DOES EQ-5D WORK IN CHINA? EXPLORING CULTURAL DIFFERENCES IN MEASURING HEALTH

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Abstract

Health-related quality of life (HRQoL) has become an essential aspect of measuring health. Most of the commonly used generic HRQoL measures were developed in Europe or North America and have been translated into other languages for use worldwide. Arguably, this adaption process assumes that health, as a concept, has universal cultural equivalence. The aim of this thesis is to explore cultural differences in defining and measuring health, by focusing on the adaption of EQ-5D, which is a widely used Western HRQoL measure, for use in China, given vast cultural differences between China and Western countries. A series of studies were conducted to attain this aim. A scoping review identified generic HRQoL measures that were developed for Chinese populations and established a preliminary conceptual framework of health to summarise health dimensions that are important in assessing health in a Chinese cultural setting. This work was followed by a qualitative study that investigated how Chinese lay people describe and appraise health to justify the preliminary framework and to identify additional health dimensions. A Q-methodological investigation and a multidimensional unfolding analysis were subsequently undertaken to establish the relative importance of these health dimensions in a diverse range of Chinese participants. The studies identified several health dimensions, such as “spirit (Shen)”, “body constitution” and “sleep”, which were highlighted in the Chinese literature and by Chinese lay participants, but have not been commonly covered in Western HRQoL measures such as EQ-5D. The results demonstrate that health is a culturally grounded concept and, due to cultural differences, it cannot be taken for granted that a well recognised Western HRQoL measure is always appropriate for use in other cultural contexts. Careful consideration and testing of conceptual equivalence is essential when deciding whether to use an existing HRQoL measure outside of the culture in which it was developed.

Table of contents

Acknowledgement ..... **iii**

Abstract ..... **v**

Table of contents ..... **vi**

List of tables ..... **xi**

List of figures ..... **xii**

Abbreviations ..... **xiv**

Chapter 1 Introduction and background **1**

1.1 Health and measuring health 1

1.1.1 What is health? 1

1.1.2 Measuring health 4

1.2 Health-related quality of life (HRQoL) as a health outcome 5

1.2.1 An overview of HRQoL and HRQoL measures 5

1.2.2 HRQoL and its related concepts 7

1.2.3 Content of HRQoL measures 9

1.2.4 Quality of HRQoL measures 15

1.2.5 Translation and adaptation of HRQoL measures into other languages 16

1.3 The use of Western-developed HRQoL measures in a Chinese cultural setting 20

1.3.1 Chinese culture and potential cultural differences between China and the West 20

1.3.2 The use of Western-developed HRQoL measures in China 23

1.4 Problems of applying Western-developed HRQoL measures in China: EQ-5D as an example 24

1.4.1 An overview of EQ-5D 24

1.4.2 The translation/adaptation of EQ-5D in China 26

1.4.3 Problems of applying EQ-5D in China 27

Chapter 2 Research objectives and study design **29**

2.1 Research objectives 29

2.2 Study design 30

Chapter 3 Chinese-developed HRQoL measures: a scoping review **32**

3.1 Background 32

3.1.1 “Health” in the Chinese language 32

3.1.2 Chinese-developed HRQoL measures....40
3.2 Research objectives....41
3.3 Methods....41
3.3.1 Identifying relevant studies and study selection....43
3.3.2 Charting the data....45
3.3.3 Analysis and synthesis....46
3.4 Results....49
3.4.1 The identified HRQoL measures....49
3.4.2 The content of the Chinese-developed HRQoL measures....53
3.4.3 A preliminary conceptual framework of health....63
3.4.4 Comparing the Chinese conceptual framework with the EQ-5D descriptive system....66
3.5 Discussion....67
3.5.1 Chinese-developed measures from TCM and non-TCM perspectives....67
3.5.2 A Chinese conceptual framework of health....71
3.5.3 Potential differences between China and the West in measuring health....72
3.6 Limitations....73
3.7 Conclusion....74
Chapter 4 Lay understandings of health in China: a qualitative study....75
4.1 Background....75
4.2 Research objectives....76
4.3 Methods....76
4.3.1 Study design....76
4.3.2 Participants....79
4.3.3 Ethics....81
4.3.4 The procedure of interviews....81
4.3.5 The procedure of data analysis....84
4.3.6 Robustness of the study....87
4.4 Results....89
4.4.1 Lay understandings of health....91
4.4.2 A revised conceptual framework of health....101
4.4.3 Opinions on the descriptive system of EQ-5D....106
4.5 Discussion....110

4.5.1 How is health defined in China? 110
4.5.2 The content validity of EQ-5D 115
4.6 Limitations 117
4.7 Conclusions 117
Chapter 5 Exploring subjective constructions of health in China: a Q-methodological investigation 119
5.1 Background 119
5.2 Introduction to Q methodology 119
5.2.1 Procedure overview 121
5.2.2 Criticisms of Q and why using Q in this study 125
5.3 Research objectives 128
5.4 Methods 129
5.4.1 Concourse development and Q-sample generation 129
5.4.2 Participants 134
5.4.3 Ethics 135
5.4.4 Data collection process 135
5.4.5 Factor analysis and rotation 139
5.5 Results 140
5.5.1 The legitimacy of the conceptual framework of health 140
5.5.2 Factor extraction and interpretation 141
5.6 Discussion 160
5.6.1 The legitimacy of the conceptual framework of health 160
5.6.2 Differences across five factors 160
5.6.3 Similarities among the views 162
5.6.4 Differences in understanding health between China and the West 165
5.7 Limitations 166
5.8 Conclusion 167
Chapter 6 Quantitative analysis of preference data: the use of multidimensional scaling 168
6.1 Background 168
6.2 Introduction to multidimensional scaling 171
6.2.1 The basic ideas of multidimensional scaling 171
6.2.2 MDS models and fitting criteria 175
6.2.3 A special case of MDS analysis: the unfolding analysis 176

6.2.4 Applications of MDS in real life....177
6.3 Research objectives....178
6.4 Analytic program and process....178
6.5 Results....179
6.5.1 Descriptive statistics....179
6.5.2 A multidimensional unfolding solution for the ranking data....183
6.5.3 Multidimensional unfolding findings vs Q-study findings....191
6.6 Discussion....193
6.6.1 A further investigation of the concept of health in China....194
6.6.2 Multidimensional unfolding technique vs Q methodology....196
6.7 Limitations....197
6.8 Conclusion....198
Chapter 7 Principal findings, research implications and future studies....199
7.1 Introduction....199
7.2 Principle findings and contributions of the thesis....200
7.2.1 Content validity of EQ-5D as commented by Chinese participants....200
7.2.2 A Chinese conceptual framework of health....201
7.2.3 Important health dimensions in China....201
7.2.4 Cultural differences in measuring health between China and the West....203
7.3 Research implications and recommendations....206
7.3.1 To use, or not to use, that is the question!....206
7.3.2 Careful consideration of conceptual equivalence of Western-developed HRQoL measures is needed....208
7.3.3 Measuring HRQoL from a “person-centred” perspective....211
7.3.4 Methodological considerations....213
7.4 Limitations and future research....214
7.5 Concluding remarks....217
References....218
Appendix....240
Appendix I: Ethics approval letter....240
Appendix II: Information sheet – Interview....242
Appendix III: Information sheet – Q-study....246
Appendix IV: Consent form....250

Appendix V: Interviewing questions in the qualitative study.....252
Appendix VI: The process of how the Q-sample was generated 256
Appendix VII: Feedback questionnaire on the Q-sample draft.....262
Appendix VIII: The instructions for the Q-sorting activity.....267
Appendix IX: The selection of factors for interpretation in the Q-study .271
Appendix X: Poster – a Pilot study on testing the appropriateness of the translated version of EQ-5D dimensions in the Chinese language277
Appendix XI: Loadings of the 110 Q-sorts on the five factors 278
Appendix XII: Demographic information of the 40 participants whose Q-sorts were not used to form any of the five factors 280
Appendix XIII: Q-grids for the five extracted factors.....281

List of tables

Table 3-1: Chinese-developed generic HRQoL measures.....51
Table 3-2: Summarised health dimensions.....54
Table 3-3: Health dimensions in the symptom domain 57
Table 3-4: Health dimensions in the function domain 60
Table 3-5: Other dimensions.....62
Table 4-1: Example questions part I 82
Table 4-2: Example questions part II 83
Table 4-3: Example coding of data extracts.....86
Table 4-4: Demographic characteristics of participants 90
Table 4-5: Comparisons in findings between the scoping review and the qualitative study.....102
Table 5-1: Terminology in Q Methodology.....121
Table 5-2: Q-sample 132
Table 5-3: Demographic characteristics of participants (n=110).....135
Table 5-4: Post-sorting questions 139
Table 5-5: Factor arrays – scores against each item by factor 143
Table 5-6: Demographic information for exemplars in each factor.....144
Table 5-7 Rankings of EQ-5D dimensions.....159
Table 6-1: Intercity distances of 10 Chinese cities (in kilometres).....172
Table 6-2: Ranks of the intercity distances of 10 Chinese cities 174
Table 6-3: Stress values for 1-6 dimensional solutions.....183
Table 6-4: Characteristics of participants in four Quadrants 187
Table 6-5: Positions of Q exemplars.....193
Table 7-1: The content of six Western-developed generic health measures 205

List of figures

Figure 1-1: Wilson-Cleary model.....10
Figure 1-2: ICF model.....11
Figure 1-3: PROMIS model.....12
Figure 1-4: Component structure of health.....14
Figure 1-5: Model for assessing cross-cultural equivalence in HRQoL measures, adapted from (Herdman et al., 1998).....18
Figure 1-6: Common approach for assessing cross-cultural equivalence in HRQoL measures, adapted from (Stewart and Napoles-Springer, 2000).....19
Figure 1-7: China topography map (China Maps Org).....21
Figure 2-1: The thinking process of setting the research objectives.....30
Figure 3-1: Searching strategies in CNKI.....44
Figure 3-2: Searching strategies in Medline.....44
Figure 3-3: Flow chart for the reviewing process.....50
Figure 3-4: Conceptual framework of health based on the Chinese-developed HRQoL measures.....64
Figure 4-1: Conceptual framework of health based on the scoping review and interviews.....105
Figure 5-1: Q-Grid sample.....124
Figure 5-2: Q-Grid used in this study.....137
Figure 5-3: Scree test.....141
Figure 6-1: Q-grid (reproduced from Figure 5-2, for the ease of presentation).....170
Figure 6-2: Complete ranking grid.....170
Figure 6-3: A two-dimensional configuration of the 10 Chinese cities (using ratio-MDS).....173
Figure 6-4 Major cities in China.....173
Figure 6-5: A two-dimensional configuration of the 10 Chinese cities (using ordinal-MDS).....174
Figure 6-6: Percentage of participants in three importance categories*.....181
Figure 6-7: Mean ranks for 42 health statements.....182
Figure 6-8: Joint plot for preference ranking of health statements.....185
Figure 6-9: Random sample's joint plot.....188
Figure 6-10: Joint plot for participants older than 60 (n=31).....190

Figure 6-11: Joint plot for participants with a <80 self-rated score (n=40) .191
Figure 7-1: Process of the four studies in the thesis 200
Figure 7-2: Example questions that can be added to EQ-5D-5L for use in China 203

Abbreviations

CHQOL	Chinese Quality of Life Instrument
CHPRO	Chinese Patient Reported Outcome Instrument
CPH42	Current Perceived Health Questionnaire-42
CPSHS	Chinese Psychosomatic Health Scale
COOP	Dartmouth Cooperative Functional Assessment Charts
EQ-5D-3/5L	EQ-5D – Three/Five-Level version
HRQoL	Health related quality of life
HSQ	Health Status Questionnaire
HSTCM	Health Scale of Traditional Chinese Medicine
HUI	Health Utilities Index
ICF	International Classification of Functioning, Disability and Health
MDS	Multidimensional scaling
NHP	Nottingham Health Profile
PROMIS	Patient-Reported Outcomes Measurement Information System
QoL	Quality of life
QOL35	General Quality of Life Instrument for Chinese People
QOLI	Quality of Life Inventory
QWB	Quality of Well-Being Scale
RO	Research objective

SD	Standard deviation
SF-36	36-Item Short Form Health Survey
SF-6D	Short-Form 6-Dimension
SIP	Sickness Impact Profile
SRHMS	Self-rated Health Measurement Scale
TCM	Traditional Chinese Medicine
TCM50	Self-rated Questionnaire of Health Status in Traditional Chinese Medicine
TCMHSS	Health Status Scale of Traditional Chinese Medicine
TCMQ	Questionnaire based on TCM for Detecting Health Status
VAS	Visual analogue scale
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life Instruments

Chapter 1 Introduction and background

1.1 Health and measuring health

1.1.1 What is health?

The whole story of this thesis begins with a short question: what is health?

Health is a simple term but is difficult to define. In fact, there is no universally agreed definition. Based on different theories or disciplines, health can be defined from different perspectives.

From a medical point of view, health can be perceived as the opposite of disease (Apple, 1960; Wylie, 1970; Larson, 1999). Understanding health by pointing out its antonym – disease – is common among medical professionals (Wood and Foster, 1986; Bowling, 2001; Barry and Yuill, 2012). It is believed that measuring departures from normality is easier than assessing health itself (Bowling, 2001). This medical model of health is also referred to as a "value-free" notion, where health can be observed objectively, based on individuals' biological indicators and statistical normality (Boorse, 1977). Health can be distinguished from disease by differentiating normal from abnormal conditions, while diseases are regarded as any situations that are inconsistent with health. A practical example is the physical examination, where health is thought of as a baseline and a variety of indicators are used to investigate if there are any deviations from the basic standard.

However, defining health as an absence of disease has been widely criticised, because it is a negative definition narrowly focusing on objective indicators (Lamb et al., 1988; Larson, 1999; Bowling, 2004). According to this, some scholars argued that health can be defined positively relating to one's functional ability (Goldsmith, 1972; Patrick et al., 1973; Feeny et al., 1995). From a functional point of view, the extent to which an individual is able to perform certain activities can indicate his/her health (Fanshel and Bush, 1970; Simmons, 1989; Mold, 1995).

Additionally, some scholars referred to the notion of homeostasis to define health (Boorse, 1977; Engel, 1953). Health, in this sense, can be understood as a status where individuals manage to maintain “a condition of stable dynamic equilibrium between the internal and external environments” (Engel, 1953, p.54). The homeostatic concept of health highlights that equilibrium is required to be maintained through changing circumstances, for example, appropriate to their age and social needs. This concept is therefore quite similar to the holistic concept of health, which understands health with a sense of coherence and considers all dimensions of an individual simultaneously (Guttmacher, 1979; Saylor, 2004). The holistic definition of health suggests that health can be described as a state where people’s mind and body are in harmony within the environment and a balance is maintained both inside and outside of each person (Saylor, 2004).

One of the most frequently quoted definitions is that of the World Health Organisation, which describes health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, n.d., para.1). Despite the frequent use of this definition, its abstractness and simplicity have been criticised widely (Goldsmith, 1972; Bowling, 2001). It uses a vague concept of “wellbeing” to describe another abstract word “health”, making the definition itself ambiguous (Tulloch et al., 2005). The definition has also received criticism for being overly idealistic by using the word “complete” (Huber et al., 2011; Spratt, 2017). A recent development of the concept of health has proposed by some scholars to reformulate the definition of health as the ability to adapt (Giacaman et al., 2009; Huber et al., 2011; Charlier et al., 2017). In this view, health is about being capable of adjusting to changing circumstances and to self-manage physically, mentally and socially (Huber et al., 2011).

While there is a lack of consensus among health professions in determining a unified health definition, it is also shown by empirical studies that lay people understand and define health differently (Baumann, 1961; Herzlich and Graham, 1973; Pierret, 1993; Mansour, 1994; Lawton, 2003; Blaxter, 2003; Nettleton, 2013). It has been reported that people with different demographic factors tend to have different ways to describe health (Blaxter et al., 1982; Cox et al., 1987;

d'Houtaud and Field, 1984). Age, gender, education, marital status, social class, health conditions/experiences, financial situation and religious affiliation are thought to be influential in forming lay people's views in understanding health (Baumann, 1961; d'Houtaud and Field, 1984; Anderton et al., 1989; Bendelow, 1993; Mansour, 1994; Henchoz et al., 2015; Bowling, 1995). For example, a study reported that younger people tended to rate physical fitness as a critical dimension in defining health, while according to elderly people over 60, physical function, or the ability to conduct activities, was a more favourable explanation of health (Blaxter, 2003). In another health survey study, women and men ranked important dimensions of health in different orders. For female participants, "never ill, no disease, never see a doctor" was the most frequently mentioned phrase, while male respondents were more likely to define health as "fit, strong, energetic, physically active" (Cox et al., 1987). It was also supported by empirical results that marital status, education and health problem experiences significantly affected lay people's definitions of health (Mansour, 1994).

Importantly, one's cultural background can bring about variations in defining health (Levesque et al., 2013; Bowling, 2014b). Taking differences between China and the West in understanding health as an example, studies have shown that Chinese people have different views about health compared to Westerners (Prior et al., 2000; Liu et al., 2005; Chen et al., 2009; Xiang et al., 2010). A paper examining lay understandings of health in two Cantonese-speaking communities in England revealed that participants utilised items comprising ideas from Traditional Chinese Medicine (TCM), such as spirits, demons, food and weather to describe health. Because those items are less common in a Western cultural setting, the understandings of health in Chinese communities seem to be different from that in the West. The authors also suggested that there might be various alternative conceptualisations that are uncovered in other populations (Prior et al., 2000). One study noted cultural differences in perceiving health by illustrating the fact that communicating with Chinese people in health services tended to be different from that with Western people. Chinese cancer patients had specific favourable and unfavourable words that clinicians should pay attention to (Liu et al., 2005). Another paper reported that Chinese Canadians used mental services less frequently than other Canadians. Ethnic factors are found to significantly

affect the likelihood of consultation; the authors explained that traditional Chinese culture may encourage people to suppress their feelings and speculated that Chinese people might have different perceptions regarding mental health (Chen et al., 2009).

1.1.2 Measuring health

Efforts have been made not only in defining health but also in measuring health. As it was proposed by Goldsmith (1972), measuring health is of significance in several aspects. It can make the public and policy-making bodies aware of the health situation. The information can also aid in administrative processes such as health program planning, health situation evaluating and financial resources allocating. Another purpose of health measurement is to assist researchers in medical care studies and to improve medical practice. It has been shown that health can be defined in various ways. The abstractness of health causes difficulties and confusions in defining health and then in measuring health. Since health measures have been developed based on different health concepts, they can be expected to be diverse.

As noted previously, health can be viewed as the opposite of diseases, or the extreme condition -- death. Mortality and morbidity are traditional indicators that are useful for measuring population health from a social perspective, especially when the objective of health services is mainly to extend the life expectancy of people (Moriyama, 1968; Fanshel and Bush, 1970; Bergner, 1985). However, in the 1960s, some researchers already started to argue that using mortality and morbidity is not sensitive enough to capture changes in health in societies (Moriyama, 1968). As for personal health, clinical indicators that are included in the physical examination are conventional health measures. Such indicators examine individuals' signs of "ill health" and are also based on defining health as the absence of diseases (Bowling, 2001), therefore, they assess the negative aspects of health mainly.

Since it was argued that physical signs and conventional clinical indicators alone were no longer sufficient to make decisions in health care (Fitzpatrick et al., 1998), health researchers have expanded such assessment of individuals' health by linking health to the functional capacity to develop health measures (Fayers

and Machin, 2013). These measures focus on physical function and physical symptoms, while some of them also assess the psychological and social aspects of health (Bergner, 1985). Examples of such functional health status measures include Quality of Well-Being Scale, Health Utilities Index, Sickness Impact Profile and Nottingham Health Profile (Fanshel and Bush, 1970; Torrance et al., 1972; Chen et al., 1975; Bergner et al., 1981; Hunt et al., 1985). Such health measures tend to define and evaluate health in a more positive way.

Built upon these early attempts of developing the measures of functional status, the most recent generation of health measures still focus on one's functional capacity, but seem to pay more attention to one's subjective aspects of health, such as emotion, cognitive function and role function (McDowell, 2006; Fayers and Machin, 2013). This may be due to an increasing awareness of the importance of people's satisfaction and feeling. Such health measures are often regarded as health-related quality of life (HRQoL) measures (Bowling, 2001). These measures can assess "subjective health status" and are expected to collect complementary information in health research and clinical trials (Fitzpatrick et al., 1998). The terms "HRQoL" as well as "HRQoL measures" are introduced in more detail in the next section.

1.2 Health-related quality of life (HRQoL) as a health outcome

1.2.1 An overview of HRQoL and HRQoL measures

The concept of HRQoL emerged with certain historical reasons. It was said that with a significant decrease in mortality and the trend of treating chronic diseases as major health problems, HRQoL was proposed as a new way of assessing health care (Lerner and Levin, 1994). Policymakers, clinicians and patients themselves developed an increasing concern over the quality of health status, instead of merely looking at traditional outcome indicators, such as physical signs and conventional clinical indexes (Guyatt et al., 1991a). HRQoL was then introduced to collect information directly from patients, which benefited symptom relief, care and rehabilitation in treatments as well as facilitated communications with patients (Fayers and Machin, 2013).

As with the difficulties of defining health, it is unlikely that we can reach an agreement on a single definition of HRQoL (Shumaker and Naughton, 1995; Bowling, 2001; Fayers and Machin, 2013). Schipper and colleagues (1996) summarised five perspectives in defining the term. From a psychological view, HRQoL focuses on patients' perceptions and experiences of illness. From a utility view, HRQoL relates to individuals' trade-offs between quality of life and quantity of life. It can also be understood as a community-centred concept, concerning the impact of illness on individuals' relations to a community. Alternatively, HRQoL is regarded as "reintegration to normal living" and can be observed by how well an individual person resumes following an illness. The last perspective is to define HRQoL as the gap between one's expectation and actual state: the smaller the difference between reality and expectation, the higher the HRQoL (Schipper et al., 1996).

Although it is difficult to find a commonly accepted definition of HRQoL, several key elements are agreed among the various published definitions. First, HRQoL is associated with people's subjective assessment of their own health (Shumaker and Naughton, 1995; WHOQOL Group, 1995). It is the information to be collected from a "patient-perceived" perspective which can reveal people's subjective evaluation of health (Schipper et al., 1996). Another characteristic of HRQoL is its multidimensionality (Haas, 1999b; WHOQOL Group, 1995). Most definitions of HRQoL mentioned dimensions of physical function, mental/psychological well-being, social function, role function and global perceptions of function and well-being (Ware, 1987; Wilson and Cleary, 1995; Shumaker and Naughton, 1995).

HRQoL measures are developed with reference to the characteristics of the concept of HRQoL. With the aim of conducting a subjective evaluation of people's health status, HRQoL measures are with person-based nature and are sometimes known as patient-reported outcome measures (Fitzpatrick et al., 1998). They normally assess multiple dimensions of health including physical function, physical or psychological symptoms, mental status, role activities and social wellbeing (Fitzpatrick et al., 1998; Fayers and Machin, 2013). Since they concern the overall health status, they are also named as general health status measures in some occasions (Schipper et al., 1996; McDowell, 2006; Fayers and Machin, 2013).

HRQoL measures can be categorised in various ways. They can be classified by their function. For example, as it was explained by Kirshner and Guyatt (1985), there are mainly three categories of HRQoL measures: discriminative, predictive and evaluative. They are applied with different purposes: distinguishing between people on certain health aspects, identifying people which may potentially develop a health condition, and evaluating changes in individual's health status over a period of time (Kirshner and Guyatt, 1985). By their scope, they can be divided into specific and generic HRQoL measures (Streiner et al., 2014). Specific measures, either disease-specific or patient-specific, are likely to be more sensitive to detect changes and differences among a specific patient group (Fayers and Machin, 2013; Streiner et al., 2014), while generic measures attempt to cover a wider range of dimensions and are more favourable when comparisons among different diseases or among general populations are conducted (Streiner et al., 2014).

1.2.2 HRQoL and its related concepts

HRQoL can be substituted with other terms intended to describe individuals' self-perceived health status (Gill and Feinstein, 1994; Haas, 1999a) and is often used interchangeably with terms like health status and quality of life (QoL) (Shumaker and Naughton, 1995; Karimi and Brazier, 2016). There is a general lack of consensus over their definitions and measurement (Bowling, 2004). As Karimi and Brazier illustrated, measures such as EQ-5D and SF-36 are referred to as "health status measures" (Ware and Sherbourne, 1992; Cunillera et al., 2010), "HRQoL measures" (Brazier et al., 2002; Makai et al., 2014) and "QoL measures" (Hill et al., 2010; Kalantar-Zadeh et al., 2001) in different papers.

Some researchers argued that there are differences among these phrases. For example, QoL is often considered to be a broader concept, incorporating "the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment" (WHOQOL Group, 1994, p28), while HRQoL can only be regarded as one component of QoL. As Torrance illustrated, "Quality of life is a broad concept that incorporates all aspects of an individual's existence. Health-related quality of life is a subset relating only to the health domain of that existence"

(Torrance, 1987, p593). According to this view, QoL covers dimensions not only about individuals' health but also their economic status, external environment conditions and all other aspects of an individual's life (Gill and Feinstein, 1994; WHOQOL Group, 1995; Bowling, 2001).

Health status, on the other hand, is considered to be a narrower concept to some scholars. Bowling suggested that although health status largely overlaps with HRQoL, it is only considered as "a narrower aspect of physical or mental health" and is "one domain of health-related quality of life" (Bowling, 2014b, p.13). Guyatt and colleagues specified what differentiated health status from HRQoL is that health status "omitted the necessary element of valuation by the patient" (Guyatt et al., 1991b). In this regard, health status is considered as functioning status, including both social and physical functioning, that can also be observed by other people; while HRQoL contains not only functioning status (namely health status) but also individuals' subjective perceptions of wellbeing, which are internal evaluation that may not be directly assessed by external observers (Moons, 2004; Hays and Reeve, 2010; van Son et al., 2013). As van Son and colleagues illustrated, HRQoL measures would normally involve questions such as "How satisfied are you with your ability to walk?"; while standard subjective health status measures include questions assessing self-perceived function status directly with questions like "Does your health limit you in walking?" (van Son et al., 2013) Some researchers, therefore, argued that many so-called HRQoL measures, such as EQ-5D or SF-6D, should be categorised as self-rated health status measures (Smith et al., 1999; van Son et al., 2013; Karimi and Brazier, 2016).

In this thesis, the term "HRQoL" is used to represent those health measures which are "health-focused" and are "self-assessed". However, since the terms "HRQoL measures", "QoL measures" and "health status measures" are often used interchangeably in many contexts (Karimi and Brazier, 2016), they are not strictly distinguished from each other in this thesis. This was because the thesis focused on exploring the content that should be embraced in individuals' subjective assessment of health, while HRQoL measures, self-perceived health status measures and those health-related questions (excluding external factors such as economic status and environment conditions) in QoL measures are all

associated with people's self-assessment of health and include multiple health-related dimensions.

1.2.3 Content of HRQoL measures

1.2.3.1 HRQoL conceptual models

With the aim of appropriately assessing people's subjective values of their own health, it is essential for HRQoL measures to include questions that are relevant and important to the target populations' subjective health evaluation (Gill and Feinstein, 1994). Despite the widespread criticism of the WHO's definition of health, the three domains – physical conditions, mental states and social wellbeing – are widely accepted to be covered in HRQoL assessment (Avis and Smith, 1994; McDowell, 2006).

There are also various dedicated conceptual models of HRQoL and the Wilson-Cleary model is the most commonly cited one (Bakas et al., 2012; Ferrans et al., 2005; Mark, 2016). The model comprises a series of typical variables that are often included in HRQoL measures and presents causal relationships between these variables (Wilson and Cleary, 1995). It describes HRQoL in a five-level hierarchy system, linking biological and physiological variables to symptom status, then to functional health, then general health perceptions and finally to the overall quality of life (Wilson and Cleary, 1995).

In the model, biological and physiological factors are referred to the radical determinants of health status. They directly affect symptom status, which consists of physical and psychological and psychophysical aspects. A symptom is defined as "a patient's perception of an abnormal physical, emotional or cognitive state" (Wilson and Cleary, 1995, p.61). More specifically, physical symptoms are described as "a perception, feeling or even belief about the state of our body". Psychological symptoms are synonymous with emotional symptoms in their definition, representing emotions "such as fear, worry and frustration". While psychophysical symptoms are referred to as "symptoms not clearly physical or psychological in origin" (Wilson and Cleary, 1995, p.61).

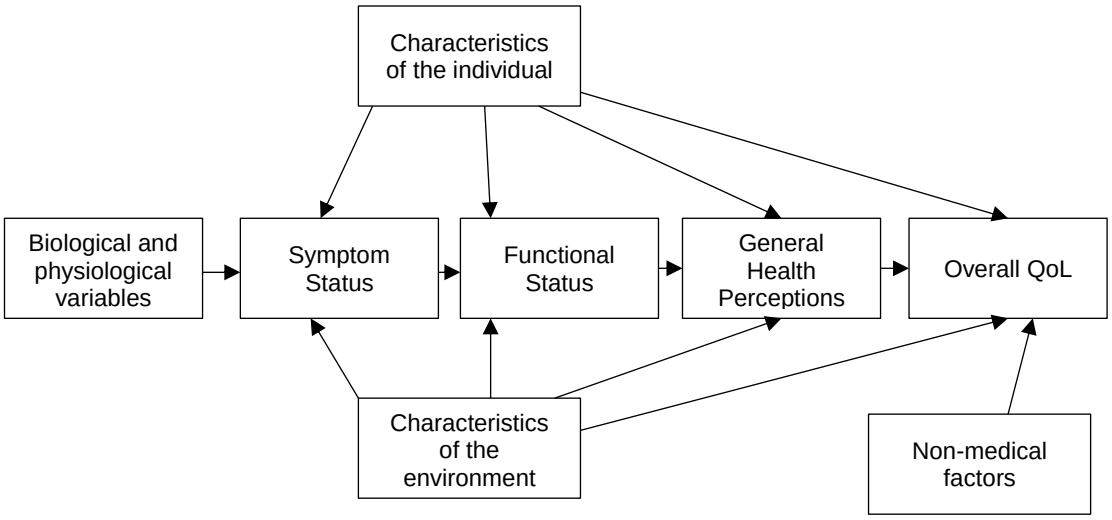


Figure 1-1: Wilson-Cleary model

The next level of the model is functional status. It is subcategorised into physical, social, role and psychological dimensions. The Wilson-Cleary model defines "function" as "the ability of the individual to perform particular defined tasks" (Wilson and Cleary 1995, p.61). In terms of the four sub-categorises of function status, a physical function can be understood as "the ability to perform self-care activities, mobility and more strenuous physical activities". A psychological function is more about cognitive function which includes "orientation with respect to time and place and such mental processes as memory, comprehension, abstract reasoning and problem solving". Social functioning is understood as "social contacts (e.g. visits with friends and relatives) and social resources (e.g. close friends and relatives that can be relied upon for tangible and intangible support)". Role functioning refers to the performance of usual role activities including formal employment, school work, and housework (Ware, 1987). Adding to the third level, an individual's symptom status and functional status lead to a general health perception: a subjective evaluation of the overall health status. The highest level is the overall quality of life. It relates to how happy and/or satisfied an individual is with life as a whole (Wilson and Cleary, 1995).

International Classification of Functioning, Disability and Health (ICF) model and Patient-Reported Outcomes Measurement Information System (PROMIS) model are also alternative conceptual models of HRQoL. The ICF coding system consists of four sections: body function, activities and participation, environmental

factors and body structure (World Health Organization, 2001). Compared with that in Wilson-Cleary's model, ICF's categories are less adequate in representing HRQoL as a concept. Although some studies successfully applied the ICF model to analyse HRQoL measures in practice (Cieza and Stucki, 2005; Mayo et al., 2011), ICF's focus is mainly on functioning and disability (World Health Organization, 2001), while the Wilson-Cleary model contains not only functional status but also symptom status and can be further classified into physical, psychological, social and role aspects.

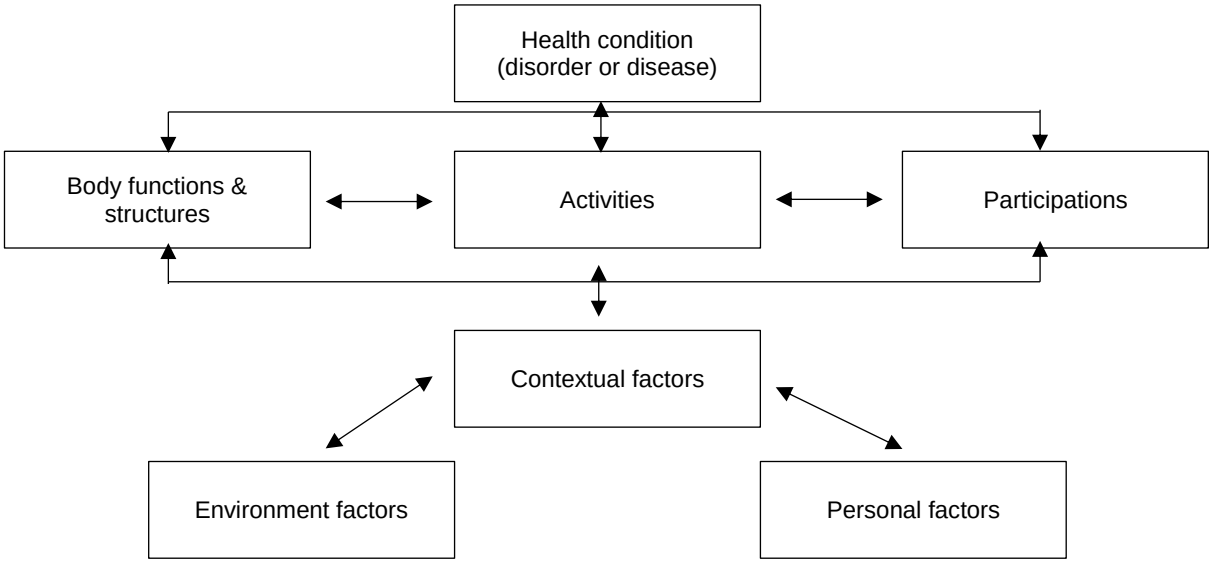


Figure 1-2: ICF model

As for PROMIS model, it firstly divides the concept of health into three domains: physical, mental and social, then further breaks three domains down into physical function, physical symptoms, emotional distress, cognitive function and social function (Cella et al., 2010). Basically, the main categories of PROMIS are similar to that in the Wilson-Cleary but the Wilson-Cleary model also reveals inner-relationships among each domain within the framework when the PROMIS does not.

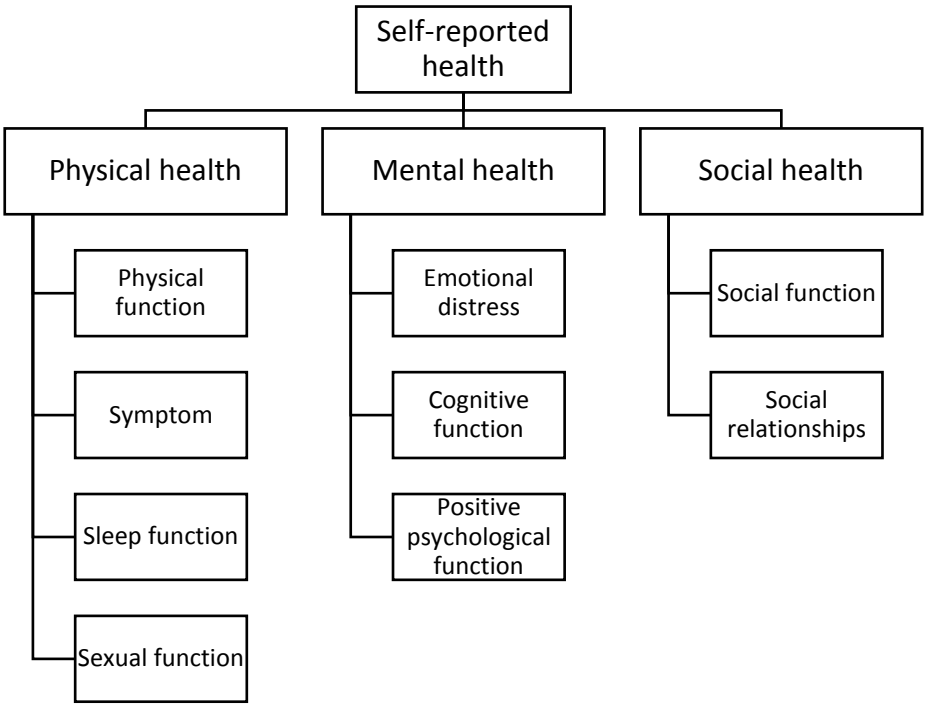


Figure 1-3: PROMIS model

1.2.3.2 Choosing items in HRQoL measures

There are mainly two ways of identifying and selecting items for HRQoL measures: conceptual and empirical (Avis and Smith, 1994). The conceptual method requires HRQoL measure designers to have a predefined concept of health, based on which they can determine main domains that are of research interest. The designers can then decide specific health questions to be included in each domain being chosen. The above conceptual models, as well as other available conceptual models from the literature, can provide a possible conceptual basis for the identification and selection process. Alternatively, HRQoL measure developers can also use experts' and/or their own expertise to define the concept of health to construct an HRQoL measure (Kind, 1996).

Apart from developing measures based on a predefined conceptual model, HRQoL items could also be generated empirically. Items in HRQoL measurement indicators can be collected via focus group, key informant interviews, clinical observations and relevant research findings (Streiner et al., 2014). For example, the items in Quality of Well-being Scale (QWB) were from the Health Interview Survey of the National Centre for Health Statistics, the Survey of the Disabled of the Social Security Administration, and several rehabilitation scales (Chen et al.,

1975). The Sickness Impact Profile (SIP) was structured from a large survey with more than 1100 participants, including professionals, patients and healthy people (Bergner et al., 1981; Damiano, 1996). As for Nottingham Health Profile (NHP), health items were obtained from 769 participants describing the effects of ill-health (Hunt et al., 1985).

1.2.3.3 HRQoL construct taxonomy in the thesis

HRQoL is a complex concept due to its multidimensionality. Previous attempts were made to define taxonomies for the construct of HRQoL (Fries, 1991; Valderas and Alonso, 2008; Erickson et al., 2009), but there is no agreement on one single framework. Terms including domain, dimension, facets, item are used differently in different descriptive systems of HRQoL measures. For example, PROMIS framework contains “broad aspect”, “domain/component” and “item” to depict the hierarchy construct of HRQoL (Cella et al., 2010), while WHOQOL refers to “domain” and “facet” as the main component and the sub-component in their description (WHOQOL Group, 1995). There are plenty of studies using those terms interchangeably without giving a clear definition (Ware and Sherbourne, 1992; Wilson and Cleary, 1995; Fitzpatrick et al., 1998).

In order to be clear and to maintain a consensus throughout the thesis, a construct taxonomy, indicating the conceptual hierarchy of HRQoL is defined as follows: top-level (Health domain), second-level (Health sub-domain), third-level (Health dimension), fourth level (Health item).

Figure 1-4 is an example to show the defined component structure of health.

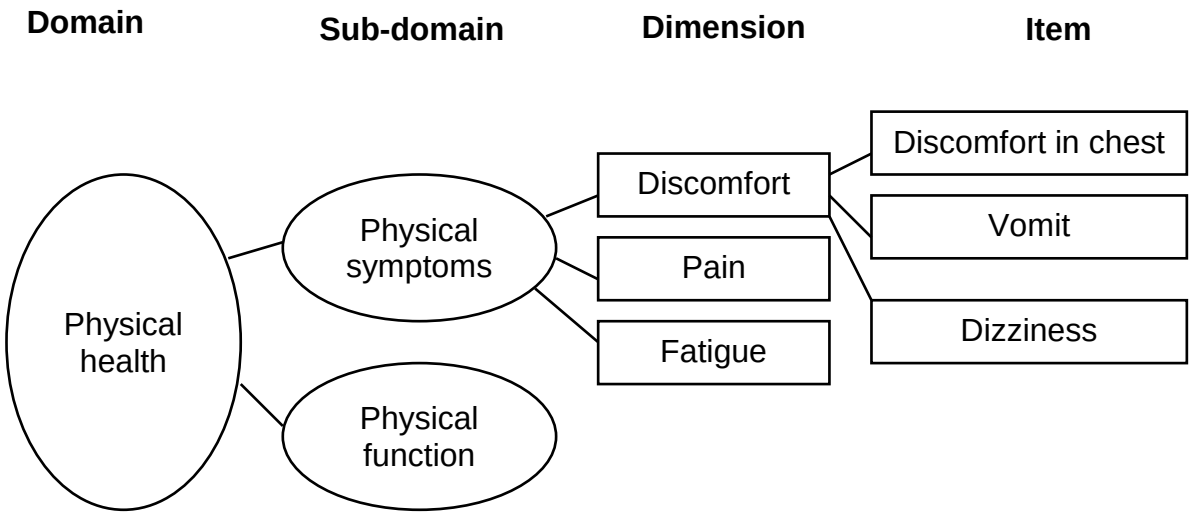


Figure 1-4: Component structure of health

"Health domains" refer to categories on the top level in the classification system to represent broadest components of health. For example, the WHO's definition of health introduced three aspects of health: physical, mental and social. It provides a general classification of health and the three aspects are regarded as domains in this report. Similarly, the broadest categories in the Wilson-Cleary model includes symptom status and functional status. They are then regarded as "health domains" in the thesis.

Inside health domains, health, as a concept, can be further divided into "sub-domains" when necessary. For instance, the domains in the Wilson-Cleary model can be categorised into physical symptom, psychological symptom, physical function, cognitive function, social function and role function.

"Health dimensions" are regarded as sub-components of sub-domains and represent more specific areas. Take the subdomain of "physical symptom" as an example, symptoms including discomfort, pain and fatigue are called health dimensions in the thesis.

Lastly, "health items" are with even narrower focuses compared to health dimensions. They are considered as specific examples representing certain aspects for health dimensions.

1.2.4 Quality of HRQoL measures

The quality of an HRQoL measure largely decides if it is to be practically useful. A higher-quality measure is more likely to reflect the actual health status of individuals and provide clinically valuable data. Because HRQoL is not measured using objective physical ways, the quality of HRQoL measures is assessed by so-called “psychometric properties” (McDowell, 2006; Bowling, 2014a). Psychometrics are associated with subjective judgements where objective physical measurement is not available to measure the thing that of interest (McDowell, 2006). Primary evaluative criteria of psychometric properties include validity and reliability. (McDowell, 2006; Fayers and Machin, 2013; Bowling, 2014a)

Validity is the extent to which an instrument measures what it is supposed to measure. It can be categorised into three types: content validity, construct validity and criterion validity (Streiner et al., 2014). Validation tests normally start from assessing content validity (McDowell, 2006). A valid measure is supposed to reflect an explicit and accepted definition of health (McDowell, 2006). More specifically, content validity concerns if a measure covers all important and relevant content to be measured and if the content all makes sense. Construct validity carries a more quantitative form and can be assessed by observing relationships between a construct and other variables. For example, a highly correlated association is expected if two measures are designed to measure theoretically similar things (convergent validity); in contrast, a low correlation should be detected when two measures are relatively unrelated (discriminant validity) (Fayers and Machin, 2013). Criterion validity involves testing a measure against another instrument that is supposed to be “a gold standard” (McDowell, 2006).

Reliability is a psychometric property of the overall consistency of a measure. It generally tests whether a measure can produce repeatable results if they are applied at a different time (test-retest reliability) or by different raters/interviewers (inter-rater reliability). It also examines internal consistency by checking item-item, item-total and split-half relationships (internal reliability) (Fayers and Machin, 2013; Bowling, 2014a).

There are other frequently mentioned evaluative criteria in assessing the quality of an HRQoL measure, including responsiveness (whether a measure is able to identify changes in an individual's health status when it improves or deteriorate), interpretability (whether the scores of a measure are meaningful and understandable), acceptability (whether a measure is accepted by respondents) and feasibility (whether a measure causes too much burden or disruption for interviewers or practitioners) (Fitzpatrick et al., 1998; Bowling, 2014a; Francis et al., 2016)

1.2.5 Translation and adaptation of HRQoL measures into other languages

Early review study suggested that most HRQoL measures are originally in English and are intended to apply to English-speakers (Guillemin et al., 1993). Well-developed English measures are often translated into other languages for use worldwide (Bowden and Fox-Rushby, 2003; Acquadro et al., 2008). One possible explanation is that developing and validating a new HRQoL measure can be time-consuming. Translating available HRQoL measures can facilitate researchers in non-English speaking countries to conduct HRQoL studies. Another reason for introducing HRQoL to other countries or cultures is that researchers are interested in doing cross-country/culture comparative studies by using the same HRQoL measure, in different languages though. Additionally, researchers tend to trust and apply those English HRQoL measures that are supported by accumulated evidence of validity and have already been recognised widely.

Various guidelines or methods offer recommended practice of translating/adapting an HRQoL measure from one language to another (Hunt et al., 1991; Guillemin et al., 1993; Bullinger et al., 1993; Ware et al., 1995; Scientific Advisory Committee of the Medical Outcomes Trust, 2002). A review study showed that most translation guidelines suggest having forward and backward translation in order to attain satisfactory quality (Acquadro et al., 2008). It is also commonly emphasised that pretesting a translated HRQoL measure in the target culture would be crucial in fulfilling the adaptation objective (Rahman et al., 2003; Swaine-Verdier et al., 2004). In addition, similar to those original HRQoL

measures, translated ones should be examined in terms of their psychometric properties (Lohr et al., 1996; Valderas et al., 2008; Mokkink et al., 2010; Reeve et al., 2013). In practice, psychometric validation tests are widely covered and reported by those studies that translated/adapted HRQoL measures (Bowden and Fox-Rushby, 2003).

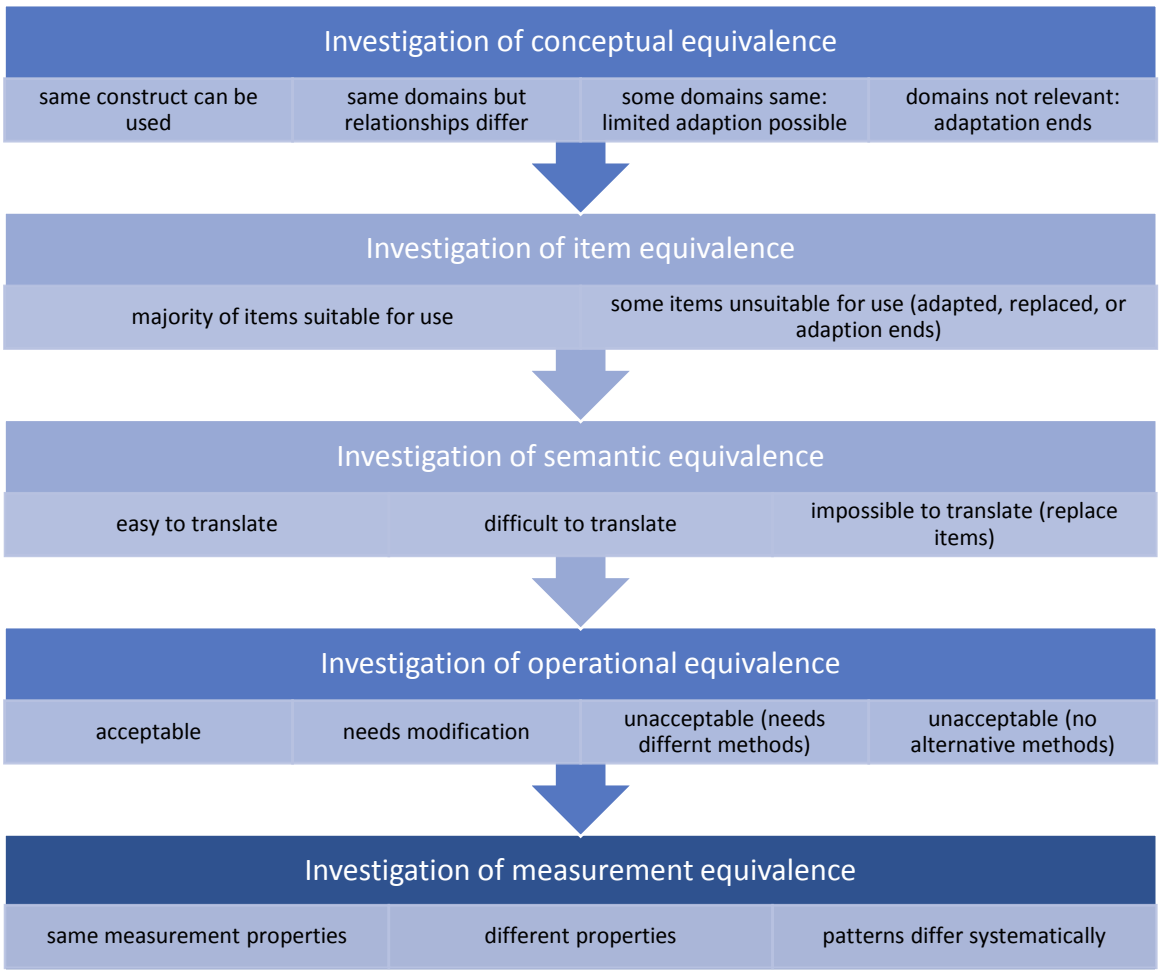
However, translating HRQoL measures into other languages for use in different countries or cultures has some limitations (Guillemin et al., 1993; Herdman et al., 1998; Stewart and Napoles-Springer, 2000; Bowden and Fox-Rushby, 2003). Guyatt summarised several arguing points. First, it is concerned that the content of an original HRQoL measure can be unclear. There might be duplicated, ambiguous and other wording issues, making it is difficult for the measure to be translated. The second difficulty is that some items cannot be translated well into another culture, while some items cannot be translated at all. It is also argued that items that are important in one culture may not be necessarily important in another culture, but including trivial items or excluding important items in countries of a new language would violate content validity (Guyatt, 1993).

It has been discussed earlier in this thesis that health is a culturally relevant concept (Section 1.1.1) and health measures are developed based on certain health concepts (Section 1.1.2). Assuming culture A has markedly different health concepts compared with culture B, it is possible that HRQoL measures developed in culture A cannot offer comprehensive or relevant items for measuring health in culture B. As a result, the measures can be inappropriate to measure HRQoL in the target cultural setting after being translated. More specifically, HRQoL measures that were developed in a Western cultural setting contain health items that are relevant and important in the Western setting, but those items may not be necessarily relevant or important in other cultures (Parker and Fox-Rushby, 1995).

From this perspective, the equivalence of health concepts should be taken into account before translation or adaptation commences. The argument is supported by Herdman and colleagues, who proposed a model showing the process of assessing cross-cultural equivalence in HRQoL measures (Herdman et al., 1998). As it is shown in Figure 1-5 below, the assessment model starts from

investigating conceptual equivalence, before the quality of translation and psychometric properties are examined. According to this model, before adapting an HRQoL measure to a target culture, first and foremost, it is essential to test whether the major domains of health are similar between the HRQoL measure's original culture and the target culture (conceptual equivalence). Then, it comes to "item equivalence" to check whether the items covered in each domain are comparable between the two cultures. Semantic equivalence is then examined to assess the quality of translation. The fourth step is to make sure the measurement methods are appropriate in the target culture (operational equivalence). Subsequently, measurement equivalence is required to test the translated measure's psychometric properties, before an overall assessment of equivalence between two cultures is conducted to reveal functional equivalence (Herdman et al., 1998).

Figure 1-5: Model for assessing cross-cultural equivalence in HRQoL measures, adapted from (Herdman et al., 1998)



In reality, however, few studies have considered cultural differences in concepts when assessing equivalence between an original HRQoL measure and a translated version (Geisinger, 1994; Stewart and Napoles-Springer, 2000; Bowden and Fox-Rushby, 2003). It was reported that limited validation studies have covered tests of content validity while most of them focused on statistical psychometric property assessments (Bowden and Fox-Rushby, 2003). As it is shown in Figure 1-6, assessing translated HRQoL measures normally concentrate on examining psychometric properties (Geisinger, 1994; Stewart and Napoles-Springer, 2000). If a translated HRQoL measure shows satisfactory psychometric properties in validation tests, the study will often draw a conclusion that the measure is valid and reliable. If the psychometric properties are tested to be unsatisfactory, conceptual equivalence will then be considered to explain the results. This approach has the risk of giving biased results because it fails to consider the fundamental conceptual equivalence in the first place (Stewart and Napoles-Springer, 2000).

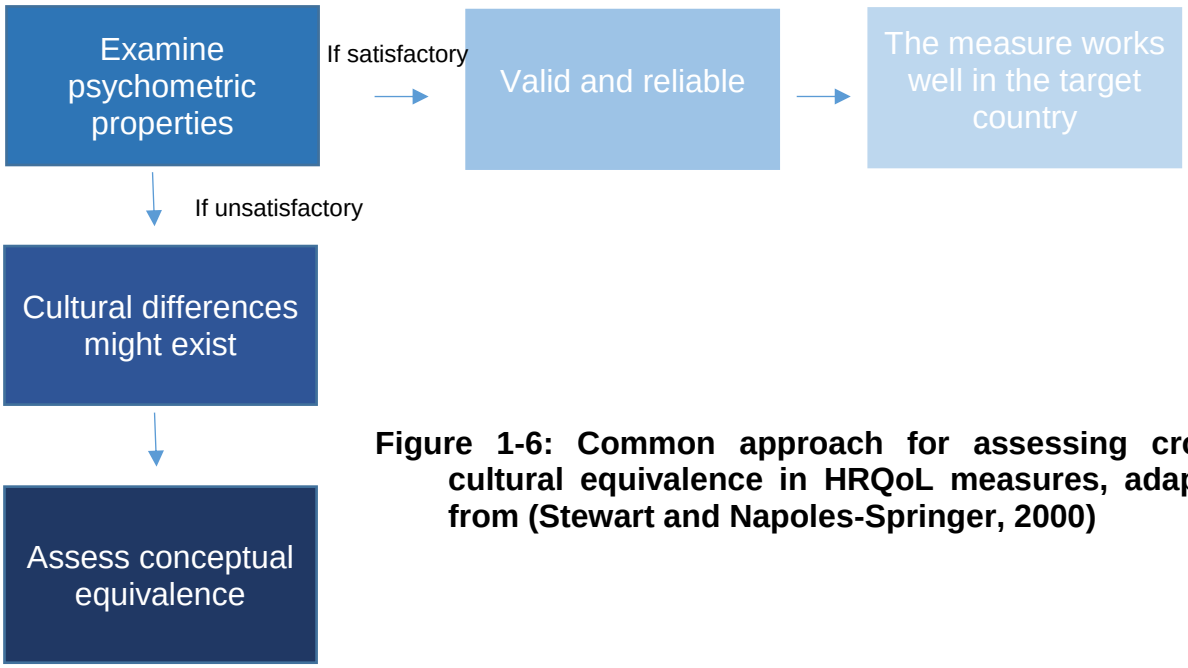


Figure 1-6: Common approach for assessing cross-cultural equivalence in HRQoL measures, adapted from (Stewart and Napoles-Springer, 2000)

1.3 The use of Western-developed HRQoL measures in a Chinese cultural setting

1.3.1 Chinese culture and potential cultural differences between China and the West

Culture is a complex concept that can be defined variously. One of the possible definitions is to understand culture as “the shared patterns of behaviours and interactions, cognitive constructs, and affective understanding that are learned through a process of socialization. These shared patterns identify the members of a culture group while also distinguishing those of another group” (The Center for Advanced Research on Language Acquisition, 2019, p.1).

In this thesis, it is assumed that there is a cultural environment that the Chinese people inhabits. This assumption was made on the grounds that despite China is a vast country with 56 ethnic groups, the Han ethnic group constitutes around 92% of the entire Chinese population (National Bureau of Statistics of the People’s Republic of China, 2011), while the Han majority group has been widely believed to form the mainstream Chinese culture through the Chinese history (Wu, 1991; Jia et al., 2012). Additionally, Chinese people from different regions and ethnic groups have also been migrating from one place to another, living together and interacting with each other through ages which can lead to cultural integration (Wu, 1991). Except for the spontaneous cultural exchanges during migration and communication, political power has also deepened the cultural fusion among Chinese ethnic groups (Ding and Saunders, 2006). For example, as early as in the Qin-Dynasty, the Chinese writing system was unified across the whole country by the emperor, which helped to unify Chinese culture for thousands of years (Wang, 2012). In the modern age, Chinese is still often treated as one single language with different dialects in different regions, while the same writing language is used among Chinese people (Wang and Sun, 2015). In this thesis, Chinese populations are thus treated as a single identity and are assumed to have shared patterns of behaviours and thinking that can distinguish them from the Westerners. The Chinese populations are supposed to have common social beliefs, traditional ideas and attached values. Those common beliefs and values are believed to be shared among Chinese people and are considered to be

different from those in other societies. A Chinese cultural setting is defined as such kind of environment where Chinese cultural values are produced and held.

It is a distinguished natural and social environment that helps Chinese cultures to become a unique image with distinct characteristics. The land of China is guarded by the Pacific Ocean in the east and fences of mountains in the northeast and the southeast (see Figure 1-7), giving China an isolated hotbed for its own civilisation (Chen, 2000).

Figure 1-7: China topography map (China Maps Org)

Apart from the natural environment, social environment, which is mainly determined by the economic foundation, has greatly influenced the creation and development of Chinese cultures. China has been commonly referred to as the country with the longest continuous history that could be dated back to about 4100 years ago (Xia Dynasty). Along with the long history, agriculture has been regarded as “a motive force in the development of Chinese civilization” (Mote, 1989, p.3). Ancient sayings like “food is the sky for people” (民以食为天) and “agriculture is the basis of a country” (国以农为本) emphasise the important role

that agriculture plays in Chinese society. It is believed that agriculture is a leading factor in the traditional Chinese economy, therefore a great influence of agriculture on culture is expected (Mote, 1989). For example, Chinese people tend to be hardworking and pragmatic and that is consistent with the requirement of agricultural production where “no pain, no gain” (Chen, 2000, p.25).

The special natural and social environment shapes Chinese cultures, including language, customs, beliefs, habits and traditions, to be unique. It is commonly believed that Confucianism has been an orthodox ideology since the Han Dynasty. Confucianism helped the Chinese ruling class to bind people’s behaviours, maintain the social order and better govern the country in the dynasties of ancient China. It created the three Cardinal Guides (ruler guides subject, father guides son, husband guides wife) and the Five Constant Virtues (benevolence, justice, ceremony, wisdom and credibility) (Chen, 2000). These Guides and Virtues to some extent shape some features of Chinese nationality, such as respecting their elders, revering higher authority, valuing social morals and being more likely to be obedient (King and Bond, 1985). To date, most of the Confucian doctrines continue to be regarded as a core of Chinese traditional culture and keep influencing Chinese communities from generation to generation (Billioud, 2007; Fan, 2011).

Cultural differences between China and the West can be demonstrated in various ways. Since Chinese cultures are greatly affected by the Confucianism (Chinese Culture Connection, 1987), Chinese people tend to respect the experience passed down by their ancestors and to be seen as less creative when compared with Westerners, whose practical wisdom and spirits of adventures benefited the establishment of modern science (Hofstede and Bond, 1988; Hofstede et al., 2010b). Additionally, Chinese people are more likely to be family-oriented: attaching great importance to family and having strong and close links with family members; while westerners tend to appreciate personal space and privacy most to pursue individual freedom and liberty (Bond and Yang, 1982; Rosenthal and Feldman, 1990; Lam, 1997). There are also different popular legends, fairy tales and common religious beliefs between China and the West. Another obvious difference is their completely different language systems – Chinese is based on ideographs, while English, along with most Western languages, is structured by

alphabets. The dissimilarity between the two languages not only causes problems for translation and adaptation from one language to another but also tends to affect individuals' perception and mental representations for the same concept (Schmitt, Pan and Tavassoli 1994).

1.3.2 The use of Western-developed HRQoL measures in China

HRQoL is fundamentally a foreign concept introduced to China from the West in the mid-1980s (Wang and Zhou, 1990). HRQoL research in China started from translating and introducing Western HRQoL measures (Fang, Wan and Hao, 2000). Although it has been frequently argued that Western HRQoL measures may not be appropriate for use in a Chinese cultural setting due to cultural differences (Fang et al., 2000; Sun, 2001; Gao et al., 2000), a growing number of studies have used Western HRQoL measures among Chinese populations. Western HRQoL measure including HUI, QWB, SF-36 and EQ-5D have been translated into Chinese for use in HRQoL research among Chinese populations.

Despite the growing trend of using Western HRQoL measures, few studies have examined the content legitimacy of those Western HRQoL measures for use in a Chinese cultural setting. As cultural differences between China and the West are expected as presented in Section 1.3.1, health concepts, which are embedded in Western-developed HRQoL measures, might not be the same as that in a Chinese cultural setting.

The legitimacy of applying Western-developed HRQoL measures in China have been questioned. For example, a study found HRQoL measures performed inconsistently between Chinese and white Canadians (Leung et al., 2007). Compared with white Canadian counterparts, Chinese participants reported better health status using EQ-5D, but at the same time, rated fair or poor health more often using a self-perceived physical and mental wellness questionnaire, which was developed by the researchers themselves. The researchers explained that such inconsistency may be caused by the different self-perceptions of health between the two ethnic groups (Leung et al., 2007). Similarly, a comparative study using SF-36 reported insufficient internal consistency and unsatisfactory item-to-scale correlation in the Chinese dataset, while the Dutch data did not have the same problems (Cnossen et al., 2017). The authors raised a concern that

there might be differences in the conceptualization of some of the SF-36 subscales between Dutch and Chinese people (Cnossen et al., 2017). It was also discussed by a paper that the cross-cultural equivalence of HRQoL measures should be further investigated since they found ethnic Chinese were more likely to endure health problems than other ethnicities (Wang et al., 2015b).

1.4 Problems of applying Western-developed HRQoL measures in China: EQ-5D as an example

The first official Chinese version of EQ-5D for mainland China was approved in the year 2003 (Selai and Rabin, 2003). The Chinese versions of EQ-5D have been widely applied to various health studies including general population studies and patient-specific studies (Zhou et al., 2016a; Zhou et al., 2016b). China National Health and Family Planning Commission, which is the Chinese national health department, has also included EQ-5D in the Chinese National Health Services Survey since 2008. The widely used Western HRQoL measure EQ-5D can be treated as one possible, popular way of how Western scholars defined health. EQ-5D has become a dominant generic measure in HRQoL research among Chinese populations due to its simple and easy-to-operate features (Zhou et al., 2016b) and in this thesis, it is taken as an example to further discuss the problems of applying Western-developed HRQoL measures in China in more detail.

1.4.1 An overview of EQ-5D

EQ-5D is one of the most widely used generic HRQoL measures (Rabin and Charro, 2001). It provides a descriptive health profile (The EuroQol Group, 1990) and an overall health status index for individuals (Brooks, 1996). It is a standardised measure that can be applied in population health surveys and in the clinical and economic evaluation of health care (Rudmik and Drummond, 2013).

The measure is presented as a questionnaire including two parts: the EQ-5D descriptive system and the EQ visual analogue scale (EQ-VAS) (Herdman et al., 2011). The descriptive system consists of five dimensions relating to health: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

These five dimensions were considered to represent “a basic ‘common core’ of QoL characteristics which most people are known highly” (Williams, 2005, p1) and to be of relevance to all groups of patients as well as the general population (Gudex, 2005). Each dimension has either 3 response levels – no problems, some problems, extreme problems – in the EQ-3D-3L version or 5 response levels – no problems, slight problems, moderate problems, severe problem, and extreme problems – in the EQ-5D-5L version. Respondents are asked to rate his/her health state by choosing the most appropriate level in each dimension then indicate their overall health on the EQ-VAS, between 100 (best imaginable health) and 0 (worst imaginable health).

The widespread application of this HRQoL measure is credited to its distinct advantages. It enables health status and those changes in health status to be quantified by constructing a five-dimension health profile with a single index score (Kind, 1996). It can be applicable to the general population, a wide range of patient groups and various health service treatments (The EuroQol Group, 1990). Another advantage of EQ-5D is that it is simple to use and imposes little burden on respondents. It only contains a few questions that are relatively undemanding for respondents to answer and only takes a few minutes to complete (The EuroQol Group, 2015).

EQ-5D was developed by a group of European researchers from Finland, Norway, Sweden and the UK (The EuroQol Group, 1990). The five dimensions of EQ-5D were selected from a detailed review of the descriptive content of previous health status measures, based on researchers’ expertise and evidence from the literature (Kind, 1996; Gudex, 2005). The original version of EQ-5D is in English and have been translated and adapted into more than 170 languages for use worldwide (Brooks et al., 2003).

To ensure to provide high quality of translations of EQ-5D, the EuroQol Group has designed a rigorous, multi-step approach to produce various language versions of EQ-5D (Rabin et al., 2014). The “full translation” approach consists of forward translation, back translation and pilot testing of a provisional translated version. When an existing language version is available, to adapt the existing language version to another country speaking the same language, a “modified

translation" procedure is used in which the available language version is reviewed before being pilot tested; for example, the Spanish version of EQ-5D for use in Argentina was produced from the Spanish version for use in Spain in a modified translation procedure. It seems that both the full translation approach and the modified translation approach emphasised the quality of the translation in order to reach the semantic equivalence between the original English version of EQ-5D and the translated version. Limited attention has been paid to address the conceptual equivalence issue of the translated EQ-5D for use in the target culture in those procedures.

1.4.2 The translation/adaptation of EQ-5D in China

The translation and adaptation of EQ-5D into Chinese followed a modified translation procedure involving "in-country review" (reviewing an available Taiwanese version of translated/adapted EQ-5D) and pilot testing with lay Chinese people (Selai and Rabin, 2003). Although the researchers of the adaption project addressed their concern on "conceptual equivalence" at the beginning in their report, they failed to cover adequate discussion over this issue. Their study recruited eight lay Chinese respondents for pilot testing and mainly asked questions relating to the clarity and length of the translated version of EQ-5D, without examining the content of the descriptive system. As they reported, the open-ended questions were "Is it (each question in EQ-5D) globally clear, easy to understand, easy to answer?", "Is it too long?" and "Are the instructions clear?" (Selai and Rabin, 2003, p.42). It shows that the researchers focused on the translation and wording issues, instead of probing whether the questionnaire items were complete or appropriate for measuring health. The Chinese version of EQ-5D-5L was translated following the English version was developed (Luo et al., 2013). Again, the development process focused on wording and labelling and did not include tests of content validity.

A diverse range of validation studies for the EQ-5D Chinese version has been conducted. Some of them tested psychometric properties of EQ-5D in a Chinese general population (Wang et al., 2005; Wang et al., 2012; Xing and Ma, 2013; Wu et al., 2016). Some examined it among various disease populations including cancer (Gao et al., 2009), type 2 diabetes (Zhu and Shen, 2014; Wang et al.,

2015c), systemic lupus erythematosus (Wang et al., 2014), hepatitis B (Jia et al., 2014) and many more. Generally speaking, these studies focused mainly on statistical tests, examining psychometric properties such as construct validity, reliability, and responsiveness, while few studies have discussed conceptual equivalence issues. Most of them drew a conclusion that EQ-5D was valid and reliable to be applied in China, based on satisfactory statistical results produced.

1.4.3 Problems of applying EQ-5D in China

Although there is an increasing trend in adopting EQ-5D in Chinese health research, problems come along with its application. A high ceiling effect is one of the most notable problems when applying EQ-5D in China. In EQ-5D general population studies, high numbers (>80%) of Chinese respondents reported that they were in good health with no problems (Wang et al., 2005; Sun et al., 2011; Tan et al., 2013; Wu et al., 2016). The result suggests EQ-5D may be unable to identify differences in health levels for a significantly large number of people in China (Sun et al., 2015). The ceiling effect of EQ-5D in China (87% in the national population study in the year 2008) was much higher compared with European countries like UK, Sweden, and Germany where the proportions reporting no problem were 45%, 42%, and 66% respectively. It may be because Chinese people are generally healthier than people living in the West, but this explanation is contradicted by data showing poorer life expectancy, mortality or morbidity in China. A more reasonable hypothesis is that the cultural differences between China and the West make the European-born HRQoL measure less effective.

EQ-5D was also found to be less sensitive in detecting differences in health status (Zhao et al., 2010; Yang et al., 2018). The relatively poorer ability to detect differences might be because EQ-5D does not cover enough health dimensions or does not have enough response options (Zhao et al., 2010). Additionally, its test-retest reliability is also questioned by Chinese studies. Fang and colleagues pointed out that it may be because many Chinese people, especially people in rural areas, found it difficult to understand EQ-5D (Fang et al., 2016). They found more than 30% of respondents reflected difficulties in completing the questions of EQ-5D during a face-to-face interview. Furthermore, a pilot study on EQ-5D translation was conducted by the author of this thesis, reporting that Chinese

participants interpreted the five dimensions of EQ-5D differently and some participants had difficulties in understanding some of the questions[1].

Various studies examined measurement equivalence of the Chinese version of EQ-5D, providing findings on its psychometric properties in China. However, few studies have considered EQ-5D's conceptual equivalence in China. As it was reported by Wang et al. (2015a), who reviewed the use of EQ-5D in Chinese general populations, few content validity tests had been conducted. Without knowing if EQ-5D is of conceptual equivalence in China, evidence on construct validity, reliability and responsiveness is likely to be biased and might not be of great value. If the five dimensions are found to be not relevant or comprehensive to measure health in China, it can be argued that EQ-5D does not work in the Chinese culture environment, as it may fail to ask the most appropriate and important questions among a Chinese population in assessing health.

[1] The pilot study was presented as a poster in the 2017 EuroQol Academy Meeting in Noordwijk, the Netherlands. The poster can be found in Appendix X.

Chapter 2 Research objectives and study design

2.1 Research objectives

In Chapter 1, the legitimacy of using EQ-5D in Chinese populations was questioned. Since few studies have addressed the content validity of EQ-5D in a Chinese cultural setting, a question was raised: “Does EQ-5D work in China?” The question comprised two levels of inquiry. The first level required a direct assessment of the descriptive system of EQ-5D: to check to what extent EQ-5D is accepted by Chinese people in assessing their health. The second level was considered to be more in-depth: to investigate how health is described in China to compare the Chinese way of describing health with the EQ-5D descriptive system. By examining the content legitimacy of the Western HRQoL measure, cultural differences between China and the West in defining and measuring health can be explored.

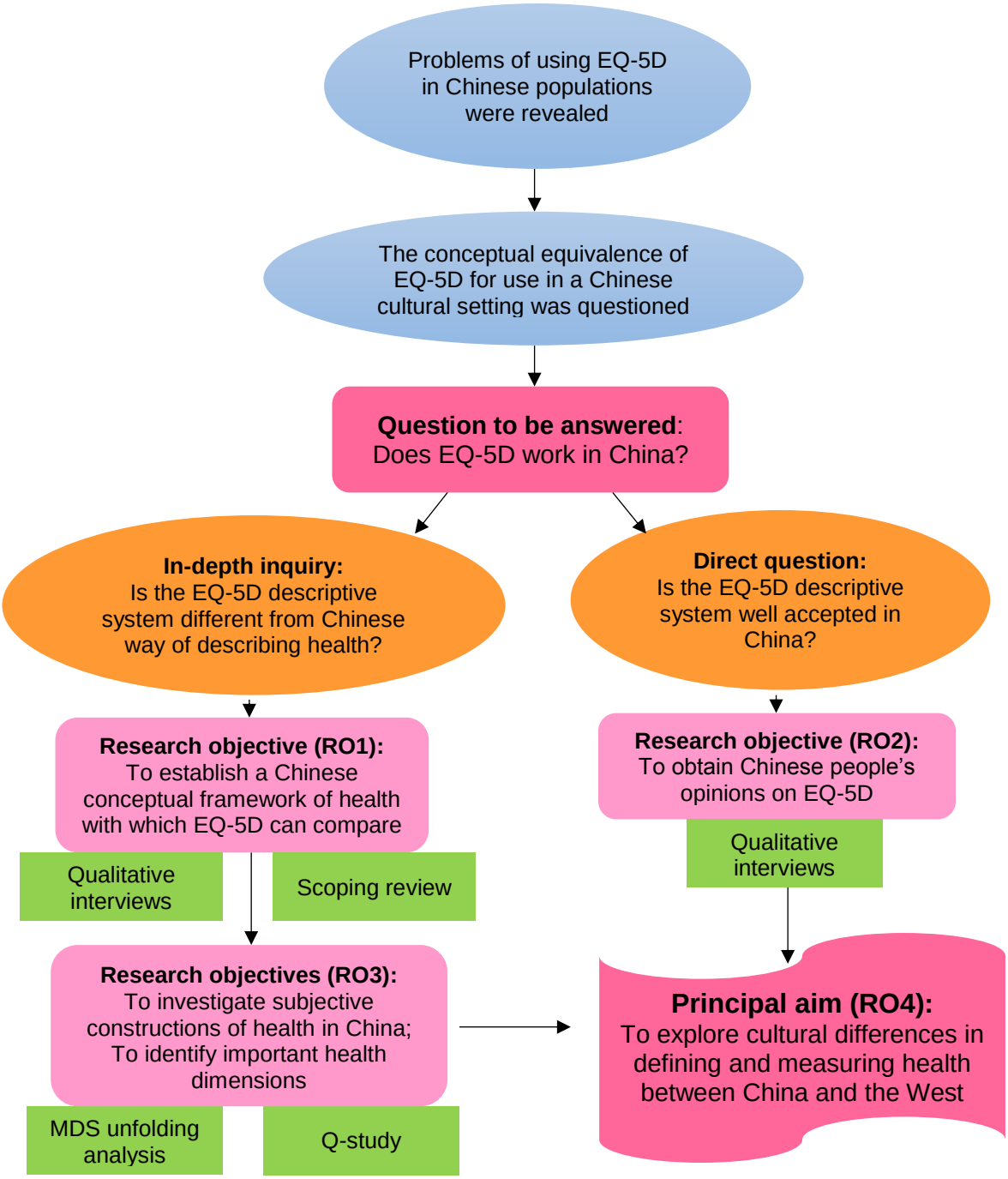
A research project was then developed and the research objectives (RO) to be fulfilled were planned as follows:

1. To establish a conceptual framework of health that can summarise how health is described and measured in a Chinese cultural setting (RO1);
2. To test the legitimacy of the widely used Western HRQoL measure EQ-5D for use in China (RO2);
3. To understand subjective constructions of health in China and to identify health dimensions that are most important in a Chinese population (RO3);

By fulfilling the three specific research objects, eventually, this research project wanted to explore potential differences in defining and measuring health between China and the West (RO4).

The thinking process of how the research objectives were designed is drawn in Figure 2-1.

Figure 2-1: The thinking process of setting the research objectives



2.2 Study design

A series of studies were conducted to fulfil the research objectives.

First, a scoping review of Chinese-developed HRQoL measures was conducted to summarise how health is measured in the Chinese literature. It helped to

establish a preliminary conceptual framework of health in China (RO1). The study is reported in Chapter 3.

Second, a series of qualitative interviews were performed to explore how lay Chinese people understand health and to refine the preliminary conceptual framework (RO1). The qualitative study also investigated the content validity of the descriptive system of EQ-5D (RO2). The study is documented in Chapter 4.

The third study was a Q-methodological investigation. It provided insights into Chinese lay participants' understandings of health (RO3) and is presented in Chapter 5.

The fourth study used a multidimensional unfolding technique to identify health dimensions that are considered to be most important (RO3). The analysis process and results are shown in Chapter 6.

The four studies together showed how health can be defined and measured differently in China, compared to that in the West (RO4). This is stated in the final discussion chapter in Chapter7.

Chapter 3 Chinese-developed HRQoL measures: a scoping review

3.0 Summary

This chapter documents a scoping review of Chinese-developed HRQoL measures. The scoping review attempted to identify currently available HRQoL measures that were developed in a Chinese cultural setting. Afterwards, a qualitative thematic analysis was conducted to categorise and summarise the content of those HRQoL measures. It enabled to establish a conceptual framework summarising content that may be important in HRQoL assessment in China. By comparing the conceptual framework with the descriptive system of a Western-developed measure EQ-5D, potential differences between China and the West in measuring health were preliminarily explored.

3.1 Background

3.1.1 "Health" in the Chinese language

The Chinese translation for health is a two-character word "健康" (Jian Kang). According to the Xinhua Dictionary, the principal meaning for the word "健" (Jian) is strong; good body. While the second character "康" (Kang) literally means peaceful and happy. The combined word "Jian Kang" shows that the Chinese expression of health conveys a positive meaning and can be interpreted that it is related to both physical and mental conditions. From the physical aspect, health is a state when the body is strong, vigorous and in a sound condition. Adding to physical fitness, being health simultaneously requires that the mental state should be with peace and happiness.

Health as a concept in China has different expressions and is of various meanings. Given the awareness of its importance, a number of Chinese studies attempted to define and describe health. The majority of the published studies were non-empirical, theoretical studies, where scholars described their

understandings of health by reviewing existing definitions and relevant studies or utilising their own expertise. One of the most frequently cited definition is that of WHO, which divides the concept of health into physical, mental and social aspects (World Health Organization, n.d.). This definition has been widely recognised in the Chinese academic field, where a large number of studies introduced or referred to this definition (Xue, 1985; Li, 2008; Ke, 2010; Li and Zhou, 2012). It has also been successfully applied to the Chinese health care industry and has been regarded as a standard way of defining health in China (Zhang, 1987; Zhang et al., 2015).

Despite the widespread use of the WHO health definition, its practical value has been questioned in China. Similar to what has been criticised in the West, some Chinese scholars argued that because the state of complete well-being is hard to reach or sustain, the definition is not suitable to be applied in practice (Liu et al., 2010). In their opinion, health should be defined by considering each individual's body constitution, age and their external environment. Different standards of being in good health should be applied to different people (Liu et al., 2010). Comparably, some researchers presented a holistic view of health by referring to Chinese traditional religions including Confucianism, Buddhism and Taoism, as they described connections between holism and these Chinese traditional religions (Zhang et al., 2015). These studies offered new insights into the concept of health in China; however, their discussions were purely theoretical with no empirical evidence supporting their arguments.

Chinese papers on the concept of health are predominantly theoretical and rarely collect data with members of the general population. One study applied self-designed surveys to probe Chinese people's understandings of health and found that different age groups and gender groups held significantly different prime concerns for health (Huang et al., 2011). Another study used qualitative techniques to explore the understandings of health among Chinese people (Wang, 2001). The author presented the multidimensionality of health as a concept; meanwhile, he also highlighted the influence of Chinese culture in structuring people's views of health. Apart from these two studies, few in the literature has empirically surveyed the understandings of health among the

Chinese general population. The limited number of empirical studies showed the lack of exploration of the meaning of “health” in lay Chinese people.

3.1.1.1 A holistic concept of health in traditional Chinese knowledge

It seems to be widely agreed that a holistic concept of health is conveyed by traditional Chinese knowledge (Spector, 2004; Wu and Lai, 2007; Liu et al., 2007; Wu et al., 2007; Zhang et al., 2015). There are old sayings, such as “Balance of Yin and Yang”; “Unity of body and spirit” and “Harmony between man and nature”, indicating such holistic view of health (Zhao et al., 2004; Zhang et al., 2015). The expressions view a human body as an integral system and integrate an individual with his/her external environment when depicting what health is (Spector, 2004).

Balance of Yin and Yang

Balance of Yin and Yang (阴阳平衡) has been used to describe health for over 3000 years (Wang, 2012; Ni et al., 2014; Zhang et al., 2015). The theory of Yin and Yang was illustrated in the book *Yellow Emperor’s Classic of Internal Medicine,* which is believed to be the oldest extant written work of Chinese medicine. In the theory, Yin and Yang are two contrary forces which can be integrated together properly to reach a harmonious state. Yin is normally understood as a negative force and is linked with darkness, coldness, inwardness and decrease; while Yang is a positive force and is associated with light, heat, outwardness and increase (Kaptchuk, 2000). The theory explains that everything has two aspects – a Yin side and a Yang side. It views all things as parts of a whole: “*No entity can ever be isolated from its relationship to other entities; no thing can exist in and of itself*.” (Kaptchuk, 2000, p.8). For example, increases in temperature are always followed by decreases and such regular increases and decreases divide a day into day-time and night-time and separate a year into four seasons.

The Yin and Yang theory presents a holistic idea in defining health, by implying that the human body is a unified system, where all parts of a body are associated with each other (Li, 2015). The inner body is Yin, while the surface is Yang; the front body is Yin, while the back is Yang; “Fu” organs (gallbladder, stomach, intestine, bladder and lymph system) are Yin“, while Zang” organs (heart, liver,

lung, spleen and kidney) are Yang (Spector, 2004). Yin and Yang should be balanced in one's body to reach a harmonious state to be in good health. It is explained in *Yellow Emperor's Classic of Internal Medicine* states that *"The key to mastering health is to regulate the yin and the yang of the body. If the yin and yang balance is disrupted, it is like going through a year with spring but no winter, or winter but no summer … Only when the yin remains calm and harmonious will the yang qi be contained and not be overly expansive, the spirit normal and the mind clear." (阴平阳秘，精神乃治) (Ni, 1995, p.11).*

This theory is widely applied in TCM practice (Tang et al., 2008). The idea that Yin and Yang create each other, control each other, transform into each other guides TCM practitioners to observe, identify, prevent and treat diseases (Zi, 2012). It is believed that an occurrence of diseases is because of an imbalance between Yin and Yang, which brings about pathological changes and affects one's energy, blood and viscera (Spector, 2004). The treatment strategy should be to re-establish the equilibrium between the two forces (Torsch and Ma, 2000; Chen, 2001; Cnossen et al., 2017). For example, fever is regarded as a Yang condition (a body with an excess of Yang) that needs the consumption of Yin diets or herbs to reobtain the balance between Yin and Yang (Ludman and Newman, 1984).

Unity of body and spirit

Similarly, "the unity of body and spirit" (形神统一) expresses a sense of coherence by considering the physical body and the spiritual aspect of life at the same time. It is written in the *Yellow Emperor's Classic of Internal Medicine* that "*(For) people … (who) ate a balanced diet at regular times, arose and rested at regular hours, avoided overstressing their bodies and minds, and refrained from overindulgence of all kinds … (they, therefore) maintained wellbeing both in the body and in the spirit"* (Ni, 1995, p.1) According to the saying, maintaining physical fitness as well as good spirit simultaneously is a good sign. The two elements jointly form a state of good health (Ni et al., 2014).

It is described by Chinese scholars that "body" stands for the physical being of humans, including all the limb, bones, organs and muscles (Zhang et al., 2015).

While “body” is regarded as something that exists objectively, “神” (spirit) does not have a physical form (Hsu, 2000). The term “神” (spirit) here is an exclusive concept in traditional Chinese knowledge and is difficult to find a conceptually equivalent word in other languages (Yang, 2004). “神” (spirit) is considered to be the thing that can master of all life activities, including physical and mental activities, in the Chinese language (Zi 2012). Because of the existence of “spirit”, there are signs of life. As it was explained by the *Yellow Emperor’s Classic of Internal Medicine, “When there is spirit, the prognosis is positive. When the spirit is gone, the condition is very grave”* (Ni 1995, p.149).

"神” (Spirit) is intangible and can be understood as the non-physical part of a person. Therefore, in this sense, “spirit” is chosen to represent "神” in English in this thesis. However, because “spirit” in the Western literature is defined as a soul, a state of mind or an attitude, this English word cannot fully reflect what "神” is defined in the Chinese language. In a broad sense, as it was covered in the last paragraph, "神(spirit)” is understood as the thing that can dominate the life process of each individual human being (Kaptchuk, 2000). In a narrower sense, "神(spirit)” is referred to the external manifestation of one’s life activities (Hsu, 2000), including people’s consciousness, mind, thoughts and/or vitality, emphasising on different meanings in different contexts (Liu and Fang, 2000; Rossi, 2007; Zi, 2012), because these things are dominated and controlled by one’s "神(spirit)”. It is illustrated in *Diagnostics in Chinese Medicine* that “having spirit” means “*one’s mind is clear, vision is bright, talking is clear, the complexion is glowing, the facial expression is natural, the response is quick, movement is agile, breathing is smooth and steady…”* (Deng and Guo, 1984, pp.10-11). Therefore, apart from translating this Chinese specific item as “spirit”, some want to keep a Chinese special form of this word and use its pronunciation in Chinese “Shen” to represent the phrase, some refer to it as “mind” and some understand it as “vitality” (Yang, 2004; World Health Organization, 2007; Pan, 2017).

Harmony between man and nature

Chinese traditional knowledge also explicitly emphasises one's relationship with his/her surrounding environment as an essential aspect of individuals' daily life. Maintaining harmony between man and nature (天人合一) has been an important saying in China (Shen, 1990). Because one's external environment is closely associated with his/her daily activities, a balance between the individual and external environment is crucial and an ability to adapt to changing circumstances is required in staying health (Zhang et al., 2015).

Again, the saying reflects the concept of holism. It points out connections between an individual and the environment he/she lives in, meanwhile, it highlighted the influences caused by external surroundings. Each person lives in a specific environment and is, in fact, a part of the environment. On the one hand, people may be able to change the environment. On the other hand, if the objective environment is less likely to be changed, it is believed that people should be capable of adjusting to such changes to reach a harmonious state. For example, going to bed early and getting up late in winter, while having a shorter sleeping time in summer is a good practice in China as a common sense. Because, from a traditional Chinese perspective, bedtime and getting-up time should be guided by sunset and sunrise and therefore should be accordingly changed to adapt to the seasonal variations. The idea of "maintaining harmony between man and nature" is also adopted by TCM practitioners, whose prescriptions of Chinese herbs are likely to be different in different geographic locations and in different seasons (He and Sun, 2014).

3.1.1.2 "Chinese-specific" health-related concepts

There are some concepts that are related to health and seem to be specific to Chinese culture. In this section, several "Chinese-specific" health-related concepts that have been frequently described by Chinese scholars and been widely used in a Chinese cultural setting are introduced.

Body Constitution

Body constitution has been closely associated with health among Chinese populations according to several studies (Lew-Ting et al., 1998; Chan and Chien, 2013). International Classification of Diseases 11th Revision (ICD-11) defines

“constitutions” as “the characteristics of an individual, including structural and functional characteristics, temperament, ability to adapt to environmental changes, or susceptibility to various health conditions” (World Health Organization, 2018). This concept was introduced by the TCM theory, which believes that “constitution” is a set of relatively stable personal characteristics. It is mostly formed by genes and largely affected by environmental factors. There are different types of body constitution such as Gentleness type, Qi-deficiency type and Yang-deficiency type (Wang, 2005). Because people have different types of body constitutions, their abilities to adapt to changes in temperature and their tendencies of having diseases tend to be various (Wang, 2005). It is thus important to know individuals’ body constitutions to aid in determining diagnoses and devising treatment plans from the TCM point of view (Wang, 2005).

“Constitution”, which literally means “body quality” in the Chinese language, was reported to be a widely accepted concept among Chinese communities in a study conducted by Lew-Ting et al. (1998). In their study, although some people explained “constitution” similarly as the official definition defined by ICD-11, most of the participants comprehended this term literally as “the quality of body”. They used words such as “good”, “excellent” and “bad” to describe one’s body constitution. The study also reported significant associations between the self-reported constitution and self-reported health: participants who believed they were with good constitution also gave relatively high self-rated scores. The findings showed that the term “body constitution” was well recognised among Chinese participants and might be a useful indicator for self-rated health among Chinese lay people.

“Sub-health”

As health carries completely positive meaning in the Chinese language, the phrase “sub-health” (亚健康) was raised in the 1990s to expand the meaning of health, because some scholars argued that there should be a state between being in (good) health and not being in (good) health (Wang, 2002). Sub-health can be understood as a state between being in good health and having diseases. It can be illustrated as a condition where a person does not show any negative clinical indicators in a physical examination but still experiences different kinds of

“sub-health” syndromes (Yuan et al., 2004; Jiang, 2010), including physical symptoms such as pain, discomfort, fatigue as well as mental features like negative mood, poor memory and the lack of concentration (Yan et al., 2009; Liu et al., 2004). The word gains its popularity in Chinese society. It is mentioned by ordinary Chinese people in their daily life and has been consistently discussed and analysed in health research in China (Yuan et al., 2004). This may be because it describes a health state that is believed to be prevalent among Chinese populations (Yan et al., 2009). It seems to strike a chord among Chinese communities where “sub-health” is agreed to be a common phenomenon.

“Yangsheng” (Health-keeping Behaviours)

“Yangsheng” (养生: (developing) health-keeping behaviours) is another term that is closely linked with the concept of health in China. “Yangsheng” emphasises the importance of good lifestyle behaviours. It conveys the idea that good behaviours are associated with “good health”, which is similar to what is defined in the previous literature that health is a reward for good behaviours (Spector, 2004).

There are various so-called “health proverbs” in the Chinese language but actually advising how to “Yangsheng” (develop health-keeping behaviours). The book *One Hundred Health Proverbs* describes that there are four cornerstones for health: balanced mentality (“Broad room, broad land, no better than the broad mind” (房宽地宽，不如心宽)), appropriate diets (“Have a good breakfast, a full lunch, and a wise dinner” (早吃好，午吃饱，晚吃巧)), a moderate amount of exercise (“100 steps after meals, 99 years old to live” (饭后百步走，能活九十九)), and good habits in daily life (“Eat well, sleep well, you will never be old” (吃好睡好，长生不老)) (Zhang et al., 2005), which are all “Yangsheng” practice. Similarly, *Health Proverbs* summarises seven categories of “Health-keeping” strategies: scientific diets, food therapies, moderate exercise, body care, mental health, attention to hygiene, and disease treatment (Li, 2006). *Wisdom of Health Maintenance Handed Down from Generation to Generation* divides the proverbs

into five types: picking food, learning diets, building body fitness, having regular daily life and maintaining peaceful mood (Huang, 2009). A study of the familiarity of the Chinese proverbs for Chinese lay people summarised that there were generally six categories of the traditional sayings about health that were widely known by ordinary Chinese residents: moral and attitude; diet and lifestyle behaviours; prevention of diseases and exercise; adapt to the environment; food as medicine (Su, 2015). It is clear that balanced diets, exercises, regular lifestyles and a good mental state are consistently referred to be good practice in staying in good health, according to the Chinese health proverbs.

These proverbs are with rich content and show substantial attention is paid to "health-keeping" in the Chinese cultural setting (Su, 2015). Proverbs are likely to be known by Chinese people generation after generation. They are the cultural products that can influence people's ways of thinking and behaving to some extent (Li, 1993). Additionally, "Yangsheng" is believed to be a universal phenomenon in China at the moment according to some researchers (Si et al., 2013; Sun, 2016). The popularity of "Yangsheng" among Chinese populations also reveals that there is a common understanding of linking one's behaviours to one's health.

3.1.2 Chinese-developed HRQoL measures

As discussed in Chapter 1, most of the commonly used HRQoL measures were developed in Europe or North America (Guillemin et al., 1993). Health is likely to be defined differently in different cultural settings (Quah, 2009; Levesque et al., 2013). Section 3.1.1 has presented how health is defined differently in a Chinese cultural setting, while previous studies have shown that Chinese people have different views about health compared to Westerners (Prior et al., 2000; Liu et al., 2005; Chen et al., 2009; Xiang et al., 2010). Therefore, the conceptual equivalence of those Western HRQoL measures in China is highly doubtful.

With Chinese characteristic concepts of health being recognised as well as the legitimacy of applying Western-developed HRQoL measures in China being questioned by empirical findings, generic HRQoL measures reflecting specific Chinese cultural background were developed, with the aim of better-examining health status among Chinese people (Liu et al., 2007). Finding out how health is

conceptualised in such HRQoL measures would help to identify those potentially important attributes (named as health dimensions in this thesis) that can be used in subjective health assessment in China.

There have been a few studies reviewing HRQoL measures that were developed in China. Liu and colleagues undertook a literature search on HRQoL measures but narrowly focused on those measures developed from a Traditional Chinese Medicine (TCM) perspective (Liu et al., 2013). Similarly, Yu and colleagues systematically reviewed Chinese HRQoL measures and evaluated the quality of them, but also with special attention to TCM HRQoL measures (Yu et al., 2015). Several studies reviewed HRQoL measures that were applied in Chinese populations, but most of them focused on reviewing studies that applied Western HRQoL measures, such as EQ-5D and SF-6D (Wang et al., 2015a; Zhou et al., 2016a; Zhou et al., 2016b). Since few studies have comprehensively reviewed HRQoL measures developed for Chinese populations, a review study was conducted with the following research objectives.

3.2 Research objectives

There were three main objectives of this review:

1. To identify currently available HRQoL measures that were developed in a Chinese cultural setting and to summarise health dimensions that were covered by those measures;
2. To establish a conceptual framework of health in a Chinese cultural context.
3. To identify differences between China and the West in measuring health by comparing the conceptual framework with the descriptive system of a Western-developed measure EQ-5D.

3.3 Methods

A scoping review was designed for this study. Scoping reviews commonly refer to those studies that summarise existing literature aiming to present the breadth and depth of a research area (Levac et al., 2010; Arksey and O'Malley, 2005).

Research questions of scoping reviews are usually exploratory, aiming to “map” key concepts, available types of evidence and research gaps in a defined topic (Colquhoun et al., 2014). The review process is equally rigorous and transparent compared to the methodology of systematic reviews (Pham et al., 2014; Munn et al., 2018; Peters et al., 2015).

Instead of choosing other types of reviewing methods, such as a systematic review or a traditional literature review, this study undertook a scoping review, for the following reasons. First, a scoping review study is appropriate in investigating in a broad research area to collect key concepts and different types of evidence available (Arksey and O'Malley, 2005). Because this current study aimed to identify those generic HRQoL measures for the Chinese general population and to summarise the content of those measures, the research topic was considered to be relatively broad. A scoping review was therefore thought to be more suitable compared to a systematic review whose research question is often with a narrowly-defined focus. Secondly, because a scoping review study usually aims to present a descriptive overview of the topic being investigated, quality assessment for included studies, which is normally required in a systematic review, is not generally conducted in a scoping review (Colquhoun et al., 2014; Grant and Booth, 2009; Munn et al., 2018). This was in line with the aim of this review because it focused on the content of those HRQoL measures and wanted to investigate how health could be defined and described, from a variety of resources. Additionally, similar to the methodological framework of a systematic review, a scoping review study is required to adopt systematic searching, selecting and synthesizing techniques to summarise research findings in a defined topic (Peters et al., 2015; Munn et al., 2018). It would be beneficial to follow such methodological framework to retrieve and summarise those Chinese-developed HRQoL measures in a robust and systematic manner.

Guidelines of a scoping review study described by Arksey and O’Malley informed the review process. Their methodological framework involves several stages: 1) identifying the research objectives (Section 3.2); 2) identifying relevant studies; 3) study selection; 4) charting the data; 5) collating, summarising and reporting the results (Arksey and O'Malley, 2005). The whole process is explained in detail in the following section.

3.3.1 Identifying relevant studies and study selection

3.3.1.1 Criteria for inclusion and exclusion

To be included in this review, first, studies had to report HRQoL measures that were developed in a Chinese cultural setting with the aim of assessing health for Chinese ethnic group. As discussed in Section 1.3.1, the distinguished natural and social environment has cultivated Chinese cultures to become a unique image with distinct characteristics. In this thesis, it is assumed that there is a cultural environment where the Chinese ethnic group lives in. This scoping review only focused on those HRQoL measures that were developed and used in a Chinese cultural context. Second, studies had to report generic HRQoL measures. In contrast to specific measures, which are designed for a particular disease, a particular age group or a particular type of people (McDowell, 2006), generic measures are applicable in the general population. This study focused on health dimensions that are believed to be important across Chinese populations, therefore, only generic measures were included in this review.

Studies excluded if they: (1) reported HRQoL measures that were originally developed in other countries and translated into the Chinese language or (2) were written in languages other than English or Chinese.

3.3.1.2 Methods for identifying relevant studies

Various resources were considered to access both published and unpublished studies, including Chinese and English databases, reference lists, key journals and experts conducting HRQoL research in China.

At the first stage, an initial search was conducted in the following databases. Two Chinese academic journals databases CNKI (unlimited to 2017[2]) and WANFANG Data (unlimited to 2017) were searched for published papers in Chinese language, while PsycINFO (1806 to 2017), Global Health (1973 to 2017), Ovid MEDLINE (1946 to 2017), and EMBASE (1947 to 2017) were included to search for studies published in English. A draft of searching strategies was developed based on the research questions. Two information specialists from the Leeds

[2] The Chinese databases were searched on October 23rd 2017. The English databases were searched on October 5th 2017.

Institute of Health Sciences (Rocio Rodrigues Lopez and Naila Dracup) were consulted and helped to revise the draft before a list of keywords was applied in the databases. Examples of searching strategies (in the English language) in Medline and (in the Chinese language) in CNKI are presented in Figure 3-1 and 3-2.

Figure 3-1: Searching strategies in CNKI

CNKI search:
(TI=('量'+'问'+'调查')*('表'+'卷')+'工具')and(AB='生命质量'+'生存质量'+'生活质量'+'健康')and(AB='制'*('定'+'订')+('编'+'研')* '制'+'测试'+'检验'+'研究'+'分析'+'修订'+'建立'+'设计')

Figure 3-2: Searching strategies in Medline

Medline search:

1. (survey* or questionna* or instrument* or tool*). ti,kw.
2. ((China* or Chinese or mandarin* or Cantonese* or macau* or macao* or Beijing* or "Hong Kong*" or Tibet*) and (validat* or form* or develop* or devis* or design* or construct* or establish* or produc* or set* or build* or creat* or evaluat*)).ti,kw.
3. 1 and 2
4. Medicine, Chinese Traditional/ or exp China/
5. exp *"Surveys and Questionnaires"/
6. exp *Psychological Tests/
7. exp *Health Status Indicators/
8. exp *"patient-reported outcome measure"/
9. 5 or 6 or 7 or 8
10. exp *health status/
11. exp *quality of life/
12. (hqol or h qol or hrqol or hr qol).tw.
13. “health related quality of life”.ti.
14. 10 or 11 or 12 or 13
15. 4 and 9 and 14
16. 3 or 15

After searching the databases, citations along with the abstracts were imported in the EndNote reference management software. Duplications were removed from the EndNote Library. Titles and abstracts were screened to identify studies that were of the research interest. Full texts of those studies that might be relevant to the research question were then downloaded for further assessment.

Next, backward and forward reference searching was conducted to broaden the scope. Reference lists of all identified reports and articles were scanned (backward reference searching). Bibliographies of systematic reviews or traditional literature reviews that were found were also checked to identify undiscovered papers. Meanwhile, papers that cited an identified report/article/review study were examined as well (forward reference searching).

A hand searching was conducted in six Chinese key relevant medical journals from the year 1990 to the year 2017. The journals included the National Medical Journal of China, Chinese Journal of Preventive Medicine, Chinese Health Economics, Chinese Journal of Behavioural Medical Science, Chinese Journal of Integrative Medicine and Chinese Journal of Health Management. Google Scholar was used to search for additional papers.

Experts who had experience in conducting HRQoL research in China were contacted via emails to enquire if they noticed relevant works, especially for those works that were not published. Professor Cindy Lam, an expert in HRQoL assessments and cross-cultural validation studies among Chinese populations and Dr Changhe Yu, an expert who reviewed HRQoL measures in the field of TCM, responded and offered suggestions on paper searching.

3.3.2 Charting the data

Eligible studies that satisfied inclusion criteria were placed for data extraction. A data charting form was designed to extract key information for each study. The form recorded the following information: name of the HRQoL measure (Chinese name and/or English name, if applicable), author(s), year of publication, aims of developing such measure, study location, study population, development method, health domains/dimensions and the number of questions.

3.3.3 Analysis and synthesis

A thematic analysis (Braun and Clarke, 2006) was undertaken both deductively and inductively to attain a condensed and broad description of the identified HRQoL measures. Deductively, a predefined conceptual framework (the Wilson-Clearly model) was used to categorise each question in the HRQoL measures. Such a conceptual framework can provide clarity and focus along the analysis process (Miles and Huberman, 1994). Inductively, when items could not be assigned in the predefined framework, new concepts or categories were generated.

More specifically, each “questionnaire item” (an individual question that was included in HRQoL measures) was categorised into a conceptual framework (the Wilson-Cleary model) to facilitate the analysis. A conceptual framework normally assists to depict a phenomenon by presenting descriptive categories and describing interrelationships among them (Walker and Avant, 2005). Within a conceptual framework, key constructs, main factors and principal variables of that phenomenon are explained, either in a graphical way or with a narrative form (Miles and Huberman, 1994). In this study, the Wilson-Cleary model (see Figure 1-2) was acted as an initial conceptual framework to summarise the content of the identified HRQoL measures. Items from the measures were classified into the main domains of the Wilson-Cleary model, including “physical symptom”, “psychological symptom”, “physical function”, “psychological function” and “social function”, based on their content. For those items that could not fit in those categories, they were placed separately in “Other”.

There were several reasons for choosing the Wilson-Cleary model as an initial classification scheme in this study. As mentioned in Chapter 1, the Wilson-Cleary model is the most commonly cited HRQoL model (Bakas et al., 2012; Ferrans et al., 2005; Mark, 2016). The model connects typical variables that are included in HRQoL measures and presents causal relationships between various health concepts (Wilson and Cleary, 1995). Its practicality in classifying the content of HRQoL measures (Valderas and Alonso, 2008) and its applicability for use in describing HRQoL in the context of a general population (Orfila et al., 2006) were supported by previous literature.

Some may argue that the suitability of using the Wilson-Cleary model, which is a "Western model", to analyse Chinese-developed HRQoL measures. One reason for choosing this Western model was that because the concept of HRQoL was originally raised and developed in the West before it was introduced to China in the 1990s (Kaplan and Bush, 1982; Liu et al., 2013), it was assumed that a widely-recognised Western HRQoL model was eligible in providing an initial structure for the Chinese conceptualisation of HRQoL, given no well-established and widely-recognised Chinese-based conceptual framework was found in the literature. This assumption was supported by a review study reporting that Chinese TCM and non-Chinese-developed HRQoL measures (SF-36 and WHOQOL-100) shared comparable measuring frames (Yu et al., 2016). Around half of the questionnaire items from TCM measures were found to be comparable to those included in Western measures. This suggested that a Western conceptual model of HRQoL was able to provide an initial structure to categorise many of the questionnaire items from Chinese-developed HRQoL measures. It was also considered that because a commonly used HRQoL conceptual model contained common language that could be better understood and shared across studies (Bakas et al., 2012), applying the Western model in this review can be beneficial. Meanwhile, the Wilson-Cleary model was used as an initial classification scheme, allowing newly discovered health concepts to be added. Main differences and similarities between China and the West in structuring HRQoL can be straightforwardly presented, by comparing the content of Chinese HRQoL measures with this Western model.

Other models, such as International Classification of Functioning, Disability and Health (ICF) model and Patient-Reported Outcomes Measurement Information System (PROMIS) model, were also applicable conceptual framework (Cieza and Stucki, 2005; Carlozzi et al., 2015) but were not chosen for data synthesis in this scoping review. The ICF coding system focuses on functioning and disability (World Health Organization, 2001), which is merely one part of the HRQoL concept, therefore its classification scheme was considered to be less adequate when compared with that in the Wilson-Cleary model. The PROMIS model divides the concept of health into three domains: physical, mental and social, then further breaks these domains down into physical function, physical symptoms,

emotional distress, cognitive function and social function (Cella et al., 2010). Although the main categories of PROMIS are similar to that in the Wilson-Cleary model, the PROMIS model does not show causal relations among health concepts, while the Wilson-Cleary model does. Additionally, since the Wilson-Cleary model clusters symptom status and functional status separately, it was considered to be potentially more beneficial in observing characteristics of the identified HRQoL measures. It helped to recognise that some measures paid more attention to individual's perceptions and feelings, while some focused more on people's functional abilities when assessing health[3].

After each item from the identified HRQoL measures was classified in a corresponding health domain within the classification scheme of the Wilson-Cleary model, through careful coding, classification and comparison, items in each domain were further classified into smaller groups. Similar health items were grouped together to generate a health dimension, which was labelled based on the content of the items that were clustered together. For example, some HRQoL measures asked the quality of sleep ("Do you sleep well?"), some assessed the length of sleep, some asked the difficulty of being asleep and some examined the condition of insomnia. These questionnaire items were all about sleep and were classified in the subdomain of "physical function" under the domain "function" before they were grouped together to generate a health dimension labelled as "Sleep". If one questionnaire item represented more than one concepts, then the item was split and coded as separate health dimensions. For example,"(in the last month) Do you have pain or discomfort?" from QOL35 was coded as two health dimensions "pain" and "discomfort".

Once the health dimensions had been specified, relationships among them were investigated. The content of the Chinese-developed HRQoL measures was also compared to analyse the similarities and differences among them. Accordingly, a Chinese conceptual framework of health, including attributes that could be used in subjective health assessment, from the identified HRQoL measures, was developed. The developed conceptual framework of health was compared with

[3] This finding is discussed later in this chapter.

the descriptive system of EQ-5D, as a preliminary attempt to explore differences in health conceptualisation between China and the West.

The analysis was conducted in the NVivo 10 software.

3.4 Results

3.4.1 The identified HRQoL measures

As Figure 3-3 presents, after removing duplications, titles and abstracts of 4040 records were screened to check if the studies were relevant to the research question. A number of 34 studies were recognised and their full texts were obtained for eligibility assessment, after which 9 papers were qualified in line with the inclusion criteria. With the reference mining, hand-searching, website-searching and experts contacting, a total number of 12 generic Chinese-developed HRQoL measures were identified and included for data extraction. The information of the included HRQoL measures is charted in Table 3-1.

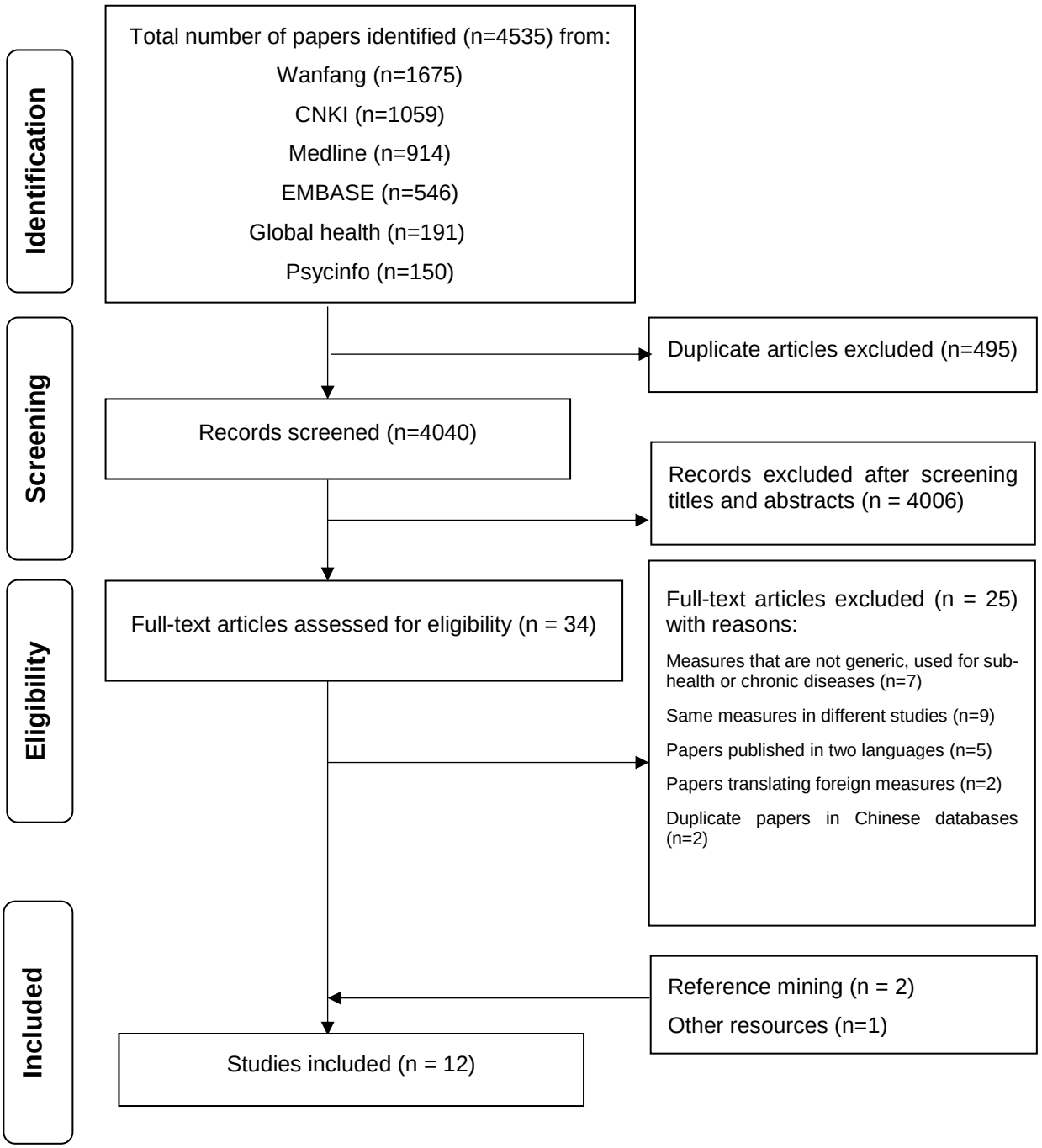


Figure 3-3: Flow chart for the reviewing process

Table 3-1: Chinese-developed generic HRQoL measures

Chinese/English name (abbreviation)	Authors, year	Research aims as defined in the paper	Development methods	Population & location	Main structure as defined in the paper	No. of items	Source
中国心身健康量表 Chinese Psychosomatic Health Scale (CPSHS)	(Zhang et al., 1993)	"To develop a scale that can measure Chinese people's psychosomatic health status"	Literature review and expert opinions	Experts from 27 provinces in China	Organ function; physical symptoms; mental status; relations with others; habits	134	CNKI
生活质量综合评定问卷 Quality of Life Inventory (QOLI)	(Li et al., 1995)	"To evaluate the quality of life among general populations in communities in China"	Literature review, expert opinions and interviews with residents	430 people in Hunan province for a pilot study	Physical function; mental function; social function; material life	99	Hand-search
自感健康量表 Current Perceived Health Questionnaire-42 (CPH42)	(Fielding and Li, 1997)	"To measure current perceived health"	Literature review and interviews with outpatients and inpatients	Participants in Guangzhou and Hong Kong	Energy/fatigue; Physical mobility; Pain; Disability; Stress; Anxiety; Confidence; Disappointment; Depression; Satisfaction; Worry; Social isolation; Activity	42	Ref
自测健康评定量表 Self-rated Health Measurement Scale (SRHMS)	(Xu et al., 2000)	"Due to the specific cultural background, China needs to develop self-rated health questionnaires that are suitable for the Chinese situation"	Literature review and expert opinions	Experts from various locations; 500 Chinese (Haikou/Guangzhou) for preselection; 200 Chinese for validation	Physical, mental and social aspects	48	Wanfang
国人生活质量普适量表 General Quality of Life Instrument for Chinese People (QOL35)	(Wu et al., 2005)	"To develop a QoL scale that is suitable for the Chinese general population"	Literature review and expert opinions	Chinese scholars; Residents in Beijing communities; A validation study in Beijing	General health and QoL; physical function; self-care; mental health; social function; environment; change in QoL	35	Wanfang
中华生存质量量表 Chinese QoL Instrument (CHQOL)	(Liu et al., 2007)	"To develop a QoL instrument reflecting Chinese culture and TCM knowledge"	Literature review and expert opinions	Health experts in Beijing, Yinchuan, Chengdu, Guangzhou, Zhengzhou and more; Participants in Guangdong and Ningxia for pilot tests	Shape, spirit and mood	50	Wanfang
中医健康量表 Health Scale of TCM (HSTCM)	(Wu et al., 2007)	"To develop a health scale based upon TCM theory"	Interviews with professionals and non-professionals	Experts from Guangdong institutes; Chinese residents in Guangdong	Three domains: physical function under natural environment, spirit and social environment plus two additional items (appetite and sleep)	88	CNKI

Chinese/English name (abbreviation)	Authors, year	Research aims as defined in the paper	Development methods	Population & location	Main structure as defined in the paper	No. of items	Source
中华 PRO 量表 Chinese PRO Instrument (CHPRO)	(Li, 2007)	“To develop a PRO measure that can be used for the curative effect appraise of the TCM”	Expert group and interviews with patients	Residents in Zhengzhou, Guangzhou, Panyun, Zhuhai	Spirit and physical function; adapt to the environment; emotions; social health	61	CNKI
中医健康状况量表 Health Status Scale of Traditional Chinese Medicine（TCMHSS)	(Liu et al., 2008)	To develop the health status scale of TCM, and to promote the domestic scale research and enlarge international scale scope based on the background of the Chinese culture and the theory of TCM	Literature review and expert opinions	Health experts in Beijing, Yinchuan, Chengdu, Guangzhou, Zhengzhou and more; Participants in Guangdong and Ningxia for pilot tests	Energy; pain; diet; sedes; urine; sleep; emotion; body constitution	30	Wanfang
健康状况测评问卷 Health Status Questionnaire (HSQ)	(Tian et al., 2009)	“To develop a health status questionnaire in line with health management demands for different physical examination receivers”	Literature review and expert opinions	Scholars for item generation; 2866 individuals in Beijing for a validation study	Sleep; pain; anxiety; depression; stress; fatigue; habits; social adaption	88	Wanfang
中医健康状态自评问卷(中医自测量表-50) Self-rated Questionnaire of Health Status in Traditional Chinese Medicine (TCM50)	(Wang et al., 2011; Zhang et al., 2017)	“To develop a health-evaluating scale from a Chinese perspective and reflecting CM conception of health”	Literature review, expert opinions and interviews with residents + focus group discussion	Chinese CM practitioners, Chinese participants from Guangzhou, Chengdu, Beijing and Nanjing	Physical feelings; mental conditions; adaptability to nature; adaptability to the society	50	Ref
中医健康状态测试表 Questionnaire Based on TCM for Detecting Health Status (TCMQ)	(Zhou et al., 2015)	“To detect health status in the community of Tianjin, China”	Literature review and expert opinions	Experts from Shandong, Jilin, Tianjin and Shanghai; pilot study with 303 participants in Tianjin	Heart system; spleen and stomach system; lung; urine and stool; endocrine and metabolic system; liver system; head; body; kidney; skin	49	Medline

3.4.2 The content of the Chinese-developed HRQoL measures

Among the twelve generic Chinese-developed HRQoL measures, most of the measures were developed by consulting with Chinese experts including clinicians and researchers. Several studies involved interviews with Chinese lay people in designing their measures. With Chinese health experts' as well as Chinese lay people's opinions obtained, it can be argued that such HRQoL measures were developed in a Chinese cultural context.

Health dimensions that were identified from the twelve HRQoL measures are summarised in Table 3-2. In the table, "1" represents that the HRQoL measure (in this column) includes the health dimension (in this row). Within each health domain, health dimensions were sorted by frequency of occurrence in descending order.

Among the twelve measures, six of them were developed based on Traditional Chinese Medicine (TCM) knowledge. Because TCM and non-TCM health HRQoL measures seemed to select health dimensions differently, they were divided into two groups (in Table 3-2, the first six are TCM measures, the other six are non-TCM), in order to present such differences more explicitly.

Table 3-2: Summarised health dimensions

	Name of the included measures												Amount		
	CHPRO	CHQOL	HSTCM	TCM50	TCMHSS	TCMQ	CPH42	CPSHS	HSQ	QOL35	QOLI	SRHMS	Total	TCM	Non-TCM
Symptom status															
Physical symptoms[4]															
Discomfort	1		1	1	1	1	1	1		1	1	1	10	5	5
Appetite	1	1	1	1	1		1	1		1	1	1	10	5	5
Fatigue	1	1		1	1	1	1		1	1		1	9	5	4
Pain			1		1	1	1	1	1	1	1	1	9	3	6
Energy	1	1	1	1	1		1	1			1		8	5	3
Complexion	1	1		1		1							4	4	0
Appearance			1					1			1		3	1	2
Spirit					1			1					2	1	1
Psychological symptoms															
Worry/anxiety	1	1	1	1	1	1	1	1	1	1	1	1	12	6	6
Depression	1	1		1	1		1	1	1	1	1	1	10	4	6
Happiness	1	1	1	1			1			1	1	1	8	4	4
Stress	1		1				1	1	1	1	1	1	8	2	6
Fear	1	1	1	1				1				1	6	4	2
Anger	1	1		1	1			1			1		6	4	2
Emotional stability	1	1	1				1	1			1		6	3	3
Confidence			1				1	1		1	1	1	6	1	5

[4] There were some TCM health items that were classified as “other signs” without being identified as a health dimension because they were too specific compared to other health dimensions. Examples are urination, stool, sweat, skin and mouth feelings.

	CHPRO	CHQOL	HSTCM	TCM50	TCMHSS	TCMQ	CPH42	CPSHS	HSQ	QOL35	QOLI	SRHMS	Total	TCM	Non-TCM
Loneliness	1						1			1	1	1	5	1	4
Satisfaction			1				1				1	1	4	1	3
Sense of security	1	1					1						3	2	1
Optimism			1								1	1	3	1	2
Functional status															
Physical function															
Sleep	1	1	1	1	1	1	1	1	1	1	1	1	12	6	6
Usual activities	1			1			1			1	1	1	6	2	4
Communication	1	1	1	1				1					5	4	1
Organ function						1		1			1	1	4	1	3
Mobility							1			1	1	1	4	0	4
Self-care							1			1	1	1	4	0	4
Sexual function								1		1	1		3	0	3
Depending on medicine										1	1		2	0	2
Psychological function															
Memory	1	1		1	1	1				1	1	1	8	5	3
Concentration	1	1	1	1			1			1	1	1	8	4	4
Thinking	1	1	1				1				1	1	6	3	3
Reaction	1	1									1		3	2	1
Decision-making			1					1			1		3	1	2
Social and role function															
Social relation	1			1			1	1		1	1	1	7	2	5
Social support	1						1			1	1	1	5	1	4
Social adaption							1	1	1			1	4	0	4
Social contact				1							1	1	3	1	2

	CHPRO	CHQOL	HSTCM	TCM50	TCMHSS	TCMQ	CPH42	CPSHS	HSQ	QOL35	QOLI	SRHMS	Total	TCM	Non-TCM
Morality								1					1	0	1

General health perceptions & QOL

General health perceptions															
Overall health rating			1							1	1	1	4	1	3
Overall QoL	1									1	1		3	1	2

Other

Other															
Weather adaption	1	1	1	1	1								5	5	0
Economic status	1									1	1		3	1	2
Living environment										1	1	1	3	0	3
Susceptibility			1		1								2	2	0
Lifestyle								1	1				2	0	2
Family history								1					1	0	1

3.4.2.1 Symptom status

Table 3-3: Health dimensions in the symptom domain

Health dimension	Item examples	HRQoL measures
Physical symptoms		
Discomfort	Discomfort feelings in the chest, throat itching, nausea, dizziness	CHPRO, HSTCM, TCM50, TCMHSS, TCMQ, CPH42, QOL35, CPSHS, QOLI, SRHMS
Appetite	The desire of having food, thinking food is tasty, food amount	CHPRO, CHQOL, HSTCM, TCM50, TCMHSS, CPH42, CPSHS, QOL35, QOLI, SRHMS
Fatigue	Tiredness, easily getting tired, tired feeling, fatigue feeling, sleepy feeling	CHPRO, CHQOL, TCM50, TCMHSS, TCMQ, CPH42, HSQ, QOL35, SRHMS
Pain	Painful feelings	HSTCM, TCMHSS, TCMQ, CPH42, CPSHS, HSQ, QOL35, QOLI, SRHMS
Energy	Body and limbs' strength, willingness to move, walk lightly or not	CHPRO, CHQOL, CPSHS, HSTCM, TCM50, TCMHSS, CPH42, QOLI
Complexion	The colour of face, the colour of lips	CHPRO, CHQOL, TCM50, TCMQ
Appearance	External outlook, body shape (obesity), body image	CPSHS, HSTCM, QOLI
Spirit	Spirit ("精神")	TCMHSS, CPSHS
*Other physical signs	Stool and urine, mouth feelings (sticky, greasy, dry…), self-sweating, hoarse voice	CHPRO, HSTCM, TCM50, TCMHSS, TCMQ, CPSHS
Psychological symptoms (emotional symptoms)		
Worry/anxiety	Anxious feelings, worrying things, feeling uneasy, feeling troubled	CHPRO, CHQOL, HSTCM, TCM50, TCMHSS, TCMQ, CPH42, CPSHS, HSQ, QOL35, QOLI, SRHMS
Depression	Depressed feelings, feeling sad, hopelessness, helplessness, feeling unhappy, wanting to cry	CHPRO, CHQOL, TCM50, TCMHSS, CPH42, CPSHS, HSQ, QOL35, QOLI, SRHMS
Happiness	Delighted feelings, happiness in life	CHPRO, CHQOL, HSTCM, TCM50, CPH42, QOL35, QOLI, SRHMS
Stress	Emotional strain, feeling nervous, under pressure	CHPRO, HSTCM, CPH42, CPSHS, HSQ, QOL35, QOLI, SRHMS
Fear	Being afraid, fear without causes, getting scared easily, feeling terrified	CHPRO, CHQOL, HSTCM, TCM50, CPSHS, SRHMS
Anger	Annoyed feeling, being angry easily, controlling temper	CHPRO, CHQOL, TCM50, TCMHSS, CPSHS, QOLI
Emotional stability	Ability to stay calm mentally, feeling peace/relaxed, surprised easily/frequently	CHPRO, CHQOL, HSTCM, CPH42, CPSHS, QOLI
Confidence	Feeling confident, self-confidence, confidence towards future	HSTCM, CPH42, CPSHS, QOL35, QOLI, SRHMS
Loneliness	Feeling lonely	CHPRO, CPH42, QOL35, QOLI, SRHMS
Satisfaction	Feeling satisfied	HSTCM, CPH42, QOLI, SRHMS
Sense of security	Feeling safe/unsafe	CHPRO, CHQOL, CPH42
Optimism	Feeling optimistic/positive	HSTCM, QOLI, SRHMS

Symptom domain consisted of two sub-domains: physical symptoms and psychological symptoms. All of the twelve identified HRQoL measures selected questionnaire items from both the two sub-domains.

Physical symptoms

Under the subdomain of physical symptom, eight health dimensions were identified. The majority of the HRQoL measures, both TCM ones and non-TCM ones, covered health dimensions about discomfort, fatigue, energy, pain and appetite. Ten out of twelve measures contained questions relating to physically uncomfortable feelings. Some asked specific types of discomfort, such as dizziness and nausea; some assessed discomfort symptoms in specific body parts like throat and chest, while some inquired whether respondents felt a feeling of discomfort in general. Ten of the identified measures included questions relating to one's eating condition, where respondents' desire for food and amount of food taken were assessed. These items were identified as a health dimension labelled "appetite". Pain was included in nine HRQoL measures, where either general (pain in general) or specific questionnaire items (pain in specific body parts) were selected. Energy was mentioned in 8 measures and fatigue was covered by 9 measures. Although it may be argued that these two terms are antonyms and could be classified in one category, they were separated as two independent health dimensions in this study. Because being energetic meant more than just being without fatigue and being without energy did not necessarily mean someone was with a symptom of fatigue, "energy" and "fatigue" should be considered as separate health dimensions.

Some health dimensions were mainly included in TCM HRQoL measures and seemed to be closely related to TCM knowledge, including complexion and spirit. Complexion was assessed in four TCM measures and represented those questionnaire items about one's face colour or lip colour. The term "spirit", in Chinese phrase "精神", was included in two HRQoL measures. Both the two HRQoL measures included "spirit" without giving further explanations of how this phrase was defined. The concept of "spirit" was introduced in Section 3.1.1.2. It can be understood as a person's overall appearance, consciousness, mind, thoughts and/or vitality, emphasising on different meanings in different contexts (Liu and Fang, 2000; Rossi, 2007; Zi, 2012). Most of the TCM measures also included specific body signs such as urine/stool, mouth feelings, skin problems, sweat and voice to evaluate health status. These dedicated TCM items seemed

to be principally used in TCM diagnosis and were too specific compared to other identified health dimensions. Therefore, they were not generated as health dimensions.

Psychological symptoms

Twelve health dimensions were identified under the subdomain of psychological symptom. Negative psychological feelings were addressed in Chinese-developed HRQoL measures. Worry/anxiety was mentioned by every identified measure, while depression and stress were also assessed by the majority of the identified HRQoL measures. Several measures comprised questionnaire items asking fear, anger and loneliness.

On the other hand, positive psychological feelings were also assessed. Eight HRQoL measures included questionnaire items about happiness. Six measures addressed emotional stability, asking whether respondents felt calm or assessing their ability to stay calm. Confidence and satisfaction were two positive health dimensions relating to one's mind and were classified under the sub-domain of psychological symptom. They were covered by six and four HRQoL measures, respectively.

Table 3-4: Health dimensions in the function domain

Health dimension	Item examples	HRQOL measures
Physical function		
Sleep	Insomnia, sleep quality, dream disturbed sleep	CHPRO, CHQOL, HSTCM, TCM50, TCMHSS, TCMQ, CPH42, CPSHS, HSQ, QOL35, QOLI, SRHMS
Usual activities	Go shopping, housework, ride bikes, work, study	CHPRO, TCM50, CPH42, QOL35, QOLI, SRHMS
Communication	Speak clearly, express ideas clearly, communicate without problems	CHPRO, CHQOL, HSTCM, TCM50, CPSHS
Organ function	Ability to see, ability to hear	TCMQ, CPSHS, QOLI, SRHMS
Mobility	Walk about, get upstairs and downstairs, bend knees, bend waist	CPH42, QOL35, QOLI, SRHMS
Self-care	Dress oneself, bath, feed, self-care	CPH42, QOL35, QOLI, SRHMS
Sexual function	Sexual function, sexual life	CPSHS, QOL35, QOLI
Depending on medicine	Depend on medicine or medical equipment	QOL35, QOLI
Psychological function (cognitive function)		
Memory	Good memory, remember things, memory deterioration	CHPRO, CHQOL, TCM50, TCMHSS, TCMQ, QOL35, QOLI, SRHMS
Concentration	Pay attention, keep the mind on things, concentration	CHPRO, CHQOL, HSTCM, TCM50, CPH42, QOL35, QOLI, SRHMS
Thinking	Clear mind, think clearly when considering problems, feel disordered or in confusion	CHPRO, CHQOL, HSTCM, CPH42, QOLI, SRHMS
Reaction	React to the external world, response quickly	CHPRO, CHQOL, QOLI
Decision-making	Make decisions	HSTCM, CPSHS, QOLI
Social function & role function		
Social relation	Family relations, relations with friends, relations with colleagues	CHPRO, TCM50, CPH42, CPSHS, QOL35, QOLI, SRHMS
Social support	Support from family and friends, give support to family and friends	CHPRO, CPH42, QOL35, QOLI, SRHMS
Social adaption	Adapt to the new life/work/study environment	CPH42, CPSHS, HSQ, SRHMS
Social contact	Participate in communal activities, contact with relatives and friends	TCM50, QOLI, SRHMS
Morality	Inappropriate behaviours	CPSHS

3.4.2.2 Functional status

The domain of function status was divided into three sub-domains: physical, mental and social/role aspects.

Questionnaire items about sleep were found in all the identified HRQoL measures. The majority of the measures asked about individuals' sleep quality, while some measures included questions about sleep length or insomnia conditions. Five HRQoL measures, including four TCM measures and one non-TCM measure, assessed respondents' ability to speak and communicate. Apart from "sleep" and "communication", other health dimensions that were identified

under the physical function category were mainly covered by non-TCM HRQoL measures. Questions about the ability to see/hear (jointly generated as one health dimension: organ function), the ability to walk about (mobility) and the ability to conduct self-care activities were rarely found in TCM measures but were included in most of the identified non-TCM measures.

Psychological function referred to cognitive functional abilities in this thesis and was covered by both TCM and non-TCM HRQoL measures. Five health dimensions were identified under this sub-domain. Memory and concentration were addressed by eight HRQoL measures. Over half of the identified measures assessed respondents' ability to think and linked a clear head with good health. The ability to respond quickly was assessed by three HRQoL measures, while the ability to make decisions was included in two.

Health dimensions under social/role function were not commonly assessed by TCM measures and they were only found in two TCM-perspective HRQoL measures. Five non-TCM measures included questionnaire items about social relations and four of these measures also evaluated people's social support. "Social adaption" considered one's relationships with the external social environment and assessed a person's ability to adapt to the environment. It was assessed in four non-TCM measures. An example of social adaption is that SRHMS asked whether a person was able to fit into a new working or studying environment within a limited time.

3.4.2.3 General health perceptions and overall Quality of Life

The fourth and fifth levels of the Wilson-Cleary model are the general assessment of health and quality of life. Four identified HRQoL measures included questions to evaluate respondents' general feelings of their own health status and three of them were the HRQoL measures from the non-TCM perspective. While one TCM and two non-TCM measures covered questionnaire items to assess individuals' overall quality of life.

3.4.2.4 Other dimensions

Table 3-5: Other dimensions

Health dimension	Item examples	HRQoL measures
Weather adaption	Ability to adapt to changes in seasons and weather, fear of cold/hot weather	CHPRO, CHQOL, HSTCM, TCM50, TCMHSS
Susceptibility	susceptibility of catching a cold, susceptibility to diseases	HSTCM, TCMHSS
Lifestyle	Drinking habits, dietary habits	CPSHS, HSQ
Family history	Family medical history	CPSHS
Economic status*	Economic problems, revenue, social welfare	CHPRO, QOL35, QOLI
Living environment*	Living condition, community service, noise	QOL35, QOLI, SRHMS

* Concepts being excluded because they were not considered as health dimensions

A number of identified health dimensions could not be classified in the domains of the Wilson-Cleary model. Five Chinese TCM HRQoL measures concerned about one's physical health state under certain weather conditions. For example, some measures asked whether the weather/season changes affected one's body; some measures assessed whether respondents were afraid of cold/hot. These questionnaire items were coded as "weather adaption" because they seemed to assess one's abilities to adapt to certain weather conditions. Two HRQoL measures included questionnaire items asking whether respondents were easy to get cold. They assessed whether respondents were susceptible to diseases and were grouped as "susceptibility". Questions about lifestyle habits, including drinking and dietary habits, were found in two non-TCM based measures. One non-TCM measure included questions relating to family medical history.

Some measures that were identified in this study included questions about one's economic status and living environment. As mentioned in Section 1.2.2 that the thesis is focused on the concept of HRQoL, which is a "health-focused" term. In this thesis, the concept of HRQoL is distinguished from the concept of QoL (quality of life). HRQoL here is associated with people's subjective assessment of their own health and is only one part of QoL. QoL is a broader concept that incorporates all aspects of an individual's existence, while HRQoL is a subset relating only to the health domain of that existence. More specifically, QoL covers dimensions not only about individuals' health but also their economic status, external environment conditions and all other aspects of an individual's life. Since the two attributes – economic status and living environment – are not about an

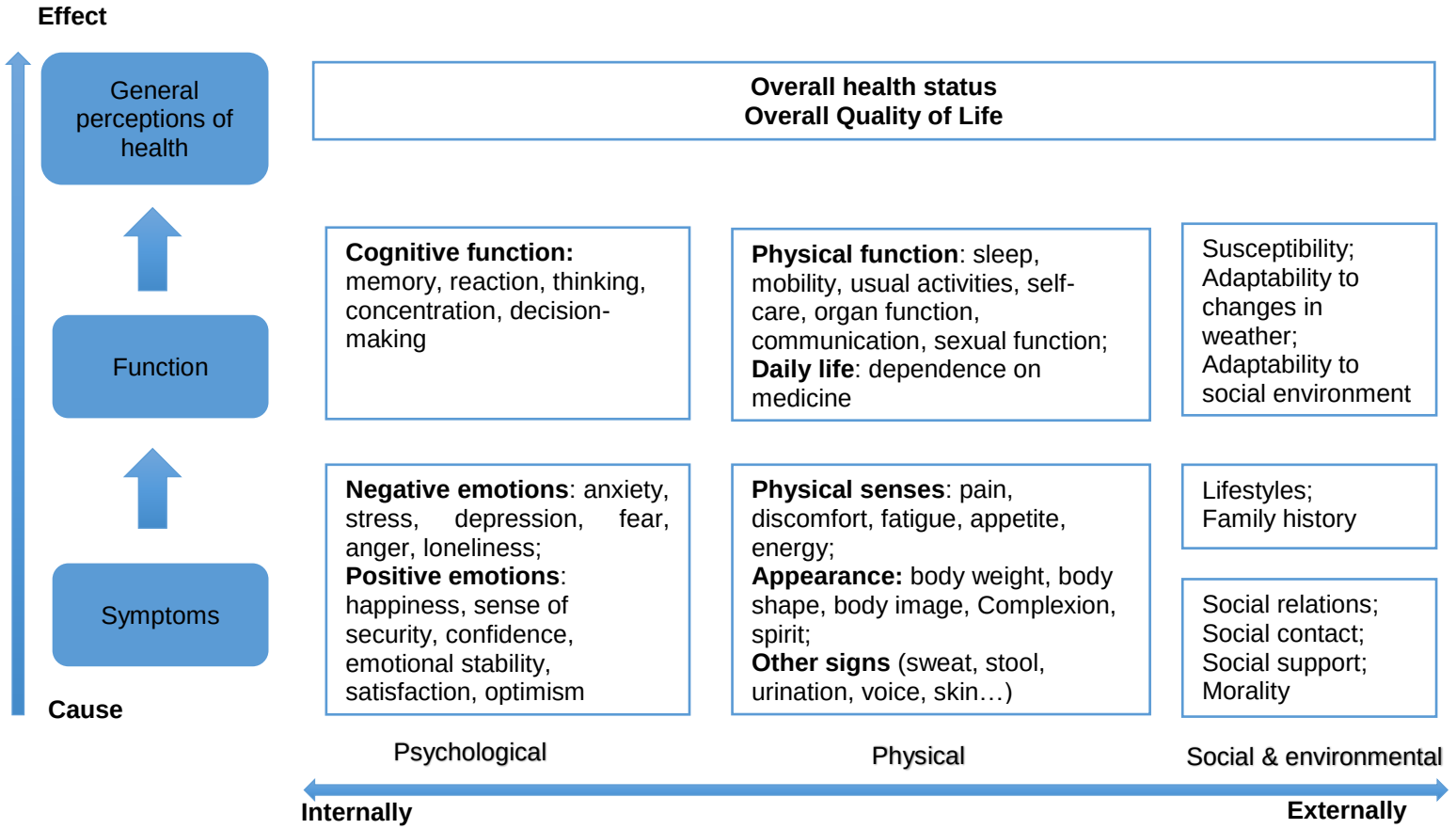
individual's health status, they were not considered as health dimensions and were excluded as being part of the conceptual framework of health in this study.

3.4.3 A preliminary conceptual framework of health

With a number of health dimensions identified from the scoping review, a Chinese conceptual framework of health was proposed. The framework is structured with two divisions: cause vs effect, internal vs external. The cause vs effect division was established based on the Wilson-Cleary model. The internal vs external division was inspired by Chinese old sayings which convey a holistic concept of health, including "Unity of body and spirit" and "Harmony between man and nature". These two phrases were introduced in Section 3.1.1.

Figure 3-4 presents the proposed Chinese conceptual framework of health.

Figure 3-4: Conceptual framework of health based on the Chinese-developed HRQoL measures



3.4.3.1 Cause vs effect

In the Wilson-Cleary model, a left-to-right arrow path connects five variables, indicating a series of approximate cause-effect relationships moving from left to right: from biological and physiological factors to symptoms, then to functioning, then to general health perceptions and then to the overall quality of life (Wilson and Cleary 1995). Although the cause-effect direction is debatable, for example, symptom status cannot fully explain variations in functioning and functioning problems may lead to some symptoms, it is believed that the indicators on the left could be an important determinant and predictor of indicators on the right of the model (Wilson and Cleary, 1995).

Reviewing Chinese-developed HRQoL measures identified health dimensions under domains of symptom, function and general perception of health. Accordingly, the cause-effect flow (from symptom status to functional status then to general health perception) of the Wilson-Cleary model was adopted in developing the Chinese conceptual framework and to be presented vertically. Health dimensions relating to symptoms were displayed at the fundamental level at the bottom, functioning concepts were allocated at an upper level in the model and general health perceptions were at the top.

3.4.3.2 Internal vs external

As discussed in Section 3.1.1, a holistic concept of health, which views all things as a part of a whole in interpreting health, is conveyed by traditional Chinese knowledge (Zhao et al., 2004; Zhang et al., 2015). It suggests an idea of paying attention to one's physical body and intangible "spirit" at the same time (Unity of body and spirit). It also emphasises the relationship between a person and his/her surrounding environment as an essential aspect of individuals' daily life (Harmony between man and nature). This holistic concept of health was well recognised in the identified HRQoL measures. These measures not only considered physical health but also mentioned mental health; meanwhile, they not only assessed one's own health status but also addressed one's relation to the external environment, by introducing health dimensions such as weather adaption and social adaption. Inspired by this, horizontally, health dimensions were divided into three sections: psychological-relating, physical-relating and external

environment-relating, with a sequence from internal indicators to external dimensions.

Because emotions are individuals' inner feelings and cognitive function indicators are commonly not perceptible, they were placed on the left-most column. Physical symptoms and function are more visible to others and these dimensions were allocated in the middle. Both physical and mental health dimensions focus on an individual person's status, while those questionnaire items about social health expanded health assessment into a wider context by considering one's relation to external surroundings. In addition to social health dimensions, there were health dimensions referring to one's ability to adapt to the external environment. Some of them assessed one's adaptability to the natural environment, while some asked one's ability to adapt to the social environment. For those health dimensions that linked a respondent to his/her outer settings, they were placed on the right-most column.

3.4.4 Comparing the Chinese conceptual framework with the EQ-5D descriptive system

The developed Chinese conceptual framework contained the five dimensions of EQ-5D [5]. Within the descriptive system of EQ-5D, Pain/Discomfort and Anxiety/Depression are about physical senses or emotions, under the domain of symptom. They were referred to in most of the identified Chinese-developed measures. On the other hand, the other three dimensions of EQ-5D, which are about physical functional abilities, were not included in the Chinese HRQoL measures as frequently as Pain/Discomfort and Anxiety/Depression.

Among the Chinese-developed HRQoL measures, sleep and appetite were included in almost all of them but are not covered in the Western HRQoL measure, EQ-5D. Health dimensions relating to one's social relations as well as cognitive function were also assessed by most of the Chinese measures, while they are not part of the descriptive system of EQ-5D. Additionally, this review study identified some health dimensions carrying Chinese cultural features. For

[5] As introduced in Chapter 1, the descriptive system of EQ-5D consists of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

example, spirit and complexion seem to be specific to Chinese culture and are not included in EQ-5D's descriptive system.

3.5 Discussion

Through systematically searching and selecting, twelve Chinese-developed generic HRQoL measures were documented in this scoping review. After synthesising the content of these HRQoL measures, a conceptual framework of health was proposed and was compared with the descriptive system of EQ-5D.

3.5.1 Chinese-developed measures from TCM and non-TCM perspectives

Among the identified HRQoL measures, half of them were developed combining TCM knowledge. TCM, working alongside with Western (Morden) Medicine, has been playing an active role in Chinese health care system and in public in China (Hesketh and Zhu, 1997; Xu and Yang, 2009; Li et al., 2017). Because TCM has its unique theoretical and practical perception of health, the TCM HRQoL measures exhibited distinctive characteristics compared with those non-TCM HRQoL measures.

TCM HRQoL measures mainly included questionnaire items about mental and physical symptoms and covered fewer questionnaire items about physical and social functional status. It seems that the designers of the TCM HRQoL measures did not define health from a functional point of view. Instead, they adopted a holistic concept of health, where one's body is understood as an integral organism and one's health is understood as "a state of spiritual and physical harmony with nature" (Spector, 2004, p212). In this holistic view of health, all body components are believed to be connected and interacted with each other, therefore, a small sign of the body is able to reflect his/her condition of health (Zi, 2012). In practice, typical diagnostic methods of TCM, involving inspection, listening, smelling, as well as pulse taking, are all about examining trivial symptoms. For example, TCM practitioners observe patients' face colour and make inquiries about patients' stool, urine, mouth feelings, sweat and skin. The fact that symptom-relevant physical and mental signs are common factors to

assess health from a TCM perspective may explain why these signs were frequently covered in the TCM HRQoL measures.

Health dimensions “weather adaption” and “susceptibility” were also mainly included in the TCM HRQoL measures, but less likely to be included in the non-TCM measures. These concepts addressed the ability to adapt as an indicator in measuring health, implying that if a person who is more capable to adapt to weather changes, he/she is less likely to catch a disease, and therefore is supposed to be in a better health state. By including such concepts, the designers of the HRQoL measures not only concerned about a person’s own health condition, but also his/her relation to the external environment, or more specifically, his/her ability to adapt to the environment. They emphasised the importance of being adaptive to changes in environments to maintain a dynamic harmonious state, which again reflects a holistic view of health.

On the other hand, health dimensions on physical and social functional status appeared mainly in the non-TCM HRQoL measures. Questions about mobility, self-care, social relation and social support were frequently referred to in the HRQoL measures developed from a non-TCM perspective, while few TCM HRQoL measures included such health dimensions. It shows that the designers of those non-TCM HRQoL measures tended to define health as abilities to do things. This is in accordance with that in the West since various Western HRQoL measures assess health from a functional perspective (McDowell, 2006).

Despite distinct differences between Chinese-developed TCM and non-TCM HRQoL measures, similarities were also obvious. Most of the non-TCM HRQoL measures, such as SRHMS, CPH42, QOL35 and QOLI, adopted the WHO’s definition of health and included questionnaire items in physical, mental and social aspects. As for those HRQoL measures that were developed from the TCM perspective, although most of them did not emphasise on the social health aspect, they still included domains of mental health and physical health. It indicates that TCM and non-TCM HRQoL measures shared a comparable measuring frame, which includes at least the domains of mental health and physical health.

Several health dimensions were covered by almost all the identified measures, no matter whether they were TCM or non-TCM theory-based. Sleep was included in all the twelve HRQoL measures. Many traditional Chinese idioms show that sleep is an important factor in staying in health. For example, the Chinese saying "One good sleep is better than taking pills for ten times[6]" expresses an idea that sleeping well can benefit one's health condition. The importance of sleep is also highlighted in TCM theory, where it is believed that sleep can help to protect a person's "Qi"[7] and restore one's energy (Lou et al., 2009; Zhou et al., 2013). The connection between health and sleep was also frequently investigated in various Chinese empirical studies (Wang et al., 2003; Zhao et al., 2006; Cheng et al., 2008). These facts support the finding that sleep is agreed to be an applicable indicator in assessing health in Chinese cultural contexts.

Besides sleep, appetite was also a favourable health dimension introduced in the majority of the Chinese HRQoL measures. The popularity of "eating" in Chinese communities has been discussed in the literature: "Have you eaten?" is one of the most common greeting ways among Chinese people (Zhang, 2004; Han and Ji, 2009); there are also numerous expressions relating to "eat", "food" and "cook" in the Chinese language (Han and Ji, 2009). The Chinese dining culture may be originated from the fact that China is a traditional agricultural country with a large population, where food production and consumption is considered as a fundamental and principal theme by Chinese governors as well as ordinary Chinese people (Zhao, 2003; Han and Ji, 2009). Given the important role "eating" plays in a Chinese cultural setting, it may explain how individuals' desire for food was frequently assessed by those Chinese HRQoL measures.

Physical senses including discomfort, pain and fatigue were also included in most of the identified Chinese HRQoL measures. In the Western literature, physical symptoms are believed to be able to provide subjective information about health and are of interest to HRQoL assessment (Wilson and Cleary, 1995). This idea seems to be well accepted in the non-TCM Chinese-developed HRQoL measures. On the other hand, as discussed earlier in this section, physical

[6] Translated from the Chinese language:"吃药十付，不如独宿一夜".

[7] In traditional Chinese culture, Qi can be understood as the vital energy that forms and protects each part of any living entity.

symptoms are emphasised by TCM knowledge and TCM practitioners depend on symptoms to diagnose and treat patients. Therefore, health dimensions about physical symptoms are also important in assessing health from a TCM perspective.

Besides, there was little difference between the TCM HRQoL measures and the non-TCM HRQoL measures in selecting health dimensions under the mental health domain. Health dimensions such as anxiety/worry, depression and happiness were recognised in both groups of measures. In the Chinese language, “emotion” is classified into seven types. “Seven emotions”, which refer to joy, anger, sadness, worry, grief, fear and fright, is a well-known Chinese expression (Zhang and Zhang, 2010; Yang et al., 2017). According to traditional Chinese knowledge, these emotions are believed to be closely linked with specific organs of the body, therefore can be determinants and indicators of health (Zhao et al., 2004; Yue et al., 2007). As *Yellow Emperor’s Classic of Internal Medicine* suggests, anger is associated with liver, fear and fight may influence kidneys, joy is linked with heart, sadness and grief are with lungs (Kaptchuk, 2000). This may be a theoretical basis for TCM HRQoL measures to include certain emotions in assessing health. Because the health dimensions about one’s emotions were both recognised in both TCM and non-TCM HRQoL measures, it shows that mental health is widely concerned in health measurement in China.

Last but not least, health dimensions about the cognitive function such as memory and concentration were also favourable across the identified Chinese generic HRQoL measures. Although TCM measures included few health items about physical function and social function, they comprised questionnaire items about cognitive function. This may be related to the concept of “spirit”. As mentioned earlier, traditional Chinese knowledge considers physical body and spirit at the same time when describing the state of health (Ni et al., 2014). While “spirit” can be referred to people’s consciousness, mind, thoughts and/or vitality (Liu and Fang, 2000; Rossi, 2007; Zi, 2012), cognitive function abilities such as the ability to concentrate and ability to think clearly are regarded as part of “spirit”. It shows that although TCM has a unique theoretical and practical perception of

health, TCM and non-TCM HRQoL measures possess a shared emphasis on cognitive function in terms of measuring health.

3.5.2 A Chinese conceptual framework of health

The proposed Chinese conceptual framework of health adopted the structure of the Wilson-Cleary model and designed its vertical division to follow a cause-effect arrow path, linking symptom status to functional status then to general health perception. It shows that the majority of the identified health dimensions was able to be categorised under a Western HRQoL conceptual model – the Wilson-Cleary model, which further indicates that Chinese and Western HRQoL measures share a comparable measuring frame. This finding is similar to what was found in a previous study (Yu et al., 2016), although that study only reviewed TCM HRQoL measures.

The horizontal axis of the Chinese conceptual framework connects physical, psychological and social/environmental using an “inner vs outer” double-headed arrow. This design is not part of the Wilson-Cleary model and is inspired based on the Chinese idioms *Unity of body and spirit* and *Harmony between man and nature* (Zhao et al., 2004; Zhang et al., 2015). According to traditional Chinese knowledge, health can be understood as reaching a harmonious state. In order to reach a harmonious state, the connection between one’s body and “spirit” (an inner relation) as well as the relation between one person and his/her environment (an outer relation) need to be concerned. This holistic view of health is revealed by reviewing Chinese-developed HRQoL measures. On the one hand, the Chinese-developed HRQoL measures paid attention to both physical and mental health. It implies that both internally existing “non-tangible” indicators and physically appeared health dimensions are considered to be important in describing and measuring health. On the other hand, the Chinese-developed measures also assessed the relations between an individual and his/her surrounding environment. These measures assessed by what extent weather/season changes affected one’s body and also asked one’s adaptability to the social environment as a way to examine one’s physical health and social wellbeing. This view of thinking about health as the ability to adapt has been

proposed by some Western scholars (Giacaman et al., 2009; Huber et al., 2011; Charlier et al., 2017) but seems to be rarely used in Western HRQoL measures.

3.5.3 Potential differences between China and the West in measuring health

Several Chinese-developed HRQoL measures conveyed a holistic concept of health. This holistic concept is not frequently adopted in developing HRQoL measures, for example, EQ-5D, in the West, in which a functional point of view of health is a more widely used concept (McDowell, 2006). This review study thus implies cultural differences between China and the West in understanding health in this regard.

This study also identified additional health dimensions that may be important in China but are not part of EQ-5D. It is noted that EQ-5D is a short HRQoL measure and includes a “common core set” of health dimensions that are of relevance to most people (Williams, 2005). Since EQ-5D was developed by a group of Western scholars, it can be argued that this “common core set” fails to involve dimensions that are important in assessing health in a Chinese cultural setting. Health dimensions, such as “spirit”, “complexion”, “weather adaptation” and “social adaption” were mainly referred to in TCM HRQoL measures and are not part of the descriptive system of the Western HRQoL measure. Aside from those concepts that may be considered TCM features, several health dimensions, such as sleep and appetite, were highly emphasised by Chinese-developed HRQoL measures but are missing in EQ-5D. Thus, cultural differences in assessing health between China and the West are further presented.

Applying translated Western HRQoL measures may facilitate researchers in non-English speaking countries to conduct HRQoL studies in some respects, but as health is a culturally relevant concept, health dimensions that are relevant and important in defining and measuring health in a Western setting, may not necessarily be relevant or important in China, and vice versa. Therefore, it is worth considering such cultural differences when selecting HRQoL measures for trials or clinical practices as well as health research involving participants with different cultural background. As shown in the current study, China and the West may share a similar structure and most concepts in measuring health, but unique

“Chinese specific” concepts exist. Similar organising frameworks and key health dimensions from a Western measure may be kept, while concepts reflecting Chinese culture may also be important to be considered in assessing health among Chinese populations. The result implies the necessity of further examining the legitimacy of applying the Western-developed HRQoL measure in a Chinese cultural setting.

3.6 Limitations

This review study only focused on those papers that had reported development and/or validation processes. Some self-designed Chinese generic HRQoL measures might be excluded due to their omission of descriptions of measure development. Therefore, there was a risk that such eligible HRQoL measures may be neglected. However, it is not practical to screen all Chinese studies involving HRQoL measures, since a significantly large number of papers had implemented Western HRQoL measures to assess health among Chinese populations.

The study used second-hand data to explore how health can be defined and measured in China, but it may not include all health concepts that are considered important in this cultural setting. Further empirical studies were conducted to better understand how health is described among Chinese populations and are reported in the subsequent chapters.

Another limitation is related to the subjectivity of the researcher, because the analytic process of this review involved the researcher’s own understandings and interpretations. Although a predefined conceptual framework, which can provide clarity and focus along the analysis process, was used, it would have been more rigorous to include a second reviewer to screen the studies and summarise the content of the identified HRQoL measures. However, the researcher had encountered difficulties in finding a second bilingual researcher who was familiar in this research field and was available in assisting the review work at that time.

3.7 Conclusion

This chapter describes a scoping review of Chinese-developed generic HRQoL measures. It proposes a Chinese conceptual framework of health based on these synthesised materials and presents an overview of how health can be defined and measured in China. It also demonstrates that Chinese-developed HRQoL measures include specific features relating to the Chinese culture and that there are cultural differences in defining and measuring health between China and the West. Empirical studies are reported in the following chapters to further explore such cultural differences.

Chapter 4 Lay understandings of health in China: a qualitative study

4.0 Summary

This chapter presents a qualitative study that explored how Chinese lay participants understood and described health. In Chapter 3, health dimensions that are potentially important in assessing health among Chinese populations were identified from the scoping review of Chinese-developed generic HRQoL measures. An empirical qualitative study was designed to further understand the concept of health in China.

A series of semi-structured one-to-one face-to-face qualitative interviews were conducted. Open-ended questions were designed to inquire about Chinese participants' understandings of health. EQ-5D was subsequently provided to ask participants to comment on. Thematic analysis was conducted both deductively and inductively to analyse the collected data. This qualitative study aimed to examine the findings from the scoping review study and to provide additional resources to build up the Chinese conceptual framework of health. It also collected feedback on EQ-5D, attempting to directly assess its content validity in China. This study further investigated cultural differences in defining health between China and the West.

4.1 Background

Reviewing those Chinese-developed HRQoL measures had developed a preliminary conceptual framework of health in a Chinese cultural setting. Although the scoping review study summarised how health can be defined and measured in the Chinese literature, it is not convincing to assume that the developed conceptual framework of health is comprehensive in capturing important aspects of health. The literature-based findings may still fail to include some health dimensions that are important in assessing health for Chinese general populations.

It is commonly believed that lay people's descriptions of health are essential sources in deciding the content of an HRQoL measure (Gill and Feinstein, 1994; Streiner et al., 2014). However, among the identified HRQoL measures, only a limited number of them obtained information from lay people to develop their measures. Since few studies have investigated Chinese lay perceptions of health, to better characterise the concept of health from a Chinese perspective, an empirical qualitative study was planned to investigate how Chinese lay participants described health.

Meanwhile, as it was addressed in Chapter 1, since the content validity of EQ-5D was inadequately tested among Chinese populations, Chinese lay people's opinions on this Western-developed HRQoL measure remained unknown. The study therefore also aimed to obtain Chinese participants' views about EQ-5D, in order to examine clarity, relevance and completeness of its descriptive system in a Chinese cultural setting.

4.2 Research objectives

The objectives of this study were set as follows:

1. To explore how health was described among a group of Chinese lay participants and to further explore cultural differences between China and the West;
2. To refine the health conceptual framework developed from the scoping review, by supplementing additional health dimensions that lay people considered to be important;
3. To obtain Chinese participants' opinions on the descriptive system of EQ-5D as a way to test its content validity.

4.3 Methods

4.3.1 Study design

Since this study aimed to make sense of how people understand a certain concept, a qualitative study design was used to meet the study objectives. Qualitative research can help to develop concepts in understanding social

phenomena (Pope and Mays, 1995; Creswell, 2014). In a qualitative study, a researcher can collect data from the field by directly interacting with people (Pope and Mays, 1995; Patton, 2002; Creswell, 2014). For example, a researcher can obtain data by talking to people or by observing their behaviours in order to gather meanings, experiences and views of participants, then he/she can try to interpret what meanings people give to a certain phenomenon (Pope and Mays, 1995).

Approaches to qualitative inquiries are diverse and there are no explicit classifications or typologies (Creswell, 2007). Grounded Theory is one of the most widely used qualitative methodologies across a wide range of subject areas (Bryant and Charmaz, 2007). It aims to develop theories and emphasises that theories should be grounded in data (Corbin and Strauss, 2008). The approach involves a systematic, cyclical procedure in terms of data collection and data analysis (Creswell, 2007; Green and Thorogood, 2004). In this approach, data collection and data analysis are in a cyclical motion, namely a process of collecting data, analysing data, developing a provisional coding system, using the provisional scheme to suggest subsequent data collection and analysis and so on (Green and Thorogood, 2004). Phenomenology, which aims to explore meaning, structure and essence of individuals' experience of a specific phenomenon, is another widely used qualitative approach (Patton, 2002). As it attempts to develop a concrete description of "essence" of the experience of research interest, it normally requires to conduct in-depth interviews with people who have directly experienced that phenomenon (Patton, 2002; Creswell, 2007). Besides, there are other approaches available that are developed from various theoretical orientations and with diverse research focuses (Patton, 2002). For example, Ethnography tends to be utilised to understand the culture of a specific group and Narrative research has a focus on stories told by individuals (Patton, 2002; Creswell, 2007).

The qualitative study reported in this chapter did not fully adopt a Grounded Theory approach. Because it commenced with a pre-defined conceptual framework and was considered to be less inductive compared to a Grounded Theory study, which normally develops theories that are "grounded" in the data. However, this study implemented elements of Grounded Theory (a cyclical procedure in collecting and analysing data as well as constant comparisons).

Because using this technique, which allows for analysis and reanalysis through continuing comparisons, can help to enhance the validity of the research output and to control the personal biases of the researcher (Green and Thorogood, 2004).

This study was not conceptualised as a Phenomenological study either, although it was planned with a phenomenological perspective and applied an in-depth interview technique to capture individuals' understandings of health. Phenomenology tends to describe what people have in common when experiencing a certain phenomenon, such as insomnia and loneliness, and how they experience it (Creswell, 2007). This approach focuses on individuals' experiences of a phenomenon and assumes that "essences" exists in shared experience (Patton, 2002). Since this study was about people's understandings of health but not about their experiences of a phenomenon, it was not considered as a Phenomenological study.

Semi-structured face-to-face interviews were conducted to ask participants to talk about health. This method enables the inclusion of structured key questions directing the interviewing process but is also open enough to give both interviewers and interviewees the freedom to discuss a response or idea in more detail (Gill et al., 2008). The principal questions were prepared for participants to describe their own current health state as well as conditions of good and poor health, in order to understand their ways of describing health. Probing questions were used to seek additional information from participants: clarifying their response, exemplifying their responses or reasoning their opinions.

Data collection was conducted through one-to-one format interviews. Focus group design was not considered, because the study was interested in personal understandings of health, instead of the interactions among participants. Besides, people generally have different health conditions and/or health experiences, individual interviews could facilitate the data collection to be in more depth. Furthermore, because a discussion about health can involve personal and sensitive topics, participants may feel not comfortable to talk about personal issues in front of other people and a group discussion may prevent them from talking about what they thought in their head. The detailed interview schedule is presented in Section 4.3.4.

Thematic analysis was undertaken to analyse the collected data. Thematic analysis is often used to identify, interpret and present themes within data and can involve both inductive and deductive analysis (Braun and Clarke, 2006). Here, a “theme” is supposed to deliver important information from the data by representing a certain level of “patterned” response or meaning within the data (Braun and Clarke, 2006). This analytic method was selected because, on the one hand, the scoping review study reported in Chapter 3 had established a preliminary conceptual framework of health, which can be served as an initial coding frame for deductive analysis. On the other hand, this approach can also provide enough flexibility to generate codes that were not covered in the established framework – through inductive analysis (Braun and Clarke, 2006). The detailed analytic process is described in Section 4.3.5 Data Analysis.

In this study, data collection and data analysis occurred simultaneously, which allowed the researcher to continuously categorise and compare across data, refine interview questions and give indications for subsequent participant recruitment. It enabled the researcher to consider what perspectives had not been covered, what data to obtain next and where to approach. The iterative process was ended once the saturation was achieved, the point at which additional data collection did not generate new themes or information (Glaser and Strauss, 2017).

4.3.2 Participants

There were two principal recruitment strategies. First, it aimed to include Chinese participants, whose views could be as diverse as possible. This was because participants with different views were expected to refer to different health dimensions in describing health. With a diverse sampling group, it was more likely to obtain a comprehensive list of health dimensions that are potentially important in China. A sample with a balance of demographic background, in terms of gender, age and with different health conditions (for example, participants with and without chronic diseases were both recruited), was believed to generate diverse views and opinions. Since China is a large country and Chinese residents from different regions may have different perceptions of health, residence locations of participants were also considered in recruitment.

The second strategy was that data collection and data analysis were conducted concurrently and the subsequent recruitment was based on previous data and generated themes. For example, interviews started with participants living in cities and with relatively higher level of education, after which recruitment focused on finding participants living in rural areas and/or with low educational attainment.

The inclusion criteria were as follows: (1) with Chinese nationality, (2) 18 years old or older, (3) using Chinese as the mother tongue and being able to communicate in Mandarin. Certain groups of people were excluded from the study. People, who had cognitive problems or had a serious health condition that may limit their participation, were not recruited for interviews.

To access a diverse group of people, the researcher utilised various ways of contacting potential participants. The researcher contacted with certain group leaders/members to access groups of potential participants that may meet inclusion criteria. For example, a member of a Mahjong game club agreed to ask other members (mostly people in middle or elder age) if they were interested in participating in this study; a manager of a care home helped to contact with people had long-term health problems; a village head offered help in distributing recruitment leaflets and introducing the researcher to his villagers, etc. Group organisers delivered prepared invitation flyers containing information about the research to their group members. If potential participants were interested in taking part in the interview, then either the potential participants contacted with the researcher directly or the researcher contacted with them by using the contact information shared by the organisers. The researcher then sent information sheets (Appendix II) and consent forms (Appendix IV) to potential participants in person or via email.

The snowballing approach was also applied to ask interviewees to nominate potential participants who may be interested in participating in the research. For people who were already enrolled in the study, they were asked if they knew anyone who may fit with certain descriptions, for example, if they knew a female friend who was less educated and whose age was older than 60, and who may be willing to take part in the study. In the end, nineteen participants were purposively recruited in this study.

4.3.3 Ethics

The study has been reviewed and approved by the School of Medicine Research Ethics Committee at the University of Leeds (Reference number: MREC17-021). See Appendix I for the ethics approval letter.

Key ethical considerations included: personal information of participants was handled strictly to protect their confidentiality; all interviewees remained anonymous as each individual participant was given a pseudonym.

4.3.4 The procedure of interviews

Once prospective interviewees had confirmed their willingness to participate, the place, date and time were discussed and arranged together by the researcher and the interviewees. For the privacy of interviewees and the quality of interviews, interviewing places were selected carefully to ensure interviews could take place with minimal interruption. The chosen sites were various, taking into account both interviewer's and interviewees' convenience and safety, including private meeting rooms in public teahouses, quiet compartments in cafes, meeting rooms in the places of interviewees' employment. Interviews were conducted in Chongqing (a southwest municipality), Shandong province (an eastern coastal province) and Beijing (capital city in northern China), between March 2018 and June 2018.

An information sheet and a consent form were prepared before each interview. After each interviewee ensured that he/she had no further concerns or questions and signed the consent form, an interview began. Key open-ended questions were prepared beforehand and were discussed with the supervisory team. The interviewing procedure was divided into two main sections. First, interviewees were asked to talk freely about their understandings of health. Table 4-1 presents some examples of the guide questions. The full list of key interviewing questions can be found in Appendix V. Some of the questions were informed by a study investigating the lay concept of health (van Dalen et al., 1994).

Table 4-1: Example questions part I

1) How do you think about your health at the moment? You just said you are in good health/not in good health/not in a very good health state/ in sub-health, why did you say that? What makes you feel you are (not) in good health? **2) What experiences do you have in good/poor health yourself?** [When appropriate] You said you are in good health, have you been in poor health yourself? What things might make you think you were not in good health? What are the differences between now and the time when you were in poor health? **3) How would you describe someone in good health?** What does "good health" mean to you? What are the features of good health? **4) How would you describe someone in poor health?** Can you think of someone you know who is in poor health? Why do you think he/she is/was in poor health? Can you describe their experiences in poor health?

In the second part of each interview, participants were given the Chinese version of EQ-5D-5L to rate their own health. After they completed the HRQoL measure, they were asked the questions that were specifically on the EQ-5D five dimensions. Participants were asked not only to talk about the clarity of the wording of the measure but also comment on the completeness and appropriateness of EQ-5D's descriptive system. Examples of the questions are listed in Table 4-2 below.

Table 4-2: Example questions part II

1) Difficulty in understanding or answering some of the questions:
Have you encountered any difficulties in understanding or completing these questions? Do you think the questions are all clear to you? Are there any unclear phrases?
2) Completeness of EQ-5D
Do you think these questions can fully describe your health status? Why or why not? Do you think there are things that the questionnaire does not include but are important in describing health status? What additional questions should the questionnaire ask? What will you do to improve the questionnaire to make it better reflect your health status?
3) The importance of the five dimensions in EQ-5D
To describe your health status, do you think the five questions are the most important ones? Are there any dimensions not important in reflecting your health status?
4) Overall impression of EQ-5D
In general, do you like this questionnaire or not? Do you have any suggestions for improving the questionnaire?

In the first two sections, apart from the prepared key questions, probing techniques were also used when necessary. This was to ask interviewees to be clearer, more specific or simply give more information. At the end of each interview, participants were asked to give their demographic information, including age, education background, current residence place (city/non-city) and birthplace.

The whole interview procedure was piloted with three Chinese people living in Leeds in the UK. The pilot study showed that the sequence of the interview was appropriate and the interviewing questions were clear to interviewees.

The lengths of interviews ranged from 25 minutes to 86 minutes with an average of 45 minutes. Each interview was audio-recorded and transcribed verbatim in Chinese. Due to linguistic and cultural differences between English and Chinese, the transcripts were not translated into English to be analysed. Instead, the analysis was conducted in Chinese to fully capture all the information through the

interviews and avoid the potential translation inaccuracies and biases. The generated themes and relevant quotes were translated into English to report.

4.3.5 The procedure of data analysis

4.3.5.1 Lay understandings of health

Referring to the thematic analysis approach described by Braun and Clarke (2006) and analytical techniques of the Grounded theory (Corbin and Strauss, 2008), the transcripts were analysed through the following steps:

First, each transcript, along with its fieldwork notes, was read and reread to allow the researcher to be familiar with the data.

The second step involved a line-by-line open coding. It was to identify words, phrases or sentences that were considered to be relevant to the research question within the transcript. The step required the researcher to be open to capture all useful information that might be applicable to the research question and label each unit of the information within the transcript. Since a preliminary conceptual framework of health had been established in the scoping review, the established categorisation scheme was applied to provide clarity and focus along the open coding process (Miles and Huberman, 1994). When words or sentences in transcripts conveyed meanings of predefined health dimensions, the names of those health dimensions were used to label those phrases. On the other hand, if pieces of information, which were emerged from discussions about health, were not able to be assigned to the initial conceptual frame, new codes were generated to add to the thematic framework. As data collection and data analysis occurred simultaneously, subsequently generated data were compared with existing findings, when subsequent interviews were coded by using either existing or new labels.

In the third step, codes, both predefined and newly-generated, were combined and contrasted, then grouped into categories. This classifying process also combined both inductive and deductive work. Deductively, since the conceptual framework developed from the scoping review included psychological symptom, physical symptoms, psychological function, physical function and social function as categories for health dimensions, it was kept as an initial structure to classify the codes. Inductively, space was left to generate new categories where newly

emerging codes could fit in with. Through the classifying process, newly emerging codes were contrasted and combined with each other, then they were restructured and refined to be finalised as health dimensions, in order to better collate data.

Then, relations across the categorical system, including relations among initial health sub-domain categories and relations among health dimensions, were interpreted and analysed to generate themes of participants' understandings of health. The initial categories were served merely as a guide in data analysis rather than to be final themes. This was because this study aimed to present how participants described and judged heath. After interpreting connections among the identified health dimensions and the meanings of qualitative data within the dimensions, initial health categories were restructured and renamed to better present "what health is" in Chinese lay participant's understandings.

Table 4-3 presents an example of how data was coded, classified and led to the final themes:

Table 4-3: Example coding of data extracts

(Step 1) Data extracted	(Step 2) Data were coded line by line	(Step 3) Codes were grouped into initial health sub-domains (Meanwhile, newly emerged codes were restructured and refined to be health dimensions)	(Step 4) Themes of "Lay Understandings of Health"
"I think I am in a sub-health state, because, firstly, my sleep, is not very good... The second reason is that my stomach and bowel system is not very healthy, especially the defecation, is difficult sometimes….and the discomfort feelings in the waist and neck." (Muqing)	Sleep	Grouped into: Physical function Health dimension: Sleep	Being able to do things without restrictions
	Stomach and bowel function	Grouped into: Physical function Health dimension: Organ function	Being able to do things without restrictions
	Discomfort feelings	Grouped into: Physical symptoms Health dimension: Discomfort feelings	Without physical senses of discomfort

4.3.5.2 Opinions on the descriptive system of EQ-5D

Thematic analysis was also adopted to analyse interviewees' opinions on EQ-5D. However, unlike the analysis that was undertaken to obtain participants' views of health, because there was no predefined framework beforehand, the codes were generated and refined based on the information emerged during interview discussions. The analytic process was as follows:

The first step involved familiarisation of data when the researcher read and reread the comments relating to EQ-5D. Then a line-by-line open coding was conducted to capture useful information about participants' opinions on EQ-5D.

Next, through constant comparisons within one transcript and across transcripts, codes were combined or contrasted, then grouped into categories. At this stage, comparisons were made both within each transcript and between individual interviewing cases. This would establish connections between generated codes before themes could be identified. As data collection and data analysis occurred simultaneously, newly obtained data were compared with existing findings, when they were coded by using either existing or new labels. The subsequently

generated data either brought new concepts or were served as a source to examine the legitimacy of existing findings. This process thus combined both inductive and deductive work. Themes were then reviewed and refined to summarise people's opinions on the descriptive system of EQ-5D.

All data analysis was conducted using the Nvivo 10 software.

4.3.6 Robustness of the study

In order to achieve the integrity of a qualitative study, the whole research process should be systematic and rigorous. Four criteria, namely credibility, objectivity, reliability and transferability, are generally considered to assess the rigour of qualitative research (Lincoln and Guba, 1985; Sandelowski, 1986; Colorafi and Evans, 2016; Miles and Huberman, 1994).

Credibility can be understood as the truth value of the data (Miles and Huberman, 1994). To enhance credibility, all interviews were audio-recorded and were transcribed verbatim to avoid missing essential information from participants. Additionally, the qualitative study recruited participants with various demographic characteristics in order to obtain an account that was as comprehensive as possible in describing health. Credibility in this research was also strengthened by conducting a pilot study before the fieldwork and by using the peer debriefing strategy. The researcher discussed the interviewing questions with the supervisory team and piloted the interviewing procedure with three Chinese participants to ensure the questions included in interviews were appropriate. The supervisory team also audited the data collection and data analysis processes by having regular supervision meetings and discussions with the researcher. The team helped to check whether the results make sense as well.

Reliability refers to the consistency of the findings (Lincoln and Guba, 1985). The following strategies were applied in fostering this study's reliability. First, the research procedure was designed beforehand based on the list of predefined research objectives. Consistency was kept for all participants by using the same interviewer (the researcher herself) and by asking similar key questions. Second, since a preliminary conceptual framework of health had been developed, a consistent coding structure was available in guiding data analysis. Additionally,

the data collection and analysis methods were documented in detail in this thesis, allowing other researchers to evaluate and critique the research procedure.

Transferability can be understood as to what extent the findings can be applied to other contexts (Lincoln and Guba, 1985). Compared to quantitative researchers that often involve a large sample size aiming to address generalisable results, it is difficult for qualitative researchers to demonstrate that their findings from qualitative research are applicable to other populations or situations (Shenton, 2004). This current study was not aiming, yet it was not possible, to present a fully complete account of how health is understood by all Chinese people. Instead, the principal objective of this study was to explore those health dimensions that were considered to be important in describing health in China. The findings were used to revise a previously established conceptual framework of health by adding additional health dimensions that were not covered in the original framework. The revised conceptual framework was therefore supported by the empirical qualitative data and was believed to better summarise how health is described in China. Meanwhile, because the findings of this qualitative study would be used in a Q-methodological study, which is reported in Chapter 5. The Q-study would further help to test the transferability of the findings to a larger sampling group.

Objectivity can be defined as “neutrality” of the findings (Lincoln and Guba, 1985). Since the data collection and data analysis processes were designed and performed by the researcher, there may be some personal and intellectual biases affecting the qualitative inquiry (Mays and Pope, 2000). A researcher’s personal background, including age, sex and professional status and personal experiences, can also potentially influence interviewees’ responses (Berger, 2015; Mays and Pope, 2000). It would be important to clarify the researcher’s understandings of her role, as a way to strengthen the transparency and objectivity of the study (Mays and Pope, 2000). For example, some Interviewees stated because they felt they were inadequately educated, they were afraid of being interviewed in a “PhD research project”. In response to this, the researcher prepared questions using language that was comprehensible to a lay person and tried to make participants understand that there would be no right or wrong answers and all views would be respected. Each interview started by asking “how

are you now?" and "how is your health at the moment?" Such questions were considered to be less challenging and answerable to participants and helped to reduce participants' potential "nervousness" in participating an "interview". Once they started to think about their own health condition, it would also be easier for them to respond the following questions from their own perspective.

4.4 Results

Nineteen participants were involved in the study. Table 4-4 presents the demographic characteristics and the self-rated health status of the participants.

Table 4-4: Demographic characteristics of participants

	Pseudonym	Gender	Age	Self-commented health[8]	EQ-5D Score	Education	Residence
1	Kaifeng	Male	25	Average	11122 (60)	University/college	City, South
2	Yubei	Female	48	“Sub-health”	11111 (85)	University/college	City, South
3	Lianglu	Female	29	“Sub-health”	11122 (70)	University/college	City, South
4	Chenggong	Female	35	“Sub-health”	11222 (85)	University/college	City, South
5	Putuo	Male	18	Good	11123 (75)	Secondary school	City, South
6	Zini	Female	66	Poor	31333 (75)	No formal education	Non-city, South
7	Yuzi	Female	73	Average	11121 (80)	Secondary school	Non-city, South
8	Fengjie	Female	52	Average	11122 (80)	University/college	Non-city, South
9	Xiaozhang	Male	55	Average	11111 (95)	University/college	City, South
10	Laoshi	Male	61	Average	11111 (90)	No formal education	Non-city, South
11	Popo	Female	65	Average	11111 (80)	No formal education	Non-city, South
12	Baozhang	Male	48	“Sub-health”	11122 (80)	Unknown	City, South
13	Muqing	Female	50	Poor	11121 (75)	University/college	City, North
14	Guoqiang	Male	53	Poor	11121 (80)	Unknown	City, North
15	Nianqing	Male	48	Excellent	11111 (100)	University/college	City, North
16	Yali	Female	37	“Sub-health”	11112 (85)	University/college	City, North
17	Jingniang	Male	26	“Sub-health”	11112 (70)	University/college	City, North
18	Yuyue	Female	24	Average	11111 (70)	University/college	City, North
19	Yangshen	Female	80	Good	22321 (85)	Secondary school	City, South

[8] Participants were asked to comment on their overall health status by answering, “How do you think about your health at the moment?” at the beginning of the interview and their “self-commented” health status was categorised into five groups: Excellent, Good, Average, “Sub-health” (This term is introduced in Chapter 1, Section 1.1.2.4.2) and Poor.

4.4.1 Lay understandings of health

Eight main themes were identified and are described in this section in detail. Compared to the conceptual framework of health that was developed in Chapter 3, new categories (themes) were generated in this study including “The opposite of diseases” and “Having a positive mind-set”. Some of the initial categories (sub-domains) of the conceptual framework were merged together: for example, Psychological function and Physical function subdomains were both relating to “abilities to do things” and were grouped together to develop the theme “Being able to do things without restrictions”. Some initial categories were divided into separate themes, such as Physical symptoms, which were separated into “physical senses” and “spirits”. “Having spirits” was identified as an independent theme here because this “Chinese-specific” health concept seemed to be valued by Chinese participants and it would be necessary to further explain how this term was explained by them.

4.4.1.1 Theme 1: “The opposite of diseases”

Describing health as the opposite of disease was a popular view among participants. They explained that health and “no disease” are closely related to each other. In some participants’ opinions, “no disease” was a synonym for health, while some participants illustrated that although being free from diseases may not necessarily mean being in good health, having no disease was a foremost requirement. For example, a participant exemplified some specific diseases to explain that he was not in good health: *I have diabetes, my blood sugar levels are high…health, in my opinion, for example, you do not have any diseases, no chronic diseases, hypertension, diabetes, cardiovascular diseases and so on…(Guoqiang, male, 53, Poor health).*

The idea of thinking about health as the opposite of disease was also reflected when some participants referred to physical examination results when talking about health. They believed that one’s health can be examined by objective clinical indicators and a physical examination helped to identify potential illnesses. If an examination showed that clinical figures were within normal ranges, it was a sign of good health, or it indicated health problems, as a participant illustrated:

> *Jingniang (male, 26, "Sub-health"): I will take a look at my body examination results, to see if they are normal or not… They (clinical indicators) can distinguish unhealthy conditions from healthy conditions. If some figures are out of the normal zone, the person needs to be aware of it and asks his doctor for further consultation.*

Additionally, interviewees were concerned about "body quality" (in Chinese "体质"), or, more formally speaking, body constitution[9], when describing health. Participants illustrated that body constitution indicated whether it was easy for a person to catch a cold or get other diseases. Individuals with better quality were believed to be less likely to have diseases, therefore were in better health. For example, one interviewee said: *for our body health, one thing is our inherited body quality… your ability to fight against diseases. Better body quality, fewer diseases (Fengjie, female, 52, Average health)*. According to participants, body constitution was believed to be inherited but could also be affected by one's lifestyle in the long run, therefore it was different for different people. Some participants thus referred to family medical history in describing health. They explained that because close relatives tended to share common genes and similar body constitution, family illness experiences indicated a person's current or future health problems.

A concept related to "body constitution" was the adaptability to weather changes. As it was discussed by participants, when outside environment, such as temperature or weather changed, a person with better body constitution was more likely to be able to adapt to changes. He/she was believed to be less likely to be ill, which should be considered as a sign of health.

In summary, the first theme showed that Chinese participants described health as the opposite of disease. Participants thought about health as a state which was not disturbed by a disease condition, a state where clinical indicators were all within normal ranges and a state that was unlikely to be ill.

[9] According to the descriptions given by participants and the definition made by WHO ICD-11, constitution here was understood as one's body quality that can indicate the susceptibility to diseases and the ability to adapt to environment changes. Body constitution was introduced in Chapter 1, Section 1.1.2.4.1.

4.4.1.2 Theme 2: "Having spirits"

"Having spirits" was emphasised by Chinese interviewees when they described health and was identified as a separate theme that may reflect Chinese culture. The phrase "spirit", in Chinese "精神", was used frequently in discussions, however, when participants were asked to explain what "spirit" is, most of them expressed it was difficult to define it by words. Participants were then asked to give some examples to clarify how they understood the concept. According to some interviewees, it was an overall appearance which can externally display one's health condition. For example, an interviewee said: *To identify a healthy person, when you see him, you immediately find he is with good spirit, then you know he is in good health… a healthy person looks like he is with a good spirit* (*Lianglu, female, 29,* "Sub-health"*).* Interviewees referred to specific body signs that they often observed to judge an individual had spirits or not. These signs included one's complexion, eye spirts, voice, sitting postures and movement.

> *Kaifeng (male, 25, Average): You can see from his eye spirits, can their eyes focus on things, if they cannot, it means he might have some disease.*
>
> *Guoqiang (male, 53, Poor health): To judge if someone is in good health, I will take a look at one's spiritual state, to see if they have a shiny face, to see if they can walk lively, with strength… you can also tell one's spiritual state by hearing his voice and seeing his eyes, they can all reflect if one is healthy or not.*

Spirit was also associated with one's body strength (the literal translation of "energy" in Chinese). According to some participants, a healthy person should have enough energy and perform daily activities with "good spirit", while a person who looked tired was not likely to "have spirit" and may have some health problems. For example, one interviewee mentioned Spirit when he illustrated why he felt he was in good health:

> *Laoshi (male, 61, Average): I feel I am with good spirit, I can take my father (who was disabled sitting in a wheelchair) to go out every day, every day we take a walk to go to the bridge, to play.*

Some participants also believed that "spirit" commanded people's activities, both physically and mentally, by directing and adjusting human beings' thoughts and behaviours. A participant illustrated that a person without sufficient spirit *"may lose interest in things and may not want to do things positively" (Putuo, male, 18,*

Good), while another participant described a person with no spirit tended to *"feel upset all the day and want to die" (Zini, female, 66, Poor health)*. Spirit, in this sense, could affect individuals' both physical and mental conditions.

"Having spirits" was repeatedly recognised by Chinese interviewees when assessing health. It was displayed as the second theme in this study.

4.4.1.3 Theme 3: "Without physical senses of discomfort"

Participants referred to various physical symptoms when describing health. According to some participants, physical feelings could indicate one's health status because undesirable feelings interfered one's wellbeing and negatively affected one's health, meanwhile one could also feel being in good health when he/she had positive bodily experiences. An interviewee, who thought himself in an "excellent" health state, described that:

> *Nianqing (male, 48, Excellent health): I ask myself: "do I feel anything unusual?" I close my eyes and ask myself this question. I don't. I close my eyes and I think very carefully. I do not have any abnormal feelings. That's it. That is my best condition. Nothing more than that. That is good.*

Some participants revealed that abnormal physical symptoms indicated health problems in the body, therefore unpleasant physical senses were linked to poor health. During interviews, various specific symptoms were mentioned, including allergies, cough, swellings, nasal congestion and dim eyesight. They were believed to be symptoms of diseases, thus signs of poor health. For example, an interviewee exemplified various physical symptoms when she described her health:

> *Chenggong (female, 35, "Sub-health"): I coughed sometimes because I smoked quite a lot … some swellings in the body … my waist and back sometimes have a little bit aches.*

Physical senses such as pain and discomfort were commonly mentioned in dialogues about health. People illustrated different kinds of physical discomfort such as dizziness, numbness in hands and feet, tinnitus, and palpitation. Some interviewees also talked about pain or discomfort in specific body parts, such as back, neck, stomach, feet and waist or discussed bodily pain and discomfort in a general sense of the words:

Zini (female, 66, Poor health): There are some people in my neighbours who are not in good health, I think. They are in pain … and they always said they had pains here and there.

Chenggong (female, 35, "Sub-health"): Clearly, whenever I feel I have some discomfort feelings, I know that I am not in good health.

Several interviewees talked about appetite and thought that the desire for food can reflect one's health. Some participants quoted a Chinese old saying "food is the sky for people" to emphasise that it might be part of the Chinese culture that they appreciated what to eat and how to eat well. They explained that if a person could only take a small amount of food, he/she may not be supplemented with enough nutrients and was likely to become ill. Additionally, because it was people's natural desire to have food, losing interest in food may reflect he/she was particularly unwell, mentally or physical or both. Appetite can thus be an effective indicator to judge someone's health.

Interviewees believed that physical symptoms were health-related body signs and referred to physical senses in describing health. Health, in this view, could be understood as the condition without undesirable physical senses.

4.4.1.4 Theme 4: "Having a good mood"

Apart from physical senses, there were also frequent discussions about emotional experiences, when participants referred to emotions and moods to describe health. Some participants explained that mental health was an important part of health itself, while some illustrated how one's emotional experiences affected the physical state, therefore one's psychological state could reveal health to some extent. For example, some participants discussed stressed feelings during interviews and highlighted that stress influenced his physical health:

Baozhang (male, 48, "Sub-health"): The stress that comes from my job makes me feel I am in sub-health… My sub-health is like, I want to do things but I feel I do not have sufficient energy… I am not energetic to my work.

Feelings of anxiety and worry were also referred to in conversations. Anxiety, or worry, which can be understood as the same thing in the Chinese language, seemed to be a common issue for participants across different age groups. Many participants stated they felt anxious, worried and had too many things in mind.

Some believed such feelings were mental health issues, for example, a participant said that *at the beginning, you cannot control yourself, then you feel anxious, you are agitated and you get a series of mental problems (Yali, female, 37, in "Sub-health")*. Some explained these psychological symptoms disturbed their normal life and made them feel in a poorer health state. For example:

> *Guoqiang (male, 53, Poor health): I worried a lot when I was in bed, I tended to think a lot of things and I could not sleep.*

Other specific emotional experiences, either negative or positive, including depressed/happy, peaceful/excitable, and fear/safe, were mentioned in conversations about mental health. Additionally, some participants described their general emotional state without specifying the exact feeling. People thought that a generally pleasant mood and a feeling without any mental discomfort could reflect a healthy mental state:

> *Yubei (female, 48, "Sub-health"): The time when I feel I am in good health, I am generally in a pleasant mood and there are few things to worry about;*
>
> *Zini (female, 66, Poor health): My heart became uneasy, uncomfortable, and I thought there were so many things and no one would help me.*

In summary, the fourth theme showed how participants regarded mental "feelings" as a component of health. They were aware of moods and emotions and their relations to health status.

4.4.1.5 Theme 5: "Being able to do things without restrictions"

Additionally, participants referred to one's ability in doing things when they described health. In this view, if a person had problems in performing certain activities, his/her life was restricted and this could be seen as a sign of poor health; if a person was able to do things without restrictions, it indicated good functional abilities, and therefore, good health.

Sleep was discussed by many interviewees. Participants mentioned the quality of sleep, difficulties in being asleep, length of sleep and insomnia conditions when they described their health. They explained that sleep was an important aspect of everyday life and poor sleep affected life quality directly. They also mentioned that one's physical body needed sufficient time of resting when sleep could help a person to restore energy. Additionally, sleep was believed to be closely linked

with one's mental state. For example, one participant said she was not in a good health state, then she illustrated:

> *Zini (female, 66, Poor health): I have one problem, I cannot sleep well. I cannot sleep. I used to be very afraid because I cannot fall asleep. I am afraid I will be diagnosed with depression.*

Mobility was another important health dimension according to participants. Many people stated activities, such as walking, climbing stairs, going out to play, exercising, running and bending one's knees, which were related to one's mobility and flexibility, when describing one's health condition. A participant illustrated that "*I think I am good … I can walk, I can go to the nearby town, I can climb stairs and slopes, without any problems" (Popo, female, 65, Average).* In addition to the activities of mobility, some participants referred to other routine activities in daily life to describe health. Some people mentioned self-care activities including brushing teeth and taking shower; some participants talked about their daily activities such as doing shopping, cooking meals and playing Mah-jong; while some also mentioned their performance in their working and studying. Whether the specific organs, such as eyes and ears, could perform well was also covered in discussions. They explained that some of these functional abilities were basic requirements in daily life, therefore were important indicators for health. For example, without the ability to move, a person would be restricted from doing many other activities and may need external help in order to do things.

Besides those physical functional activities, cognitive function was considered by interviewees in judging health as well. Abilities to think things clearly, to remember things, to make decisions, to concentrate on things and to perceive surrounding changes and respond were identified as health dimensions from the conversations. They believed that those cognitive functional abilities were essential to their work, study, conducting daily activities and social wellbeing. Some participants highlighted the importance of cognitive function to health by making examples of elderly relatives losing memory. They explained that because their relatives were losing memory, they had deteriorating health condition as well as life quality.

The fifth theme conveyed that health could be defined from a perspective of function. Health was described and assessed by referring to abilities to perform various activities in interviews.

4.4.1.6 Theme 6: "Having satisfying social relationships"

During interviews, participants also talked about social wellbeing in describing one's health. Many of them referred to the WHO health concept, highlighting the social aspect was a component of health. Some participants stated that although social health was not part of the "traditional" concept of health, which consisted of physical health and mental health only, social relating issues such as abilities in dealing with social relations were closely linked with one's health condition and were essential to each individual. They explained that one's state of social relations influenced one's health state, especially one's mental health state. For example, one participant revealed that he felt lonely and unhappy because he did not have many friends and he was aware this situation would affect his mental wellbeing:

> *Putuo (male, 18, Good health): Interpersonal relations, the ability to deal with interpersonal relations, I have some problems… I do not have many friends at school; for other people, they get friends to have lunch together … I am always alone and do not have classmates or roommates to chat with, we don't have common topics… I don't like being in this situation, I feel if I always live in this way, I will be not healthy... mentally.*

Some interviewees mentioned that one's ability to deal with social relations can largely determine if he/she adapted well into the social environment, enjoyed living in a community and in return contributed to the community. Being well involved in one's community and welcomed by other people in one's community was believed to be beneficial to both the individual and the community, and was therefore regarded as a sign of good health, from both an individual perspective and a social perspective. On the other hand, some participants illustrated those criminal offenders who conducted anti-social behaviours. They highlighted that even if a person was physically healthy if he/she caused negative influences on society, this person would not be considered as in good health. They believed that the misbehaviours of those criminal offenders were due to the fact that they failed to be involved in a community, which was a sign of poor health itself. For example, a participant described:

Xiaozhang (male, 55, Average): There was a Chinese college student, Jiajue Ma (a university student who killed his four roommates after having quarrels with them), he was surely an example of being in bad health, although he might have a strong body… he is not able to communicate with people...

Social support was also regarded to be crucial for many participants. They highlighted that supports from friends and family could influence one's health status, especially mental health. An elder participant mentioned how financial support and sufficient care from their children affected her mood, making her did not feel lonely most of the time and was satisfied with her life. Feeling supported was believed to be able to bring about positive emotional experiences such as confidence and sense of security, as a participant explained:

Yuyue (female, 24, Average): I think social health is so important, it can largely affect your mental health … People are very easily affected. It is very hard to stick to your opinions when everyone else thinks you are wrong … Are there many people supporting you? If not, you may feel upset and start to doubt about yourself.

"Having satisfying social relationships" was named as the sixth theme, given the general recognition of people's sociality during discussions.

4.4.1.7 Theme 7: "Having a positive mind-set"

Some participants believed that one's mind-set, which can be understood as one's mental attitude towards life, was a component of health. They described a healthy person as being with "positive energy" and "sunny attitudes", while suggested people with "negative attitudes" and being "lazy" were unhealthy. They seemed to understand health as a positive state, where a person should be not only physically positive (doing things without restrictions) but also mentally positive (with a positive life attitude). In this view, with a positive mind-set, a person was more likely to act energetically in daily life and was more likely to be "full of spirit" according to some participants, as one interviewee described:

Muqing (female, 50, Poor health): you can see people who are very sunny, who are with positive energy, he would normally do things with his own initiative and was always energetic, with spirits.

Participants also held an opinion that one's life attitude could largely affect one's health, both physically and mentally. They referred to those people who were physically disabled but still lived positively and optimistically and eventually

overcame physical restriction to explain such influence. They believed that one's positive attitude could give him/her a good signal and caused positive effects.

One's mind-set also consisted of one's attitude towards others, as interviewees suggested, it was "healthy" to be "open-minded", "big-hearted" and "tolerant" to other people, instead of being "aggressive" or "narrow-minded". They again highlighted the importance of social wellbeing, which was believed to be closely linked with people's attitude to others, as a participant illustrated, *"one should be more generous, this can reflect health too, if someone has a narrow mind, he may treat his family, friends, boss, or colleagues in a way that was not favourable. He may not be welcomed by others. He may not feel happy himself because he could not deal with relationships very well (Xiaozhang, male, 55, Average)"*. In this view, being open-minded and tolerant to people, a person would be liked by people surrounding him/her and was expected to have a better state of social wellbeing.

Some participants also illustrated abilities to cope with stress or to adjust temper in describing health. These abilities addressed conditions requiring people to deal with external stimulants or external relations with other people. Such abilities were considered to be associated with one's mind-set because it was explained that with better ability to cope with unfavourable external challenges or conflicts with others, individuals were more likely to stay optimistic in mind or to be lenient to treat other people. Thus the individuals tended to hold a more positive mental attitude and to be in better health from mental and social perspectives.

The seventh theme was about individuals' mind-set and life attitude. It expanded the concept of health in a wider context by considering how individuals dealt with external relations and external stimulants.

4.4.1.8 Theme 8: "Behaving well in everyday life"

One's lifestyle behaviour was considered to be directly linked with health in interviews. Positive health behaviours, such as maintaining regular excise, keeping a balanced eating diet and maintaining a regular work-and-rest schedule, as well as negative health behaviours, such as smoking, drinking too much alcohol and sleep too late, were mentioned.

It was discussed in interviews that one's daily behaviours could affect one's current health state. A participant illustrated that she stayed up late last night and that was why she felt tired and unwell in the morning (Yuyue, female, 24, Average). She added that she felt less energetic and her work efficiency was affected and did not think she was in a good health state.

Some participants referred to the long term effect of lifestyle behaviours on health, as a participant illustrated, *"if a person continued to go to bed late for a long time, his/her energy would be difficult to be restored and immunity may decline eventually"* (Yali, female, 37, in "Sub-health"), one's everyday behaviour can reflect one's future health status. Good lifestyle behaviours were expected to help a person to gain better health status in the future, while unhealthy lifestyle behaviours were likely to damage one's future health. Unhealthy habits such as drinking alcohol and smoking were frequently mentioned in interviews by participants. Participants explained that although the negative health behaviours may not cause an immediate effect on one's health, they affect one's health in the long run, as a participant described, *"some teenagers think smoking is cool… they cannot foresee smoking's bad influence. Once smoking becomes their habits, it will damage their health... They will have health problems later."(Baozhang, male, 48, "Sub-health")*

Under the last theme, it was suggested by participants that lifestyle behaviours could affect health now and in the future, therefore one's lifestyle was considered as an important aspect in describing one's health.

4.4.2 A revised conceptual framework of health

The conceptual framework of health developed from the scoping review study was used to guide the qualitative analysis in this study. To better present how Chinese participants described health and assessed health status, the categorisation scheme of the preliminary conceptual framework was refined and renamed to develop themes of Chinese participants' understandings of health. Table 4-5 below presents how the themes were developed from the initial categorisation scheme. The finalised themes (fourth column), which were developed from the qualitative study, were compared with the initial categories derived from the scoping review study (first column). The identified health

dimensions in the qualitative study were listed in the third column in the Table 4-5 and were compared with the health dimensions identified in the scoping review study (second column).

Table 4-5: Comparisons in findings between the scoping review and the qualitative study

Initial categories for health dimensions	Health dimensions identified from the scoping review study	Health dimensions identified from the qualitative study	Themes of "lay understandings of health"
Other		Disease	"The opposite of diseases"
		Physical examination results	
	Family history	Family history	
Physical symptoms	Susceptibility	Body constitution (Susceptibility)	
	Weather adaption	Weather adaption	
	Appearance	Appearance	"Having spirits"
	Spirit	Spirit	
	Fatigue	Fatigue	
	Energy	"Body strength" (Energy)	
	Complexion	Complexion	
	Discomfort	Discomfort	"Without physical senses of discomfort"
	Pain	Pain	
	Appetite	Appetite	
	Other abnormal signs	Other abnormal signs	
Psychological symptoms	Stress	Stress	"Having a good mood"
	Depression	Depression	
	Worry/anxiety	Worry/anxiety	
	Emotional stability	Emotional stability	
	Anger	Anger	
	Fear	Fear	
	Sense of security	Sense of security	
	Happiness	Happiness	
	Loneliness	Loneliness	
	Confidence	Confidence	
	Satisfaction	Satisfaction	
Physical function	Sleep	Sleep	"Being able to do things
	Mobility	Mobility	
	Usual activities	Usual activities	

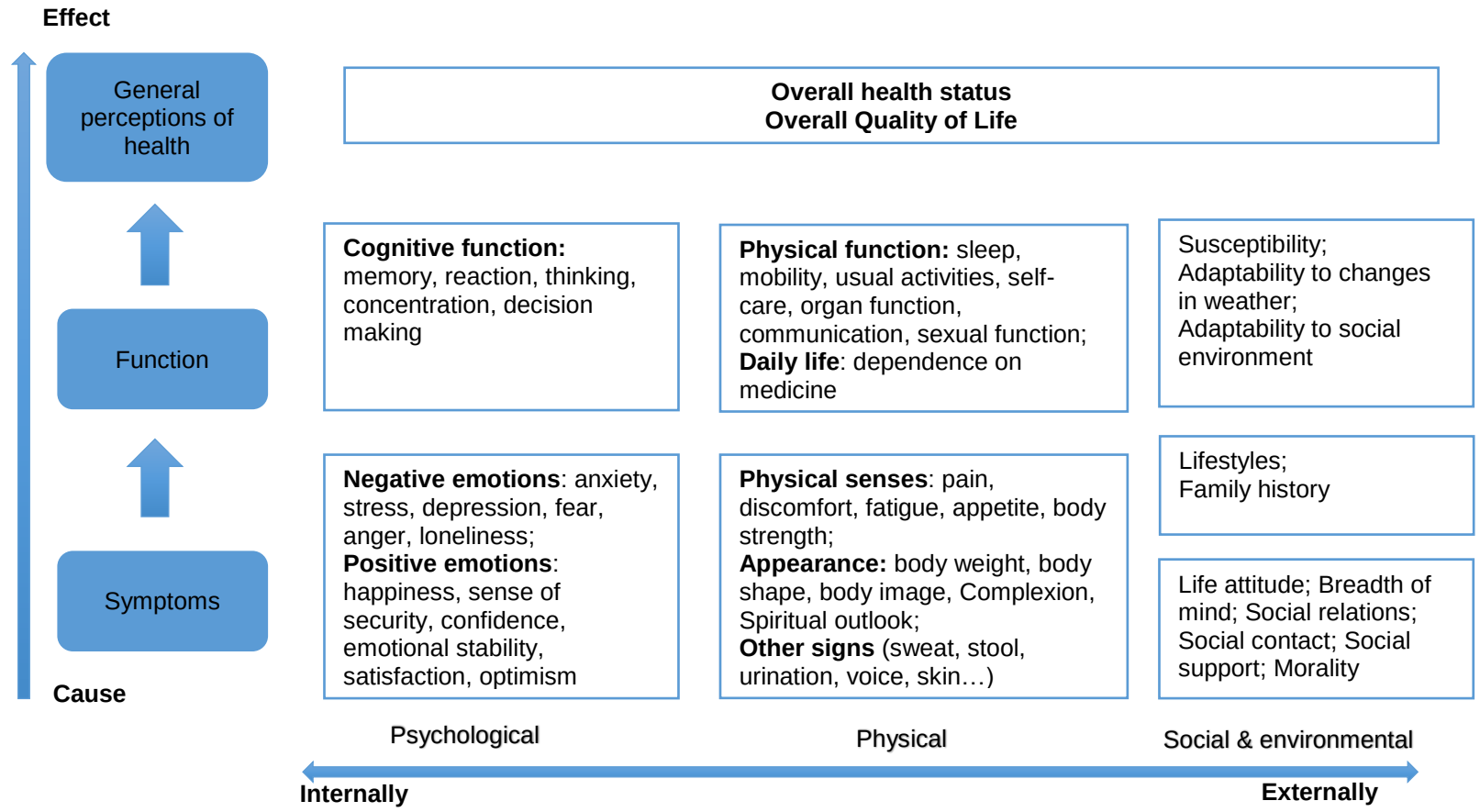
	Organ function	Organ function	without restrictions”
	Self-care	Self-care	
	Sexual function		
	Dependence one medicine		
Psychological function	Thinking	Thinking	
	Reaction	Reaction	
	Memory	Memory	
	Decision-making	Decision-making	
	Concentration	Concentration	
Social and role function	Social relation	Social relation	“Having satisfying social relationships”
	Social adaption	Social adaption	
	Social support	Social support	
	Communication	Communication	
	Morality	Morality	
	Social contact		
N/A	Optimism	Life attitude (including optimism)	“Having a positive mind-set”
		Breadth of mind	
		Ability to deal with stress	
		Ability to adjust the mood	
		Personality	
Other	Lifestyle	Lifestyle	“Behaving well in everyday life”

Generally speaking, health dimensions identified from this qualitative study were found to be highly comparable with that from the scoping review study. Meanwhile, there were some differences between the scoping review and the qualitative study in terms of the identified health dimensions. Diseases, physical examination results were referred to by participants to describe health but were not included in the reviewed HRQoL measures. This may be because the principal aim of the HRQoL measures was to collect information on subjective health status and did not include objective clinical indicators. Second, “Having spirits” was identified as an independent theme in this study. This was because “spirit” was widely recognised by Chinese participants and seemed to be an important theme of health in describing health among them. It was distinguished from other physical senses to show its importance in a Chinese cultural setting.

Health dimensions relating to individuals' attitudes towards other people ("breadth of mind") and personality were considered to be important in assessing health according to many participants but were not covered in the initial conceptual framework. They were therefore added to the conceptual framework. Sexual function was not mentioned by participants in this qualitative study but was part of the preliminary conceptual framework. This may be because sex was considered as a private and sensitive topic by participants and they did not feel comfortable to talk about it during interviews.

A revised conceptual framework was updated with newly added health dimensions from lay participants. Figure 4-1 below presents the revised conceptual framework.

Figure 4-1: Conceptual framework of health based on the scoping review and interviews



4.4.3 Opinions on the descriptive system of EQ-5D

Both positive and negative comments about the EQ-5D were obtained during the interviews. The simplicity of the HRQoL measure was acknowledged by participants, while some participants also pointed out that EQ-5D may not be satisfactory in assessing his/her health due to several reasons. There were some conversations about the visual analogue scale, however, as this study was mainly interested in the descriptive system of EQ-5D, the discussions on the VAS with the interviewees were not analysed and reported here. The following themes were identified to summarise their opinions on the descriptive system of EQ-5D.

4.4.3.1 Theme 1: "The clarity of EQ-5D"

All participants completed EQ-5D within 3 minutes and almost all participants stated that the questionnaire was short and simple. None of the participants reported they had problems to complete it, as a participant described, *"the questions are simple … relating to my daily life... I can understand all of them" (Xiaozhang, male, 55, Average).* Participants generally demonstrated a good understanding of the dimensions of EQ-5D. Almost all participants were able to describe that the first three questions were about the abilities to conduct physical activities, including walking, self-care activities and usual activities, while the fourth and fifth questions were relating to one's "feelings".

Although participants did not report problems in completing EQ-5D themselves, it was suggested that because the five dimensions included in EQ-5D were broadly defined items, some of the dimensions may cause confusions or inconsistent understandings. A participant illustrated that "Pain/Discomfort" could stand for different physical and/or emotional experiences: some may think the feeling of tiredness is a type of discomfort, while some may not relate tiredness as discomfort; some may understand "Pain/Discomfort" as psychological pain/discomfort, but some may think it is a question just about physical symptoms (*Kaifeng, male, 25, Average*). It was also mentioned that some discomfort feelings may not indicate poor health. For example, after physical exercise, people's muscles may ache, but such a painful feeling was not a sign for poor health (*Kaifeng, male, 25, Average*). It showed that because five dimensions of

EQ-5D were not defined in a definite manner, they were potentially not clear enough for participants.

The first theme addressed the clarity of the descriptive system of EQ-5D. Participants expressed that they did not encounter problems to complete EQ-5D and demonstrated a generally good understanding of it. However, it was also mentioned that the descriptive system of EQ-5D was not defined in a definitely clear manner and caused some confusions.

4.4.3.2 Theme 2: "Relevant vs redundant"

Participants tended to agree that EQ-5D comprises health dimensions that were important and relevant to health. It was mentioned that the first three health dimensions were about one's physical functional abilities, which were basic components of one's daily life, as a participant described: *the questionnaire begins with the most fundamental dimension of the body health, then moves to daily life, then to mood, step by step… A healthy person must be able to walk, to do these activities...These things should be assessed (Baozhang, male, 48, "Sub-health").* The other two dimensions were also believed to be able to reflect one's health, as participants explained that these two dimensions asked whether a person had unfavourable physical or emotional experiences, which would affect one's current health status.

However, although the dimensions were believed to be important in a general sense, some participants, especially those participants who were young and in a relatively good health state, mentioned that because they did not have any problems in such basic physical functional activities, the first three questions were not that relevant to them in assessing their health. For example, a participant addressed: *The five questions, I think most people do not have these problems, especially the first four problems, but in my understating, people rarely can be in full health… I think you should consider the age groups. People in their 40s and 50s, you design a different questionnaire for them (Yubei, female, 48, "Sub-health").* Participants stated that they did not think they were in full health but their EQ-5D health profile appeared to be as a full health state because they did not have any problems as asked by EQ-5D. They suggested that the questions may

be more relevant to old people since dimensions such as mobility and self-care were more likely to be problems among the elderly.

Some participants also concerned about the redundancy of the five dimensions. They thought mobility, usual activities, self-care were overlapping with each other. Some participants thought the three questions were all about physical activities and were not necessary to ask them together: *Walking about and doing usual activities, I feel they are quite similar ... It is confusing to arrange them in a questionnaire and ask these questions together (Yali, female, 37, "Sub-health").* Some explained that they felt mobility was a prerequisite to be able to do self-care and being able to do self-care activities was a necessary condition for being able to conduct usual activities. Therefore, it was redundant to include all of them in one questionnaire. For example, a participant stated that: *Usual activities, self-care, and … (Mobility) the first three are all about self-care. If you cannot walk, you cannot conduct self-care activities, they are in the same range… If you can completely take care of yourself, you can do well in the other two dimensions (Muqing, female, 50, Poor health)*.

The second theme summarised participants' opinions on the content of the descriptive system of EQ-5D. While the five dimensions of EQ-5D were agreed to be important aspects of health, they were mentioned to be not relevant in assessing health among participants who were in a relatively good health state. The redundancy of some of the dimensions was also revealed by participants

4.4.3.3 Theme 3: "Incompleteness as a measure to assess health"

It was stated in the interviews that the descriptive system of EQ-5D was incomplete in describing health. It was already reported in Theme 2 that, although the five dimensions of EQ-5D were believed to be important health aspects, many participants argued that these health dimensions were too basic to reflect one's health: *These five questions are basic… washing, dressing myself, walking about, usual activities, I don't have these problems. They are very basic* (*Lianglu, female, 29, "Sub-health").* Some participants addressed that EQ-5D defined health in a negative way because EQ-5D only assessed whether individuals had problems in doing things and examined whether individuals had unwilling feelings. However, they believed that a state of being free from dysfunction and

unpleasant senses was only a prerequisite of being in good health but did not indicate full health, as a participant illustrated: *these indicators are quite basic to judge whether someone is healthy or not… If you can do these things mentioned here, without problems, you are not definitely in good health; but if you cannot, you are certainly not in good health (Jingniang, male, 26, "Sub-health").* It was suggested that including questions describing health from a positive perspective, such as examining whether a person felt happy or whether a person felt energetic, may be necessary.

Participants illustrated various health dimensions that they believed to be important in describing and assessing health. They recapped how they described health and highlighted health dimensions that they considered to be relevant and important to his/her health. For example, one participant illustrated: *Five questions, the number of questions is too few. For health, I care about other things, for example, mental attitude… I think mental attitude is the most important thing. Here, anxiety/depression is quite close to mental attitude, but mental attitude is far more than this… like I just said (it is also about) I am not good at communication… I feel under pressure; I do not accept my current situation when I compare with other people (Xiaozhang, male, 55, Average)*. Many participants mentioned medical history records, current health problems (diseases), spiritual states, fatigue and sleep to assess physical health. Emotions, mood, the ability to deal with stress, mind-set (mental attitude) social relations and social support were frequently mentioned by participants as well.

It seems that different participants tended to refer to different health dimensions that he/she thought as most important. For example, there was a participant who spent much time in working, he, therefore, stated that he concerned more about work-relevant issues when thinking about health*: I think the questionnaire cares more about basic abilities to do things in daily life. It looks like the first three questions are all about daily life. I think apart from daily life, I care about my work… I spend a lot more time working, so you can ask more about work-relevant things. Stress? Working efficiently or not? That kind of things (Baozhang, male, 48, "Sub-health").* Some participants paid more attention to mental health. They mentioned that there were four questions about physical health and only one about mental health and argued that the designers of EQ-5D emphasised on

physical health but ignored other aspects of health, which may be not appropriate: *The questionnaire is more about the body aspect, is that right? The first four questions are about body health and the last one refers to the mental aspect… I think mental health and physical health are equally important (Yuyue, female, 24, Average)*.

The third theme addressed the problem of the incompleteness of EQ-5D and suggested that there were other important health dimensions that should be included in assessing health.

4.5 Discussion

4.5.1 How is health defined in China?

This qualitative study explored lay understandings of health among Chinese participants. Health dimensions identified from this study are highly comparable with that from the scoping review study. It shows that those Chinese-developed HRQoL measures covered most of the aspects of health that a Chinese population may consider important. It, therefore, helps to justify that the initial conceptual framework is applicable in describing the content of health in a Chinese cultural setting. On the other hand, this qualitative study identified several health dimensions that were not covered in the identified HRQoL measures but seemed to be important to lay Chinese participants. This helps to revise the established conceptual framework of health by adding these health dimensions. With the empirical evidence, the conceptual framework is expected to be more comprehensive in summarising potential important health dimensions among a Chinese population.

This qualitative study identified eight themes to summarise how people in China may describe health. The study showed that Chinese participants understood health from a medical perspective and referred to health as being “the opposite of disease”. Meanwhile, they also introduced a Chinese concept “spirit” as an indicator of health. Some participants illustrated physical senses and emotional experiences in describing health, while understanding health from a functional perspective was another way of thinking about what health was. Additionally, some participants concerned about one’s social wellbeing as a component of

health. A person's mind-set and one's lifestyle were also mentioned by participants in interviews. Various health dimensions from different aspects were included in the discussion with participants, which indicates that health is a multi-dimensional concept that can be described in various ways.

4.5.1.1 Comparing across participants

Generally speaking, the Chinese interviewees shared comparable views in describing health. Almost all participants held the point that health contained at least two main domains: body health (physical health) and mental health. Social relations, sleep, fatigue, body strength, lifestyle habits, appearance and discomfort were frequently mentioned in describing health across participants.

On the other hand, since health is a subjective concept, despite similarities shared among participants, different opinions were raised. It seems that individuals' demographic characteristics affect how they perceive health. One potential influencing factor is age, as it was reported in previous studies that people in different age groups had different concerns when describing health (d'Houtaud and Field, 1984; van Dalen et al., 1994; Krause and Jay, 1994; Simon et al., 2005; Peersman et al., 2012). For example, participants who were at a younger age talked more about work stress and negative emotions than the elderly. More specifically, six out of seven participants who were in the age between 40 and 60 mentioned the feeling of nervous, while only one participant with an age elder than 60 referred to stress as a health dimension. Meanwhile, participants in an older age tended to consider more about chronic diseases and physical function such as mobility and self-care. All of the five participants, whose age was more than 60, named mobility for health assessment, while only two participants in the 40-60 age group did. A reason might be that one's health status tends to decline with age and elder people are more likely to be bothered by physical functional problems and various chronic diseases. It may also be because participants in different life stages have different activities in their daily life and perform different social roles. Generally speaking, younger people are more likely to have a job and work under stress compared to the elderly, therefore are more likely to address this particular aspect in describing health.

Participants' understandings of health may also be shaped by his/her current and past health experiences (van Dalen et al., 1994; Idler et al., 1999; Simon et al., 2005; Peersman et al., 2012). When they are asked to think about and describe health, they are likely to make reference to their current health problems or disease experiences. For example, a participant kept mentioning interpersonal relationships as an aspect of health and he also stated that he confronted problems in dealing with social relations himself. It was also the sufferers of particular diseases mentioned specific symptoms of those diseases. In addition, participants who were in a good health state generally had a more positive definition of health and were less likely to talk about negative health experiences such as pain or functioning problems than participants in poorer health state. For example, participants who commented themselves as in "Good health" or "Excellent health" were more likely to refer to one's mind-set (mental attitude) in describing health. This may be because people who are in a good health state are rarely disturbed by physical health disorders in general. They are, therefore, more likely to have a higher expectation of their own health and define health in a more positive way.

The findings also imply that education may affect how people perceived health, as it was covered in the literature (Krause and Jay, 1994; van Dalen et al., 1994; Idler et al., 1999; Peersman et al., 2012). Participants who were less educated were less likely to be aware of mental health: they seldom mentioned emotional experiences such as stress and anxiety and tended to understand health from a physical perspective only. One reason might be that they had no access to information relating to mental health and were not aware of it. It may also be because they were more likely to conduct manual work, due to their limited education level, and were less frequently to expose to mental health problems. Additionally, participants' descriptions of health are closely related to one's living environment, similar to what was reported in previous studies (Hughner and Kleine, 2004; Bowling, 1995). Participants who lived in cities were more likely to refer to mental health problems, as they may be experiencing more anxiety and stress from work and family, compared with participants living in the countryside.

4.5.1.2 Comparing with the Western literature

Most themes identified in this qualitative study are found to be similar to previous studies about lay understandings of health, which were mainly conducted in the West. Similar to what was reported in the current qualitative study, previous Western studies also referred to the absence of ill-health as a core aspect of self-evaluated health (d'Houtaud and Field, 1984; Krause and Jay, 1994; van Dalen et al., 1994; Manderbacka, 1998; Idler et al., 1999; Hughner and Kleine, 2004; Simon et al., 2005; Singh-Manoux et al., 2006; Peersman et al., 2012). Describing health from a functional point of view, which was identified in interviews with Chinese participants, was another widely recognised theme in the Western literature (Williams, 1983; Krause and Jay, 1994; van Dalen et al., 1994; Manderbacka, 1998; Idler et al., 1999; Simon et al., 2005; Peersman et al., 2012). Physical symptoms, as well as emotional experiences, were also identified to be important components of subjective health in the West (Manderbacka, 1998; Simon et al., 2005; Peersman et al., 2012). Further, lifestyle was covered in many Western studies as a theme of the lay concept of health (Krause and Jay, 1994; Manderbacka, 1998; van Dalen et al., 1994; Peersman et al., 2012).

The theme “Having spirits” in this study proposed a Chinese-specific concept and potentially suggests cultural differences between China and the West. “Spirit”, in Chinese, can partly be understood as energy and this is comparable to what was shown in several Western studies that energy was regarded as an aspect of health (d'Houtaud and Field, 1984; Peersman et al., 2012), However, this concept also comprises other meanings in the Chinese language. It was illustrated by participants that “spirit” is an overall impression on a person and it can be assessed through one’s physical appearance, such as eye spirits and complexion; some regarded it as concentration or consciousness. These descriptions are compatible with how “spirit” was described in the Chinese literature (Hsu, 2000; Kaptchuk, 2000; Liu and Fang, 2000). “Spirit” was well understood by Chinese participants when describing health in this study, it was also reported elsewhere that the Chinese ethnics frequently characterised health as “positive spirit” (Damron-Rodriguez et al., 2005). It suggests that “spirit” is a widely-recognised concept in a Chinese cultural setting and indicates cultural differences between China and the West when thinking about health.

Social wellbeing and one's mind-set were frequently referred to by participants in this study but were mentioned by fewer Western literature (Idler et al., 1999), compared to the other themes. Chinese culture is considered to be "collectivism" and "low-individualism", as opposed to most Western societies (Hofstede, 1984; Hofstede and Bond, 1988; Hofstede et al., 2010a). Chinese people are believed to be generally more family-oriented and have stronger and closer links with family relatives than Western people (Bond and Yang, 1982; Rosenthal and Feldman, 1990; Lam, 1997). Therefore, Chinese people may value about social wellbeing as well as abilities to cope with social relations more than Westerners do.

Chinese culture emphasises on reaching a harmonious state with the external environment (Shen, 1990). This idea is consistent with what was found in the study, where Chinese participants highlighted the importance of mind-set and life attitude in coping with external relations. The emphasis on life attitude may also be because with the largest population, the Chinese society is with fierce competition and Chinese people are likely to live in a relatively stressful environment. Confucianism, such as the Doctrine of Mean (it is about keeping a balance in life, to compromise and to tolerate when needed), advises people to avoid conflicts and stay in harmony (Zhang et al., 2015). Those mental abilities to deal with stress, stay positive, as well as get along well with people are thus believed to be of high importance in staying in a harmonious state to be in good health in China.

Some western studies included a "religious" aspect of health (Idler et al., 1999; Hughner and Kleine, 2004), which was not mentioned by participants in this study. It is frequently reported that religious beliefs and theistic views are influential in shaping lay understandings of health in the Western literature when people "view health as a product of 'right living', spiritual well-being, and God's care" (Hughner and Kleine, 2004: p40). In contrast, none of the Chinese participants in this study referred to this view. This may be because the Chinese government is officially atheist and a relatively small percentage of the population is religious (Albert, 2018).

Apart from the differences between China and the West in the broad themes of health, there were other differences in terms of specific health dimensions. Some health dimensions that were identified in this study seems to be specifically valued by Chinese participants but were not commonly mentioned in those Western studies. Body constitution, or in lay participants' words, "body quality", was defined to be closely linked with one's immunity to diseases and was determined by both inherited indicators and acquired factors such as lifestyle behaviours and living environment. This term was not only found to be a frequently discussed concept in describing health among lay participants in this study but was also found to be an understandable and commonly-used health indicator across a Chinese community in the literature (Lew-Ting et al., 1998). Additionally, eating/appetite and sleep were frequently mentioned by Chinese interviewees but were not frequently covered in the Western literature. The scoping review showed that sleep and appetite were two commonly included health dimensions in the identified Chinese-developed HRQoL measures. This current qualitative study again reported that these two dimensions were considered to be important in describing and assessing health among a group of Chinese participants. It indicates that these health dimensions are potentially important in a Chinese cultural setting but are not emphasised in the West. This also shows possible cultural differences between China and the West in describing health.

4.5.2 The content validity of EQ-5D

The content validity of EQ-5D was questioned by participants in terms of its clarity, relevance and completeness. The participants of this study expressed some doubt on the descriptive system of EQ-5D. Some of them suggested that the dimensions of EQ-5D were not stated in a definite and clear manner and may lead different participants to have different understandings on the same term. In fact, even the developers of EQ-5D were found to have various interpretations of terms and phrases within EQ-5D (Fox-Rushby, 2005). This issue was also reported in a previous study, where the authors found that participants interpreted the dimensions of EQ-5D differently. For example, some of them narrowly interpreted EQ-5D, focusing on one aspect of "Pain/Discomfort" and

“Anxiety/Depression” or on one type of activities for “Usual activities” (van Leeuwen et al., 2015).

EQ-5D was also commented to be not sufficient in assessing health according to some participants. Many participants thought the five dimensions were too basic to reflect one’s health. This may be because most of the participants recruited in this study did not have dysfunctional problems, while a general well population has a more positive view of health compared to patient populations (Patrick and Erickson, 1993). As a result, it is suggested that EQ-5D is not comprehensive and fails to cover health dimensions that are considered important. Similarly, a South Korean study showed that EQ-5D did not fully capture dimensions of health which might be important to the Korean general public and the authors proposed vitality and sleep should be added (Kim et al., 2017). Another recent study which surveyed a patient sample from 38 countries also argued that the EQ-5D might not be comprehensive in assessing health (Efthymiadou et al., 2019). Apart from the problem of completeness, some dimensions are believed to be overlapping with each other and redundant. This is comparable to what was reported in the Korean study, where self-care was found not significant in describing one’s health status (Kim et al., 2017).

Importantly, the content validity of EQ-5D can also be questioned from a cultural perspective. It was mentioned in Section 4.5.1 that although there are considerable similarities in describing health between Chinese participants and what was reported in the Western literature, cultural differences in understanding health between China and the West are apparent. Chinese participants highlighted social wellbeing and mind-set in describing health, while the two themes of health were less frequently to be discussed in Western studies of lay understandings of health. There were also unique health dimensions, such as spirit, body constitution, sleep and appetite, which were valued by Chinese participants but were not commonly mentioned in those Western studies. It seems these health dimensions are relevant and important in a Chinese cultural setting, but they are not covered in EQ-5D. The content validity of EQ-5D can, therefore, be further questioned in a Chinese cultural setting.

4.6 Limitations

The nineteen interviewees were purposively selected to be relatively diverse in terms of demographic characteristics and were expected to present views from various perspectives. However, because the recruited participants were from certain regions of China, it would be hard to justify that their views are transferable to other Chinese populations in a different geographical location. Some participants may have their dialects and it may be the case that the usage of some phrases was exclusively restricted to people there. A sample of participants from a wider range of geographical living places would be recruited in the next empirical study to further justify the results of the current qualitative study.

The nature of a cross-cultural qualitative study brought about problems caused by language differences. Due to linguistic and cultural differences between Chinese and English, the process of transferring Chinese data into English results was challenging. One may always argue that the results being reported can be biased and cannot fully reflect what was conveyed in the original texts. To minimise the effect of the researcher's interpretations on the transcripts and to reduce the possibility of losing information, the Chinese transcripts were coded in their original form without being translated into English. The identified health concepts and the developed themes were then translated and described in a detailed manner to be reported in English.

Additionally, with difficulties in finding a second bilingual researcher to analyse transcripts and discuss codes together, the analysis was conducted by only one researcher. The researcher was aware of her potential influences on the study and tried to minimise such biases to a minimum during data collection and data analysis by applying rigorously designed research process. The researcher also had continuous discussions about identifying codes and themes with the supervisory team through the analytic process.

4.7 Conclusions

To conclude, this chapter describes a qualitative study which explored lay understandings of health in China. It summarises how Chinese lay people may

understand and describe health. It presents that several health concepts were highlighted by Chinese lay participants, such as “spirit”, “body constitution”, eating/appetite and sleep, but are less likely to be emphasised in Western HRQoL measures such as EQ-5D. It also reports Chinese participants’ opinions on EQ-5D and addresses the problem of the incompleteness of it.

The qualitative study again indicated cultural differences in defining health between China and the West. To further explore how health is defined and described in China and to establish the relative importance of various health dimensions in a Chinese population, a Q-methodological study is reported in the next chapter.

Chapter 5 Exploring subjective constructions of health in China: a Q-methodological investigation

5.0 Summary

This chapter presents a Q-methodological study to further explore how health is described among a Chinese general population. A scoping review of Chinese generic HRQoL measures, supplemented by a series of qualitative interviews, produced a list of 42 statements representing aspects of health considered as being important in a Chinese cultural setting. A total number of 110 Chinese participants with various demographics characteristics were recruited to rank and sort these statements in face-to-face interviews. Data were analysed to identify clusters of participants who shared a similar perspective, using a by-person factor analysis procedure. Previous qualitative studies showed there were many health statements that are not commonly mentioned in Western-developed HRQoL measures. The present Q-study confirmed that these statements were well recognised by a diverse range of Chinese participants and again highlighted cultural differences between China and the West.

5.1 Background

A conceptual framework of health in a Chinese cultural setting was developed as reported in Chapter 3 and Chapter 4. With a pool of health dimensions available, the task was then to establish the relative importance of these health dimensions among a sample of Chinese participants. A Q-methodological study was planned to further explore Chinese people's views regarding health.

5.2 Introduction to Q methodology

Q methodology was introduced by William Stephenson in 1935 as a way to scientifically assess subjective viewpoints (Stephenson, 1935b; Watts and Stenner, 2005). It enables researchers to observe individuals' personal opinions and identify patterns of views across a participant group (Stainton Rogers and

Dyson Rogers, 2011; McKeown and Thomas, 2013). The main idea of this approach is to ask participants to sort and rank a stack of items according to their own preference. The ranking materials are normally various statements on the subject that of research interest, but they can also be of other formats such as pictures or objects (Watts and Stenner, 2005; Baker et al., 2006). Based on the ranking data collected, each participant' individual opinion can be observed and patterns of views across the whole sample group can be recognised.

Q methodology was originally adapted from conventional factor analysis, which is commonly used as a statistical tool for quantitative analysis (Watts and Stenner, 2005). Compared to traditional factor analysis that combines dependent variables measuring similar things to potentially reduce data, Q methodology treats participants as variables (Stephenson, 1935a; Stephenson, 1936). It is able to group participants who sort statements in similar ways. Those identified groups are then regarded as factors in Q methodology. If there is a significant association between participants and a given factor, these participants are supposed to share a common viewpoint (McKeown and Thomas, 2013).

Q methodology, therefore, involves both qualitative and quantitative components, and to be "qualiquantological" (Stenner and Stainton-Rogers, 2004; Ramlo, 2015). Qualitatively, the methodology focuses on individuals' subjective understands and personal views and can be used to explore subjective viewpoints across a participant group. While quantitatively, the data are collected in a mathematical way involving sorting and ranking activities and are analysed using statistical approach named "by-person" factor analysis. It has been regarded as one of the most effective approaches for combining both qualitative and quantitative techniques to analyse individuals' subjective opinions (Ward, 2009).

Q methodology is believed to substantially contribute to theory building and policy-making and has been widely used in different research areas such as education, communication, nursing and political science (Stainton Rogers and Dyson Rogers, 2011). An increasing number of health-related studies has employed this technique (Baker et al., 2006), including studies that assessed concepts of QoL, experiences of pain and understandings of illnesses (Eccleston et al., 1997; Stenner et al., 2000; Stenner et al., 2003).

5.2.1 Procedure overview

Before explaining how to conduct Q-methodological research in detail, the concepts and terminology that are specifically defined in a Q-study are summarised in Table 5-1 below.

Table 5-1: Terminology in Q Methodology

Terminology	
Concourse	A pool of contents that can be said and thought about the topic being investigated.
Q-sample	A set of statements that are selected to represent the concourse and that would be presented to participants for rank ordering.
Q-grid	A graph that is prepared for the rank-ordering activity.
Q-sorting	The process of placing a Q-sample onto the Q-grid.
Q-sort	Ranking results obtained after each participant place all statements of a Q-sample onto the Q-grid. Each Q-sort represents an individual's personal opinions on the research topic.
P set	The group of participants involved in a Q-study.
Factor	A viewpoint that can represent one sorting pattern, namely one understanding of the research topic of a Q-study.
Exemplar	A Q-sort that significantly associates with one Factor, therefore, can exemplify the view reporting by that Factor.
Factor array	A merged Q-sort which is calculated with a weighted average method and can represent a particular factor.

Q-methodological research usually comprises several steps: concourse development, Q-sample generation, P-set recruitment, Q-sorting administration, Q-sorts analysis and data interpretation. These steps are explained in detail in the following sections.

5.2.1.1 Concourse development

With a clearly defined research question available, a concourse can be developed accordingly for a Q-methodological investigation. It is important to ensure the objective of the research is well prepared and explicitly stated before a Q-study commences (Watts and Stenner, 2005). It decides the content of a concourse as well as a Q-sample. It also serves as an instruction to guide participants in the Q-sorting practice.

A concourse consists of the things that are written or said about a topic that can be “socially contested, argued about and debated… matters of values and beliefs” (Stainton Rogers, 1995: p.180). With the aim of investigating people’s subjective viewpoints regarding a topic, a concourse should be prepared carefully beforehand to be as representative as possible to cover various opinions and perspectives about the research subject (Baker et al., 2006; Stainton Rogers, 1995). To develop a concourse, both “ready-made” or “naturalistic” resources can be considered (McKeown and Thomas, 2013). Written materials like academic papers, reports, books, newspapers and magazines are typical resources for a concourse. Statements in a concourse can also be collected from verbal conversations such as formal face-to-face interviews and informal discussions on a TV program.

5.2.1.2 Q-sample generation

The next step is to generate a Q-sample from a concourse. A Q-sample is a set of statements that are supposed to represent the content of a concourse. A Q-sample is required to include the diversity of opinions and perspectives about the research topic so that participants may rank order statements to express their views (Watts and Stenner, 2005). Q-sample selection can be structured or unstructured, which means a Q-sample can be developed either with or without a pre-existing categorical structure (Du Plessis, 2005; Dziopa and Ahern, 2011; Paige and Morin, 2016): the selection can be conducted under a predefined categorical scheme to generate a structured Q-sample; it can also be conducted inductively without a predefined framework to generate an unstructured Q-sample.

After selecting a Q-sample from the concourse, ideally, a preliminarily draft of the Q-sample should be consulted with experts to examine if the statements within the Q-sample cover comprehensive perspectives about the research topic. A satisfactory Q-sample should also be without ambiguity, without repetition and understandable to lay people. The statements should then be piloted with a few participants and be refined before a final version of Q-sample is retained and to be applied in the fieldwork (Paige and Morin, 2016).

For practical reasons, the number of statements in a Q-sample should not be either too large or too small. On the one hand, because the whole Q-sorting process requires participants to comprehend each statement and compare one statement with another, if there are too many items for participants to rank and sort, the task might be too challenging for them. On the other hand, the by-person factor analysis is likely to be less effective when the Q-sample size is too small. The number of a Q-sample is recommended to be between 40 and 80 (Watts and Stenner, 2005; Stainton Rogers, 1995). A systematic review reported that the number of statements in the reviewed Q-studies varied from 27 to 82 items (Dziopa and Ahern, 2011).

5.2.1.3 P-set recruitment

It is recommended to recruit participants strategically to access as many various subjective understandings as possible (Watts and Stenner, 2005). The direct reason is that Q methodology is a qualitative-driven tool and, in essence, an exploratory technique (Watts and Stenner, 2005). Because Q methodology treats participants as variables and attempts to identify similarities and differences in perspectives about a research topic, participants of a Q-study are supposed to have a diverse range of views. Participants should be selected purposefully. Because personal traits, demographic characteristics and one's social groups may more or less affect individuals' opinions on a certain subject, they need to be considered in recruitment (Watts and Stenner, 2005; Baker et al., 2006).

Unlike quantitative studies that normally select participants by probability sampling and rely on a large number of participants, Q methodology does not require a large sampling pool (Watts and Stenner, 2005) because Q methodology is essentially a qualitative technique. Additionally, it is the statements of a Q-sample, instead of participants, that are required to be representative in a Q-study (Stainton Rogers, 1995).

5.2.1.4 Q-sorting administration

In this step, participants are provided with a Q-sample and are asked to assign the statements of the Q-sample on a Q-grid (see Figure 5-1 below as an example of a Q-grid). A Q-grid contains as many blank cells as the items in the Q-sample. It provides a quasi-normal distribution forcing participants to rank order

statements ‘along a simple, face-valid dimension, for example, most agree to most disagree, most characteristic to most uncharacteristic, most attractive to most unattractive’ (Stainton Rogers, 1995, p.180). The activity requires participants to comprehend and compare the statements of the Q-sample before they can make decisions to rank the statements according to their own understandings and preferences.

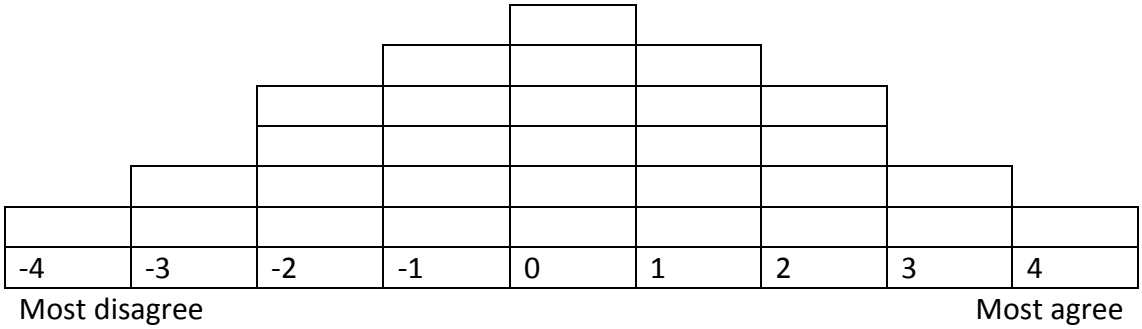


Figure 5-1: Q-Grid sample

Participants are free to adjust the sorting results before his/her Q-sort (the distribution of statements on the Q-grid) being captured. Following each ranking exercise, a post-sorting interview is usually conducted to further investigate how participants understand the research topic being investigated and why they rank the Q-sample in certain ways. Information collected in post-sorting interviews can be useful in data interpretation.

5.2.1.5 Q-sorts analysis and interpretation

Once Q-sorts data have been prepared, it can be put into a by-person factor analytic procedure where statistical similarities and differences in views are analysed by person. More specifically, if some participants’ Q-sorts are highly correlated with each other, they will be clustered together. The by-person factor analysis thus is able to identify groups of participants who sort statements in a similar way. These participants are assumed to share a comparable way of thinking. Their views will define and form a “factor” and they are regarded as exemplars of the factor.

A Q-study normally produces several factors. Each factor represents a view that is significantly different from the views that represented by other factors. (McKeown and Thomas, 2013). Each factor can be shown as a particular factor array. A factor array is generated based on a weighted averaging calculation: a higher loading Q-sort (a Q-sort with a stronger association with a given factor) is given more weight in the calculation (Stenner et al., 2003). This merged factor array thus can be regarded as a conceptually best estimate of all the Q-sorts of the exemplars clustered under this factor and can represent the viewpoint of the exemplars.

Generated factors then are ready for interpretation. The interpretation process should be supplemented by exemplars' personal understandings and explanations provided by them during the post-sorting interviews. Interpretation of each factor can be achieved directly by observing the rankings of the Q-sample in its factor array (Stainton Rogers, 1995) as well as by recognising similarities and differences across the factors (Dziopa and Ahern, 2011). The statements assigned in the rightmost and the left-most columns of a factor tend to be the items those exemplars, whose Q-sorts define this factor, feel strongly about and, therefore, should be given attention when depicting this factor and making comparisons between this factor and other factors (Dziopa and Ahern, 2011). At the same time, the statements that are ranked in the middle should not be ignored, because the interpretation process aims to deliver a holistic view of each factor (Watts and Stenner, 2014a). Watts and Stenner suggested using "Crib Sheet" as a systematic way to interpret data (Watts and Stenner, 2005). Under this approach, items placed at the highest and the lowest ranking in each factor array as well as those items ranked higher or lower by this particular factor than by any other factors will be identified and listed. Those items can show how this particular factor is different from other factors and are the main materials for interpretation.

5.2.2 Criticisms of Q and why using Q in this study

Q methodology has limitations. One of its main criticisms is that is not a quantitative tool and the results generated by this method may not be generalised into a larger population (Baker et al., 2006). However, the criticism may be

regarded as unjustified. Because Q methodology is not aiming to identify a commonly agreed opinion across the whole sample of participants for generalisation. This methodology is essentially a qualitative approach, its major aim is to have an in-depth investigation into participants' perceptions of the research topic being investigated and to identify similarities and differences across their perceptions.

Another disadvantage of Q methodology is that the whole process is extremely time-consuming and demanding to participants. The instructions of the Q-sorting exercise are expected to be more complicated compared with other interview techniques, while the validity of the study will be affected if participants do not well understand the procedure. Therefore, efforts need to be made to provide clear and well-structured Q-sorting guides for participants.

While Q methodology has some weaknesses, it was applied in this study for the following reasons. First, since this study intended to gain an insight into Chinese people's understandings of health, Q methodology, which is a well recognised tool for studying subjectivity, was believed to be appropriate for such an investigation. As health is a multidimensional concept that could be defined differently, it was assumed that there would be various viewpoints regarding "what is health?" among a group of Chinese participants. Because the Q-methodological tool is suitable for probing different perspectives and consensuses (Ramlo, 2008), it would enable the researcher to follow a robust research process to observe Chinese individuals' personal opinions and identify patterns of views of health across a group of Chinese participants to fulfil research objectives.

Another strength of Q methodology is that it could efficiently combine both qualitative and quantitative components in one study. Qualitatively, it takes each Q-sort, which represents an individual's personal opinions on the research topic, into account and respects the integrity of each participant (Peritore, 1989). The qualitative attribute of the methodology is also enhanced by its post-Q-sorting interviews when participants are asked to explain their ranking results. Quantitatively, the by-person factor analysis is an effective tool to observe similarities and differences in viewpoints across a group of participants. Additionally, because Q methodology involves ranking activities, the method

would enable the researcher to collect ranking data from Chinese participants to quantitatively explore which health dimensions were most important.

There were other optional methods that were used by other researchers in assessing people's opinions about health. One study investigated things that were important and relevant to caregivers of advanced cancer patients by conducting in-depth interviews and doing thematic analysis (Lee et al., 2015). Another study designed a RAND Delphi study to obtain a list of core items for health measurement (Howell et al., 2013). Such pure qualitative methods were productive in exploring the concept of health and recognising various health dimensions from separate participants. However, they were less effective to synthesise those qualitative data or to investigate similarities and differences across diverse views given by a group of participants. Q methodology was thought to be able to build on such qualitative work. It could take an insight into various views of health to explore their similarities and differences.

Some studies used self-designed surveys to assess the importance of different health dimensions quantitatively. One study designed an "Importance Rating Questionnaire", asking if each health dimension was "extremely important", "very important", "somewhat important", "not very important", "not at all important", or "don't know", and calculated the frequency of the ordinal rating rank for each item (Hellmann et al., 2003). Although Likert-style surveys could collect people's ratings on health dimensions, they were not able to make direct comparisons between diverse health dimensions.

Another study asked each participant to give five most important health items and obtained those items that were mentioned most frequently (Bowling, 1995). Similarly, a study asked participants to choose and rank the five most important items among sixteen items to find out the most frequently chosen health dimensions (Paap et al., 2014). This kind of ranking exercise could help to identify important health dimensions that were agreed to be important across a group. However, as they only considered the top five items given by each participant, the information collected was limited while substantial health dimensions were not rated.

With a large number of health dimensions being identified, it was considered to be more appropriate to use Q methodology, when participants can compare and rank all of these health dimensions following a well-organised process. Additionally, conventional ranking techniques are only able to recognise one shared opinion across the whole sample, while Q methodology can identify differing viewpoints. Since health is believed to be a complex concept that can be defined in various ways, it would be logical to use Q methodology to probe such variety. What's more, surveys normally require a large number of participants to generalise results and are more likely to be troubled by non-response biases. Q methodology can effectively reduce the problem because participants would be selected purposefully and approached individually. Each Q-sort would be collected in a one-to-one face-to-face session.

5.3 Research objectives

Following the scoping review study as well as the empirical qualitative investigation, a Q-methodological study was designed to serve the following purposes.

1. To justify if the previously established conceptual framework of health worked in practice.
2. To further investigate subjective understandings of health by identifying differing viewpoints as well as consensuses among a group of Chinese participants.
3. To better answer the questions "How is health defined in China? Which health dimensions are important to Chinese people?" by establishing the relative importance of health dimensions among a group of Chinese participants.

The next section describes the whole procedure of the Q-investigation in detail.

5.4 Methods

5.4.1 Concourse development and Q-sample generation

The development of the concourse of this study involved: (i) a scoping review of Chinese generic HRQoL measures, and (ii) qualitative interviews conducted in China focusing on aspects of health considered important in judging health for a Chinese population. In the scoping review, health dimensions included in 12 Chinese-developed HRQoL measures were systematically summarised to develop a Chinese conceptual framework of health. The qualitative study explored how Chinese lay people may describe and appraise health. It justified the conceptual framework and identified additional health dimensions with empirical evidence. The resulting conceptual framework included a wide range of health dimensions likely to be valued by a Chinese population.

Since a conceptual framework had already established, it served as a basis to generate a Q-sample in a more systematic way. There were six main categories of health dimensions under the conceptual framework: physical symptoms, physical function, psychological symptoms, cognitive function, social wellbeing and abilities to adapt to the environment. These categories were the basic structure for the Q-sample generation. It was not pragmatic to keep a complete balance in numbers of statements for each category since numbers of health dimensions in each category were not equal. This was considered to be acceptable, as the major aim of Q-sample selection was to develop a set of statements that could be "broadly representative of the opinion domain at issue" (Watts and Stenner, 2005).

Health dimensions that were summarised in the predefined conceptual framework were considered potentially important in a Chinese cultural setting. They were transformed as the statements of the Q-sample of this study. The five dimensions of EQ-5D were also generated as statements, as a way to compare the descriptive system with other "Chinese-specific" health dimensions. The process of selecting and converting health dimensions into the Q-sample is presented in Appendix VI.

Some health dimensions were excluded due to practical reasons. Dimensions like “Disease”, “Other abnormal signs” and “Personality” were recognised from the empirical study but were not included as Q-statements. They represented a broad range of sub-items and were too general compared to other health dimensions. Happiness & Depression; Security & Fear were two pairs of opposites. They were all identified as separate dimensions to cover both positive wellbeing and negative emotions. However, considering the risk that participants may feel confused in the ranking exercise when there were both positive and negative emotions at the same time, dimensions of Happiness and Sense of security were excluded to avoid the redundancy and potential confusions.

A draft version of the Q-sample was generated. The “condition of instruction” (guide for participants to sort the Q-sample) was “When judging a person’s health, how important is it to know about their ___?” “A person” in this instruction can be understood as the participants themselves as well as other people. It was considered that such instruction can help participants to think about health and to decide which aspects of health are more important not only from their own perspective, but also from an external perspective. This was because important aspects of judging a person’s own health can be very different from those for judging other people’s health. The principal aims of the Q-study were to explore the subjective understandings of health and to establish the relative importance of health dimensions in China. The instruction of Q-sorting was used to help participants to concentrate on thinking about “health”, instead of thinking about their own health status. If the instruction of Q-sorting was restricted to “me/my health”, it would be very likely for participants to only consider their own specific health problems or health concerns, instead of thinking about health from a more general perspective. This was also in line with the questions being asked in the qualitative study as reported in Chapter 4. In Chapter 4, participants were asked to not only describe their health status, but also talk about other people’s good/poor health status as a way to identify all aspects of health that were likely to be important among Chinese participants. To ensure that respondents can follow the instruction consistently, it would be explained in each interview that “a person” in this instruction can be anyone: it could be the participants themselves or be other people. However, it was expected that people’s own health status

would significantly affect how they perceive health and how they sort the health dimensions.

The English version[10] of the draft was sent to the researcher's supervisors for feedback. Following discussions with the supervisory team, the first draft was revised before sent out to 10 Chinese people (two Chinese clinicians, two Chinese academic researchers who had worked on HRQoL projects and six lay people) for comments. A feedback questionnaire was prepared for the ten people, who were asked if the statements were understandable, without repetition and comprehensive in describing health. The feedback questionnaire is presented in Appendix VII. As a result of feedback from participants, the statements were revised to eliminate ambiguity and repetition and ensured readability to lay people.

The revised Q-sample was then printed on paper for a pilot study. The pilot study began with the researcher's two supervisors. They made comments on experimental tools (eg. card size, grid size) and the instructions of sorting. Three Chinese people were also involved in the pilot study where the Chinese version of the Q-sample was tested. As the participants of the pilot study confirmed that they understood the statements and had no problem in following instructions, no further revisions were made on the Q-sample.

The final version of the Q-sample contained 42 statements (See Table 5-2):

[10] The Chinese version of the Q-sample was developed at first then translated into English.

评判一个人的健康状况时，了解这个人的__有多重要？ When judging a person's health, how important is it to know about their __?

Table 5-2: Q-sample

	Chinese statements	English language equivalent	Source[11]
1	身体素质对疾病的抵抗力	Body constitution that can indicate the susceptibility to diseases	SR&Qua
2	对天气变化的适应能力	Ability to adapt to weather changes	SR&Qua
3	身体体重 （是偏瘦，正常，偏重还是肥胖）	Body weight（whether he/she is underweight, normal, overweight or obese)	SR&Qua
4	精神面貌 （是精神饱满还是无精打采）	Spiritual appearance (whether he/she is full of spirit or lack of spirit)	SR&Qua
5	面色	Natural colour and appearance of the face	SR&Qua
6	疲劳、困倦想睡觉的感受	Feeling of tiredness	SR&Qua
7	体力，身体四肢的力气	Body strength of doing things	SR&Qua
8	身体不舒服的感受 （例如头晕，恶心，心悸等）	Feeling of discomfort (such as dizziness, nausea, palpitation)	SR&Qua
9	身体上疼痛的感受	Feeling of pain	SR&Qua
10	胃口，食欲	Desire of having food	SR&Qua
11	精神的压力	Feeling of pressure	SR&Qua
12	抑郁、心情低落的心理状态	Feeling of depression	SR&Qua
13	焦虑不安的心理状态	Feeling of anxiety	SR&Qua
14	容易生气发火的性情	Tendency of being angry	SR&Qua
15	恐惧感	Feeling of fear	SR&Qua
16	孤独感	Feeling of loneliness	SR
17	自信心	Self-confidence	SR
18	调整心情，使心情平和的能力	Ability to remain stable and peaceful in mood	SR&Qua
19	睡眠的质量	Sleep quality	SR&Qua
20	四处走动的能力	Ability to walk about	SR&Qua
21	进行日常活动的能力（例如上学工作，上街，做家务事）	Ability to perform usual activities (such as working, studying, shopping, doing housework)	SR&Qua
22	视力	Vision	SR&Qua

[11] The sources of Q-statements were from either the scoping review study or the qualitative interviews. In the table, "SR" stands for the scoping review study, "Qua" represents the qualitative interview study.

23	听力	Hearing	SR&Qua
24	交流沟通的能力	Ability to communicate with people	SR&Qua
25	自理的能力（如自己给自己穿衣、洗澡）	Ability to wash and dress oneself	SR&Qua
26	日常生活对药物的依赖程度	Dependence on medication	SR
27	性生活的情况	State of sex life	SR
28	清楚思考的能力，大脑清晰度	Ability to think things clearly	SR&Qua
29	反应力，对外部环境的变化敏捷作出反应的能力	Ability to perceive changes in surrounding and to respond swiftly	SR&Qua
30	记忆力，能记忆事物的能力	Ability to remember things	SR&Qua
31	决策力，需要做选择时的决断程度	Ability to make decisions	SR&Qua
32	注意力，集中精神的能力	Ability to concentrate	SR&Qua
33	人际关系的情况（家庭关系、与朋友的关系，与同事的关系等的数量和质量）	State of social relations (such as the relations with family, friends or colleagues)	SR&Qua
34	融入社会环境的能力（如适应工作、生活、学习环境，适应社会法律制度）	Ability to adapt to the social environment (such as working environment, living environment, social rules and regulations)	SR&Qua
35	获得的社会支持的情况（如家人、朋友的支持）	Support from one’s social network (such as supportive resources from friends and family)	SR&Qua
36	公德心（行为是否遵从社会公德）	Social morality (whether someone follows moral norms)	SR&Qua
37	人生态度（比如对待生活是否积极乐观，做事积极或是消极）	Life attitude (such as viewing things optimistically or pessimistically)	Qua
38	心胸（比如心胸宽广或是狭隘，是否对他人经常抱怨、耿耿于怀）	“Breadth of mind” (such as being tolerant of other people or narrow-minded to other people)	Qua
39	生活作息的规律性	Regularity in daily life	SR&Qua
40	饮食习惯	Diet habits	SR&Qua
41	生活的满足感	Sense of satisfaction with life	SR
42	家族疾病史 （近亲属是否患有重大疾病）	Family medical history (whether his/her close relatives diagnosed with critical illnesses)	SR&Qua

5.4.2 Participants

While there is no such golden rule in deciding the number of participants in a Q-study, the principal guideline was to strategically recruit participants to access as many views as possible. To explore the diversity of views, a group of Chinese participants (with Chinese nationality; living in China; using Chinese as the mother tongue;18 years old or older) with various demographic characteristics, including age, gender, geographical locations, rural/urban areas, education background and his/her health condition, were purposively recruited.

As the study required participants to comprehended, compare and rank 42 statements written in Chinese, participants were expected to be able to read and communicate in Mandarin. Potential participants were not recruited if they had cognitive problems or had a serious health condition that may limit their ability to complete the Q-sorting exercise. The recruitment strategies were similar to the ones documented in Chapter 4. Potential participants were accessed with the help of group leaders/members of recreational groups as well as heads of nursing homes and villages. The snowballing approach was also applied to ask interviewees to nominate potential participants who may be interested in participating in the research. Once prospective interviewees had confirmed their willingness to participate, the place, date and time were discussed and arranged together by the researcher and the interviewees. Various people were purposively reached and in the end, 110 participants were involved in the investigation. See Table 5-3 for sample characteristics.

Table 5-3: Demographic characteristics of participants (n=110)

		Number (percentage)
Gender	Male	57 (52%)
	Female	53 (48%)
Age	<40	44 (40%)
	40-60	35 (32%)
	60+	31 (28%)
Education background	Under high school	20 (18%)
	High school	14 (13%)
	Secondary	15 (14%)
	College	18 (16%)
	University	42 (38%)
Self-rated health state using EQ-5D*	11111	42 (38%)
	11112	15 (14%)
	11121	16 (15%)
	11122	14 (13%)
	Other	22 (20%)
Self-rated health score	80-100	69 (63%)
	60-80	35 (32%)
	<60	5 (5%)
Residence place	City	63 (57%)
	Non-city	47 (43%)
Region	Southwest China	54 (49%)
	East China	34 (31%)
	North China	13 (12%)
	Other	9 (8%)

*The Chinese version of the EQ-5D-5L questionnaire was provided to each participant to complete after the sorting exercise. One participant declared he did not have time for completing the questionnaire and his health status information was missing.

5.4.3 Ethics

Personal information of the participants was handled strictly to protect their confidentiality. All interviewees remained anonymous as each individual participants was given a pseudonym.

The study has been reviewed and approved by the School of Medicine Research Ethics Committee at the University of Leeds (Reference number: MREC17-021).

5.4.4 Data collection process

Since China is a large country and Chinese residents from different regions may have different perceptions of health, the researcher travelled in cities and villages

in Southwest China (Chongqing), East China (Shanghai, Jiangsu, Zhejiang) and North China (Beijing and Tianjin), accessing participants from 21 differing provinces, between October 2018 and January 2019. Interviewing sites were various, taking into account both interviewer's and interviewees' convenience and safety, including private meeting rooms in public teahouses, quiet compartments in coffee shops, meeting rooms in the places of interviewees' employment. An information sheet (Appendix III) and a consent form (Appendix IV) were prepared before each interview.

The instructions for the Q-sorting activity are as follows. Each interview started by asking a participant to think about health. Interviewees needed to give a score (0-100) on their own current health status and were encouraged to explain why gave that score. They were also asked to describe what good health and poor health were in their opinion. The pre-sorting interviews that were conducted in the Q-study were not as in-depth as the qualitative study reported in Chapter 4. There were mainly two reasons for asking these questions. First, participants could be prepared with some thinking that may help them rank and sort health statements in the latter stage. The second reason for doing this was to identify if there were any additional health dimensions that were not covered by the previously established conceptual framework of health. Such information can test the appropriateness of the pre-established conceptual framework of health and examine if the selected health dimensions can cover all important aspects of health. Since the main focus of this chapter is the Q-study, therefore, the qualitative data obtained from pre-sorting interviews were not systematically analysed and reported.

Having asked the warming-up questions, the researcher introduced the Q-sorting exercise. Participants were provided with the Q-sample (42 statements individually printed on numbered cards) and were explained that the statements on the cards were different aspects of subjective experiences, feelings or perceptions that may be relevant to health and may affect the quality of life. This interview would like to see how participants ranked these statements by the importance level of each statement, according to participants' own personal preferences. The guide for participants to sort the Q-sample was "When judging a person's health, how important is it to know about their ___?" Participants were

informed that “a person” in this instruction can be anyone: it could be himself/herself or other people. They were also told that there should be no right or wrong answers. All views would all be respected.

Next, participants were asked to sort the statements into three piles. They were asked to read each statement carefully and split them up to three piles:

- “a pile for statements that you think are most important”
- “a pile for statements that you think are least important”
- “a pile for the rest”

The researcher took a picture to record the three piles for each interviewee. Next, participants were provided with a Q-grid (See Figure 5-2) and were asked to sort the cards following the instructions below:

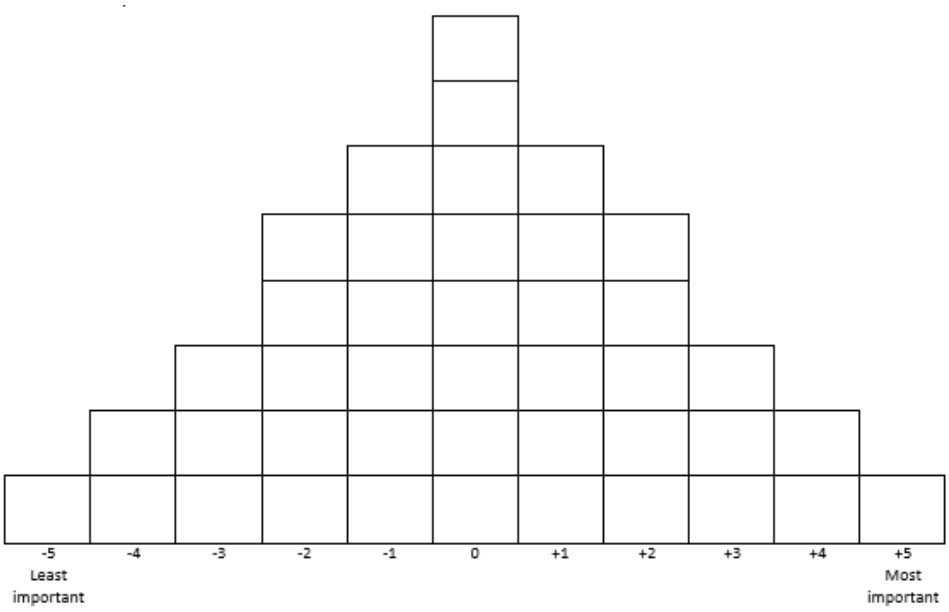


Figure 5-2: Q-Grid used in this study

1. “Take the MOST IMPORTANT pile, and select the one statements which you think are MOST important and place them on the one box on the right side of the grid - above the ‘+5’.”

2. “Take the remaining statements from your MOST IMPORTANT pile, select the two statements which you now think are MOST important and place them in the four boxes above the ‘+4’. (It does not matter which you place at the top or at the bottom)”

3. “Take the remaining statements from your MOST IMPORTANT pile, select the three statements which you now think are MOST important and place them in the four boxes above the ‘+3’. Proceed until all statements you think are important have been placed on the grid. (It does not matter which you place at the top or at the bottom)”

3. “Take the LEAST IMPORTANT pile, and select the one statements which you think are least important and place them on the one box on the left side of the grid - above the ‘-5’.”

4. “Take the remaining statements from your LEAST IMPORTANT pile, select the two statements which you now think are least important and place them in the four boxes above the ‘-4’. Proceed until all statements you think are least important have been placed on the grid.”

5. “Take the remaining statements and place them in the remaining boxes on the grid, just like you feel it should be done.”

Participants were asked to check their completed Q-sort (distribution of statements on the Q-grid) and make any changes. The researcher took a photograph of the completed Q-sorts.

Then, participants needed to compare health statements in each column and ranked them according to the importance levels one by one. Statements were then presented one by one from the most important one to the least important one. This ranking result was recorded.

Following this, the researcher conducted post-sorting interviews to explore why participants ranked statements as they did. Table 5-4 below shows several examples of the questions. At the end of each interview, participants were asked to give their background information, including age, education background, current residence place (city/non-city) and birthplace. They were also asked to complete EQ-5D-5L to indicate their health status as described by this HRQoL measure. The full instructions (both in English and in Chinese) for the Q-sorting activity can be found in Appendix VIII.

Table 5-4: Post-sorting questions

1) Why did you choose ___ as the most important statements? Why did you choose ___ as the least important statements? How did you understand those health statements that were chosen to be the most/least important?
2) How did you interpret Ability to walk about; Ability to perform usual activities; Feeling of discomfort; Feeling of pain; Feeling of depression; Feeling of anxiety (those health statements that were transformed from the five dimensions in EQ-5D)? Why did you assign them to certain cells in the Q-grid?
3) When we are judging one's health, do you think there are additional important issues that are missing from these statements?
4) Are there any statements that you did not understand or you would like to comment on?

5.4.5 Factor analysis and rotation

The assigned category ("most important", "least important" and "the rest") of each statement as well as the complete (from 1-42) rank orderings of the 42 statements for each participant were put into Excel (the data were prepared for a study that is reported in Chapter 6). Participants' Q-sorts were put into the PQMethod (version 2.35) package for analysis.

PQMethod offered two analytic techniques (Centroid Analysis and Principal Component Analysis (PCA)) as well as two rotation methods (Varimax and hand rotation) in processing the Q-sorts data. Centroid and PCA have been found to produce equally satisfying results in practice (Watts and Stenner, 2005). Either Hand rotation or Varimax rotation has its own pros and cons. The study adopted PCA along with Varimax rotation to analyse the data. Because such combination can automatically and efficiently produce factors that can explain the maximum level of the study variance (Watts and Stenner, 2005). It can generate a mathematically superior solution where the similarities within factors and the differences across the factors are maximised (Baker et al., 2006).

The next step was to determine how many factors should be retained for rotation and interpretation. The principal aim of factor extraction is to keep those factors that are reasonably interpretable and each can represent a distinct viewpoint

(McKeown and Thomas, 2013). Several criteria can help to decide how many factors should be retained for rotation. One of the most common requirements is to select factors whose eigenvalues are larger than 1.00 to “safeguard factor reliabilities” (Watts and Stenner, 2005; McKeown and Thomas, 2013). The eigenvalue (characteristics value) of a factor is closely associated with the variance accounted for by that factor (Eigenvalue = × number of participants/100) (Watts and Stenner, 2005). If the eigenvalue of a factor is below 1.00, the factor accounts for limited study variance and has limited explanatory power. Additionally, the Scree test has also been applied in many studies (Watts and Stenner, 2014b), where eigenvalues would be plotted on a line chart. The slope of the line would indicate which factors should be retained: those factors to the left of the point where the slope is evidently levelling off. Another standard requirement is that a factor should have at least two exemplars whose Q-sorts load significantly on that factor (Watts and Stenner, 2005; Dziopa and Ahern, 2011). Because most Q-researchers tend to be interested in “shared orientations” among participants (Watts and Stenner 2005).

5.5 Results

5.5.1 The legitimacy of the conceptual framework of health

The pre-sorting questions asked participants to describe their own health status as well as scenarios of good health and poor health. Participants in the Q-study described health in a largely comparable way to those who were recruited in the qualitative study (Chapter 4). Aspects of health that were mentioned by participants in the pre-sorting interviews in the Q-study were found to be covered by the previously developed conceptual framework of health.

During the post-sorting interviews, most of the participants confirmed that they understood the statements, which were generated based on the developed conceptual framework. They also commented that they had no problem in following the sorting instruction. The majority of the participants stated that the statements were comprehensive to judge a person’s health. Some participants suggested adding items, such as financial condition and air quality, to the statement list. However, those items are environmental factors that could affect

health but are not about people's own experiences, feelings or perceptions, thus are not within the scope of HRQoL as defined in this study.

5.5.2 Factor extraction and interpretation

Originally, eight factors were extracted in PQMethod, all with an eigenvalue of 1.00 or more and at least one exemplar. Inspection of factors six to eight showed that they did not provide distinct viewpoints that were not captured in factors one to five. Therefore, a five-factor solution seemed most appropriate, given that it explained 55% of the total variance. The scree plot with eigenvalues (Figure 5-3) also suggested that the five-factor solution was potentially eligible for interpretation. The detailed process of the selection of factors was presented in Appendix IX.

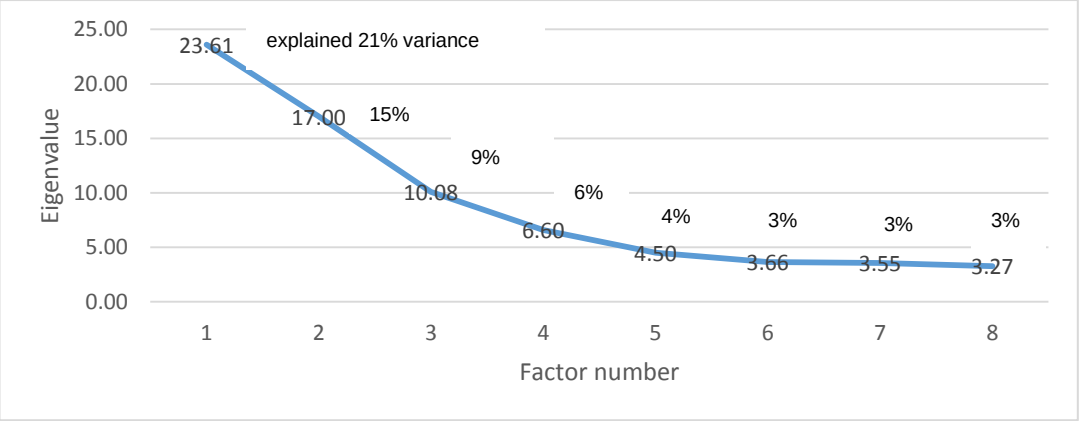


Figure 5-3: Scree test

For each factor, exemplars were identified (participants with Q-sorts loading +0.4 ($p < 0.01$) on one factor only[12]). These exemplars were merged to produce a factor array, a single "ideal" Q-sort that best represented each factor. The factor array for each factor represents how a participant with a correlation coefficient of 1 would have ranked the 42 statements. The five factor arrays are presented in Table 5-5.

70 of the 110 Q-sorts were identified as exemplars and were used to form the five factors. It means that 70 Q-sorts were significantly associated with these extracted factors, while 40 Q-sorts did not significantly load on the factors. It suggested that Q-methodology was not able to present all subjective viewpoints

[12] Loadings of the 110 Q-sorts on the five factors are presented in Appendix XI.

from the whole sample. Nevertheless, this study did not aim to capture all possible subjective understandings of health. Instead, it aimed to identify some of the main differing viewpoints among a group of Chinese participants. By putting all Q-sorts from the 110 participants into a by-person factor analytic procedure, where statistical similarities and differences in views were analysed by person, the study effectively identified patterns of views to address the research objectives. Demographic information for the 70 exemplars in the five factors is presented in Table 5-6. For the 40 participants whose Q-sorts were not used to form any of the five factors, their demographic characteristics are presented in Appendix XII.

Interpretation of each factor can be achieved by observing the rankings of Q-sample in its factor array. The factor arrays of the five extracted factors are listed in Table 5-5. The factor arrays are also presented as Q-grids in Appendix XIII. A higher value on either end of the continuum indicated how strongly participants believed the statement was important or not. For example, Statement 1 had a value of '+5' and Statement 22 had a value of "-5" in Factor Three, which suggested that Statement 1 was considered most important and Statement 22 was considered least important by participants whose views constructed Factor Three.

Table 5-5: Factor arrays – scores against each item by factor

		Factors				
		1	2	3	4	5
	Eigenvalue	23.6	17.0	10.1	6.6	4.5
	% variance explained	21%	15%	9%	6%	4%
		Factor Arrays				
	Statements	1	2	3	4	5
1	Body constitution that can indicate the susceptibility to diseases	2	3	5	3	3
2	Ability to adapt to weather changes	-3	-1	-3	-1	-5
3	Body weight	-2	0	-1	0	-1
4	Spiritual appearance	2	2	4	3	0
5	Natural colour and appearance of face	-2	1	-2	1	-4
6	Feeling of tiredness	-1	1	1	-1	-2
7	Body strength of doing things	-1	2	0	-1	2
8	Feeling of discomfort	-2	2	2	0	-2
9	Feeling of pain	-1	4	2	2	-3
10	Desire of having food	0	2	0	3	-3
11	Feeling of pressure	-1	0	2	-3	3
12	Feeling of depression	-2	1	3	-3	0
13	Feeling of anxiety	-1	0	2	-2	1
14	Tendency of being angry	-2	-1	0	-1	-1
15	Feeling of fear	-5	-2	-2	-5	0
16	Feeling of loneliness	-3	-2	-2	-4	-1
17	Self-confidence	3	-2	1	2	2
18	Ability to remain stable and peaceful in mood	2	0	1	0	1
19	Sleep quality	1	3	3	4	0
20	Ability to walk about	3	4	-1	-4	2
21	Ability to perform usual activities	4	3	0	-2	-1
22	Vision	0	1	-5	0	5
23	Hearing	0	0	-4	1	4
24	Ability to communicate with people	1	-2	-1	1	0
25	Ability to wash and dress oneself	5	5	0	-3	0
26	Dependence on medication	-3	1	0	-2	-2
27	State of sex life	-4	-2	-4	-2	0
28	Ability to think things clearly	2	0	-1	0	2
29	Ability to perceive changes in surrounding and to respond swiftly	0	0	-2	-1	1
30	Ability to remember things	1	-1	-3	2	1
31	Ability to make decisions	-1	-4	-3	1	0
32	Ability to concentrate	0	-1	-2	2	2
33	State of social relations	1	-4	0	1	-2
34	Ability to adapt to the social environment	3	-3	0	-1	-1
35	Support from one's social network	0	-3	-1	-2	-2
36	Social morality	1	-5	-1	0	1
37	Life attitude	4	-1	4	2	4
38	"Breadth of mind"	2	-3	1	1	3
39	Regularity in daily life	0	1	3	4	1
40	Diet habits	0	0	2	5	-4
41	Sense of satisfaction with life	1	-1	1	0	-3
42	Family medical history	-4	2	1	0	-1

Table 5-6: Demographic information for exemplars in each factor

		Factor 1 (n=19)	Factor 2 (n=25)	Factor 3 (n=16)	Factor 4 (n=6)	Factor 5 (n=4)
Gender	Male	7	8	10	6	3
	Female	12	17	6	0	1
Age	<40	4	13	12	1	3
	40-60	7	4	3	3	1
	60+	8	8	1	2	0
	(Mean age)	55	43	34	52	30
Education background	Under high school	3	6	3	1	0
	High school	4	1	2	1	0
	Secondary	3	1	1	3	1
	College	3	4	2	1	1
	University	6	13	8	0	2
Self-rated health state using EQ-5D	11111	8	7	8	4	0
	11112	2	3	2	0	0
	11121	3	5	1	0	1
	11122	1	3	2	2	1
	Other	5	6	3	0	2
Self-rated health score	80-100	10	17	9	3	3
	60-80	8	4	7	3	1
	<60	1	3	0	0	0
Residence place	City	12	13	10	2	3
	Non-city	7	12	6	4	1
Region	Southwest China	13	12	4	3	1
	East China	5	4	7	3	2
	North China	0	5	4	0	1
	Other	1	4	1	0	0

5.5.2.1 Factor One: Physical independence and social interaction skills

Factor One had an eigenvalue of 23.61 and explained 21% variance of the study. Q-sorts of 19 participants exemplified this factor: 12 women and 7 men. 8 participants were older than 60, 7 were in the 40-60 years old age group and 4 were younger than 40. Ten participants had a self-rated score for their health status higher than 80 (out of 100) and one scored lower than 60. 16 out of 19 participants stated they did not have any problems in walking, self-care and usual activities, while one participant had a moderate problem in walking, one had a

slight problem in doing usual activities and one was not able to walk, to conduct self-care activities or to conduct usual activities.

Factor One exemplars tended to agree that one's physical function was important in judging his/her health. Statements including "Ability to wash and dress oneself" (+5), "Ability to perform usual activities (such as working, studying, shopping, doing housework)" (+4) and "Ability to walk about" (+3) were ranked as most important. Participants revealed that it was essential to be physically independent and keep self-control over one's own life, and according to them, being able to take care of themselves, to conduct usual activities and to walk around were all basic requirements in obtaining such independence. Exemplars who lost or partly lost physical independence revealed that their daily activities had been significantly restricted, therefore their quality of life was largely damaged. For participants who were physically well, they also held the same point that one's physical function was a fundamental component in life. They explained that people could have other pursuits, such as happiness and fortunes, only if they had no problem in conducting these basic physical activities. Some elderly participants also illustrated that because they did not want to become a burden for the family, they would hope to maintain their physical independence and regarded it as a most important theme when talking about health:

"Self-care is the most important thing … it is a very good condition if you can eat, you can move around and you can do things without problems. For people in our generation, our children are so busy at work, who has free time to take care of me? I am the only one who can take care of me." (No.29, female, 66 years old)

In addition to functional abilities, participants also emphasised social interaction. "Ability to adapt to the social environment" (+3), "State of social relations" (+1), "Ability to communicate with people" (+1), "Social morality" (+1) were considered to be most important in this viewpoint. Although being physically independent was important, participants indicated that people are by nature social beings and cannot live in isolation from society. Some exemplars referred to the WHO's definition of health and mentioned that social health was as important as physical health and mental health. Some participants linked social wellbeing with one's physical and mental health state to highlight the importance of social health. For

example, participant 89 mentioned that maintaining good social relations was critical to one's health by illustrating its positive effects on her health condition:

"If you have some physical or mental health problems, it will be good if you have someone who can listen to you or help you … There was one time when I broke my leg, a lot of my friends came to visit me, cared about me, I felt much better, my bodily pain could even be neglected." (No.89, female, 56 years old)

Statements on individuals' mind-set, including "Life attitude (such as viewing things optimistically or pessimistically)" (+4), "Self-confidence" (+3) and "Breadth of mind" (+2), were chosen to be most important as well. Participants stated that because it was likely for people to encounter different kinds of troubles or challenges in life, they were supposed to face problems optimistically and confidently to be mentally healthy. Additionally, because a positive thinking mind-set was believed to be connected with good "ability to adapt to the social environment" and good "state of social relations", those confident and positive people were more likely to be welcomed by others and more likely to attain social wellbeing:

"For people who can share happiness, hopefulness and optimism with other people, they tend to leave a good impression and be popular among people in his/her social network." (No.107, male, 84 years old)

Some participants explained that a positive mental attitude could give one's body as well as one's mind a good signal, therefore could affect one's physical and mental states in a positive way. For example, participant 89 referred to her sister, who stayed positively in fighting cancer and overcame the life-threatening condition as an example to emphasise the positive influence of being optimistic.

Participants in this account did not place much emphasis on psychological feelings: "Feeling of fear" (-5), "Feeling of loneliness" (-3), "Feeling of depression" (-2), "Tendency of being angry" (-2), "Feeling of anxiety" (-1) and "Feeling of pressure" (-1) were considered as less important items to the exemplars who defined this factor. Some participants said that they normally did not have those negative feelings such as depression or loneliness, therefore, they did not think these statements were important. Some participants stated that they may have experienced some of these feelings but the temporary state of these feelings was

“adjustable” and was “not a big deal” (no.37, female, 46 years old). The exemplars tended to agree that it was normal for people to have different states of mood to feel happy or upset. Those negative feelings may last only a limited period of time and could be easily relieved.

Physical symptoms were also less valued in this viewpoint. Statements such as “Feeling of discomfort” (-2), “Feeling of pain” (-1), “Feeling of tiredness” (-1) were ranked as less important, although they were related to physical health. Similar to those psychological feelings that were addressed in the last paragraph, these physical symptoms were believed to be varied from time to time and were temporary states on most occasions. As long as they were not chronic problems, they could not provide reliable information for health assessment. For example, as participant 85 suggested, people could feel pain after doing exercise but that was not a sign for poor health. Some elder participants also explained that these physical feelings were not fatal and did not interfere with their normal life. They could still conduct routine activities by tolerating with such physical symptoms, thus these symptoms were least important in judging their health:

“When I do not think about my pain, I feel less painful. I have backache but I still do housework. When I feel really painful I will lie on a sofa to have a rest and I will feel better. It is not a fatal problem, why important?” (no.29, female, 66 years old)

To summarise, the exemplars whose views constructed this factor tended to think about physical independence, social interpersonal skills and optimism of mind-set when judging one’s health. Meanwhile, they did not place much emphasis on psychological feelings or physical senses

5.5.2.2 Factor Two: Physical health

The eigenvalue of Factor Two was 17.00. The factor explained 15% of the study variance. Twenty-five participants were significantly associated with this factor: 17 women and 8 men. 13 were younger than 40, 8 participants were older than 60 and 4 were in the 40-60 years old age group. 17 participants had a self-rated score for their health status higher than 80 and 3 scored lower than 60. 12 participants stated they felt pain or discomfort, 10 reported they had (different

levels of) depression/anxiety, while 4 participants had problems in doing physical activities.

Physical health is the central focus of this factor. Compared to the previous factor, physical function statements including “Ability to wash and dress oneself” (+5), “Ability to walk about” (+4) “Ability to perform usual activities (such as working, studying, shopping, doing housework)” (+3) were ranked as most important in this group of participants. They underlined the importance of being physically independence with similar reasons reported in Factor One.

In addition to physical functional abilities, participants also highlighted physical symptoms including “Feeling of pain” (+4), “Sleep quality” (+3), “Feeling of discomfort” (+2), “Desire of having food” (+2), “Spiritual appearance” (+2), “Body strength of doing things” (+2) and “Feeling of tiredness” (+1) as important health statements. Participants tended to linked undesirable physical signs with disease conditions. If a person got sick, certain physical symptoms such as pain or discomfort would appear in the body and he/she may not be able to sleep well or have a good appetite. On the other hand, it was also believed that if a person did not have good sleep or lost the desire for food, he/she would not have adequate energy and would fall ill easily. Therefore, these physical symptoms could directly reflect one’s health, as one participant described here:

“My husband doesn’t sleep well recently. He always says he feels uncomfortable waking up and doesn’t want to go to work because he doesn’t have energy. He often gets cold and I think this is because his lack of sleep wakes his immunity.” (no.55, female, 41 years old)

Participants of this group tended to understand health as the opposite of disease and held the opinion that no disease indicated good health. This may explain why they valued those statements that were relevant to diseases as most important in judging heath: “Body constitution that can indicate the susceptibility to disease” (+3), “Family medical history” (+2) and “Dependence on medicine” (+1). They explained that one’s body constitution and family medical history closely related to one’s possibility of getting certain diseases; one’s dependence on medicine suggested that he/she may have some chronic diseases. Therefore, these statements could directly be used to judge one’s health.

The factor showed a clear preference for physical statements. Those statements relating to psychological symptoms (such as “Feeling of loneliness”(-2), “Feeling of fear”(-2), “Tendency of being angry” (-1) “Feeling of anxiety”(0), “Feeling of pressure”(0)) as well as cognitive function (such as “Ability to make decisions”(-4), “Ability to remember things”(-1), “Ability to concentrate” (-1) “Ability to think things clearly”(-1), “Ability to perceive changes in surrounding and to respond”(-1)) were ranked as less important. Some participants stated that they only considered those physical statements to be relevant to health, as a participant told *“Do these (mental) feelings matter? I think a healthy person can also be depressed or fear of things… I think if a person can eat and sleep well, he is fine” (no. 55, female, 41 years old)*. Some participants mentioned mental health but emphasised that they may not be as important as physical wellbeing because they believed mental wellbeing cannot be obtained without a healthy physical body. A participant illustrated that doctors mainly provided biological intervention to improve patients’ physical health and he also thought patients may not care about their mental condition until such mental condition affected their physical health (no.81, male, 23). Participant 93 mentioned that he lost a leg due to a car accident, making his mental condition sharply worsen. He believed that being mentally unwell may deteriorate one’s health gradually, but being physically unable could ruin his life fundamentally.

In contrast to the first factor where statements relating to social wellbeing were placed as most important, Factor Two regarded those statements as least important. According to them, when judging one’s heath, it was less important to assess one’s behaviours in front of others (“Social morality” (-5)) or one’s interaction with other people in the society (“State of social relations” (-4), “Ability to adapt to the social environment” (-3), "Breadth of mind" (-3), “Support from one’s social network” (-3), “Ability to communicate with people” (-2)), or one’s personality (“Self-confidence” (-2)). Some participants considered social wellbeing as “luxuries” (no.81, male, 23). They stated that things like social support or confidence were not necessities for individuals and people could still be healthy even without these things. Some participants said they could not find connections between these statements and health, because, in their understanding, one’s heath was about one’s physical state and mental state and

was irrelevant to one's social connections or social environment. Participants illustrated that one's social interaction skills and personality were influenced by many factors including his/her education, life experience and family environment. Each individual may have a distinctive character and it was not appropriate to decide which character was better. Therefore, these statements were not able to be used to judge between good health and poor health. For example, a participant explained that:

"People can be confident or shy … Some people are born with good interpersonal skills and they are good at making friends. Some people simply do not like to socialise with others. I cannot see which character is better." (no.77, male, 28)

An individual was identified as an exemplar with a Q-sort significantly but negatively loaded on Factor two. This means the individual had a Q-sort that represents a reverse view. For example, he viewed physical function and physical symptom statements as least important, while considered one's mind-set as well as social wellbeing as most important. With comparable reasons which were addressed in Factor One, he valued social health and mind-set. He also explained that he did not experience physical functional problems and considered them as least important. This part of the view was shared by Factor Three and Four, which will be presented in the later paragraphs.

In short, Factor Two placed great emphasis on physical health. Exemplars considered physical function and physical symptoms as most important and were less likely to value social wellbeing as an important aspect in describing health.

5.5.2.3 Factor Three: Sensations and feelings

Factor Three had an eigenvalue of 10.08 and explained 9% of the study variance. A total number of 16 exemplars were identified when their Q-sorts formed the third factor. Among them, 6 women and 10 men. 12 were younger than 40, 3 were in the 40-60 years old age group and 1 participant was older than 60. 9 participants had a self-rated score for their health status higher than 80 and none scored lower than 60. None of them had a problem in doing physical activities and 8 exemplars reported no problem using EQ-5D. 7 participants said they felt depressed/anxious and 6 informed their physical pain/discomfort.

The participants whose sorts generated this factor were likely to emphasise on things that directly influenced their life and regarded those things with which they had no problem as less important. Unlike Factor One and Factor Two where physical functional abilities were placed as most important, participants in this group did not favour them that much: “Ability to wash and dress oneself” (0), “Ability to perform usual activities (such as working, studying, shopping, doing housework)” (0), “Ability to walk about” (-1). They considered those functional abilities as less important because they did not have such problems. For example, a participant described that:

“Walking about, working, dressing myself, I do these things every day. Nothing stops me (from doing these things)… I think people around me, all of them do not have such problems… Only those disabled people have these problems.” (no.53, female, 32 years old)

With a roughly similar reason, they regarded “Vision” (-5), “Hearing” (-4) as well as those cognitive function (“Ability to make decisions” (-3), “Ability to remember things” (-3), “Ability to concentrate” (-2), “Ability to perceive changes in surrounding and to respond” (-2), “Ability to think things clearly” (-1)) as less important. It seems that this group of participants did not consider those worst scenarios when people totally lost vision, hearing or cognitive abilities. They seemed to assume that those abilities only had limited influence on people. Some participants illustrated that in his/her age, they were able to see and hear things. They believed that even if people had poor vision or hearing, they could use glasses and hearing-aid and their life would not be affected. Participants also thought it was not likely for people to lose their cognitive abilities until reaching a certain age:

“*People’s thinking abilities are more or less the same... When you are old, you may not remember things quite well, you may not have a clear head, but when you are young, you don’t have such problems*” *(no.86, female, 27 years old).*

Despite the fact that the exemplars of this group viewed physical function as less important in health judgement, they emphasised the importance of physical health by highlighting “Body constitution that can indicate the susceptibility to disease” (+5), “Spiritual appearance” (+4) and “Sleep quality” (+3). Participants

generally held an opinion that people with a better body constitution tended to have a lower possibility of catching diseases and were healthier. They also believed that one's spiritual appearance directly indicated his/her health status. Participants' understandings of spiritual appearance were similar to what was found in the previous qualitative study (see Chapter 4). They related this term with one's overall appearance (eye spirit, voice, sitting postures and movement) as well as one's energy. They explained that a person who was free from diseases and had few things to worry about would generally have a good spiritual appearance, therefore, it was supposed to be a straightforward sign reflecting one's health.

Participants also tended to regard lifestyle behaviours ("Regularity in daily life" (+3), "Diet habits" (+2)) as most important. They explained that one's behaviours in daily life would affect or predict one's health. Good practices such as maintaining a regular life circle, keeping a healthy diet and having a good rest, in this sense, could suggest one's current health condition and/or could predict one's future health. Physical feelings including "Feeling of pain" (+2), "Feeling of discomfort" (+2) and "Feeling of tiredness (+1) were also valued by the exemplars of this factor. Most of them explained that they had experienced these undesirable feelings and such feelings had affected their daily life. For example, a participant described: *"Most patients went to hospitals because they feel something wrong with their body… They rely on what they feel at the current moment: they may have pain in their head, waist or legs and may decide to see a doctor." (no.84, male, 34 years old)*

Another central theme of this factor was mental wellbeing. Participants tended to highlight the importance of mental health: "Feeling of depression" (+3), "Feeling of pressure" (+2), "Feeling of anxiety" (+2), "Ability to remain stable and peaceful in mood" (+1). Exemplars of this group mentioned that people who were mentally unwell may harm themselves, conduct suicide or even hurt other people. They thus believed that mental health issues were more detrimental than physical diseases. They also tended to believe that nowadays mental health issues may be more prevalent than physical problems. Participant 12 talked about her and her friends' experience of having negative emotional experiences interfering their sleep and work. She considered physical diseases were not as common as those

mental health issues, especially among young people (no. 12, female, 25 years old). Participant 34 thought physical diseases were always controllable with the development of medical technology, but mental disorders seemed to be more difficult to be cured (no.34, female, 51 years old). Participants also held the view that one's overall health was mainly affected by one's mental state because those emotions can be controlled subjectively, while one's physical state tended to be stable and sometimes was not able to be changed. They believed that people could choose to stay in a good mental condition as a way to improve their health. For example, participant 71 described that: *"Some people born disabled and it is not fair to say they are unhealthy. They cannot control these objective factors but they can choose to live their own life happily." (no.71, male, 28 years old)*. While "Feeling of loneliness" (-2) and "Feeling of fear" (-2) were both emotional experiences, they were not placed as most important in this factor. Participants seemed to agree that their life was not troubled by such two feelings. Some stated they enjoyed their own space and did not regard loneliness was a bad thing. Some stated they did not feel fearful very often thus did not regard it as important.

In general, participants whose views defined this factor tended to emphasise those things that had a direct influence on their daily life. They regarded body constitution, physical appearance, lifestyle behaviours and physical senses as important indicators in assessing health. They also strengthen the importance of mental wellbeing but viewed physical function as less important in health judgement.

5.5.2.4 Factor Four: Lifestyles

Factor Four had an eigenvalue of 6.60 and explained 6% of the study variance. 6 male participants loaded significantly on this factor. 1 of them was younger than 40, 3 were in the 40-60 years old age group and 2 participants were older than 60. 3 participants had a self-rated score for their health status higher than 80 and none scored lower than 60. None of the participants had a problem in doing physical activities. Two reported that they had slight pain/discomfort and were slightly anxious/depressed.

Similar to Factor Three, exemplars whose sorts defined the fourth factor valued things, they believed, that had a direct influence on their life. They seemed to be

convinced that lifestyles can significantly affect one's health: "Diet habits" (+5), "Regularity in daily life" (+4). They tended to believe that people who had regular eating and sleeping time and kept a balanced diet were likely to be healthy, while bad lifestyles undermined one's health condition. For example, participants 14 explained the importance of life regularity to health by exemplifying its influence on his friend's life quality:

> *"I have a friend who is now 59 (years old) but looks very young. His life is very regular. For most friends of mine, we often play card games until 2 am or 3 am, but he never did that. He would go home by 9 pm… He gets up on time, eats three meals on time, and sleep on time. He swims in the morning." (no.14, male, 48 years old)*

Exemplars rated "Sleep quality" (+4), "Desire of having food" (+3), "Spiritual appearance" (+3) and "Body constitution" (+3) to be most important health indicators, as they believed those aspects were closely associated with one's life quality and could straightforwardly reflect one's health. They mentioned that people who were in good health were supposed to have good sleep and appetite. They also illustrated how "Spiritual appearance" was different between a person who was in good health and one who was ill. On the other hand, exemplars did not emphasise the importance of physical function: "Ability to walk about" (-4), "Ability to wash and dress oneself" (-3), "Ability to perform usual activities (such as working, studying, shopping, doing housework)" (-2). They believed those things were less likely to affect most people's normal life because most people would not have problems in these aspects.

While this factor was comparable with Factor Three in terms of the points addressed above, there were distinct differences between the two views. This group of participants recognised cognitive function abilities were important factors in judging health, when they placed "Ability to remember things" (+2), "Ability to concentrate" (+2), "Ability to make decisions" (+1), and "Ability to think things clearly" (0) to be relatively important. This may be because exemplars in the group of Factor Four were older than participants of the previous group. As elder people may not have an as good cognitive function ability as youths and/or the elderly may have witnessed more cases where friends/relatives suffered from cognition problems, they were more likely to concern about such cognitive abilities in this respect. For example, participant 52 stated that *"My uncle suffered*

fr,om senile dementia, I think he has a very hard life. He does not remember anyone. He cannot enjoy his life anymore… I should not say this but without a clear head, the body is useless." (no.52, male, 70 years old)

Another difference between the Fourth and Third factors was that participants in this group did not regard emotional experiences as most important: "Feeling of fear" (-5), "Feeling of loneliness" (-4), "Feeling of pressure" (-3), "Feeling of depression" (-3), "Feeling of anxiety" (-2), "Ability to remain stable and peaceful in mood" (0). The reasons for why emotional experiences were less important in this account were similar to what was described in Factor One. Participants either felt they normally did not experience such negative emotional experiences, or they believed those negative feelings could be relieved and would not influence their normal life, as participant 13 argued that *"why people feel anxious or depressed? If some terrible things happen, he would be affected and feel bad. But for most people, if they can sleep well, eat well, have a good body, I think they will hardly feel anxious." (no.13, male, 50 years old)*

In short, Factor Four tended to appraise one's health by referring to one's lifestyle behaviours as well as everyday life quality. Exemplars of this group were also likely to emphasise one's cognitive function in health judgement, while viewed physical function and emotions as less important.

5.5.2.5 Factor Five: Learning and Working abilities

Factor Five had an eigenvalue of 4.50 and explained 4% of the study variance. 4 participants whose age was 40 or under 40 were identified as exemplars of this factor. 1 woman 3 men. 3 of them had a health self-rated score higher than 80, one scored her health at 70. 2 reported they had problems in conducting usual activities, 2 had slight pain/discomfort and 3 had anxiety/depression.

Vision and hearing were placed as the most important statements: "Vision" (+5), "Hearing" (+4). It is interesting to notice that participants prioritised the abilities to see and hear. Participant 68 explained that vision and hearing were essential if a person wanted to perceive the world and to learn things. If a person lost abilities to see or hear, it became harder for him to get new information (no. 68, male, 24 years old). But on the other hand, participants of the group tended to think other physical functional abilities, such as "Ability to wash and dress oneself" (0) and

"Ability to perform usual activities" (-1), were less important, because they thought those abilities were too basic for them to worry about. For example, participant 42 stated that *"I don't think normal people would have self-care problems. It is not important for most people because I think almost everyone can do this." (no. 42, male, 40 years old)*

The group of exemplars valued one's mind-set and chose to believe "Life attitude" (+4), "Breadth of mind" (+3), "Self-confidence" (+2) as most important criteria in judging health. Very similar to the reasons given in Factor One, where one's mental attitude was regarded as most important, exemplars of Factor Five tended to believe that people who had an optimistic attitude, who were tolerant of things and who were confident were more likely to face challenges and deal with problems in life positively, therefore, they were more likely to have a good mental health state. Participants also mentioned the positive influence of a good mind-set on one's physical health state. For example, participant 42 illustrated that *"a trivial person who concerned petty things and often had quarrels with people, would hardly be happy. He may always be resentful, keeps worrying about things and cannot sleep well… And if you always complain, always worry, your spirit appearance must be poor." (no. 42, male, 40 years old)*

While exemplars of Factor One jointly highlighted the mind-set and social interaction and explained the inner relations between the two aspects, participants in this account only chose one's mind-set as most important and placed statements relating to social wellbeing as less important: "State of social relations" (-2), "Support from one's social network" (-2), "Ability to adapt to the social environment" (-1), "Ability to communicate with people" (0). This may be explained by the age difference between the two groups of participants. Exemplars of Factor Five (mean age 30) were younger than people of Factor One (mean age 55). Participants in younger age may be more concentrated on their own work thus did not appreciate social wellbeing as much as exemplars of Factor One.

They placed cognitive abilities, including "Ability to think things clearly" (+2), "Ability to concentrate" (+2), "Ability to perceive changes in surrounding and to respond" (+1), "Ability to remember things" (+1), as important statements. They

explained that such abilities were vital in their day-to-day work. Similarly, their emphases on “Feeling of pressure” (+3) and “Feeling of anxiety” (+1) over other emotional experiences may also be because of their work. Participants in this group were likely to be under stress and be bothered by anxiety, as participant 20 expressed her concern on anxiety and work stress, *“I cannot control my anxiety. I have too much work stress, even when I go back home, I keep thinking about the work I haven’t finished. I could not sleep, I want to sleep but I can’t.” (no.20, female, 30 years old)* Participant 42 thought statements about anxiety and pressure were more important than “Feeling of depression” because he had too many responsibilities and stress from work and he *“has no time to be depressed” (no. 42, male, 40 years old)*.

Physical signs or feelings were regarded as less important in this account: “Natural colour and appearance of face” (-4), “Feeling of pain" (-3), “Desire of having food” (-3), “Feeling of discomfort” (-2), “Feeling of tiredness” (-2). One reason was that exemplars in this group were relatively young and they may less likely to be troubled by negative physical symptoms, as participant 68 illustrated, even he had those physical symptoms, such feelings would cease and could cause little interference in life: *“If I stayed up late yesterday, I may feel discomfort or tired today. But the feeling will go away once I have enough rest.” (no.68, male, 24)* Another reason referred to by participants was comparable to what was described in Factor One: participants tended to believe these physical symptoms were temporary states and could not provide reliable information about an individual’s health status. They believed health was a relatively stable state, except for dramatic changes, such as an accident. Therefore, participants believed that health should not be judged by symptoms that varied from time to time.

It worth noting that participants who were loaded significantly on this factor emphasised abilities to perceive, cognitive abilities and negative emotional experiences that were closely linked with their working experience. But they did not value health indicators relating to social wellbeing and physical signs or feelings were regarded as less important

5.5.2.6 Most/least important health dimensions across the five factors

Although each of the five extracted factors represented a view that was significantly different from the views that represented by other factors, similarities among the five factors can also be detected. Some health statements were consistently rated as most important by most of or all of the five factors. The statement “Body constitution that can indicate the susceptibility to diseases” was agreed to be important across the five factors. It was rated as “+5” in Factor Three, “+3” in Factor Two, Four and Five, “+2” in Factor One. Similarly, “Spiritual appearance” was rated as important in the majority of the extracted factors: “+4” in Factor Three, “+3” in Factor Four, “+2” in Factor One and Two. The statement about sleep quality was also agreed to be important: Factor Four rated it as “+4”, Factor Two and Three rated it as “+3” and Factor One rated it as “+1”. Apart from Factor Two, one’s “Life attitude (such as viewing things optimistically or pessimistically)” as well as “Breadth of mind” (such as being tolerant of other people or narrow-minded to other people) were most important in judging one’s health. “Life attitude” was with an importance level of “+4” in Factor One, Three, Five and “+2” in Factor Four. “Breadth of mind” was rated as “+3” in Factor Five, “+2” in Factor One and “+1” in Factor Three and Four. Life regularity also received positive importance rankings in four factors: “+4” in Factor Four, “+3” in Factor Three, “+1” in Factor Two and Five.

On the other hand, some health statements were not rated highly in most of the five factors. “Feeling of loneliness” received negative importance rankings in all factors: “-4” in Factor Four, “-3” in Factor One, “-2” in Factor Two and Three, “-1” in Factor Five. “Adaptability to weather changes” was agreed to be less important across the extracted views: “-5” in Factor Five, “-3” in Factor One and Three, “-1” in Factor Two and Four. “Feeling of fear” was rated as “-5” in Factor One, Four and “-2” in Factor Two, Three. “State of sex life” was another statement placed to be less important in the majority of the identified factors: “-4” in Factor One and Three; “-2” in Factor Two and Four.

5.5.2.7 Rankings of EQ-5D in the five extracted factors

The five dimensions of EQ-5D were also generated as statements, as a way to observe their relative importance among various health dimensions that may be

important in a Chinese cultural setting. As shown in Table 5-7, unlike the health statements mentioned in Section 5.5.2.6 that were consistently treated as most important or least important across the extracted factors, for the statements generated from the EQ-5D dimensions, some factors treated them as most important, while some factors rated them as least important. Physical function statements including “Ability to walk about”, “Ability to wash and dress oneself” and “Ability to perform usual activities” received high positive rankings (at least “+3”) in Factor One and Two. Meanwhile, these statements were rated as less important in other factors. Views according to “Feeling of pain” and “Feeling of discomfort” were also diverse. In Factor Two and Three, the two statements were rated as important with positive rankings (“+2” / “+4”), while they were with negative rankings in Factor One and Five. The same applied to “Feeling of depression” and “Feeling of anxiety”.

The exemplars of Factor Two tended to value most of the EQ-5D dimensions, as those EQ-5D related health statements, except “Feeling of depression” and “Feeling of anxiety”, received positive ranking scores. Factor Four and Five exemplars rated most of the statements as less important. The exemplars of Factor One only valued those EQ-5D dimensions relating to physical function (Mobility, Self-care and Usual activities), while the rest of the EQ-5D dimensions (Pain/Discomfort and Anxiety/Depression) were regarded as important by Factor Three exemplars.

Table 5-7 Rankings of EQ-5D dimensions

	Statements	Factor arrays				
		1	2	3	4	5
8	Feeling of discomfort	-2	2	2	0	-2
9	Feeling of pain	-1	4	2	2	-3
12	Feeling of depression	-2	1	3	-3	0
13	Feeling of anxiety	-1	0	2	-2	1
20	Ability to walk about	3	4	-1	-4	2
21	Ability to perform usual activities	4	3	0	-2	-1
25	Ability to wash and dress oneself	5	5	0	-3	0

5.6 Discussion

5.6.1 The legitimacy of the conceptual framework of health

One objective of this Q-methodological study was to justify the legitimacy of the previously established conceptual framework of health. It was based on the developed conceptual framework that the Q-sample of the study was generated. A number of 110 Chinese participants were asked to rank and sort these statements. As it was reflected in interviews, most of the participants confirmed that they understood the statements and had no problem in following instructions. This shows that the statements were reported to be clear to most of the Chinese participants.

Additionally, since participants were aware of the condition of instruction ("When judging a person's health, how important is it to know about their ___?") and were able to complete the Q-sorting task, it indicates that they accepted these statements as health dimensions which can be used to assess health. Therefore, it suggests that the developed conceptual framework of health includes relevant health dimensions in a Chinese cultural setting.

During the pre-sorting interviews, aspects of health that were mentioned by participants were found to be covered by the previously established conceptual framework of health. The feedback from the post-sorting interviews also shows that the Q-sample was considered to be able to broadly represent health dimensions that may be important in describing health across the participants.

Therefore, the clarity, relevance and completeness of the developed Chinese conceptual framework of health were found to be acceptable among a group of Chinese participants. It implies that this conceptual framework of health is able to provide a list of eligible and comprehensive health dimensions in assessing health in China.

5.6.2 Differences across five factors

The second aim of the study was to further explore Chinese participants' subjective understandings of health. The study identified five distinct views of judging health. The five diverse views in sorting health statements demonstrate that health is a complicated concept that can be understood differently by

participants. There were various perspectives in thinking about health: exemplars of Factor One and Two were likely to perceive health from a functional point of view, exemplars of Factor Three tended to define health as the opposite of diseases, while it was widely agreed by exemplars of Factor Four that health was closely linked with one's lifestyles and daily life quality in terms of sleeping and eating. The five viewpoints also show debate between evaluating health as a temporary state or as a longer-term status. While exemplars whose sorts defined Factor One and Five tended to assess health from a long-term basis and held a point that because those temporary signs or symptoms varied from time to time, they were not reliable in assessing health, participants of Factor Three were likely to perceive health as a short-term state and valued current sensations and feelings. Additionally, findings suggest that diverse priorities are given to different aspects of health in different viewpoints. For example, participants of Factor One jointly highlighted social wellbeing with physical conditions; Factor Three emphasised mental states; while some exemplars whose sorts generated Factor Two revealed that they only considered one's physical fitness to be most important when thinking about health.

The findings illustrate how individuals' demographic characteristics, social surroundings and their own health experiences shaped their perceptions of health. Similar to the previous literature (Bury, 1982; Mansour, 1994; Baumann, 1961; Lawton, 2003), age is found to be one of the most influential factors in shaping lay understandings of health. It was revealed from this study that younger participants talked about mental health more frequently. It might be because young participants were generally in a better physical health state and were more likely to be aware of mental health issues. Meanwhile, elder participants tended to have more physical and cognitive function problems compared to younger participants and were more likely to highlight the importance of physical and cognitive abilities. In addition, elder participants were more likely to raise social wellbeing issues in defining health. This may be because they had more experiences in appreciating the impact of social relations and hoped to be well involved in social communities more, as explained in the literature (Depp and Jeste, 2006).

Education is also found to be a salient indicator in shaping participants' understandings of health. This is also similar to previous findings (Baumann, 1961; Mansour, 1994; van Dalen et al., 1994; Blaxter, 2003). While participants with higher levels of education were more likely to be aware of mental health and social wellbeing, participants in lower levels of education were more likely to restrict the scope of health within physical fitness. An extreme example was that several participants who were with limited education declared they never heard about "Anxiety" and did not understand its meaning (participant 27 and 101) and they placed the statement randomly on a less important place. Besides, residence place may also influence individuals' views according to health. As it is shown in Factor Five, most of the exemplars whose sorts defined this factor lived in cities and illustrated they had a stressful job and lived in a competitive environment. It may explain why they were more likely to emphasise statements on cognitive abilities and mental health issues and tended to associate those statements with their work.

Apart from demographic characteristics, one's health conditions and past health experiences influence one's interpretation of health (van Dalen et al., 1994; Blaxter, 2003; Baumann, 1961). Participants who reported problems in mobility or doing self-care activities were likely to place statements about physical functional abilities as most important. As a result, none of these participants exemplified Factor Three, Four and Five. It can also be noted that exemplars of Factor Three and Four were generally in a good health state in terms of their EQ-5D results (half of them were in a "11111" full health state and the majority of them had their self-rated health scores higher than 80). They highlighted the quality of sleeping and eating in judging one's health and emphasised lifestyle behaviours in maintaining health. It may be because those people in a better health condition are less troubled by function limitation or negative feelings/sensations and are more likely to think about health with a higher expectation and define health in a more positive way.

5.6.3 Similarities among the views

In addition to the differences described above, similarities in understanding health are also detected across the five factors. Some health dimensions were

simultaneously valued by the majority of participants and may be essential in assessing health among Chinese populations.

The statement “Body constitution that can indicate the susceptibility to diseases” was agreed to be important across the five factors. “Body constitution” has been closely associated with the concept of health in Chinese populations according to several studies (Lew-Ting et al., 1998; Chan and Chien, 2013). This term was found to be an understandable and widely referred concept in describing health among Chinese lay people in the previous qualitative study as well as in the published literature (Lew-Ting et al., 1998). The current Q-investigation further proves that it is widely accepted by lay people in Chinese communities as an indicator to assess one’s health.

“Spiritual appearance” was another statement that was highly emphasised in the majority of the extracted factors. It was discussed in both Chapter 3 and Chapter 4 that “spirit” is a central notion in traditional Chinese knowledge and could be referred to one’s consciousness, mind, thoughts and/or vitality (Liu and Fang, 2000; Rossi, 2007; Zi, 2012). It was already recognised in previous qualitative interviews (Chapter 4) that “spirit” was part of lay participants’ common knowledge, while again, the statement about spirit was highly valued in this Q-study. It further indicates that spirit can be an important dimension in evaluating health among Chinese general populations.

Apart from Factor Two, which firstly prioritised physical health statements, other factors all held the point that one’s “Life attitude (such as viewing things optimistically or pessimistically)” as well as “Breadth of mind” (such as being tolerant of other people or narrow-minded to other people) were most important in judging one’s health. In this study, many participants linked a positive mind-set with good health and indicated that facing problems in life positively and confidently and avoiding conflicts with other people were good practices in adapting to the changes in the environment to stay in health. This may reflect Chinese traditional knowledge in appreciating balance and harmony between an individual and the surroundings. It was explained in Chapter 3 and Chapter 4 that according to Chinese traditional knowledge, because one’s external environment is closely associated with his/her daily activities, ideally, a person should be

capable of adjusting to the external environment to reach a harmonious state (Zhang et al., 2015). This study shows that this idea seems to be well accepted among a group of Chinese participants.

The statement about sleep quality was also extensively agreed to be important, as the four of the extracted factors rated it with a positive importance level and three of them regarded the statement as most important (at least +3). In the previous scoping review study (Chapter 3), sleep was found to be assessed in all identified Chinese-developed HRQoL measures, the findings of the current Q-study provide additional evidence that sleep was regarded as an important health dimension among a group of Chinese participants, from an empirical perspective. Life regularity was also rated using positive importance levels by four factors. This may be in line with the influential phenomenon of “Yangsheng” (Health-keeping Behaviours) across Chinese communities (Si et al., 2013; Sun, 2016). This idea conveys that good behaviours, such as keeping a regular lifestyle, can potentially be associated with “good health”.

On the other hand, there are also statements that were agreed to be less important across the five factors. Although adaptability to weather changes was assessed in several Chinese-developed HRQoL measures (Wu et al., 2007; Liu et al., 2007; Li, 2007), it was not rated highly in the extracted views, as most of the participants revealed that this statement was less relevant to health compared to other statements. Feelings of fear and loneliness were also found to be less important across the five factors. Participants seemed to agree that their life was not troubled by such two feelings. Some stated they enjoyed their own space and did not regard loneliness was a bad thing. Some stated they did not feel fearful very often thus did not regard it as important. Moreover, “State of sex life” was another statement placed to be less important in the majority of the identified factors. The sensitive nature of this health dimension and its difficulty to be applied in assessing health among Chinese populations was mentioned in the literature (Yu et al., 2016). It was also revealed by participants that they concerned this as a private topic and preferred not to discuss it with other people. For those health statements that were consistently ranked as least important, they may not be useful to be included in HRQoL measures for assessing health among Chinese populations.

5.6.4 Differences in understanding health between China and the West

The findings suggest that Chinese participants' comprehensions of health are comparable to the Western ways to a large extent. Statements about functional abilities, physical symptoms and emotions were well recognised by Chinese participants when they were asked to think about health. Those aspects have also been frequently reported as principal health domains in the Western literature (Wilson and Cleary, 1995; Manderbacka, 1998; Simon et al., 2005; Peersman et al., 2012). However, it is also clear to note that there are differences in understanding health between China and the West. Such differences can be shown from two aspects: first, the content validity of a commonly used Western HRQoL measure in a Chinese cultural setting was again questioned by this study; second, several Chinese-specific health dimensions were identified to be important.

The five dimensions of EQ-5D were included as statements in this study to be directly compared with other identified health dimensions of the developed Chinese conceptual framework of health. Although self-care, mobility and usual activities were acknowledged to be important in two of the extracted factors, some participants tended to define health in a more positive way and mentioned that these physical function abilities were too basic for them to worry about therefore were less important. Views towards physical feelings of pain and discomfort were also diverse. Some believed pain and discomfort were effective indicators to detect one's physical health status, while several participants argued pain/discomfort could only indicate temporary states and, in most occasions, could not provide reliable information for health assessment. Similarly, anxiety and depression were also believed to be not reliable in evaluating health according to some participants. Furthermore, anxiety and depression were found not be well understood by some Chinese participants, especially those received limited education. The results thus imply that the five dimensions may not be relevant in measuring health for some people in China. It can be argued that the HRQoL measure may fail to ask the most relevant and important questions among a Chinese population in assessing health. The content validity of this

Western HRQoL measure for use in a Chinese general population, therefore, can be questioned.

Some “Chinese-specific” concepts, such as body constitution and spirit, were identified from the Chinese literature (Chapter 3) and from Chinese lay participants (Chapter 4). This study shows that these “Chinese-specific” concepts were well understood and accepted as health dimensions by a group of Chinese participants. Although participants may hold different perspectives when thinking about health, these health dimensions seem to be emphasised by most of them. These “Chinese-specific” health dimensions demonstrate cultural differences in defining health between China and the West. In addition, health dimensions such as sleep, life attitude, “breadth of mind” and life regularity were found to be important in assessing health in studies reported in Chapter 3 and 4. The importance of such concepts is now supported by this Q-investigation. Since they are not commonly included in Western-developed HRQoL measures, such as EQ-5D, differences in measuring health between China and the West are further justified.

5.7 Limitations

This Q-methodological study was in nature exploratory and identified a broad range of views in understanding health among a Chinese population. Although Q methodology was an effective tool in investigating subjective constructions of a concept and was appropriate in studying similarities and differences across diverse views, it was not able to report a particular view of a population, directly answering which health dimensions are most important. Alternative quantitative analysis is reported in Chapter 6 to further investigate the concept of health in China.

Another limitation was that, because the study investigated Chinese lay perceptions of health and recruited only Chinese participants, it was not possible to compare Chinese participants’ views with Westerners’ to explicitly test cultural differences in understanding health between China and the West. A Q-methodological investigation was planned to be conducted in the UK using a similar study design and materials, but potential obstacles in translating the Q-

statements into English to make them clear and understandable to non-Chinese participants are expected.

Although the statements were written carefully, aiming to be without ambiguity and be understandable to lay people, a small number of participants did not understand some specific statement (“Feeling of anxiety”) or interpret some statements differently. For instance, for those statements on functional abilities, some participants imagined situations when one totally lost physical abilities, such as cannot walk or cannot see or cannot hear, thus sorted the statements as most important, while some participants did not expect conditions could be that extreme and did not regard them as most important. Such variations in participants’ interpretation of statements were difficult to control in the sorting exercise and may have influenced how they sorted cards.

5.8 Conclusion

Results from previous qualitative studies indicated that many of these statements were not commonly mentioned in Western-developed HRQoL measures such as EQ-5D. The present Q-study confirmed that these statements were well recognised by a diverse range of Chinese participants and suggested that the EQ-5D descriptive system might need modification to improve its capacity to measure health status. The Q-investigation, therefore, reinforced the cultural differences between China and the West.

Chapter 6 Quantitative analysis of preference data: the use of multidimensional scaling

6.0 Summary

In this chapter, ranking data that were obtained from participants in the Q-study were analysed quantitatively using a multidimensional scaling (MDS) method. In the previous chapter, the Q-study identified five distinct views of ranking 42 statements of health dimensions. The result only presented the most important health statements within each view but was not able to provide an overview of which health statements were most important among the whole sample of participants. An additional quantitative analysis was considered to understand the preferences across the whole sample for the 42 health statements. The MDS analysis was conducted to analyse the ranked preference data. The results further indicated how lay people coming from a Chinese cultural setting may perceive health and which aspects of health are most important to them.

6.1 Background

The complexity of the concept of health has been acknowledged in the previous chapters. The scoping review (Chapter 3) and the qualitative study (Chapter 4) produced a list of 42 statements representing those aspects of health that may be important for use in subjective assessment of health in a Chinese cultural setting. With such a large number of health statements available, a research objective was set to establish the relative importance of those health statements. In the previous chapter, Q methodology, which allowed participants to compare and rank all of these health statements following a well-organised process, was selected to attain the research objective.

However, since Q methodology is a qualitative-driven mixed method, although it can effectively investigate lay Chinese participants' subjective constructions of health by identifying patterns of views, it was not able to report which health statements were most important across the whole group of Chinese participants. The Q-study clustered participants who shared a similar view of health and

presented five distinct views of ranking those health statements. As a result, it could only present the most important statements within each view but was not able to report a unified opinion directly showing which statements were rated to be most important across the whole sample. Therefore, an additional quantitative analysis was considered to address this problem to further explore the conceptualisation of health in China.

In the Q-study as reported in Chapter 5, each participant was asked to assign various statements on a Q-grid (see Figure 6-1, reproduced here for the ease of presentation) as a way to show their preference for these statements. For each participant, the statements of the right-side column were more important than the left-side, while the statements sorted in the same column were with the same importance level. In order to obtain more detailed information about participants' preferences for the statements, this standard sorting process of Q methodology was extended to create a direct rank order of 42 health statements for each participant.

This extended ranking process was undertaken as follows: after completing the Q-sorting exercise, each participant was asked if he/she was happy with the distribution of statements on the Q-grid. Then they were asked to compare health statements in each column of the Q-grid separately and to rank them according to their importance within that column. Statements were then placed one by one on a second, separate grid (see Figure 6-2), from the most important one (rank number 1) to the least important one (rank number 42). It generated a set of complete ranking data, where each health statement was placed at a different rank.

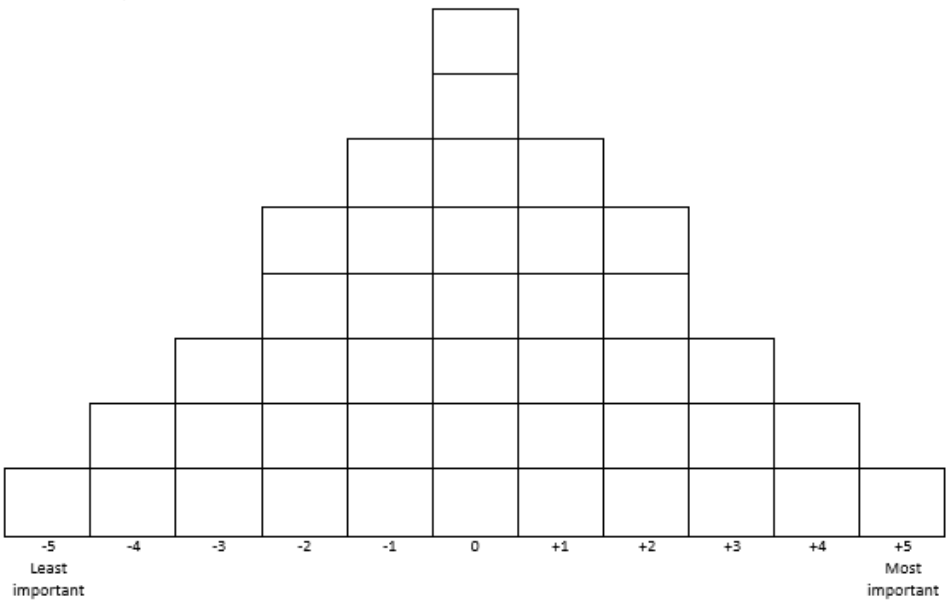


Figure 6-1: Q-grid (reproduced from Figure 5-2, for the ease of presentation)

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42								

Figure 6-2: Complete ranking grid

Instead of asking participants to rank and sort all 42 statements at the same time, with the help of the Q-grid, the extended data collection process only required participants to compare a limited number of statements each time. For example, they only needed to compare two statements when they sorted the column (+4). Column (0) was with the largest number of items and was with only 8 statements. Since the legitimacy of using direct rank-ordering exercise, which was with a much larger number of items (20 objects) to obtain the complete ranking data,

was justified in previous work (Thurstone, 1931), the current task was less laborious and was considered to be feasible to participants.

This process ended up in providing the preference data of 110 participants ranking 42 statements. A multidimensional scaling (MDS) approach, which can be used to analyse subjective judgements about a set of objects, was chosen to analyse such preference ranked data to discover the empirical relationships in the dataset. An introduction of the basic ideas and uses of MDS is described in the following sections.

6.2 Introduction to multidimensional scaling

6.2.1 The basic ideas of multidimensional scaling

Multidimensional scaling (MDS) is a suite of analytic methods based on “proximities” between objects (Kruskal and Wish, 1978). It can produce “a spatial representation, consisting of a geometric configuration of points” that can help researchers to uncover a “hidden structure” in data (Kruskal and Wish, 1978, p.7). “Proximities”, which form the input in MDS, refer to how similar/dissimilar two objects are. When similarities or dissimilarities between objects are known, MDS programs typically generate coordinates of these objects in a multidimensional space; these coordinates can be subsequently used to plot these objects as points in that space. MDS represents similarities or dissimilarities between objects by distances between points, allowing researchers to visually explore the structure of the dataset (Dunn-Rankin et al., 2004; Borg et al., 2018; Ding, 2018; Kruskal and Wish, 1978). If there is a large dissimilarity between two objects, they should be far apart on the plotted configuration; if there is a smaller dissimilarity between two objects, the two objects are expected to be placed closer.

In order to better explain the basic ideas of MDS, an example of the application of MDS is described as follows. Table 6-1 shows Great-circle distances (shortest-distance on a sphere) between 10 Chinese cities and these geographical distances are treated as dissimilarities (dissimilarity is lower when a pair of objects are more alike) between the cities. With dissimilarities between pairs of cities are known, the task is to plot a map displaying relative positions of all those cities. For a small number of cities, it would be relatively easy to draw a map of

these cities' relative locations; but if there are more cities involved, the task becomes infeasible to complete manually. MDS can be used in dealing with such problems. In this example, by using intercity dissimilarities, MDS can generate coordinates of these cities in a multi-dimensional space and plot these cities as points in a configuration. Figure 6-3 and Figure 6-4 show, the configuration, generated by the SPSS PROXCAL program (which is one of the statistical programs providing MDS analysis), closely approximates the real locations of those cities on a map of China.

Table 6-1: Intercity distances of 10 Chinese cities (in kilometres)

	Shanghai	Tianjin	Chongqing	Harbin	Chengdu	Hangzhou	Kunming	Lanzhou	Guangzhou
Beijing	1065	104	1465	1055	1518	1126	2086	1185	1892
Shanghai		963	1445	1675	1660	169	1950	1720	1214
Tianjin			1447	1069	1521	1027	2067	1228	1822
Chongqing				2515	269	1314	621	768	980
Harbin					2576	1815	3136	2194	2795
Chengdu						1540	640	601	1239
Hangzhou							1798	1650	1045
Kunming								1232	1074
Lanzhou									1705

Figure 6-3: A two-dimensional configuration of the 10 Chinese cities (using ratio-MDS)

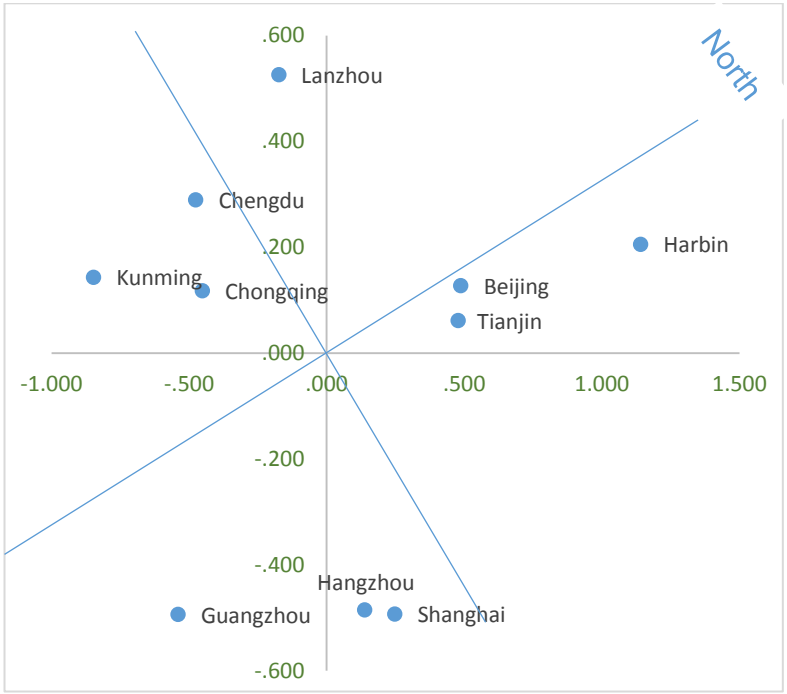


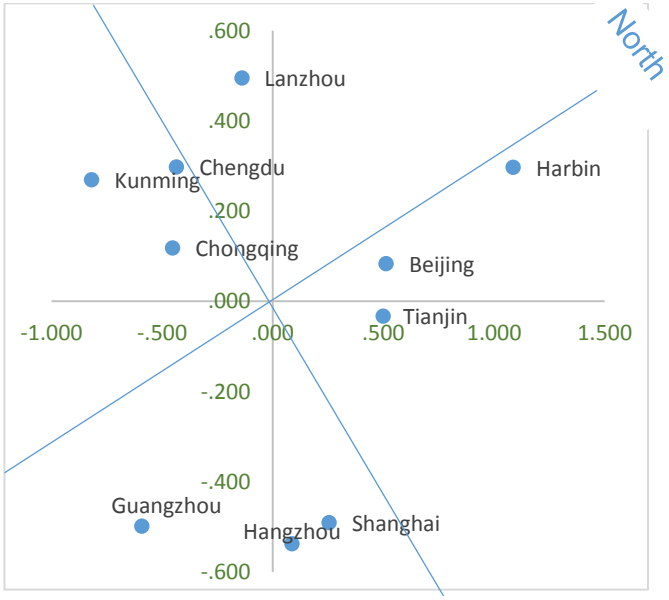
Figure 6-4 Major cities in China

In the example above, using MDS based on measured distances, which are verifiable objective data representing dissimilarities between cities, shows that this analytic approach works in practice. Apart from analysing such metric data, MDS can also be used based on non-metric forms of data. Table 6-2 presents ranks of distances between 10 Chinese cities. Interestingly, an almost identical map of the 10 Chinese cities can be plotted by using ranks of measure distances, as it is shown in Figure 6-5.

Table 6-2: Ranks of the intercity distances of 10 Chinese cities

	Shanghai	Tianjin	Chongqing	Harbin	Chengdu	Hangzhou	Kunming	Lanzhou	Guangzhou
Beijing	13	1	25	12	26	16	40	17	37
Shanghai		8	23	31	30	2	38	33	18
Tianjin			24	14	27	10	39	19	36
Chongqing				42	3	22	5	7	9
Harbin					43	35	45	41	44
Chengdu						28	6	4	21
Hangzhou							34	29	11
Kunming								20	15
Lanzhou									32

Figure 6-5: A two-dimensional configuration of the 10 Chinese cities (using ordinal-MDS)



6.2.2 MDS models and fitting criteria

As already mentioned, MDS represents proximities between objects by distances between points in a configuration. Assume that proximities (p_{ij}) between object i and object j are obtained for the pairs (i, j) of n objects. MDS attempts to find coordinates of objects i and j in a multidimensional space, so that the distances between the objects (d_{ij}) in that space agrees with the corresponding observed proximities (p_{ij}) as much as possible. For a given MDS model (f), the objective is to transform the given proximities into distances between points in a configuration such that the following is true:

$$f(p_{ij}) \approx d_{ij} \qquad (2)$$

Because empirical proximities are likely to contain measurement errors, instead of finding a precise representation where $f(p_{ij}) = d_{ij}$, looking for an approximate presentation of the data (that is $f(p_{ij}) \approx d_{ij}$) seems to be more feasible (Borg and Groenen, 2005).

The most frequently used distance model to calculate d_{ij} in MDS is the Euclidean distance model (Borg and Groenen, 2005). Let x_{ik} denote the coordinate of point i (representing object i) on dimension k. The Euclidean distance between point i and point j can be calculated as follows:

$$d_{ij} = [\sum_{k=1}^{m}(x_{ik} - x_{jk})^2]^{1/2} \qquad (1)$$

where m stands for the dimensionality of the space. For example, suppose the two points i and j are in a 2-dimensional space, the coordinates of the point i on the two dimensions are 1 and 1 ($x_{i1}=1$, $x_{i2}=1$) and the coordinates of the point j on the two dimensions are 2 and 2 ($x_{j1}=2$, $x_{j2}=2$), the Euclidean distance between i and j can be calculated as $d_{ij}=[(2-1)^2+(2-1)^2]^{1/2}=\sqrt{2}$.

One of the most frequently used indicators in evaluating the fitness of an MDS model is called stress value (Kruskal, 1964). As noted above, MDS attempts to find a best approximation of the observed proximities (p_{ij}), thus it aims to minimise the discrepancy between the observed proximities (p_{ij}) and the corresponding distance between the points d_{ij}. That is, in the following badness-of-fit function, σ^2should be minimised.

$$\sigma^2 = \sum_{(i,j)}[\mathrm{f}(p_{ij}) - d_{ij}]^2 \quad (3)$$

The square root of σ^2 in equation (3) is commonly referred to as raw stress in the MDS literature (Busing et al., 2005).

It is important to note that, in some special cases of MDS, for example, ordinal MDS, optimising the badness-of-fit function of stress can lead to the degeneracy problem (Busing et al., 2005; Borg and Groenen, 2005), where the stress value is very low (approaches to zero) but the observed proximities are not systematically related the corresponding distances in the configuration, for example, the distances between points in the configuration are approximately equal or points are too close to each other. A degenerate solution often occurs when the constraints of MDS models are not sufficient(Borg and Groenen, 2005). Various approaches have been proposed to avoid such problems (Busing et al., 2005). Because introducing those approaches requires additional technical concepts, which go beyond the scope of this chapter, these approaches are not described here.

6.2.3 A special case of MDS analysis: the unfolding analysis

Unfolding – a technique that is especially useful for analysing ranked preference data – is a special case of MDS analysis (van Deun et al., 2007; Borg et al., 2018). This is because unfolding is also based on "proximities" between objects and can produce a low-dimensional configuration of points representing the objects. In unfolding, the data are usually preference data (such rank-orders) of participants for a set of stimuli, while such data can be regarded as proximities between individual participants and the stimuli (Borg and Groenen, 2005).

Unfolding was originally proposed by Coombs (Coombs, 1950; Coombs, 1964), based on the concept of "I scale" and "J scale" on a unidimensional model (where I scale stands for each participant's rank ordering for stimuli, J scale represents a line on which each participant and each stimulus are jointly located). The unidimensional unfolding model was later extended to the multidimensional case (Bennett and Hays, 1960; Hays and Bennett, 1961). Multidimensional unfolding can estimate the coordinates of both sets of objects (the set of participants and the set of stimuli) simultaneously on a multidimensional space and can represent

both of them as points on the same configuration (Borg and Groenen, 2005). Each participant is represented by an “ideal point”, plotted in a way that the distance of the ideal point of this participant to the stimuli in the configuration is closely associated with the participant’s preference for the stimuli (Borg and Groenen, 2005).

Similar to what was introduced in MDS, the main task of unfolding is to convert participants’ preferences for stimuli into Euclidean distances in a multidimensional space. The Euclidean distance between participant x_i and stimuli y_j in an unfolding analysis can be represented by using the similar formula as Equation (1). A participant’s preference for a certain stimulus is a decreasing function of the distances between them, which means a stimulus that is most preferable to a participant will be placed closer to the participant in the configuration (Borg and Groenen, 2005). Hence, the stimuli that are placed at the centre of the configuration usually indicate that they are the most preferable among this set of participants, while the stimuli at the outer parts of the configuration are likely to be least preferred by the participants.

6.2.4 Applications of MDS in real life

MDS was first introduced by Torgerson in the discipline of psychology (Torgerson, 1952) and has been applied in various other subjects, including marketing, social science and ecology (Amato, 1990; Hornberger et al., 2009; Carroll and Green, 1997; Kenkel and Orlóci, 1986; Hout et al., 2013). Its use has also been reported in the health field in a wide range of applications, including conceptualising the meaning of citizenship within health and social care contexts (Cogan and MacIntyre, 2019), developing a measure of patients’ satisfaction with dental and medical care then testing its validity (Roghmann and Goldberg, 1976; Patrick et al., 1983), comprehending words of doubt and certainty in health communication (Segalowitz et al., 2016) and comparing health status indicators among various countries/regions (Önder et al., 2017). Interestingly, the MDS analytical tool has also been previously reported in the analysis of ranking data generated in a study of preferences for EQ-5D health states. For example, Krabbe and colleagues asked participants to ranked a set of EQ-5D health states and used an MDS technique to generate cardinal values of health states, which

were nearly identical to the mean VAS values (Krabbe et al., 2007). The findings suggested that MDS can reproduce observed mean VAS values, therefore a rank-based MDS method may be used to value health states (Krabbe et al., 2007).

In an MDS study, objects being analysed can be inanimate stimuli, people or a combination of inanimate stimuli and people, as long as a matrix of proximities among the objects can be obtained (Hout et al., 2013; Ding, 2018). The data used in an MDS analysis can be generated from questionnaires or surveys involving judgement tasks, such as magnitude estimation, category rating, category sorting and graphic rating (Ding, 2018).

6.3 Research objectives

The current study attempted to use the multidimensional unfolding technique to serve the following research objectives:

1. To investigate the preference of a group of Chinese participants for various health statements to further explore health as a concept in China.
2. To offer an alternative analytic method and to generate with results that could be compared with the findings in the Q-study.

6.4 Analytic program and process

In this study, the preference data of 110 participants ranking 42 statements were obtained as described in Section 6.1. Multidimensional unfolding was implemented in PREFSCAL, which is a dedicated program in carrying out the unfolding analysis, within SPSS Statistics 22. The PREFSCAL program has been reported to outperform other methods in providing a better fit solution and satisfactorily tackle degeneracies in multidimensional unfolding (Busing et al., 2005) and has been recommended for use in the multidimensional unfolding analysis (Borg, Groenen and Mair 2018).

The ranked preference data of this study were held in a rectangular 110*42 matrix in which participants are represented by rows and stimuli (health statements) are represented by columns. Each row recorded the rank order of health statements

for a single participant. These sets of rank orders were interpreted as proximities in PREFSCAL, containing information about dissimilarities (a higher rank of the statement indicates that it was less favourable) between an individual participant and health statements. The observed dissimilarities were then converted into Euclidean distances in a multidimensional space and the PREFSCAL program generated coordinates of the participants and the health statements. Afterwards, the objects (participants and health statements) would be plotted as points in a configuration, where the distance between a participant and a health statement represents this participant's preference for the statement.

To compare solutions with different dimensionality, the model was initially set with a higher dimension then reducing the number of dimensions in further runs of PREFSCAL program from 6 to 1.

6.5 Results

The 110 participants, whose demographic characteristics were described in the Q-study chapter (Chapter 5), were involved in this study. In the following paragraphs of this section, descriptive statistics are first presented to provide an overview of the ranking data. Then the multidimensional unfolding solution is described. A comparison between the findings of the multidimensional unfolding analysis and the Q-study results is covered in the final part.

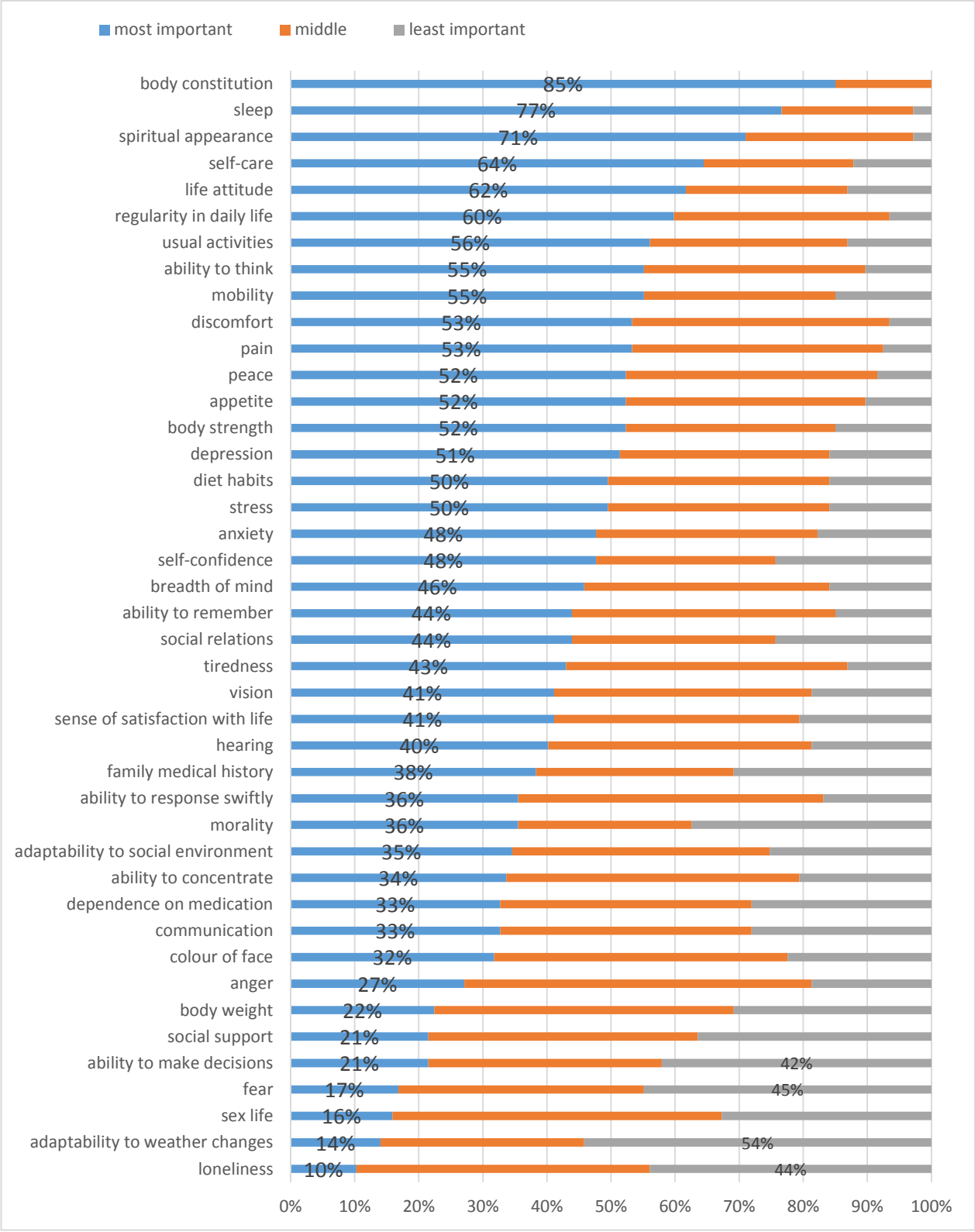
6.5.1 Descriptive statistics

During the Q-sorting process, 42 statements were allocated by participants into three piles: "most important", "least important" and "the rest". This information was photographed, because it was considered to be useful in indicating participants' preference on the health statements. Figure 6-6 presents the frequency distribution of each health statement in the three categories. Statements in the figure were sorted by values of the "most important" category, from largest to smallest. Among the 42 dimensions, body constitution, sleep, spiritual appearance, self-care and life attitude were considered to be most important by the majority of the participants (>60%). In contrast, adaptability to weather changes, fear, loneliness and ability to make decisions were most likely

to be assigned to the “least important” category, when more than 40% of participants considered they were least important.

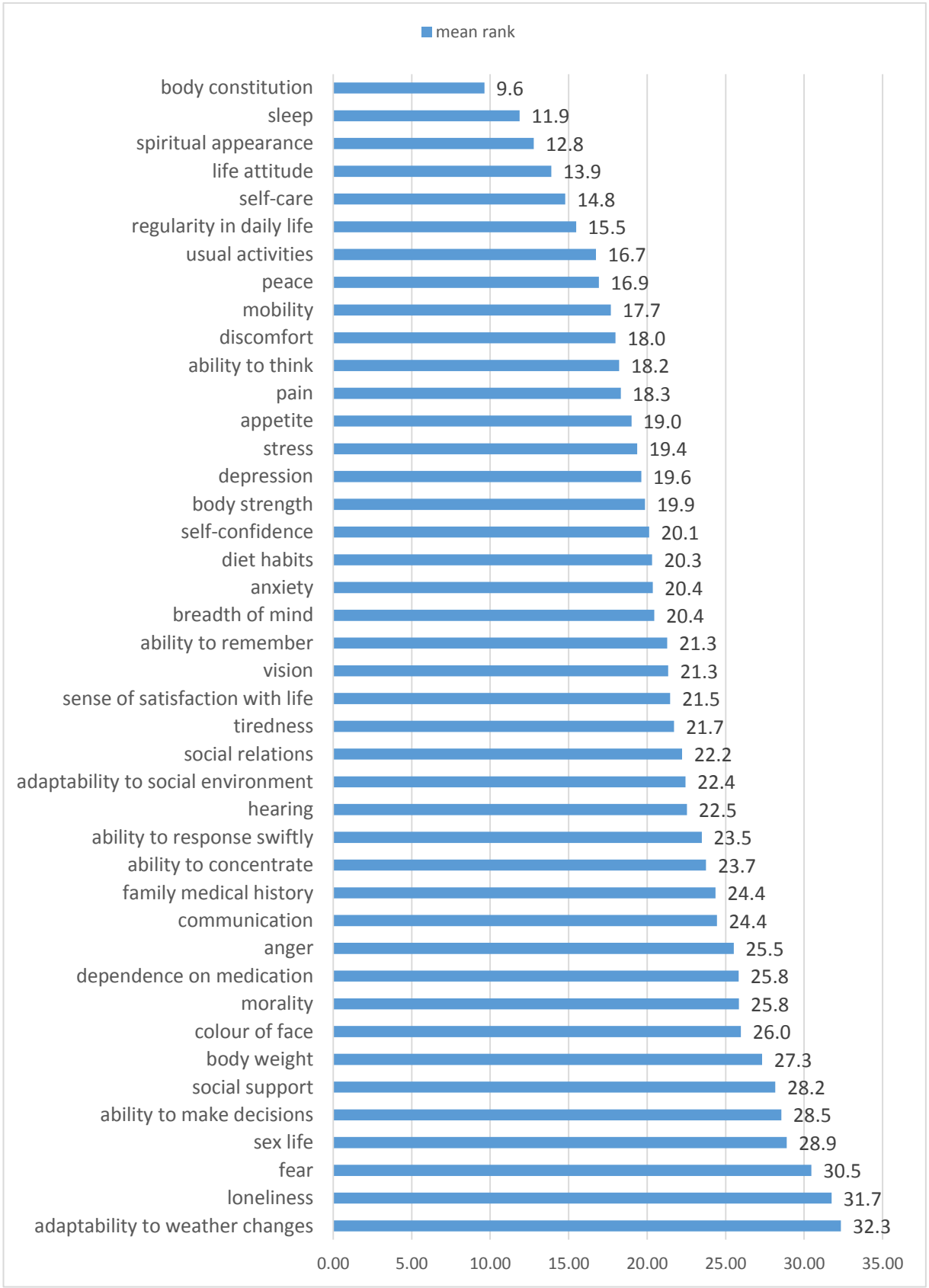
The complete rank ordering for the 42 statements also reflected participants’ views on the importance level of each statement. Because the number of ranking places was too many (n=42), calculating how many participants had placed Statement x onto Rank y to obtain a full frequency distribution table was less informative. Instead, the mean rank attributed to each health statement was used to show the central tendency of the ranks. Figure 6-7 shows that body constitution, sleep, spiritual appearance, life attitude and self-care were most likely to be valued by the participants as most important, as they were with the smallest ranking scores. On the other hand, adaptability to weather changes, loneliness, fear, sex life and ability to make decisions were most frequently to be regarded as least important, as their mean ranking scores were at the bottom 5 positions. The result is similar to what was found using the preliminary classification data as shown in Figure 6-6.

Figure 6-6: Percentage of participants in three importance categories*



* The researcher failed to record 3 participants' initial classification of 42 statements (in three piles), therefore, percentages in this figure was calculated by using 107 participants' responses.

Figure 6-7: Mean ranks for 42 health statements



6.5.2 A multidimensional unfolding solution for the ranking data

A two-dimensional solution for this dataset was accepted. This was because, on the one hand, it can provide more information about the structure of the dataset than a one-dimensional solution; on the other hand, a higher-dimension model did not fit the data substantially better. The normalised stress value, which shows the proportion of the sum of squares of the observed proximities that are not accounted for by the distances (Borg and Groenen, 2005), is a badness-of-fit measure (the lower the stress value, the better fitness of the model). As it is presented in Table 6-3, the normalised stress value was 0.13 in a 2-dimensional model, 0.12 in a 3-dimensional model and 0.11 in a 4-dimensional model. It shows that increasing dimensionality of the model did not considerably decrease the badness-of-fit. In addition, since MDS intends to compress the complexity of data and to produce information more easily, constituting a lower-dimensional space is usually more favourable. A two-dimensional solution, while it is also considered to be sufficient enough for interpretation in most cases (Borg and Groenen, 2005; Ding, 2018).

Table 6-3: Stress values for 1-6 dimensional solutions

	1-dimension	2-dimension	3-dimension	4-dimension	5-dimension	6-dimension
Normalised stress values	0.16	0.13	0.12	0.11	0.10	0.10

There have been no such “rules of thumb” for stress values for multidimensional unfolding in the literature (Mair et al., 2016). Because many factors can influence the stress value in MDS analysis, including the dimensionality of the MDS model (the higher the dimensionality, the smaller the expected stress), number of objects (the greater the number of objects, the larger the expected stress), the reliability of the data (the larger the error component of the data, the larger the expected stress) (Borg et al., 2018), there is not a definite threshold for the stress values. Some researchers proposed that one way to benchmark stress values is to calculate the stress value expected for random data (Borg et al., 2018). They explained that because there should be no real structure within a set of random data, such data should produce a worst value of stress (Sturrock and Rocha,

2000). Following this idea, 15 matrices, each consisting of 110 cases of 42 randomly ranked statements, were generated and analysed by PREFSCAL program. The mean stress value of the 2-dimensional solution for the randomly-generated data was 0.22 (with a standard deviation of 0.001), which was significantly larger than the observed stress value (0.13) of the 2-dimensional solution for the collected preference data in this study. Therefore, the stress value of the 2-dimensional solution of the unfolding model was considered to be acceptable.

Figure 6-8 displays a 2-dimensional representation of the joint space shared by the 42 health statements (in orange dots) and 110 participants (in purple dots). Dimension I (in the horizontal direction in Figure 6-8) seems to discriminate between endogenous and exogenous health statements. At the extreme of the right-hand side, most of the statements were about physical health conditions, such as body weight (+25.70) and colour of face (+23.77). Health statements about mental senses, including depression (+11.05), anxiety (+8.64) and the others, were also located on the right-hand side in the figure, with positive values. On the left-hand side, the statements relating to one's social wellbeing such as social support (-27.91), morality (-25.35), adaptability to social environment (-21.14) and social relations (-20.51), received the lowest (negative) scores.

Dimension II (in the vertical direction in Figure 6-8) appears to differentiate between function indicators and symptoms/feelings. On top of the figure, statements were most likely to be related to functional abilities. Cognitive function, such as ability to response (+22.11) and ability to concentrate (+18.74) as well as physical function, such as ability to hear (+21.60), ability to see (+20.28) and ability to conduct usual activities (+14.94) were found at the extreme (positive) end of the vertical line. While at the bottom of the graph, most of the statements were about one's emotional experiences. For example, loneliness (-30.60), fear (-28.68) and anger (-23.75) were found to hold lowest (negative) values in the vertical dimension. An exception was the statement about sex life, which was found at the extreme (negative) end of the vertical dimension, with a score -27.86, although it was not about one's emotional feelings.

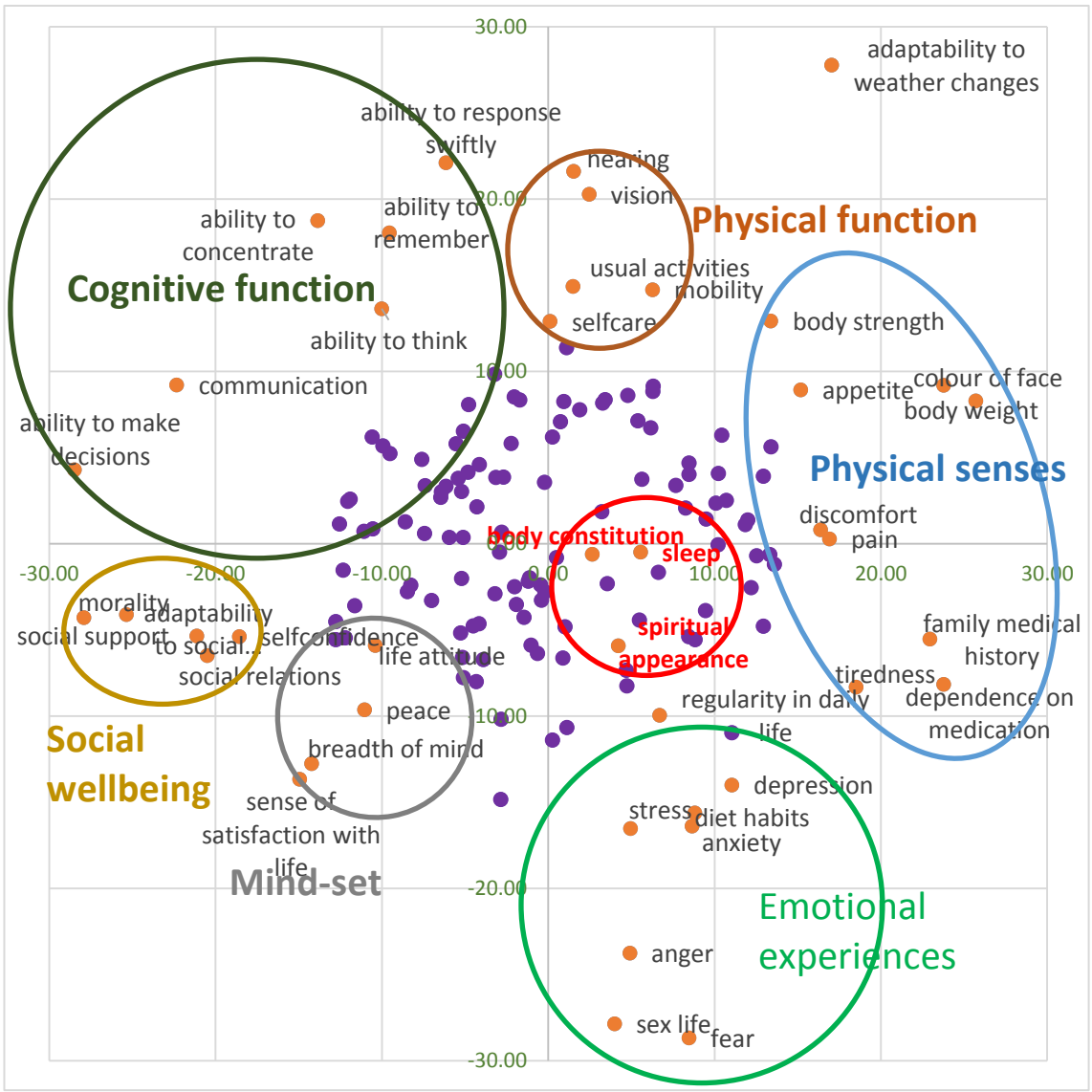


Figure 6-8: Joint plot for preference ranking of health statements

It is also shown in Figure 6-8 that health statements could be roughly clustered into six categories on the graph: Physical function, Physical sense, Emotional experiences, Mind-set, Social wellbeing and Cognitive function, in a clockwise direction. It seems that health items that share a similar attribute were plotted close to each other in the configuration. For example, self-care, mobility, vision, hearing and usual activities tended to be clustered together and it appeared to be that they were all relating to one's ability in doing physical activities. Further, it was also shown that for clusters that tended to be more relevant to each other were placed closer in the configuration: items relating to function abilities (cognitive function and physical function) were near to each other on the graph; items that were about physical health (physical function and physical senses) appeared to be close; physical senses and emotional experiences can be considered both as symptoms and were located next to each other; the same applied to the mind-set cluster and the social wellbeing cluster.

The 110 participants (shown in purple dots in Figure 6-8) were spread in the middle of the configuration, around by the six health statement clusters. Participants whose views were more comparable were likely to be placed closer, while for those participants whose views were different tended to be placed further to each other. It showed that participants had different preferences for those health statements. Their views of health might be affected by their demographic characteristics such as age as well as their health conditions. When participants were divided into four groups (in Quadrant I, II, III and IV, respectively), as it is shown in Table 6-4, participants that were plotted in Quadrant IV were with the lowest mean age and they were close to statements about mental health, which suggested that younger participants tended to value mental health more frequently. It was also found that elder participants were more likely to emphasise cognitive function statements and physical health statements, as participants placed in Quadrant I and II were with highest mean ages. In addition, social wellbeing and mind-set aspects were likely to be emphasised by participants who were located in the Quadrant III and whose mean self-rated scores were the highest compared to that of other Quadrants.

Table 6-4: Characteristics of participants in four Quadrants

	Mean age (SD)	Mean VAS score (SD)	Clusters of health items within the quadrant
Quadrant I (n=27)	46 years (18)	76.5 (16)	physical function and physical sense
Quadrant II (n=33)	53 years (18)	78.3 (13)	cognitive function
Quadrant III (n=30)	42 years (13)	78.5 (14)	social wellbeing and mind-set
Quadrant IV (n=20)	38 years (12)	75.8 (10)	emotional experiences and physical senses

Health statements that were derived from the dimensions of EQ-5D can be classified into three groups and were spread on the configuration. Statements about self-care, mobility and usual activities were placed close to each other in Physical function category. Pain and discomfort were approximately at the same place in Physical senses group on the graph. Anxiety and depression were also close to each other and were within the cluster of Emotional experiences.

Three health statements (body constitution, sleep quality and spiritual appearance) were in the middle of the configuration which indicated that they seemed to be rated as most important across the whole sample. On the other hand, statements including adaptability to weather changes, family medical history, dependence on medicine, colour of face, body weight, fear, loneliness and sex were far from the origin, where most participants were allocated, therefore seemed to be less important to the group of participants.

6.5.2.1 The stability of the solution

The stability of this solution was checked by using a random sample within the whole sample group. A group of 80 participants were randomly selected and their ranking data were analysed using the same program. PREFSCAL generated a two-dimensional arrangement for the selected samples. This arrangement was found to be comparable to the solution that was generated for the whole sample. The normalised stress value was 0.13.

The graphic representation of the configuration shown in Figure 6-9 can be viewed as a reflected version of Figure 6-8. As Figure 6-9 shows, Dimension I (in the horizontal direction) of this configuration was comparable to that in Figure 6-

8, with statements about physical health on the right-hand side and statements relating to social wellbeing on the left-hand side. On the other hand, Dimension II (in the vertical dimension) of Figure 6-9 was inverse to what was shown in Figure 6-8. Emotional feelings tended to be placed on the top of the figure while functional abilities were at the bottom. Because rotated or reflected transformations of an MDS configuration are considered as "similarity transformations" (Borg, Groenen and Mair 2018), two solutions shown in Figure 6-8 and Figure 6-9 represented a similar structure of the configuration. Since the randomly selected samples were found to fit with the two-dimensional solution of the whole sample, it can be argued that this two-dimensional solution was stable.

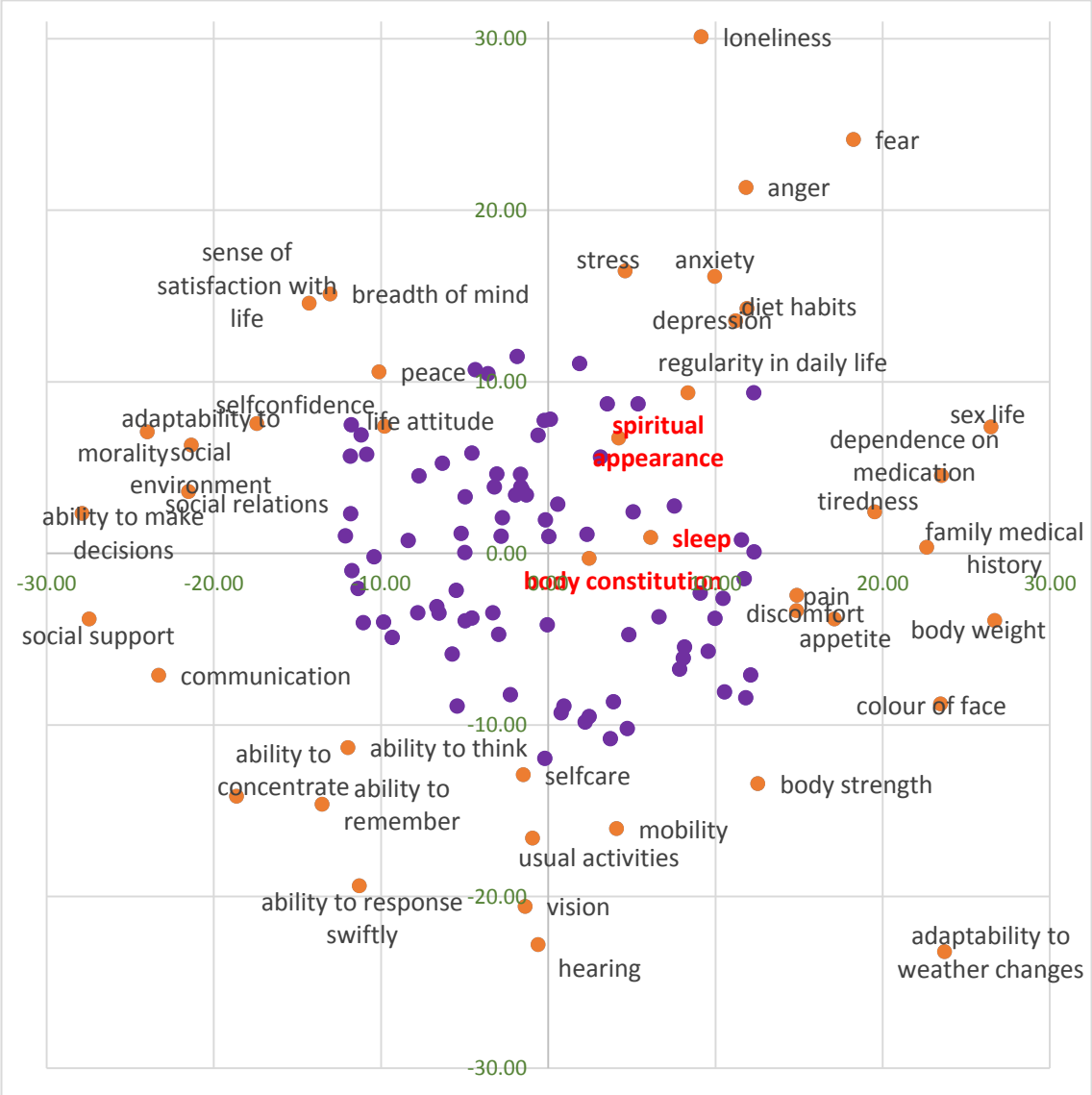


Figure 6-9: Random sample's joint plot

Interestingly, when participants older than 60 years old were purposively selected, their ranking data produced a different configuration (see Figure 6-10) and the same applied to participants whose self-rated EQ-VAS scores were lower than 80 (see Figure 6-11). Meanwhile, for participants in other age groups (<40 and 40-60) or the group of participants with a health score larger than or equal to 80, ranking data of these groups generated a comparable configuration which was similar to that of the whole dataset.

As it is shown in Figure 6-10 and Figure 6-11, participants were not located in the middle of the configurations, surrounded by most of the health items. Instead, they tended to be clustered in the upper/bottom right of the configurations, with approximately half of the 42 health statements located further away from them. It indicated that these participants may be more likely to agree on which health statements were most important and which were least important, compared to other groups of participants. For example, in Figure 6-10, participants were surrounded by health statements on physical senses and appearance (such as pain, discomfort, tiredness, appetite, spiritual appearance, body constitution), physical function (such as self-care, mobility, sleep, usual activities) as well as social wellbeing and mind-set (such as social relation, self-confidence, life attitude, breadth of mind). While around half of the 42 health statements, many of which seemed to be relating to emotional experiences, were plotted further from these participants. Similarly, in Figure 6-11, participants were close to health statements including pain, discomfort, mobility and usual activities, sleep, body constitution, life attitude, anxiety and depression, while more than half of the 42 health statements were placed further in the upper left of the configuration. It is interesting to note that health statements that were developed from the EQ-5D descriptive system, seemed to be recognised as most important aspects of health by elder participants (>60 years old) and by participants with relatively poor self-assessed health status.

Figure 6-10: Joint plot for participants older than 60 (n=31)

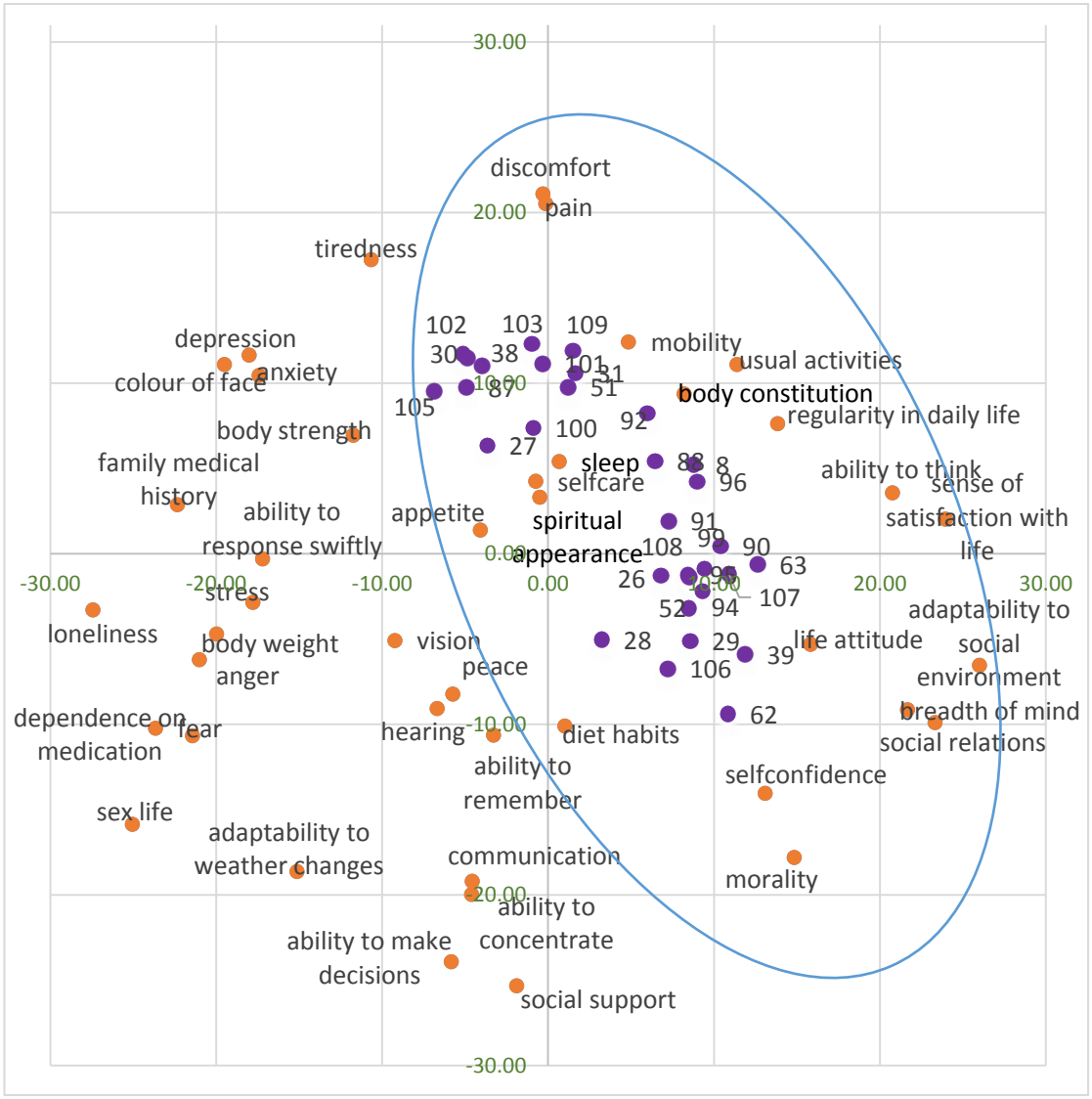
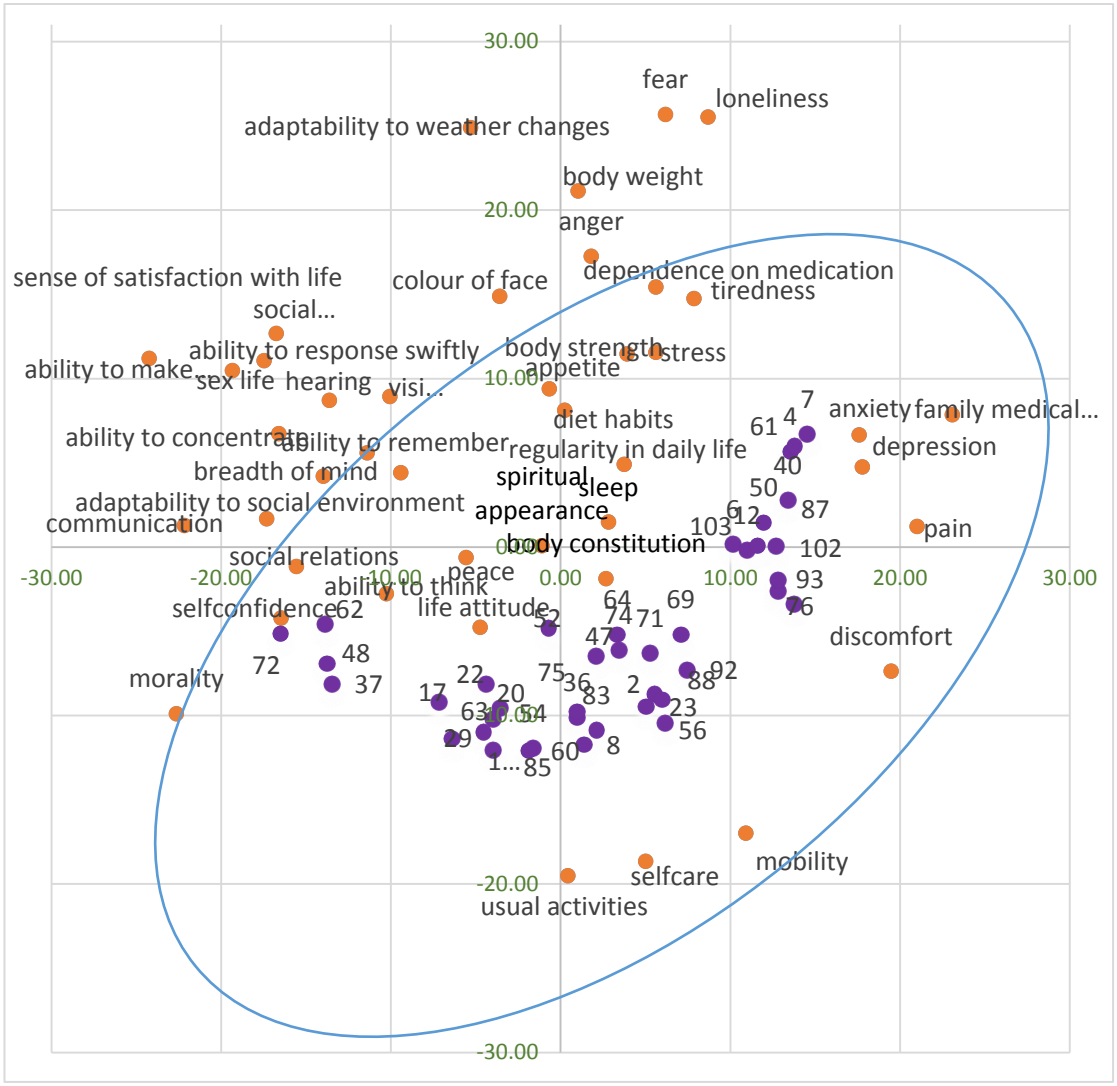


Figure 6-11: Joint plot for participants with a <80 self-rated score (n=40)



6.5.3 Multidimensional unfolding findings vs Q-study findings

Since the data of this study were collected after conducting a standardised Q-sorting process, when the complete ranking data were obtained based on each participant's completed Q-grid, those complete ranking data were supposed to produce comparable information to that in the Q-study.

The results computed by unfolding were comparable to what was found in the Q-study. As it is shown in Table 6-5, exemplars of Factor One tended to rate physical functional abilities, social wellbeing as well as one's mind-set. Similarly, it is presented in the current study that 18 out of the 19 exemplars were located in the Quadrant II, close to statements relating to physical function, social

wellbeing and mind-set. The majority of the exemplars of Factor Two were located in the Quadrant II on the graph and were close to health statements relating to physical health. It is consistent with the finding in the Q-study, where Factor Two emphasised on physical function and physical symptom statements. Participants whose views defined Factor Three were likely to rate physical senses and psychological feelings to be most important. They were plotted in the Quadrant III and IV, which were close to Physical senses and Emotional experiences clusters. Although exemplars of Factor Five spread over three quadrants (I, II and III), it was still consistent with the findings in the output of the Q-study. The statements that they rated as most important, such as abilities to see and hear as well as cognitive function abilities, were placed close to the exemplars in these quadrants.

Table 6-5: Positions of Q exemplars

Factor 1 N=19		Factor 2 N=25		Factor 3 N=16		Factor 4 N=6		Factor 5 N=4	
No.	Quadrant	No.	Quadrant	No.	Quadrant	No.	Quadrant	No.	Quadrant
8	II	1	I	6	IV	13	II	20	III
21	III	5	I	9	IV	14	III	42	II
29	II	11	I	12	IV	22	III	67	I
35	II	23	I	34	III	49	I	68	II
37	II	25	I	40	IV	52	II		
39	II	30	IV	50	IV	62	II		
48	II	32	I	53	III				
54	II	38	I	58	IV				
60	II	46	I	59	IV				
63	II	55	I	65	III				
66	II	69	I	71	III				
85	II	70	I	75	III				
89	II	72*	III	80	IV				
90	II	76	I	84	III				
96	II	77	IV	86	IV				
98	II	78	IV	103	IV				
104	II	81	I						
107	II	82	I						
108	II	87	I						
		93	I						
		100	I						
		101	I						
		102	I						
		105	I						
		109	I						
Number of exemplars in each quadrant									
I	0	I	21	I	0	I	1	I	1
II	18	II	0	II	0	II	3	II	2
III	1	III	1	III	6	III	2	III	1
IV	0	IV	3	IV	10	IV	0	IV	0

6.6 Discussion

The Multidimensional unfolding technique was used to analyse a set of complete ranking data, which were obtained in addition to the standardised Q-sorting process. It provided a reasonably interpretable solution and demonstrated that the method itself is of practical value. By dealing with the complete ranking data of various health statements, it explored which health statements might be most important and which might be less important in a Chinese population. It offered an additional way in investigating how health is understood and described in China, adding to the Q-methodological study.

6.6.1 A further investigation of the concept of health in China

Multidimensional unfolding generated a two-dimensional graph to visually present relationships among participants and health statements. The left-right path (Dimension I) appeared to differentiate between endogenous and exogenous health statements. The top-bottom direction (Dimension II) distinguished items relating to functional abilities from items about senses or feelings. The structure is comparable to the conceptual framework that was established from the scoping review (Chapter 3) and the qualitative study (Chapter 4). The conceptual framework is structured with two divisions that are similar to the divisions in the multidimensional unfolding solution. One division of the conceptual framework shows a cause-effect relationship, dividing health statements between symptoms and function. The other division presents an internal-external relationship, where health statements are categorised into physical, mental and social health domains. In this regard, the unfolding analysis provides further justification of the earlier established Chinese conceptual framework of health.

The unfolding technique grouped health statements into several clusters based on participants' preferences. This shows that participants tended to assign similar importance to health statements within a similar attribute of health as shown by the clustering in Figure 6-8. It identifies at least six aspects of health: physical function, cognitive function, physical senses, emotional experiences, mind-set and social wellbeing. The clusters are comparable to aspects of health that were summarised in the previous literature (Bergner et al., 1976; Wilson and Cleary, 1995; Fitzpatrick et al., 1998; Cella et al., 2010) as well as the themes identified in the qualitative study that was reported in Chapter 4.

The multidimensional unfolding technique not only clustered health statements but also clustered participants. The unfolding analysis indicates that participants had distinct preferences in choosing which health statements were more important than others. For example, participants with a lower self-rated score tended to have a strong preference for those endogenous health statements, including those health statements that were derived from EQ-5D, while participants with a higher self-rated score were more likely to emphasise

exogenous health statements such as social wellbeing and life attitude. It may be because people in a poorer health condition are more likely to be worried about function limitation or negative feelings/sensations and would emphasise those items when appraising health. While, in contrast, people in a better health condition are less likely to be troubled by those functional problems or negative experiences. They tend to think about health with a higher expectation, thus may define health in a more positive way and consider those statements about wellbeing as more important. This indicates that the five dimensions of EQ-5D may be especially important to people in poor health status in China but may not be the most important aspects of health in other groups of Chinese people.

Participants recruited in this study were with various demographic factors and under different health conditions, it was expected that they would hold different views in understanding health. This is consistent with the literature which reports that demographic characteristics including age, gender, education and health conditions are likely to largely affect people's views of health (d'Houtaud and Field, 1984; Bendelow, 1993; Mansour, 1994). Since the variances of the understandings of health across participants were discussed in detail in both Chapter 4 and Chapter 5, they are not explained again here in the current chapter.

Apart from showing differences among participants in ranking health statements, the unfolding analysis conducted an overall evaluation of the relative importance of 42 health statements, by considering the preference of the whole sample. It is shown that body constitution, sleep quality and spiritual appearance were rated to be the most important health statements. The result is consistent with what was reported in the previous studies (the scoping review, the qualitative interviews and Q-study). In the scoping review, sleep was found to be included in all the identified Chinese-developed HRQoL measures as a health indicator. Spiritual appearance and body constitution were also included in several Chinese-developed HRQoL measurers, especially in those TCM-based ones. During the qualitative interviews, the three health statements were frequently mentioned by lay Chinese participants when they were asked to describe what health is. The Q-study also showed that these three health statements were rated to be most important in the majority of the extracted factors.

Although it was already covered in the previous chapters that body constitution, sleep quality and spiritual appearance are likely to be most important in China, those studies in nature were qualitative and were not able to give a clear-cut answer. The current analytic method made direct comparisons among the health statements and the importance of the three health statements was made explicit. It demonstrates that the “Chinese-specific” health statements, such as body constitution and spiritual appearance, which are less likely to be included in Western descriptive systems of health, such as EQ-5D, tend to be rated as most important among Chinese participants. It once again indicates cultural differences between China and the West in describing health and measuring health.

6.6.2 Multidimensional unfolding technique vs Q methodology

Multidimensional unfolding offered an alternative way to process the Q-sorts data. Although the unfolding results were comparable to the findings of the Q-study, there are differences between the two methods. First, Q methodology is, in essence, a qualitative investigation, while unfolding is a quantitative tool. The Q-study aimed to obtain a deep understating of the subjective construction of health in China. It identified five distinct viewpoints and explored similarities as well as differences among the five viewpoints. The interpretation of the results integrated participants’ personal explanations which were obtained in post-sorting interviews. In contrast, the unfolding was not as in-depth as the Q-investigation and the interpretation was more descriptive. The unfolding technique generated a configuration, aiming to represent all participants’ preferences. The graphic representation of the configuration was interpreted by merely describing the relative distances between points.

The second difference is that the Q-study offered several distinct viewpoints in understanding health, while the unfolding analysis generated one all-inclusive solution. The by-person factor analysis of the Q-study produced five factors that are significantly different from each other. It presented five possible viewpoints in thinking about health and showed five distinct ways in ranking the 42 health statements. Therefore, it can only present importance levels of health statements within each viewpoint. On the other hand, multidimensional unfolding visualised relations among all participants and all health statements by considering every

participant's ranking data. As a result, it can identify which health statements were ranked as most important across the whole sample.

Third, the Q-study can only cluster participants, but multidimensional unfolding can cluster participants as well as health statements. Unlike the Q methodology, which can only group participants with shared views in sorting health statements in the same cluster, the multidimensional unfolding analysis also placed health statements, which were likely to be ranked in similar positions, together. The fourth difference is that clusters generated by multidimensional unfolding are less definite than clusters (factors) in the Q-study. The factors that were identified by the Q-study were all clearly defined. Each factor is shown as a particular factor array, representing the viewpoint of a group of exemplars that were clustered together. As for multidimensional unfolding, it did not offer an "either-or" solution, since participants were not clustered into a certain category.

Despite the differences, the Q methodology and the multidimensional unfolding analysis jointly enable an understanding of how health was perceived by Chinese participants and identify health statements that were considered to be important in China. Both provide complementary findings which produce explicable and informative participant perspectives. They provide an in-depth view as well as a holistic evaluation of the concept of health in China.

6.7 Limitations

A limitation of conducting a multidimensional unfolding analysis is related to the assumption made by this method. This method assumes that the degree of preference of a certain stimulus given by a participant can be represented by a Euclidean distance but the validity of the assumption may not be true in general (Cohen and Mallows, 1980). Nevertheless, it is widely recognised that this method can efficiently visualise ranking data, which is informative in exploring the structure of the dataset (Kruskal and Wish, 1978; Cohen and Mallows, 1980; Borg et al., 2018).

The nature of the research presented in this study, as well as in the whole thesis, is exploratory. Despite that the multidimensional unfolding technique provided a reasonably interpretable solution, this study can be criticised due to the subjective

role of the researcher in describing the output of the unfolding analysis. The processes of determining numbers of dimension, interpreting Dimension I/II and drawing the clusters of health statements inevitably involved the researcher's subjective understanding. The credibility of the findings of this study can be supported by the results reported in the previous chapters, but more research is needed to further explore the multidimensionality of health as a concept.

Another limitation is that the majority of the participants were in relatively good health status and/or with a high level of education and their views may largely affect the results. Therefore, the sample may not well represent the Chinese population as a whole. Future studies with a more representative sample are needed to further justify the findings.

6.8 Conclusion

The multidimensional unfolding analysis offered a quantitative solution to process the ranking data. Along with the Q-study, it provided an insight into Chinese participants' understandings of health. Three health statements were considered to be most important across the whole sample: sleep quality, body constitution and spiritual appearance. They were highlighted by Chinese participants, but are not included in the descriptive system of EQ-5D, a commonly used Western HRQoL measure. The current study, again, reinforced the cultural differences between China and the West in defining and measuring health.

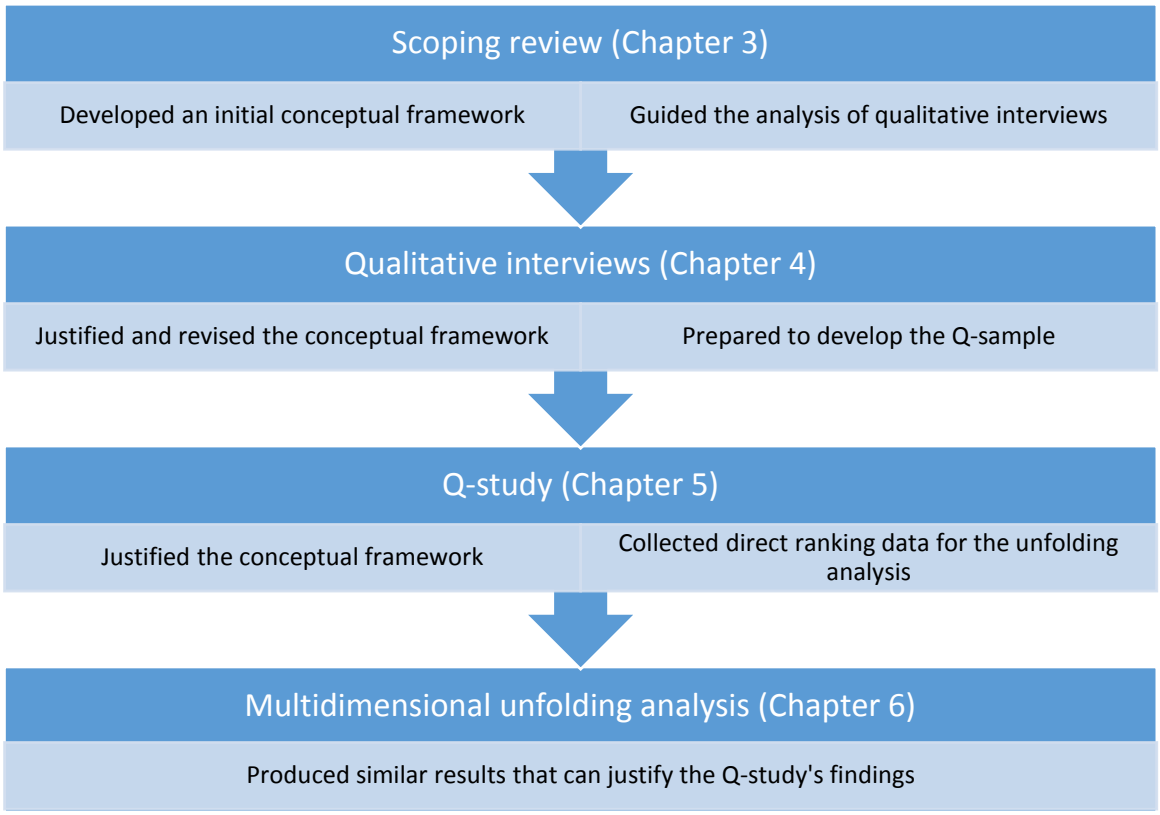
Chapter 7 Principal findings, research implications and future studies

7.1 Introduction

In the context of the widespread application of Western-developed HRQoL measures worldwide, a question “Does EQ-5D work in China?” was raised concerning the legitimacy of such application. Referring back to the rationale as presented in Figure 2-1, a number of research objectives were set to answer this question. Firstly, it was necessary to obtain lay Chinese people’s comments and opinions on the descriptive system of EQ-5D. Secondly, it was important to establish a Chinese conceptual framework of health, with which EQ-5D could be compared. Thirdly, it was essential to further investigate the subjective constructions of health in China and to identify the most important health dimensions among Chinese people. A series of studies, which were closely linked with each other, were undertaken to fulfil these research objectives. As shown in Figure 7-1, the previous studies provided essential materials for the subsequent studies, while the subsequent studies helped to justify the preliminary results. By undertaking the four studies step by step, the whole research was able to evaluate whether the descriptive system of EQ-5D is legitimate for use in a Chinese cultural setting while exploring cultural differences between China and the West.

The subsequent sections of this chapter (1) summarise the main findings of this research project and discuss how this research have added to previous knowledge, (2) offer research implications of the findings, (3) address the limitations of the thesis and make recommendations for future studies and (4) finish this thesis with concluding remarks.

Figure 7-1: Process of the four studies in the thesis



7.2 Principle findings and contributions of the thesis

7.2.1 Content validity of EQ-5D as commented by Chinese participants

Several studies questioned the content validity of EQ-5D for use in China (Fang et al., 2016; Wang et al., 2015a), but few studies have empirically investigated this issue. This thesis has filled a gap in the literature by obtaining lay Chinese participants' opinions on the descriptive system of EQ-5D. As reported in Chapter 4, although participants generally agreed that EQ-5D was short and easy to complete and the five questions were relevant to health, EQ-5D was criticised for being inadequate to assess health according to many participants. Health dimensions, such as sleep and eating, were mentioned by participants as being important in appraising one's health but are not included in EQ-5D. Apart from the problem of incompleteness, according to some participants, the descriptive system was redundant: dimensions including mobility, self-care and usual activities were believed to be overlapping with each other. The findings suggest

that the content validity of EQ-5D may not be satisfactory for use in China and EQ-5D may need revision to better assess the health status of a Chinese population.

7.2.2 A Chinese conceptual framework of health

The scoping review, which was documented in Chapter 3, identified 12 generic HRQoL measures that were developed to assess health in a Chinese cultural setting. As far as is known, the scoping review is the first study to identify and summarise the content of generic HRQoL measures that were developed for Chinese populations. Subsequently, a series of qualitative interviews were undertaken to investigate how Chinese lay people may understand health and appraise their health status (Chapter 4). The scoping review, along with the qualitative study, enabled the development of a Chinese conceptual framework of health. This is also one of the first attempts at using empirical evidence to establish a conceptual framework of health in China.

Since most of the empirical studies investigating the subjective understanding of health have been conducted in the West and very limited empirical evidence has shown how health is conceptualised in China, the conceptual framework that was developed in this thesis is of practical use. It offers a classification scheme of health dimensions that may be important in a Chinese cultural setting. It can, therefore, be used as a starting point to design an HRQoL measure that is sensitive to the Chinese culture. By using this conceptual framework, health researchers can determine main domains that are of their research interests and decide on the specific health dimensions in each domain, as a way to develop an HRQoL measure to assess the health status of a Chinese population.

7.2.3 Important health dimensions in China

In Chapter 5 and Chapter 6, the Q-study and the unfolding analysis enabled the establishment of the relative importance of health dimensions and provided further evidence of Chinese people's subjective constructions of health. Few empirical studies are available in China addressing this issue and the thesis fills this gap. The Q-study identified five distinct views on health and established the relative importance of these health dimensions within each view. Although the five views were different from each other, the study showed that there were health

dimensions, such as “body constitution”, “spiritual appearance”, “sleep quality” and “breadth of mind”, that were simultaneously valued as most important by most of the views. Subsequently, the multidimensional unfolding analysis provided additional quantitative evidence that body constitution, sleep quality and spiritual appearance were emphasised as the most important across the whole sample of participants. This finding is useful in advising which core health dimensions should be used in assessing health among a Chinese general population. Because health dimensions including spiritual appearance, sleep quality and body constitution were believed by most participants to be essential in assessing health in China, they may be the common core set of health dimensions that are of relevance to most Chinese people and may need to be included to assess the subjective health of a Chinese population. Identifying the core health dimensions in China may also facilitate the modification of Western measures, such as EQ-5D, to make it more sensitive to the Chinese culture. They can be the “bolt-on” dimensions of a Western HRQoL measure. By including these health dimensions in the descriptive system of EQ-5D, it may improve its capacity to measure health in a Chinese cultural context. A list of example questions that may be added to EQ-5D-5L is presented in Figure 7-1. In future EQ-5D research with Chinese populations, it is logical to apply those additional heath dimensions to see the performance of such modification.

Figure 7-2: Example questions that can be added to EQ-5D-5L for use in China

Under each heading, please tick the ONE box that best describes your health.

SLEEP

I have no problems in falling asleep ❑
I have slight problems in falling asleep ❑
I have moderate problems in falling asleep ❑
I have severe problems in falling asleep ❑
I am unable to fall asleep ❑

SPIRITUAL APPEARANCE

I am full of spirt ❑
I am slightly short of spirit ❑
I am moderately short of spirit ❑
I am severely short of spirit ❑
I am extremely short of spirit ❑

BODY CONSTITUTION

My body constitution is very good ❑
My body constitution is good ❑
My body constitution is average ❑
My body constitution is poor ❑
My body constitution is very poor ❑

7.2.4 Cultural differences in measuring health between China and the West

By arguing that a widely used Western HRQoL measure, namely EQ-5D, may not work well in China, whose culture is considered to be significantly different from that in the West, this thesis explored cultural differences in defining and measuring health. Currently, as Western-developed HRQoL measures are applied widely, since limited studies have paid enough attention to the fact that health is a culturally grounded concept, this thesis made a contribution to the

literature by explicitly pointing out differences in measuring health between the two cultural settings.

As EQ-5D is one of the most commonly used Western HRQoL measures in China, it was selected as an example to show cultural differences between China and the West. Generic measures such as Sickness Impact Profile (SIP), Quality of Well-being Scale (QWB), Nottingham Health Profile (NHP), Health Utilities Index (HUI), the COOP Chart and SF-36, are also widely used Western-developed measures in assessing individuals' subjective health status (Fitzpatrick et al., 2006; Bowling, 2004). Compared with EQ-5D, most of these measures include more health dimensions – for example, SIP comprised 136 questions and NHP included 38 questions – and can be more comprehensive in content. They provide a broader image of how health is described and measured from a Western perspective. The content of these measures is presented in Table 7-1 and can be used to compare with the findings of this thesis to further present cultural differences between China and the West. Almost all of these Western measures include questions relating to physical functioning abilities and emotional symptoms. For example, health dimensions such as mobility, pain, social activity and depression are included in most of the health measures. However, these health dimensions seem to be less emphasised in China. The scoping review of Chinese-developed HRQoL measures showed that sleep and appetite were included in most of the identified Chinese-developed measures, but only a limited number of the aforementioned Western measures cover such health dimensions. Additionally, the Q-investigation and the unfolding analysis reported that lay Chinese people tend to attach importance to body constitution and spiritual appearance. These two health dimensions are Chinese-specific health concepts and are even less included in the Western HRQoL measures. Therefore, it further proved that cultural differences in defining and measuring health between China and the West exist.

Table 7-1: The content of six Western-developed generic health measures

	Physical symptoms	Emotional symptoms	Physical functioning	Cognitive functioning	Social/role functioning	General perceptions
SIP (Bergner et al., 1981)		emotional behaviours (eg. laugh or cry, irritable)	sleep and rest, eating, ambulation, **mobility**, body care and movement	Communication, alertness behaviour	work, **social interaction**, recreation and pastimes, home management	
QWB/QWB-SA (Kaplan et al., 1976; Kaplan et al., 1997)	symptoms and problem complexes: chronic (eg. vision, hearing, speech); acute (eg. appetite, weight, fatigue, discomfort, **pain**, sleep)	Mental health symptoms (stress, anxiety, **depression**, anger)	**mobility**, physical activities/ambulation		self-care & **social activity**	
NHP (Hunt et al., 1985)	**pain**, energy level	emotional reactions (lonely, **depressed**, on edge, angry)	sleep, physical abilities (bend, take stairs, stand, **mobility)**		**social isolation**	
COOP (Nelson et al., 1987)	**pain**	emotional feelings (anxious, **depressed**)	physical fitness (**walk**, run), daily activities		**social activities**, social support	current overall health, quality of life
SF-36 (Ware and Sherbourne, 1992)	**pain**, energy/vitality	mental health (nervous, **down-hearted**, calm, down, **happy**)	physical functioning (vigorous activities, moderate activities, **walk**, self-care activities)		role limitation (work, regular activities), social functioning (**social activities**, visiting friends/relatives)	general health perceptions
HUI (Feeny et al., 1995)	**Pain**	emotion (**happy/unhappy**)	vision, hearing, speech, **ambulation**, dexterity	cognition (ability to remember)		

7.3 Research implications and recommendations

7.3.1 To use, or not to use, that is the question!

The thesis has presented the limitations of EQ-5D, a Western HRQoL measure in describing health in a Chinese cultural setting. With an increasing trend in adopting EQ-5D in Chinese health research being observed, it is recommended in this thesis that EQ-5D should be used with caution in China. For example, Chinese national health department has chosen EQ-5D in the Chinese National Health Services Survey since 2008 to assess the health status of Chinese residents and EQ-5D may not be the best choice in this circumstance. This is because such health surveys are with an exclusively national focus and aim to monitor and track the health status of Chinese populations. They should be sensitive to how the population conceptualises health. While EQ-5D, which fails to include aspects of health that are considered most relevant and important in a Chinese cultural setting, may not be able to satisfactorily capture health among Chinese people. Using an inappropriate HRQoL measure may then lead to poor policy decision making and poor resource allocation.

However, EQ-5D does bring some pragmatic benefits when measuring health in China: it is simple, easy-to-operate, has gained international recognition and is currently the only HRQoL measure with a value set representing the preferences of Chinese general population, which can be used to calculate utility scores for economic evaluation. This means that EQ-5D may still be preferred by Chinese researchers and clinicians who undertake cross-country comparison studies and/or economic evaluations of health care interventions. In addition, the findings of Chapter 6 showed that the five dimensions of EQ-5D were likely to be especially important to Chinese participants in poor health status, thus EQ-5D can be used as an outcome measure to assess Chinese patients' health in a clinical context. Nevertheless, since this thesis provided evidence that the content validity of EQ-5D may not be sufficient among Chinese populations in general, which means that EQ-5D may not be able to provide valid health data in China as intended. This can weaken the credibility of cross-country comparison studies, clinical trials as well as economic evaluations conducted using EQ-5D. Health

researchers may still need to be tentative when applying EQ-5D data for decision making and policy recommendation.

“Bolt-on” (adding culturally specific health dimensions to EQ-5D) might be a possible solution to both retain the original descriptive system of EQ-5D and to make the HRQoL measure more culturally sensitive. As shown in Section 7.2.3, adding health dimensions, such as sleep and spiritual appearance, in the descriptive system of EQ-5D, may improve its capacity to measure health in a Chinese cultural context, as the bolt-on version would now comprise health dimensions that are considered most important and relevant among Chinese people. Various studies have used the add-on approach to increase the coverage of EQ-5D trying to make it more relevant to a particular group of people, while presented mixed evidence of the impact of bolt-on dimensions to EQ-5D. Some studies argued that adding new dimensions to EQ-5D seemed to have no benefits (Yang et al., 2014); some showed that bolt-ons can improve psychometric properties of EQ-5D (Hoogendoorn et al., 2019; Geraerds et al., 2019). The impact of adding new health dimensions that are relevant to Chinese culture remains unknown. In addition, introducing bolt-on dimensions to EQ-5D can reduce the comparability of the results to other populations. Further, while new dimensions can be added, logically speaking, health dimensions that are not that relevant or important can also be removed (“bolt-off”). Such significant changes will make EQ-5D no longer what it used to be, then why not just choose another HRQoL measure or simply develop a new one. Therefore, bolt-ons and bolt-offs should be further considered and tested before being applied in practice.

There are other Western-developed HRQoL measures as alternatives to EQ-5D for use in China, as presented in Table 7-1. These measures have been recognised by Chinese researchers, been translated into Chinese and been used in HRQoL research with Chinese populations. However, similar to EQ-5D, these measures were developed in a Western cultural setting and are not likely to include health dimensions that are culture-specific to Chinese people. Since those culture-specific health dimensions such as body constitution and spiritual appearance may be essential to assess the health of Chinese populations, the content legitimacy of the Western HRQoL measures can always be questioned.

Therefore, the use of those measures in a Chinese cultural context is not recommended based on the findings of the thesis.

Alternatively, a measure that is conceived and developed in China is expected to be more sensitive to the Chinese culture and may outperform those Western-developed HRQoL measures in assessing health among Chinese populations. The scoping review (Chapter 3) identified several HRQoL measures that were developed in a Chinese cultural setting. New measures are also being developed in China for use in HRQoL measurement, health technology assessment and drug evaluation in China, as presented in a recent EuroQol meeting (Zhao et al., 2020). Being Chinese culture specific can limit the application of such HRQoL measures. If an HRQoL measure includes aspects of health that are only relevant and important to a specific culture group, it may not be very useful in cross-country/culture comparative studies or international clinical trials. However, such Chinese-developed HRQoL measures may be able to collect better quality health status information of Chinese populations and are supposed to lead to better policymaking and resource allocation decisions.

7.3.2 Careful consideration of conceptual equivalence of Western-developed HRQoL measures is needed

In the context of the widespread application of Western-developed HRQoL measures worldwide, health researchers are likely to take it for granted that those commonly used HRQoL measures are always appropriate for use globally. This thesis argues that because subjective understandings of health are structured in a certain cultural setting, there are cultural differences in defining and measuring health. It questions the legitimacy of those Western-developed HRQoL measures from a cultural perspective. By presenting such cultural differences with empirical evidence, the thesis delivers an important message that careful consideration and testing of conceptual equivalence of Western-developed HRQoL measures for use in a different cultural setting is necessary.

As mentioned earlier, most of the commonly used HRQoL measures were developed in Europe or North America (Guillemin et al., 1993). Some of these measures, such as EQ-5D and SF-36, were developed based on an extensive review on existing health instruments as well as relevant literature (Ware and

Sherbourne, 1992; Kind, 1996); some measures, including NHP and SIP, were developed based on interviews with patients, lay people and/or health professionals (Hunt et al., 1985; Bergner et al., 1981); some (such as the COOP chart) were developed by using both of the empirical sources (Nelson et al., 1987). Because those existing health instruments and the literature reviewed were mainly in English, while participants recruited in interviews were most likely to be “Westerners”, inevitably, these commonly used HRQoL measures were developed in a Western-oriented cultural setting. Without considering cultural differences or testing the conceptual equivalence of health before applying such measures in a different cultural setting, as this thesis shows, the content validity of the HRQoL measures can be questioned.

Although most studies in the field of HRQoL have failed to take cultural differences into consideration, some researchers did recognise this issue. However, the development of a cross-cultural HRQL measure for international use seems to be challenging and has not escaped criticism. For example, the WHOQOL group set up several culturally diverse field centres, which collaboratively generated and piloted a QoL assessment tool (WHOQOL Group, 1995). Although substantial joint efforts were made to develop WHOQOL-100, the instrument is imperfect. It has been criticised for being too laborious and including potentially duplicated questions in order to be comprehensive (Skevington, 2002). Another criticism is that because some health dimensions that are important in one culture may not be important in another culture, developers of the WHOQOL would be unable to justify whether to include or exclude such dimensions. For example, the WHOQOL-100 consists of questions relating to one’s personal beliefs and explains in the questionnaire that those questions refer to religion, spirituality and any other beliefs. Religion and spirituality might be closely related to one’s health and be important in many cultural settings, but their practicality for use in China is doubtful. Only a relatively small percentage of the Chinese population is religious and the current Chinese government is officially atheist (Albert, 2018). It is also shown in this thesis that neither the scoping review nor the qualitative study covered a religious aspect of health, hence, the inclusion of the religious belief questions is likely to be less valuable among Chinese populations.

The ongoing EQALY project also addressed cross-cultural issues along the development process (Brazier, 2018). The EQALY team aimed to develop a generic HRQoL measure and generated items by reviewing qualitative literature and existing health and wellbeing measures (Brazier, 2018). They then conducted semi-structured cognitive interviews in six countries, including Argentina, Australia, China, England, Germany and the USA, to test the content and face validity of the draft items (Brazier, 2018). However, given the results of this thesis, the methodology used has its limitations: the review study mainly focused on the literature that was published in English to generate health items, while the content validity test was undertaken after the item generation process. As argued earlier, there might be other important health dimensions that are not covered in the English literature, and it would be challenging for the EQALY team to identify and/or justify irrelevant and missed-out items.

Indeed, there are many advantages in translating available HRQoL measures or developing HRQoL measures with an international perspective. For example, it is beneficial to use an HRQoL measure, which has different language versions, to carry out cross-country/culture comparative studies. It also facilitates researchers who want to conduct HRQoL studies in non-English-speaking countries, where no existing HRQoL measures are available. These benefits are acknowledged in this thesis. However, if an HRQoL measure is not able to measure health convincingly among a population, the health data collected using the measure may not be as useful as expected, which makes cross-cultural studies less informative (Haase and Braden, 2012). Additionally, if the objective of a study is with an exclusively national focus, for example, with an auditing or health policy development purpose, it might be better to use an HRQoL measure that is sensitive to the culture of that country/area (Kuyken et al. 1994). Overall, this thesis presents evidence that, due to cultural differences, a widely recognised Western HRQoL measure may not always be appropriate for use in a non-Western cultural context. It is thus suggested that the conceptual equivalence of health should be carefully considered and tested before translating/adapting existing HRQoL measures in a different cultural setting.

7.3.3 Measuring HRQoL from a "person-centred" perspective

Unlike objective health indicators, HRQoL refers to individuals' perceptions of their own health status (Shumaker and Naughton, 1995) and is by definition open to the challenge of subjectivity (McDowell, 2006). When measuring HRQoL, it is essential to be "person-centred" to focus on the understandings of the target population (which refers to the designate group of people for whom HRQoL measures are designed) when developing and validating an HRQoL measure. Undertaking person-centred studies is a necessary and informative precondition to improving the description and measurement of HRQoL. This thesis shows the importance of listening to lay people in the following two areas.

First, this thesis demonstrates that a "person-centred" approach, which pays adequate attention to a person's own understanding and experience of health, is informative to construct the subjective understanding of health in the target population and can facilitate the development of an HRQoL measure. In this thesis, by conducting qualitative interviews and a Q-study with lay people, the perceptions and views of lay participants were focused upon. The studies enabled the identification of several health dimensions that were considered important to lay Chinese participants but were not covered in those identified HRQoL measures. This helped to develop a more comprehensive conceptual framework of health and to understand the attributes of health that are most important and relevant to be measured. Since such studies provided additional health dimensions that are likely to be overlooked by researchers, it indicates the importance of conducting "bottom-up" studies to obtain lay people's views. However, in reality, many developers of HRQoL measures seem to adopt a "top-down" approach (McColl, 2005). They focus on the views of health professionals, such as clinicians and researchers to determine the content of an HRQoL measure and pay limited attention to lay people's understandings (McColl, 2005). Health professionals tend to select items for inclusion in an HRQoL measure based on their experience as clinicians or researchers, yet those health items considered to be most important by health professionals do not necessarily bear the same importance to participants who are non-health professionals (lay people) (Mansour, 1994). Therefore, it may not be appropriate for health researchers to make decisions on behalf of the target population when designing

an HRQoL measure. If the designers of HRQoL measures do not pay enough attention to how lay people perceive health, HRQoL measures may not be able to satisfactorily capture the subjective perceptions of the target population (Guyatt and Cook, 1994).

The thesis also shows that it is important to be “person-centred” when validating an HRQoL measure. Testing the quality of an HRQoL measure normally focuses on the statistical psychometric properties, while less attention has been paid to investigate the content validity and the acceptability of the HRQoL measure in the target population (Bowden and Fox-Rushby, 2003; Stewart and Napoles-Springer, 2000). For example, the statistical psychometric properties of EQ-5D have been tested in various studies in China, but few studies have asked people from a Chinese general population to comment on EQ-5D to look into its content validity (Wang et al., 2015a). This thesis argues that when evaluating the legitimacy of EQ-5D, it is equally, if not more, important to investigate whether lay participants can understand EQ-5D well and whether they consider the HRQoL measure comprehensive and relevant. It was found in this thesis that EQ-5D may not be able to capture information related to the intended concept, in the same way as the developers of the HRQoL measure would expect, because lay participants may understand the concepts within EQ-5D differently. For example, some participants thought that having pain/discomfort was not necessarily an indicator of bad health, because one can feel pain or discomfort after an intense exercise. These findings reflect those of van Leeuwen et al. (2015) who also found that health dimensions of EQ-5D were narrowly interpreted by participants. For instance, "Usual Activities" appeared to be a broad category including activities such as work, study, leisure and social activities as illustrated by the developers of EQ-5D (Fox-Rushby, 2005). However, lay participants did not interpret this in the same way and did not consider that some of the activities, for example, social functioning activities, are part of Usual Activities (van Leeuwen et al., 2015). These findings cannot be obtained in pure quantitative validation research but are important in suggesting that EQ-5D may not be satisfactory in measuring health. Such evidence should not be neglected in testing the legitimacy of an HRQoL measure. Therefore, the thesis generally suggests that apart from accepting the confirmation of statistical results as sufficient evidence

that the HRQoL measure works well in a population, it is important for health researchers to assess lay individuals' opinions on an HRQoL measure in validation research.

Because a health measurement must be based on a specific definition of health (McDowell, 2006), health can only be measured better when the concept of health is better defined. Since HRQoL refers to individuals' perceptions of his/her own health status and has its person-based nature, it is recommended in this thesis that obtaining information from target populations is essential when developing and validating an HRQoL measure.

7.3.4 Methodological considerations

The thesis shows that its study design was efficient to explore subjective understandings of health within a Chinese cultural setting and was feasible to evaluate the content of an adapted/translated HRQoL measure in China. Generally speaking, the study design can give a comprehensive and in-depth understanding of how lay people judge their own health and to check the content validity of an HRQoL measure in a specific cultural context. Since limited studies have evaluated the conceptual equivalence issue of an adapted HRQoL measure for use in the target culture, health researchers may replicate the approach of this thesis in other countries/regions. The study design of the thesis has the following advantages.

First, the study used a bottom-up method to identify potentially important health dimensions in China. In this way, it is less likely to omit those culturally specific health dimensions. It was pointed out earlier, the EQALY project only reviewed the English published literature, but there may be health dimensions that are considered important in other cultures and were not published in English. In this thesis, Chinese-developed HRQoL measures were reviewed, while Chinese lay participants were recruited and interviewed. Meanwhile, the study not only considered literature-based evidence but also incorporated empirical evidence from Chinese lay participants. This can help better justify the health dimensions that are identified are relevant and comprehensive in the target culture under investigation.

The second advantage is that the study design comprised both qualitative and quantitative techniques, which helped attain the research objective in an efficient and robust manner. Two qualitative studies – the scoping review and the qualitative study – helped the researcher to take an in-depth insight into how health is defined in a Chinese cultural setting. This was followed by a Q-methodological study, which combines both qualitative and quantitative components itself, to provide an in-depth analysis of the subjective constructions of health among participants. While the Q-study was not able to provide a single view representing the whole sample group of participants, the last study – a multidimensional unfolding analysis – presented an overall view and identified three core health dimensions. Therefore, the study design of the thesis took a more in-depth insight into the subjective understandings of health, when compared with those pure quantitative, survey-based studies. On the other hand, the study design of the thesis was more effective to identify various patterns in thinking about health and to discover health dimensions considered most important than those pure qualitative studies.

7.4 Limitations and future research

Limitations of the included individual studies of the thesis were discussed separately in relevant chapters and are not restated here. In this section, only general considerations of the limitations of the whole thesis are presented.

The first limitation was associated with the assumption made at the beginning of the thesis. Because the thesis aimed to explore differences in defining health between two general cultural identities (China vs the West), Chinese populations were treated as one single identity and the Han ethnic majority group, which constitutes around 92% of the entire Chinese population and form the mainstream Chinese culture (Jia et al., 2012), was focused, while few ethnic minorities were recruited in the empirical studies. Future research is needed to examine within-China cultural differences by investigating how health may be understood differently by Chinese ethnic minorities. Similarly, the fieldwork data collection was only conducted in China and almost all the participants recruited were Chinese residents living in the country. When designing the research

protocol, the researcher chose to focus on recruiting Chinese residents to explore how health is described in a Chinese cultural setting. However, as it has been reported that differences in perceiving health exist when population subgroups are compared (Damron-Rodriguez et al., 2005; Zarate et al., 2008), it would be interesting to obtain views from Chinese nationals living outside China or Western people living in China to investigate how these people understand health. This may help reveal how influential “inborn culture” and “acquired culture” are in shaping the understandings of health.

The empirical studies reported in this thesis tended to have an unbalanced sample with less socio-economically disadvantaged people, for example, those living in underdeveloped rural areas or with lower education attainment. The researcher travelled across China accessing participants from differing provinces and from both urban and rural areas. Efforts were made to recruit Chinese participants with various demographic characteristics in order to obtain a diverse view of health. However, because on the one hand, the studies required participants to be able to read and communicate to rank and sort health statements, it was more challenging or even impossible for less educated people to complete the tasks; on the other hand, due to the restrictions of time and resources, the researcher was not able to identify and recruit more people living in underdeveloped areas and with lower economic status, eventually socioeconomically disadvantaged people were less represented in the empirical studies. For the qualitative study (Chapter 4) and the qualitative driven Q-study (Chapter 5), the views of socioeconomically disadvantaged people were included, as a number of participants living in rural areas and/or with lower education attainment were approached and recruited. As for the quantitative MDS study (Chapter 6), because the group of socioeconomically disadvantaged participants was with a smaller sample size, their views of health tended to load less weight in determining the final MDS solution. Although the qualitative study, the Q-study and MDS study all presented the similar findings that health dimensions including “body constitution”, “sleep quality” and “spiritual appearance” were well understood and widely recognised even by participants with low education attainment, future studies with a more representative sample are needed to further justify the findings.

The thesis focused on Chinese general populations' views of health. Both the qualitative interview study and the Q-study recruited Chinese participants from the general population and most of the participants seemed to be in a relatively good health state. While it is widely agreed that patient groups are likely to understand health differently than a general population (Patrick and Erickson 1993), few participants in poor health were recruited to undertake comparisons between them and the general population. Although attempts were made to collaborate with researchers in hospitals in Beijing and Guangzhou in China, the researcher was confronted with many difficulties. In order to obtain additional ethical approval from the hospitals, the researcher was required to sign a collaboration agreement with their institutes and to pay a high amount of ethics application fee. Because the researcher was a full-time student at the University of Leeds, it was considered that such collaboration may potentially violate the university's policy. Additionally, the researcher also wanted to maintain her own control over the whole data collection and analysis. Other concerns included intellectual properties and, eventually, this project was not able to collect data from patients in hospital settings. Future studies could aim to investigate the understandings of health of patient groups in China.

The fourth limitation may be better considered as a difficult challenge throughout the whole study and research process. Health is a multidimensional and abstract concept and it is not likely to come up with a single "correct" health conceptual framework. Although the process of generating health dimensions and developing the conceptual framework was conducted in a systematic manner and was described in detail, the researcher was still tentative in stating that the identified health dimensions were free from criticism. Some health dimensions, such as complexion and appearance, may be considered to be too "superficial" to act as a health dimension. They may be captured by function-related dimensions, which are likely to be more directly linked with health outcomes. Such symptoms, in this sense, may be considered less useful in advising decision-making in a clinical setting. Additionally, some health dimensions, such as fatigue and discomfort, may be thought to overlap with each other. The current research was not able to respond to these problems. The internal relationships,

such as the cause-effect relationship, among various health dimensions needs further research.

Further, the findings of the research have not been used to revise the descriptive system of EQ-5D and to test the revision. Although this research project has identified several health dimensions that may be important among Chinese populations, these health dimensions have not been checked whether they would be effective in assessing health in Chinese populations. Possible examples of the additional health dimensions are shown in Figure 7-1 but revising EQ-5D then testing the revision is beyond the scope of this thesis. Future research should examine the legitimacy of the culturally important health dimensions reported in this thesis to measure health in China.

7.5 Concluding remarks

This thesis contributes to knowledge in a variety of ways. First, it offers evidence that the content validity of EQ-5D may mean that it should be used with caution in China. Second, it outlines a conceptual framework of health that can be used to design HRQoL measures that are sensitive to the Chinese culture. Third, it identifies health dimensions that may be essential in assessing HRQoL among a Chinese general population.

The fundamental purpose of this thesis has been to explore cultural differences in defining and measuring health between China and the West. The main findings emphasise that health is a culturally grounded concept. Consequently, it cannot be taken for granted that any Western HRQoL measure is appropriate for use in other cultural contexts. Careful consideration and testing of conceptual equivalence is important in deciding whether an existing HRQoL measure is appropriate for use in any selected population. The findings documented here are specific to China but the implications can and should be considered in other countries/regions and other cultural settings.

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Appendix

Appendix I: Ethics approval letter

UNIVERSITY OF LEEDS

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 9.29, level 9
Worsley Building
Clarendon Way
Leeds, LS2 9NL
United Kingdom

✆ +44 (0) 113 343 1642

20 February 2018

Zhuxin Mao
PhD Student
School of Medicine
Leeds Institute of Health Sciences
Faculty of Medicine and Health
Worsley Building
University of Leeds
Clarendon Way
LEEDS LS2 9NL

Dear Zhuxin

Ref no: **MREC17-021**

Title: **Does EQ-5D work in China? Exploring Cultural Diversities in Measuring Health**

Your research application has been reviewed by the School of Medicine Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documentation received from you and subject to the following condition:

- **The fieldwork risk assessment must be signed by your supervisor and returned to FMHUniethics@leeds.ac.uk prior to any travel**

Document	*Version*	*Date Submitted*
New_ethical_review_form Zhuxin Mao V 2.0	2.0	11/01/2018
Supporting Material 1.1-information sheet-interview_v2	2.0	11/01/2018
Supporting Material 1.2-information sheet Q-sorting_v2	2.0	11/01/2018
Supporting Material 2-consent form_v2	2.0	11/01/2018
Supporting Material 3-verbal consent script	1.0	12/10/2017
Supporting Material 4-instructions and questions	1.0	12/10/2017
Supporting Material 5-Fieldwork_Assessment_Form_medium_risk_Zhuxin Mao V1	1.1	20/02/2018
Supporting Material 6-recruitment poster_v2	2.0	11/01/2018
Supporting Material 7-Email from Chinese scholars	1.0	12/10/2017
Supporting Material-8 Email from Dr Alice Temple	1.0	12/10/2017

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

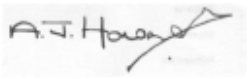
Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you every success with the project.

Yours sincerely



Dr Anthony Howard, Co-Chair, SoMREC, University of Leeds
(Approval granted by Co-Chair Dr Anthony Howard on behalf of the committee).

Appendix II: Information sheet – Interview

"What is Health?" Exploring Chinese Perceptions of Health

Information about the research

You are being invited to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please read the following information carefully and ask if anything is unclear or you would like further information.

What is the purpose of the study?

Health. Everyone knows the word "health".

Health seems to be a familiar word to most people, but the word itself is abstract and can be defined differently by different people.

The study aims to explore the concepts of health among Chinese people. We want to understand how Chinese people define health and to identify those health dimensions that are most important to them. The study then can help to construct a health conceptual framework and assist to develop a more appropriate descriptive system for Chinese people to measure health status.

Why have I been chosen?

This research is interested in seeking Chinese people's views of health and Chinese people's preference for various health dimensions. The interview will approximately recruit 25 Chinese people living in China.

Do I have to take part?

No. It is up to you to decide whether to take part or not. If you agree to take part in this study, you will be asked to sign a consent form.

Can I change my mind?

Yes. If you decide to take part you are still free to withdraw at any time and without giving a reason. You will also be able to withdraw your provided data up to 48 hours after the interview, after which time data analysis will have begun.

What will I have to do if I agree to take part?

The researcher will arrange to meet you for an interview at a convenient venue. This interview will last approximately 45 minutes and will be audio-recorded. During the interview, you will be asked questions about your views of health and influential factors that affect health status.

Are there any possible advantages of taking part?

There are no personal advantages of taking part. Your participation will help to develop a health conceptual framework in China and construct a more appropriate descriptive

system for Chinese people to measure health status. Your opinions and comments will be beneficial to the development of health sciences in China.

Are there any possible disadvantages and risk of taking part?

There are little personal disadvantages or risks of taking part. However, if you feel any discomfort or distressed during the interview, please tell the researcher. It is your choice to take a break or stop the interview entirely. Following the interview, if you subsequently feel distressed, please contact the research team who will contact local counselling services, the University of Leeds Student Counseling, and/or Mental Health Support Centre that are available for further counselling.

What happens to information about me and answers that I give?

All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will be removed from any information you give so that you cannot be recognised from it. Your details will be held securely on a database and deleted once the study is complete.

Direct quotes from the interviews may be used in the study report. Your confidentiality and anonymity will be protected by removing any identifying information about you from these quotes.

Who is funding the research?

This is a PhD research project, which is jointly supported by the University of Leeds in the United Kingdom and China Scholarship Council.

Who can I contact for further information?

Zhuxin Mao, PhD student
Leeds Institute of Health Sciences
Email: umzm@leeds.ac.uk
Tel: +44 0113 343 9813

Prof. Paul Kind, Professor in
Academic Unit of Health Economics
Email: p.kind@leeds.ac.uk
Tel: +44 01133 430 879

The study has been reviewed and approved by the School of Medicine Research Ethics Committee at the University of Leeds (Ethics Reference: MREC17-021)

You will be given a copy of this information sheet and a signed consent form to keep.

“什么是健康？” —— 探索中国健康概念的研究

参与者信息书

我们在此邀请您参加这项研究，在您决定是否参加本项调查前，我们想让您了解我们为什么要进行这项研究以及这项研究的程序和过程。请您仔细阅读以下信息，如果有任何疑问或者您需要更多有关研究的相关信息，请向研究人员提出。

这项调查的目的是什么？

几乎所有人都知道“健康”这个词语。但“健康”是抽象的，不同的人对它可能会有不同的定义。

这项研究旨在探索中国居民对于“健康”的定义。我们想要知道中国居民怎样定义健康，也想要知道生活中的哪些方面、哪些因素最能影响他们的健康状态。这项研究将搭建起一个健康的概念框架，并探索出适应于中国文化背景的健康描述系统，来更准确地观测和量化中国人群的健康状态。

为什么选择您来参与这项调查？

为了探索中国居民对于健康的理解，我们需要招募不同年龄、各行各业的中国居民进行采访。我们计划招募大约 25 名受访者参与本项调查。

这项调查是必须要参加的吗？

不。这完全取决于您自己的意愿。如果您有意愿参与这项调查，并决定参加本项研究，请您在接受采访前签署知情同意书表明同意。

采访进行中可以退出吗？

可以。如果您同意参与采访，在采访进行中的任何时候、任何阶段，您有权利与自由退出调查，而且不用提供任何理由。在采访结束后 48 小时内，您仍然可以要求删除您已提供的所有信息和数据，而该数据则不会被用于本次研究中。但采访结束 48 小时后，采集的数据将会被处理与分析，您将无法要求删除已经提供的数据。

如果您同意参与调查，您需要做什么？

调查员将会与您取得联系，约定时间与地点进行面对面的采访。这项采访大致会占用您 45 分钟的时间，并且会被录音。在采访过程中，我们会询问您对于健康的理解以及您认为哪些因素最能够影响您的健康状态。

参与调查会有好处吗？

参与采访不会有直接的个人受益，但您的参与会帮助我们搭建起一个健康的概念框架，并探索出更适应于中国文化背景的健康描述系统，来更准确地观测和量化中国人群的健康状态。您的观点和评论将会对我国健康科学的进步与发展带来有益的帮助。

参与调查会有潜在的风险或者伤害吗？

这项采访不会为您带来个人的风险或者伤害。但如果在采访过程中，某一些问题引起您的不适或者影响到您的心情，请您及时告诉调查员，您可以选择暂停或者终止采访。在采访结束后，如果您依然感到不适，请您联系调查团队。调查团队将会联系利兹大学心理健康求助中心或者本地心理咨询中心，为您安排心理舒缓及咨询服务。

调查组将怎样处理您提供的个人信息和回答？

我们将严格保密在调查过程中搜集到的关于您的个人信息。您的名字，公司名称，家庭住址将会从采集的数据中删除掉，您的所有联系方式也会在调查结束后全部清除。

调查报告也许会直接引用您的回答，但不会泄露您个人的任何资料。我们将维护您的个人隐私，您的姓名将会以化名的形式出现；在引用的您的回答中，所有能够识别出您身份的个人信息将会被移除。

这项调查研究是由谁资助？

该项调查是由英国利兹大学与中国留学基金委联合资助的博士研究生课题。

如果想要了解更多相关信息，您可以联系谁？

毛竹欣，利兹大学博士研究生

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Paul Kind，教授

利兹健康经济学研究中心

电子邮箱：p.kind@leeds.ac.uk

电话：+44 01133 343 0879

该项调查研究已经通过利兹大学医学院伦理审查委员会的审核。

（伦理审查编号：REC 17-021）

我们将把参与者信息书与已签名的知情同意书的副本交给您留存。

Appendix III: Information sheet – Q-study

"What is Health?" Exploring Chinese Perceptions of Health

Information about the research

You are being invited to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please read the following information carefully and ask if anything is unclear or you would like further information.

What is the purpose of the study?

Health. Everyone knows the word "health". Health seems to be a familiar word to most people, but the word itself is abstract and can be defined differently by different people.

The study aims to explore the concepts of health among Chinese people. We want to understand how Chinese people define health and to identify those health dimensions that are most important to them. The study then can help to construct a health conceptual framework and assist to develop a more appropriate descriptive system for Chinese people to measure health status.

Why have I been chosen?

This research is interested in seeking Chinese people's views of health and Chinese people's preference for various health dimensions. The interview will approximately recruit 90 Chinese people living in China.

Do I have to take part?

No. It is up to you to decide whether to take part or not. If you agree to take part in this study, you will be asked to sign a consent form.

Can I change my mind?

Yes. If you decide to take part you are still free to withdraw at any time and without giving a reason. You will also be able to withdraw your provided data up to 48 hours after the interview, after which time data analysis will have begun.

What will I have to do if I agree to take part?

The researcher will arrange to meet you for an interview at a convenient venue. This interview will last approximately 90 minutes and will be audio-recorded. During the interview, you will be asked to conduct a sorting experiment and be asked questions about your views of different health dimensions. You will be given different statements relating to health and will be asked to rank order the statements from the most important ones to the least important ones according to your own preference.

Are there any possible advantages of taking part?

There are no personal advantages to take part in. Your participation will help to develop a health conceptual framework in China and construct a more appropriate descriptive system for Chinese people to measure health status. Your opinions and comments will be beneficial to the development of health sciences in China.

Are there any possible disadvantages and risk of taking part?

There are little personal disadvantages or risks of taking part. However, if you feel any discomfort or distressed during the interview, please tell the researcher. It is your choice to take a break or stop the interview entirely. Following the interview, if you subsequently feel distressed, please contact the research team who will contact local counselling services, the University of Leeds Student Counseling, and/or Mental Health Support Centre that are available for further counselling.

What happens to information about me and answers that I give?

All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will be removed from any information you give so that you cannot be recognised from it. Your details will be held securely on a database and deleted once the study is complete.

Direct quotes from the interviews may be used in the study report. Your confidentiality and anonymity will be protected by removing any identifying information about you from these quotes.

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Zhuxin Mao, PhD student	Prof. Paul Kind, Professor in
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Tel: +44 0113 343 9813	Tel: +44 01133 430 879

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“什么是健康？” —— 探索中国健康概念的研究

参与者信息书

我们在此邀请您参加这项研究，在您决定是否参加本项调查前，我们想让您了解我们为什么要进行这项研究以及这项研究的程序和过程。请您仔细阅读以下信息，如果有任何疑问或者您需要更多有关研究的相关信息，请向研究人员提出。

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几乎所有人都知道“健康”这个词语。但“健康”是抽象的，不同的人对它可能会有不同的定义。

这项研究旨在探索中国居民对于“健康”的定义。我们想要知道中国居民怎样定义健康，也想要知道生活中的哪些方面、哪些因素最能影响他们的健康状态。这项研究将搭建起一个健康的概念框架，并探索出适应于中国文化背景的健康描述系统，来更准确地观测和量化中国人群的健康状态。

为什么选择您来参与这项调查？

为了探索中国居民对于健康的理解，我们需要招募不同年龄、各行各业的中国居民进行采访。我们计划招募大约 90 名受访者参与本项调查。

这项调查是必须要参加的吗？

不。这完全取决于您自己的意愿。如果您有意愿参与这项调查，并决定参加本项研究，请您在接受采访前签署知情同意书表明同意。

采访进行中可以退出吗？

可以。如果您同意参与采访，在采访进行中的任何时候、任何阶段，您有权利与自由退出调查，而且不用提供任何理由。在采访结束后 48 小时内，您仍然可以要求删除您已提供的所有信息和数据，而该数据则不会被用于本次研究中。但采访结束 48 小时后，采集的数据将会被处理与分析，您将无法要求删除已经提供的数据。

如果您同意参与调查，您需要做什么？

调查员将会与您取得联系，约定时间地点进行面对面的采访。这项采访大致会占用您 90 分钟的时间，并且会被录音。您会被邀请做一个排序实验，在调查中，调查员会给您一些卡片，每张卡片上都是一项与健康相关的、关于生活某个方面的描述，您需要将这些卡片进行排序，并告诉我们，在您的观点看来，哪些描述是您认为最重要的，哪些是您认为最不重要。

参与调查会有好处吗？

参与采访不会有直接的个人受益，但您的参与会帮助我们搭建起一个健康的概念框架，并探索出更适应于中国文化背景的健康描述系统，来更准确地观测和量化中国人群的健康状态。您的观点和评论将会对我国健康科学的进步与发展带来有益的帮助。

参与调查会有潜在的风险或者伤害吗？

这项采访不会为您带来个人的风险或者伤害。但如果在采访过程中，某一些问题引起您的不适或者影响到您的心情，请您及时告诉调查员，您可以选择暂停或者终止采访。在采访结束后，如果您依然感到不适，请您联系调查团队。调查团队将会联系利兹大学心理健康求助中心或者本地心理咨询中心，为您安排心理舒缓及咨询服务。

调查组将怎样处理您提供的个人信息和回答？

我们将严格保密在调查过程中搜集到的关于您的个人信息。您的名字，公司名称，家庭住址将会从采集的数据中删除掉，您的所有联系方式也会在调查结束后全部清除。

调查报告也许会直接引用您的回答，但不会泄露您个人的任何资料。我们将维护您的个人隐私，您的姓名将会以化名的形式出现；在引用的您的回答中，所有能够识别出您身份的个人信息将会被移除。

这项调查研究是由谁资助？

该项调查是由英国利兹大学与中国留学基金委联合资助的博士研究生课题。

如果想要了解更多相关信息，您可以联系谁？

毛竹欣，利兹大学博士研究生

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利兹健康经济学研究中心

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电话：+44 01133 343 0879

该项调查研究已经通过利兹大学医学院伦理审查委员会的审核。

（伦理审查编号：REC 17-021）

我们将把参与者信息书与已签名的知情同意书的副本交给您留存。

版本 2 参与者信息书 日期：08/01/2018

Appendix IV: Consent form

Participant Identification Number for this study: _____

Consent to take part in "What is Health?" Exploring Chinese Perceptions of Health	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated 08/01/2018 (version 2) explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. I will also be able to withdraw the provided data up to 48 hours after the interview, after which time data analysis will have begun.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, therefore I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential.	
I agree with the data collected from me to be stored and used in relevant future research in an anonymised form. If quotations are used, anonymity will be preserved.	
I understand that other genuine researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	
I understand that other genuine researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	
I understand that relevant sections of the data collected during the study may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and agree to the interview being audio recorded.	

Name of participant	
Participant's signature	
Date	
Name of the lead researcher	
Signature	
Date*	

Project title	*Document type*	*Version #*	*Date*
Exploring Chinese Perceptions of Health	consent form	2.0	08/01/2018

受访者编号:

“什么是健康？” —— 探索中国健康概念的研究 研究知情同意书	同意请打勾
我确认已经阅读并理解了此项研究的参与者信息书（版本 2，日期 08/01/2018）。该信息书已经解释了研究过程中可能出现的问题及解决方法，并且我有机会提出自己的疑问。	
我已明确参加这项研究属于自愿行为，我能够在采访进行中的任何时候、任何阶段退出调查，而且不需提供任何理由，拒绝参加研究不会损害我的任何利益。我明确自己可以拒绝回答任何一个问题或者任何一类问题。在采访结束后 48 小时内，我可以要求删除已提供的所有信息和数据，该数据将不会被用于本次研究的分析中，但 48 小时后，数据分析将开始，我将无法要求删除已经提供的数据。	
我同意研究组成员能够查看、使用、分析我匿名化后的受访记录。我明确我的名字不会直接出现在研究资料中，因此我的个人身份不会在调查报告或者调查结果中被识别。我的个人信息将会被严格保密。	
我同意将我提供的，匿名化后回答和数据用于今后的相关研究中。如果我的回答被直接引用在调查报告中，也将是匿名的。	
我明确如果有其他研究人员想要查看、使用这些数据，他们必须同意维护这些资料信息的保密性。	
我明确如果有其他研究人员想要在学术文章、学术报告、网页和其他研究成果中使用我的回答，他们必须同意维护这些资料信息的保密性。	
我明确利兹大学以及法规机构的相关人员可能会查看这项研究所收集的部分信息和数据。我同意上述人员查看我的受访记录。	
我同意参加上述的调查研究课题，并同意调查员对采访进行录音。	

受访者姓名	
受访者签名	
日期	
调查员姓名	
调查员签名	
日期	

Appendix V: Interviewing questions in the qualitative study

Section 1: self-introduction; research aim explanation

Hello! I'm a PhD student from the Institute of Health Sciences, University of Leeds, in England. I am conducting a research study on exploring Chinese perceptions of health. I want to know how people usually think of health and how people describe their health.

Thank you for taking the time to talk with me today. There are no right or wrong answers. I would like you to feel comfortable saying what you really think and how you really feel. Please have a look at the information sheet … *(go through the information sheet with the participant, pointing out the voluntariness and confidentiality of the research, reminding the participant that the interview will be audio-recorded)*

Do you have any questions?

Please sign the consent form here if you are fine with it.

Do you have any questions before we start?

Section 2: warm-up/background information

What should I call you?

How are you today? How do you feel about your health status at the moment?

Section 3: Questions relating to "health"

1) How do you think about your health at the moment?

You just said you are healthy/not healthy/not very healthy/ in sub-health, why did you say that? What makes you feel you are (not) healthy?

2) What experiences do you have in good/poor health yourself?

[When appropriate] You said you are in good health, have you been in poor health yourself? What things might make you think you were not in good health? What are the differences between now and the time when you were in poor health?

3) How would you describe someone in good health?

What does "good health" mean to you? What are the features of good health?

4) How would you describe someone in poor health?

Can you think of someone you know who is in poor health? Why do you think he/she is/was in poor health? Can you describe their experiences in poor health?

Section 4: Opinions on the EQ-5D questionnaire

Here is a short questionnaire that was developed in Europe and was translated into Chinese. The questionnaire was designed with the purpose of describing and measuring people's health status. Could you please complete this questionnaire?

…

1) Difficulty in understanding or answering some of the questions:

Have you encountered any difficulties in understanding or completing this questionnaire? Do you think the questions are all clear to you? Are there any unclear phrases?

2) Completeness of the questionnaire

Do you think the questionnaire can fully reflect your health status? Why or why not? Do you think there are dimensions that the questionnaire does not include but are important in describing health status? What additional questions should the questionnaire ask? What will you do to improve the questionnaire to make it better reflect your health status?

3) The importance of the five dimensions in EQ-5D

To depict your health status, do you think the five questions are the most important ones? Are there any dimensions not important in reflecting your health status?

4) Overall impression of the questionnaire

In general, do you like the questionnaire or not? Do you have any suggestions for improving the questionnaire?

I've asked all the questions that I needed to. Is there anything that you would like to add?

Section 5: Additional background information

Would you mind telling me your age?

What do you do (job)? Are you busy at work?

If you want to tell me about your education background?

Is __ (the city/town he/she lives in now) your hometown? Where did you grow up?

Do you have any questions for me?

Thank you for your time!

一、自我介绍和课题介绍

您好，我是英国利兹大学健康科学院的博士生。我现在在做一项调查，想要探索中国居民对于健康的理解，中国居民是怎样看待健康的，在评价和描述自身健康状态的时候一般会考虑哪些方面。

非常感谢您愿意花时间接受接受我的采访。我的问题都是开放性的问题，所以回答不会有对错和好坏之分，我希望您可以有一个放松的、聊天式的状态，告诉我您的真实想法，真实观点就可以。在访谈开始之前，您可以再看一下这个信息书，如果您不介意的话，我将在采访的过程中进行录音，这是为了便于在采访后能够更系统更细致地分析这段访谈的内容。

请问您还有什么不清楚的地方吗？您还有什么问题吗？如果没有问题的话，请您在这个知情同意书上签字。

二、引入主题

您今天感觉怎么样？您觉得您现在处于一个怎样的健康状态呢？（您觉得您现在健康吗？）

三、关于健康的问题

1.1）您说您觉得自己处于一个健康的状态，为什么？您是根据什么做出的这个判断？您能具体描述一下您的健康状态吗？

那您之前有没有经历过让您感觉自己是不健康的时候呢？

（回答有）您能描述一下当时的状态吗？不健康的状态跟您现在的状态相比有怎样的不同？

（回答没有）您一直都处于一个健康的状态，那您能不能想象一下，您觉得有哪些事情/哪些情况，会让您感觉到您自己的状态是不健康的呢？

您提到的这些事情中，哪个是您认为最重要的？哪个是第二重要的？

1.2）您说您处于一个不健康的状态，您能具体描述一下不健康体现在哪些方面呢？您是根据什么做出的判断，觉得自己不健康的？您觉得跟您健康的时候相比，现在不健康的状态有哪些方面的不同？您提到的这些事情中，哪个是您认为最重要的？哪个是第二重要的？

2）您觉得健康对您来说意味着什么？健康有什么特点？您会怎么去描述一个健康的人？您会通过哪些方面去判断这个人是否健康？

3）那您能告诉我什么是不健康呢？您会通过哪些方面去判断然后觉得这个人是不健康的？您身边有没有您认为不健康的人？您为什么觉得他们不健康？

4）除了刚刚您提到过的这些，在描述您自己健康的时候，您还有其他会考虑的方面吗？

5）您觉得您生活中有哪些事情／哪些情况在正面积极地影响您的健康状态？它们怎样在对您的健康状态进行正面的影响？生活中的哪些方面／哪些事情又在负面影响您的健康状态，对您的健康状态产生不好的影响呢？它们怎样在对您的健康状态产生负面的影响？

您觉得健康状态又会对生活产生哪些方面的影响呢呢？

四、五维量表问题

1）刚才您在填写问卷的过程中有没有遇到困难？具体困难是什么？

您对问卷中的表述的意思有没有不确定的地方？您对您的答案有没有不确定的地方？您在选择答案时有没有因为不确定而难以选择？

2）您认为这份问卷充分反映、充分描述了您今天的健康状况吗？为什么/为什么不呢？为了更好地描述您今天的健康状况，您觉得这个问卷应该怎样改进？

您认为这份问卷中是否缺少一些比较重要的健康方面的问题？在您看来，需要增哪一些健康方面问题呢？

3）在您看来，这个问卷的五个方面对于描述您的健康来说重不重要？有没有哪一方面或几方面不重要？为什么？

4）您对这份问卷的总体印象是什么？有什么好或者不好的地方吗？对于改善问 卷您有什么建议吗？

五、其他背景问题

您介意告诉我您的年纪吗？

您是做什么工作的？您平时工作忙吗？我应该怎样称呼您呢？

这是您的出生地吗？您是在这里长大的吗？

您介意告诉我您的教育背景吗？

关于这项研究，您有什么想要问我的问题吗？

非常感谢您！

Appendix VI: The process of how the Q-sample was generated

Top level – Domains: Symptom Status, Function Status

Second Level – Subdomains: Physical Symptom, Psychological Symptom, Physical Function, Cognitive Function, Social Function and Role Function

Third Level – Dimensions: sub-components of sub-domains and represent more specific areas. **Q-statements were chosen from this level.**

Fourth Level – Items: with even narrower focuses compared to health dimensions. They are considered as specific examples representing certain aspects for health dimensions.

Health Dimension	Health Items	Questionnaires	Qua_study	Q-statements	Reasons to exclude
Physical symptoms					
Discomfort	Discomfort in specific body parts	CHPRO, HSTCM, CPSHS, TCMQ	X	Feeling of discomfort	
	Discomfort when breathing	CPH42, CPSHS, HSTCM, TCM50, TCMQ			
	Nausea, vomit	CPSHS, TCMQ	X		
	Palpitation	CPSHS, HSTCM,			
	Dizziness	CPSHS, HSTCM, TCMHSS, TCMQ	X		
	Dyspepsia	CPSHS, HSTCM, SRHMS	X		
	Tinnitus	CPSHS, HSTCM, TCMQ			
	Pruritus	TCMQ			
	Discomfort (without specifying)	QOL35, QOLI	X		
	Numbness	CPSHS	X		
Appetite	The desire of having food	CHPRO, CHQOL, HSTCM, TCM50, TCMHSS, CPH42, CPSHS, QOL35, QOLI, SRHMS	X	The desire of having food	
	Food amount	CHPRO, CHQOL, TCMHSS, CPSHS, QOLI	X		
Fatigue	Tiredness	CHPRO, CHQOL, TCM50, TCMHSS, TCMQ, CPH42, HSQ, QOL35, SRHMS	X	Feeling of tiredness	
Pain	Pain (without specifying)	HSTCM, TCMHSS, TCMQ, CPH42, QOL35, QOLI, SRHMS	X	Feeling of pain	
	Painful feelings in specific parts of the body	CPSHS, HSQ	X		
	Intensity of pain	CPH42	X		
	Duration of pain	CPH42	X		
Body strength (energy)	The energy in the body to do things	CHPRO, CHQOL, CPSHS, HSTCM, TCM50, TCMHSS, CPH42, QOLI	X	Body strength of doing things	

	Willingness to move	CPH42	X		
Complexion	Colour of face	CHPRO, CHQOL, TCM50, TCMQ	X	Natural colour and appearance of the face	
	Colour of lips	CHPRO, CHQOL, TCM50	X		
	Eye spirit	CHPRO, CHQOL	X		
	Shininess on face	CHPRO, CHQOL	X		
Appearance	Body weight	CPSHS	X	Body weight (is it underweight, normal, overweight or obese)	
	Body image	HSTCM, QOLI			
	Body shape		X		
Spirit	Spirit	TCMHSS, CPSHS	X	Spiritual appearance (is it full of spirit or lack of spirit)	
Other abnormal signs	Stool and urination	CHPRO, HSTCM, TCM50, TCMHSS, TCMQ	X		Represented a broad range of sub-items and were too general compared to other health dimensions
	Feelings in mouth	CHPRO, HSTCM, TCM50, TCMHSS, TCMQ			
	Voice	HSTCM, TCMQ			
	Sweating	CHPRO, HSTCM, TCM50,			
	Skin problems	CPSHS, TCM50, TCMQ			
Psychological symptoms					
Worry/anxiety	Worried about things	CHPRO, CHQOL, HSTCM, TMCHSS, CPH42, CPSHS, QOLI, SRHMS,	X	Feeling of anxiety	
	Agitated feeling	CHPRO, CHQOL, HSTCM, TCM50, TCMHSS, TMCQ, CPH42, CPSHS, HSQ, QOL35, QOLI	X		
Depression	Sad feeling	CHPRO, CHQOL, CPH42, CPSHS, QOL35, QOLI, SRHMS, TCMHSS	X	Feeling of depression	
	Hopelessness and helplessness	CHPRO, CHQOL, CPSHS, QOLI, SRHMS	X		
	Tendency to cry	CHPRO, CHQOL, CPSHS	X		
	The tendency to kill oneself	CPSHS			
	Depression	TCM50, HSQ	X		
Happiness	Happiness	CHPRO, CHQOL, CPH42, HSTCM, QOL35, QOLI, SRHMS, TCM50			Is opposite to sadness and may create confusions for participants to rank
Stress	Nervous feeling	CHPRO, CPSHS, HSTCM, QOLI, QOL35, SRHMS, CPH42	X	Feeling of stress	
	Pressure	HSQ, QOLI	X		
	Stress from work		X		
	Stress from family	CPSHS	X		
	Economic stress		X		
	Ability to deal with stress		X		
Fear	Fear feeling	CHPRO, CHQOL, CPSHS, SRHMS	X	Feeling of fear	
	The tendency to be scared	CHPRO, CHQOL, HSTCM, TCM50			

Anger	The tendency to be angry	CHPRO, CHQOL, CPSHS, QOLI, TCM50, TCMHSS	X	The tendency of being angry	
Emotional stability	Peace in mind	CHPRO, CHQOL, CPH42, QOLI	X	Ability to remain stable and peaceful in mood	
	The tendency to be surprised	CPSHS, HSTCM, QOLI	X		
	Ability to adjust the mood		X		
Confidence	Confidence in oneself	HSTCM, CPH42, CPSHS, QOL35, QOLI, SRHMS	X	Self-confidence	
Loneliness	Loneliness	CHPRO, CPH42, QOL35, QOLI, SRHMS	X	Feeling of loneliness	
Satisfaction	Satisfaction with life	CPH42, HSTCM, QOLI, SRHMS	X	Sense of satisfaction with life	
Sense of security	Sense of security	CHPRO, CHQOL, CPH42	X		Is opposite to fear and may create confusions for participants to rank
Physical function					
Sleep	Insomnia	CHPRO, CHQOL, CPSHS, HSTCM, TCM50, TCMHSS, TCMQ, QOL35	X	Sleep quality	
	Sleep quality	CHPRO, CHQOL, HSQ, HSTCM, QOLI, SRHMS, TCMHSS, TCMQ	X		
	Sleep length	CPH42	X		
Usual activities	Ability to conduct usual role activities (work role, family role, study role)	CHPRO, TCM50, QOLI, SRHMS	X	Ability to perform usual activities (such as working, studying, shopping, doing housework)	
	Ability to go shopping	QOL35, QOLI, SRHMS	X		
	Ability to do housework	QOL35, QOLI, SRHMS	X		
	Ability to feed oneself	SRHMS	X		
Communication	Ability to communicate with people	CPSHS, HSTCM, TCM50	X	Ability to communicate with people	
	Ability to speak clearly	CHPRO, CHQOL	X		
	Ability to express ideas clearly	CHPRO, CHQOL			
Organ function	Vision	CPSHS, QOLI, SRHMS, TCMQ	X	1) Vision 2) Hearing	
	Hearing	CPSHS, QOLI, SRHMS, TCMQ	X		
	State of teeth and gums	TCMQ			
	State of chest and abdomen	TCMQ			
	State of heart		X		
	State of limbs	TCMQ	X	Ability to walk about	
Mobility	Ability to walk about	CPH42, QOL35, QOLI, SRHMS	X		
	Ability to take stairs	CPH42, QOL35, SRHMS	X		
	Ability to bend ones' knees	CPH42, QOL35, SRHMS	X		
	Ability to run/exercise	QOL35, SRHMS	X		
Self-care	Ability to dress and bath oneself	CPH42, QOL35, QOLI, SRHMS	X	Ability to take care of oneself (such as washing and dressing oneself)	
Sexual function	Satisfaction with sex life	CPSHS, QOL35		State of sexual life	

	State of sex life	QOLI			
Dependence on medicine	Dependence on medication	QOL35, QOLI		Dependence on medicine	
Psychological function					
Memory	State of memory	CHPRO, CHQOL, TCM50, TCMHSS, TCMQ, QOL35, SRHMS	X	Ability to remember things	
	Ability to remember things	QOLI	X		
Concentration	Ability to concentrate	CHPRO, CHQOL, HSTCM, TCM50, CPH42, QOL35, QOLI, SRHMS	X	Ability to concentrate	
Thinking	Ability to think clearly	CHPRO, CHQOL, CPH42, HSTCM, QOLI, SRHMS	X	Ability to think things clearly	
	Being clear-headed or in confusion	CHPRO, CHQOL, CPH42	X		
Reaction	Ability to perceive changes in surrounding and to respond swiftly	CHQOL, QOLI	X	Ability to perceive changes in surrounding and to respond swiftly	
	Speed of response	CHPRO, CHQOL	X		
Decision-making	Ability to make decisions	HSTCM, CPSHS, QOLI	X	Ability to make decisions	
Social wellbeing					
Social relations	Satisfaction with social relations including relations with friends, family and colleagues	QOLI	X	State of social relations (such as the relations with family, friends or colleagues)	
	Quality (good or bad) of social relations including relations with friends, family and colleagues	CHPRO, TCM50, CPH42, CPSHS, QOL35, QOLI, SRHMS	X		
	Quantity of social relations (enough friends)	CPH42, SRHMS	X		
Social support	Satisfaction with the support from family and friends	CHPRO, QOLI, SRHMS	X	State of the support from one's social network (such as supportive resources from friends and family)	
	Existence of social support	CPH42, QOL35	X		
	Ability and willingness to offer support	QOL35, QOLI, SRHMS			
Social contact	Frequency of Participating in communal activities or contacting relatives and friends	TCM50, QOLI, SRHMS			Very similar to social relation according to the feedback from participants
Morality	One's s willingness to follow moral norms.	CPSHS	X	Social morality (does he/she follow moral norms)	
Ability to adapt to the environment					
Social adaption	Ability to adapt to the social environment, to adapt to policies/regulation	CPH42, CPSHS, HSQ, SRHMS	X	Ability to adapt to the social environment (such as working environment,	

				living environment, social rules and regulations)	
Weather adaption	Adaptability to changes in seasons and weather	CHPRO, CHQOL, HSTCM, TCM50	X	Ability to adapt to weather changes	
	Fear of cold/hot weather	HSTCM, TCM50, TCMHSS			
	Adaptability to a noisy environment	HSTCM			
Susceptibility	Susceptibility to diseases	HSTCM	X	Body quality that can indicate susceptibility to diseases	
	Inherited body quality		X		
	Susceptibility to catch a cold	TCMHSS	X		
Breadth of mind	One's attitude to other people (e.g. being tolerant or narrow-minded to others)		X	"Breadth of mind" (such as being tolerant of other people or narrow-minded to other people)	
Optimism	Feeling optimistic/positive	HSTCM, QOLI, SRHMS	X	Life attitude towards life (such as viewing things optimistically or pessimistically)	
General health perceptions					
Overall health rating	Overall health status	HSTCM, QOL35, QOLI, SRHMS			Too general
Overall QoL	Overall QoL	CHPRO, QOL35, QOLI			Too general
Other					
Lifestyle	Diet habits	CPSHS, HSQ	X	1) Diet habits 2) regularity in daily life	
	Regularity in daily life	HSQ	X		
Family medical history	Family medical history	CPSHS	X	Family medical history (Whether his/her close relatives diagnosed with critical illnesses)	
Economic status	Economic status	CHPRO, QOL35, QOLI			Not considered as health dimensions defined in this thesis
Living environment	Living environment	QOL35, QOLI, SRHMS			Not considered as health dimensions defined in this thesis
Disease	Disease		X		Represented a broad range of sub-items and were too general compared to other health dimensions
Physical examination results	Physical examination results		X		Represented a broad range of sub-items and were too general

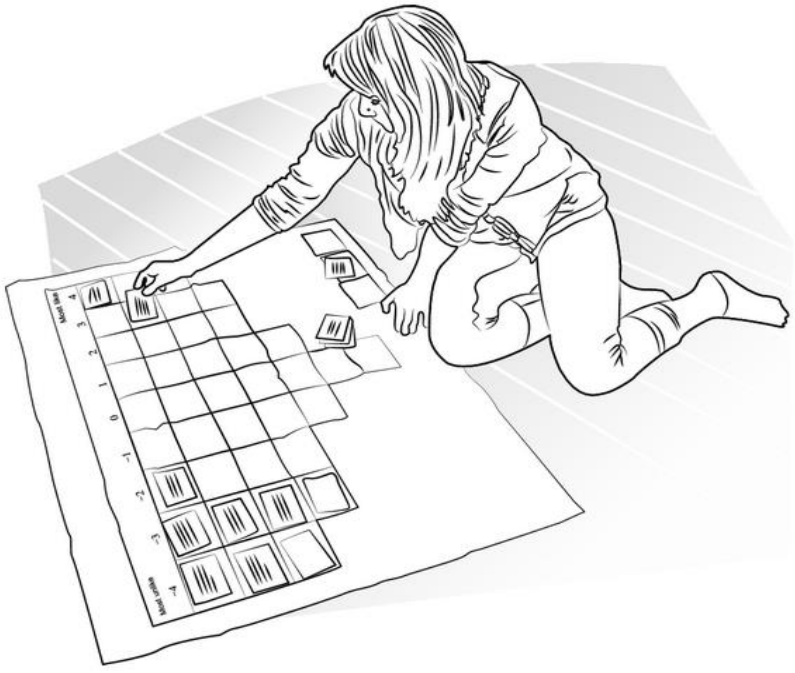
					compared to other health dimensions
Personality	Character flaws, problems in personality		X		Represented a broad range of sub-items and were too general compared to other health dimensions
	Positive personality including being friendly, generous, open-minded and brave		X		

Appendix VII: Feedback questionnaire on the Q-sample draft

意见与反馈 (with English translation)

您好，我是英国利兹大学健康科学院的博士研究生。我的博士研究课题想要探索中国人对于健康的理解：中国人是怎样看待健康的，在评价和描述自身健康状态的时候一般会考虑哪些方面。我的课题采用 Q 研究的方法收集数据， Q 研究会要求受试者按照指导语，将一系列卡片（Q 样本）进行排序。如下图所示，受试者会将每一个 Q 样本排列在事先设计好的表格里，按照最重要（5 分，最右列）到最不重要（-5 分，最左列）进行整理和排列。

Hello. I am a PhD student from the Leeds Institute of Health Sciences. I am in the process of designing a Q-sample for a Q-methodological study of people's preference for different health dimensions. A Q-sample consists of a set of statements about a topic, intended to broadly cover the range of things people within a particular community might think that are influential in judging their health. The research consists of printing statements onto small bits of paper and asking people to sort them along a scale from, say, +5 (most important) to -5 (least important). The diagram below shows somebody doing a Q-sort.



在课题的当前阶段，我仍在设计实验所需的 Q 样本。现有的 Q 样本初稿是从学术文献和质性采访中提取出来的，与健康相关的、关于生活某个方面的描述。设计 Q 样本的目的是想要尽可能广泛地囊括，中国人在评价自身健康状况时可能会提到的具体方面。

希望您可以帮忙读一读这份 Q 样本的草稿，并告诉我您的意见。在您的意见反馈里，我想要知道的是：

1. 它们通俗易懂吗？

我想要确保受试者能够清楚明白这些陈述的含义。您觉得这些陈述能被大多数人理解吗？您有没有发现有哪些陈述让您感到困惑，不太好理解。如果有的话，您觉得应该怎么去改善描述？

2. 它们有互相重复的吗？

我想要确保每一条陈述都是有独特性的陈述。您觉得有哪些陈述是非常相似或重复的？

3. 用于描述健康，它们完整吗？

我希望可以尽可能地涉及到人们在描述评价健康状况时会提到的具体东西，及确保没有遗漏任何重要的方面。在您看完这个 Q 样本之后，您觉得还有哪些健康相关的描述或陈述，是可以添加进样本的？如果可以的话，您能列出几条吗？文档的下一页就是 Q 样本的初稿。非常感谢您的反馈与帮助。祝您心情愉悦，健康幸福。

I have collected statements from various sources to use in the study. Most of the statements were from a scoping review study (reviewing those Chinese-developed Health-related quality of life questionnaires) and a qualitative study (asking lay people to talk about their understandings of health). I now need help to make sure the statements I have chosen will “work” in the study, and get together a comprehensive but manageable Q-sample for people to sort.

In your feedback, I am interested in three main things:

a) **Clarity** - I need to ensure that people find the statements easy to read, with words they understand. Please say if you find anything unclear, and do, if you can, suggest alternative wording that you think is clearer.

b) **Duplication** - I want to make sure each statement is different from all the others. Please indicate if any statements seem too much the same to you.

c) **Comprehensiveness** - I want to cover as many health dimensions as possible, and ensure that I have not missed something important. When you have looked at all of the statements on the list, if possible, please suggest other statements about the topic that are not on our list.

Please see the table from the next page and give me your feedback. I will be really grateful for your help. Do let me know too if you can think of somebody with really interesting ideas on this topic, different from yours, and ask them if it’s OK for me to contact them. Thanks for your help!

受访者会被问道：评判一个人的健康状况时，了解这个人的____有多重要？

Participants will be asked: When judging a person's health, how important is it to know about their _____?

受访者会对以下的陈述进行排序：Participants will then be given the following statements to rank：

	Chinese statements	English language equivalent	语义清晰，易懂吗？(如不，请标记 X) Clear or not? (If 'No', please mark with "x")	如果不清楚，是什么原因呢？应该怎样修改呢？ Reason/revisions/ any other comments
1	身体体质	Body constitution		
2	对天气变化的适应能力	Ability to adapt to weather changes		
3	身体体形	Body weight		
4	精神面貌	Spiritual appearance		
5	疲倦程度	Fatigue		
6	体力	Body strength		
7	面色	Facial complexion		
8	身体不舒服的感受	Physical discomfort		
9	生理上疼痛的感受	Physical pain		
10	胃口，食欲	Appetite		
11	精神的紧张感	Stress		
12	抑郁、心情低落的心理状态	Feeling of depression		
13	焦虑不安的心理状态	Feeling of anxiety		
14	情绪的平稳程度	Emotional stability		
15	脾气	Temper		
16	恐惧感	Feeling of fear		
17	孤独感	Feeling of loneliness		
18	自信心	Self-confidence		

19	睡眠的质量	Sleep quality		
20	行动能力	Ability to walk about		
21	处理日常活动的能力（如工作，学习，家务事）	Ability to perform usual activities		
22	视力	Vision		
23	听力	Hearing		
24	交流沟通的能力	Ability to communicate with people		
25	自理的能力（如自己给自己穿衣、洗澡）	Ability to take care of oneself		
26	日常生活对药物的依赖程度	Dependence on medication		
27	性生活	Sexual life		
28	清楚思考的能力，大脑清晰度	Ability to think things clearly		
29	反应力，对外部环境的变化敏捷作出反应的能力	Ability to be quick to perceive surrounding changes and respond		
30	记忆力，能记忆事物的能力	Ability to remember things		
31	决策力，需要做决定时的犹豫程度	Ability to make decisions		
32	注意力，集中精神的能力	Ability to concentrate on things		
33	社会关系的情况（比如家庭关系、与朋友的关系，与同事的关系等）	Social relations		
34	适应社会环境的能力（如适应工作、生活、学习环境，适应社会法律制度）	Ability to adapt to the social environment		

35	社会接触（比如参加社交活动的频率、与家人朋友联系的频率）	Social contacts		
36	社会支持（如家人、朋友的支持）	Social support		
37	公德心（行为是否遵从社会公德）	Social morality		
38	人生态度（比如对待生活是否积极乐观，做事积极或是消极）	Life attitude		
39	心胸（比如心胸宽广或是狭隘，是否对他人经常抱怨、耿耿于怀）相处	“Breadth of mind”		
40	生活习惯	Lifestyle habits		
41	生活的满足感	Sense of satisfaction with life		
42	家族疾病史（近亲属是否患有重大疾病）	Family medical history		

有哪些是相类似/重复的吗？ (Are there any statements that are similar?)

还可以添加哪些陈述吗？(If possible, please suggest other statements about the topic that are not on our list)

Appendix VIII: The instructions for the Q-sorting activity

Step one: Introduce the Q-sorting activity, when participants will be informed that:

- The statements on the cards are different health dimensions, which are those aspects of subjective experiences, feelings or perceptions that are relevant to health and can affect the quality of life.
- The interview would like to see how these dimensions are ranked by their importance levels according to individuals' personal preferences.
- There are no right or wrong answers. All views will all be respected.

Step two: Ask participants to sort the statements into three piles.

42 paper cards will be presented in front of participants, who will be asked to read each statement carefully and split them up to three piles:

- "a pile for statements that you think are most important"
- "a pile for statements that you think are least important"
- "a pile for the rest"

Step three: Ask participants to sort the cards in each pile.

Provide participants with a Q-Grid. In each Q-sorting interview, participants will be asked to sort the cards following the instructions below:

1. "Take the MOST IMPORTANT pile, and select the one statements which you think are MOST important and place them on the one box on the right side of the grid - above the '+5'."

2. "Take the remaining statements from your MOST IMPORTANT pile, select the two statements which you now think are MOST important and place them in the four boxes above the '+4'. (It does not matter which you place at the top or at the bottom)"

3. "Take the remaining statements from your MOST IMPORTANT pile, select the three statements which you now think are MOST important and place them in the four boxes above the '+3'. Proceed until all statements you think are

important have been placed on the grid. (It does not matter which you place at the top or at the bottom)"

3. "Take the LEAST IMPORTANT pile, and select the one statements which you think are least important and place them on the one box on the left side of the grid - above the '-5'."

4. "Take the remaining statements from your LEAST IMPORTANT pile, select the two statements which you now think are least important and place them in the four boxes above the '-4'. Proceed until all statements you think are least important have been placed on the grid."

5. "Take the remaining statements and place them in the remaining boxes on the grid, just like you feel it should be done."

Step four: Ask participants to check the sorted statements and take pictures.

Ask participants to check the sorted statements and make sure that they are happy with where they have placed the statements. Then take a picture of the Q-grid.

Step five: Ask participants to rank the statements one by one.

Ask participants to compare health statements in each column and rank them according to their importance levels. Remind participants that, "in each column, the statement above should be the one that is more important than the one below, according to your opinion". Statements will then be presented one by one from the most important one to the least important one. The ranking result will be recorded.

Step six: Conduct post-sorting interview. (Audio-record it with permission from participants)

Ask participants the following questions:

1) Why did you choose ___ as the most important statements? Why did you choose ___ as the least important statements? How did you understand those health statements that were chosen to be the most or least important?

2) How did you interpret Ability to walk about; Ability to perform usual activities; Feeling of discomfort; Feeling of pain; Feeling of depression; Feeling of anxiety (those health statements that were closely linked to the five dimensions in EQ-5D)? Why did you assign them to certain cells in the Q-sort grid?

3) When we are judging one's health, do you think there are additional important issues that are missing from these statements?

4) Are there any statements that you did not understand or you would like to comment on?

The Chinese version of the instructions:

第一步：排序实验的介绍

告知受访者以下信息：

- 卡片上是与健康相关的，对个人生活质量会或多或少产生影响的各个方面的描述。这些描述是个人的主观感受与认知，是个人评价自己健康状态时可能会涉及到的因素。例子："行动的能力"、"身体感受到的疼痛"、"焦虑的情绪"、"抑郁的情绪"、"疲惫困倦"、"食欲"、"睡眠"等等。
- 这项调查想要探寻受访者对于这些描述的重要性的认知。在受访者看来，哪些有关健康的方面是最重要，哪些是次要的。
- 答案没有对和错之分，所有的观点都是有价值且会被尊重的。

第二步：将所有的卡片分成三类

将一叠卡片摆在受访者面前，每一张卡片上是一个与健康相关的描述。受访者需要认真阅读每一张卡片，并将这些卡片分成三大类：

1）"您认为最重要的"

2）"您认为最不重要的"

3）"剩下的"

第三步：将卡片进行排序

受访者需要将卡片放进事先准备好的 Q 表格中：

1. 让受访者从"您认为最重要的"这类卡片中，选择出他/她认为最重要的一张卡片，并将它摆放在表格的最右端（+5）。

2. 让受访者从剩下的“最重要的”卡片中再选出两张最为重要的卡片，并放在表格右侧的第二栏里（+4）。重复这项步骤直到受访者认为的所有最重要的卡片都已经被放进表格中。

3. 让受访者从“您认为最不重要的”这类卡片中，选择出他/她认为最不重要的一张卡片，并将它们摆放在表格的最左端（-5）。

4. 接着，让受访者从剩下的“最不重要的”卡片中再选择出两张最不重要的卡片放进表格左侧的第二栏里（-4）。重复这项步骤直到受访者认为的所有最不重要的卡片都已经被放进表格中。

5. 之后，让受访者将剩余的卡片按照他认为的重要程度放进表格中的对应位置。

第四步：检查排序的结果

让受访者对表格里的排序结果进行检查，并让受访者确认这些卡片的排列顺序不需要其他更改，是他们最为满意的排序结果。将结果通过拍照的方式记录下来。

第五步：将卡片进行从最重要到最不重要的排序

受访者需要对同一重要等级的卡片进行排序。在表格的每一列里，把最重要的卡片放在上面，比较次要的放在下面。将结果通过拍照的方式记录下来。

第六步：进行排序后的采访

问题主要包括：

1） 为什么认为___卡片最重要/最不重要？您是怎样理解这几张卡片上的内容的？

2）您是怎样理解（走动，自理，一般活动，疼痛，不适，焦虑，抑郁）的？为什么认为它重要 / 不重要 / 一般？

3）您认为在评价健康的时候，还有哪些方面是您会关注但是却没有出现在这些卡片里的？

4）这些卡片中，有没有您认为不太容易理解的表述？

Appendix IX: The selection of factors for interpretation in the Q-study

Criteria are as follows:

1) Factors with an eigenvalue larger than 1.00

2) An interpretable factor must ordinarily have at least two sorts that load significantly upon on it alone.

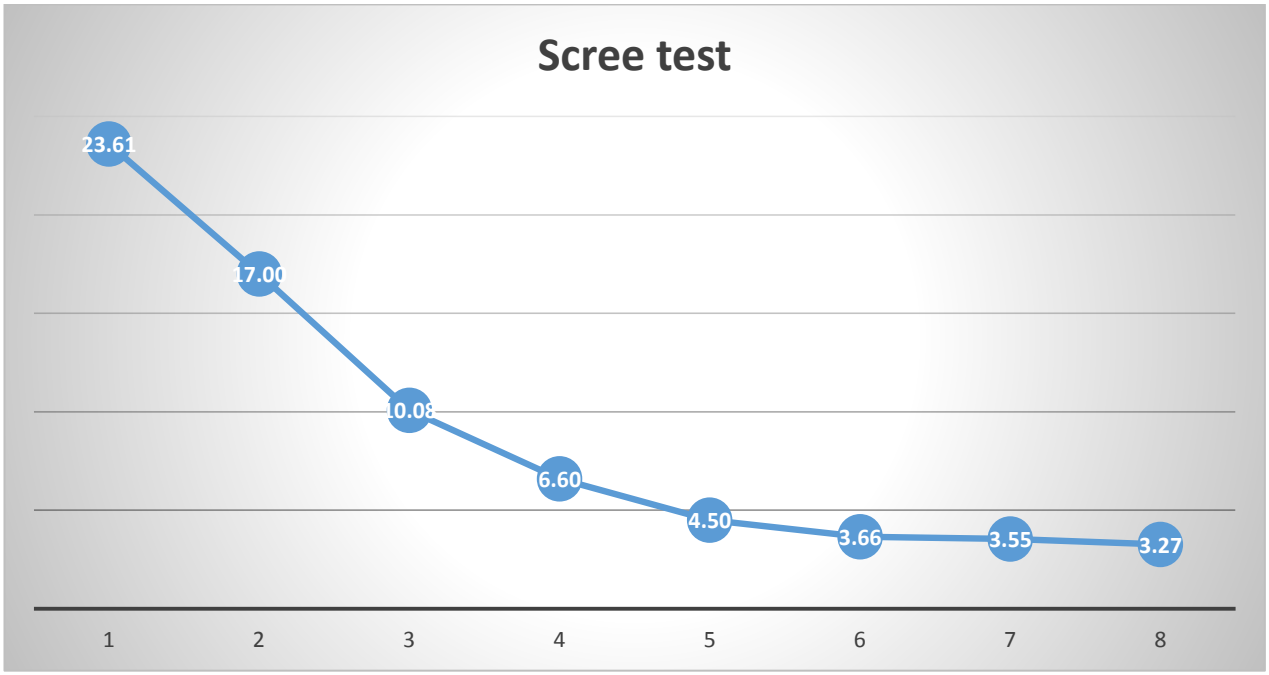
- unflag exemplars:

- loading on more than one factor with a difference of less than 0.1
- not loading significantly at at least P>0.01 (Loading significantly (P>0.01): $2.58 \times {}^{1}/_{\sqrt{42}}$ = 0.3981)
- loading on more than one factor at P>0.01

Eigenvalues and the percentage of the study variance explained by each factor

	1	2	3	4	5	6	7	8
Eigenvalues	23.6078	17.0046	10.0836	6.5963	4.4999	3.6605	3.5512	3.2734
% expl.var.	21	15	9	6	4	3	3	3

Scree test:



1) 8 rotated factors:

Factor Characteristics

	Factors							
	1	2	3	4	5	6	7	8
No. of Defining Variables	15	25	18	2	3	3	1	3
Average Rel. Coef.	0.800	0.800	0.800	0.800	0.800	0.800	0.800	0.800
Composite Reliability	0.984	0.990	0.986	0.889	0.923	0.923	0.800	0.923
S.E. of Factor Z-Scores	0.128	0.100	0.117	0.333	0.277	0.277	0.447	0.277

Correlations between factor scores:

Correlations Between Factor Scores

	1	2	3	4	5	6	7	8
1	1.0000	0.1074	0.2343	0.4091	0.4143	0.1682	0.2323	0.3139
2	0.1074	1.0000	0.3165	0.2479	0.0411	0.2145	-0.1545	0.1348
3	0.2343	0.3165	1.0000	0.1484	-0.0149	-0.0470	0.1744	0.1665
4	0.4091	0.2479	0.1484	1.0000	0.0829	-0.0704	0.1214	0.1022
5	0.4143	0.0411	-0.0149	0.0829	1.0000	0.3197	0.1454	0.3402
6	0.1682	0.2145	-0.0470	-0.0704	0.3197	1.0000	-0.1699	0.0383
7	0.2323	-0.1545	0.1744	0.1214	0.1454	-0.1699	1.0000	0.2399
8	0.3139	0.1348	0.1665	0.1022	0.3402	0.0383	0.2399	1.0000

Factor 7 has one exemplar f64_106. The participant ranked social morality and breadth of mind as the most important items and care most about life regularity and diet habits. Her view and explanation can be captured in other factors: factor 4 values life activities most, factor 1 values self-confidence and breadth of mind.

Factor 8 has three exemplars: f30_20, f69_27, m40_42

2) 7 rotated factors:

Factor Characteristics

	Factors						
	1	2	3	4	5	6	7
No. of Defining Variables	20	26	14	3	2	4	2
Average Rel. Coef.	0.800	0.800	0.800	0.800	0.800	0.800	0.800
Composite Reliability	0.988	0.990	0.982	0.923	0.889	0.941	0.889
S.E. of Factor Z-Scores	0.111	0.098	0.132	0.277	0.333	0.243	0.333

Correlations Between Factor Scores

	1	2	3	4	5	6	7
1	1.0000	0.1266	0.2038	0.3576	0.2954	0.2320	0.3188
2	0.1266	1.0000	0.3172	0.2559	0.1045	0.3000	-0.1688
3	0.2038	0.3172	1.0000	0.2632	0.1862	0.0282	0.2015
4	0.3576	0.2559	0.2632	1.0000	0.1016	-0.1237	-0.0103
5	0.2954	0.1045	0.1862	0.1016	1.0000	0.0924	0.2541
6	0.2320	0.3000	0.0282	-0.1237	0.0924	1.0000	0.1946
7	0.3188	-0.1688	0.2015	-0.0103	0.2541	0.1946	1.0000

- unflag exemplars:

- loading on more than one factor with a difference of less than 0.1 (…) total unflagged = 0
- not loading significantly at at least P>0.01 (…) total unflagged = 0
- loading on more than one factor at P>0.01, 0.3981 (…) total unflagged = 3 (f37_44 on factor 7; f41_55 on factor 2; m65_99 on factor 1)

After unflagging:

Correlations Between Factor Scores

	1	2	3	4	5	6	7
1	1.0000	0.1120	0.2011	0.3310	0.3036	0.2389	0.3630
2	0.1120	1.0000	0.3196	0.2402	0.1063	0.3078	-0.2049
3	0.2011	0.3196	1.0000	0.2632	0.1862	0.0282	-0.1430
4	0.3310	0.2402	0.2632	1.0000	0.1016	-0.1237	0.0659
5	0.3036	0.1063	0.1862	0.1016	1.0000	0.0924	0.3008
6	0.2389	0.3078	0.0282	-0.1237	0.0924	1.0000	0.2741
7	0.3630	-0.2049	-0.1430	0.0659	0.3008	0.2741	1.0000

Factor Characteristics

	Factors						
	1	2	3	4	5	6	7
No. of Defining Variables	19	25	14	3	2	4	1
Average Rel. Coef.	0.800	0.800	0.800	0.800	0.800	0.800	0.800
Composite Reliability	0.987	0.990	0.982	0.923	0.889	0.941	0.800
S.E. of Factor Z-Scores	0.114	0.100	0.132	0.277	0.333	0.243	0.447

Factor 7 has one exemplar m24_68, who valued life attitude and self-confidence most (as factor 1 does) and valued vision and hearing. His explanation that “work is important and those abilities, especially abilities relevant to work are the most important dimensions” can be very similar to those views represented in factor 1 and factor 5.

3) 6 rotated factors:

Factor Characteristics

	Factors					
	1	2	3	4	5	6
No. of Defining Variables	15	28	16	6	3	3
Average Rel. Coef.	0.800	0.800	0.800	0.800	0.800	0.800
Composite Reliability	0.984	0.991	0.985	0.960	0.923	0.923
S.E. of Factor Z-Scores	0.128	0.094	0.124	0.200	0.277	0.277

Factor 6 has 2 negative exemplars

Factor 2 has m30_72 as a negative exemplar

Correlations Between Factor Scores

	1	2	3	4	5	6
1	1.0000	0.1069	0.2118	0.4263	0.4319	-0.1003
2	0.1069	1.0000	0.2688	0.2141	0.0125	0.2852
3	0.2118	0.2688	1.0000	0.2916	-0.0069	-0.2429
4	0.4263	0.2141	0.2916	1.0000	0.1508	-0.2328
5	0.4319	0.0125	-0.0069	0.1508	1.0000	0.0629
6	-0.1003	0.2852	-0.2429	-0.2328	0.0629	1.0000

- unflag exemplars:

- loading on more than one factor with a difference of less than 0.1 (…) total unflagged = 07
- not loading significantly at at least P>0.01 (…) total unflagged = 0
- loading on more than one factor at P>0.01, 0.3981 (…) total unflagged = 7 (m29_18 on factor 2, f70_31 on factor 2, m24_41 on factor 5, f41_55 on factor 2, m76_95 on factor 3, m65_99 on factor 4)

Factor Characteristics

	Factors					
	1	2	3	4	5	6
No. of Defining Variables	15	25	15	5	2	3
Average Rel. Coef.	0.800	0.800	0.800	0.800	0.800	0.800
Composite Reliability	0.984	0.990	0.984	0.952	0.889	0.923
S.E. of Factor Z-Scores	0.128	0.100	0.128	0.218	0.333	0.277

Factor 6 has 2 negative exemplar (f64_106, m27_22), one positively significant exemplar (m29_25)

m27_22 gets a very similar view and explanation held by factor 4 (it actually became an exemplar when extracting five factors), f64_106 was previously identified as an only exemplar for Factor 7 when extracting eight factors, this participant's view has been discussed that it could be captured in other extracted factors. m29_25's view could be captured in factor 2 and 1 (it actually became an exemplar for factor 2 when extracting five factors)

Factor 2 has m30_72 as a negative exemplar

Correlations Between Factor Scores

	1	2	3	4	5	6
1	1.0000	0.1105	0.1916	0.3287	0.3468	-0.1003
2	0.1105	1.0000	0.2954	0.1675	-0.0882	0.2822
3	0.1916	0.2954	1.0000	0.2924	-0.0249	-0.2370
4	0.3287	0.1675	0.2924	1.0000	0.1376	-0.2495
5	0.3468	-0.0882	-0.0249	0.1376	1.0000	-0.0054
6	-0.1003	0.2822	-0.2370	-0.2495	-0.0054	1.0000

4) 5 rotated factors:

Factor Characteristics

	Factors				
	1	2	3	4	5
No. of Defining Variables	19	28	18	7	5
Average Rel. Coef.	0.800	0.800	0.800	0.800	0.800
Composite Reliability	0.987	0.991	0.986	0.966	0.952
S.E. of Factor Z-Scores	0.114	0.094	0.117	0.186	0.218

Enough exemplars for each factor

Factor 2 has m30_72 as a negative exemplar

Correlations Between Factor Scores

	1	2	3	4	5
1	1.0000	0.1261	0.2354	0.3852	0.4492
2	0.1261	1.0000	0.3243	0.1495	0.0852
3	0.2354	0.3243	1.0000	0.3413	0.0299
4	0.3852	0.1495	0.3413	1.0000	0.0897
5	0.4492	0.0852	0.0299	0.0897	1.0000

- unflag exemplars:

- loading on more than one factor with a difference of less than 0.1 (…) total unflagged = 0 (f69_27 on factor 2)
- not loading significantly at at least P>0.01 (…) total unflagged = 0
- loading on more than one factor at P>0.01, 0.3981 (…) total unflagged =6 (f49_10 on factor 2, f43_17 on factor 4, f70_31 on factor 2, m24_41 on factor 5, m67_91 for factor 3, m64_92 for factor 3)

Correlations Between Factor Scores

	1	2	3	4	5
1	1.0000	0.0946	0.2141	0.3233	0.3882
2	0.0946	1.0000	0.3264	0.1514	-0.0130
3	0.2141	0.3264	1.0000	0.3174	0.0164
4	0.3233	0.1514	0.3174	1.0000	0.0644
5	0.3882	-0.0130	0.0164	0.0644	1.0000

Enough exemplars for each factor

Factor 2 has m30_72 as a negative exemplar

Factor Characteristics

	Factors				
	1	2	3	4	5
No. of Defining Variables	19	25	16	6	4
Average Rel. Coef.	0.800	0.800	0.800	0.800	0.800
Composite Reliability	0.987	0.990	0.985	0.960	0.941
S.E. of Factor Z-Scores	0.114	0.100	0.124	0.200	0.243

Appendix X: Poster – a Pilot study on testing the appropriateness of the translated version of EQ-5D dimensions in the Chinese language

Pilot Study on Testing the Appropriateness of the Translated Version of EQ-5D Dimensions in Chinese Language

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Background:

EQ-5D has been translated into various languages using a standardised protocol that involves a forward/backward translation process and cognitive briefing. Although several studies have been conducted to test the validity of the Chinese version of EQ-5D[1],[2],[3], few mention the appropriateness of wordings and concepts of translated versions when used outside Europe.

In population studies, high numbers (>80%) of respondents report having no problem[4]. China's culture is different from the West; whether the translated five dimensions of EQ-5D are consistent with a common understanding in China when describing health status, should always be doubted.

Objectives:

This pilot study was designed to judge the appropriateness of the translated EQ-5D dimensions in Chinese language. More specifically, it aims to test:

1) if there are alternative Chinese phrases that better represent the five dimensions

2) the suitability of EQ-5D for application in a Chinese culture setting.

Methods:

A number of bilingual (Mandarin/English) Chinese people living in Leeds were invited to attend a face-to-face interview. Each candidate was asked to complete tasks separately.

1) They were given the title headings for each dimension in the EQ-5D-3L (English version); they were told that the headings stand for five dimensions of health.

2) They were then asked to interpret and translate these words from English to Chinese.

3) They were shown the official Chinese translated version of each dimension and were invited to compare their answers with the official translated version and to provide comments regarding the translation and its meaning.

Results:

1) Some participants interpreted the order of the five dimensions as a hierarchy system with an order taking each dimension forward one by one, to a higher requirement of health. Figure 1 draws the hierarchy system of EQ-5D described by several participants.

2) Only a few English/Chinese translations were identical with the official translated version. The English wording of each dimension in EQ-5D is not represented by one single Chinese phrase. At least five different Chinese phrases were found for each dimension. Table on the right-hand side summarises Chinese phrases collected for each title of dimension.

3) Subject headings like 'mobility' and 'self-care' were difficult for some respondents to find appropriate translation in Chinese, even though they could comprehend these two words' meaning well in English.

Summary:

This pilot study indicates the necessity of a more thorough testing of the linguistics and concepts of the translated EQ-5D in Chinese:

1) The variation in Chinese characters provided by participants illustrates the possibility of finding alternative translation versions that can define the five dimensions better.

2) The difficulty of understanding some labels in EQ-5D as a health dimension shows that a cultural difference in defining health might exist between China and western countries.

The study only recruited young mandarin speakers who know English well and this can be one of its limitations. More work needs to be done to understand how ordinary Chinese population define health in order to develop a more appropriate descriptive system for them to measure health status.

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Figure 1:
Understood EQ-5D as a hierarchy system

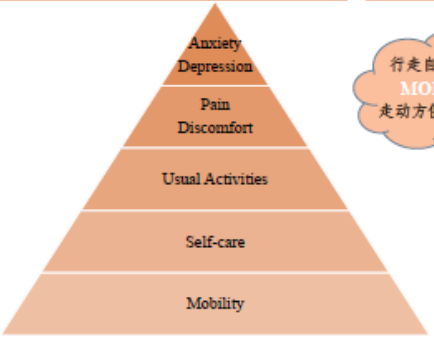

Figure 2: Different Chinese phrases can present one word 'Mobility'

Table: Chinese translation collected

Original Version	Official translation	Answers Collected with backward translation
Mobility	行动	灵动: can move alertly and flexibly; smart and intelligent 行动: move about, get about; take actions 灵活性: flexibility, agility 活动性: the ability to move around; activity 能动性: activeness; dynamic role; human's initiative in social life 行走自如: can walk freely/normally/comfortably 走动方便: walk around conveniently/easily
Self-care	自己照顾自己	自顾: care for oneself; think about oneself 自理: take care of oneself; self-maintenance; the ability to conduct one's own basic daily activities 可自理: be able to take care of oneself 自我照顾: care for oneself 自我照料: care for oneself 自我保养: maintain one's own health condition 自我关怀: care for oneself (more often in the mental aspect)
Usual Activities	日常活动	通常活动: activities that are customary/accustomed to one individual 日常活动: daily activities 寻常活动: activities that are ordinary/common/not special 平常活动: activities that are ordinary/common in everyday life 惯常活动: activities that one individual gets used to
Pain/ Discomfort	疼痛 / 不舒服	Pain: 痛: physically feeling painful 疼痛: physically feeling painful (the two Chinese characters "疼" and "痛" have the same meaning) 痛苦: bitter, miserable, grieved feeling (can be mentally) 难受: feeling ill/unhappy/uncomfortable 痛痒: feeling painful and itchy Discomfort: 不适: feeling unwell/uncomfortable 不舒服: feeling unwell/uncomfortable 不舒适: not cozy/uncomfortable/unpleasant 不安: feeling uneasy/unstable/anxious
Anxiety/ Depression	焦虑 / 抑郁	Anxiety: 忧虑: feeling worried; fear 焦虑: feeling worried; a mental disorder 不安: feeling uneasy/unstable/anxious 担心: be worried about; be afraid of 焦躁: feeling impatient; restless; fretful 紧张: feeling nervous; stressful; tension Depression 抑郁: feeling despondent/gloomy; a type of mental illness 忧郁: melancholy; feeling dejected 沮丧: feeling dispirited/disappointed/disheartened; dismay 消沉: feeling downhearted; low-spirited

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Appendix XI: Loadings of the 110 Q-sorts on the five factors

	Participant	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
1	f28_1	-0.2105	0.7963X	0.0517	0.0257	0.0055
2	f50_2	0.3317	0.3374	0.2909	-0.1610	0.0743
3	m25_3	0.4159	-0.4932	0.4052	0.0049	0.3217
4	m29_4	-0.4328	0.5162	0.4412	0.1217	0.1380
5	f32_5	0.1968	0.7481X	-0.0162	-0.2460	0.2596
6	m28_6	-0.0231	0.0494	0.6156X	0.2488	-0.1768
7	m27_7	-0.4599	0.4042	0.4913	-0.1024	0.0510
8	f83_8	0.5759X	0.2482	0.1004	-0.2067	-0.2342
9	m23_9	0.0876	0.3362	0.6611X	0.0614	0.1440
10	f49_10	0.4032	0.6766	-0.0948	-0.0673	0.2056
11	m25_11	0.1327	0.6916X	0.2123	-0.2772	-0.1508
12	f25_12	-0.0260	0.1719	0.6722X	0.0629	0.1543
13	m50_13	0.2162	0.1195	-0.0810	0.6233X	0.0007
14	m48_14	0.0255	0.0693	0.3542	0.5838X	-0.0018
15	m46_15	0.3904	-0.3428	-0.0615	0.3728	0.2714
16	m51_16	-0.2961	0.4874	0.2696	0.2938	0.1513
17	f43_17	0.4850	0.0142	0.0861	0.5137	-0.0651
18	m29_18	0.4227	-0.6003	0.2967	-0.0741	0.3151
19	m46_19	0.4745	-0.4630	0.2704	-0.0827	0.1421
20	f30_20	0.2656	-0.1077	0.2321	0.1077	0.4168X
21	f43_21	0.7466X	-0.0734	0.3236	-0.0129	-0.0756
22	m27_22	-0.0782	-0.0660	0.1671	0.4948X	0.0025
23	f48_23	0.3474	0.6268X	0.0210	0.1922	0.2171
24	f41_24	-0.1302	-0.3036	0.6069	-0.3838	0.4079
25	m29_25	0.2715	0.4709X	-0.1247	-0.2636	-0.0307
26	m75_26	0.4795	0.1922	0.0268	0.4376	0.2432
27	f69_27	0.1284	0.3496	-0.1452	0.0795	0.2700
28	m67_28	0.2641	0.1588	-0.1295	0.0753	0.1604
29	f66_29	0.7158X	0.0911	0.0630	0.2668	0.0278
30	f62_30	-0.1661	0.6728X	0.2712	0.0776	0.0745
31	f70_31	0.4443	0.6231	-0.0221	-0.0974	0.0619
32	f54_32	0.2001	0.6757X	0.0675	0.2202	0.2265
33	m47_33	0.4917	0.3576	-0.2279	0.3259	0.2243
34	f51_34	0.2054	-0.1875	0.6220X	0.1154	0.2788
35	f26_35	0.6131X	-0.3164	0.2400	0.0113	0.0897
36	m49_36	0.4670	0.5247	-0.1711	0.3110	0.2340
37	f46_37	0.4766X	-0.1484	-0.1310	0.2562	0.3328
38	f63_38	0.0767	0.6510X	-0.0452	0.0539	0.1216
39	f75_39	0.7793X	-0.0898	-0.2490	0.1697	-0.0644
40	f31_40	-0.0495	-0.0796	0.6461X	-0.2120	-0.2320
41	m24_41	0.4153	0.2430	-0.0994	-0.0385	0.6255
42	m40_42	-0.0209	0.2193	0.0328	0.2719	0.5230X
43	m40_43	0.4453	-0.1878	0.4256	0.5255	0.0595
44	f37_44	0.1287	-0.2211	0.5288	-0.1215	0.4549
45	f39_45	0.5343	-0.5124	0.3899	0.0009	0.1027
46	f42_46	0.2243	0.6411X	0.1998	0.2555	-0.2051
47	m41_47	0.2928	0.1820	0.3939	0.3893	0.4326
48	m54_48	0.5376X	-0.2174	0.0829	0.1565	0.1731
49	m52_49	0.0829	0.3148	-0.0890	0.6320X	0.0202
50	f23_50	-0.2165	0.3232	0.6055X	0.1664	-0.0460
51	f66_51	0.0755	0.3719	0.4624	0.4098	-0.2595
52	m70_52	0.0541	0.0230	0.2986	0.5852X	0.0470
53	f32_53	0.1792	-0.0684	0.5941X	0.3177	-0.3119
54	m41_54	0.6283X	0.0715	0.3152	-0.0602	0.1458

55	f41_55	-0.0008	0.6484X	-0.0369	0.5142	-0.1970
56	f28_56	0.2650	0.2998	0.1823	-0.3063	0.4480
57	m46_57	-0.2584	0.4288	0.3775	0.1344	-0.1353
58	m40_58	0.0010	0.2682	0.4407X	-0.0896	-0.0092
59	m29_59	-0.0853	0.0579	0.7895X	0.0454	0.0954
60	f28_60	0.6052X	0.2848	-0.0607	-0.0063	0.0971
61	f40_61	-0.4071	0.3952	0.2327	-0.0626	0.3740
62	m65_62	0.3072	-0.2823	-0.0069	0.5554X	-0.1587
63	f68_63	0.5266X	0.1096	0.1229	0.4083	-0.0316
64	m36_64	0.1453	0.2138	0.4707	0.5032	0.2742
65	m39_65	0.0798	-0.1913	0.6713X	0.0161	0.0105
66	f31_66	0.8478X	-0.0484	-0.0066	0.1838	0.1322
67	m26_67	0.0366	0.3602	0.0646	-0.1338	0.4150X
68	m24_68	0.3054	-0.2350	-0.1574	0.0066	0.7254X
69	f26_69	0.0555	0.5758X	0.2199	0.2952	0.3224
70	f27_70	0.0419	0.7276X	0.3938	-0.1413	-0.3058
71	m28_71	0.3170	0.2303	0.4804X	0.1695	0.1495
72	m30_72	0.2292	-0.5814X	0.1133	0.2943	0.2915
73	m48_73	0.4004	-0.2562	0.4999	0.3615	0.0859
74	m46_74	0.2751	0.1926	0.4675	0.4024	0.0459
75	m53_75	0.4964	0.0729	0.5325X	0.1508	-0.0928
76	f27_76	-0.0074	0.8812X	0.0052	-0.1164	-0.2349
77	m28_77	-0.3592	0.6569X	0.3501	-0.0192	0.2677
78	m24_78	-0.4636	0.6618X	0.3137	0.1510	0.0932
79	m29_79	0.2802	0.2505	0.4491	-0.1969	0.4305
80	m26_80	0.2254	0.2624	0.6120X	0.0909	0.0348
81	m23_81	-0.2442	0.7589X	0.3300	0.2544	0.0302
82	f26_82	0.1186	0.6423X	0.3509	-0.1563	-0.0387
83	f29_83	0.4671	-0.0615	0.5075	-0.1922	-0.0712
84	m34_84	0.2500	0.0648	0.5687X	0.1485	0.2236
85	m25_85	0.5917X	0.1559	0.1588	0.0434	0.3487
86	f27_86	-0.0402	0.1591	0.7870X	0.2112	-0.1091
87	f85_87	0.0342	0.7081X	0.1821	0.0102	-0.0984
88	f60_88	0.4244	0.2693	0.3495	-0.1297	0.3184
89	f56_89	0.5128X	0.0971	0.2096	-0.4034	0.1792
90	f64_90	0.6997X	0.1497	0.1332	0.1997	0.1906
91	m67_91	0.0809	0.0167	0.5578	0.4794	0.2671
92	m64_92	0.3233	0.3985	0.5563	0.1404	0.0112
93	m37_93	-0.1494	0.7169X	0.1346	0.1122	0.0911
94	f68_94	0.3864	0.0399	0.2213	0.3836	0.1178
95	m76_95	0.3792	-0.0556	0.5052	0.1833	0.3030
96	f80_96	0.6019X	0.3977	-0.0951	0.2987	-0.1681
97	f53_97	0.4117	0.0224	0.4421	-0.0505	0.3005
98	m55_98	0.7423X	-0.1497	0.0601	0.2453	0.2169
99	m65_99	0.5819	0.2207	0.0226	0.5765	-0.0337
100	f65_100	0.1814	0.6952X	-0.0486	0.3560	0.1547
101	f60_101	0.2309	0.8238X	0.2046	0.2641	0.0118
102	f66_102	-0.0008	0.7353X	0.0663	0.1430	0.0331
103	m61_103	0.0110	0.3207	0.7279X	0.2555	-0.2090
104	m53_104	0.7009X	0.1680	0.1884	0.0060	0.2448
105	m66_105	-0.0145	0.6428X	-0.0257	-0.1979	0.1774
106	f64_106	0.1933	-0.2306	0.1411	0.3010	0.0544
107	m84_107	0.4948X	-0.0380	0.0867	0.3406	-0.0832
108	m63_108	0.5257X	0.1113	0.0540	0.1603	0.3473
109	f67_109	0.3372	0.7521X	0.0882	-0.0816	0.0977
110	f48_110	0.4620	-0.0090	0.2169	0.6084	0.4369

“X” indicates those participants with Q-sorts loading +0.4 ($p < 0.01$) on one factor only.

Appendix XII: Demographic information of the 40 participants whose Q-sorts were not used to form any of the five factors

			%
Gender	Male	23	57.5%
	Female	17	42.5%
Age	<40	11	27.5%
	40-60	18	45.0%
	60+	11	27.5%
	(Mean age)	48	
Education background	Under high school	7	17.9%
	High school	6	15.4%
	Secondary	6	15.4%
	College	7	17.9%
	University	13	33.3%
EQ-5D state	11111	15	37.5%
	11112	8	20.0%
	11121	6	15.0%
	11122	5	12.5%
	Other	6	15.0%
VAS score	80-100	27	67.5%
	60-80	12	30.0%
	<60	1	2.5%
Residence place	City	23	57.5%
	Non-city	17	42.5%
Region	Southwest China	22	52.5%
	East China	13	32.5%
	North China	3	7.5%
	Other	3	7.5%

Appendix XIII: Q-grids for the five extracted factors

Factor one

					39 Regularity in daily life					
					22 Vision					
				7 Body strength of doing things	10 Desire of having food	33 State of social relations				
			8 Feeling of discomfort	31 Ability to make decisions	32 Ability to concentrate	36 Social morality	1 Body quality that can indicate the susceptibility to disease			
			12 Feeling of depression	11 Feeling of pressure	29 Ability to perceive changes in surrounding and to respond	24 Ability to communicate with people	38 "Breadth of mind"			
		2 Ability to adapt to weather changes	5 Natural colour and appearance of face	6 Feeling of tiredness	35 Support from one's social network	41 Sense of satisfaction with life	28 Ability to think things clearly	20 Ability to walk about		
	27 State of sex life	26 Dependence on medication	14 Tendency of being angry	9 Feeling of pain	23 Hearing	19 Sleep quality	4 Spiritual appearance	34 Ability to adapt to the social environment	21 Ability to perform usual activities	
15 Feeling of fear	42 Family medical history	16 Feeling of loneliness	3 Body weight	13 Feeling of anxiety	40 Diet habits	30 Ability to remember things	18 Ability to remain stable and peaceful in mood	17 Self-confidence	37 Life attitude	25 Ability to wash and dress oneself

Factor Two

					23 Hearing					
					13 Feeling of anxiety					
				30 Ability to remember things	3 Body weight	39 Regularity in daily life				
			15 Feeling of fear	32 Ability to concentrate	28 Ability to think things clearly	6 Feeling of tiredness	8 Feeling of discomfort			
			27 State of sex life	14 Tendency of being angry	40 Diet habits	26 Dependence on medication	10 Desire of having food			
		34 Ability to adapt to the social environment	24 Ability to communicate with people	2 Ability to adapt to weather changes	29 Ability to perceive changes in surrounding and to respond	22 Vision	4 Spiritual appearance	19 Sleep quality		
	33 State of social relations	38 "Breadth of mind"	17 Self-confidence	37 Life attitude	11 Feeling of pressure	12 Feeling of depression	7 Body strength of doing things	21 Ability to perform usual activities	20 Ability to walk about	
36 Social morality	31 Ability to make decisions	35 Support from one's social network	16 Feeling of loneliness	41 Sense of satisfaction with life	18 Ability to remain stable and peaceful in mood	5 Natural colour and appearance of face	42 Family medical history	1 Body quality that can indicate the susceptibility to disease	9 Feeling of pain	25 Ability to wash and dress oneself
-5 Least important	-4	-3	-2	-1	0	+1	+2	+3	+4	+5 Most important

Factor Three

-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
					14 Tendency of being angry					
					26 Dependence on medication					
				24 Ability to communicate with people	33 State of social relations	38 "Breadth of mind"				
			5 Natural colour and appearance of face	20 Ability to walk about	7 Body strength of doing things	41 Sense of satisfaction with life	11 Feeling of pressure			
			16 Feeling of loneliness	28 Ability to think things clearly	34 Ability to adapt to the social environment	42 Family medical history	13 Feeling of anxiety			
		31 Ability to make decisions	15 Feeling of fear	35 Support from one's social network	21 Ability to perform usual activities	6 Feeling of tiredness	9 Feeling of pain	12 Feeling of depression		
	27 State of sex life	30 Ability to remember things	32 Ability to concentrate	36 Social morality	10 Desire of having food	17 Self-confidence	40 Diet habits	39 Regularity in daily life	37 Life attitude	
22 Vision	23 Hearing	2 Ability to adapt to weather changes	29 Ability to perceive changes in surrounding and to respond	3 Body weight	25 Ability to wash and dress oneself	18 Ability to remain stable and peaceful in mood	8 Feeling of discomfort	19 Sleep quality	4 Spiritual appearance	1 Body quality that can indicate the susceptibility to disease

Least important — Most important

Factor Four

-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
					18 Ability to remain stable and peaceful in mood					
					22 Vision					
				6 Feeling of tiredness	28 Ability to think things clearly	5 Natural colour and appearance of face				
			35 Support from one's social network	34 Ability to adapt to the social environment	8 Feeling of discomfort	23 Hearing	30 Ability to remember things			
			13 Feeling of anxiety	7 Body strength of doing things	36 Social morality	33 State of social relations	32 Ability to concentrate			
		25 Ability to wash and dress oneself	27 State of sex life	14 Tendency of being angry	3 Body weight	38 "Breadth of mind"	37 Life attitude	1 Body quality that can indicate the susceptibility to disease		
	20 Ability to walk about	12 Feeling of depression	21 Ability to perform usual activities	29 Ability to perceive changes in surrounding and to respond	41 Sense of satisfaction with life	24 Ability to communicate with people	17 Self-confidence	4 Spiritual appearance	19 Sleep quality	
15 Feeling of fear	16 Feeling of loneliness	11 Feeling of pressure	26 Dependence on medication	2 Ability to adapt to weather changes	42 Family medical history	31 Ability to make decisions	9 Feeling of pain	10 Desire of having food	39 Regularity in daily life	40 Diet habits

Least important

Most important

Factor Five

-5 Least important	-4	-3	-2	-1	0	+1	+2	+3	+4	+5 Most important
					31 Ability to make decisions					
					24 Ability to communicate with people					
				16 Feeling of loneliness	27 State of sex life	36 Social morality				
			8 Feeling of discomfort	42 Family medical history	25 Ability to wash and dress oneself	29 Ability to perceive changes in surrounding and to respond	28 Ability to think things clearly			
			33 State of social relations	3 Body weight	4 Spiritual appearance	13 Feeling of anxiety	17 Self-confidence			
		10 Desire of having food	35 Support from one's social network	14 Tendency of being angry	19 Sleep quality	30 Ability to remember things	20 Ability to walk about	1 Body quality that can indicate the susceptibility to disease		
	5 Natural colour and appearance of face	41 Sense of satisfaction with life	26 Dependence on medication	34 Ability to adapt to the social environment	12 Feeling of depression	39 Regularity in daily life	7 Body strength of doing things	38 "Breadth of mind"	23 Hearing	
2 Ability to adapt to weather changes	40 Diet habits	9 Feeling of pain	6 Feeling of tiredness	21 Ability to perform usual activities	15 Feeling of fear	18 Ability to remain stable and peaceful in mood	32 Ability to concentrate	11 Feeling of pressure	37 Life attitude	22 Vision