health Sciences Education*, 18, 15-31.
22. Creswell, J.W., Klassen, A.C., Plano Clark, V.L. & Smith, K.C. (2010). *Best practices for mixed methods research in the health sciences*. United States: Office of Behavioural and Social Sciences Research.
23. Coleman, K., Austin, B.T., Brach, C. & Wagner, E.H. (2009). Evidence on the chronic care model in the new millennium. *Health Affairs*, 28, 75-85.
24. Cook, D.A. & Beckman, T.J. (2006). Current concepts in validity and reliability for psychometric instruments: Theory and application. *The American Journal of Medicine*, 199, 166.e7-166.e16.
25. Dickson, V.V., McCauley, L.A. & Riegel, B. (2008). Work-heart balance: The influence of biobehavioral variables on self-care among employees with heart failure. *AAOHN Journal*, 56(2), 63-73.
26. Drennan, J. (2003). Cognitive interviewing: Verbal data in the design and pretesting of questionnaires. *Journal of Advanced Nursing*, 42(1), 57-63.
27. Fowles, J.B., Terry, P., Si, M., Hibbard, J., Bloom, C.T. & Harvey, L. (2009). Measuring self-management of patients' and employees' health: Further validation of the Patient Activation Measure (PAM) based on its relation to employee characteristics. *Patient Education & Counselling*, 77(1), 116-122.
28. Gale, N.K., Heath, G., Cameron, E., Rashid, S. & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13, 117. doi:10.1186/1471-2288-13-117.
29. Garcia, A.A. (2011). Cognitive interviews to test and refine questionnaires. *Public Health Nursing*, 28(5), 444-450.
30. Gardetto, N.J. (2011). Self-management in heart failure: Where have we been and where should we go? *Journal of Multidisciplinary Healthcare*, 4, 39-51.
31. Gerber, L.M., Barron, Y., Mongoven, J., McDonald, M., Henriquez, E., Andreopoulos, E. & Feldman, P.H. (2011). Activation among chronically ill older adults with complex medical needs: Challenges to supporting effective self-management. *Journal of Ambulatory Care Management*, 34(3), 292-303.
32. Greene, J. & Hibbard, J.H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), 520-526.



33. Green, C.A., Perrin, N.A., Polen, M.R., Leo, M.C., Hibbard, J.H. & Tusler, M. (2010). Development of the Patient Activation Measure for mental health. *Administration and Policy in Mental Health, 37*, 327-333.
34. Goodwin, L.D. (2002a). Changing conceptions of measurement validity: an update on the new standards. *Journal of Nursing Education, 41*(3), 100-106.
35. Goodwin, L.D. (2002b). The meaning of validity. *Journal of Pediatric Gastroenterology and Nutrition, 35*(1), 6-7.
36. Guillemin, F., Bombardier, C. & Beaton, D. (1993). Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology, 46*, 2242-2245.
37. Ham, C. (2001). Values and health policy: The case of Singapore. *Journal of Health Politics, Policy and Law, 26*(4), 739-745.
38. Hammer, M., & Alladin, W. (2010). Transcending east/west boundaries: Pittu Languani and cross-cultural counselling. In R. Moodley, A. Rai, & w. Alladin (Eds.), *Bridging east-west psychology and counselling: Exploring the work of Pittu Laungani*. Thousand Oaks, CA: Sage.
39. Harzing, A. (2006). Response styles in cross-national survey research: A 26-country study. *International Journal of Cross Cultural Management, 6*(2), 243-266.
40. Heine, S.J., Lehman, D.R., Peng, K. & Greenholtz, J. (2002). What's wrong with cross-cultural comparisons of subject Likert scales?: The reference-group effect. *Journal of Personality and Social Psychology, 82*(6), 903-918.
41. Hibbard, J.H. (2003). Engaging health care consumers to improve the quality of care. *Medical Care, 41*(1), I61-I70.
42. Hibbard, J.H., Mahoney, E.R., Stockard, J. & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research, 39*, 1005-1026.
43. Hibbard, J.H., Mahoney, E.R., Stockard, J. & Tusler, M. (2005). Development and testing of a short form of the Patient Activation Measure. *HSR: Health Services Research, 40*(6), 1918 – 1930.
44. Hibbard, J.H. & Tusler, M. (2007). Assessing activation stage and employing a 'next steps' approach to supporting patient self-management. *Journal of Ambulatory Care Management, 30*, 2-8.

45. Hibbard, J.H., Mahoney, E.R., Stock, R. & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research, 42*(4), 1443-1463.
46. Hibbard, J.H., Collins, P.A., Mahoney, E. & Baker, L.H. (2010). The development and testing of a measure assessing clinician beliefs about patient self-management. *Health Expectations, 13*(1), 65-72.
47. Hibbard, J.H. & Mahoney, E. (2010). Toward a theory of patient and consumer activation. *Patient Education and Counselling, 78*(3), 377-381.
48. Hibbard, J.H. & Gilburt, H. (2014). *Supporting people to manage their health: An introduction to patient activation*. United Kingdom: The King's Fund. Retrieved from: <http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health>
49. Hibbard, J.H. & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs, 32*(2), 207-214.
50. Hinkle, D.E., Wiersma, W. & Jurs, S.G. (1998). *Applied Statistics for the Behavioural Sciences (4<sup>th</sup> edition)*. Boston, MA: Houghton Mifflin Company.
51. Hung, M., Carter, M., Hayden, C., Dzierzon, R., Morales, J., Snow, L., Butler, J., Bateman, K. & Samore, M. (2013). Psychometric assessment of the patient activation measure short form (PAM-13) in rural settings. *Quality of Life Research, 22*, 521-529.
52. Insignia Health, LLC. (2014). *Patient Activation Measure (PAM) 13 TM: License Materials*. US: Insignia Health.
53. Institute of Medicine's Committee on Quality of Health Care in America. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Press.
54. Jeon, Y.H., Kraus, S.G., Jowsey, T. & Glasgow, N.J. (2010). The experience of living with chronic heart failure: A narrative review of qualitative studies. *BMC Health Services Research, 10*, 77. doi: 10.1186/1472-6963-10-77.

55. Kiang Nang, E.E., Khoo, E.Y., Salim, A., Tai, E.S., Lee, J., Van Dam, R.M. (2010). Patterns of physical activity in different domains and implications for intervention in a multi-ethnic Asian population: A cross-sectional study. *BMC Public Health*, 10, 644.
56. Khoo, C.M. & Tai, E.S. (2014). Trends in the incidence and mortality of coronary heart disease in Asian Pacific Region – The Singapore experience. *Journal of Atherosclerosis and Thrombosis*, 21, S2-S8.
57. Khoo, K.L., Tan, H., Liew, Y.M., Deslypere, J.P. & Janus, E. (2003). Lipids and coronary heart disease in Asia. *Atherosclerosis*, 169, 1-10.
58. Laine, C., Davidoff, F., Lewis, C.E., Nelson, E.C., Nelson, E.N., Kessler, R.V. & Delbanco, T.L. (1996). Important elements of outpatient care: A comparison of patients' and physicians' opinions. *Annals of Internal Medicine*, 125(8), 640-645.
59. Lim, S.M., Rodger, S. & Brown, T. (2009). Using Rasch analysis to establish the construct validity of rehabilitation assessment tools. *International Journal of Therapy and Rehabilitation*, 16(5), 251-260.
60. Lee, J.W., Jones, P.S., Mineyama, Y. & Zhang, X.E. (2002). Cultural differences in responses to a Likert Scale. *Research in Nursing & Health*, 25(4), 295-296.
61. Lim, T.S. (2015). Shared Values. Retrieved from [http://eresources.nlb.gov.sg/infopedia/articles/SIP\\_542\\_2004-12-18.html](http://eresources.nlb.gov.sg/infopedia/articles/SIP_542_2004-12-18.html)
62. Linacre, J. M. (1999). Investigating rating scale category utility. *Journal of Outcome Measurement*, 3(2), 103-122.
63. Linacre, J.M. (2002). Optimising rating scale category effectiveness. *Journal of Applied Measurement*, 3(1), 85-106.
64. Lorig, K., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioural Medicine*, 26(1), 1-7.
65. Lorig, K.R., Sobel, D.S., Ritter, P.L., Laurent, D. & Hobbs, M. (2001). Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 256-262.
66. Lubetkin, E.I., Lu, W.H. & Gold, M.R. (2010). Levels and correlates of patient activation in health center settings: Building strategies for improving health outcomes. *Journal of Health Care for the Poor and Underserved*, 21(3), 796-808.
67. Manafo, E., Petermann, L., Lobb, R., Keen, D. & Kerner, J. (2011). Research, practice, and policy partnerships in Pan-Canadian coalitions for cancer and chronic disease prevention. *Journal of Public Health Management Practice*, 17(6), E1-E11.

68. Maindal, H.T., Sokolowski, I. & Vedsted, P. (2009). Translation, adaptation and validation of the American short form Patient Activation Measure (PAM-13) in a Danish version. *BMC Public Health*, 9, 209. doi: 10.1186/1471-2458-9-209.
69. Magnezi, R., Glasser, S., Shalev, H., Sheiber, A. & Reuveni, H. (2014). Patient activation, depression and quality of life. *Patient Education and Counselling*, 94, 432-437.
70. Magnezi, R. & Glasser, S. (2014). Psychometric properties of the Hebrew translation of the Patient Activation Measure (PAM-13). *PLoS ONE*, 9(11), e113391. doi:10.1371/journal.pone.0113391
71. Mair, P., & Hatzinger, R. (2006). *eRm; extended Rasch models. R package version 0.3.2*. <http://CRAN.R-project.org/> (Accessed October 2013).
72. Mair, P., & Hatzinger, R. (2007). CML based estimation of extended Rasch models with the eRm package in R. *Psychology Science*, 49(1), 26–43.
73. McDowell, I. (2006). *Measuring Health – A Guide to Rating Scales and Questionnaires*. Oxford, UK: Oxford University Press, Inc.
74. McHorney, C.A. & Tarlov, A.R. (1995). Individual-patient monitoring in clinical practice: are available health status surveys adequate? *Quality of Life Research*, 4(4), 293-307.
75. Mead, H., Andres, E., Ramos, C., Siegel, B. & Regenstein, M. (2010). Barriers to effective self-management in cardiac patients: The patient’s experience. *Patient Education and Counselling*, 79, 69-76.
76. Mehrotra, S. (2007). Cognitive interviewing: An overview and an illustration. *Journal of the Indian Academy of Applied Psychology*, 33(1), 81-84.
77. Messick, S. (1989). Validity. In: Linn, R.L. (Ed), *Educational Measurement* (13-101). New York: American Council on Education.
78. Messick, S. (1995). Validity of psychological assessment: Validation of inferences from person’s responses and performances as scientific inquiry into score meaning. *American Psychologist*, 50(9), 741-749.
79. Mead, H., Andres, E., Ramos, C., Siegel, B. & Regenstein, M. (2010). Barriers to effective self-management in cardiac patients: The patient’s experience. *Patient Education and Counselling*, 79, 69-76.
80. Ministry of Health, Singapore. (2013). *Health Ministry shares details on key policy shifts to alleviate medical costs*. Retrieved from

- [https://www.moh.gov.sg/content/moh\\_web/home/pressRoom/pressRoomItemRelease/2013/health-ministry-shares-details-on-key-policy-shifts-to-alleviate.html](https://www.moh.gov.sg/content/moh_web/home/pressRoom/pressRoomItemRelease/2013/health-ministry-shares-details-on-key-policy-shifts-to-alleviate.html)
81. Ministry of Health, Singapore. (2014). *Top 10 Conditions of Hospitalisation*. Retrieved from [https://www.moh.gov.sg/content/moh\\_web/home/statistics/Health\\_Facts\\_Singapore/Top\\_10\\_Conditions\\_of\\_Hospitalisation.html](https://www.moh.gov.sg/content/moh_web/home/statistics/Health_Facts_Singapore/Top_10_Conditions_of_Hospitalisation.html)
  82. Ministry of Health, Singapore. (2014). *Principal Causes of Death*. Retrieved from [https://www.moh.gov.sg/content/moh\\_web/home/statistics/Health\\_Facts\\_Singapore/Principal\\_Causes\\_of\\_Death.html](https://www.moh.gov.sg/content/moh_web/home/statistics/Health_Facts_Singapore/Principal_Causes_of_Death.html)
  83. Ministry of Health, Singapore. (2014). *Disease Burden*. Retrieved from [https://www.moh.gov.sg/content/moh\\_web/home/statistics/Health\\_Facts\\_Singapore/Disease\\_Burden.html](https://www.moh.gov.sg/content/moh_web/home/statistics/Health_Facts_Singapore/Disease_Burden.html)
  84. Ministry of Health, Singapore. (2011). *National Health Survey*. Retrieved from [https://www.moh.gov.sg/content/dam/moh\\_web/Publications/Reports/2011/NHS2010%20-%20low%20res.pdf](https://www.moh.gov.sg/content/dam/moh_web/Publications/Reports/2011/NHS2010%20-%20low%20res.pdf)
  85. Morell, L. & Tan, R.J.B. (2009). Validating for use and interpretation: A mixed methods contribution illustrated. *Journal of Mixed Methods Research*, 3, 242-264.
  86. Mosen, D.M., Schmittiel, J., Hibbard, J., Sobel, D., Remmers, C. & Bellows, J. (2007). Is patient activation associated with outcomes of care for adults with chronic conditions. *Journal of Ambulatory Care Management*, 30(1), 21-29.
  87. Moljord, I.E.O., Lara-Cabrera, M.L., Perestelo-Perez, L., Rivero-Santana, A., Eriksen, L. & Linaker, O.M. (2015). Psychometric properties of the Patient Activation Measure-13 among out-patients waiting for mental health treatment: A validation study in Norway. *Patient Education and Counselling*, 98(11), 1410-1017. doi: 10.1016/j.pec.2015.06.009.
  88. Newman, S., Steed, L. & Mulligan, K. (2004). Self-management interventions for chronic illness. *The Lancet Seminars*, 364(9444), 1523-1537.
  89. Ngooi, B.X. (2016). *Validation of the Patient Activation Measure (PAM-13) among adults with cardiac conditions in Singapore: A mixed methods study*. (Unpublished master's thesis). Dalhousie University, Halifax, Canada.
  90. O'Connell, S. (2014). Cardiac rehabilitation 1: Barriers to attending cardiac rehabilitation. *Nursing Times*, 110(19), 15-17.

91. Omar, A.R., Suppiah, N., Chai, P., Chan, Y.H., Seow, Y.H., Quek, L.L., Poh, K.K. & Tan, H.C. (2007). Efficacy of community-based multidisciplinary disease management of chronic heart failure. *Singapore Medical Journal*, 48(6), 528-531.
92. Packer, T.L., Kephart, G., Ghahari, S., Auduly, A., Versnel, J. & Warner, G. (2015). The Patient Activation Measure: A validation study in a neurological population. *Quality of Life Research*, 24(1). doi: 10.1007/s11136-014-0908-0
93. Pasick, R.J., Burke, N.J., Barker, J.C., Jospeh, G., Bird, J.A., Otero-Sabogal, R., ... Guerra, C. (2009). Behavioural theory in a diverse society: Like a compass on Mars. *Health Education & Behaviour*, 36(5 Suppl), 11S-35S.
94. Peng, K., Nisbett, R.E. & Wong, N.Y.C. (1997). Validity problems comparing values across cultures and possible solutions. *Psychological Methods*, 2, 329-344.
95. Perk, J., De Backer, G., Gohlke, H., Graham, I., Reiner, Z., Verschuren, M., .... Zannad, F. (2012). European Guidelines on cardiovascular disease prevention in clinical practice (version 2012). *European Heart Journal*, 2012(33), 1635–1701.
96. Pruitt, S.D. & Epping-Jordan, J.E. (2005). Preparing the 21st century global healthcare workforce. *British Medical Journal*, 330, 637–639.
97. R Development Core Team. (2006). *R: A language and environment for statistical computing*. Vienna: R Development Core Team.
98. Rademaker, J., Nijman, J., Heek, L., Heijmans, M. & Rijken, M. (2012). Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). *BMC Public Health*, 12, 577-583.
99. Rasch, G. (1960). *Probabilistic models for some intelligence and attainment tests*. Copenhagen, Denmark: Danish Institute for Educational Research.
100. Remmers, C., Hibbard, J.H., Mosen, D.M., Wagenfield, M., Hoye, R.E. & Jones, C. (2009). Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? *Journal of Ambulatory Care Management*, 32(4), 1-8.
101. Reise, S.P. & Yu, J. (1990). Parameter recovery in the graded response model using MULTILOG. *Journal of Educational Measurement*, 27(2), 133-144.
102. Renders, C.G., Valk, S., Griffin, E., Wagner, J.E.V. & Assendelft, W. (2001). Interventions to improve the management of diabetes in primary care, outpatient, and community settings. *Diabetes Care*, 24(10), 1821-1833.

103. Richards, A.M., Lam, C., Wong, R.C. & Ping, Chai. (2011). Heart failure: A problem of our age. *Annals Academy of Medicine*, 40(9), 392-293.
104. Ritchie, J., & Spencer, L. (1993). Qualitative data analysis for applied policy and research. In A. Bryman & R. Burgess (Eds.), *Researching social life*. London: Routledge.
105. Saha, S., Koley, M., Mahoney, E.R., Hibbard, J., Ghosh, S., Goutam, N., ... Choubey, G. (2014). Patient Activation Measures in a government homeopathic hospital in India. *Journal of Evidence-Based Complementary & Alternative Medicine*, 1-7. DOI: 10.1177/2156587214540175
106. Seah, D., Sim, Y.F. & Ong, V. (2013). Photograph-assisted dietary review amongst Type 2 Diabetics in primary care. *Annals of the Academy of Medicine, Singapore*, 42(9), S22. Retrieved from [http://2013.shbc.com.sg/wp-content/uploads/2014/01/SHBC\\_2013\\_Annals.pdf](http://2013.shbc.com.sg/wp-content/uploads/2014/01/SHBC_2013_Annals.pdf)
107. Singhealth Group. (2009). *Projects: Grant funded*. Retrieved from [http://www.davejunia.com/chsr/projects\\_gf\\_Assessment%20of%20Patient%20Activation.html](http://www.davejunia.com/chsr/projects_gf_Assessment%20of%20Patient%20Activation.html)
108. Singapore Department of Statistics. (2014, Dec 17). *Latest Data*. Retrieved from [http://www.singstat.gov.sg/statistics/latest\\_data.html#16](http://www.singstat.gov.sg/statistics/latest_data.html#16)
109. Singapore Department of Statistics. (2010). *Census of population 2010 statistical release 1: Demographics characteristics, education, language and religion*. Retrieved from [http://www.singstat.gov.sg/publications/publications\\_and\\_papers/cop2010/census\\_10\\_stat\\_release1.html](http://www.singstat.gov.sg/publications/publications_and_papers/cop2010/census_10_stat_release1.html).
110. Singapore Department of Statistics. (2012). *Key Household Income Trends*. Retrieved from [http://www.singstat.gov.sg/publications/publications\\_and\\_papers/household\\_income\\_and\\_expenditure/pp-s19.pdf](http://www.singstat.gov.sg/publications/publications_and_papers/household_income_and_expenditure/pp-s19.pdf)
111. Singapore Ministry of Health. (2011, Nov). *National Health Survey 2010*. Retrieved from [https://www.moh.gov.sg/content/moh\\_web/home/Publications/Reports/2011/national\\_health\\_survey2010.html](https://www.moh.gov.sg/content/moh_web/home/Publications/Reports/2011/national_health_survey2010.html)
112. Singapore. Parliament. *Parliamentary debates: Official report*. (1991, January 15). Shared values (Vol. 56). Singapore: Govt. Printer, cols. 967–968. (Call no.: RSING 328.5957 SIN)

113. Sitzia, J. (1999). How valid and reliable are patient satisfaction data? An analysis of 195 studies. *International Journal of Qualitative Health Care*, 11, 319–328.
114. Skolasky, R.L., Mackenzie, E.J., Wegener, S.T. & Riley, J.H. (2008). Patient activation and adherence to physical therapy in persons undergoing spine surgery. *Spine*, 33(21), E784-E791.
115. Skolasky, R.L., Green, A.F., Scharfstein, D, Boulton, C., Reider, L & Wegener, S.T. (2011). Psychometric properties of the Patient Activation Measure among multimorbid older adults. *HSR: Health Services Research*, 46(2), 457-478.
116. Skolasky, R.L., Mackenzie, E.J., Riley, L.H. & Stephen, T.W. (2009). Psychometric properties of the Patient Activation Measure among individuals presenting for elective lumbar spine surgery. *Quality of Life Research*, 18(10), 1357-1366.
117. Smith, Jr.E.V. (2001). Evidence for the reliability of measures and validity of measure interpretation: A Rasch measurement perspective. *Journal of Applied Measurement*, 2(3), 281-311.
118. Spitzer, R.L., Kroenke, K., Williams, J.B.W., for the Patient Health Questionnaire Primary Care Study Group. (1999). Validation and utility of a self-report version of PRIME-MD: the PHQ Primary Care Study. *JAMA*, 272, 1749-1756.
119. Stanford Patient Education Research Center. (2012). *Self-efficacy for Managing Chronic Disease 6-item Scale*. Retrieved from <http://patienteducation.stanford.edu/research/secd6.html>.
120. StataCorp. (2015). Stata 14 [computer software]. USA: StataCorp LP.
121. Stepleman, L., Rutter, M., Hibbard, J., Johns, L., Wright, D. & Hughes, M. (2010). Validation of the patient activation measure in a multiple sclerosis clinic sample and implications for care. *Disability and Rehabilitation*, 32(19), 1558-1567.
122. Sudman, S., Bradburn, N. & Schwarz, N. (1996). *Thinking about answers: The application of cognitive processes to survey methodology*. San Francisco: Jossey-Bass Publishers.
123. Sung, S.C., Low, C.C., Fung, D.S. & Chan, Y.H. (2013). Screening for major and minor depression in a multiethnic sample of Asian primary care patients: A comparison of the nine-item Patient Health Questionnaire (PHQ-9) and the 16-item Quick Inventory of Depressive Symptomatology – Self-report (QIDS-SR16). *Asia-Pacific Psychiatry*, 5(4), 249-258.



124. Tourangeau, R. (1984). Cognitive sciences and survey methods. In T. B. Jabine, M. L. Straf, J. M. Tanur, & R. Tourangeau (Eds.), *Cognitive aspects of survey methodology: Building a bridge between disciplines* (pp. 73–101). Washington, DC: National Academy Press.
125. The World Bank Group. (2014). *GDP per capita, PPP (current international \$)*. Retrieved from <http://data.worldbank.org/indicator/NY.GDP.PCAP.PP.CD>
126. Ueshima, H., Sekikawa, A., Miura, K., Turin, T.C., Takashima, N., Kita, Y., et al. (2008). Cardiovascular disease and risk factors in Asia: A selected review. *Circulation*, *118*, 2702-2709.
127. US Department of Health and Human Services, Agency for Healthcare Research and Quality. (2006). *The Guide to Clinical Preventive Services: 2006 Recommendations of the US Preventive Services Task Force*. Washington, DC: US Dept of Health and Human Services.
128. The World Bank Group. (2014). *GDP per capita, PPP (current international \$)*. Retrieved from <http://data.worldbank.org/indicator/NY.GDP.PCAP.PP.CD>
129. Wagner, E.H., Austin, B.T. & Von Korff, M. (1996). Improving outcomes in chronic illness. *Managed Care Quarterly*, *4*, 12-25.
130. Wang, R., Hempton, B., Dugan, J.P. & Komives, S.R. (2008). Cultural differences: Why do Asian avoid extreme responses? *Survey Practice*, *1*(3). Retrieved from <http://www.surveypractice.org/index.php/SurveyPractice/article/view/224>
131. Wang, V. & Marsh, F.H. (1992). Ethical principles and cultural integrity in health care delivery: Asian ethnocultural perspectives in genetic services. *Journal of Genetic Counselling*, *1*(1), 81-92.
132. Willis, G.B. (n.d.). *Cognitive Interviewing: A "How To" Guide*. North Carolina: Research Triangle Institute. Retrieved from <http://www.uiowa.edu/~c07b209/interview.pdf>.
133. Wolfe, E.W. & Smith, S.V. (2007a). Instrument development tools and activities for measure validation using Rasch Models: Part I – Instrument development tools. *Journal of Applied Measurement*, *8*(1), 97-123.
134. Wolfe, E.W. & Smith, S.V. (2007b). Instrument development tools and activities for measure validation using Rasch Models: Part II – Validation activities. *Journal of Applied Measurement*, *8*(2), 204-234.

135. World Health Organization. (2013). *Adherence to long-term therapies: Evidence for action*. Retrieved from [www.who.int/chp/knowledge/publications/adherence\\_full\\_report.pdf](http://www.who.int/chp/knowledge/publications/adherence_full_report.pdf)
136. World Health Organization. (2013). *Health Systems Strengthening Glossary*. Retrieved from [http://www.who.int/healthsystems/hss\\_glossary/en/index8.html](http://www.who.int/healthsystems/hss_glossary/en/index8.html).
137. World Health Organization. (2014). *Cardiovascular diseases (CVDs)*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs317/en/>
138. Ueshima, H., Sekikawa, A., Miura, K., Turin, T.C., Takashima, N., Kita, Y., Watanabe, M., Kadota, A., Okuda, N., Kadowaki, T., Nakamura, Y. & Okamura, T. (2008). Cardiovascular disease and risk factors in Asia: A selected review. *Circulation*, *118*, 2702-2709.
139. Zill, J.M., Dwinger, S., Kriston, L., Rohenkohl, A., Harter, M & Dirmaier, J. (2013). Psychometric evaluation of the German version of the patient activation measure (PAM 13). *BMC Public Health*, *13*, 1027. doi: 10.1186/1471-2458-13-1027.

## Appendix A Patient Activation Measure (PAM-13)

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1.	When all is said and done, I am the person who is responsible for taking care of my health	Disagree strongly	Disagree	Agree	Agree strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree strongly	Disagree	Agree	Agree strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree strongly	Disagree	Agree	Agree strongly	N/A
4.	I know what each of my prescribed medications do	Disagree strongly	Disagree	Agree	Agree strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree strongly	Disagree	Agree	Agree strongly	N/A
6.	I am confident that I can tell a doctor concerns I have even when he or she does not ask	Disagree strongly	Disagree	Agree	Agree strongly	N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree strongly	Disagree	Agree	Agree strongly	N/A
8.	I understand my health problems and what causes them	Disagree strongly	Disagree	Agree	Agree strongly	N/A
9.	I know what treatments are available for my health problems	Disagree strongly	Disagree	Agree	Agree strongly	N/A
10.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree strongly	Disagree	Agree	Agree strongly	N/A
11.	I know how to prevent problems with my health	Disagree strongly	Disagree	Agree	Agree strongly	N/A
12.	I am confident I can figure out solutions when new problems arise with my health	Disagree strongly	Disagree	Agree	Agree strongly	N/A
13.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	Disagree strongly	Disagree	Agree	Agree strongly	N/A

Insignia Health "Patient Activation Measure; Copyright © 2003-2010, University of Oregon All Rights reserved"

For use with a valid PAM Copyright License only  
Contact Insignia Health at [www.insigniahealth.com](http://www.insigniahealth.com)

## **Appendix B Ethics approval from Dalhousie University**

### **Health Sciences Research Ethics Board Letter of Approval**

June 15, 2015

Ms Bi Xia Ngooi  
Health Professions\Occupational Therapy

Dear Bi Xia,

**REB #:** 2015-3512

**Project Title:** Validation of Patient Activation Measure (PAM 13) Among Adults With Cardiac Conditions in Singapore

**Effective Date:** June 15, 2015

**Expiry Date:** June 15, 2016

The Health Sciences Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*. This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Dr. Brenda Beagan, Chair

## Appendix C Ethics approval from National Healthcare Group, Singapore



3 Fusionopolis Link  
#03-08 Nexus@one-north  
Singapore 138543  
Tel: 6496 6600 Fax: 6486 6870  
www.nhg.com.sg  
RCB No. 200002150H

**NHG DSRB Ref: 2015/00231**

28 May 2015

Ms Ngooi Bi Xia  
Department of Rehabilitation  
National University Hospital

Dear Ms Ngooi

### **NHG DOMAIN SPECIFIC REVIEW BOARD (DSRB) APPROVAL**

**STUDY TITLE: Validation of Patient Activation Measure (PAM 13) among adults with cardiac conditions in Singapore**

We are pleased to inform you that the NHG Domain Specific Review Board has approved the application as titled above to be conducted in **National University Hospital**.

The approval period is from **28 May 2015** to **27 May 2016**. The NHG DSRB reference number for this study is **2015/00231**. Please use this reference number for all future correspondence.

The documents reviewed are:

- a) NHG DSRB Application Form: **Version No.1**
- b) Participant Information Sheet and Informed Consent Form: **Version 2 dated 13/05/2015**
- c) Patient Activation Measure (PAM-13): **Version Insignia Health "Patient Activation Measure; Copyright © 2003-2010, University of Oregon**
- d) Patient Health Questionnaire (PHQ-9)
- e) Confirmation of Compensation Received: **Version 2 dated 13/05/2015**

- f) **Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale (SSE): Version Effective Clinical Practice, 4, 2001**
- g) **Demographics and Health Characteristics questionnaire: Version 2 dated 13/05/2015**
- h) **Semi-Structured Interview Guide: Version 1 dated 13/05/2015**

Continued approval is conditional upon your compliance with the following requirements:

1. Only the approved Informed Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.
2. No deviation from or changes to the study should be implemented without documented approval from the NHG DSRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.
3. Any deviation from or changes to the study to eliminate an immediate hazard should be promptly reported to the NHG DSRB within seven calendar days.
4. Please note that for studies requiring Clinical Trial Certificate, apart from the approval from NHG DSRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.
5. Please note that all research studies submitted from National University Hospital (NUH), involving the use of radioactive materials and/or radiation-emitting equipment are subjected to the NUH Radiation Safety Committee (RSC) review. Approval from the NUH RSC is mandatory prior to commencement of the study.
6. Please submit the following to the NHG DSRB:
  - a. All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NHG DSRB. All problems involving local deaths must be reported immediately within 24 hours after first knowledge by the Investigator, regardless of the causality and expectedness of the death. All other problems must be reported as soon as possible but not later than seven calendar days after first knowledge by the Investigator.
  - b. Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.
  - c. NHG DSRB Study Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond 27 May 2016 until approval is renewed by the NHG DSRB.
  - d. Study completion – this is to be submitted using the NHG DSRB Study Status Report Form within 4 to 6 weeks of study completion.
7. Established since May 2006, the NHG Research Quality Management (RQM) Program seeks to promote the responsible conduct of research in a research culture with high ethical standards, identify potential systemic

weaknesses and make recommendations for continual improvement. Hence, this research study may be randomly selected for a review by the Research Quality Management (RQM) team. For more information, please visit [www.research.nhg.com.sg](http://www.research.nhg.com.sg).

Yours Sincerely

A/Prof Low Yin Peng  
Chairman  
NHG Domain Specific Review Board D

Cc: Institutional Representative, NUH  
c/o Research Office, NUH  
Departmental Representative of Rehabilitation, NUH

*(This is an electronic-generated letter. No signature is required.)*

## **Appendix D Participant information sheet and consent form**

**Bi Xia Ngooi BAppSc (OT).**  
**Masters Candidate in Occupational Therapy**  
**Validation of PAM-13**



### **PARTICIPANT INFORMATION SHEET**

You are being invited to take part in a research study.

Before you take part in this research study, the study must be explained to you and you must be given the chance to ask questions. Please read carefully the contents provided here. If you agree to take part, please sign the informed consent form. You will be given a copy of this to take home with you.

#### **STUDY INFORMATION**

**Protocol title:**

Validation of Patient Activation Measure (PAM-13) among adults with cardiac conditions in Singapore

**Principal Investigator(s):**

Ngooi Bi Xia  
National University Hospital, Department of Rehabilitation  
5 Lower Kent Ridge Road  
Main Building 1, Level 1  
Singapore 119074  
91527369 / bi.xia.ngooi@dal.ca

**Supervisor(s):**

Dr Tanya L. Packer  
School of Occupational Therapy  
Dalhousie University  
+1 (902) 494-8804 / tanya.packer@dal.ca

**Sponsor:**

Singapore Association of Occupational Therapists

#### **PURPOSE OF THE RESEARCH STUDY**

This study wants to see if an assessment tool can be used in Singapore. This tool is called the Patient Activation Measure (PAM-13), which tests how much one knows,



has the skills and feels able to take care of their health. Information from the PAM-13 will help the healthcare team know whether people feel they can take care of their chronic diseases. This study aims to recruit 300 participants and is expected to take place from 8<sup>th</sup> June 2015 – 31<sup>st</sup> March 2016.

### **WHO CAN PARTICIPATE**

You are eligible for this study if you are resident of Singapore (Citizens or Permanent Residents), are at least 21 years old, able to speak and read English, and have any of the two types of heart disease, known as ischemic heart diseases or heart failure.

### **STUDY PROCEDURES**

We will ask you to complete a brief (5 minutes or less) form which will ask you questions about yourself, such as your age. These will help us describe the people in this research study and will only be reported in group form. No names will be written on any of the questionnaires.

We will ask you to answer some questions about your thinking in health and taking care of it. The three forms (PAM-13, Patient Health Questionnaire, and Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale) will take around 15-20 minutes. PAM-13 has some statements that people sometimes make when they talk about their health. You will be required to circle the answers saying how much you agree or disagree with each statement. The Patient Health Questionnaire (PHQ-9) asks if you have any of 9 specific problems. The Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale (SSE) asks how sure you are in doing certain things. Filling in the PHQ-9 and SSE will help us to see if the PAM-13 can be use in Singapore.

There will also be chances for some people to take part in a one-to-one talk to know how you feel filling up PAM-13. If you agree to take part, you would be asked to give consent to take part in one one-to-one talk that would take around 30 minutes to 1 hour. Completion of both the questionnaires and one-to-one talk can be completed on the same day and there is no need for additional appointments. However, if you are unable to complete the one-to-one talk on the same day but still wish to take part, we can offer the option of doing it via telephone, at your convenient date and time. If you agree, the talk would be audio-recorded and written down. Again, no names will be collected and we will anonymize any names or personal information mentioned during the interview.

### **WHAT IS NOT STANDARD CARE IN THIS STUDY**

This study is not part of your standard care. All questionnaires and interview described in the study procedures are part of a research study.

### **WITHDRAWAL FROM STUDY**

You can leave this study at any time before you complete and submit the questionnaires and/or before you complete the interview. There will be no impact on you and your medical care will not be affected.

If you decide to stop taking part in this study, you should tell the Principal Investigator (the person talking to you about this). Once you complete and submit the questionnaires and/or interview, it will not be possible to leave this study as the data is not linked to your name.

### **POSSIBLE RISKS, DISCOMFORTS AND INCONVENIENCES**

There are no known risks or costs to you. Filling in the forms may be difficult if you are not happy with your current health status. You may choose not to answer any question on the forms and may opt not to return the forms if you feel upset with the materials or the research process.

Also the PHQ-9 helps to detect clinical depression (long period of sadness). Should your score be above the cut-off score for depression, we hope you will allow us to inform your doctor-in-charge about the result. This is so that you can be treated early and have the most suitable care. This will only be done if you allow us to do so. If you do not want us to inform your doctor-in-charge, we will give you a list of places you can go to for help.

### **POTENTIAL BENEFITS**

There are no known direct gains to you for taking part in this study. You may gain from helping in a study designed to ensure that a useful measure, suitable to Singapore is developed and available for health providers. Having a suitable measure like PAM, can help to improve healthcare by providing more details about patients and to improve learning through research.

### **SUBJECT'S RIGHTS**

You are free to choose if you wish to take part in this study. All your questions will be answered until you feel you understand everything. You may refuse to answer any or all questions during the interview.

Even after signing and taking part in the study, you can still choose to void your consent before you submit the questionnaires and/or before you complete the interview. By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

### **CONFIDENTIALITY OF STUDY AND MEDICAL RECORDS**

Information collected for this study will be kept private. If you decide to withdraw from the study after the questionnaires are submitted and/or completion of the interview, your data will still be kept and analyzed. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. Only the research team will have access to the information being collected.

However, Regulatory Agencies, Institution Review Board and Ministry of Health will be granted direct access to your original medical records to check study plans and data, without making any of your information public. By signing the Informed Consent Form attached, you are allowing such access to your study and medical records.

In the event of any publication regarding this study, your identify will remain unknown.

### **COSTS OF PARTICIPATION**

As a token of your appreciation, you will receive a \$5.00 Gift Voucher when you complete the forms. If you are invited to participate in the one-to-one interview, you will also receive a \$10.00 Gift Voucher when you complete the interview.

You will still be required to pay for your routine clinical care.

### **RESEARCH FINDINGS**

Research findings can be made available to you in a one-page summary upon request.

### **WHO TO CONTACT IF YOU HAVE QUESTIONS**

If you have questions about this research study and your rights or in the care of any injuries during the course of this study, you may contact the Principal Investigator, Ngooi Bi Xia at 9152 7369 and [bi.xia.ngooi@dal.ca](mailto:bi.xia.ngooi@dal.ca).

If you have questions about the study or your rights as a participant, you can call the NHG Domain Specific Review Boards (DSRB), which is the committee that reviewed and approved this study, the telephone number is 6471 3266 during office hours.

The principal investigator is a postgraduate research student from the Dalhousie University in Canada and this study is being completed in partial fulfillment of the requirements of her Master's degree in Occupational Therapy (Post-professional), under the supervision of Dr Tanya L. Packer. Should you need further clarification about the research, you may contact Dr Tanya L. Packer at +1 (902) 494-8804 and [tanya.packer@dal.ca](mailto:tanya.packer@dal.ca).

Alternatively, if you have any difficulties with, or wish to voice concern about any aspect of your participation in this study, you may contact Catherine Connors, Director of Dalhousie University's Office of Human Research Ethics Administration for assistance at +1 (902) 494-1462, and [catherine.connors@dal.ca](mailto:catherine.connors@dal.ca).

## CONSENT BY RESEARCH SUBJECT

### Details of Research Study

**Protocol Title:**

Validation of Patient Activation Measure (PAM-13) among adults with cardiac conditions in Singapore

**Principal Investigator:**

Ngooi Bi Xia (HP: 9152 7369)  
National University Hospital, Department of Rehabilitation  
5 Lower Kent Ridge Road, Main Building 1, Level 1  
Singapore 119074

### Part I

I voluntarily consent to take part in this research study. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all the questions have been answered to my satisfaction.

By signing the Informed Consent Form attached, you are authorizing (i) collection, access to, use and storage of your “Personal Data, and (ii) disclosure to authorized service providers and relevant third parties.

“Personal Data” means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organization has or likely to have access. This includes medical conditions, medications, investigations and treatment history. Research arising in the future, based on this Personal Data, will be subject to review by the relevant institutional review board.

By participating in this research study, you are confirming that you have read, understood and consent to the Personal Data Protection Notification available at <http://www.nuhs.edu.sg/personal-data-protection.html>.

Data collected and entered into the Case Report Forms are the property of National University Hospital. In the event of any publication regarding this study, your identity will remain confidential.

I would like to help by participating in the individual interview. If I am interviewed, I agree to have the interview audio-recorded.

If I am interviewed, I agree for my quotes to be used in a publication.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

### Part II– Investigator’s Statement

I, the undersigned, certify to the best of my knowledge that the patient/patient’s legally acceptable representative signing this informed consent form had the study fully explained and clearly understands the nature, risks and benefits of his/her participation in the study.

\_\_\_\_\_  
Name of Investigator

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix E Confirmation of compensation received form

CONFIRMATION OF COMPENSATION RECEIVED	
<b>Research Study</b>	
<b>Protocol Title:</b> Validation of Patient Activation Measure (PAM-13) among adults with cardiac conditions in Singapore	
<b>Principal Investigator:</b> Ngooi Bi Xia National University Hospital, Department of Rehabilitation 5 Lower Kent Ridge Road Main Building 1, Level 1 Singapore 119074 9152 7369	
<b>Participant's acknowledgement</b>	
I, _____ (NRIC/Passport No. _____) (Name of participant)	
acknowledge that I have received the following compensation from the research team.	
<u>Tick as applicable</u>	
<input type="checkbox"/> <u>\$5.00 Gift voucher</u> for the completion of questionnaires	
<input type="checkbox"/> <u>\$10.00 Gift voucher</u> for the completion of individual interview	
_____	_____
[Signature of Participant]	(Date of signing)



6) What is your current employment status?

- 1. Employed full-time
- 2. Employed part-time
- 3. Unemployed
- 4. Retired
- 5. Full-time student
- 6. Housewife

7) Please indicate your total *household* income in a month.

- 1. Below S\$1,999
- 2. S\$2,000 – S\$4,999
- 3. S\$5,000 – S\$7,999
- 4. S\$8,000 – S\$12,999
- 5. S\$13,000 and above.

8) Overall, how would you rate your health during the past 4 weeks?

- 1. Excellent
- 2. Very good
- 3. Good
- 4. Fair
- 5. Poor
- 6. Very poor

## Appendix G Patient Health Questionnaire-9 (PHQ-9)

### PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(Use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING:   0   +        +        +         
=Total Score:       

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.



## Appendix H Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale (SSE)



### Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?
 

not at all												totally
confident	1	2	3	4	5	6	7	8	9	10		confident
  
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?
 

not at all												totally
confident	1	2	3	4	5	6	7	8	9	10		confident
  
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?
 

not at all												totally
confident	1	2	3	4	5	6	7	8	9	10		confident
  
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?
 

not at all												totally
confident	1	2	3	4	5	6	7	8	9	10		confident
  
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?
 

not at all												totally
confident	1	2	3	4	5	6	7	8	9	10		confident
  
6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?
 

not at all												totally
confident	1	2	3	4	5	6	7	8	9	10		confident

### Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

## Characteristics

Tested on 605 subjects with chronic disease

No. of items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
6	1-10	5.17	2.22	.91	NA

## Source of Psychometric Data

Stanford/Garfield Kaiser Chronic Disease Dissemination Study. Psychometrics reported in: Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

## Comments

This 6-item scale contains items taken from several SE scales developed for the Chronic Disease Self-Management study. We use this scale now, as it is much less burdensome for subjects. It covers several domains that are common across many chronic diseases, symptom control, role function, emotional functioning and communicating with physicians. For internet studies, we add radio buttons below each number. There are 2 ways to format these items. We use the format on this document, the other is shown on the web page. A 4-item version of this scale available in Spanish.

## References

Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

*This scale is free to use without permission*

**Stanford Patient Education Research Center**  
1000 Welch Road, Suite 204  
Palo Alto CA 94304  
(650) 723-7935  
(650) 725-9422 Fax  
self-management@stanford.edu  
<http://patienteducation.stanford.edu>

Funded by the National Institute of Nursing Research (NINR)

## Appendix I Semi-structured Cognitive Interview Guide

Thank you for agreeing to participate in this individual interview. I will be asking open-ended questions about your experience with filling up of PAM-13. Before we start, I would like to review the details of what you consented to so as to ensure that you are still willing to participate. Your participation is voluntary and you can choose not to respond to a question or withdraw at any time with no negative consequences. The information you give will only be available to the research team. Your name will not appear in any reports. Direct quotes may be used when publishing the study results; however, any quotes used will be unidentifiable. I will ask for your verbal consent at the end of the interview to confirm permission to use quotes. I would also like to remind you that the interview will be audio recorded. Are you still interested in participating in this interview? *(If yes, ask if they have any questions before we start. If no, thank them for their time).*

We will now be going through the questionnaire question by question.

- 1) Please explain question one in your own words.
- 2) Are there are any items, words or phrases in question one that you found difficult, irrelevant or ambiguous? *(If any, prompt participants to give suggestions for change)*
- 3) I noted that you circle *(e.g. agree)* in question one, can you elaborate on what you think through before coming to this answer?

The above questions will be repeated from question one to thirteen. Additional probes for each question, such as the following may be asked if necessary.

- 1) What do you think the term ‘responsible for taking care of my health’ mean?  
What does it include?
- 2) What do you think ‘taking an active role’ require you to do?
- 3) Are there any problems associated with your health? If so, what are those that you can prevent or reduce and what are not?
- 4) Can you share about your medications and what they do?

- 5) What are the situations that you need to visit a doctor and what are those that do not warrant a visit?
- 6) Does your doctor typically ask you about concerns that you have? What are some of these concerns? Were there situations when the doctor did not ask about the concerns that you had, but you still managed to ask?
- 7) Are there any medical treatments that you need to do at home? If yes, what are they?
- 8) Can you share about the health problems that you have and what you think causes them?
- 9) What are the treatments available for your health problems?
- 10) Are there lifestyle changes that you have been maintaining? How have you been maintaining them?
- 11) In what ways do you think are necessary to prevent problems with your health?
- 12) What do you think are potential new problems that may arise with your health? How do you think you may go about solving them?
- 13) What are some potential times of stress? What strategies do you think you may adopt to maintain the lifestyle changes during those times?

During conclusion, ask if they have anything else that they will like to share with the interviewer. If not, thank them for their time. Confirm permission to use quotes, as the participants will have a clearer understanding of what might be contained in quotations at this time.