Universidade Nova de Lisboa

Instituto de Higiene e Medicina Tropical

THE CHRONIC CARE MODEL USE IN THE EMIRATE OF ABU DHABI HEALTH SYSTEM: IS IT ENOUGH TO ADDRESS THE GROWING PROBLEM OF CHRONIC DISEASES?

MARÍLIA RAQUEL BETTENCOURT SILVA PAULO

DISSERTAÇÃO PARA A OBTENÇÃO DO GRAU DE DOUTOR EM SAÚDE INTERNACIONAL ESPECIALIDADE EM POLÍTICAS DE SAÚDE E DESENVOLVIMENTO

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The Chronic Care Model use in the emirate of Abu Dhabi Health System: Is it enough to address the growing problem of chronic diseases?

Autor: Marilia Raquel Bettencourt Silva Paulo

MSc

Orientador: Doutor Luis Velez Lapão

Co-orientador: Doutor Tom Loney

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Dedication

To my dad, to whom I dedicate this work.

Acknowledgements

To Professor Luís, who said that moving from one country to the other was not an obstacle and always believed that we would find a local co-supervisor.

To Dr Tom, who answered my e-mail and made a partnership between colleagues possible taking me into his own research group.

To IHMT colleagues, for all the good moments that we had in the first academic year.

To IPH colleagues, for all the support.

Resumo

Abu Dhabi é a capital dos Emirados Árabes Unidos e o maior emirado em termos de área e população. Os emirados árabes unidos tem um elevado índice de morbilidade e mortalidade relacionados com as doenças crónicas. Para abordar o crescente problema das doenças não comunicáveis, o Modelo de Doença Crónica (CCM) tem a intenção de ter cuidados diários baseados na população, com intervenções de equipa estruturadas e planeadas; com o objectivo de converter a vida dos doentes crónicos de reactiva a proactiva. O modelo integra seis elementos para facilitar uma qualidade elevada dos cuidados.

Objectivos

Esta tese tem como objectivo explorar o sistema de saúde de Abu Dhabi usando a abordagem do CCM para melhorar e desenvolver a prestação de cuidados a pessoas com doenças crónicas.

Foram desenhados quatro objectivos específicos:

- Caracterizar os serviços de saúde do emirado de Abu Dhabi;
- Analisar o alinhamento dos serviços de saúde com o CCM, identificando as principais lacunas;
- Explorer a percepcão dos profissionais de saúde sobre o nível de integração do CCM nos cuidados diários a doentes com diabetes, doenças cardiovasculares e cancro;
- Priorizar os subcomponentes e as barreiras para o desenvolvimento do CCM no sistema de saúde do emirado de Abu Dhabi.

Métodos

Para operacionalizar os objectivos foi desenhado um estudo com três componentes distintas:

- Revisão sistemática da literatura usando o CCM como uma *framework* para explorar a sua implementação e desenvolvimento nos cuidados de saúde primários;

- Estudo transversal misto para recolher informações sobre a percepção dos profissionais de saúde sobre os cuidados diários a doentes crónicos;
- Painel Delphi utilizado para ordenar as prioridades e barreiras da implementação e desenvolvimento do CCM.

Resultados

As clinicas que prestam cuidados de saúde primários adotaram os princípios do modelo *Patient-centered medical home*, que está alinhado com o CCM. Parece que existe um esforço em seguir as últimas evidências científicas com a intenção de atingir ganhos em saúde. A implementação dos elementos do CCM está alinhada com os standards e é positivamente associada com o uso de intervenções dirigidas a comportamentos de alto risco. Os profissionais de saúde têm a percepção de que cinco elementos (sistemas de informação clínica, decisão suportada, comunidade, autogestão e sistema de saúde) foram considerados razoavelmente bons. Os participantes deram pontuações elevadas a alguns componentes, no entanto, os resultados qualitativos nem sempre suportaram os resultados quantitativos, indicando ainda a transição do modelo centrado no médico para o modelo centrado no doente. A 'liderança organizacional para os cuidados da doença crónica' foi considerada como a primeira prioridade (26.3%) e 'participação do doente' foi considerada como a primeira barreira (36.8%).

Conclusão

O sistema de saúde do emirado de Abu Dhabi está internacionalmente bem posicionado e competitivo face a outros países desenvolvidos, mesmo enfrentando o desafio da sua população única. Tem um razoavelmente bom suporte aos cuidados de doença crónica e o top cinco das prioridades e barreiras estão delineados. Este estudo representa um importante passo para compreender onde e mais relevante intervir de forma a maximizar o desenvolvimento do CCM no Sistema de saúde de Abu Dhabi.

Palavras-chave: Abu Dhabi, Cuidados de Saúde Primários, Modelo de Doença Crónica, Mudanças Organizacionais, Melhoria da Qualidade.

Abstract

Abu Dhabi is the capital of the United Arab Emirates (UAE) and the largest emirate in terms of land mass and population. The UAE has a high population-burden of morbidity and mortality related to chronic diseases. To address the growing burden of non-communicable diseases, the Chronic Care Model (CCM) has the purpose of having population-based daily care for all with structured and planned team care interventions; aiming to convert the life of patients with chronic disease from reactive to proactive. The model integrates six elements to facilitate high-quality care.

Aim and Objectives

This thesis aims to explore the health system of the Abu Dhabi emirate, using the CCM approach to improve and develop the healthcare delivery to people with chronic diseases.

Four specific objectives were outlined:

- Characterize the healthcare services in the emirate of Abu Dhabi;
- Analyze the alignment of the healthcare services with the CCM, identifying main gaps;
- Explore the perception of the healthcare workers about the level of integration of the CCM in the daily care of patients with chronic diseases: diabetes, cardiovascular diseases, and cancer;
- Prioritize the subcomponents and the barriers for the development of the CCM in the health system of the emirate of Abu Dhabi.

Methods

To operationalize the objectives, a study with three different components was designed:

- Systematic review used the CCM as a framework to further explore its implementation or development in primary health care;

- The cross-sectional mixed-methods study collected information about the perception of the healthcare workers about the stage of implementation and development of the CCM in the daily care of patients;
- Modified Delphi technique was used to rank the priorities and barriers of the implementation and development of the CCM.

Results

The primary health care clinics adopted the principles of the patient-centred medical home model, a model aligned with the CCM. It seems there is an effort in following the latest scientific evidence with the intention to achieve health gains. The implementation of the CCM elements aligns with those standards and is positively associated with the use of interventions targeting high-risk behaviours. The healthcare workers have the perception that five elements (i.e. clinical information system, decision support, community, self-management, health system) were rated as reasonably good. Participants awarded high scores for some components; however, the qualitative findings did not always support the quantitative data indicating that the transition from doctor-centred to patient-centred is still in process. The 'overall organizational leadership in chronic illness care' was considered as the priority to address (26.3%) and 'patient compliance' the top barrier (36.8%).

Conclusion

The Abu Dhabi emirate health system is internationally well positioned and competing with others from the high-income developed countries, even facing the challenge of the unique population. It has reasonably good support for chronic illnesses care and the top five priorities and barriers to further improve it was outlined. This study represents an important step to understanding where it is more relevant to intervene in order to maximize the development of the CCM in the Abu Dhabi health system.

Key words: Abu Dhabi, Chronic Care Model, Organizational Change, Primary Health Care, Quality Improvement

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List of Acronyms

ACIC – Assessment Chronic Illness Care

AHS – Ambulatory Healthcare System

CCM – Chronic Care Model

DALYs – Disability-adjusted life years

DHA – Dubai Health Authority

DHCC – Dubai Healthcare City

GCC – Gulf Cooperation Countries

GDP – Gross Domestic Product

HAAD – Health Authority – Abu Dhabi

HDI – Human Development Index

JCI – Joint Commission International

MoHP – Ministry of Health & Prevention

NCD – Non-communicable diseases

PHC – Primary Health Care

SDGs – Sustainable Development Goals

SEHA – Abu Dhabi Health Services Company

UAE – United Arab Emirates

UN – United Nations

USA – United States of America

WHO – World Health Organization

YLDs – Years lived with disability

YLLs – Years of life lost

CHAPTER 1

1. Introduction

This dissertation is a compilation of three studies on the field of health systems in the biggest emirate of the UAE – Abu Dhabi. These studies are mentioned as study 1, study 2 and study 3. Study 1 was a systematic review designed to contribute to the knowledge of the primary healthcare services in Abu Dhabi and investigate whether it is aligned with the six elements from the CCM. To perform this, a systematic review was conducted to synthesize the facilities available to deliver PHC for the populations and which guidelines and models are being followed and implemented to address the chronic disease problem.

Following the identification of the implementation and main gaps of the CCM in Abu Dhabi's health system, by the literature review, there was a need to further explore it. Study 2 was designed as a cross-sectional study using a mixed methods data collection tool – a semi-structured interview guide and a score – to understand the perspectives of the healthcare workers about its implementation on the daily delivery of care to chronic patients. Study 3 was designed as a modified Delphi technique, on the sequence of study 2, to prioritize the subcomponents and the barriers for the development of the CCM in Abu Dhabi's health system.

The United Arab Emirates (UAE) is a country located in the southeast of the Arabian Peninsula that was formed by the union of seven emirates: Abu Dhabi, Ajman, Dubai, Fujairah, Ras Al Khaimah, Sharjah and Umm Al-Quwain, led by His Highness Sheikh Zayed bin Sultan Al Nahyan, in 1971, who became the first president of the nation. Since 1971, the UAE has experienced major transformations moving from a predominantly herding, fishing and pearl trading based economy to industry on petroleum, telecommunication, aviation,

maritime, construction, and healthcare[2,3]. This transformation started in 1973-1974 with the oil boom allowing the government to invest in modernizing housing, education, and transport infrastructure, in addition to the creation of numerous globally recognized landmarks such as the tallest build in the world – Burj Khalifa – or the largest shopping complex – Dubai Mall[3].

1.1.1 United Arab Emirates history & economy

The Gross Domestic Product (GDP) represents the sum of value added by all the country producers. In Figure 1, it is possible to observe the GDP per capita (2010 US$) from 1976 until the latest data (2015). Along with the developed countries, the UAE GDP reflects the economic depressions and market trends. For this reason, between 2008 and 2010 we can see a decrease in the GDP per capita, but the increase tends to come back to shape from 2010. There is also the need to note that this is data per capita and the population has been increasing. According to the Ministry of Economy, in 2014, the distribution and investment of the GDP in non-financial sectors accounted for 90.5%. The contribution of crude oil and natural gas for the total of the GDP was 31.5% and the retail and repair services contributed 12.0%[4]. The emirate of Abu Dhabi together with Dubai accounts for more than two-thirds of non-oil GDP[5]. The total expenditure on health of GDP was 2.2% in 2000 and 3.7% in 2010. The general government expenditure on health in 2000 was 7.6% of all government expenditures rising from 8.8% in 2010. In 2014, the expenditure on health was 3.6% of the total GDP[6]. This result is close to the neighbouring Gulf Cooperation Council (GCC) countries with Qatar spending 2.2% of the total GDP on health[7], Saudi Arabia spending 4.7%[8], and Bahrain 5.0%[9]. In the same year, 2014, Portugal spent 9.5% of its GDP on health[10].

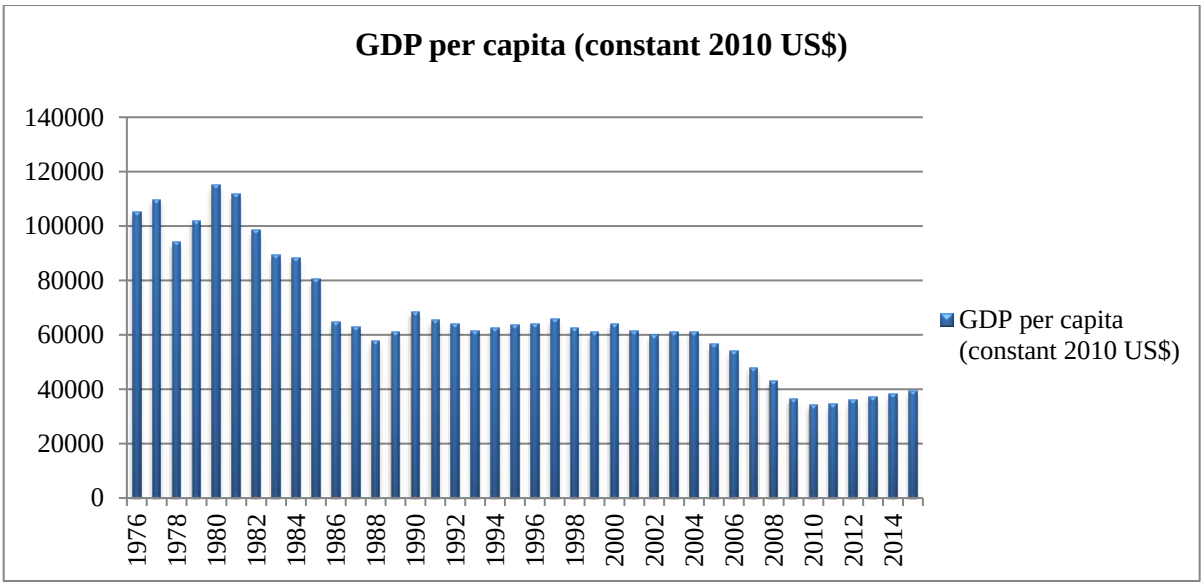

Figure 1: United Arab Emirates GDP per capita (2010 US$). Data adapted from the World Bank[11].

The Human Development Index (HDI) is a summary measure for assessing long-term progress in three basic dimensions of human development: a long and healthy life, access to knowledge, and a decent standard of living. From 1990 and 2015, the HDI of the UAE increased 15.7%, being 0.84 in 2015, which positioned the country at 42 out of 188 countries and territories. This value is below the average of 0.89 for countries in the very high human development group and above the average of 0.69, for countries in Arab States[12].

1.1.2 Population

Since 1971, the population has grown from 287,000 to 9.156 million in 2015[11] (Figure 2) and between 1975 and 1980, the growth was about 86.0%, with the influx of foreign workers [13]. In 2000, the population had increased almost 50.0% on the 1990s, with an average growth by 5.0% a year. In 2015, the population growth was 0.8%. Yet in 1971, 78.1% of the

population lived in urban areas, consistent with 2015 where the population was concentrated in the urban areas with 85.5% of the total and only 14.5% in rural areas. In the same year, the population density in the UAE was 109,5 people per km of land area[11].

In 2015, the majority of the population was male, with only 26.7% of women. Regarding age groups, the age group 0-14 years was 13.9% of the population, with the largest population, 84.9%, in the age group 15-64 years and 1.1% of all the population aged above 65 years[11]. This exponential growth is due to both the natural population growth and the result of the quality of life and job opportunities that the country has that attracts migrants from all over the world [3]. Inward migration explains the unequal distribution of the population among nationals and expatriates, where approximately 11% of the total population is Emirati[14], and regarding gender and age, with a high percentage of male workers, especially, between 25-39[15] years old from Asia and other Arab countries (Figure 3).

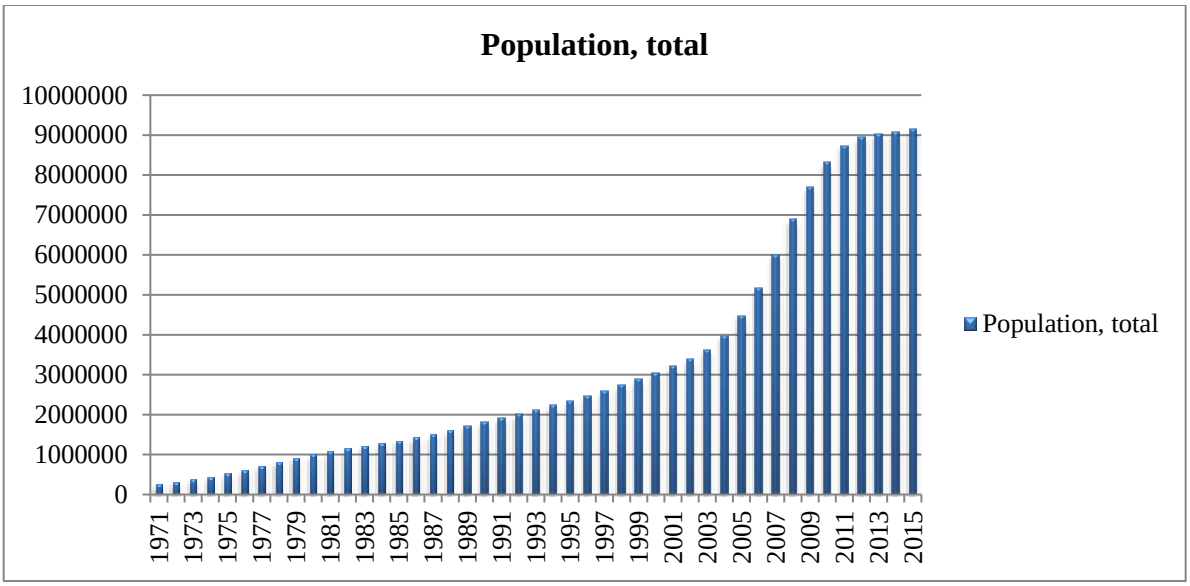

Figure 2: Total population in the UAE from 1971 to 2015. Data adapted from the World Bank[11].

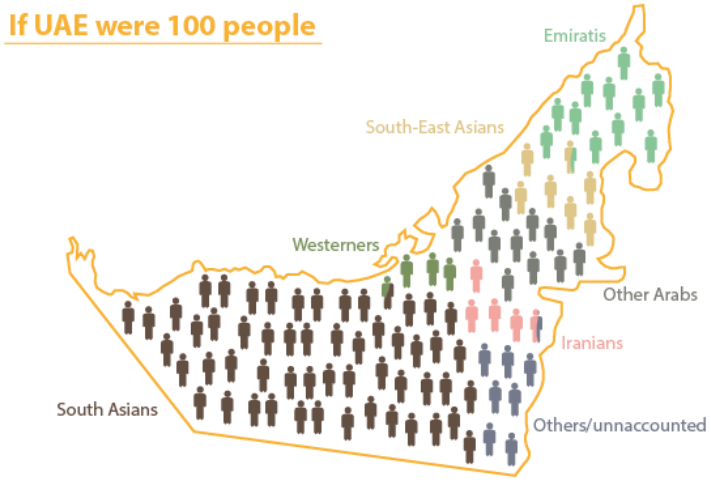

Figure 3: Population in the UAE by nationality[14].

1.1.3 Health indicators – Sustainable Development Goals

In 2015, the life expectancy in the UAE at birth for males was 76 years and for females was 78 years in all country[15]. The probability of dying between 15 and 60 years was 81 for males and 57 for females per 1 000 population, another alteration since 1971 when the probability of dying for males was 242 and 190 for females per 1 000 population [16].

The sustainable development goals (SDGs) of the United Nations (UN) 2030 Agenda integrate the three considerable dimensions for sustainable development and for eradicating poverty and inequality. The considered dimensions are economic, social and environmental. From the 17 SDGs, health is expressed through SDG 3: good health and well-being. In 2015, the UAE maternal mortality ratio was 6 per 100 000 live births and the proportion of births attended by skilled health professional between 2006 and 2014 was 100% (SDGs 3.1)[17]. Between 2005 and 2015 the UAE adolescent birth rate was 34.2 per 1 000 women aged 15-19 years (SDGs 3.7)[17]. The probability of dying by the age of 1 was 3.5 per 1 000 live births, and the probability of dying under five was 6.8 per 1 000 live births, it reduced exponentially from the 88.3 per 1 000 live births in 1971 (SDGs 3.2)[17].

This impact on mortality rates since 1971 reflects the high levels of public spending in healthcare after the oil-boom. Before the discovery of oil, the health system situation in the Emirates was poor and the majority of the population only had access to traditional medicines unless they could afford severe treatments aboard[13]. During the early decades of the UAE, infectious diseases were one of the predominant causes of death but the mortality patterns changed as the UAE passed through the epidemiological transition with chronic diseases now the major cause of morbidity and premature mortality. In 2014, the tuberculosis incidence per 100 000 population was 1.6, the percentage of infants receiving three doses of hepatitis B vaccine was 94%, and the reported number of people receiving interventions against neglected tropical diseases was 57. There is no data available about the new HIV infections

among adults and about malaria incidence (SDGs 3.3)[17]. In 2012, the probability of dying from any cardiovascular disease, cancer, diabetes or cardiorespiratory disease between the age of 30 and 70 was 18.9% and the suicide rate per 100 000 population was 3.0 (SDGs 3.4)[17]. The total alcohol per capita consumption, in litres of pure alcohol and per estimates, was 4.3 in 2015 (SDGs 3.5)[17]. The road traffic mortality rate per 100 000 population in 2013 was 10.9 (SDGs 3.6)[17].

The UAE is better positioned than the average countries of the Eastern Mediterranean Region, except for alcohol per capita consumption[17]. The UAE Vision 2021 is aligned with the UN 2030 Agenda for sustainable developmen[18]t. The UAE Vision 2021 was launched by His Highness Sheikh Mohammed bin Rashid Al Maktoum in 2010 and aims to make the UAE one of the best countries in the world by the Golden Jubilee of the Union. This vision has six national priorities representing the sectors' focus for the coming years. The national priority that reflects health is the 'World-Class Healthcare' and to achieve this priority 10 indicators were designed as the national key performance indicators and between them, we have, for example, the number of deaths from cardiovascular diseases per 100 000 population and the number of nurses per 1 000 population[19]. The World Health Organization (WHO) is also committed to, leading and coordinating the 2030 Agenda recognizing the noncommunicable diseases (NCD) as a major challenge to reach sustainable development.

1.1.4 Challenges in UAE populations' health – Non-communicable diseases

At a global scale, 40 million people die from NCD each year, which is 70% of all the deaths[20]. In 2012, 9,700 people died from an NCD in the UAE and it was estimated that NCD accounted for 65% of all deaths and the probability of dying between 30 and 70 years from the NCD was 19%[21]. The proportional mortality causes were cardiovascular diseases (30%),

injuries (23%), others NCD (16%), cancer (13%), communicable diseases (12%), chronic respiratory diseases and diabetes (3%)[21].

Besides the problem of mortality, specifically premature mortality, NCDs cause severe losses in terms of years of life lost (YLLs), years lived with disability (YLDs) and disability-adjusted life years (DALYs) which has an economic impact on countries by increasing health costs and decreasing the economically-active population. The Global Burden of Disease Study, performed by the Institute for Health Metrics and Evaluation, identified ischemic heart disease, road injury, cerebrovascular disease, chronic kidney disease and chronic obstructive pulmonary disease as major causes of YLLs in the UAE in 2015. Concerning YLDs, the top five causes in the UAE were major low back and neck pain, depressive disorders, diabetes, other musculoskeletal disorders, and migraine. Quantifying both YLLs and YLDs, the top five DALYs in the UAE were ischemic heart disease, road injury, low back and neck pain, diabetes and cerebrovascular diseases[22].

The top 10 risk factors for the DALYs in UAE are dietary risks, high body mass index, high fasting plasma glucose, high systolic blood pressure, high total cholesterol, alcohol and drug abuse, tobacco smoke, air pollution, occupational risks and low physical activity[22].

In the UAE, four of the five causes of YLLs, all the five causes of YLDs, and four of the DALYs causes are NCDs. These type of diseases are driven by forces that include globalization of unhealthy lifestyles and population ageing[20]. There are two types of risk factors among the UAE' top ten: the modifiable behavioural and metabolic risk factors. The first ones comprise the tobacco and alcohol abuse and lack of physical activity, and the metabolic risk factors are, for example, the high blood pressure or high cholesterol. It is known that tobacco use is one of the most preventable causes of death[23], in terms of the behavioural risk factors, while high blood pressure is the leading metabolic risk factor being attributable to 19% of the NCDs deaths[20].

The approach to tackle the NCDs is to focus on decreasing the prevalence of the associated risk factors and to invest in better management, including detecting services, screening centres and treatment for people in need. Evidence shows that the primary health care (PHC) centres have a high impact to strengthen early detection and timely treatment to the population reducing health services cost and saving time[20]. These interventions are essential to achieving the global target of a 25% relative reduction of mortality from NCDs by 2025 and the SDG target of a one-third reduction in premature deaths from NCDs by 2030.

The four public health priority areas in the UAE are cardiovascular diseases, injuries (including road traffic, child, and occupational injuries), cancers, and respiratory disorders[3].

1.1.5 Abu Dhabi

Abu Dhabi is the largest emirate in population and land size accounting for almost 87% of the total area of the UAE[13] and it is also the capital of the country where the government is based. Abu Dhabi has three different regions called the Abu Dhabi Central Capital region, the Al Ain region and the Western Al Gharbia region. The Abu Dhabi Central Capital region comprises the Abu Dhabi city, the capital of the country, and it is the headquarters of the President of the state. The Al Ain region has the oasis city of Al Ain as capital and the Western region has its capital in Zayed city (Figure 4).

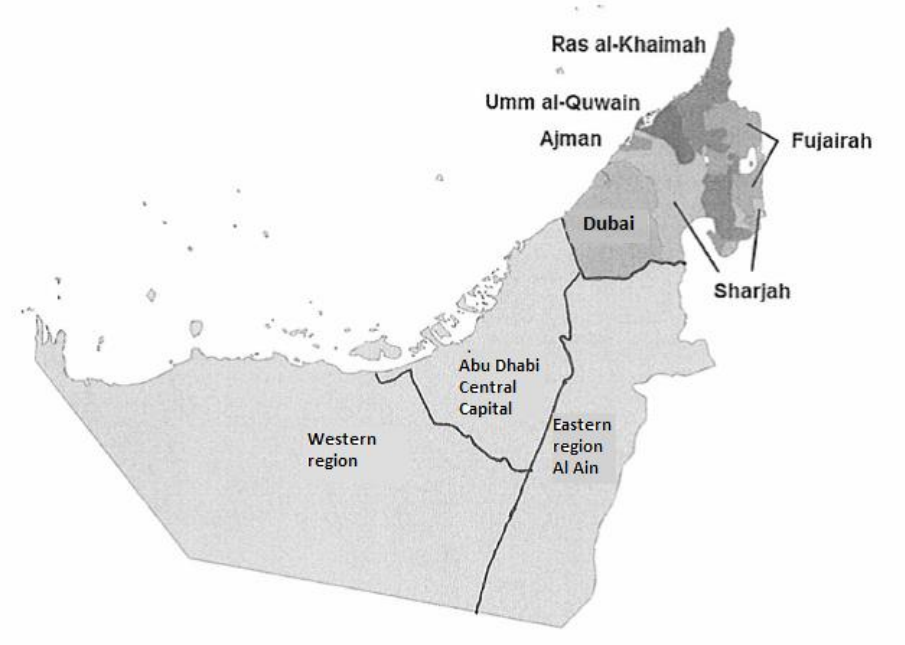

Figure 4: Geographical regions of the Abu Dhabi emirate.

The 2014 mid-year population estimate for the emirate of Abu Dhabi was 2,656,448[24]. In this emirate, the majority of the population were male, with only a third (33.5%) comprised of women (see Figure 5). The age group between 0-14 years constituted 16.9% of all the population, with the largest proportion aged between 15-64 years (82.1%) and only 1.0% of the population were aged ≥ 65 years[24] (see Figure 5). Since 2000, there has been a slight decrease in the age group 0-14 years with a continuous increase in the age group 15-64 years, but in 2009-2010 the trend was reversed.

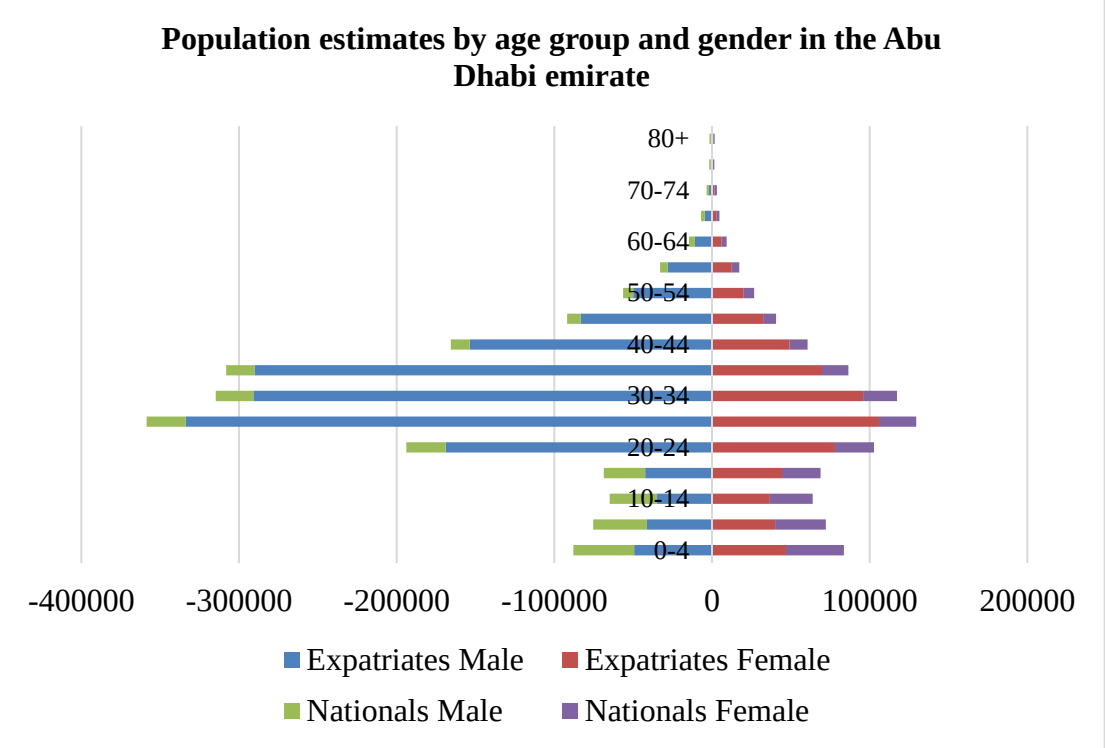

Figure 5: Population pyramid in the emirate of Abu Dhabi, in Mid 2014 (data from SCAD Yearbook 2015).

The UAE's population's pyramid has an unusual shape and structure, showing a young population and a disproportion of males and females (see Figure 5). This disproportion between genders in the emirate of Abu Dhabi follows the country trend, a similar pattern to other developing countries in the GCC such as Qatar and Bahrain[25,26]. The population structure of these countries is characterized by a predominantly young population and an expected equal ratio of males to females among the nationals. However, the unusual structure of the expatriate population is due to the mass recruitment of males employed in the industrial and construction sector and a heavy reliance on females in the service sector as domestic staff

and shop workers. In 2014, nearly two-thirds (66.5%) of the Abu Dhabi population were males[24].

There is an unequal distribution among UAE nationals and expatriates, not just regarding the age of the population, but also regarding the regions. Only 19.0% of the total population living in Abu Dhabi are UAE nationals. Over half (52.0%) of UAE nationals live in the Abu Dhabi Capital Center, 42.0% live in the Eastern region of Al Ain and 6.0% live in the Western region (Figure 6). Expatriates comprise 81.0% of the population in the emirate of Abu Dhabi and 64.0% of them live in Abu Dhabi Capital Center region[24].

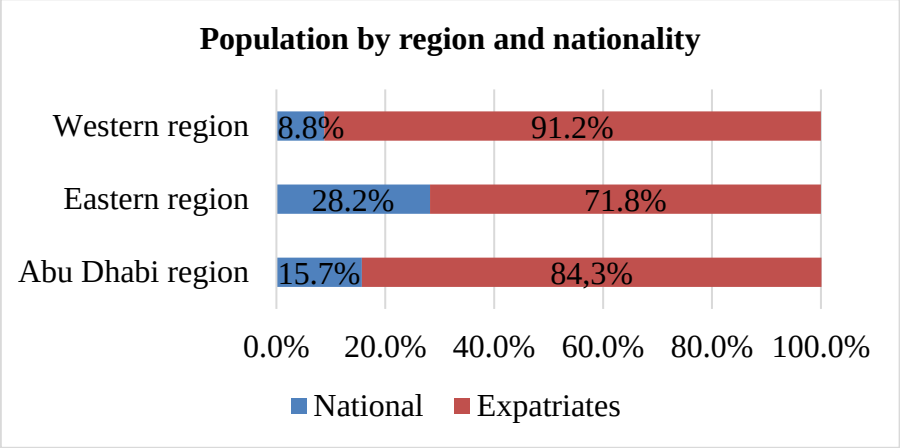

Figure 6: Population by Abu Dhabi emirate region and nationality (data from SCAD Yearbook 2015).

In 2015, the main causes of mortality in Abu Dhabi were diseases of the circulatory system (35.0%), other causes (22.0%), injuries (21.0%), neoplasms (16.0%), endocrine, nutritional and metabolic diseases (3.0%), congenital malformations, deformations and chromosomal abnormalities (3.0%)[15].

CHAPTER 2

2. Literature review

2.1 Primary Health Care

In 1978, the International Conference on Primary Health Care held in Alma-Ata originated the first declaration stating the relevance of PHC to reach health for all and standing the world government's position to healthier populations. The first statement of this crucial document was the reaffirmation of health as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" and as "a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector"[27].

In point six of the Alma Ata Declaration, a PHC was defined as "essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part, both of the country's health system, of which it is the central function and focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process"[27]. This declaration was the first attempt to unify thinking about health delivery into a single policy framework[28].

The concept of PHC encloses the word primary, meaning, first contact level, between the patient and the healthcare organization, usually in the health district or community. After almost 40 years, one of the main values is still the same, where the PHC centre aims at providing as much care as possible at the first point of contact effectively backed up by secondary level facilities – hospitals – that concentrate on more complex care"[28]. As the noncommunicable diseases burden is growing fast and the development of new diagnostic and therapeutic technologies is expanding, the principles of the PHC – universal access, equity, participation and intersectoral action – assured by evidence on intervention cost-effectiveness, remains very important to both developed and developing countries.

In 1986, the Abu Dhabi government launched the cabinet decree No. 39 declared that "primary health care is the essential tool to achieve Health for All by 2000 goal and emphasized the PHC principles of equity, accessibility, acceptability and community participation"[29].

2.2 Health system

A health system is more than a set of public or private facilities that deliver personal health services to the population. According to the WHO, it consists of all organizations, people, and actions whose aim is "to promote, restore or maintain health", including influence on determinants and health-improving activities[28]. In 2000, the World Health Report from WHO, focused on health systems, defining goals and outcomes for this wide concept as improving health and health equity in a responsive way, being financially fair and making the best and most efficient use of the resources[30]. In 2007, to strengthen the health systems concept, WHO launched the six building blocks of a health system to help health systems achieving their goals. The six essential build blocks are health services delivery, health

workforce, health information system, medical products, vaccines and technologies, health financing and leadership and governance[28].

The health systems are required to constantly adapt and adequate their priorities and services based on socio-demographic changes, epidemiologic transitions, health costs, changes in population levels and health status, and disease patterns. Thus, each country faces its own unique characteristics to deal with, as in UAE we mention the unusual population structure. Although, mutual challenges include factors associated with governance, finance, human resources, accessibility and quality of service delivered[2].

2.2.1 UAE health system

The health system in the seven emirates has distinct federal and emirate level authorities. The federal level is ensured by the Ministry of Health and Prevention (MoHP) and the emirate level is ensured by the different specific emirate entities, the Health Authority Abu Dhabi (HAAD), by the Dubai Health Authority (DHA) and Sharjah Health Authority (SHA). The MoHP was renamed in 2016, previously it was simply Ministry of Health. This change had the intention of shifting the Ministry's focus from simple healthcare services provision to prevention of the diseases.

In 2002, there were 35 public hospitals in the UAE, as well as 14 private hospitals and 128 outpatient clinics. At this time, although several small private hospitals had been set up over the past years[13] there was still a tendency for UAE nationals to seek treatment aboard in the United States of America and Europe. In 2015, there were 38 public hospitals and 74 private hospitals, becoming 112 hospitals in the UAE, an increase of 68% mainly due to private investment. Table 1, shows the hospitals by the public or private sector and by the emirate.

This rapid expansion of the number of hospitals increases the health system capacity, but it does not mean that morbidity decreases and that new models of care are not needed to face

the challenges of an unusual and expanding population structure and shifting disease patterns. As it was already mentioned, the unique characteristics of the UAE population need to be taking into account, and the expatriate population generally has low morbidity and requires different services such as ambulatory care, occupational health, and preventive services[31].

Table 1: Number of hospitals in UAE by emirate[32].

Emirate	Number of Hospitals	Public Hospitals	Private
Abu Dhabi	37	12 SEHA	25
Ajman	13	2 MoHP, 1 Government of Ajman	7
Dubai	35	2 MoHP, 4 DHA	29
Fujairah	6	2 MoHP	4
Ras Al Khaimah	8	2 MoHP, 2 Government of Ras Al Khaimah	4
Sharjah	13	4 MoHP	9
Umm Al Quwain	3	2 MoHP	1

2.2.1.1 Dubai health system

The emirate of Dubai has the unique characteristic of having three entities managing and regulating health: the Dubai Healthcare City (DHCC), the DHA, and the MoHP. The DHCC was created in 2002 and it is the world's largest healthcare free zone with the aim of being an internationally recognized location of choice for quality care and excellence for clinical and wellness services, medical education and research. It comprises more than 160 clinical partners and facilities and one university – the Mohammed Bin Rashid University of Medicine and Health Sciences. This free zone has its own regulation and authority – the Dubai Healthcare City Authority and the Dubai Healthcare City Authority - Regulation[33]. The DHA was created in 2007 to provide an accessible, effective and integrated healthcare system with the aim of protecting public health issues to increase the quality of life. The

DHA works as a regulatory and health strategic body, but also as a healthcare services provider with its own hospitals, speciality centres, and PHC centers[34].

2.2.1.2 Northern Emirates health system

The MoHP is the entity that regulates the healthcare services in the five Northern Emirates (Ajman, Fujairah, Ras Al Khaimah, Sharjah and Umm Al-Quwain). Similar to the role of the DHA in Dubai, the MoHP is a regulatory body and also a provider through its network of PHCs, preventive medicine centres, hospitals and specialized centres.

From these five emirates, only the emirate of Sharjah has an independent health authority – the Sharjah Health Authority, launched in 2010 with the aim of regulating the healthcare system in the emirate and to develop the ambitious project of the Sharjah Healthcare City, similar to the DHCC[35].

2.2.2 Abu Dhabi health system

In 2001, the Abu Dhabi government created the General Authority of Health Services, which came to be deposed in 2007, to give origin to two organizations: the HAAD (Abu Dhabi Law No. 1 of 2007) and the Abu Dhabi Health Services Company (SEHA) (Abu Dhabi Amiri Decree No. 10 of 2007)[29].

HAAD is responsible for the definition of health system strategies, evaluation, and analysis of health issues of the population and performance of the system regulating all healthcare actors (public/private, provider/payer/professionals). The aims of HAAD are to achieve, develop, follow-up and monitor high standards in health, curative, preventive, medical services and health insurance in the Abu Dhabi Emirate and to keep high international standards[29]. HAAD has a healthcare strategy with clear priorities and goals and its own public health programs. The HAAD public health priorities and goals are the following:

cardiovascular disease prevention and management, tobacco control, communicable disease prevention and control, occupational and environmental health, mother, infant and school health, cancer control, and prevention, road safety, other chronic conditions include asthma and oral health[36]. Consequently, the eleven public health programs established by HAAD are: Cancer Prevention, Schools for Health, Weqaya (the Arabic word for "prevention"; cardiovascular disease screening for UAE nationals), Premarital Screening and Counseling, Newborn Screening, Safety in the Heat, Drive Safe-Save Lives, H1N1, Height Aware, Asthma, and Vaccination[37].

SEHA (the Arabic word for health) is responsible for operating the public health system of Abu Dhabi and to upgrade and deliver world-class healthcare. The purpose of SEHA is to provide comprehensive healthcare services in cities and in rural areas, with the latest technology and treatments and technical and medical specialists in all facilities. SEHA owns and manages the public healthcare system of the emirate and upgrades and improves healthcare delivery based on international standards and external accreditation[38].

2.3 Chronic Care Model

To address the growing burden of NCDs, the Improving Chronic Illness Care team at the MacColl Center for Health Care Innovation at Group of Health Research Institute created the Chronic Care Model (CCM). The purpose of this model is to promote population-based daily care for all with structured and planned team care interventions[1]. It was designed to help PHC practices improve health outcomes by changing the routine delivery of ambulatory care. The aim of the CCM is to convert the life of the patients with chronic disease from reactive to proactive, planned and population-based. The CCM is a multicomponent model that integrates six elements which facilitate high-quality care and each element of the model has its own strategies (Table 2) and development concepts that can be applied to a variety of

healthcare settings, chronic diseases, and target populations[1]. The six major basic elements that integrate the model are (i) self-management support; (ii) community; (iii) health system; (iv) delivery system design; (v) decision support; and (vi) clinical information systems. The CCM was idyllically conceptualized as a holistic combination of all the six elements working to foster quality improvement, although, sometimes the interventions may only emphasize one or two components according to the specificity of the change[39,40]. For example, to facilitate patient engagement in proactive care (delivery system design), practices need to be able to view all of the patients in their panels (clinical information systems), who need certain guided treatments (decision support), and patients must agree to any changes in their care and integrate them into lives (self-management support). Recent research has provided emerging evidence that changes in at least four of the six categories (as the above example) led to advances in health outcomes[41]. Patients with diabetes, congestive heart failure and chronic obstructive pulmonary disease (in Australia and the United States of America (USA)) benefitted from health care adjustments guided from CCM[42–44]. These benefits, which have an impact on both individual and population level, turn this model as an important tool to consider for public health approaches. In public health, approaches targeting chronic diseases aim to increase the quality of life of the patients and better health outcomes and the incorporation of patients, providers and health systems interventions with the CCM contribute for that. These benefits, which have an impact on both individual and population level, turn this model as an important tool to consider for public health approaches. In public health, approaches targeting chronic diseases aim to prevent the development of disease, to increase the quality of life of the patients and better health outcomes. The CCM enhances the connection between the health system and the community through the incorporation of patients, providers and health systems interventions anticipating diseases patterns and acting on health promotion and disease prevention.

Table 2: Chronic Care Model elements and respective strategies.

Model Elements	Approaches/Strategies
Self-Management Support	- Emphasize the patient's central role in managing their health; - Use effective self-management support strategies; - Organize resources to provide self-management support to patients.
Community	- Encourage patients to participate in community programs; - Form partnerships with community organizations; - Advocate for policies to improve patient care.
Health System	- Support improvement at all levels of the organization; - Promote strategies aimed at comprehensive system change; - Encourage open and systematic handling of errors and quality problems; - Provide incentives based on the quality of care; - Develop agreements that facilitate care coordination across organizations.
Delivery System Design	- Define roles and distribute tasks among team members; - Use planned interactions to support evidence-based care; - Provide clinical case management services for complex patients; - Ensure regular follow-up by the care team; - Give care that patients understand and that fits with their cultural background.
Decision Support	- Embed evidence-based guidelines into daily clinical practice; - Share evidence-based guidelines and information with patients; - Use proved provider education methods; - Integrate specialist expertise and primary care.
Clinical Information System	- Provide timely reminders for providers and patients; - Identify relevant subpopulations for proactive care; - Facilitate individual patient care planning; - Share information with patients and providers to coordinate care; - Monitor performance of the practice team and care system.

2.3.1 Assessment Chronic Illness Care

In response to the need of the healthcare organizations to have a practical assessment tool to guide the quality improvement efforts and to evaluate changes, the Improving Chronic Illness Care team designed the Assessment Chronic Illness Care (ACIC) survey[45] "Copyright 2000, the MacColl Institute for Healthcare Innovation, Group Health Cooperative" (ANNEX 1). With the increased need to have specific tools to specific settings, after the design of the ACIC, other surveys were designed: the Academic Chronic Care Collaborative Assessment of Chronic Illness Care (ACCC-ACIC), the Assessment Chronic Illness Conditions Prison (ACIC-Prison), the Patient Assessment Chronic Illness Conditions (PACIC), the Patient Assessment Chronic Illness Conditions for Home Health Care (PACIC) and the Patient-Centered Medical Home Assessment (PCMH-A)[46].

The aim of the ACIC is to help health managers evaluate and diagnose the strengths and weaknesses of their organizations' delivery of care for chronic illness according to the six components: it mainly assesses" what is working" and "what needs to be improved"[47]. This survey was developed as a practical quality improvement tool to be used within healthcare organizations and medical teams to (i) identify areas for improvement in care for chronic illness before beginning quality improvement work; (ii) develop improvement strategies; and (iii) evaluate the level and nature of improvements made in response to quality improvement interventions[48]. Although, this health professionals survey has also been widely used for research purposes[49–51]. The ACIC can have multiple uses, as in interventional studies where it has been used as a tracking tool to identify areas for improvement (baseline) and to assess the progress of the CCM implementation (follow-up)[51].

CHAPTER 3

3. Methods

3.1 Objectives

This thesis had the overall aim to explore the health system of the Abu Dhabi emirate, using the CCM approach to improve and develop the healthcare delivery to chronically ill people.

In order to operationalize this main aim, four specific objectives were outlined:

- To characterize the healthcare services in the emirate of Abu Dhabi;
- To analyze the alignment of the healthcare services with the CCM, and identify main gaps;
- To explore the perception of the healthcare workers about the level of integration of the CCM in the daily care of patients with diabetes, cardiovascular diseases and cancer;
- To prioritize the subcomponents and the barriers for the development of the CCM in the health system of the emirate of Abu Dhabi.

These specific objectives are repeated in the correspondent chapters, along with the detailed description of the methods used to achieve them.

3.2 Study design

This thesis emerged from a problem, the research problem which is an issue or concern from the researcher that needs to be addressed[52]. In our case, the research problem incorporates

the need to both explore and explain. The main research question to address the problem led to the need for more specific ones on understanding the problem (Figure 7).

To achieve the mentioned research questions of our study there was a need for designing three studies. These studies are mentioned as study 1, study 2 and study 3 (Figure 7). The reason for this choice was the specification of the objectives and the need for having specific methods to address them.

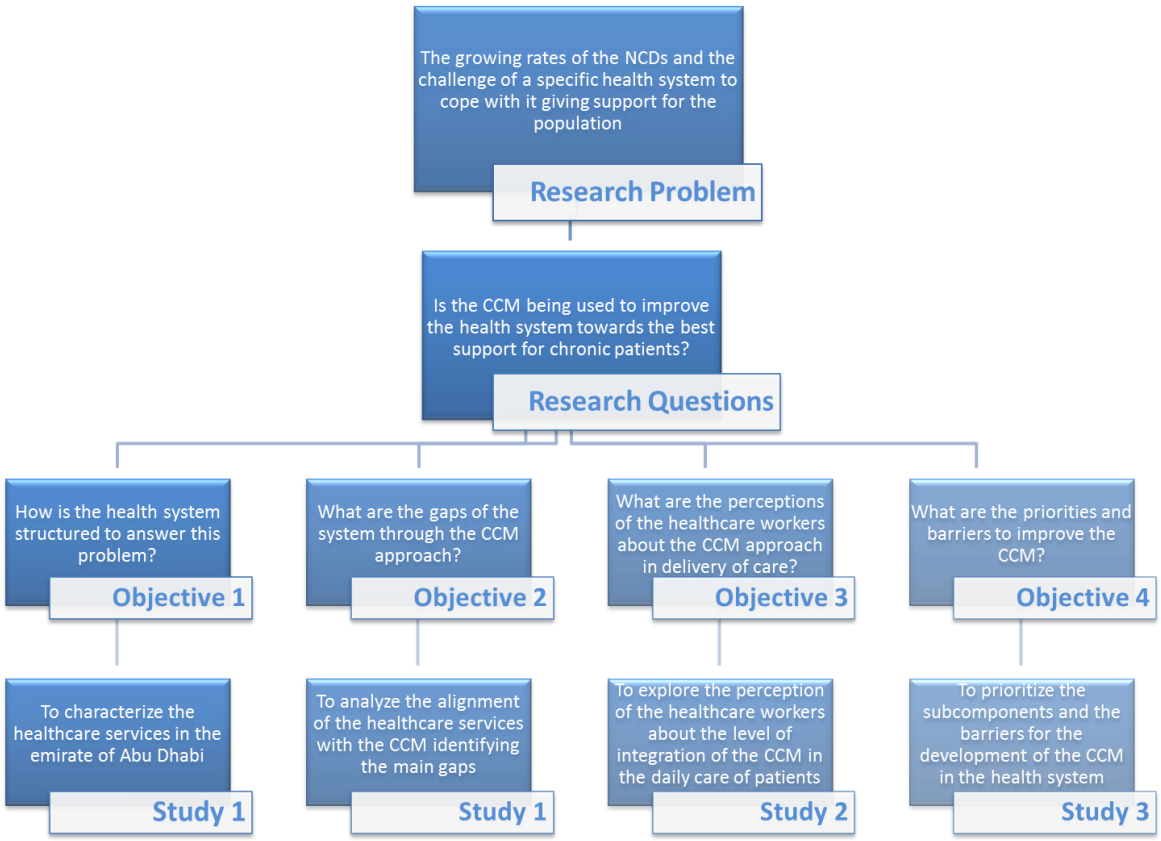

Figure 7: Study design.

3.3 Methods

3.3.1 Systematic review

A systematic literature review attempts to "collect all empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question". Systematic reviews have five key characteristics according to the Cochrane Handbook for Systematic Reviews: (i) a clear set of objectives with pre-defined eligibility criteria; (ii) an explicit and reproducible methodology; (iii) a systematic search to identify all studies that would meet the eligibility criteria; (iv) an assessment of the validity of the findings; and (v) a systematic presentation of the characteristics and findings of the studies[53]. To report the study the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement was followed. This consists of a 27 item checklist (ANNEX 2) and a four phases diagram (Figure 8) and has the aim to help authors to better write systematic reviews and meta-analysis[54].

3.3.2 Mixed methods

A mixed methods approach was used. It included collecting both qualitative and quantitative data simultaneously and sequentially to provide a deeper understanding of the research problem [52].

Semi-structured interviews are suitable when the researcher wants to know specific information that can be compared and contrasted with information from other interviewers. Also, the researcher wants the interview to remain flexible in case of some important information arises[55]. This is the type of interview more common in qualitative social studies.

Content analysis was used to guide the qualitative analysis of the results using words as a unit. Content analysis is a cluster of methodological tools that can be applied to speeches

(contents) extremely diverse. The common factor among all the methodological tools that can be applied to the content analysis is the deduction based on the inference, the subjectivity seeking for objectivity[56]. To analyze the material under study, codification is one of the most important steps as it corresponds to the transformation, according to specific rules, of the data to allow one representation of the content. It is in this step that the context unit analysis, which can be words, themes, objects, persons or documents[56].

3.3.3 Delphi technique

The Delphi technique is one of the methods to reach consensus from a group of selected independent expert participants, whose relying on their expertise, analyze scenarios and assess them using Likert scales to produce ordinal data[57]. This technique was early developed by Dalkey and Helmer in 1950s[58] and it is considered to be one of the best three methods to reach consensus among with the nominal group technique and the consensus development conference[59]. The modified Delphi method itself starts with a series of questionnaires used to identify a list of topics. Through an interactive process of nominal scoring, they are reduced until a pre-specified number of topics remain to be ranked in order of priority, and finishes when consensus has been established at a sufficient level[58,60].

CHAPTER 4

4. Results and Discussion: The Primary Healthcare Services in Abu Dhabi – Are they aligned with the Chronic Care Model elements?

Before the use of a model to tackle the growing problem of the chronic diseases, there was the need to map the healthcare services in the emirate of Abu Dhabi due to the need of characterization to understand this health system and its specifications.

The aim of this study was to systematically review the available information and data to characterize and analyze the PHC public services in the emirate of Abu Dhabi in the United Arab Emirates using the CCM as a framework.

4.1 Methods

This study follows the Cochrane Collaboration guidelines for conducting systematic reviews and the focus was the specific research question: "How is the health system structured to support chronic diseases" and "What are the gaps in the system through the CCM approach". To report the study the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement was followed.

4.1.1 Eligibility criteria

This review was performed based on secondary data sources that are available in the public domain. The search was limited to English language journals or reports. The specific search

terms and strategy are displayed in Table 3. Only recently published reports and data that was no more than three years old (i.e. before 2013) were included in the review.

Table 3: Study selection of information sources.

Information sources		**Search strategy**	**Studies found**
Data bases	PubMed and manual search: Google Scholar	"United Arab Emirates" AND "Abu Dhabi" AND "Primary Health Care" AND "Chronic Care Model"	"A successful chronic care program in Al Ain-United Arab Emirates"
			"Effectiveness of chronic care models: opportunities for improving healthcare practice and health outcomes: a systematic review"
		"United Arab Emirates" AND "Primary Health Care" AND "Chronic Care Model"	“The “Arab World” is Not a Useful Concept When Addressing Challenges to Public Health, Public Health Education, and Research in the Middle East”
			“Population structure and the burden of disease in the United Arab Emirates”
			"Healthcare Regulation in the United Arab Emirates. The Health Authority – Abu Dhabi"
		"United Arab Emirates" AND	“Health and health system performance in United Arab Emirates”
			“Financing health care in the United Arab Emirates.”

Information sources		Search strategy	Studies found
		"Abu Dhabi" AND "Health System"	"Health systems in United Arab Emirates: progression, challenges and future directions"
		"Chronic Care Model" AND "aims"	"Improving Chronic Care: *The "Guided Care" Model*"
			"Evidence on the chronic care model in the new millennium"
			"Does the Collaborative Model Improve Care for Chronic Heart Failure?"
			"Improve Chronic Illness Care: Translating Evidence Into Action"
			"Interventions to Improve the Management of Diabetes in Primary Care, Outpatient and Community Settings: A Systematic Review"
			"Rethinking Prevention in Primary Care: Applying the Chronic Care Model to Address Health Risk Behaviors"
		"Patient-Centered Medical Homes"	"Evidence Showing Effectiveness of NCQA Recognition: Benefits of the Patient-Centered Medical Home"
			"Patient-centered medical home demonstration: a prospective, quasi-experimental, before and after evaluation."
			"Value and the Medical Home: Effects of Transformed Primary Care"

Information sources		Search strategy	Studies found
			"Is patient-centred care the same as person-focused care?"
Metaresources of infroamtion	MoHP		Healthcare facilities
	HAAD	Revision of Annual Health Reports	Health Statistics 2012
			Health Statistics 2013
		Direct search about relevant topics	Book 1: legislation Establishing the Health Sector
			Public Health Priorities and Goals
			Public Health Programs
	SEHA	Revision of Annual Health Reports	Annual Report 2013
		Direct search about relevant topics	Why SEHA exists
			Mission, Vision and Values
			JCI Accreditation
			Ambulatory Healthcare Systems
	SCAD	Revision of Annual Health Reports	Statistical yearbook 2015
	WHO	Revision of Annual Health Reports	World Health Statistics - 2013
			World Health Statistics - 2015
		Direct search about relevant topics	United Arab Emirates - country profile
			Non-Communicable Profile - UAE
			Country Cooperation Strategy at glance - UAE

4.1.2 Information sources

The data collection was obtained through the consultation of bibliographic databases and meta-resources of information as the World Health Organization, World Bank, Institute of Health Metrics and Evaluation, UAE MoHP, HAAD, SEHA, and bibliographic references of the official reports obtained. This stage went from September 2014 to March 2016.

4.1.3 Search/Study selection

The primary search on Google Scholar and PubMed included the following medical subject headings: "United Arab Emirates", "Abu Dhabi", “Health System”, "Primary Health Care" and "Chronic Care Model". Some references of the articles that we found interesting were also screened and a manual search was conducted in all the health-related UAE official websites: MoHP, HAAD, SEHA, DHA, and Statistics Center of Abu Dhabi.

4.1.4 Data collection process/ Data items

Relevant data were independently extracted from available reports and reviewed considering the study PICOs (population, intervention, comparisons, and outcomes) [54]. The population under study and the comparisons should be from UAE or the same geographic regions and the interventions and outcomes relevant to primary healthcare or chronic diseases settings.

4.2 Results

4.2.1 Studies selection

With the utilization of the selection strategy described above, it was found 295 studies in the databases and another 13 reports were considered important. 231 titles and abstracts were

screened and 211 were excluded, mainly due to the population (we found lots of studies from another Arab country or specifically addressing one health conditions). The studies and 13 reports were selected to analyze and it was felt the need of a search for some extra articles included in the references of the articles we analyzed, so at the end, we reached the number of 20 articles and 13 reports (Figure 8).

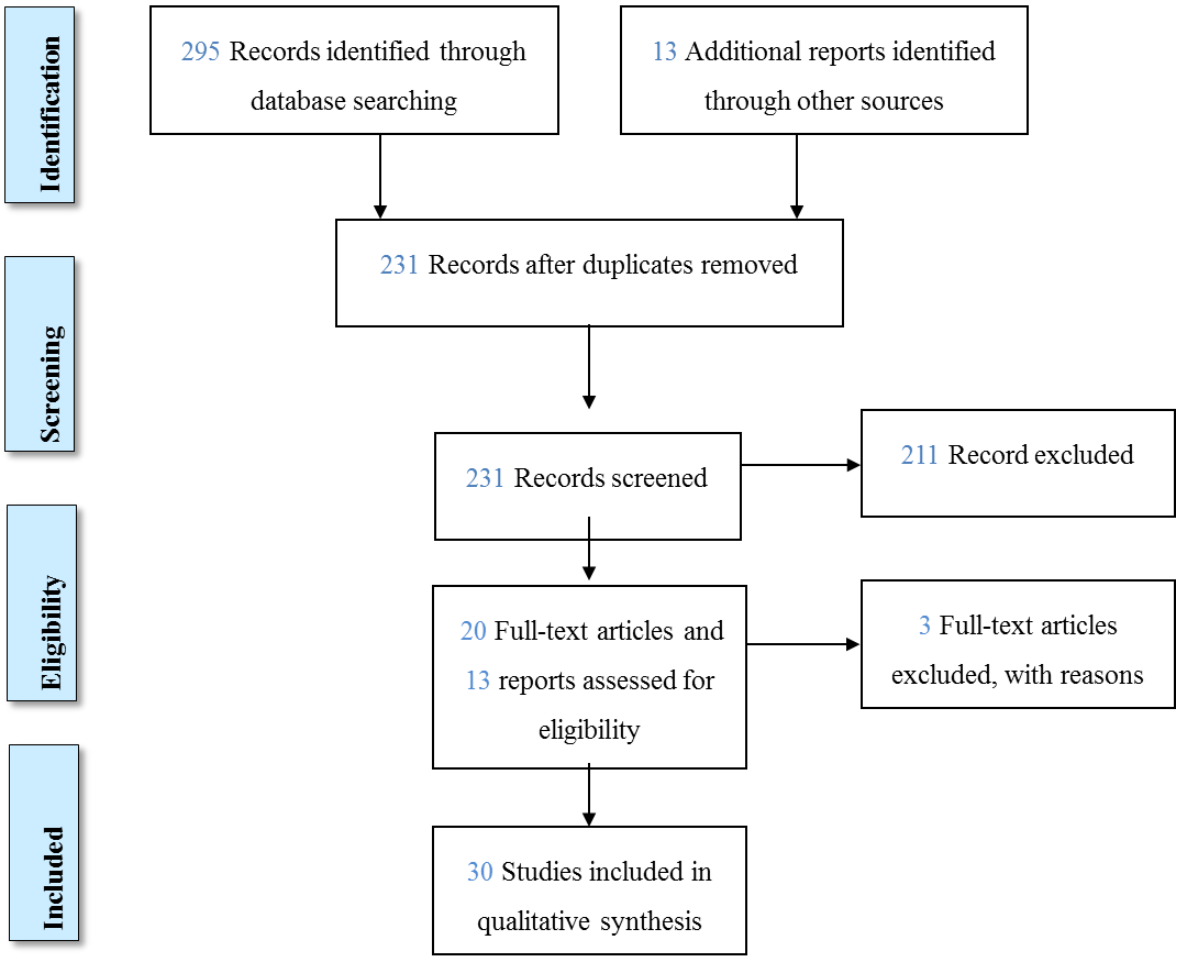

Figure 8: PRISMA Flow-chart.

After screening their eligibility criteria, we have included 33 studies and reports in our qualitative analysis. Three of them were not used due to the studies specifications, as an economic vision of the healthcare system.

4.2.2 Synthesis of results

4.2.2.1 Health workforce

The health workforce is one of the key components of the health system and between 2007-2013 the UAE's health system had an active health workforce density of 25.3 physicians, 31.6 nursing and midwifery personnel, 4.3 dentists and 5.9 pharmacists per 10 000 population [61]. During the period 2005-2012, the physician density increased from 19.3 per 10 000 population, while the nursery and midwifery personnel decreased from 40.9 per 10 000 population, and the dentists and pharmacists remained approximately the same[62]. In 2013, the Abu Dhabi emirate presented high ratios of physicians (25.1) and of nurses (52.1) per 10 000 population[63]. Translating these figures into absolute numbers, there were 6.864 physicians, 1.220 dentists, 14.235 nurses, 5.332 allied health professionals and 2.396 pharmacists divided by 1.626 licensed healthcare facilities (public and private)[64]. The physician's ratio per 10 000 population is increasing (6 per 10 000 population from 2012 to 2013) and the nurses and midwifery personal is decreasing in the country (4 per 10 000 population from 2012 to 2013), but increasing in the emirate of Abu Dhabi (from 42 to 52 per 10 000 in the last 5 years – 24%)[15]. Although all the growth in physician's ratios, the severe capacity gaps by speciality are in Intensive & Critical Care Medicine, Emergency Medicine, Neonatology, Orthopedics, Pediatrics, Oncology, Pediatric Surgery, Physical Medicine & Rehabilitation and Psychiatry[64].

Regarding the regions of the emirate, taking the physicians as an example, from the 6864 in the emirate (both public and private sector), 68.83% are in Abu Dhabi Capital Center, 26.38% are in the Eastern region and 4.79% are in the Western region[64].

4.2.2.2 SEHA – Abu Dhabi Health Services Company

The Ambulatory Healthcare Services (AHS) is a SEHA Health System Facility responsible for managing the facilities in community-based services across the emirate of Abu Dhabi[65]. SEHA is responsible and operates 12 hospitals, 11 dialysis centres, 62 ambulatory healthcare centres and clinics and 2 blood banks [66], employing a total of more than 17 500 professional staff across all three geographical regions of Abu Dhabi emirate (Figure 4)[65]. From the 62 ambulatory healthcare centres, only one is an occupational healthcare centre, 10 are disease prevention and screening centres primarily for infectious disease residency visa screening, and 9 dialysis centres and clinics [65].

Hospitals

In 2002, there were 35 public hospitals in the UAE, as well as 14 private hospitals and 128 outpatient clinics. At this time, although several small private hospitals have been set up over the past years[13] there was still a tendency for UAE nationals to seek treatment aboard in the United States and Europe. In Abu Dhabi, there were 41 private and public hospitals (10% of all are SEHA's), 587 healthcare centres (13% of all are SEHA's), 335 clinics (1% of all are SEHA's) and 402 pharmacies (14% of all are SEHA's) in 2013[64]. During the same year, the private PHC centres and clinics attended more outpatients (5,034,581) comparing with the public ones by SEHA (2,339,645)[66].

Primary Health Care

The AHS, under SEHA, has 38 clinics. From those, 18 facilities are in the region of Abu Dhabi and 20 facilities are in the Eastern region (Al Ain). The AHS does not provide PHC services in the Western region[67].

Ambulatory Healthcare Services

The Joint Commission International (JCI) is considered the gold standard in global health care and is part of a global enterprise of dynamic and non-profit organizations that led the innovative solutions to help health care organizations improving performances and outcomes. The focus of JCI is to "identify, measure and share best practices in quality and patient safety with the world." In 2012, the AHS was recognized by the JCI with 'Gold Seals', becoming the first institution of this type with such accreditation, in the world[68]. All of the ambulatory healthcare centres and clinics of the eastern region were part of this accreditation scheme[69]. To achieve this reward, these facilities must fulfil specific standards, specific for its own type, in this case – Ambulatory Care, and must address international patient safety/infection control goals, patient access, and assessments, patient records and information flows and certain administration procedures[70]. These standards are validated by JCI.

The AHS is also responsible for the Mobile Health Clinics and the School Health Services, which encompass 298 school clinics (including higher schools, universities and private schools)[66]. Approximately 80% of all AHS patients visits are primary health care consultations[66] with diabetes and cardiovascular disease comprising the majority of the chronic disease caseload managed in these centers[71].

4.2.2.3 Primary Health Care/Ambulatory Healthcare Services goals

In 2013, the PHC under AHS adopted the Patient-Centered Medical Home (PCMH) model and principles. This is a healthcare model redesigned in 2007 by the American Academy of

Family Physicians, the American College of Physicians, the American Osteopathic Association and the American Academy of Pediatrics to be a practice-based team care model[72], with the main objective to provide structure, proactive, and coordinated care for patients rather than episodic treatments for illnesses[66]. As the name of the model suggests, it has the patient in the centre surrounded by the primary care physician, the dietician, the nurse case manager, the counsellor, the speciality physician, the laboratory, radiology, pharmacy, and the hospital (Figure 9).

Globally, the PCHM is influencing some of the reforms in PHC delivery, it was vital to the primary care reform in USA[73]. There is evidence that this model is improving patient outcomes, moderating health disparities and reducing health resources by reducing the number of hospitals visits. The PCMH aims to inspire quality care, engage patients and expand access and delivery options[74]. These aims are aligned with the CCM ones and there is more than one study evaluating the PCMH interventions, such as patient registers, care plans, e-mails between the patient and health professional (team), self-management strategies and population profiles[73,75,76]. These PCMH interventions can be easily linked to the CCM elements: clinical information systems, delivery system design, self-management, and community. The PCMH model was only recently implemented in the Abu Dhabi emirate in 2013 and there are currently no publicly available records or reports on the monitoring or evaluation process.

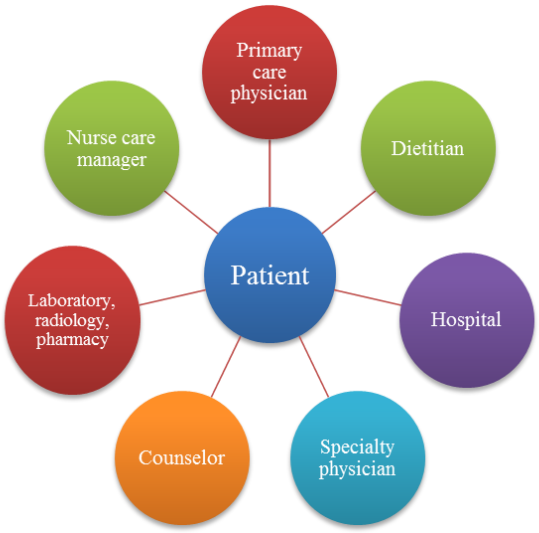

Figure 9: Patient-centered medical home model[66].

4.2.2.4 CCM aims

The CCM was designed with the main goal of transforming the daily care routine of the patients with chronic conditions from acute and reactive to proactive, planned and population-based[44]. SEHA developed a Health Education program to help to transform the routine of the patients with Diabetes, Heart and Circulation Diseases, Kidney Diseases and Health Lifestyle. Conferring with the 2012 Heath Statistics of Abu Dhabi "There are no systems in place to support patient self-care and management of chronic disease"[63], however, we found some evidence that it exists. Table 4 shows the evidence that we collect for each element of the CCM.

Table 4: CCM elements evidence in the AHS.

Model Elements	Evidence in Primary Healthcare Centers	Gaps
Self-Management Support	Through Health Education in SEHA's website and App: - Information about the importance of patients decisions and daily routines that affect their health and specifically according to the disease; - Information available about how to manage the types of Diabetes, Heart and Circulation Diseases, Kidney Diseases, and Health Lifestyle	Use effective self-management support strategies that include assessment, goal-setting, action planning, problem-solving and follow-up
Community	- SEHA is establishing electronic programs and communication channels (interactive when possible); - In 2013, lectures on health and nutrition were delivered for family foundation development schools;	- Encourage patients to participate in effective community programs; - Form partnerships with community organizations to support and develop interventions that fill gaps in needed services; - Advocate for policies to improve patient care
Health System	- In 2013 SEHA launched the National Hospital Quality Measure; - Provides performance data to the different professions;	- Promote effective improvement strategies aimed at comprehensive system change;

Model Elements	Evidence in Primary Healthcare Centers	Gaps
	- Set out procedures that will create shared responsibility for individuals towards their duties. - Provides incentives based on the quality of care; - Names and rewards outstanding individual contributors in different categories; - Each SEHA's hospital have linked Ambulatory Healthcare Services; - SEHA establishes partnerships with healthcare providers to ensure the accessibility (e.g. John Hopkins Hospital, Cleveland Clinic)	- Visibly support improvement at all levels of the organization, beginning with the senior leader;
Delivery System Design	- Care Plans; - Give care that patients understand and that fits with their cultural background	- Define roles and distribute tasks among team members; - Use planned interactions to support evidence-based care; - Provide clinical case management services for complex patients; - Ensure regular follow-up by the care team;
Decision Support	- In 2013, SEHA launched "Kafu", consumer care development program to standardize customer care by adopting the best practice; - Provides useful and specialized data; - SEHA offers interactive tutorials, videos, PDF's and quizzes about the topics in Health Education;	- Embed evidence-based guidelines into daily clinical practice; - Share evidence-based guidelines and information

Model Elements	Evidence in Primary Healthcare Centers	Gaps
	- Integrative teams with specialist expertise in primary care (ex: Dieticians following up diabetes patients in ambulatory centres)	with patients to encourage their participation;
Clinical Information System	- In the case of patients with health disease SEHA facilitates an emergency plan that the patient must know; - The patient's information is available in the SEHA database and any clinic can see it when it's needed; - The PCMH dash board has graphs, charts, and spreadsheets about chronic disease patients and doctor's performance;	- Identify relevant subpopulations for proactive care; - Provide timely reminders for providers and patients; - Share information with patients and providers to coordinate care; - Monitor performance of the practice team and care system.

4.3 Discussion

4.3.1 Summary of evidence

According to the 2013 Health Statistics of Abu Dhabi, there was an unequal distribution in speciality care across the three geographical regions of the Abu Dhabi emirate. Rural primary care is not well developed in the emirate, especially in the Western region and need several improvements like solving the critical shortages of healthcare workers. One important factor that is still affecting this ratio problem is the high turnover of qualified and competent healthcare professionals. It is a challenge to attract and retain qualified staff, especially in the rural areas of the emirate.

The PCMH adopted by SEHA to the AHS has the same base of care as the CCM. The MacColl Center for Health Care Innovation developed the Primary Care Team Guide to help the leaders and engage the staff transforming to a more effective team. "Team-based care can enhance the support and health outcomes of individuals with chronic diseases and be integral to implement the CCM and becoming a PCMH"[72].

However, one of the challenges of the current model of care is the lack of sufficiently self-management support and prevention (screening programs and diagnostic services are not integrated into care plans) and patients have undirected access to services and speciality care increasing inappropriate use and over-supply of services[63]. Although this review found evidence of the patient's central role in managing their health, as well as community resources available to provide on-going self-management to support the patients.

4.3.2 Limitations

The limitations of this study are the lack of recently available data and monitoring/evaluation of data publicly available. Also, the continuous need for research in fast-developing countries with such a different pattern of nationalities and regulated entities.

4.3.3 Conclusions

HAAD aims at promoting a future healthcare system based on empowered patients. To achieve this goal, pro-active check-ups and convenient routine follow-up should help to prevent disease and must be implemented in well-developed primary and sub-acute care (with home care and integrated telemedicine).

Now that three years have passed since the implementation of the PCMH, there is the requirement to monitor and oversee its implementation and evaluate the short-term results. It will be fundamental to conduct further research to understand some questions like "how health professionals are adapting to changes and challenges in care? Do the patients already notice significant differences in the service provided?" that can lead us to achieve even more improvements in the health system of Abu Dhabi emirate.

4.4 Bibliographic elements

As a result of this study posters, oral presentations and paper were published. A poster with the title "Characterization of the primary healthcare services in the emirate of Abu Dhabi – a systematic review of the ambulatory health services goals" was presented at VII Jornadas Científicas do IHMT, Lisbon, 12 December 2016. At the 21st WONCA World, Rio de Janeiro, 2-6 November, 2016, an oral communication entitled "Primary health care challenges and chronic care model in the United Arab Emirates" presented (https://proceedings.galoa.com.br/wonca/trabalhos/primary-health-care-challenges-and-chronic-care-model-in-the-united-arab-emirates). An oral communication on the topic "Primary Health Care Challenges and the Chronic Care Model in the Emirate of Abu Dhabi, United Arab Emirates" was also presented at UAE Annual Research & Innovation Week, Al Ain, 21-22 November, 2016. This study was published in the Journal BMC Health Services Research in November 2017. The bibliographic reference is Paulo, M. S., Loney, T. and Lapão, L. V. (2017). The primary health care in the emirate of Abu Dhabi: are they aligned with the chronic care model elements? BMC Health Services Research, 17:725. On-line in: https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2691-4.

CHAPTER 5

5. Results and Discussion: Healthcare workers' perspective on the pathway towards chronic care integration in Abu Dhabi: A mixed method study

After the systematic review where it was possible to identify how the CCM is being implemented in Abu Dhabi's health system and the main gaps, there was still the need of deeper explore this model development and "how the delivery of care is being done". For that reason, the objective of this study is to explore and gain a deeper understanding of the perception of the healthcare workers about the level of integration of the CCM in the daily care of patients with diabetes, cardiovascular disease, and cancer in the emirate of Abu Dhabi.

5.1 Methods

Due to the specific nature of the study that intends to explore, a mixed methods study design (both quantitative and qualitative) was used and reported according to the COnsolidated criteria for REporting Qualitative research (COREQ) Checklist (ANNEX 3).

5.1.1 Research team and reflexivity

5.1.1.1 Personal characteristics

One female researcher, with a Master degree in Public Health and who is currently finishing her Ph.D. in International Health, was responsible for conducting all interviews whilst bracketing her own preconceived beliefs or experiences. *Bracketing* involves the continual concerted attempt by the researcher to *'suspend'* their previous knowledge or experience of

the phenomenon which in this study was the health system [77]. In addition, another researcher independently completed the researcher's score of the ACIC for each transcript to ensure consistency of scoring across interviews and to minimize interviewer bias that can result from using only one researcher.

5.1.1.2 Relationship with the participants

No relationship was established with the participants prior to the study.

5.1.2 Study design

5.1.2.1 Theoretical framework

In this study, qualitative and quantitative data were collected simultaneously, with a semi-structured topic guide and quantitative scoring system for each question. Content analysis was used to guide the qualitative analysis of the results using words as the unit.

5.1.2.2 Participant selection

A purposive snowball sample method was used to recruit physicians, nurses, and allied professionals working with patients with chronic diseases in both public and private healthcare facilities in the emirate of Abu Dhabi, UAE. In qualitative research, many times the ability to generalize the work to the whole research population it is not the goal. That was the case in the present study, the reason why we used the purposive sample – snowball – where one participant names the following participant in the research, and through their social network, other participants, that meet the inclusion criteria, contribute to the study[55].

Thus, the first step was to identify a person who was eligible to participate according to the inclusion criteria: speak and understand English, worked in the same facility for more than one year, and currently providing care to more than 20 patients (monthly average) with

diabetes, cardiovascular diseases, or cancer. This first-person named one other person, who subsequently named another one. In total, 33 participants were approached by e-mail and telephone with 14 of these completing interviews (42% response rate). From the nonresponse participants, 17 (52%) did not respond to the email and telephone call and 2 (6%) stated that they were too busy as the reason for not participating in the study.

5.1.2.3 Setting

The Ph.D. student led the interviews in a quiet, comfortable, and a private room in the Clinical Skills Simulation and Training Center (College of Medicine and Health Sciences, UAE University, Abu Dhabi, UAE) with only the participant present. The interviews were recorded using a digital app recorder Voice Memos and the mean duration of the interviews was 36.1 ± 10.6 minutes (range 23-62 minutes). The study recruitment and data collection were completed between November and December 2016.

From the 14 participants, 11 were females with an average age of 36.4 years old. Seven were nurses, six were physicians and one was a dietitian. All participants worked in healthcare facilities in the emirate of Abu Dhabi and three of them in the private sector. Regarding the chronic diseases services under analysis, seven participants reported about diabetes, four reported to cardiovascular diseases and three to cancer (Table 4).

Table 5: Socio-demographic characterization of the participants.

Participant	Gender	Age group	Professional category	Overall years of experience	Years of experience - facility	Healthcare sector	Chronic Disease
P1	Female	30-34	Nurse	10	10	Public	Diabetes

Participant	Gender	Age group	Professional category	Overall years of experience	Years of experience - facility	Healthcare sector	Chronic Disease
P2	Female	25-29	Nurse	7	2.5	Public	Cancer
P3	Female	30-34	Nurse	10	10	Public	Cardiovascular diseases
P4	Female	25-29	Nurse	5	5	Public	Diabetes
P5	Female	45-49	Physician	14	1	Public	Diabetes
P6	Female	30-34	Dietitian	10	4	Private	Diabetes
P7	Female	30-34	Nurse	11	1	Private	Cancer
P8	Male	40-44	Nurse	19	16	Public	Cancer
P9	Male	35-39	Physician	6	4	Private	Cardiovascular diseases
P10	Female	60-64	Physician	36	8	Public	Diabetes
P11	Female	30-34	Physician	4	2	Public	Diabetes
P12	Female	25-29	Physician	3	1	Public	Diabetes
P13	Female	30-34	Nurse	11	11	Public	Cardiovascular diseases
P14	Male	35-39	Physician	12	1	Public	Cardiovascular diseases

*NOTE: Age groups defined according to World Health Organization age-standardized classification.

5.1.2.4 Data collection

Prior to data collection, the researcher explained the aim of the study and the Informed Consent to the participants (APPENDIX A). The participant had time to read it, and just after signed, the data collection process started.

In order to characterize the sample of physicians and nurses that participated in the present study, a socio-demographic survey was administered (APPENDIX B).

The semi-structured topic guide was designed (APPENDIX C) based on the ACIC, of the "Copyright 2000, the MacColl Institute for Healthcare Innovation, Group Health Cooperative" (ANNEX 1) and it was completed for one chronic care condition (diabetes, cardiovascular diseases, and cancer). The guide was piloted in three healthcare workers and reviewed and updated subsequently. After each question, the participant was asked to score its own answer through the ACIC subscale scores: between 0 and 2 = limited support for chronic illness care; between 3 and 5 = basic support for chronic illness care; between 6 and 8 = reasonable good support for chronic illness care and between 9 and 11 = fully developed chronic illness care.

There were no repeated interviews or transcripts returned to the participants and they were audio recorded, so there was no need to collect field notes.

5.1.3 Data analysis and findings

5.1.3.1 Data analysis

In the first stage of data analysis, descriptive statistic techniques were applied to characterize the individual characteristics of the participants and the participant's responses to each ACIC question. As the ACIC is based on a Likert scale the analysis was simple, following the cut-

offs established and previously mentioned. The scores for each section were obtained by summing the values and dividing by the number of items within that section. The overall score is derived by summing the average scores of each section and dividing by the number of sections administered[1].

All the interviews were transcribed *verbatim* into QRS International's Nvivo 11 qualitative data analysis Software. Each element of the ACIC was considered as a parenting node and the subcomponents were considered as child nodes. While reviewing each transcript and analyzing the qualitative data, two researchers, independently, completed the ACIC, according to participant's answers, and the average score of researchers and the average score for participants were tested for statistical significance. Triangulation was used. It is a method used by qualitative researchers to check and establish validity in their studies by analyzing a research question from multiple perspectives. In this case, two researchers score the ACIC based on participant's interview answers. During the content analysis, using words as a unit of analysis to form word clouds, it was observed that 'patient' and 'care' where appearing and the three most frequent words in all the six elements influencing the emerging concepts. Therefore, a second qualitative analysis was performed removing these two words considered as noise. Therefore, a second qualitative analysis was performed removing these two words considered as noise.

Participants were classified by profession, health sector and patient's chronic disease condition they were reporting, to allow to query if "Is there a difference in the approach to chronic care between physicians and nurses?", "Is there a difference in the approach to chronic care between public and private workers?" or "Is there a difference between the care provided to diabetic patients and cancer patients?". It was not possible to complete respondent validation on the qualitative findings due to the demanding schedules of the

healthcare workers. This study was approved by the Social Sciences Ethical Committee of the United Arab Emirates University.

5.2 Results

The element health system, the organization of healthcare, showed a mean score of 8.1, which reflects reasonably good support for chronic illness care within a health system. The subcomponent 'overall organizational leadership in chronic illness care' was the highest ranked element with an average score of 9.2 (Table 6), with 13 (93.0%) participants reporting a score from 9-11. In this element, the 'incentives and regulations for chronic illness care' (score of 7.2) and the 'benefits' (score of 7.3) are the areas with the lowest score showing room for improvements in chronic illness management programs (Table 6).

Table 6: Health system results in analysis.

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
Organizational leadership in CIC	9.2 ± 1.9 (3, 11)	…is part of the system's long-term planning strategy, receive necessary resources, and specific people are held accountable.	P1 – "*they are taking it seriously and are playing a big role*". P6 – "*good quality of care, yes, is reflected in the long-term strategy, yes, we have the resources, we have the staff and we have the money*". P7 – "*we will have discussions way before and we will allocate budgets and human resources for recruitment and we will have updated*

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
			policies and procedures and clinical guidelines".
Organizational goals for chronic care	8.6 ±2.2 (3, 11)	…are measurable, reviewed routinely, and are incorporated into plans for improvement.	P4 – "*monthly we have specific people who do auditing on our documentation, especially about education (…) and if it is low then we have to do an action plan and our manager will be involved*". P6 – "*it is a high score because they are actually renewing even the policies yearly or after 2 years*".
Improvement strategy for CIC	8.1 ±2.8 (1, 11)	…utilizes a proven improvement strategy for targeted problems.	P2 – "*we have things that measure our improvement if it is not (good) (…) there are improvement strategies for everything*". P7 – "*we would have task-forces of committees settled for specific services, "ok this is what we want to do", from qualitative perspectives or costs, they will gather everyone representative from different departments and they will work on it*". P11 – "*it is proactively in meeting organizational goals to be as the international*".

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
Incentives and regulations for CIC	7.2 ±3.6 (1, 11)	…are used to support patient care goals.	P1 – "*they are trying to let us do the maximum without a budget*". P7 – "*it is mostly focused on utilization and costs effectiveness*". P10 – "*I don't think they do it as motivation to patient care. I think it is done because it must be done*".
Senior leaders	8.1 ±2.1 (3, 11)	…encourage improvement efforts in chronic care.	P4 – "*they encourage the improvement because they have that policy that they have to follow*". P12 – "*they encourage only, I don't think they are participating in improving efforts*".
Benefits	7.3 ±2.5 (4, 11)	…encourage patient self-management or system changes.	P1 – "*they encourage, but not in a nice way. You need tools to at least to give the patient the maximum*". P4 – "*it is encouraging but not designed to promote, we are good we are giving education. But verbally*". P10 –"*Self-management is missing, it is very doctor-centered*".

The content analysis of this element showed that the more frequent words, with synonyms, were 'improvement' and 'encourage' (Figure 10). This suggests that the health system is oriented, or at least is making an effort, to a patient-centred chronic care model. However,

some quotes such as from P10 in 'benefits', suggest that the health system is still in transition from a doctor-centred model to a patient-centred model, showing the improvements being implemented and the encouragement from the senior leaders of the organization (Table 6).

Figure 10: Health System word cloud (resulting from the qualitative content analysis of the interviews).

The community element reflected by the linkages between the health system and the community resources presented the lowest score of 6.3. The 'partnerships with the community organizations' were considered to be either non-existent or not yet implemented by 64.3% of participants with an average score of 4.7. The 'linking patients to outside resources' show an inconsistent range of values from 1-11 with an average score of 6.1 and the 'health regional plans' were considered from 9-11 by 57.2% of participants with an average score of 8.1 (Table 7).

Table 7: Community results in analysis.

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
Link patients with outside resources	6.1 ±3.8 (1, 11)	…is accomplished through a designated staff person or resource responsible for ensuring providers and patients make maximum use of community resources.	P7 – "*we don't have a systematic way, (…) it is more limited to a patient-specific (…) it is limited and poorly coordinated as well*". P8 – "*we have a social worker and they have designated people to link people to other resources in the country*". P11 – "*we do the referral electronically, but the patients have to carry it on from there and it is a limited list*".
Partnerships with community organizations	4.7 ±3.0 (0, 10)	…are being considered but have not yet been implemented.	P1 – "*we have it with a gap, it needs to be improved because we don't have the facilitator to show us where the patient is*". P4 – "*we don't have*". P8 - *there is not a system to link these resources together (…) we have the designated person and we can refer and we can support, but it comes from our initiative, the resources and institutions it is not linked together. It is not a real partnership*".

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
Health regional plans	8.1 ±3.2 (1, 11)	…currently coordinate guidelines, measures or care resources in one or two chronic illness areas.	P7 – "*we try to implement the International Guidelines on each patient, so we discuss each patient case in the light of…*" P10 – "*we have structured plans, actually they have guidelines, (…) which actually are very well structured with algorithms in there and regulations as well. And they are published regularly and they circulated on a monthly basis. It's available freely and on a monthly basis, we get the updates*". P13 – "*the health plans are more linked financially and the guidelines never have a financial component, so when they try to put the guidelines and the health plans together if it doesn't make financial sense them there is a divergence (...) the health plan is dependent on the employer so the guidelines will say you need to have this, this and this and they say no, we don't cover those tests".*

'Guidelines', 'link' and 'designated', plus synonyms, were the words most referenced in the community element answers (Figure 11). This analysis translates the constant reference to

the guidelines when referring the health plans, showing the concern of health authority to design plans and programs in line with the latest recommendations.

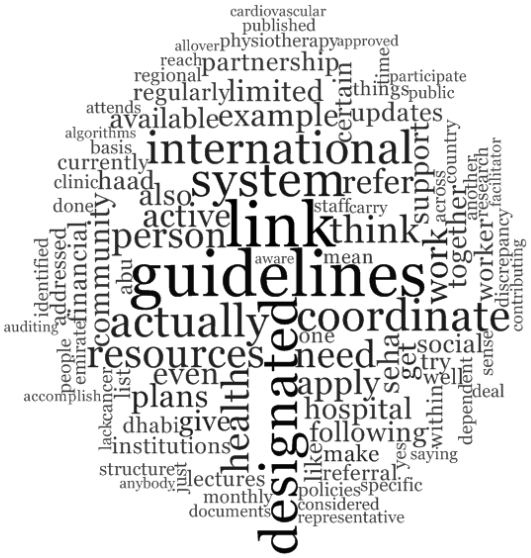

Figure 11: Community word cloud (based on qualitative content analysis of the interviews).

Although standardized treatment guidelines from the Health Authority Abu Dhabi exist, there seem to be inconsistencies between physicians with regard to the clinical use of the guidelines in practice. Two participants (P4 and P10) highlighted this point which is exemplified by the following quotes from P4 'there is no differentiation, they are just following the guidelines' and P10 'it is individualized per doctor and each doctor has a mindset of which guideline to follow' (P4 and P10). The reference to 'link' between patients and resources and the designated staff person illustrates that a 'designated person' already exists in almost all the settings, as the CCM recommends. This feature may help to further redesign the partnerships. When questioned about possible factors for the lack of community links and partnerships, cultural and traditional concepts emerged as an explanation: P10 – 'we try to make a walking

or running group, but patients are not interested in doing things together. They will do it individually on their one, with the families, but as a group they have difficulty'.

Self-management support appears as the second lowest score with an average of 7.0. The first part of the elements' strategy is being implemented, as we can see the 'assessment of self-management support needs and activities' has an average score of 8.3. However, the part of the education itself is lacking reflecting the lowest average score of 6.0. For example, over half of the participants (57.1%) reported only 'addressing the concerns of the patients and the families' for specific patients, 28.6% of them limited the education to the distribution of pamphlets, but 42.8% confirmed that education about self-management was an integral part of the routine care (Table 8).

Table 8: Self-management results in analysis.

Subcomponent	**Mean ± SD (Minimum, Maximum)**	**Score Level**	**Quotes**
Assessment of self-management needs	8.3 ± 3.4 (2, 11)	…are completed in a standardized manner.	P3 – "*we assess the patient holistically – his knowledge, his awareness, compliance, what he knows and doesn't know – and then we work on his weaknesses. So it is regularly assessed*". P8 – "*it is part of the work, it is a daily basis, we have policy and procedures to be followed, clear guidelines about documentation and everything is documented electronically*".
Self-management support	6.0 ±3.2 (1, 11)	… is provided by trained clinical educators who are	P2 – "t*he nurse herself is the educator, we don't have a designated person for education*".

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
		designated to do self-management support, affiliated with each practice and see patients on referral.	P5 – "*the nurse is doing the job of a clinical educator, as well. Before me, she is the one who educates the patient and if the patient still has some issues or some concerns to be cleared then I'm the one".* P12 – "*the doctor and the nurse the ones that educate the patient*".
Address concerns of patients and families	6.2 ±2.5 (3, 10)	…is encouraged, and peer support, groups, and mentoring programs are available.	P4 – "*for me as a nurse I'm not allowed to tell him and explain him the report*". P6 – "*it depends on the type of information that he wants, if it is related to the medication I will send them to the nurse of pharmacy if it is related to his condition I will send him back to the doctor*". P11 – "*this is a part where we kind of fall behind, so, it is provided for specific patients when I see that they are ready, the setting is ready*".
Effective behaviour change interventions and peer support	7.5 ±3.1 (1, 11)	…are available only by referral to specialized centres staffed by trained personnel.	P5 – "*I explain to them what is the required value, and we call them back to see how the values are going. So, this will show us the change of behaviours and the results in the values*".

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
			P12 – "*we are giving them the booklets, we discuss with them, sometimes if they need a referral for the doctor we refer*". P14 – "*effective change behaviour requires multiple physician visits, it is not a one-time visit (…) and there is a serious lack of follow-up*".

The content analysis highlighted 'educator', 'needs' and 'know' as the most common words (Figure 12), once again it is possible to see the patient in the centre, with the educator (role played by the nurses or physicians) assessing the health literacy needs of the patient. In this range of questions, emerging concepts focused on the lack of time available of the professionals due to multitasking and non-standardized procedures.

Figure 12: Self-management Support word cloud (based on qualitative content analysis of the interviews).

Decision support presented an average score of 7.7, the third highest score, which according to the scoring guidelines, also translates to reasonably good support for chronic illness care. However, the score for this element is below the top score 9-11 required for a fully developed chronic illness care. The scores for 'involvement of the specialists in primary healthcare' varied between participants. Although the mean score for this element was 6.2 the range was from the lowest possible score (1) to the highest score (11) with 35.7% of participants reporting that specialist involvement was through traditional referral (scores until 2) and 50.0% of participants affirmed that the specialists are involved and improving primary healthcare (from 9-11). The components 'providing education' and 'informing the patient about the guidelines' were both ranked with 7.9 and availability of the 'evidenced-based guidelines' was ranked with 9.0 which means fully developed support for chronic illness care (Table 9).

Table 9: Decision support results in analysis.

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
Evidence-based guidelines	9.0 ± 2.4 (4, 11)	…are available, supported by provider education and integrated into care through reminders and other proven provider behaviour change methods.	P5 – "*they are on the computer all the time, whenever you want to review you just click and it is there*". P9 – "*we use up to date and it is readily available. I have it even on my smartphone"*. P10 – "*they are definitely available or even on the system on the computer, so, if you want to you can just open them, but if you don't want to…"*
Involvement of the specialists in improving primary care	6.2 ±4.2 (1, 11)	…includes specialist leadership and designed specialists who provide primary care team training.	P4 – "*the specialists are not available and sometimes you have to "fight" with them to come and see the patient, they are not always accessible. So it is primarily through traditional referral"*. P6 – *"they train us we have a weekly case discuss and another (meeting) with topics"*. P13 –*"it is primarily through traditional referral*".
Education for CIC provided	7.9 ±3.1 (1, 11)	…is provides optimal methods.	P4 – "*we involve the family in the patient education because we have old people and usually they forget so we ask the son, daughter, wife to come and attend the education session,*

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
			or the caregiver who will be with him all the time". P6 – "*start from the doctor, then the dietitian and then the educator. It is a practice team*". P13 – "*provided systematically through traditional methods, like instruction, we are giving them instructions, do this, this and that*".
Informing patients about guidelines	7.9 ±3.5 (0, 11)	…is are done through specific patient education materials for each guideline.	P2 – "*it happens sometimes if the patients ask. We do inform them but not everyone, depends on the situation, the requirements of the patient*". P6 – "*we give them and our educational material is based on the latest recommendation*". P12 – "*when they ask and when they are not sure about the treatment we are giving, we are saying: according to the guidelines who were built upon lots of research this is what we have to do next. So yes, we are providing them with lots of information*".

'Available', 'give' and 'need' were the words that came out from the content analysis (Figure 13), suggesting a duality where both the healthcare workers and the healthcare organization provide what is needed for the patient and for the health professional, respectively.

Figure 13: Decision Support word cloud (based on qualitative content analysis of the interviews).

The delivery system design was the element of the model with the highest average score of 8.5, which translates to a fully developed support system for chronic illness care. 'Continuity of care', 'follow-up' and 'practice team leadership' were the three components that scored below 8.5 (fully developed). The majority (85.7%) of professionals have 'planned visits for chronically ill patients' and this was the highest component ranked with 9.5 (Table 10).

Table 10: Delivery system design results in analysis.

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
Practice team functioning	8.7 ± 2.7 (2, 11)	…is assured by teams who meet regularly and have clearly defined roles including self-management education, proactive follow-up and resource coordination and other skills in CIC.	P8 – "*we have a team meeting, we discuss cases, we introduce cases and the changes that are happening in the patients*". P10 – "*the chronic care nurse sees the patient first, she does the sifting, she identifies what tests need to be done. And there is definitely a nutritionist that you know and there is a physiotherapist that you know and you know the pharmacist...*"
Practice team leadership	8.4 ±3.1 (1, 11)	…is assure by the appointment of a team leader but the role in chronic illness is not defined.	P3 – "*it is appointed for the team, either assured that the role and responsibilities of the chronic care are clear*". P10 – "*the leader's role is very specific and they are accountable, I think this is the thing why they push and pushing because the accountability at this stage goes to income generation*".
Appointment system	8.8 ±2.7 (4, 11)	…includes organization of care that facilitates	P1 – "*we have an appointment for the system (…) we have the time, period of time, everything*

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
		the patient seeing multiple providers in a single visit.	*is on the system. However, if the patient needs to come he just gives me a call*". P4 – "*we have a clerk person and he is responsible for doing the appointment for the person*". P11 – "*patients can come and see multiple providers, but that is sometimes based on the request. We don't do that proactively*".
Follow-up	8.2 ±3.3 (1, 11)	…is assured by the practice team by monitoring patient utilization.	P3 – "*the doctor will write after 2 or 3 weeks according to the guidelines and it will be automatically, but we don't have the team we don't have guidelines for follow-up it is just from the doctor*". P13 – "*we are giving them follow-up, schedule by the guidelines, we are not making sure if it is utilized or not*". P14 – "*the physician has to decide and customize it to the patient needs*".
Plan visits for CIC	9.5 ±2.5 (3, 11)	…are used for all the patients and include regular assessment, preventive interventions and	P4 – "*we have a plan for chronic care visit, we give them appointment on discharge and it is used for all the patients*". P5 – "*if today your blood test is ready, you have an appointment in a week time to review your results and discuss. It is a system*".

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
		attention to self-management support.	P11 – "*it is for all patients including preventive and screening tests*".
Continuity of care	7.7 ±3.4 (0, 11)	…between primary care providers and specialists and other relevant providers is a priority but not implemented systematically.	P2 – "*it is a high priority and all chronic disease interventions include active coordination between primary care and specialists*". P3 – "*it is a routine thing they will do for all the patients, not specific*". P11 – "*it is a priority but it is not implemented. Because sometimes patients do not get to see the same doctors and do not follow the continuity of care*".

From the content analysis, the words 'see', 'follow' and 'appointment' were the most repeated ones (Figure 14). 'See' refers to 'the doctor sees the patient', which is deeply related to follow-up through appointments and explains the good score for this element.

Figure 14: Delivery System Design word cloud (base on qualitative content analysis of the interviews).

The clinical information system presented an average score of 7.4 (reasonably good support for chronic illness care). The 'registry' was the highest ranked subcomponent (8.9), while 35.7% of participants reported a lack of access to reminders in the system and 92.9% reported access to the relevant subgroups upon request. 'Feedback' presented a wide range of values, showing no consistency in the process and with an average score of 7.3 (Table 11).

Table 11: Clinical information system results in analysis.

Subcomponent	**Mean ± SD (Minimum, Maximum)**	**Score Level**	**Quotes**
Registry	8.9 ±2.7	…is tied to guidelines which	P1 – "*I can open the file (…) access to everything he was done or he would do.*

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
	(3, 11)	provide prompts and reminders about needed services.	*Everything will be documented down and in the system.*" P5 – "*we have reminders for whatever screening or what the patient is due for*". P10 – "*it does not give you prompts and that, but (…) if you prescribe medication that is contraindicated or which they have drug interaction there is a pop-up as a warning*".
Reminders to providers	6.4 ±4.3 (0, 11)	…includes indications of needed service for populations of patients through periodic reporting.	P1 – "*we don't have*". P4 – "*if the patient was admitted without height and weight, it will appear for you like a small message saying "this patient doesn't have height and weight information".* P13 – "*we have, but depends on what the doctor enter the system. We have but it is not effective*".
Feedback	7.3 ±2.9 (2, 11)	…occurs at frequent enough intervals to monitor performance and is specific to the team's population.	P5 – "*we have our performances, every beginning of the year, middle of the year and end of the year (…) we have things to achieve and there are numbers of productivity and things like that*". P6 – "*it is at infrequent intervals and delivered, but, not impersonally, it is personally*".

Subcomponent	Mean ± SD (Minimum, Maximum)	Score Level	Quotes
			P11 – "*we do have information about how well we are adhering the guidelines, it is not specific for the team's population, as we just said the doctor wouldn't be sure if this patient is coming back or not (for him) so specific populations does not apply to all the physicians*".
Information about relevant subgroups	5.9 ±2.7 (1, 11)	…can be obtained upon request but is not routinely available.	P7 – "*I would say it is established between me and the patient and according to the guidelines*". P8 – "*that is with the IT if I'll give them the list I will get it*". P13 – "*not available like that, I can request, by the disease specifically*".
Patient treatment plans	8.4 ±3.2 (2, 11)	…are established collaboratively and include self-management as well as clinical goals.	P3 – "*we have (…) with the times, specific. Following the SMART objectives*". P4 – "*we have to have a care plan for each patient, what type of education we need to give and what type of monitoring we need to do for him*". P9 – "*I would say it is established between me and the patient and according to the guidelines*".

'Available', 'give and 'guidelines' were the most common words in the content analysis for this element, revealing the availability of the guidelines in the clinical information system and, in some cases, providing on-screen prompts to the providers (Figure 15). In this element, there seemed to be clear differences between the public and the private sector with the private system lacking a well-designed and efficient system in place capable of integrating all of the patient's' needs with links to the appropriate treatment and self-management guidelines. In contrast, the public system seemed to be well-integrated (Table 11).

Figure 15: Clinical information system word cloud (based on qualitative content analysis of

the interviews).

In general, the overall mean score (±SD) reported by physicians was higher than the score reported by nurses 7.9±1.5 versus 6.7±2.1, respectively. In addition, the overall average score reported by healthcare workers from the public sector was greater than healthcare workers from private settings 7.7±1.7 and 6.9±3.0, respectively. Comparing the overall mean score for the three different chronic diseases under analysis, the score for diabetes mellitus (8.7

±1.1) represented a fully supportive chronic illness care system, followed by cardiovascular diseases with a good support score (6.3±1.7), and cancer with a slightly lower average score of 6.1±2.2.

The ACIC participants' score and the ACIC researchers' score were tested for the equality of the means and they were significantly different (p-value≤0.01). As mentioned, the researchers scored the ACIC according to the participants' qualitative answers. These findings show that the participants' quantitative score was incongruent with their individual qualitative data; specifically, there was a trend for participants to report a higher score for their organization's processes that were not reflected in their description of the processes. The quantitative findings suggest the health system has completed the transition from a doctor-centred model to the patient-centred model; however, the rich qualitative data implies that the transition is still in process (Figure 16).

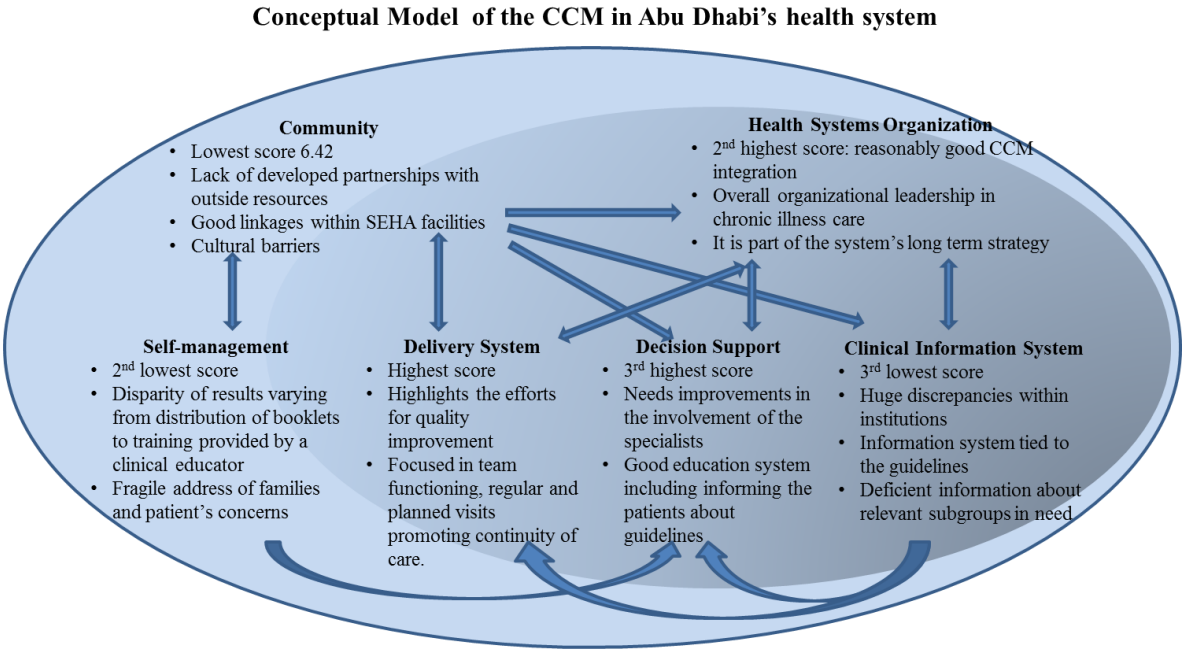

Figure 16: Integration of the element's results.

5.2 Discussion

This study describes the level of implementation and integration of the six elements of the CCM in the daily care of patients with diabetes, cardiovascular diseases, and cancer in the emirate of Abu Dhabi, UAE.

The health system's organization had a good score (8.1) which is consistent with other studies[41,78]. Actions to promote organizational leadership encouraging system changes may lead to best practices and quality improvement. This was used in previous interventional studies in primary care centres in the USA, where the health system's organization was one of the elements that the organization highlighted as a priority improvement area, as it is

apparently easy to translate results in the delivery of care to patients with chronic illness conditions [41,51].

The community component received the lowest score and this is consistent with other studies where it is not unusual that community is one of the elements that the health organizations do not choose to intervene. Hung and Shelley (2009) posited that it is easier to designate special roles in the delivery system design than to implement changes in external environments of the community element[78]. Culture emerged as a concept to explain the low score of this element. A cross-sectional descriptive study investigating the factors affecting participation in a community-based diabetes education program in Al Ain (Abu Dhabi, UAE) with 109 type 2 diabetes patients, showed that the barriers to participation in a community group were transportation issues, time constraints, employment status, and not willing to exercise with other patients[79]. This last reason was mentioned by one of the participants as shown in the results, and as Ali et al. (2015) refer in their study more than 50% of the participants were housewives or were raising a family, being considered unemployed[79]. Previous research has shown that participation in type 2 diabetes mellitus education services among unemployed individuals is higher than among employed individuals[80], so cultural barriers might explain part of these findings.

One of the actions that are currently perceived in interventional studies, to address self-management support, is the emphasis of patient education brochures and the referral to nurses educators. We found that Abu Dhabi's health system has implemented nurse educators, especially for diabetes self-care in some facilities. There is evidence that the UAE is moving from print-based patient education in pamphlets and booklets to active education and self-management support as it is conceptualized by the CCM. One of our findings was that the establishment of collaborative clinical (with doctor's goals) and self-management goals (with

patient goals) in one plan is currently in place in some but not all public healthcare organizations.

Decision support was the third element to be ranked on the average participant score. Evidence-based guidelines (both national and international) were reported to be available in all the facilities and fully developed to support chronic illness care; however, further work is needed in several settings to involve the specialists. The current model of care where specialists are available in the primary care clinic may be negatively affecting the family medicine doctor's role in referral and managing the patient's health and long-term follow-up[81,82].

Portugal had this model of the family medicine doctor's role and abandoned it after understanding its limitations and adopting the United Kingdom model where the family medicine physician act as a gatekeeper between the patient and the specialized healthcare centres or services. Through the selected quotes (Table 9) it is possible to observe that concepts such as 'instruction' and 'lots of information' emerged. Between 2006 and 2007, Al Maskari and colleagues conducted a knowledge, attitude and practices study in Al Ain (Abu Dhabi, UAE) with 575 diabetic patients (65% UAE nationals; 20% other Arabs) and reported that 46% of the sample were illiterate and 31% had poor knowledge about diabetes mellitus[83]. Low health literacy can cause misunderstandings.

Some of the interventions described to improve delivery system design in the USA interventional studies, such as the implemented planned visits, are currently in place in Abu Dhabi's health system[45,51]. Evidence on planned visits was collected showing that public organizations have scheduled and routinely available home visits for chronic illness patients; however, at present only UAE nationals are eligible for these services (Table 10). A previous study that analyzed the relationship between ACIC scores and changes in quality of care at

primary healthcare clinics in the USA between 2003-2005 reported that the delivery system design was the only element significantly related to change in the quality of care[41]. In the current study, this element of the model was found to have the highest score showing a health system that is proactive within its teams, has planned visits, which incorporate patient goals, and allows the healthcare organization to better manage their resources.

A clinical information system is one of the elements that should be consistently implemented by the organizations to lead to organizational changes [50]. For this reason, in the present study, this element was expected to have the highest score, but it was ranked as the 4th highest score revealing the vast inconsistencies between public and private organizations.

Our study revealed a difference in the overall mean score for the three chronic diseases with the score for diabetes mellitus indicating a fully supportive chronic illness care system whereas the scores for cardiovascular diseases and cancer represented good support. This finding may be related to the changing patterns of morbidity and mortality in the UAE following the completion of the epidemiological transition over the past three decades. Obesity and diabetes rates have steadily risen during the past two decades and subsequently, the health system and available services have focused on the needs of these patients over the past 10-15 years. The burden of morbidity and mortality associated with cardiovascular diseases and cancer has also risen in the last 5-10 years and this is most likely a consequence of high population rates of obesity and diabetes coupled with an ageing population.

5.2.1 Strengths and limitations

To our knowledge, this is the first study that has explored Abu Dhabi's health system using a standardized framework and instrument. One of the main strengths of this study was the use of the ACIC to understand the level of integration of the CCM and to provide guidance

on what health system changes may need to be considered in order to improve processes and outcomes of care. In addition, the mixed-method design provides important numerical data and rich qualitative data that help to explore the meaning behind values assigned, providing a deeper understanding of the research problem. It should be noted the positive feedback of the participants, they found the interview based on the ACIC extremely useful creating awareness of 'what they are actually doing', in some cases they are doing more than it seems and in another one, they identified areas and issues to improve. Despite these strengths, there are several limitations that need to be highlighted. The snowball sampling methodology is a non-random process that may have created a sampling and community bias, as once in the snowball sample participants tend to recommend friends or colleagues that may share similar characteristics or views[55]. As this is a mixed-methods study and interviews were conducted it is also possible that the personal experiences of the researcher may have influenced the interview; however, bracketing was performed to minimize this bias[84]. Finally, our findings represent the views of a purposive sample and may not reflect the views and opinions of all the healthcare workers in Abu Dhabi.

5.3 Bibliographic elements

As a result, from this study, a Poster entitled "Improvement of Chronic Diseases in Abu Dhabi: Is it innovative enough to tackle the challenges?" was presented at the 4th East Mediterranean Region WONCA in Adu Dhabi, 2-4 April 2017. another poster with the title "Assessing the Chronic Care Model Development in the emirate of Abu Dhabi" was presented at VIII Jornadas Cientificas do IHMT, Lisbon, 13 December 2017. A paper based on the present study was also produced and submitted to the *Global Health Action* Journal. The paper is under review since September 2017.

CHAPTER 6

6. Results and Discussion: Pushing Chronic Care Model forward in Abu Dhabi by emphasizing priorities and barriers: a modified Delphi technique

On the sequence of the cross-sectional study to understand the perception of the healthcare workers about the implementation and the development of the CCM in Abu Dhabi's health system, there was the need of ranking the top priorities to intervene and its' barriers. With that intention, the aim of this study is to prioritize the subcomponents and the barriers for the development of the CCM in the health system of the emirate of Abu Dhabi.

Due to the specific nature of the study that intends to reach consensus on the priorities and barriers, the Conducting and REporting of DElphi Studies (CREDES)[85] (ANNEX 4) was used.

6.1 Rationale and aim of this study

One of the key strategic goals of the UAE Vision 2021 National Agenda is to achieve a world-class healthcare system. The main rationale for this study was the need to conduct the first consensus exercise with key stakeholders to understand the role of the CCM in Abu Dhabi's healthcare system. The primary aim was to use a modified Delphi technique to identify and subsequently rank the priorities and barriers of the CCM in Abu Dhabi's healthcare system, UAE, in order to achieve full support for chronic illnesses. Utilizing a health policy prioritization approach to strengthen health services requires proper and focused policymaking. Therefore, the modified Delphi technique sought to elucidate the five

most significant priorities and barriers identified by participants that can be used to facilitate policy-making and health care reform in Abu Dhabi, UAE.

6.1.1 Prevention of bias

To maximize privacy and confidentiality, all participants were provided with an individual keypad (Keepad Interactive, NSW, Australia) to electronically log their responses. The software is extremely efficient in terms of avoiding missing data, as the number of people who answered each question appears at the corner of the slideshow. The polling results for each question can be shown in real-time to the participants; however, in this study, the participants did not receive any feedback until they were presented with the reduced list of priorities and barriers at the start of the subsequent round. The researchers conducting the modified Delphi technique did not have any conflicts of interest, so there was no need for an independent research team to coordinate the study.

6.2 Reporting

6.2.1 Expert panel

A purposive sample of 20 health systems' experts on the Abu Dhabi emirate health system was used to perform the modified Delphi technique. The inclusion criteria to be considered as a health systems' expert was: speak and understand English, work in the public or private sector of the healthcare system in Abu Dhabi, work in the same facility for more than one year and work in the delivery of care to patients with diabetes, cardiovascular or cancer. The participants were invited to attend three brief meetings to complete the three interactive rounds of the modified Delphi technique.

Table 12: Participants socio-demographic characterization.

Socio-demographic variable		Percentage
Gender	Male	30%
	Female	70%
Age group	25-29	43.75%
	30-34	18.75%
	35-39	12.50%
	40-44	0%
	45-49	18.75%
	50-54	0%
	55-59	0%
	60+	6.25%
Professional category	Physician	25%
	Nurse	37.50%
	Allied health professionals	18.75%
	Academia	18.75%
Healthcare sector	Public	93.33%
	Private	6.67%
Region	Al Ain	81.25%
	Abu Dhabi	18.75%
Average overall years of experience		14.83
Average years of experience – facility		6.33

The majority of the participants were females (70%), nurses (37.5%), working in the public sector (93.3%) and in the Eastern Region of Al Ain (81.3%). The average years of experience

were 14.8±13.7 years and the mean working time in the same facility was 6.3±3.3 years (Table 12).

6.2.2 Description of the methods

The modified Delphi method supports health policy decision-making and has been used previously to reach expert consensus on definitions, guidelines, and strategies for occupational health, elderly care, rural health, palliative care, primary health care, migrant health, diabetes, and medical professionalism. This study follows the recently published Guidelines to Conduct and Report Delphi Studies (CREDES)[85].

Study researchers prepared tables with the priorities and barriers to be provided for the participants on arrival. They also performed a pilot test of the modified Delphi technique to ensure the correct configuration and set-up of the wireless voting system through the PowerPoint presentation using the TurningPoint software, which has specific configurations for the type of question to be addressed and works as an interface with the wireless keypads. The participants used these individual computer-linked electronic keypads to vote and rank the priorities and barriers. The information provided from each wireless keypad was automatically logged on the computer system and the results (i.e. frequency and percentage) were provided immediately. After each round, the researchers analyzed the results to prepare the reduced list of tables and the PowerPoint presentation for the next round of the modified Delphi study.

6.2.3 Procedure and definition of consensus

Three brief meetings were conducted to execute the three selection rounds and achieve consensus through this technique. Each of the three rounds was conducted in three separate consecutive days where the priorities and barriers were voted to reach the “top five” by the

end of the third meeting. At the start of each meeting, two coloured sheets with the priorities and barriers on a table with a *Likert scale* (yellow for priorities and blue for barriers) were delivered for the participants on arrival (ANNEXX D). The participants were asked to use the coloured sheets to score the priorities and barriers according to the provided *Likert scale* 'not very relevant', 'relevant' or 'very relevant'. Once all the participants had completed the *Likert scale* on the paper, wireless keypads were distributed and oral instructions about how to use them were given in order to record their answers. At the end of the first round, the researchers reviewed the results of each priority subcomponent and barrier that were voted 'very relevant', 'relevant' or 'not very relevant', according to participants' previous handwriting choices (on the given coloured paper). The priorities and barriers that were considered 'very relevant' by at least 30% of the participants were selected for the next round. In this case, from the 28 priorities, there was a reduced to 16 and from the 20 barriers to 14. During the second round, the participants were asked to repeat the process and identify the five most relevant priorities and barriers by marking them as 'very relevant'. The five priorities and barriers with the highest percentage of participants ranking them as 'very relevant' were selected to be ranked in the third round. Three of the priority subcomponents: 'Improvement strategy for chronic illness care', 'evidence-based guidelines' and 'patient treatment plans' received the same proportion of votes. As a result of this tie, seven priorities were selected for the final rank (Figure 17).

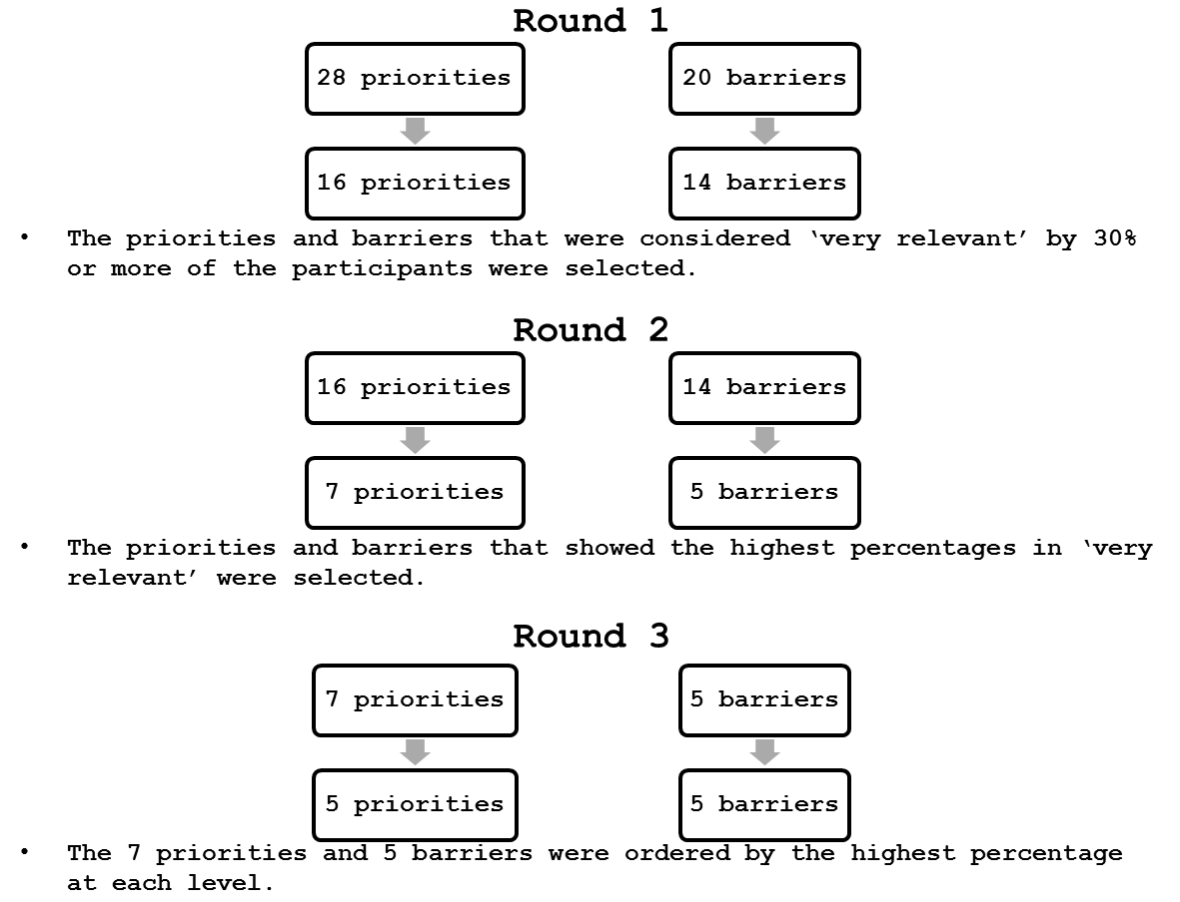

Figure 17: Delphi technique rounds.

6.3 Results

6.3.1 What are the top five priority areas to intervene?

Table 13 shows that 26.3% of expert participants selected the 'overall organizational leadership in chronic illness care' as the most important priority subcomponent of the CCM to address. The two subcomponents 'continuity of care' and 'effective behaviour change

interventions and peer-support' were voted as the second priority by 21.1% of the participants leading to a tie in the priority rank. The 'evidence-based guidelines' was voted as the third most important priority by 15.8% of the participants. The subcomponent 'improvement strategy for chronic illness care' was voted as the fourth most important priority by 10.5% and the subcomponent 'provider education for chronic illness care' was voted as the fifth by 5.3% of the participants.

Table 13: Round 3 results: top five priorities subcomponents of the CCM.

Rank	Percentage	Priorities
1	26.3%	Overall Organizational Leadership in Chronic Illness Care
2	21.1%	Continuity of care
2	21.1%	Effective behaviour change interventions and peer support
3	15.8%	Evidence-based guidelines
4	10.5%	Improvement strategy for chronic illness care
5	5.3%	Provider education for chronic illness care

6.3.2 What are the top five barriers to the development of the CCM?

'Patient compliance' was voted as the most important barrier to the development of the CCM by 36.8% of the participants. 'Lack of standardized processes/procedures' was voted as the second barrier by 31.6% of the participants, 'differences between insurances' was voted as the third barrier by 15.8% of the participants, 'lack of regional plans and standardizing guidelines between facilities' was voted to be the fourth barrier by 10.5% of the participants and 'lack of monitoring' was voted as the fifth barrier by 5.3% of the participants (Table 14).

Table 14: Round 3 results: top five barriers of the CCM.

Rank	Percentage	Barriers
1	36.8%	Patient compliance
2	31.6%	Lack of standardized processes/procedures
3	15.8%	Differences between insurances
4	10.5%	Lack of regional plans standardizing guidelines between facilities
5	5.3%	Lack of monitoring

6.4 Discussion

Among the six elements of the CCM that enclose the 28 subcomponents that the expert participants voted and ranked, the element "health system" was present twice in the subcomponents 'overall organizational leadership in chronic illness care' and 'improvement strategy for chronic illness care', while the elements "delivery system design", "self-management", and "decision support" appeared once linked to the other subcomponents. The elements "clinical system design" and "community" were not represented in the final priorities.

The 'overall organizational leadership in chronic illness care' was the subcomponent ranked as the most important priority to address, relating to health system organization and different leadership models. According to Lapão and colleagues (2017), the development of a healthcare organization is directly proportional to the leadership process, the professional's management ability, the incentives and the resources available[86]. The aim of any health system is to have higher awareness and more proactive participation of the managers. In order to provide the right environment to approach the managers and the health professionals exploring the dynamics of the relationships is crucial. Especially between leadership values,

culture, capabilities and the organizational context, supporting a high level of self, team and organizational awareness[86–88]. A study in Iran used the Delphi technique to facilitate designing an excellence and quality model for a primary health care training center[89]. The study authors also found that leadership was the component with most sub-criteria. Another Delphi study in South Africa (2013), identified governance and leadership as the most important priority and the fifth-ranked challenge to intervene in care provision in rural areas[90]. One should recognize that although "leadership" is now a clearer concept its operationalization is still not mature, which can explain some of the difficulties acknowledged by health organizations[91]. This first subcomponent ('overall organizational leadership in chronic illness care') is linked with the fourth priority 'improvement strategy for chronic illness care'. This 'improvement strategy for chronic illness care' is a core base of the CCM, addressing the need for the healthcare system reorganization to face the growing problem of chronic diseases. The development of the CCM advocates organizational changes in health delivery to a patient-centered model where, for example, the patient has a proactive role managing their own disease (e.g. through access to their personal health data), all the providers are able to see patients information in their workstations and agree to follow the same guidelines and treatments with patients agreement[44]. This example and suggestion of an 'improvement strategy for chronic illness care' integrate four of the six elements of the CCM (delivery system design, clinical information system, decision support, and self-management). Further analysis should be conducted to design an appropriate improvement strategy for each healthcare services centre. 'Continuity of care' was ranked as the second most important priority and it shows the perception of the experts for the need for a change in the delivery system design. In the Abu Dhabi health system, a patient is not allocated to a specific family medicine physician; rather, the family medicine physician working at the chronic care clinics, often does not follow the same patient every time the patient reaches the

system which causes a lack of continuity of care from the perspective of the doctor-patient relation. 'Effective behaviour change interventions and peer support' was also ranked as the second most important priority. In the United Kingdom, Spain or in Portugal, there is a general practitioner, or family medicine doctor, attributed to each person according to the residency area who acts as the first line of contact between the patient and the health system[92–94]. This allows the doctor to know their patient's history (and families), establish a relationship with them and to promote behaviour changes that are in the base of the prevention of the chronic diseases[93]. Implementing a similar general practitioner/family medicine physician model in Abu Dhabi may improve the continuity of care and enhance the effectiveness of behaviour change interventions.

'Evidence-based guidelines' was considered the third most important priority to improve the care of chronic diseases in Abu Dhabi, however, the UAE was a pioneer using evidence-based medicine, the concept was introduced in 1998[95]. One of the reasons for this subcomponent to be ranked as a priority might be the multinational origin of the healthcare workers, who tend to follow the guidelines of the country where they are from and/or training. For example, physicians from North America may follow the North American guidelines related to a specific chronic disease. A previous study concluded that the diagnosis and management of type 2 diabetes differed substantially between the United States of America, United Kingdon, and Germany[96]. Despite this issue, the competent health authority should have the mission to regulate and develop the healthcare sector and the individuals working within the health systems[64]. "Evidence-based guidelines" is also related to electronic health records and decision-support systems that might help health professionals improve their performance, in terms of better decisions and time.

'Patient compliance' was identified by the participants as the most important barrier. A study conducted in the Netherlands (2012) with the aim of understanding the development and coordination of disease management programs, also reported that patient involvement in their own care as a barrier to implementing the CCM[97]. From the literature, it is known that one way to address patient compliance is through patient education and participation[98,99]. The patient needs to be able to understand that they can have a proactive role in the management of their own disease if they are provided with self-management support sessions (the "how to comply").

A 'lack of standardized processes/procedures' was considered to be the second most relevant barrier and there is a need to integrate the delivery of care with the clinical systems for all professionals working in the health system. Also, this barrier seems to be related to the third one: 'differences between insurances'. Although health insurance is mandatory in the emirate of Abu Dhabi, there are different insurance packages depending on the type of employment and residence visa. These different insurance packages provide access to different coverage and access to services. For example, diabetes education or lactation consultations are not available for patients with the lower health insurances, which makes the delivery of care not standardized for the healthcare workers, as they are not able to provide the same procedure to all the patients. The 'differences between insurances' was also considered a barrier by Haggstrom and colleagues (2012) when they assessed the CCM implementation for cancer screening in community centres in the United States of America[100]. The 'lack of regional plans standardizing the guidelines between the facilities' was considered to be the fourth barrier. Similarly to other models, like the Portuguese or the Saudi Arabian health system[86,101], the Abu Dhabi's publicly funded health system seems to have a centralized organizational model[66] where all the facilities with the same level of care follow the same instructions: decisions tend to be centered in the administration of a whole group. The

decentralized model is when the facilities have some degree of autonomy, as for example, in Rio de Janeiro, Brazil[86]. In this case, further work inside the organization, engaging top managers, and healthcare workers are needed to understand why the same level of care following the same directions is not provided in all facilities. The barrier ranked as the fifth most important barrier was 'lack of monitoring'. This barrier is linked to the 'lack of standardized processes/procedures' and shows that the healthcare workers and clinical directors feel the need for monitoring and feedback of their performance, interventions or implemented measures. There is also the need to examine the effectiveness and efficiency of the different communication channels, both horizontally and vertically, within an organization. Hroscikoski and colleagues (2006) also in the United States of America, reported barriers related to the 'lack of monitoring' when they implemented the CCM in a group of 18 clinics: insufficient time to measure the change, lack of measures to assess change, and a lack of specific details and desired care changes[50].

This study addresses one of the UAE's Vision 2021 agenda aims which is to achieve a world-class healthcare system. It is hoped that our findings of the priorities and barriers of the CCM implementation in the Abu Dhabi health system will contribute to the continuous improvement of the quality of healthcare delivery both for the patient and healthcare workers. In addition, the UAE can serve as an example for other high income and/or rapidly developing countries facing the same challenges within their health system.

6.4.1 Strengths

The wireless computer-linked keypads ensured participant privacy and confidentiality during the modified Delphi technique and this should have minimized response bias. In addition, completing the study over three consecutive days, as opposed to weeks and months required with a postal or email methodology, resulted in a 95% response rate and a low attrition rate.

Overall, our methodology using wireless handheld keypads enabled a rapid consensus process to effectively identify priorities and barriers for the CCM in Abu Dhabi's health system. There are at least three previous studies that have used a Delphi technique in the UAE to reach consensus on occupational health, elderly care, and medical professionalism [102–104]; however, our study is the first to use a modified Delphi technique to elucidate the priorities and barriers of the CCM in Abu Dhabi's healthcare system.

6.4.2 Limitations

One of the limitations of this modified Delphi technique is the requirement for the participants to be physically present, which can introduce a selection bias if the attendance reduces significantly during the rounds[104]. However, the response rate in this study was 95%, as from day one to the end of the study only one participant was absent, round 2 and 3 had 19 participants instead of 20. Another limitation is the inability to generalize our results to the health systems operating in other emirates in the UAE, but that was not the purpose of this study.

The modified Delphi technique achieved the aim of identifying the priorities and barriers of the CCM in Abu Dhabi's healthcare system; specifically, 'Overall Organizational Leadership in Chronic Illness Care' was ranked as the top priority and 'Patient Compliance' as the most important barrier. This study represents an important step in the process of understanding the key barriers and priority areas for intervention to maximize the development of the CCM in the health system of Abu Dhabi.

6.5 Bibliographic elements

The study was submitted to the Journal *BMJ Open* in September 2017 and it was accepted in April 2018. The paper entitled "Pushing Chronic Care forward in Abu Dhabi by identifying priorities and addressing barriers: a modified Delphi technique" is currently being published.

CHAPTER 7

7. Conclusions and final recommendations

The UAE has experienced a profound change from an underdeveloped region of small desert principalities to a modern state. The major transformation started in 1973-74 with the extraction and exportation of oil, and wise investments of the UAE leadership. Nowadays the UAE is a high-income developing country with a competitive health system, which has been earning multiple international awards. The healthcare is regulated at both Federal and Emirate level (various entities at Emirate level) which mean that the division of power and regulatory entities are sometimes unclear in certain areas, as in relation to licensing and monitoring/control medical institutions[105]; however, in Abu Dhabi emirate there is only one institution, HAAD, responsible for healthcare regulation.

The UAE healthcare system is faced with rising demand due to high population growth caused by natural growth and positive net migration. Moreover, the UAE national population is young, but with high rates of chronic disease risk factors; therefore, the rates of chronic disease are projected to increase greatly as the young population ages.

The focus of Abu Dhabi's model of care is on empowering the patients, which is a key focus of the CCM components. There is evidence that the strategies implemented in the PHC of this emirate are linked to and share what the CCM defines as better approaches to each of its elements. To answer the growing problem of chronic diseases, the health system of Abu Dhabi adopted the PCMH. The adoption of this model by the PHC providers, the ambulatory healthcare centres, was undoubtedly a strategic choice and the model is aligned with the CCM. The future challenges will address the need to put in practice the conceptualization

between the chronic disease/condition centre to the patient and focusing on the dynamics of the multidisciplinary healthcare team.

Overall, the quantitative and qualitative study findings show that the Abu Dhabi health system has reasonably good and well-developed support for chronic illness care with the delivery system design being the highest scored element. According to the participants, Abu Dhabi's health system has a strategic plan reflecting a commitment to apply the best practices of the CCM and is moving to achieve the integration of leaders and all the members of the team. Although, regarding the partnerships with the community, their perception is that there are no partnerships linking the health services with the community. Additional efforts and new ideas are needed to mobilize community resources, from schools to governments, non-profit or faith-based organizations to work together with the health system in order to meet the needs of the patients[47]. Also regarding education, one fact to consider is the diversity of nationalities living in the UAE, where a large number of healthcare workers are from non-Arabic speaking countries and language barriers can play a role in optimal patient communication[106]. As such, future research may want to address questions such as 'are the physician guidelines and patient information materials appropriate to the population of the UAE?'

Our study revealed a difference in the overall mean score for the three chronic diseases with the score for diabetes mellitus indicating a fully supportive chronic illness care system whereas the scores for cardiovascular diseases and cancer represented good support. This finding may be related to the changing patterns of morbidity and mortality in the UAE following the completion of the epidemiological transition over the past three decades. Obesity and diabetes rates have steadily risen during the past two decades and subsequently, the health system and available services have focused on the needs of these patients over the past 10-15 years. The burden of morbidity and mortality associated with cardiovascular

diseases and cancer has also risen in the last 5-10 years and this is most likely a consequence of high population rates of obesity and diabetes coupled with an ageing population. Therefore, Abu Dhabi's health system is implementing the specific health system requirements to ensure that the chronic illness care system for these diseases will also transform into a fully-supportive patient-centred model of healthcare. The Weqaya (Arabic for "Prevention") program led by HAAD is an excellent example of a population-based cardiovascular screening program for individuals with or at risk of developing diabetes and/or cardiovascular disease which links both the clinical information system, the self-management and the decision support element. At present, the Weqaya program is only available to UAE citizens (aged ≥16 years) in the emirate of Abu Dhabi and therefore, excludes expatriates and UAE nationals living in the other six emirates.

One of the aims of any health system is to have higher awareness and a more proactive participation of the managers approaching them to the health professionals in order to provide the right environment to explore the dynamic relationships between leadership values, culture, capabilities and the organizational context, supporting a high level of self, team and organizational awareness [86–88]. It is expected that our findings on healthcare workers perception and on the priorities and barriers of the CCM implementation will contribute to expanding the quality of the healthcare delivery both for the patient and healthcare workers' satisfaction.

The United Arab Emirates shows to be an extremely good example in terms of the development and implementation of new health policies. The leadership stability, the availability and proper allocation of resources and the long-term economic, social and healthcare strategies allow the country to successfully develop and implement new policies, integrating the international evidence-based guidelines with the specific and unique social, religious and cultural aspects of the country.

To continue improving the delivering and quality of the chronic care, it would be interesting to conduct an interventional study using the ACIC at the baseline and at the end of the intervention, in order to measure the changes resulting from quality improvement efforts. To do this, engagement with key stakeholders from all sectors and positions of the Abu Dhabi health workforce will help to provide consensus on the next steps required to ensure Abu Dhabi's health system is prepared for the changing demographics and epidemiological disease patterns predicted for the UAE.

The ageing population and the increase of the chronic diseases suggest an evolution of global health through a pattern more and more related to lifestyle, behaviours and environmental health. To be prepared, the healthcare services should be community-oriented to provide continuous and coordinated care to meet the health needs of the population. Some recommendations to achieve this are:

- Educating the population about chronic diseases and prevention;
- Understanding the concerns and beliefs of the young UAE nationals to approach them using the model "person in the centre" (person because we want to engage them before they become a patient);
- Establishing partnerships with the community aligned with their cultural beliefs and practices;
- Standardizing the healthcare worker's policies – this is already completed by HAAD and the licensing exam, but, perhaps it should be reviewed;
- Engaging leaders to work together with their teams, creating, for example, linked community nurses;
- Monitoring policies for the private sector, to uniform the results with the public sector.

Abu Dhabi emirate's health system is internationally well-positioned and competing with others from developed countries, even facing the challenge of the unique characteristics of the population, both UAE citizens, and expatriates. Study findings from our fieldwork show that there is an effort in following the latest scientific evidence with the intention to achieve health gains (patient outcomes and limited resources) and prevent economic reductions. Abu Dhabi's health system is implementing the specific health system requirements to ensure that the chronic illness care system for these diseases will also transform into a fully-supportive patient-centred model of healthcare. These results emerged from expert participants, but they meet with the results from previous studies in the region. It also represents an important step to understanding where it is more relevant to intervene in order to maximize the development of the CCM.

The three studies have been submitted to peer-review journals, to enable both broader dissemination and the discussion toward the design of new policies.

Findings like this are very important in a moment where the country is working with all the authorities to achieve the UAE Vision 2021 National Agenda aiming world-class healthcare for all.

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APPENDIX A – INFORMED CONSENT

Research Study:

The Chronic Care Model use in United Arab Emirates Health System: is it enough to address the growing problem of chronic diseases?

Dear Healthcare Professional,

You have been invited to take part in a research study conducted by my colleagues and me from the United Arab Emirates University. Dr. Tom Loney from the Institute of Public Health, College of Medicine and Social Sciences of the UAE University is the Principal Investigator. Before you decide whether you will be willing to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

The main aim of the research study is to understand the Chronic Care Model and its scope in the health system of Abu Dhabi, concretely in the Eastern region of Al Ain.

Specifically, the research study is interested in the care of chronic disease patients and if it is related to the aims of the Chronic Care Model. Therefore, we need to understand how the delivery of care to patients with chronic disease has been done. We will focus on the major chronic disease in the country: cardiovascular disease, diabetes and cancer and we aim to contribute to the continuous improvement in the daily care to patients. We think this research is really important, and it may help researchers to understand the delivery of care to chronic patients in UAE.

Participation in the study is completely optional. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not have any negatives consequences for you.

Procedure

Your name was given by a colleague and you will be invited to attend an interview at the Clinical Skills Simulation and Training Center, in the College of Medicine and Health Sciences of the United Arab Emirates University. The interview will be conducted by one of the investigators and will last about 30-40minutes. There are no "right" or "wrong" responses to any of the questions or themes discussed in the interview or questionnaire as we just want to hear your view of how the care to chronic diseases has been done. The interview will be tape-recorded for later analysis, but your name will not be recorded or written on the tape copy or questionnaire, instead, you will be allocated a number to ensure anonymity.

The tapes will only be played back by researchers at UAE University in order to transcribe the interview, and will not be used for any other purpose. Only University researchers will have access to the interview transcripts and questionnaires; and your interview transcription, questionnaire responses, and identity will remain confidential, locked in cabinets and password locked computers at UAE University. The results of the study will be reported as a group, so you will not be identified in any way after taking part.

There are no disadvantages or risks taking part in this study and the benefit is to help the researchers to understand in more detail the delivery of care to chronic disease patients.

Unfortunately, we cannot offer you payment for participating in this study, as it is not being funded, but hope that you realize the importance of such research.

IMPORTANT

This research is entirely optional, and your rights will not be affected in any way if you choose not to take part. You will have the option to withdraw at any time, before or during the interview, questionnaire or measurements without needing a reason. If you are happy to take part, we would ask you to let us know by completing and signing the consent form below. If you would prefer not to take part, you need to take no further action. You are free to withdraw from the study at any time without any repercussions and are under no obligation to participate in the study. Further Information or if you have any queries regarding this study please contact Dr. Tom Loney (Tel: +971 3 713 7487 or email: tom.loney@uaeu.ac.ae).

Version number:_____

Thank you!

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Reply Slip

United Arab Emirates University Research Project

The Chronic Care Model use in United Arab Emirates Health System: is it enough to address the growing problem of chronic diseases?

Name: _____

I would like to take part in this research ☐

I would prefer not to take part in this research ☐

I understand that participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected. ☐

I consent to allow the researchers to use audio-taping ☐

I consent to allow the researchers to use direct quotes ☐

Please sign below:

_____ _____

Signature Date

APPENDIX B – SOCIODEMOGRAPHIC CHARACTERIZATION SURVEY

Research Study:

The Chronic Care Model use in United Arab Emirates Health System: is it enough to address the growing problem of chronic diseases?

Socio-demographic characterization survey	
Gender	Male ☐ Female ☐
Age:	**Nationality:**
Professional category	Physician ☐ Nurse ☐
Region of Abu Dhabi emirate:	
Years of Experience:	**Years of work in this facility:**
Healthcare Sector	Public ☐ Private ☐
Type of Service	Primary Healthcare Services ☐ Secondary Services ☐

Care to chronic disease patients (n. of patients monthly average)	Until 20 patients ☐ Between 21 to 40 patients ☐ Between 41 to 60 patients ☐ More than 61 patients ☐

Contact of the next person: _____

Version Number: _____

APPENDIX C – INTERVIEW SEMI-STRUCTURE TOPIC GUIDE

Semi-structured Interview, adapted from Assessment of Chronic Illness Care, Version 3.5

Part 1: Organization of the Healthcare Delivery System. Chronic illness management programs can be more effective if the overall system (organization) in which care is provided is oriented and led in a manner that allows for a focus on chronic illness care.

1. How is the organizational leadership in Chronic Illness Care reflected in your workplace? Please answer it in terms of vision statements and business plans, reflected by senior leadership or part of the system's long-term planning strategy.
    a. How do you consider it is?
    b. Can you give me some examples?
    c. Score it, please.
2. What are the organizational goals for chronic care? Are they limited to one condition, measurable, reviewed and incorporated into plans for improvement?
    a. How do you think they are?
    b. Score it, please.
3. What is the improvement strategy for chronic illness care? Is it an ad hoc not organized, uses ad hoc approaches for target problems, utilizes a proven improvement strategy or includes a proven improvement strategy and uses it proactively in meeting organizational goals?
    a. Score it, please.

4. How are the incentives and regulations for chronic illness care being done? Are not used, are used to influence utilization and costs, are used to support patient care goals or are used to motivate and empower providers to support patient care goals?
    a. Do they use economic incentives or allocate resources to influence building the chronic care?
    b. Score your answer from 0 to 11, please.
5. What is the position of the Senior Leaders regarding chronic illness care? Do they discourage enrollment of the chronic illness or do not make improvements to chronic illness care? Do they encourage the improvement efforts in chronic care or visibly participate in improvement efforts in chronic care?
    a. Score your answer from 0 to 11, please.
6. How is the organization of the healthcare benefits promoting self-management or system changes? Is not and it discourages patient self-support or system changes, neither encourage nor discourage, encourage patient self-management and system changes or are specifically designed to promote better chronic illness care?
    a. How is it?
    b. Score your answer from 0 to 11, please.

Part 2: Community Linkages. Linkages between the health delivery system (or provider practice) and community resources play an important role in the management of chronic illness.

1. How do you link patients to outside resources? Is it done systematically or limited to a list of identified resources? Are they accomplished through a designated staff person and do they use the maximum of community resources? Is it accomplished through active coordination between the health service, community services, agencies or patients?

   a. How do you do it?
   b. Do you do it due to your position or all nurses and physicians can do it?
   c. Score your answer from 0 to 11, please.
2. How are the partnerships with the community organizations supportive of your programs and policies? Do not exist, are being considered but not implemented yet, are formed or are actively sought to develop formal supportive programs?
   a. Score your answer from 0 to 11, please.
3. How are the health regional plans coordinate with chronic illness guidelines? Are not coordinate with chronic illness guideline, measures or care resources at the practical level? Would consider some degree of coordination of guidelines or currently coordinate guidelines, measures or care resources in one or two chronic illness or currently coordinate chronic illness guidelines, measures and resources at the practice level for most chronic illnesses.
   a. Score your answer from 0 to 11, please.

Part 3: Practice Level. Several components that manifest themselves at the level of the individual provider practice (e.g. individual clinic) have been shown to improve chronic illness care. These characteristics fall into general areas of self-management support, delivery system design issues that directly affect the practice, decision support, and clinical information systems.

Part 3a: Self-Management Support. Effective self-management support can help patients and families to cope with the challenges of living with and treating chronic illness and reduce complications and symptoms.

1. How do you do the assessment of self-management needs and activities? Are not done, are expected, are completed in a standardized manner or are regularly assessed and recorded in a standardized form.

    a. How do you document it?
    b. Score your answer from 0 to 11, please.
2. How is the self-management support education being done? It is limited to booklets distribution, available by referral to self-management educators, provided by trained clinical educators designated to do self-management support affiliated with each practice or provided by trained clinical educators affiliated with each practice and trained in patient empowerment.
    a. How do you do it?
    b. Score your answer from 0 to 11, please.
3. How do you address concerns of patients and families? It is not consistently done, is provided for specific patients and families through referral, is encourage and peer support groups and mentoring programs are available or is an integral part of care and includes systematic assessment and routine involvement peer support groups and mentoring programs.
    a. Do you have mentoring and supportive groups?
    b. Score your answer from 0 to 11, please.
4. How do you provide effective behavior change interventions and peer support? Are not available, are limited to the distribution of booklets, are available only by referral to specialized center staffed by trained personnel or are readily available and an integral part of routine care.
    a. How do you guarantee that the patient will change what he needs to?
    b. Score your answer from 0 to 11, please.

Part 3b: Decision Support. Effective chronic illness management programs assure that providers have access to evidence-based information necessary to care for patients-decision support. This includes evidence-based practice guidelines or protocols, specialty

consultation, provider education, and activating patients to make provider teams aware of effective therapies.

1. What about the evidence-based guidelines? Are they not available, are available but not integrated, are available and supported by provider education or available, are supported by provider education and integrated into care through reminders and other proven provider behavior change methods?
    a. Explain how do you do it.
    b. Score your answer from 0 to 11, please.
2. How is the involvement of specialists in improving primary care? The involvement is through tradition referral, achieved through specialist leadership to enhance the capacity of the overall system, includes specialist leadership and designated specialists who provide primary care team training or includes specialist leadership and specialist involvement in improving the care of primary care patients.
    a. How does it work? Who trains you?
    b. Score your answer from 0 to 11, please.
3. How is the education for chronic illness care provided? It is provided sporadically, through traditional methods, through optimal methods (academic detailing) or includes training all practice teams in chronic illness care methods.
    a. Score your answer from 0 to 11, please.
4. How do you inform patients about guidelines? It is not done, happens on request, through specific patient education materials or includes specific materials developed for patients which describe their role in achieving guidelines adherence.
    a. Score your answer from 0 to 11, please.

Part 3c: Delivery System Design. Evidence suggests that effective chronic illness management involves more than simply adding additional interventions to a current system focused on acute care. It may necessitate changes to the organization of practice that impact provision of care.

1. How is the practice team functioning? It is not addressed, is addressed by assuring the availability of the individuals with appropriate training, is assured by regular team meetings to address guidelines or is assured by teams who meet regularly and have clearly defined roles.
    a. Where do you meet? What is the frequency of the meetings?
    b. Score your answer from 0 to 11, please.
2. How is the practice team leadership? It is not recognized, is assumed by the organization, is assured by the appointment of a team leader but the role is not defined or is assured by the appointment of a team leader who assures that roles and responsibilities for chronic illness are clearly defined.
    a. Do you recognize the leader?
    b. Score your answer from 0 to 11, please.
3. How do you use the appointment system? It can be used to schedule acute care visits, follow-up and preventive visits, it assures scheduled follow-up with chronically ill patients, it is flexible and can accommodate innovations (customized visit length or group visits), or includes organization of care that facilitates the patient seeing multiple providers in a single visit.
    a. Score your answer from 0 to 11, please.
4. How do you follow-up the patients? Is scheduled by the patient, is scheduled by the practice in accordance with guidelines, is assured by the practice team by monitoring patient utilization or is customized to patient needs, varies in intensity and methodology and assures guidelines follow-up.

    a. Score your answer from 0 to 11, please.

5. How do you plan the visits for chronic illness care? Are not used, are occasionally used for complicated patients, are an option for interested patients or are used for all patients and include regular assessment, preventive interventions and attention to self-management support.
    a. Score your answer from 0 to 11, please.
6. How do you promote the continuity of care? Is it a priority? Depends on written communication between primary care providers and specialists, case managers or disease management companies or between primary care providers and specialists and other relevant providers is a priority but not implemented systematically. Or is a high priority and all chronic disease interventions include active coordination between primary care, specialists and other relevant groups.
    a. Score your answer from 0 to 11, please.

Part 3d: Clinical Information Systems. Timely, useful information about individual patients and populations of patients with chronic conditions is a critical feature of effective programs, especially those that employ population-based approaches.

1. What does the registry (list of patients with specific conditions) contain? It is not available, includes names, diagnosis, contact information and date of the last contact either on paper or in a computer database, allows queries to sort sub-population by clinical priorities or is tied to guidelines which provide prompts and reminders about needed services.
    a. Score your answer from 0 to 11, please.
2. How the reminders to providers work? Are not available, include general notification of the existence of a chronic illness but does not describe needed services at the time of the encounter, includes indications of needed service for populations of patients

through periodic reporting or includes specific information for the team about guidelines adherence at the time of individual patient encounters.

   a. Do you have notification systems? Saying the next steps?
   b. Score your answer from 0 to 11, please.

3. How do you have feedback of you interventions? It is not available, is delivered impersonally, occurs at frequent enough intervals to monitor performance and it is specific to team's population or is timely, specific to the team, routine and personally delivered.
   a. Score your answer from 0 to 11, please.
4. How does the information about relevant subgroups of patients need services? It is not available, is can only be obtained with special efforts or additional programming, can be obtained upon request but it is not routinely available or it is provided routinely to providers to help them deliver planned care.
   a. Can you target them?
   b. Through your system?
   c. What this information contains?
   d. Score your answer from 0 to 11, please.
5. How are the patient treatment plans? Are not expected, are achieved through a standardized approach, are established collaboratively and include self-management as well as clinical goals or are established collaboratively and include self-management as well as clinical management.
   a. Each patient has its own treatment plan?
   b. Score your answer from 0 to 11, please.

APPENDIX D – PRIORITIES AND BARRIERS TO RANK

Chronic Care Model

28 subcomponents of the six elements

Clicker number:____

Please rate the following subcomponents as priority relevant.

Priorities	A. Very relevant	B. Relevant	C. Not very relevant
Overall Organizational Leadership in Chronic Illness Care			
Organizational Goals for Chronic Care			
Improvement strategy for chronic illness care			
Incentives and regulations for chronic illness care			
Senior Leaders			
Benefits			
Linking patients to outside resources			
Partnerships with community organizations			
Regional health plans			
Assessment and documentation of self-management needs and activities			

Priorities	A. Very relevant	B. Relevant	C. Not very relevant
Self-management support			
Addressing concerns of patients and families			
Effective behavior change interventions and peer support			
Evidence-based guidelines			
Involvement of specialists in improving primary care			
Provider education for chronic illness care			
Informing patients about the guidelines			
Practice team functioning			
Practice team leadership			
Appointment system			
Follow-up			
Planned visits for chronic illness care			
Continuity of care			
Registry			
Reminders to providers			

Priorities	A. Very relevant	B. Relevant	C. Not very relevant
Feedback			
Informing about subgroups of patients needing services			
Patient treatment plans			

Chronic Care Model

20 barriers for the CCM development/improvement

Clicker number:____

Please rate the following barriers.

Barriers	A. Very relevant	B. Relevant	C. Not very relevant
Clinical information system			
Differences between insurances			
Discrimination between nationalities			
Health professionals demotivation			
Lack of someone specific for education			
Lack of time for education			

Barriers	A. Very relevant	B. Relevant	C. Not very relevant
Lack of doctor-nurse team work			
Lack of staff education			
Lack of time for documentation			
Lack of regional plan standardizing the guidelines between facilities			
Lack of standardized processes/procedures			
Lack of monitoring			
Language barriers between the patients and the professionals			
Insufficient budget			
Insufficient tools			
No coordination between facilities private and public			
Overlap of functions			
Patient compliance			
Psychological stage of the patient			
Senior leaders' availability			

Chronic Care Model

16 subcomponents of the six elements

Clicker number:____

Please rate the following subcomponents as priority relevant.

Priorities	A. Very relevant	B. Relevant	C. Not very relevant
Overall Organizational Leadership in Chronic Illness Care			
Organizational Goals for Chronic Care			
Improvement strategy for chronic illness care			
Partnerships with community organizations			
Regional health plans			
Self-management support			
Addressing concerns of patients and families			
Effective behavior change interventions and peer support			
Evidence-based guidelines			
Involvement of specialists in improving primary care			
Provider education for chronic illness care			

Priorities	A. Very relevant	B. Relevant	C. Not very relevant
Follow-up			
Planned visits for chronic illness care			
Continuity of care			
Registry			
Patient treatment plans			

Chronic Care Model

14 barriers for the CCM development/improvement

Clicker number:____

Please rate the following barriers.

Barriers	A. Very relevant	B. Relevant	C. Not very relevant
Clinical information system			
Differences between insurances			
Lack of someone specific for education			
Lack of time for education			

Barriers	A. Very relevant	B. Relevant	C. Not very relevant
Lack of doctor-nurse team work			
Lack of staff education			
Lack of regional plan standardizing the guidelines between facilities			
Lack of standardized processes/procedures			
Lack of monitoring			
Language barriers between the patients and the professionals			
Insufficient budget			
Patient compliance			
Psychological stage of the patient			
Senior leaders' availability			

Chronic Care Model

Top 7 subcomponents of the six elements

Clicker number:____

Please rank the following priorities from 1 to 7 according to the level of relevance.

Priorities	
Overall Organizational Leadership in Chronic Illness Care	
Improvement strategy for chronic illness care	
Effective behavior change interventions and peer support	
Evidence-based guidelines	
Provider education for chronic illness care	
Continuity of care	
Patient treatment plans	

Chronic Care Model

Top 5 barriers for the CCM development/improvement

Clicker number:____

Please rank the following barriers from 1 to 5 according to the level of relevance.

Barriers	
Differences between insurances	
Lack of regional plan standardizing the guidelines between facilities	
Lack of standardized processes/procedures	
Lack of monitoring	
Patient compliance	

ANNEX 1 – Assessment Chronic Illness Care survey

Assessment of Chronic Illness Care
Version 3.5

Please complete the following information about you and your organization. This information will not be disclosed to anyone besides the ICIC/IHI team. We would like to get your phone number and e-mail address in the event that we need to contact you/your team in the future. Please also indicate the names of persons (e.g., team members) who complete the survey with you. Later on in the survey, you will be asked to describe the process by which you complete the survey.

Your name:	**Date:** _____/_____/_____ Month Day Year
Organization & Address:	**Names of other persons completing the survey with you:** 1. 2. 3.
Your phone number: (_____) __ __ __ - __ __ __ __	**Your e-mail address:**

Directions for Completing the Survey

This survey is designed to help systems and provider practices move toward the "state-of-the-art" in managing chronic illness. The results can be used to help your team identify areas for improvement. Instructions are as follows:

1. **Answer each question** from the perspective of one physical site (e.g., a practice, clinic, hospital, health plan) that supports care for chronic illness.

   Please provide name and type of site (e.g., Group Health Cooperative/Plan) _____

2. **Answer each question** regarding how your organization is doing with respect to one disease or condition.

   Please specify condition _____

3. For each row, **circle the point value** that best describes the level of care that currently exists in the site and condition you chose. The rows in this form present key aspects of chronic illness care. Each aspect is divided into levels showing various stages in improving chronic illness care. The stages are represented by points that range from 0 to 11. The higher point values indicate that the actions described in that box are more fully implemented.

4. **Sum the points in each section** (e.g., total part 1 score), calculate the average score (e.g., total part 1 score / # of questions), and enter these scores in the space provided at the end of each section. Then sum all of the section scores and complete the average score for the program as a whole by dividing this by 6.

For more information about how to complete the survey, please contact:

Judith Schaefer, MPH **tel. 206.287.2077; Schaefer.jk@ghc.org**
Improving Chronic Illness Care
A National Program of the Robert Wood Johnson Foundation
Group Health Cooperative of Puget Sound
1730 Minor Avenue, Suite 1290
Seattle, WA 98101-1448

Assessment of Chronic Illness Care, Version 3.5

Part 1: Organization of the Healthcare Delivery System. Chronic illness management programs can be more effective if the overall system (organization) in which care is provided is oriented and led in a manner that allows for a focus on chronic illness care.

Components	Level D	Level C	Level B	Level A
Overall Organizational Leadership in Chronic Illness Care	…does not exist or there is a little interest.	…is reflected in vision statements and business plans, but no resources are specifically earmarked to execute the work.	…is reflected by senior leadership and specific dedicated resources (dollars and personnel).	…is part of the system's long term planning strategy, receive necessary resources, and specific people are held accountable.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Organizational Goals for Chronic Care	…do not exist or are limited to one condition.	…exist but are not actively reviewed.	…are measurable and reviewed.	…are measurable, reviewed routinely, and are incorporated into plans for improvement.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Improvement Strategy for Chronic Illness Care	…is ad hoc and not organized or supported consistently.	…utilizes ad hoc approaches for targeted problems as they emerge.	…utilizes a proven improvement strategy for targeted problems.	…includes a proven improvement strategy and uses it proactively in meeting organizational goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Incentives and Regulations for Chronic Illness Care	…are not used to influence clinical performance goals.	…are used to influence utilization and costs of chronic illness care.	…are used to support patient care goals.	…are used to motivate and empower providers to support patient care goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Senior Leaders	…discourage enrollment of the chronically ill.	…do not make improvements to chronic illness care a priority.	…encourage improvement efforts in chronic care.	…visibly participate in improvement efforts in chronic care.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Benefits	…discourage patient self-management or system changes.	…neither encourage nor discourage patient self-management or system changes.	…encourage patient self-management or system changes.	…are specifically designed to promote better chronic illness care.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Health Care Organization Score _____ Average Score (Health Care Org. Score / 6) _____

Part 2: Community Linkages. Linkages between the health delivery system (or provider practice) and community resources play important roles in the management of chronic illness.

Components	Level D	Level C	Level B	Level A
Linking Patients to Outside Resources	…is not done systematically.	…is limited to a list of identified community resources in an accessible format.	…is accomplished through a designated staff person or resource responsible for ensuring providers and patients make maximum use of community resources.	… is accomplished through active coordination between the health system, community service agencies and patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Partnerships with Community Organizations	…do not exist.	…are being considered but have not yet been implemented.	…are formed to develop supportive programs and policies.	…are actively sought to develop formal supportive programs and policies across the entire system.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Regional Health Plans	…do not coordinate chronic illness guidelines, measures or care resources at the practice level.	…would consider some degree of coordination of guidelines, measures or care resources at the practice level but have not yet implemented changes.	…currently coordinate guidelines, measures or care resources in one or two chronic illness areas.	…currently coordinate chronic illness guidelines, measures and resources at the practice level for most chronic illnesses.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Community Linkages Score _____ Average Score (Community Linkages Score / 3) _____

Part 3: Practice Level. Several components that manifest themselves at the level of the individual provider practice (e.g. individual clinic) have been shown to improve chronic illness care. These characteristics fall into general areas of self-management support, delivery system design issues that directly affect the practice, decision support, and clinical information systems.

Part 3a: Self-Management Support. Effective self-management support can help patients and families cope with the challenges of living with and treating chronic illness and reduce complications and symptoms.

Components	Level D	Level C	Level B	Level A
Assessment and Documentation of Self-Management Needs and Activities	…are not done.	…are expected.	…are completed in a standardized manner.	…are regularly assessed and recorded in standardized form linked to a treatment plan available to practice and patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Self-Management Support	…is limited to the distribution of information (pamphlets, booklets).	…is available by referral to self-management classes or educators.	…is provided by trained clinical educators who are designated to do self-management support, affiliated with each practice, and see patients on referral.	…is provided by clinical educators affiliated with each practice, trained in patient empowerment and problem-solving methodologies, and see most patients with chronic illness.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Addressing Concerns of Patients and Families	…is not consistently done.	…is provided for specific patients and families through referral.	…is encouraged, and peer support, groups, and mentoring programs are available.	…is an integral part of care and includes systematic assessment and routine involvement in peer support, groups or mentoring programs.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Effective Behavior Change Interventions and Peer Support	…are not available.	…are limited to the distribution of pamphlets, booklets or other written information.	…are available only by referral to specialized centers staffed by trained personnel.	…are readily available and an integral part of routine care.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Self-Management Score_____ Average Score (Self Management Score / 4) _____

Part 3b: Decision Support. Effective chronic illness management programs assure that providers have access to evidence-based information necessary to care for patients--decision support. This includes evidence-based practice guidelines or protocols, specialty consultation, provider education, and activating patients to make provider teams aware of effective therapies.

Components	Level D	Level C	Level B	Level A
Evidence-Based Guidelines	…are not available.	…are available but are not integrated into care delivery.	…are available and supported by provider education.	…are available, supported by provider education and integrated into care through reminders and other proven provider behavior change methods.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Involvement of Specialists in Improving Primary Care	…is primarily through traditional referral.	…is achieved through specialist leadership to enhance the capacity of the overall system to routinely implement guidelines.	…includes specialist leadership and designated specialists who provide primary care team training.	…includes specialist leadership and specialist involvement in improving the care of primary care patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Provider Education for Chronic Illness Care	…is provided sporadically.	…is provided systematically through traditional methods.	…is provided using optimal methods (e.g. academic detailing).	…includes training all practice teams in chronic illness care methods such as population-based management, and self-management support.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Informing Patients about Guidelines	…is not done.	…happens on request or through system publications.	…is done through specific patient education materials for each guideline.	…includes specific materials developed for patients which describe their role in achieving guideline adherence.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Decision Support Score_____ Average Score (Decision Support Score / 4) _____

Part 3c: Delivery System Design. Evidence suggests that effective chronic illness management involves more than simply adding additional interventions to a current system focused on acute care. It may necessitate changes to the organization of practice that impact provision of care.

Components	Level D	Level C	Level B	Level A
Practice Team Functioning	…is not addressed.	…is addressed by assuring the availability of individuals with appropriate training in key elements of chronic illness care.	…is assured by regular team meetings to address guidelines, roles and accountability, and problems in chronic illness care.	…is assured by teams who meet regularly and have clearly defined roles including patient self-management education, proactive follow-up, and resource coordination and other skills in chronic illness care.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Practice Team Leadership	…is not recognized locally or by the system.	…is assumed by the organization to reside in specific organizational roles.	…is assured by the appointment of a team leader but the role in chronic illness is not defined.	…is guaranteed by the appointment of a team leader who assures that roles and responsibilities for chronic illness care are clearly defined.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Appointment System	…can be used to schedule acute care visits, follow-up and preventive visits.	…assures scheduled follow-up with chronically ill patients.	…are flexible and can accommodate innovations such as customized visit length or group visits.	…includes organization of care that facilitates the patient seeing multiple providers in a single visit.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Follow-up	…is scheduled by patients or providers in an ad hoc fashion.	…is scheduled by the practice in accordance with guidelines.	…is assured by the practice team by monitoring patient utilization.	…is customized to patient needs, varies in intensity and methodology (phone, in person, email) and assures guideline follow-up.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Planned Visits for Chronic Illness Care	…are not used.	…are occasionally used for complicated patients.	…are an option for interested patients.	…are used for all patients and include regular assessment, preventive interventions and attention to self-management support.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Continuity of Care	…is not a priority.	…depends on written communication between primary care providers and specialists, case managers or disease management	…between primary care providers and specialists and other relevant providers is a priority but not implemented systematically.	…is a high priority and all chronic disease interventions include active coordination between primary care, specialists and other relevant

Components	Level D			Level C			Level B			Level A		
				companies.						groups.		
Score	0	1	2	3	4	5	6	7	8	9	10	11

(From Previous Page)

Total Delivery System Design Score_____ Average Score (Delivery System Design Score / 6) _____

Part 3d: Clinical Information Systems. Timely, useful information about individual patients and populations of patients with chronic conditions is a critical feature of effective programs, especially those that employ population-based approaches.[7, 8]

Components	Level D			Level C			Level B			Level A		
Registry (list of patients with specific conditions)	…is not available.			…includes name, diagnosis, contact information and date of last contact either on paper or in a computer database.			…allows queries to sort sub-populations by clinical priorities.			…is tied to guidelines which provide prompts and reminders about needed services.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Reminders to Providers	…are not available.			… include general notification of the existence of a chronic illness, but does not describe needed services at time of encounter.			…includes indications of needed service for populations of patients through periodic reporting.			…includes specific information for the team about guideline adherence at the time of individual patient encounters.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Feedback	…is not available or is non-specific to the team.			…is provided at infrequent intervals and is delivered impersonally.			…occurs at frequent enough intervals to monitor performance and is specific to the team's population.			…is timely, specific to the team, routine and personally delivered by a respected opinion leader to improve team performance.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Information about Relevant Subgroups of Patients Needing Services	…is not available.			…can only be obtained with special efforts or additional programming.			…can be obtained upon request but is not routinely available.			…is provided routinely to providers to help them deliver planned care.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Patient Treatment Plans	…are not expected.			…are achieved through a standardized approach.			…are established collaboratively and include self management as well as clinical goals.			…are established collaborative an include self management as well as clinical management. Follow-up occurs and guides care at every point of service.		
Score	0	1	2	3	4	5	6	7	8	9	10	11

Total Clinical Information System Score_____ Average Score (Clinical Information System Score / 5) _____

Integration of Chronic Care Model Components. Effective systems of care integrate and combine all elements of the Chronic Care Model; e.g., linking patients' self-management goals to information systems/registries.

Components	Little support	Basic support	Good support	Full support
Informing Patients about Guidelines	…is not done.	…happens on request or through system publications.	…is done through specific patient education materials for each guideline.	…includes specific materials developed for patients which describe their role in achieving guideline adherence.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Information Systems/Registries	…do not include patient self-management goals.	…include results of patient assessments (e.g., functional status rating; readiness to engage in self-management activities), but no goals.	…include results of patient assessments, as well as self-management goals that are developed using input from the practice team/provider and patient.	…include results of patient assessments, as well as self-management goals that are developed using input from the practice team and patient; and prompt reminders to the patient and/or provider about follow-up and periodic re-evaluation of goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Community Programs	…do not provide feedback to the health care system/clinic about patients' progress in their programs.	…provide sporadic feedback at joint meetings between the community and health care system about patients' progress in their programs.	…provide regular feedback to the health care system/clinic using formal mechanisms (e.g., Internet progress report) about patients' progress.	…provide regular feedback to the health care system about patients' progress that requires input from patients that is then used to modify programs to better meet the needs of patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Organizational Planning for Chronic Illness Care	…does not involve a population-based approach.	…uses data from information systems to plan care.	…uses data from information systems to proactively plan population-based care, including the development of self-management programs and partnerships with community resources.	…uses systematic data and input from practice teams to proactively plan population-based care, including the development of self-management programs and community partnerships, that include a built-in evaluation plan to determine success over time.
			6 7 8	

Components	Little support	Basic support	Good support	Full support
Score	0 1 2	3 4 5		9 10 11
Routine follow-up for appointments, patient assessments and goal planning	…is not ensured.	is sporadically done, usually for appointments only.	is ensured by assigning responsibilities to specific staff (e.g., nurse case manager).	is ensured by assigning responsibilities to specific staff (e.g., nurse case manager) who uses the registry and other prompts to coordinate with patients and the entire practice team.
	0 1 2	3 4 5	6 7 8	9 10 11
Guidelines for chronic illness care	…are not shared with patients.	…are given to patients who express a specific interest in self-management of their condition.	…are provided for all patients to help them develop effective self-management or behavior modification programs, and identify when they should see a provider.	…are reviewed by the practice team with the patient to devise a self-management or behavior modification program consistent with the guidelines that takes into account patient's goals and readiness to change.
	0 1 2	3 4 5	6 7 8	9 10 11

Total Integration Score (SUM items): _____ ➢ **Average Score (Integration Score/6) =** _____

Briefly describe the process you used to fill out the form (e.g., reached consensus in a face-to-face meeting; filled out by the team leader in consultation with other team members as needed; each team member filled out a separate form and the responses were averaged).

Description: _____

_____

Scoring Summary
(bring forward scoring at end of each section to this page)

Total Org. of Health Care System Score	_____
Total Community Linkages Score	_____
Total Self-Management Score	_____
Total Decision Support Score	_____
Total Delivery System Design Score	_____
Total Clinical Information System Score	_____
Total Integration Score	_____

Overall Total Program Score (Sum of all scores) _____

Average Program Score (Total Program /7) _____

What does it mean?

The ACIC is organized such that the highest "score" (an "11") on any individual item, subscale, or the overall score (an average of the six ACIC subscale scores) indicates optimal support for chronic illness. The lowest possible score on any given item or subscale is a "0", which corresponds to limited support for chronic illness care. The interpretation guidelines are as follows:

Between "0" and "2" = limited support for chronic illness care
Between "3" and "5" = basic support for chronic illness care
Between "6" and "8" = reasonably good support for chronic illness care
Between "9" and "11" = fully developed chronic illness care

It is fairly typical for teams to begin a collaborative with average scores below "5" on some (or all) areas the ACIC. After all, if everyone was providing optimal care for chronic illness, there would be no need for a chronic illness collaborative or other quality improvement programs. It is also common for teams to initially believe they are providing better care for chronic illness than they actually are. As you progress in the Collaborative, you will become more familiar with what an effective system of care involves. You may even notice your ACIC scores "declining" even though you have made improvements; this is most likely the result of your better understanding of what a good system of care looks like. Over time, as your understanding of good care increases and you continue to implement effective practice changes, you should see overall improvement on your ACIC scores.

ANNEX 2 – PRISMA Checklist 2009

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Page 1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Page 4-10
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Page 10
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	NA
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Page 11

Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Page 11
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Page 12
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Page 12
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Page 12
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Page 12
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	NA
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	NA
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NA
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Page 12
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	NA

Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	NA
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	NA
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	16
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	25
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	27
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	27
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	28

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

ANNEX 3 – COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) (COREQ)

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	**Guide questions/description**	**Reported on Page #**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	
3. Occupation	What was their occupation at the time of the study?	
4. Gender	Was the researcher male or female?	
5. Experience and training	What experience or training did the researcher have?	
Relationship with participants		

6. Relationship established	Was a relationship established prior to study commencement?	
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	
12. Sample size	How many participants were in the study?	

13. Non-participation	How many people refused to participate or dropped out? Reasons?	
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	
20. Field notes	Were field notes made during and/or after the interview or focus group?	
21. Duration	What was the duration of the inter views or focus group?	
22. Data saturation	Was data saturation discussed?	

23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	
25. Description of the coding tree	Did authors provide a description of the coding tree?	
26. Derivation of themes	Were themes identified in advance or derived from the data?	
27. Software	What software, if applicable, was used to manage the data?	
28. Participant checking	Did participants provide feedback on the findings?	
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
30. Data and findings consistent	Was there consistency between the data presented and the findings?	
31. Clarity of major themes	Were major themes clearly presented in the findings?	

32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process, please select the file type: *Checklist*. You will NOT be able to proceed with submission unless the checklist has been uploaded. Please DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

ANNEX 4 – Recommendations for the Conducting and REporting of DElphi Studies (CREDES)

Rationale for the choice of the Delphi technique

1. *Justification.* The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified. When selecting the method to answer a particular research question, it is important to keep in mind its constructivist nature

Planning and design

2. *Planning and process.* The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be applied systematically and rigorously

3. *Definition of consensus.* Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with certain items or topics in the next survey round, (b) the required threshold to terminate the Delphi process and (c) procedures to be followed when consensus is (not) reached after one or more iterations

Study conduct

4. *Informational input.* All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to examine the effect on experts' judgements and to prevent bias

5. *Prevention of bias.* Researchers need to take measures to avoid directly or indirectly influencing the experts' judgements. If one or more members of the research team have a conflict of interest, entrusting an independent researcher with the main coordination of the Delphi study is advisable

6. *Interpretation and processing of results.* Consensus does not necessarily imply the 'correct' answer or judgement; (non)consensus and stable disagreement provide informative insights and highlight differences in perspectives concerning the topic in question

7. *External validation.* It is recommended to have the final draft of the resulting guidance on best practice in palliative care reviewed and approved by an external board or authority before publication and dissemination

Reporting

8. *Purpose and rationale.* The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided

9. *Expert panel.* Criteria for the selection of experts and transparent information on recruitment of the expert panel, socio- demographic details including information on expertise regarding the topic in question, (non)response and response rates over the ongoing iterations should be reported

10. *Description of the methods.* The methods employed need to be comprehensible; this includes information on preparatory steps (How was available evidence on the topic in question synthesized?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey round and methodological decisions taken by the research team throughout the process

11. *Procedure.* Flow chart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps

12. *Definition and attainment of consensus.* It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus

13. *Results.* Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds

14. *Discussion of limitations.* Reporting should include a critical reflection of potential limitations and their impact of the resulting guidance

15. *Adequacy of conclusions.* The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance

16. *Publication and dissemination.* The resulting guidance on good practice in palliative care should be clearly identifiable from the publication, including recommendations for transfer into practice and implementation. If the publication does not allow for a detailed presentation of either the resulting practice guidance or the methodological features of the applied Delphi technique, or both, reference to a more detailed presentation elsewhere should be made (e.g. availability of the full guideline from the authors or online; publication of a separate paper reporting on methodological details and particularities of the process (e.g. persistent disagreement and controversy on certain issues)). A dissemination plan should include endorsement of the guidance by professional associations and health care authorities to facilitate.