

Department of Public Health & Primary Care
Trinity College Dublin

**Chronic Disease Management in Ireland
Perspectives from patients and clinical stakeholders
– implications and recommendations for the
Irish healthcare system**

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**Trinity
College
Dublin**

The University of Dublin



THE ADELAIDE HEALTH FOUNDATION

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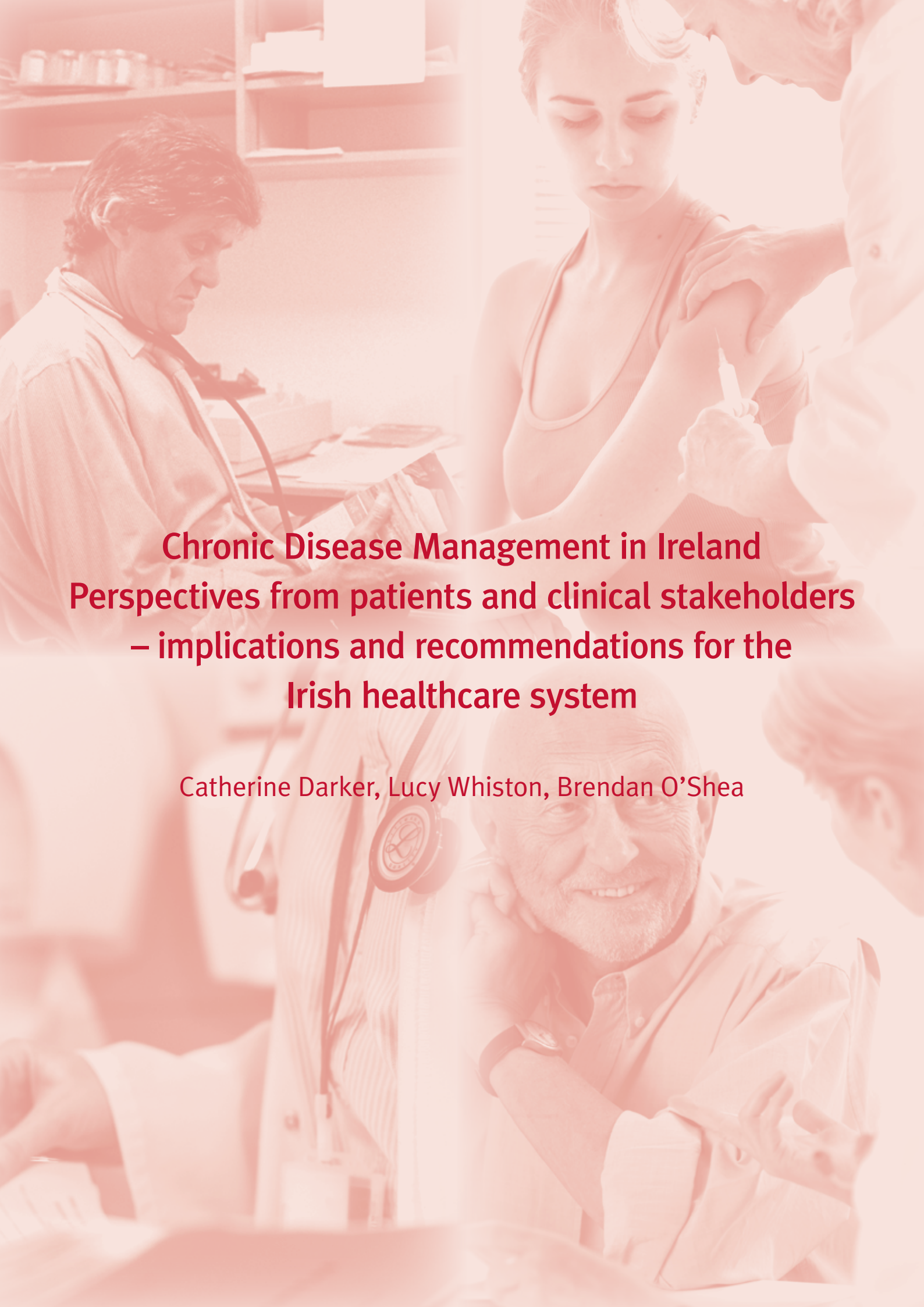
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Foreword

The term ‘epidemiological transition’ is medical jargon for the price society is paying for a rising standard of living. Nowadays, we are less likely to die in early childhood or from infections and have replaced the malnutrition of starvation with the malnutrition of excess – excess calories, fat and sugar with consequent overweight. Combine this with inactivity and our liking for tobacco and alcohol, and the scene is set for our biggest causes of death and disability, the chronic diseases – heart attacks, stroke, cancer, lung disease, diabetes, arthritis and depression. “Chronic” in this context means long-term. While some of these diseases may kill quickly, most cause prolonged suffering and disability.

As a population such as ours ages, chronic disease increases in frequency. Meeting the complex needs of patients with chronic diseases is the single greatest challenge facing our healthcare system today. Therefore, as expected, there are many expert reports on tackling chronic diseases, from the World Health Organization¹ (WHO), through our own Health Service Executive (HSE) reports and recommendations^{2,3}, to the Adelaide Health Foundation’s paper on integrated care⁴.

To add to the wealth of these expert reports we have sought the opinions of those at the coal face – the general practitioners⁵, hospital consultants⁶, practice nurses⁷ and most recently, those on the receiving end of our healthcare system, the patients⁸.

Uniquely, this current report summarises the views and wisdom of these stakeholders. We also make ten evidence-based recommendations for improving the management of chronic conditions here in Ireland.

The Chronic Care Model (CCM) is a WHO endorsed evidence-based model which outlines the elements which are essential to high quality chronic illness care. The publication of this important report is therefore timely to help identify what elements of the CCM are currently in place. This will provide a baseline measure of chronic disease management against which to judge future developments.

In preparing this report, we gratefully acknowledge the enthusiastic collaboration and support from the Irish College of General Practitioners, the Royal College of Physicians of Ireland, the Irish Practice Nurses Association and community pharmacists. We offer a particular thanks to the patients who gave their time and shared their experiences with us.

It is the Adelaide Health Foundation’s policy to contribute to healthcare reform in Ireland through innovative research, positive criticism and evidence-based suggestions. It is our hope that this report will contribute to this endeavour and help to inform national policy.

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Summary

- This report presents an overview of the views of four key stakeholder groups within the Irish healthcare system – general practitioners, hospital consultants, practice nurses and patients, with data provided directly by individuals as opposed to their representative organisations.
- The evidence from this programme of research provides a baseline measure of the readiness of the Irish healthcare system to respond effectively to common chronic diseases such as cardiovascular disease (heart attacks and stroke), cancers (particularly breast, prostate and colonic cancer), chronic respiratory diseases (chronic obstructive pulmonary disease and asthma) and diabetes.
- Effective chronic disease programmes are dependent on well-functioning national health systems. The efficacy of chronic disease management is a proxy measurement of both the impact of reform within the health services in Ireland and an indicator of how effective our health service is.
- There is consensus amongst stakeholders with the majority of hospital consultants (n=180/221; 81.4%), general practitioners (n=240/368; 65.2%), practice nurses (n=251/307; 81.8%) and patients (n=278/502; 55.4%) recognising that there are some good things in our health system but that fundamental changes are needed to make it work better.
- Inequities exist within the system for both private and public patients. Private patients delay attending primary care services because of cost. Public patients are disadvantaged in accessing secondary care services and specialised tests. Access to allied health professionals (such as physiotherapists, psychologists, dieticians and occupational therapists) is problematic for both groups. Paying for medications or other out-of-pocket expenses is a difficulty for both groups.
- Most patients (n=390/506; 77.0%) reported being happy with the care they received for their chronic illness within the last 6 months. Despite this, patients are generally not asked for their ideas (n=251/503; 49.9%) or goals (n=188/501; 37.6%) when making a treatment plan.
- There are clear dissonances between clinical stakeholders and patient respondents. Clinical stakeholders indicate that they frequently provide written information to patients relating to the management of their illness at home and written medication lists, but patients report this to a far lesser extent. Patients rate close and coordinated communication between hospitals and general practice as being extremely important but clinical stakeholders indicate that poor communication between hospital teams and general practitioners is an important current barrier to care.

- Constraints within the current system include the continued failure of co-ordinated and integrated information technology within secondary care and the failure of healthcare professionals to engage meaningfully with individual patients as partners in decisions. Poor access to diagnostics is a limiting factor for primary care. Key barriers to chronic disease management identified by clinical stakeholders include increased workload and lack of time, lack of skills and a knowledge gap and poor communication between primary care and hospitals.
- Facilitative factors within the current system include effective use of information technology by GPs and practice nurses, evidence of increasing use of clinical audit as a driver of improvement, and reasonable levels of use of disease registers and recall systems among GPs. Hospital consultants also reported reasonable levels of use of disease registers and recall systems but limited availability of electronic patient medical records in hospitals.
- There is a high level of support from all stakeholders for chronic disease management to be located within primary care.
- Further research into the impact of chronic diseases on the population, the health and social care system and the economy, is required. Such research must become systematic and on going. It should be based substantially on real time automated electronic return of documented clinical activities relevant to chronic disease management, originating from electronic medical records in both general practice and in secondary care. We must move beyond epidemiological data if we are to guide service development meaningfully and effectively, especially in a situation where demand is likely to continuously outstrip resources. Analysis of data thus obtained should consider the extent of the burden of these conditions (including financial costs), how the burden is distributed across the population, how that burden changes in the future, and the implications for the health and social care workforce and its training and operational requirements.

Recommendations

1. Adopt the Chronic Care Model as the template to measure and monitor progress as Ireland reforms its healthcare service from our currently predominately acute and episodic model of care to a lifelong model of promotion, prevention, early intervention and chronic care.
2. Start improving the management of patients with chronic conditions by strengthening and investing in primary care. Health systems built on the principles of primary care achieve better health and greater equity in health, than systems with a speciality care orientation.
3. Incentivise the provision of comprehensive, co-ordinated and continuous care for the prevention and management of chronic illness. Current funding systems continue to reward isolated activities and not joined up packages of care. General practice state funding is presently based on a model that predominantly reflects a simple capitation based approach, which fails to reward good and advanced practice and makes no provision for co-ordinated care. Efficiencies may be gained within general practice if a proportion of funding relates to documented achievements in agreed markers of quality of care around the major chronic diseases (such as diabetes, cardiovascular disease, chronic pulmonary obstructive disease) and in a manner which embraces the needs of complex patients with multimorbidities.
4. Put in place a well-resourced integrated clinical information system (CIS). The extent to which the hospital sector in particular, but also other parts of the health system have inadequate or fragmented information technology is a major limiting factor for the provision of effective CDM. Our hospitals have very poor availability of electronic medical records, while evidence indicates that primary care services are better equipped for CIS. Ultimately we need a mechanism to integrate the information systems between, within and across services, providing a large volume of real time data, guiding service development giving a reliable indication of care provided and ensuring the best use of resources. This has been achieved in several other health systems.
5. Measure what matters. Ensure that CDM is framed through both the experience and outcomes of patients. Include patient feedback into the measurement of how the healthcare system is performing and place patient satisfaction in the context of overall quality improvement.
6. Adopt clinical decision systems, such as guidelines for the management of the major chronic diseases, more consistently in practice. Clinicians should be supported through multidisciplinary postgraduate training and professional development exercises, to incorporate guidelines into their standard clinical practice and treatment management, which in turn should be run on electronic platforms to include disease coding, automated prompts, recalls, and integrated decision support.

7. Promote the use of disease registers that can track both individual patients as well as populations of patients. Registries are fundamental to the successful integration of all the elements of the CCM. The entire care team should use the registry to guide the course of treatment, anticipate problems, measure outcomes and track progress.
8. Incorporate quality of access more strongly into the implementation of key government policies. It should be focused on both equity of access and availability and quality of care. Speeding up the implementation of universal access to primary care to all citizens as outlined within the Programme for Government is part of the solution to the evident inequality reflected in this series of studies. Real time return of data on access and waiting times will allow Irish citizens to understand whether inequities in the system are being addressed or not.
9. Focus on prevention. Most chronic diseases reflect a failure of prevention. Key government policies and strategies all need to promote healthier lifestyles and strengthen the earlier assessment and diagnosis of chronic conditions. Chronic disease prevention programmes need to take a life course perspective with a strong focus on prenatal care and early childhood, and developing interventions based on the needs of vulnerable and disadvantaged groups.
10. Employ these data as a starting point to measure chronic disease management in Ireland. The data presented in this report provide a clear baseline measure of key features of effective chronic disease management. Results reported here form the baseline against which future change can be measured. Changes over time and progress should be measured to enable identification of areas in which further development is required.

Introduction

The World Health Organization (WHO) chronic disease profile for Ireland in 2014 attributed 88% of deaths in Ireland to chronic illnesses such as cardiovascular disease, diabetes, cancer and chronic respiratory disease¹. Worldwide, chronic illnesses are increasingly becoming a primary concern for healthcare systems⁹. As populations age and those with chronic illnesses live longer, the number of chronically ill patients increases^{10,11}. By 2020 it is estimated that chronic illnesses will account for 60% of the global burden of disease¹² and by 2030 that 70% of the global disease burden will be due to chronic diseases, with an increasing number of individuals having multiple chronic conditions in their lifetime¹³. Chronic illnesses usually have long durations with progression of symptoms impacting on physical, emotional and mental wellbeing of individuals, leading to a reduced quality of life and increased morbidity and mortality^{10,11,14}. For society as a whole, chronic illnesses increase healthcare costs, impact negatively on economic development and decrease productivity¹⁴.

Healthcare systems increasingly need to address the management of individuals with chronic illnesses. The effects of chronic illness can be mitigated by high quality evidence-based care¹⁴. However, this is rarely the case in most healthcare systems where poor access and quality of care is typical for patients with chronic illnesses^{9,14}. An increasing care burden juxtaposed with finite resources results in pressurised practitioners not following best practice guidelines, lack of care coordination, lack of follow up and patients being inadequately supported to manage their illness at home¹⁵. Poor quality care also stems from the complexity of this patient group with more than half having multimorbidities (i.e. more than one chronic illness)¹⁵. In a recent study of Irish general practice patients with one or more chronic illnesses, a significant increase was reported in healthcare utilisation and cost among patients with multimorbidities¹⁶. The underdevelopment of healthcare systems, lagging behind in diagnostic capacity, treatment developments and technological advances and deployment of integrated information technology also contributes to this problem^{9,14,17}.

Management of the complex needs of chronic illness patients is one of the biggest challenges facing healthcare professionals and systems worldwide¹¹. A consistent definition of chronic disease management does not exist. We define chronic disease management in the clinical setting as an organised, proactive, multi-component, patient-centred approach to healthcare delivery, guided by data automatically and continuously generated from the electronic medical record, made available in real time for the main disease centres for the population. Care is focused on and integrated across, the entire spectrum of disease, effectively delaying the onset of complications and multimorbidities and encompassing the relevant aspects of the delivery system. Essential components include identification of the population with the conditions, implementation and constant review of clinical practice guidelines or other decision-making tools, implementation of additional patient, provider, or healthcare system focused interventions, the use of clinical information systems and the real time measurement, analysis and management of clinical outcomes and costs.

The WHO has recommended the Chronic Care Model (CCM) to guide healthcare system reform worldwide^{14,17}. This current stakeholder research utilised the CCM as its theoretical underpinning. The CCM is an internationally recognised evidence-based theoretical model which identifies the essential elements of a healthcare system that encourages high-quality chronic illness care^{10,15}. The emergence of the CCM represents a response to growing numbers of chronically ill patients, the inability of current healthcare systems to meet the medical needs of chronically ill patients, the era of cost constraints alongside increased performance expectations from an informed public and the acknowledgement of the need for a shift from reactive to proactive healthcare systems^{10,14,17,18}. The underlying premise is that enabling healthcare providers and their patients to deal proactively with chronic illness will lead to patients receiving better and more acceptable care, improved clinical outcomes and quality of life, resulting in reduced need for healthcare in the future¹¹. At present, healthcare systems are reactive, organised to deal with acute illnesses or injuries with the patient playing a passive role¹⁰. Effective management of chronic illnesses requires a shift in the organisation of healthcare systems to a proactive, planned and population based model, focused on promoting health and preventing disease, in which the patient plays an active role^{19,20}. This means earlier care delivered to ambulant patients in the community rather than delayed care delivered to patients admitted into the hospital setting.

Primary care is considered the cornerstone of any health system²¹⁻²³ and has a central role in integrating care within a health system²⁴. Health systems built on the principles of primary care (first contact, continuous, comprehensive and coordinated care) achieve better health and greater equity in health than systems with a speciality care orientation^{22,25}.

Ireland is unusual amongst its European neighbours in not having universal access to primary care²⁶. A recent analysis conducted by the European Observatory on Health Systems and Policies found that the highest formal payments in any primary care system exist in Ireland, where patients without a medical card pay between €45 and €65 for each general practice visit, with no reimbursement²⁶. In Ireland the Programme for Government entitled 'Towards Recovery, Programme for a National Government 2011-2016'²⁷, has committed to ending the "unfair, unequal and inefficient two-tier health system" by introducing universal health insurance (UHI). The Government favours universal healthcare through an insurance-based system drawing on the model introduced in 2006 in the Netherlands. This is a system of compulsory private-for-profit insurance companies with strong government regulation and input, with payments related to ability to pay and not to gender, age or health status. Health insurers will be obliged to provide the same basic package for all but may also have the option of providing supplementary packages. These supplementary packages will not be able to provide faster access to procedures already provided in the basic package. Risk equalisation will ensure that health insurers are unable to refuse any applicant. The Government will pay the premia for people on low or no income and subsidise those on middle incomes. The Programme for Government states, "under this system there will be no discrimination between patients on the grounds of income or insurance status. The two-tier system of unequal access to hospital care will end." (p32).

The Irish Government states that it is “committed to reforming our model of delivering healthcare, so that more care is delivered in the community. The first point of contact for a person needing healthcare will be primary care, which should meet 90-95% of people’s health and personal social care needs” (p 30)²⁸. The vision for primary care in Ireland is one where:

- No one pays fees for GP care at point of contact
- GPs work in teams with other primary care professionals
- The focus is on the prevention of illness and structured care for people with chronic conditions
- Primary care teams work from dedicated facilities
- Staffing and resourcing of primary care is allocated rationally to meet regularly assessed needs.

Alongside the health policy advocating for the expanding role of primary care was a recent reconfiguration of our hospital services into Hospital Groups. Ireland has forty-nine hospitals and these hospitals have been recently organised into seven independent Hospital Groups under plans to reform Ireland’s acute hospital system. The report on ‘The Establishment of Hospital Groups as a transition to Independent Hospital Trusts’²⁹ from the Hospital Group Strategic Board, chaired by Professor John Higgins, paves the way for the establishment of Hospital Trusts. Key details suggest, “the integration between primary and hospital care is vital in the implementation of hospital groups. Groups should be managed so that they enable and encourage movement, working in close synergy with their colleagues in primary care as well as within and between hospital groups. How they are managed and run must acknowledge the direction of travel for healthcare across the developed world, where in the future most healthcare will be delivered outside traditional hospital settings” (p 11).

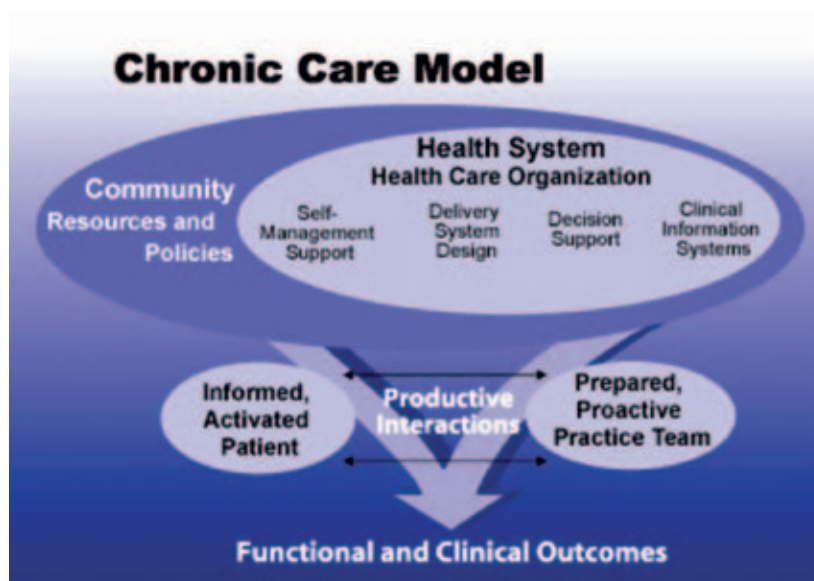
In Ireland, the thinking specifically relating to improving chronic conditions is reflected in policy documents such as ‘Tackling Chronic Disease’²² and ‘Healthy Ireland’³⁰ which emphasise the need for chronic illness prevention and management. ‘Healthy Ireland’ is the new national policy framework to improve the future health and wellbeing of the Irish people. It aims to increase the proportion of people who are healthy at all stages of life, and to reduce health inequalities. The Programme for Government²⁷ prioritises the need to address the inadequate and fragmented services for chronic illnesses. This policy recognises the need to implement a model for the prevention and management of chronic illnesses, and to achieve high quality care through comprehensive and integrated programmes in the community.

The CCM is designed on evidence-based research and practice interventions to assist this transition from a reactive to a proactive healthcare system. It includes a combination of patient, provider and system level interventions delivered in tandem through six key elements:

- 1) Healthcare system organisation (i.e. policies, goals and structures of healthcare systems)
- 2) Self-management supports (i.e. information and supports to facilitate patients to manage their care)
- 3) Delivery system design (i.e. coordinating care processes proactively to determine and address individual health needs)
- 4) Decision supports (i.e. healthcare provider access to evidence-based processes and clinical expertise and experience)
- 5) Clinical information systems (i.e. timely access to data about patients and populations)
- 6) Community resources and policy (i.e. sustaining care through utilising community resources and public policy to facilitate care outside of the clinical setting)^{10,11}.

As illustrated in Figure 1, community resources and policies, health systems and healthcare organisations use self-management supports, delivery system designs, decision supports and clinical information systems to achieve productive and evolving interactions between informed enfranchised patients and prepared proactive practice teams, resulting in improved outcomes. Key focal points of the CCM are the development of interactions between the healthcare system and the community, and also between patients and healthcare providers^{9,10,18}. Optimal chronic care is achieved when a prepared, proactive healthcare team interacts with an informed, enfranchised patient, and when the healthcare system interacts productively with the community.

Figure 1. The Chronic Care Model³¹



The WHO has recommended the CCM for healthcare systems worldwide^{14,17}. The CCM has been implemented in a variety of countries including the United States^{18,19,32}, Mexico⁹, Norway³³, Canada¹¹, Belgium³⁴ and Japan³⁵. CCM initiatives have become the foundation of patient care for heart disease/failure^{11,19,36,37}, diabetes^{18,19,34,37-41}, asthma^{19,37}, chronic obstructive pulmonary disease (COPD)⁴², depression^{37,43}, HIV⁴⁴ and primary care counselling²⁰. The sum of the components of CCM create more effective healthcare delivery systems¹⁸. Research has associated the CCM with improvements in healthcare processes^{18,37,40}; better patient care, health outcomes and quality of life^{11,19,20,34}; reduced healthcare costs and lower use of healthcare services^{32,40}. Recent data from the United States is strongly encouraging, demonstrating higher levels of patient satisfaction, reduced costs and greater volumes of care delivered in the community⁴⁵, much of this is being achieved in discrete insured populations, utilising the Patient Centred Medical Home concept, itself utilising much theory and many features of the CCM.

According to the CCM, optimal chronic care is achieved when a prepared, proactive healthcare team interacts with an informed, enfranchised patient. Patients are seen as partners in managing chronic illness⁴⁶. The opinions of key stakeholders in relation to the readiness of the healthcare system to deliver effective CDM are vital to understanding on-going reforms within our health service. We believe that in this context it is most important to understand the beliefs, experiences and attitudes of frontline clinical staff such as general practitioners, hospital consultants and practice nurses working within primary care, as well as patients with chronic multimorbidities. Understanding stakeholders' views and needs and how these may vary with factors such as age, sex, geography and local socio-economic circumstances, is essential for good planning and monitoring of chronic disease management within Ireland.

Section One: Aim of Research

1.1 Aim of Research

The views of the stakeholder groups surveyed (general practitioners⁵, hospital consultants⁶, practice nurses⁷ and patients⁸) are reported in detail in stand alone reports. The aim of this current report is to take an overview of the four stakeholder perspectives across key criteria for effective chronic disease management and to offer an appraisal of what elements of the CCM are currently in place. It provides a baseline measure against which future transformation in CDM can be benchmarked. It provides an opportunity to compare the opinions of patients with those of GPs, hospital consultants and practice nurses, and enables a comparison between Ireland and other countries. Data contained herein can be used to inform patients, healthcare professionals and policy makers.

Section Two: Method

This section serves as an overview of the methods taken within each stakeholder project. For details on specific methods employed within a particular stakeholder analysis, general practitioners⁵, hospital consultants⁶, practice nurses⁷ and patients⁸ – refer to the corresponding report.

2.1 Design

Each stakeholder study used a cross-sectional design with a self-completed questionnaire, employing questions from previously used study instruments to allow comparisons across stakeholder groups. The general practitioner survey was conducted in 2010, the hospital consultant survey was conducted in 2012, the practice nurse survey was conducted in 2014 and the patient survey was conducted in 2013 and published in 2015.

2.2 Sampling

2.2.1 General practitioners

We compiled a national database of general practitioners in Ireland by cross-referencing the General Medical Scheme, Mother and Infant scheme, Cervical Screening and Medical Directory Databases. The GP database was then checked to remove doctors whom we knew to be no longer in practice. This resulted in a database with 2,636 doctors actively in general practice. A 20% random sample was generated from this database using a random numbers generator. This resulted in a total of 527 doctors selected to participate in the study.

2.2.2 Hospital consultants

The questionnaire was sent to Members and Fellows of the Royal College of Physicians of Ireland (RCPI) practicing in Ireland at the time of the research, with a speciality listed in the RCPI's database as one of the following: Endocrinology (N=49), Cardiology (N=42), Respiratory Medicine (N=62), Gerontology (N=83), Nephrology (N=33), Neurology (N=29), Rheumatology (N=42) and Rehabilitation Medicine (N=6). This resulted in a total sampling frame of 346 hospital consultants.

*It is important to note that the participants in the hospital consultants' arm of the study were members and fellows of the Royal College of Physicians of Ireland. Our sample did not include all hospital consultants working within hospital posts in Ireland.

2.2.3 Practice nurses

The Irish Practice Nurses Association has a total of 636 members. A total of 469 (75%) practice nurses who are members of the IPNA indicated their willingness to receive research invitations. The survey was sent to all 469 practice nurses.

*It is important to note that not all practice nurses in Ireland are members of the IPNA. There are in total approximately 1700 practice nurses in Ireland⁴⁷.

2.2.4 Patients

Ten pharmacies across the Leinster area were purposively selected in order to provide good variation in socioeconomic settings and the pharmacists were asked to recruit patients for inclusion in the study. Inclusion criteria necessitated that patients be on 3 or more regular medications over the preceding six months, ensuring that they were patients likely to have at least two chronic diseases.

2.3 Survey instrument

2.3.1 General practitioners, hospital consultants and practice nurses

The questionnaires used in the general practitioners', hospital consultants' and practice nurses' surveys were similar to allow for comparison. The survey was based upon the Use of Chronic Care Model Elements Survey⁴⁵ and included questions from A Survey Of Primary Care Physicians In Eleven Countries⁴⁸. This resulted in a modified thirty-one item questionnaire which covered topics such as respondents' perception of CDM, access to care for patients, evidence of managed care within the services, resources available to the stakeholder, the use of information technology within the services, respondents' perceptions of the barriers to effective CDM, future development of CDM and demographic details. These studies are, therefore, strongly couched within the conceptual framework of the CCM.

2.3.2 Patients

Two further validated survey tools designed specifically for patients were incorporated in the patient survey instrument – the Patient Assessment of Chronic Illness Care Survey⁴⁹ and the Assessing Disease Burden Morbidity Self-Assessment⁵⁰.

All questionnaires were piloted with the relevant stakeholder group for comprehension and ease of completion. See Appendices 1, 2, 3 and 4 for the survey instruments.

2.4 Procedure

2.4.1 General practitioners, hospital consultants and practice nurses

The procedure for the clinical stakeholder surveys was identical. Surveys were distributed through the post. The postal questionnaire was sent in three separate

waves at one-month intervals, to secure good response rates. Each participant received a questionnaire accompanied by a cover letter outlining the purpose of the study and assuring respondents of total confidentiality within the research team and a stamped addressed envelope for ease of return of the questionnaire. A unique identifying number (UIN) available only to the research team ensured the anonymity of the respondent. As the respondents completed and returned the questionnaire they were checked off the database using their UIN to ensure that they did not receive another questionnaire in a subsequent wave.

2.4.2 Patients

The survey was presented to patients fulfilling the entry criteria in ten pharmacies. Notices were displayed in the dispensing area and a summary information sheet was provided to patients to inform them of the study. The information sheet also included an option for patients to opt out of the study. The survey was completed during a visit to the pharmacy, while the patient was awaiting preparation and dispensing of their prescription. Pharmacists presented the survey to the patient and assisted with completion as necessary. A note was taken of all non-responders.

2.5 Response rates

2.5.1 General practitioners

Throughout the three months of data collection questionnaires were sent to 527 randomly selected GPs and 380 were completed and returned. This resulted in a response rate of 72%.

2.5.2 Hospital consultants

Throughout the three months of data collection questionnaires were sent to 346 hospital consultants and 227 were completed and returned. This resulted in a 66% response rate.

2.5.3 Practice nurses

Throughout the three months of data collection questionnaires were sent to 469 practice nurses and 341 were completed and returned. This resulted in a 73% response rate.

2.5.4 Patients

Throughout the four months of data collection a total of 600 questionnaires were distributed and 517 completed and returned. This resulted in an 86% response rate.

Section Three: Results

The results consider the critical components of the chronic care model (CCM) from the perspectives of the four stakeholder groups. These include: how the healthcare system is organised and its responsiveness to the management of chronic conditions, key issues within an Irish context relating to access to services and inequalities, provision of clinical information systems, an assessment of whether there are decision supports available for evidence-based managed care, self-management supports to facilitate patient engagement and barriers to effective chronic disease management (CDM) and potential pathways forward.

3.1 Healthcare system organisation and responsiveness

Respondents were surveyed on their opinions regarding the organisation and the responsiveness of the Irish health system to respond effectively to the demands inherent in good CDM and on their views regarding their preferred location for delivery of CDM services.

All four stakeholder groups were asked their opinion of the readiness of the Irish healthcare system to respond effectively to CDM.

Figure 2: Stakeholders’ perceptions of the Irish healthcare system’s ability to respond effectively to the management of chronic conditions.



A total of 221 (97.4%) hospital consultants answered this question. Missing data 6 (2.6%).
 A total of 368 (96.8%) GPs answered this question. Missing data = 12 (3.2%). A total of 307 (90.0%) practice nurses answered this question. Missing data = 34 (10.0%). A total of 502 (97.1%) patients answered this question. Missing data = 12 (2.9%)

There is consensus amongst stakeholders with the majority of hospital consultants (n=180/221; 81.4%), general practitioners (n=240/368; 65.2%), practice nurses (n=251/307; 81.8%) and patients (n=278/502; 55.4%) recognising that there are some good things in our health system but fundamental changes are needed to make it work better (Figure 2). Patients were most likely to be positive about the healthcare system, with a greater proportion of patients advocating for the least level of change. A total of 19.3% (n=97/502) of patients advocated for only minor changes within the current system, in comparison with 5.7% (n=21/368) of GPs, 4.5% (n=10/221) of hospital consultants and 4.9% (n=15/307) of practice nurses.

Clinical stakeholders were asked a series of questions about the location of services for the management of chronic conditions (Table 1).

Table 1: Clinical stakeholders' views on the location and provider of chronic disease management services.

	Responder	Strongly disagree	Disagree	Neither	Agree	Strongly agree
CDM should take place largely at a GP practice level and delivered by GPs	General practitioners (N=373; 98.1%)	18 (4.8%)	36 (9.7%)	76 (20.4%)	159 (42.6%)	84 (22.5%)
	Hospital consultants (N=220; 96.6%)	10 (4.5%)	42 (19.1%)	68 (30.9%)	78 (35.5%)	22 (10.0%)
	Practice nurses (N=335; 98.2%)	17 (5.1%)	57 (17.0%)	90 (26.9%)	128 (38.2%)	43 (12.8%)
CDM should take place largely at GP practice level delivered by nurses, under GP supervision	General practitioners (N=373; 98.1%)	19 (5.1%)	55 (14.7%)	103 (27.6%)	139 (37.3%)	57 (15.3%)
	Hospital consultants (N=217; 95.6%)	31 (14.3%)	60 (27.6%)	65 (30.0%)	48 (22.1%)	13 (6.0%)
	Practice nurses (N=336; 98.5%)	15 (4.5%)	28 (8.3%)	60 (17.9%)	163 (48.5%)	70 (20.8%)
CDM should take place largely at GP practice level delivered by nurses working independently of GPs	General practitioners (N=372; 97.8%)	137 (36.8%)	155 (41.7%)	56 (15.1%)	15 (4.0%)	9 (2.4%)
	Hospital consultants (N=218; 96%)	94 (43.1%)	78 (35.8%)	31 (14.2%)	9 (4.1%)	6 (2.8%)
	Practice nurses (N=332; 97.4%)	85 (25.6%)	108 (32.5%)	83 (25.0%)	34 (10.2%)	22 (6.6%)

General practitioners were more likely than practice nurses and hospital consultants to indicate that CDM should take place at general practice level, delivered by general practitioners (Table 1). Practice nurses were more likely than general practitioners and hospital consultants to indicate that CDM should take place at general practice level by nurses under general practitioner supervision. Very few respondents wish to see CDM delivered by practice nurses working independently of general practitioners.

Patients were asked for their views on their preferred location of treatment for their chronic condition and also their preferred provider of care (Table 2).

Table 2: Patients' opinions on the location and provider of chronic disease management services.

	Yes	No
My chronic illness should be managed within general practice (N= 512; 99.0%)	322 (62.9%)	190 (37.1%)
In general practice a GP should look after my chronic illness (N= 510; 98.6%)	389 (76.3%)	121 (23.7%)
In general practice a nurse under GP supervision should look after my chronic illness (N= 509; 98.5%)	139 (27.3%)	370 (72.7%)
In general practice a nurse independent of GP supervision should look after my chronic illness (N= 510; 98.6%)	10 (2.0%)	500 (98.0%)
My chronic illness should be managed within a hospital (N= 512; 99.0%)	91 (17.8%)	421 (82.2%)
My chronic illness should be managed in the community, led by a hospital consultant team (N= 512; 99.0%)	126 (24.6%)	386 (75.4%)

There was a strong preference for CDM to take place within a general practice setting with 62.9% (n=322/512) in favour of CDM within general practice as opposed to 17.8% (n=91/512) who supported CDM in a hospital setting. Within a general practice setting the patients' preference is for care provided by a general practitioner (n=389/510; 76.3%). Only a minority of respondents favoured care provided by a nurse under the supervision of a general practitioner (n=139/509; 27.3%) and 2.0% (n=10/510) of respondents were in agreement with CDM care provided by a nurse independent of a general practitioner.

3.2 Healthcare system organisation – access and inequality

Ireland is unusual amongst its European neighbours in not providing universal access to primary care. It was therefore important to ask a series of questions within the stakeholder surveys, which would measure the perceived extent of the inequities within the system with regard to access, payment, diagnostics, and treatment of both private and public patients.

Of the 86% (n=517/600) of patients who completed the survey, a total of 270 (52.2%) patients were public patients with a GMS medical card or doctor visit card. GMS status refers to patient eligibility under the Primary Care Reimbursement Scheme and is a marker of deprivation. A further 231 (44.7%) patients were private fee-paying patients. The remaining 16 (3.1%) did not indicate their GMS status.

Table 3: Comparison between patients', GPs', hospital consultants' and practice nurses' perception of difficulties experienced in accessing services and paying for medical costs for private patients.

	Responder	Often	Sometimes	Rarely	Never
*Private patients have difficulty paying for medications or other out-of-pocket costs	Private patients (N=231; 100.0%)	59 (25.5%)	95 (41.1%)	36 (15.6%)	41 (17.7%)
	General practitioners (N=373; 98.1%)	151 (40.5%)	178 (47.7%)	43 (11.5%)	1 (0.3%)
	Hospital consultants (N=205; 90.3%)	35 (17.1%)	133 (64.9%)	31 (15.1%)	6 (2.9%)
	Practice nurses (N=324; 95.0%)	119 (36.7%)	176 (54.3%)	27 (8.3%)	2 (0.6%)
*Private patients experience long waiting times to see a hospital consultant	Private patients (N=230; 99.6%)	32 (13.9%)	58 (25.2%)	77 (33.5%)	63 (27.4%)
	General Practitioners (N=376; 98.9%)	132 (35.1%)	129 (34.3%)	98 (26.1%)	17 (4.5%)
	Hospital consultants (N=210; 92.5%)	25 (11.9%)	81 (38.6%)	88 (41.9%)	16 (7.6%)
	Practice nurses (N=327; 95.9%)	105 (32.1%)	126 (38.5%)	91 (27.8%)	5 (1.5%)
*Private patients have difficulty getting specialised diagnostic tests (e.g., CT imaging)	Private patients (N=230; 99.6%)	18 (7.8%)	55 (23.9%)	69 (30.0%)	88 (38.3%)
	General practitioners (N=376; 98.9%)	120 (31.9%)	135 (35.9%)	106 (28.2%)	15 (4.0%)
	Hospital consultants (N=209; 92.1%)	23 (11.0%)	86 (41.1%)	81 (38.8%)	19 (9.1%)
	Practice nurses (N=327; 95.9%)	69 (21.1%)	144 (44.0%)	105 (32.1%)	9 (2.8%)
*Private patients experience long waiting times to receive treatment after diagnosis	Private patients (N=227; 98.3%)	18 (7.9%)	30 (13.2%)	86 (37.9%)	93 (41.0%)
	General practitioners (N=376; 98.9%)	76 (20.2%)	148 (39.4%)	133 (35.4%)	19 (5.1%)
	Hospital consultants (N=210; 92.5%)	13 (6.2%)	62 (29.5%)	108 (51.4%)	27 (12.9%)
	Practice nurses (N= 325; 95.3%)	50 (15.4%)	142 (43.7%)	126 (38.8%)	7 (2.2%)

*Note: Phrasing of questions put to clinical stakeholder groups referenced their perception of their patients experience. Example: 'How often do your private patients experience difficulties in paying for medications or other out-of-pocket costs?'

There is broad consensus between stakeholders that private patients experience difficulties paying for both medications and other medical costs (Table 3). Hospital consultants and to a slightly greater extent GPs and practice nurses appear to overestimate the difficulties faced by private patients in accessing hospital consultants, specialist diagnostic tests and treatment after a diagnosis has been made.

Table 4: Comparison between patients', GPs', hospital consultants' and practice nurses' perception of difficulties experienced in accessing services and paying for medical costs for public patients.

	Responder	Often	Sometimes	Rarely	Never
*Public patients have difficulty paying for medications or other out-of-pocket costs	Public patients (N=265; 98.1%)	39 (14.7%)	75 (28.3%)	62 (23.4%)	89 (33.6%)
	General practitioners (N=368; 96.8%)	87 (23.6%)	92 (25.0%)	123 (33.4%)	66 (17.9%)
	Hospital consultants (N=215; 94.7%)	76 (35.3%)	76 (35.3%)	48 (22.3%)	15 (7.0%)
	Practice nurses (N=329; 96.5%)	121 (36.8%)	111 (33.7%)	84 (25.5%)	13 (4.0%)
*Public patients experience long waiting times to see a hospital consultant	Public patients (N=267; 98.9%)	112 (41.9%)	78 (29.2%)	40 (15.0%)	37 (13.9%)
	General practitioners (N=369; 97.1%)	342 (92.7%)	25 (6.8%)	1 (0.3%)	1 (0.3%)
	Hospital consultants (N=217; 95.6%)	151 (69.6%)	58 (26.7%)	8 (3.7%)	0 (0.0%)
	Practice nurses (N= 334; 97.9%)	297 (88.9%)	35 (10.5%)	2 (0.6%)	0 (0.0%)
*Public patients have difficulty getting specialised diagnostic tests (e.g., CT imaging)	Public patients (N=262; 97.0%)	55 (21.0%)	110 (42.0%)	25 (9.5%)	72 (27.5%)
	General practitioners (N=369; 97.1%)	326 (88.3%)	34 (9.2%)	6 (1.6%)	3 (0.8%)
	Hospital consultants (N=216; 95.2%)	116 (53.7%)	70 (32.4%)	24 (11.1%)	6 (2.8%)
	Practice nurses (N= 334; 97.9%)	220 (65.9%)	98 (29.3%)	15 (4.5%)	1 (0.3%)
*Public patients experience long waiting times to receive treatment after diagnosis	Public patients (N=263; 97.4%)	52 (19.8%)	85 (32.3%)	62 (23.6%)	64 (24.3%)
	General practitioners (N=368; 96.8%)	253 (68.8%)	93 (25.3%)	20 (5.4%)	2 (0.5%)
	Hospital consultants (N=215; 94.7%)	86 (40.0%)	86 (40.0%)	37 (17.2%)	6 (2.8%)
	Practice nurses (N= 334; 97.9%)	203 (60.8%)	106 (31.7%)	25 (7.5%)	0 (0.0%)

*Note: Phrasing of questions put to clinical stakeholder groups referenced their perception of their patients' experience. Example: 'Have your GMS patients had difficulties in paying for medications or other out-of-pocket costs?'

There is broad consensus between public patients, GPs, hospital consultants and practice nurses that public patients experience delays in accessing, and difficulties paying for, services, diagnostics and treatment (Table 4). GPs particularly, but also to a lesser extent hospital consultants and practice nurses, rate more highly the difficulties public patients experience in accessing and paying for care.

Table 5: General practitioners', hospital consultants' and practice nurses' perceptions of effective local access to services for both private and public patients.

	Responder	Yes (private patients)	Yes (public patients)
Physiotherapist	General practitioners (N= 379; 99.7%)	350 (92.3%)	238 (62.8%)
	Hospital consultants (N= 223; 98.2%)	152 (68.1%)	134 (60.1%)
	Practice nurses (N=340; 99.7%)	302 (88.8%)	247 (72.6%)
Occupational therapist	General practitioners (N= 379; 99.7%)	139 (36.7%)	156 (41.2%)
	Hospital consultants (N= 223; 98.2%)	86 (38.6%)	114 (51.1%)
	Practice nurses (N=340; 99.7%)	132 (38.8%)	152 (44.7%)
Speech and language therapist	General practitioners (N= 379; 99.7%)	151 (39.8%)	141 (37.2%)
	Hospital consultants (N= 223; 98.2%)	76 (34.1%)	104 (46.6%)
	Practice nurses (N=340; 99.7%)	142 (41.8%)	132 (38.8%)
Psychologist	General practitioners (N= 379; 99.7%)	219 (57.8%)	92 (24.3%)
	Hospital consultants (N= 223; 98.2%)	59 (26.5%)	46 (20.6%)
	Practice nurses (N=340; 99.7%)	195 (57.4%)	129 (37.9%)
Dietician	General practitioners (N= 379; 99.7%)	245 (64.6%)	189 (49.9%)
	Hospital consultants (N= 223; 98.2%)	110 (49.3%)	123 (55.2%)
	Practice nurses (N=340; 99.7%)	222 (65.3%)	202 (59.4%)
Social worker	General practitioners (N= 379; 99.7%)	143 (37.7%)	197 (52%)
	Hospital consultants (N= 223; 98.2%)	50 (22.4%)	101 (45.3%)
	Practice nurses (N=340; 99.7%)	130 (38.2%)	178 (52.4%)
Chiropodist*	General practitioners	-	-
	Hospital consultants	-	-
	Practice nurses (N=340; 99.7%)	266 (78.2%)	198 (58.2%)

* Not asked in hospital consultant or general practitioner surveys.

There is general consensus between all three clinical stakeholder groups about access to services for both public and private patients (Table 5). Most hospital consultants and general practitioners and practice nurses reported effective local access to physiotherapist and dietician services. Ineffective local access to occupational therapist (OT) services was reported by most stakeholders with the exception of hospital consultants' perception of access to OT services for public patients. Psychologist services were deemed marginally more accessible for private patients by GPs and practice nurses; and access to social worker services were perceived as better for public patients, by GPs and practice nurses.

Table 6: Public and private patients' experience of delay in attending a general practitioner or hospital consultant due to cost.

	Responder	Often	Sometimes	Rarely	Never
How often have you delayed attending a general practitioner because of cost?	Public patient (N=263; 97.4%)	15 (5.7%)	12 (4.6%)	45 (17.1%)	191 (72.6%)
	Private patient (N=230; 99.6%)	58 (25.2%)	86 (37.4%)	32 (13.9%)	54 (23.5%)
How often have you delayed attending a hospital consultant because of cost?	Public patient (N=262; 97.0%)	58 (22.1%)	35 (13.4%)	49 (18.7%)	120 (45.8%)
	Private patient (N=229; 99.1%)	68 (29.7%)	88 (38.4%)	24 (10.5%)	49 (21.4%)

As reported in Table 6, private patients are more likely than public patients to delay attending a GP or hospital consultant due to cost. A total of 62.6% (n=144/230) of private patients indicated that they often or sometimes delay attending the GP because of cost, compared with 10.3% (n=27/263) of public patients surveyed. A total of 68.1% (n=156/229) of private patients indicated that they often or sometime delay attending a hospital consultant because of costs, compared with a total of 35.5% (n=93/262) of public patients.

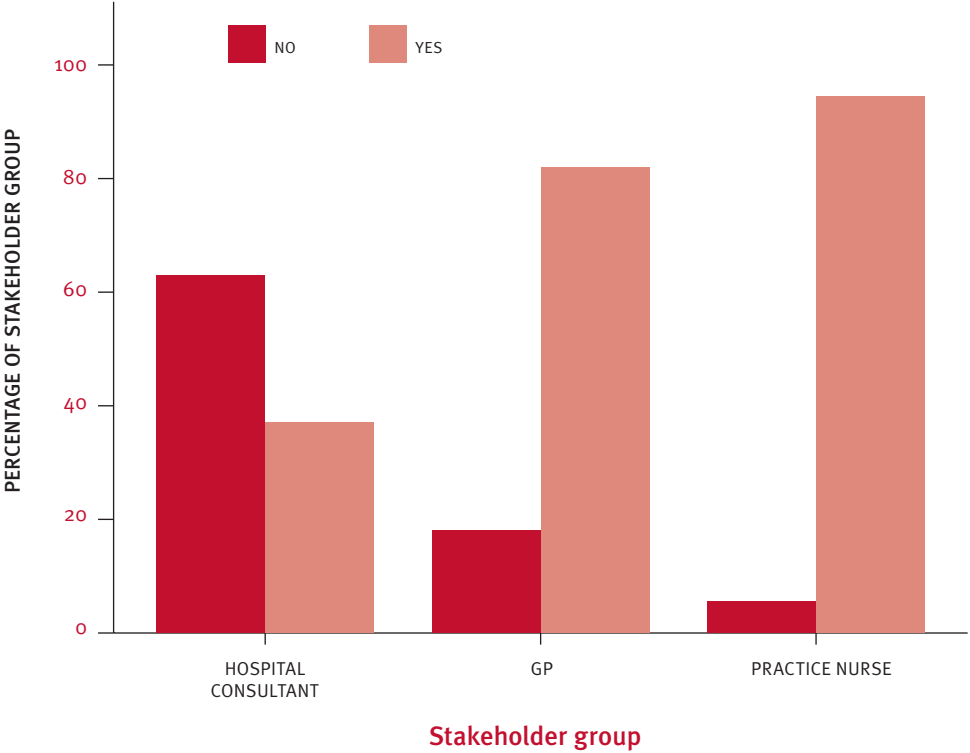
Responses from all four stakeholder groups indicate the current two-tiered health system is a difficult reality for them.

3.3 Clinical information systems

Clinical information systems (CIS) interventions are centred around establishing timely access to essential data about individual patients and populations of patients⁹.

We asked all of the clinical stakeholders to indicate whether they used electronic patient medical records in the service in which they practice.

Figure 3: Clinical stakeholders stated availability of electronic patient medical records where they practice.



A total of 217 (95.6%) hospital consultants answered this question. Missing data = 10 (4.4%). A total of 373 (98.2%) GPs answered this question. Missing data = 7 (1.8%). A total of 329 (96.5%) practice nurses answered this question. Missing data = 12 (3.5%).

There is very good availability of electronic patient medical records in primary care services, with high numbers of general practitioners (83.1%; n=310/373) and practice nurses (97.2%; n=320/329) indicating that they had electronic medical records for patient notes (Figure 3), compared to a little over a third of hospital consultants (37.3%; n=81/217), who use electronic records.

Clinical stakeholders were asked a series of questions about their use of technology in their service or practice (Table 7).

Table 7: The use of technology within services.

	Responder	Yes, used routinely	Yes, used occasionally	No
Electronic access to your patients' laboratory test results	General practitioners (N=378; 99.4%)	272 (72.0%)	11 (2.9%)	95 (25.1%)
	Hospital consultants (N=222; 97.8%)	190 (85.6%)	25 (11.3%)	7 (3.2%)
	Practice nurses (N=338; 99.1%)	319 (94.4%)	3 (0.9%)	16 (4.7%)
Electronic ordering of laboratory tests	General practitioners (N=373; 98.1%)	85 (22.8%)	6 (1.6%)	282 (75.6%)
	Hospital consultants (N=217; 95.6%)	68 (31.3%)	23 (10.6%)	126 (58.1%)
	Practice nurses (N=329; 96.5%)	78 (23.7%)	13 (4.0%)	238 (72.3%)
Electronic entry of clinical notes, including medical history and follow-up	General practitioners (N=378; 99.4%)	292 (77.2%)	13 (3.4%)	73 (19.3%)
	Hospital consultants (N=221; 97.4%)	35 (15.8%)	30 (13.6%)	156 (70.6%)
	Practice nurses (N=339; 99.4%)	305 (90.0%)	15 (4.4%)	19 (5.6%)
Electronic prescribing of medication	General practitioners (N=377; 99.2%)	311 (82.5%)	8 (2.1%)	58 (15.4%)
	Hospital consultants (N=220; 96.9%)	14 (6.4%)	11 (5.0%)	195 (88.6%)
	Practice nurses (N=339; 99.4%)	315 (92.9%)	8 (2.4%)	16 (4.7%)
Electronic alerts or prompts about ADRs* or drug interactions	General practitioners (N=376; 98.9%)	240 (63.8%)	35 (9.3%)	101 (26.9%)
	Hospital consultants (N=219; 96.5%)	11 (5.0%)	23 (10.5%)	185 (84.5%)
	Practice nurses (N=334; 97.9%)	258 (77.2%)	27 (8.1%)	49 (14.7%)

* ADRs – adverse drug reactions

Almost all clinical stakeholders reported being able to access patients' laboratory test results electronically. More hospital consultants report not having access to electronic entry of clinical notes, electronic prescribing of medication or electronic alerts or prompts about adverse drug reactions or drug interactions when compared to practice nurses and general practitioners.

Table 8: Frequency of use of strategies to improve care for patients.

	Responder	Never	Rarely	Occasionally	Usually	Always
Use a register to identify/track care	General practitioners (N=375; 98.6%)	120 (32.0%)	60 (16.0%)	84 (22.4%)	57 (15.2%)	54 (14.4%)
	Hospital consultants (n=222; 97.8%)	80 (36.0%)	36 (16.2%)	51 (23.0%)	39 (17.6%)	16 (7.2%)
	Practice nurses (N=334; 97.9%)	36 (10.8%)	30 (9.0%)	74 (22.2%)	83 (24.9%)	111 (33.2%)
Use a tracking system to remind patients about visits	General practitioners (N=376; 98.9%)	166 (44.1%)	83 (22.1%)	55 (14.6%)	43 (11.4%)	29 (7.7%)
	Hospital consultants (N=225; 99.1%)	97 (43.1%)	49 (21.8%)	25 (11.1%)	41 (18.2%)	13 (5.8%)
	Practice nurses (N=331; 97.1%)	63 (19.0%)	54 (16.3%)	61 (18.4%)	72 (21.8%)	81 (24.5%)
Follow up patients between visits (you or your staff)	General practitioners (N=376; 98.9%)	79 (21.0%)	57 (15.2%)	126 (33.5%)	89 (23.7%)	25 (6.6%)
	Hospital consultants (N=225; 99.1%)	30 (13.3%)	33 (14.7%)	103 (45.8%)	42 (18.7%)	17 (7.6%)
	Practice nurses (N=334; 97.9%)	38 (11.4%)	47 (14.1%)	118 (35.3%)	78 (23.4%)	53 (15.9%)
Use published team guidelines as the basis for your patient management	General practitioners (N=375; 98.6%)	51 (13.6%)	42 (11.2%)	81 (21.6%)	136 (36.3%)	65 (17.3%)
	Hospital consultants (N=222; 97.8%)	20 (9.0%)	26 (11.7%)	50 (22.5%)	91 (41.0%)	35 (15.8%)
	Practice nurses (N=331; 97.1%)	24 (7.3%)	23 (6.9%)	39 (11.8%)	120 (36.3%)	125 (37.8%)
Involve office staff in reminding patients in need of follow-up or other services	General practitioners (N=376; 98.9%)	68 (18.1%)	45 (12.0%)	102 (27.1%)	128 (34.0%)	33 (8.8%)
	Hospital consultants (N=222; 97.8%)	28 (12.6%)	25 (11.3%)	70 (31.5%)	73 (32.9%)	26 (11.7%)
	Practice nurses (N=328; 96.2%)	46 (14.0%)	43 (13.1%)	85 (25.9%)	96 (29.3%)	58 (17.7%)
Assist patients in setting and attaining self-management goals	General practitioners (N=378; 99.4%)	28 (7.4%)	29 (7.7%)	90 (23.8%)	178 (47.1%)	53 (14.0%)
	Hospital consultants (N=224; 98.7%)	13 (5.8%)	19 (8.5%)	61 (27.2%)	100 (44.6%)	31 (13.8%)
	Practice nurses (N=334; 97.9%)	10 (3.0%)	14 (4.2%)	60 (18.0%)	149 (44.6%)	101 (30.2%)
Refer patients to someone within your service for education about their condition	General practitioners (N=373; 98.1%)	87 (23.3%)	46 (12.3%)	51 (13.7%)	119 (31.9%)	70 (18.8%)
	Hospital consultants (N=224; 98.7%)	13 (5.8%)	11 (4.9%)	51 (22.8%)	108 (48.2%)	41 (18.3%)
	Practice nurses (N=330; 96.8%)	51 (15.5%)	33 (10.0%)	49 (14.8%)	99 (30.0%)	98 (29.7%)
Refer patients to someone outside your service for education about their condition	General practitioners (N=374; 98.4%)	34 (9.1%)	53 (14.2%)	98 (26.2%)	133 (35.6%)	56 (15.0%)
	Hospital consultants (N=224; 98.7%)	57 (25.4%)	75 (33.5%)	61 (27.2%)	21 (9.4%)	10 (4.5%)
	Practice nurses (N=331; 97.1%)	15 (4.5%)	34 (10.3%)	117 (35.3%)	102 (30.8%)	63 (19.0%)
Use flow sheets to track critical elements of care	General practitioners (N=373; 98.1%)	169 (45.3%)	83 (22.3%)	61 (16.4%)	33 (8.8%)	27 (7.2%)
	Hospital consultants (N=224; 98.7%)	59 (26.3%)	58 (25.9%)	53 (23.7%)	33 (14.7%)	21 (9.4%)
	Practice nurses (N=330; 96.8%)	148 (44.8%)	72 (21.8%)	51 (15.5%)	31 (9.4%)	28 (8.5%)

Note: General practitioners and practice nurses were asked the above questions in relation to diabetes care. Hospital consultants were asked more generally in terms of care for patients with chronic diseases.

A total of 29.6% (n=111/375) of general practitioners, 24.8% (n=55/222) of hospital consultants and 58.1% (n=194/334) of practice nurses report usually or always using a register to identify or track care (Table 8). Uptake in the use of a tracking system to remind patients about visits usually or always was reported by 19.1% (n=72/376) of GPs, 24.0% (n=54/225) of hospital consultants and 46.3% (n=153/331) of practice nurses. Published evidence-based guidelines are a commonly used approach to improving care for patients with chronic illnesses, with 53.6% (n=201/375) of general practitioners, 56.8% (n=126/222) of hospital consultants and 74.1% (n=245/331) of practice nurses reporting usually or always using published team guidelines. The majority of clinical stakeholders report assisting patients in setting and attaining self-management goals with 61.1% (n=231/378) of general practitioners, 58.4% (n=131/224) of hospital consultants and 74.8% (n=250/334) of practice nurses reporting usually or always assisting patients in setting and attaining self-management goals. Flow sheets to track critical elements of care were not reported to be used by clinicians with 45.3% (n=169/373) of general practitioners, 26.3% (n=59/224) of hospital consultants and 44.8% (n=148/330) of practice nurses reporting never using flow sheets. Hospital consultants were least likely to report referring a patient to somebody outside of their service for education about their condition, with 25.4% (n=57/224) of hospital consultants reporting never referring patients in comparison to 9.1% (n=34/374) of general practitioners and 4.5% (n=15/331) of practice nurses.

It would appear from the reported uptake of strategies to improve patient care by general practitioners, hospital consultants and practice nurses, which attempts have been made to implement strategies to improve patient care. However, there remains considerable work to be done in this area.

3.4 Decision supports – evidence-based managed care

For effective high quality healthcare and improved health outcomes, treatment decisions need to be based on explicit evidence-based guidelines⁵⁵. Developments in medical science are continuous and to provide effective treatment it is necessary for healthcare professionals to follow developments and medical innovations and incorporate the latest evidenced findings in their daily clinical practice⁵¹. Decision support (DS) interventions aim to ensure that evidence-based guidelines and knowledge are incorporated within chronic care treatment. This is achieved through interventions embedding evidence-based practice and guidelines or protocols within daily clinical practice and the decision making process for determining a diagnosis or recommending a treatment^{9,52}.

Table 9: General practitioners' and practice nurses' use of evidence-based treatment guidelines for various chronic conditions.

	Responder	Yes, routinely use guidelines	No, do not routinely use guidelines	No guidelines available
Diabetes	General practitioners (N=375; 98.6%)	267 (71.2%)	103 (27.5%)	5 (1.3%)
	Practice nurses (336; 98.5%)	291 (86.6%)	41 (12.2%)	4 (1.2%)
Depression	General practitioners (N=375; 98.6%)	126 (33.6%)	227 (60.5%)	22 (5.9%)
	Practice nurses (N=315; 92.3%)	173 (54.9%)	121 (38.4%)	21 (6.7%)
Asthma or COPD	General practitioners (N=375; 98.6%)	279 (74.4%)	89 (23.7%)	7 (1.9%)
	Practice nurses (N=333; 97.6%)	264 (79.3%)	61 (18.3%)	8 (2.4%)
Hypertension	General practitioners (N=375; 98.6%)	297 (79.2%)	73 (19.5%)	5 (1.3%)
	Practice nurses (N=333; 97.6%)	284 (85.3%)	45 (13.5%)	4 (1.2%)
ADHD	General practitioners (N=367; 96.5%)	54 (14.7%)	213 (58.0%)	100 (27.2%)
	Practice nurses (N=306; 89.7%)	120 (39.2%)	131 (42.8%)	55 (18.0%)

Utilisation of evidence-based treatment guidelines was reported by 86.6% (n=291/336) of practice nurses for diabetes, 79.3% (n=264/333) of practice nurses for asthma or COPD and 85.3% (n=284/333) of practice nurses for hypertension, as shown in Table 9. A total of 18.0% (n=55/306) of practice nurses reported that there were no guidelines available for ADHD. The majority of general practitioners reported that they are using evidence-based guidelines for diabetes, asthma or COPD and hypertension, and not using guidelines routinely for depression and ADHD.

Table 10: Hospital consultants' use of evidence-based guidelines for treatment of common conditions within their speciality.

	Yes, routinely use guidelines	Yes, sometimes use guidelines	No, do not routinely use guidelines	No guidelines available
In your speciality, to what extent, do you routinely use written, evidence-based treatment guidelines, for common conditions (N=226; 99.6%)	141 (62.4%)	78 (34.5%)	5 (2.2%)	2 (0.9%)

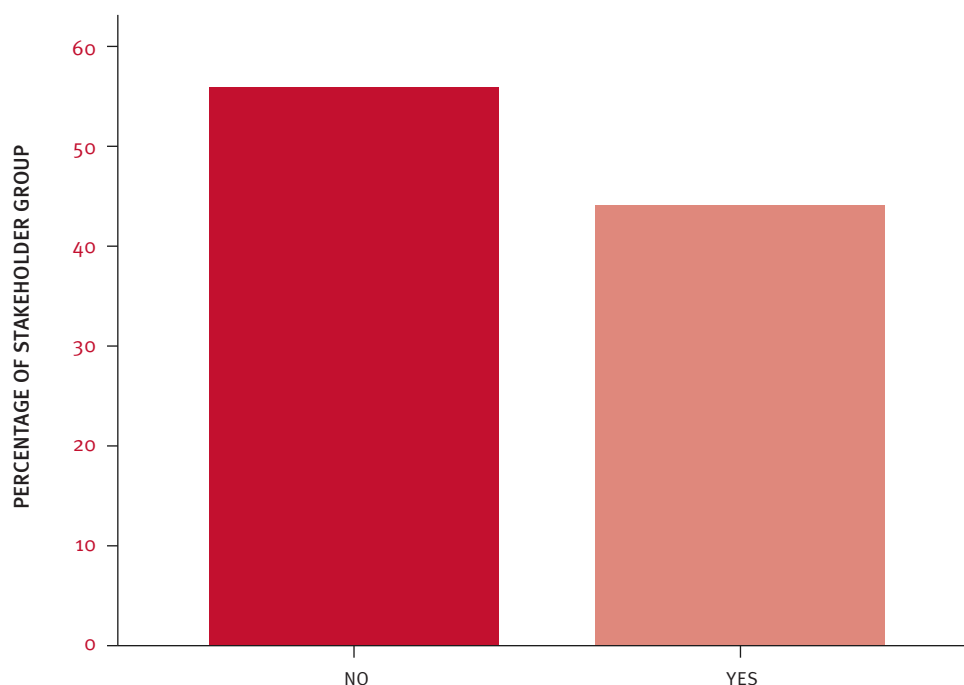
The majority of hospital consultants indicated they routinely use written evidence-based treatment guidelines in the conditions that they most commonly treat within their speciality (Table 10).

3.5 Self-management support

Self-management support (SMS) is a cornerstone of CDM⁵³. All patients with a chronic illness self-manage their health making day-to-day decisions and engaging in behaviours that affect their health and chronic illness¹⁵. As a result, it is necessary for patients to have more than the traditional patient education providing information and technical skills but also self-management education including problem solving skills⁵⁴.

Patients were asked if their GP or hospital consultant provided them with a written list of their medications.

Figure 4: Percentage of patients provided with a written list of their prescribed medications by their GP or hospital consultant.



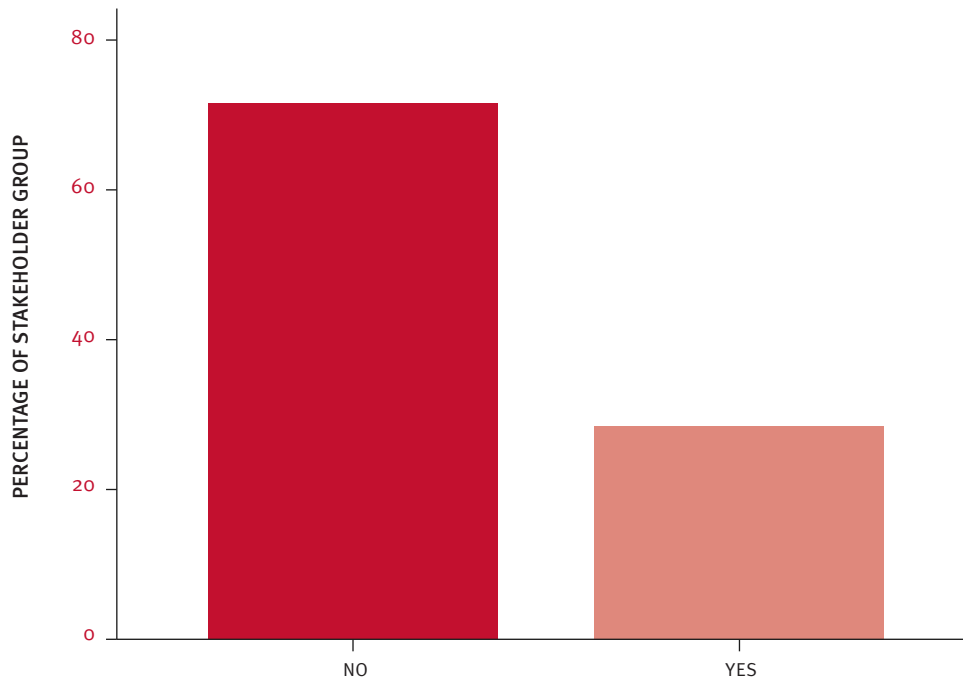
Does your GP or hospital consultant provide you with a written list of the medications that you are on?

A total of 508 (98.3%) patients answered this question. Missing data = 9 (1.7%)

Less than half of patients (44.0%; n=224/508) reported being provided with a written list of medications by their GP or hospital consultant (Figure 4). This is in comparison with 71.9% (n=272/378) of GPs, 78.4% (n=178/227) of hospital consultants and 66.4% (n=224/337) of practice nurses reporting routinely or occasionally providing patients with a written list of their medications. Private patients were more likely to receive a written list of their medications than public patients. Those in favour of a greater amount of change to CDM were less likely to have received a written list of their medications.

Patients were asked if their GP or hospital consultant provided them with written instructions about managing their care at home.

Figure 5: Percentage of patients provided with written advice to manage their chronic illness at home



Does your GP or hospital consultant provide you with written advice to manage your illness at home?

A total of 509 (98.5%) respondents answered this question. Missing data = 8 (1.5%)

When patient respondents were asked if their GP or hospital consultant provided them with written advice on how to manage their chronic disease at home, a total of 28.4% (n=145/509) of patients reported that they were provided with written advice (Figure 5). However, when the same question was asked of GPs, hospital consultants and practice nurses some discrepancies emerged. A total of 56.9% (n=216/379) of GPs, 70.0% (n=159/227) of hospital consultants and 70.2% (n=238/339) of practice nurses reported routinely or occasionally providing patients with written advice on care at home.

Patients were asked about their views on their experience of receiving treatment for their chronic condition in the last 6 months, including the organisation of their care and whether they were encouraged to set goals for treatment.

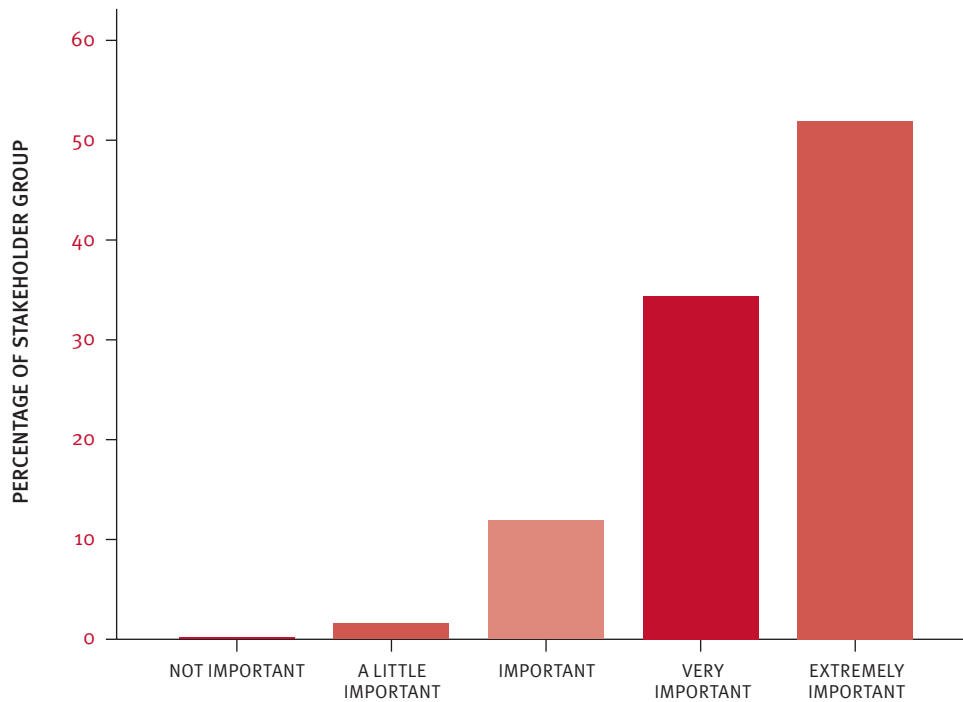
Table 11: Patients' experiences of the management of their chronic disease in the last 6 months.

In the last 6 months I was...	Almost never	Generally not	Sometimes	Most of the time	Almost always
...Asked for my ideas when making a treatment plan (N=503; 97.3%)	112 (22.3%)	139 (27.6%)	135 (26.8%)	88 (17.5%)	29 (5.8%)
...Given choices for treatment to think about (N=499; 96.5%)	85 (17.0%)	103 (20.6%)	183 (36.7%)	96 (19.2%)	32 (6.4%)
...Satisfied that my care was well organised (N=506; 97.9%)	22 (4.3%)	28 (5.5%)	66 (13.0%)	208 (41.1%)	182 (36.0%)
...Asked to talk about my goals in caring for my illness (N=501; 96.9%)	103 (20.6%)	85 (17.0%)	179 (35.7%)	101 (20.2%)	33 (6.6%)
...Encouraged to go to a specific group or class to help me cope with my chronic illness (N=498; 96.3%)	229 (46.0%)	99 (19.9%)	101 (20.3%)	43 (8.6%)	26 (5.2%)
...Asked how my chronic illness affects my life (N=504; 97.5%)	90 (17.9%)	82 (16.3%)	187 (37.1%)	104 (20.6%)	41 (8.1%)
...Sure that my doctor or nurse thought about my values and traditions when they recommended treatments to me (N=501; 96.9%)	71 (14.2%)	69 (13.8%)	156 (31.1%)	106 (21.2%)	99 (19.8%)
...Asked how my visits with other doctors were going (N=507; 98.1%)	198 (39.1%)	79 (15.6%)	92 (18.1%)	76 (15.0%)	62 (12.2%)

The majority of patients (77.0%; n=390/506) were satisfied most or all of the time with the organisation of their care in the last six months (Table 11). Despite this high level of satisfaction with care we see that patients are almost never or generally not asked for their ideas (49.9%, n=251/503) or their goals (37.6%, n=188/501) when making a treatment plan. As illustrated in Table 11 this pattern continues with many patients not advised to attend a group or class to cope with their chronic illness (65.9%, n=328/498) or asked about how their visits were with other doctors (54.7%, n=277/507). On the other hand the majority of patients report sometimes, mostly or always being asked about the impact of their chronic illness on their life (65.8%, n=332/504), given treatment choices to think about (62.3%, n=311/499), and feel that their values and traditions are thought about by nurses and doctors when recommending treatments (72.1%, n=361/501).

Patients were asked about the importance of their own personal knowledge about their condition.

Figure 6: Patients' views on the importance of good personal knowledge of their condition in the overall management of their care.



How important is it, in the overall management of your chronic illness, that YOU should have good knowledge of your condition?

A total of 512 (99.9%) respondents answered this question. Missing data = 5 (1.0%)

Good knowledge of their condition was important, very important or extremely important to 98.2% (n=503/512) of patients (Figure 6).

Patients were also asked about the importance of communication between their GP and hospital in the management of their chronic illness. Communication between the hospital and GP was important, very important, or extremely important to 99.2% (n=508/512) of patients.

3.6 Barriers to effective chronic disease management

Perceived barriers to CDM will need to be identified and addressed for progress to be made to improve the readiness of the Irish healthcare system to respond effectively to CDM.

Table 12: Perceived importance of barriers to effective management of chronic diseases within the Irish healthcare service.

	Responder	Extremely important	Important	Not important
Lack of appropriate funding	General practitioners (N=378; 99.4%)	286 (75.7%)	59 (15.6%)	33 (8.7%)
	Hospital consultants (N=224; 98.7%)	111 (49.6%)	108 (48.2%)	5 (2.2%)
	Practice nurses (N=331; 97.1%)	261 (78.9%)	61 (18.4%)	9 (2.7%)
Increased workload/lack of time	General practitioners (N=379; 99.7%)	310 (81.8%)	51 (13.5%)	18 (4.7%)
	Hospital consultants (N=224; 98.7%)	103 (46.0%)	114 (50.9%)	7 (3.1%)
	Practice nurses (N=333; 97.7%)	281 (84.4%)	44 (13.2%)	8 (2.4%)
Poor communication between hospital teams and general practitioners	General practitioners (N=379; 99.7%)	206 (54.4%)	107 (28.2%)	66 (17.4%)
	Hospital consultants (N=225; 99.1%)	60 (26.7%)	153 (68.0%)	12 (5.3%)
	Practice nurses (N=333; 97.7%)	212 (63.7%)	115 (34.5%)	6 (1.8%)
Lack of ongoing access to hospital consultants for advice	General practitioners (N=379; 99.7%)	217 (57.3%)	107 (28.2%)	55 (14.5%)
	Hospital consultants (N=222; 97.8%)	39 (17.6%)	156 (70.3%)	27 (12.2%)
	Practice nurses (N=332; 97.4%)	237 (71.4%)	90 (27.1%)	5 (1.5%)
Lack of skills and education/knowledge gaps	General practitioners (N=377; 99.2%)	91 (24.1%)	132 (35.0%)	154 (40.8%)
	Hospital consultants (N=223; 98.2%)	35 (15.7%)	164 (73.5%)	24 (10.8%)
	Practice nurses (N=331; 97.1%)	174 (52.6%)	130 (39.3%)	27 (8.2%)
*Poor communication between Practice Nurse and GP	Practice nurses (N=325; 95.3%)	84 (25.8%)	102 (31.4%)	139 (42.8%)
*Patients not attending scheduled appointments	Practice nurses (N=334; 97.9%)	176 (52.7%)	142 (42.5%)	16 (4.8%)

*Question not asked in either general practice or hospital consultant survey.

A large majority of general practitioners (81.8%; n=310/379) reported viewing increased workload and lack of time as an extremely important barrier to effective management of chronic disease (Table 12). Similarly, a slightly larger majority of practice nurses (84.4%; n=281/333) also viewed increased workload and lack of time as an extremely important barrier.

Some difference is evident in how clinical stakeholders view the extent of poor communication between hospitals and general practice as a barrier. General practitioners (54.4%; n=206/379) and practice nurses (63.7%; n=212/333) are more than twice as likely as hospital consultants (26.7%; n=60/225) to view poor communication as an extremely important barrier to good care, although the majority of hospital consultants do recognise this as an important barrier (68.0%; n=153/225).

When asked about lack of skills and education or the knowledge gap as a barrier, practice nurses (52.6%; n=174/331) were twice as likely to view this as an extremely important barrier compared with general practitioners (24.1%; n=91/377) and more than three times more likely as hospital consultants (15.7%; n=35/223). Similar differences are evident in terms of the extreme importance or importance of the issue of access to hospital consultants for advice.

Overall fewer hospital consultants identified barriers to chronic disease management as extremely important than general practitioners and practice nurses.

3.7 Future development of chronic disease management

This section examines stakeholders' perceptions of the importance of resources for the development of CDM and their opinion on shared care initiatives between primary and secondary care.

Table 13: General practitioners', hospital consultants' and practice nurses' ratings of future resources in terms of importance in the development of chronic disease management within the service.

	Responder	Extremely important	Important	Not important
Specific payments for patients with a major chronic disease	General practitioner (N=374; 98.4%)	292 (78.1%)	49 (13.1%)	33 (8.8%)
	Hospital consultant (N=218; 96%)	46 (21.1%)	151 (69.3%)	21 (9.6%)
	Practice nurse (N=335; 98.2%)	284 (84.8%)	44 (13.1%)	7 (2.1%)
GP led CDM clinics	General practitioner (N=370; 97.3%)	199 (53.8%)	110 (29.7%)	61 (16.5%)
	Hospital consultant (N=221; 97.4%)	40 (18.1%)	154 (69.7%)	27 (12.2%)
	Practice nurse (N=326; 95.6%)	153 (46.9%)	153 (46.9%)	20 (6.1%)
Specialist nurse led clinics in the community	General practitioner (N=374; 98.4%)	184 (49.2%)	108 (28.9%)	82 (21.9%)
	Hospital consultant (N=222; 97.8%)	38 (17.1%)	165 (74.3%)	19 (8.6%)
	Practice nurse (N=334; 97.9%)	266 (79.6%)	61 (18.3%)	7 (2.1%)
Targeted funding for GPs as in the NHS model	General practitioner (N=365; 96.0%)	244 (66.8%)	75 (20.5%)	46 (12.6%)
	Hospital consultant (N=216; 95.2%)	29 (13.4%)	155 (71.8%)	32 (14.8%)
	Practice nurse (N=328; 96.2%)	282 (86.0%)	42 (12.8%)	4 (1.2%)
Increased practice nurse time for GP led clinics	General practitioner (N=372; 97.8%)	232 (62.4%)	102 (27.4%)	38 (10.2%)
	Hospital consultant (N=219; 96.5%)	24 (11.0%)	166 (75.8%)	29 (13.2%)
	Practice nurse (N=335; 98.2%)	282 (84.2%)	51 (15.2%)	2 (0.6%)

When asked to indicate the level of importance for a number of options for future resources the greatest proportion of practice nurses and general practitioners reported targeted funding for general practitioners as in the NHS model to be extremely important and specific payments for patients with major chronic disease to be extremely important (Table 13). Fewer hospital consultants indicated options for targeted funding to be extremely important.

Table 14: General practitioners', hospital consultants' and practice nurses' opinions regarding shared care between general practice and hospitals.

	Responder	Yes
Would you support a shared care initiative in CDM between your service and local hospital/GP?	General practitioner (N=376; 98.9%)	367 (97.6%)
	Hospital consultant (N=227; 100%)	221 (97.4%)
	Practice nurse (N=337; 98.8%)	333 (98.8%)
Do you think there is a place for shared care in CDM between general practice and the hospital?	General practitioner (N=372; 97.8%)	258 (69.4%)
	Hospital consultant (N=225; 99.1%)	217 (96.4%)
	Practice nurse (N=336; 98.5%)	330 (98.2%)
Do you think a shared care initiative between GP and the hospital could be run by nurses?	General practitioner (N=378; 99.4%)	373 (98.7%)
	Hospital consultant (N=222; 97.8%)	131 (59.0%)
	Practice nurse (N=334; 97.9%)	292 (87.4%)
Are you currently involved in any shared care of chronic disease?	General practitioner (N=376; 98.9%)	168 (44.7%)
	Hospital consultant (N=226; 99.6%)	101 (44.7%)
	Practice nurse (N=335; 98.2%)	179 (53.4%)

A consensus exists across all three clinical stakeholder groups regarding shared care for chronic diseases between the hospital and general practice (Table 14). Similar proportions of hospital consultants and practice nurses believe there is a place for shared care in CDM between general practice and hospitals. Practice nurses, hospital consultants and general practitioners would be equally supportive of a shared care initiative in CDM. Practice nurses and general practitioners are both strongly supportive of shared care run by nurses. Hospital consultants are less inclined to favour this option.

Section Four: Discussion

Chronic diseases are responsible for a significant proportion of early deaths. They reduce quality of life for many individuals and incur substantial financial costs to patients, to health and social care systems and cause a significant loss of productivity to the economy⁵⁵. The management of chronic disease should be a litmus test for strengthening the Irish healthcare system. For too long the management of common chronic conditions has focused on single diseases and health system responses have usually been fragmented. Properly executed chronic disease management could contribute to strengthening the capacity of the Irish health system to deliver a comprehensive range of services.

4.1 Healthcare system organisation and responsiveness

The Chronic Care Model (CCM) views the healthcare system as part of the larger community. Effective chronic disease management (CDM) requires an appropriately organised healthcare system linked with necessary resources available within the community³¹. As such, two key CCM elements are healthcare system organisation and community resources and policies. Current typical healthcare systems are reactive and geared towards addressing acute illnesses and emergency events. Within the system it is difficult to co-ordinate and deliver effective on-going care required for chronic illnesses. An Institute of Medicine report makes clear that for effective improvements in CDM minor changes within the current reactive system will not be adequate. For effective improvements change needs to occur at the healthcare system level with a change in focus of the system^{17,31}. In 2008 the Department of Health and Children report entitled ‘Tackling Chronic Disease – A Policy Framework for the Management of Chronic Disease’² was launched. It stressed the importance of “management of chronic disease at different levels through a reorientation towards primary care and the provision of integrated health services that are focused on prevention and returning individuals to health and a better quality of life” (p 7). This recommendation was echoed in the Ruane Report ‘An Expert Group on Resource Allocation and Financing in the Health Sector’⁵⁶ where it was noted that there is a need to move resources out of hospitals and into the community in the context of developing the appropriate infrastructure and governance to deliver effective chronic disease management.

In the current research, taking all four stakeholder groups’ views into consideration, it is apparent that there is support for the Government proposal to move the management of patients with complex multimorbidities into the community and out of hospital care. This is in line with findings in the current literature which argue for primary care as the cornerstone of the health system^{21–23} and interventions proven to be effective in strengthening the CCM element of healthcare system organisation through facilitating coordination of care^{15,18}.

4.2 Healthcare system organisation – access and inequality

Accessibility and equity must be core features of an effective primary care system. Ireland is markedly anomalous within Europe in still not having universal coverage for GP and primary care services. The continuing trend of increasing co-payments for primary care in Ireland, levied both by the State and by practitioners, is a growing obstacle to access and a threat to affordability to medical card patients. Access is especially an issue for those with incomes that are just above the threshold for eligibility for the GMS card. The recent European Observatory analysis of primary care within Europe stated that Ireland has the highest formal payment in the primary care system²⁶. While Government policy is to end the two-tiered system, it is apparent that reforms to date have not worked. Data presented here highlight the need for all stakeholders and agencies concerned to focus on implementing these policies, to improve equity and remove barriers to essential care within the health system. Overwhelming international consensus exists confirming that ready access to primary care is the most effective way for societies to achieve best health outcomes at lower, affordable costs. It is evident from results presented here that the key stakeholders surveyed experience key deficiencies in the Irish healthcare system that still need to be addressed.

In the current research, responses from all four stakeholder groups indicate the current two-tiered health system is a difficult reality for them. In particular patients, both public and private, are exposed to the hazards of the system. Private patients have more difficulties paying for medication costs and out-of-pocket expenses. GMS entitled public patients report longer waits for access to services, including hospital consultant evaluation, difficulty accessing specialised diagnostic tests and longer waiting times to receive treatment after diagnosis. Private patients report delays in seeing their GP because of costs. Both private and public patients report delaying seeing a hospital consultant because of costs. Clinical stakeholders are very aware and sensitive to the difficulties in access and costs associated with healthcare. The inequitable Irish two-tiered health system continues to feature.

4.3 Clinical information systems

Clinical information systems (CIS) interventions are critical for effective CDM^{9,15}. Many of the processes to improve CDM are only possible with the support of robust system wide information and communication technology systems that allow data management and effective tracking of patients. CIS interventions include patient or disease registries, patient medical records, reminders, tracking patient progress, and reporting of outcomes to patients and providers¹⁸. The aim of CIS interventions is to organise patient and population data in order to improve the quality and delivery of care and patient health outcomes⁴⁴. This is achieved through enabling multiple healthcare providers to review detailed reports, identification of lapses in treatment, identification of relevant sub-populations for proactive care, facilitation of individual patient care planning, setting and reviewing of progress of self-management goals, guideline directed alerts and reminders, interactive workflow and care co-ordination, summaries of health data, aggregated, clinical, administrative and cost data in comprehensive data sets, monitoring performance of practice team and care systems^{15,18,41}. Alongside the benefits to the CCM, additional factors encouraging the implementation of CIS interventions include improved clinical processes, greater work flow efficiencies, improved ability to share patient information and improved healthcare quality⁵⁷. Implementation of CIS interventions has been illustrated to have positive effects on healthcare processes and patient health outcomes^{52,58,59}. The use of patient registers in general practices is associated

with higher levels of good health, fewer unhealthy days and fewer activity limited days²⁰. The use of electronic health records and patient registries informs health policy and planning while providing infrastructure for future clinical and health service research and support measures^{60,61}. In addition, the employment of electronic medical records improves the quality of patient care and decreases medical errors⁶². Cost benefit analysis of the financial effects of electronic medical records in primary care settings in the United States found benefits with savings in drug expenditure, improved utilisation of radiology tests, better capture of charges and decreased billing errors and positive financial return on investment⁶².

In the current research, data from practice nurses appear particularly well aligned with the principles of good chronic disease management. This reflects well on their individual (personal) practice, and it may also reflect the fact that they have been employed in more progressive general practices. Overall the data presented do indicate that many of the features of CIS are in place to a varying degree. A pressing concern is the very limited extent to which hospital consultants are able to use electronic medical records and electronic prescribing. Reliance on handwritten notes for maintaining clinical records and prescribing is intrinsically less reliable, and it makes reliable audit very difficult, whereas automated data returned from searchable clinical record systems provides real time data which can be used to guide both service providers and administrators in quality assurance and service development on a continual basis. Furthermore, the maintenance of a paper based records system carries a significant administrative overhead, in order to ensure that the patient, the practitioner and the file are in consultation together, particularly so in the case of patients with complex care needs, whose records may include several volumes of notes. Correcting this deficiency is a priority.

4.4 Decision supports – evidence-based managed care

For effective high quality healthcare and improved health outcomes treatment decisions need to be based on explicit evidence-based guidelines¹⁵. Decision support (DS) interventions aim to ensure that evidence-based guidelines and knowledge are incorporated within chronic care treatment. DS interventions may include the discussion of guidelines with patients, inbuilt reminders, access to clinical expertise and experience as necessary, distribution of educational material, case discussions, coordinating care processes and training in guidelines^{9,10,15,18,31,44}. Similar to clinical information system interventions, the aims of DS interventions are often achieved through IT with interactive software systems which offer support in medical decision making, particularly through making a diagnosis and deciding on treatment^{51,52}. This is key as the computerisation of DS interventions is likely to be an important feature contributing to their effectiveness^{37,44,58}. Generally, employment of DS interventions improves the quality of care and health outcomes, promoting clinical care that is consistent with scientific evidence and patient preferences¹⁵. DS interventions improve clinical practice 68% of the time⁵⁸. Healthcare services that use evidence-based guidelines, are associated with higher patient health level, fewer unhealthy days and less activity limited days²⁰. Utilisation of DS interventions such as providing education on guidelines has been shown to aid implementation of and increase adherence to guidelines in services for diabetes and depression^{18,63}. The CCM is most effective when a number of interventions spanning across the various elements of CCM are introduced. However, a systematic literature review has highlighted that DS interventions on their own are more effective than clinical information system interventions on their own⁴⁴. It is important to note that a significant impact on healthcare treatment as a result of DS interventions is not always reported. An assessment

of outpatient care in the United States using DS interventions found no significant impact on quality of care⁶⁴. Similarly, a randomised control trial examining the effectiveness of electronic DS systems with primary care healthcare professionals found no significant impact on health outcomes but they did find a decrease in costs⁶⁵ associated with care.

In the current research, the most striking features in this context are the limited extent to which information technology is used by hospital consultants in chronic disease management, and also the very limited extent to which GPs and practice nurses use a managed approach towards mental health conditions. Overall reported use of evidence-based guidelines reveals a high uptake of this process by clinical stakeholders. A greater proportion of hospital consultants reported using evidence-based guidelines than practice nurses and general practitioners. Practice nurses were more likely to report using evidence-based guidelines than general practitioners. It is probable that care of individuals with mental health conditions would be improved by a more systematic approach to their care.

4.5 Self-management support

Self-management support (SMS) includes active involvement of patients in the management of their treatment including medical management (taking medication and dietary advice), behavioural management (assuming a new meaningful active patient role) and emotional management (dealing with feelings experienced by chronically ill patients)⁶⁶. This can be achieved through strategies such as individual assessment, collaboration between patients and healthcare professionals to define problems, setting priorities and goals and treatment plans, skills enhancement, patient empowerment, provision of information and support for patients and family members, access to resources and continuity of care and patient involvement in the designing of care. On successful implementation SMS have been reported to increase patient levels of health, disease control, health outcomes, quality of life, standard of chronic illness care and self-management with a reduction in healthcare costs^{10,11,15,18,20,31,35,53,54,67}. The positive impacts of SMS interventions extend beyond the patient to family members. The ability of family members to cope with the challenges of living with a family member with a chronic illness have also been shown to be improved after implementation of an SMS intervention^{10,31}. Despite the key role and importance of SMS this element of CCM is the least implemented and most challenging⁶⁷. An exploration of SMS integration in 13 EU countries found that this area is underdeveloped in Europe. Interventions that have been developed and implemented so far have primarily focused on medical and behavioural management, with the exclusion of interventions dedicated to the improvement of emotional management⁶⁷. Obstacles to the implementation of SMS include funding, IT, the medical culture, the lack of appropriate training in skills for healthcare providers in necessary communication and counselling techniques and the need for such interventions and supports to be tailored specifically to meet the individual needs of each patient, increasing time and resources demands⁶⁷.

In Ireland the essence of SMS is reflected in current policy through 'Healthy Ireland' in which the responsibility for health and a healthy Ireland is given to everybody and not just healthcare professionals³⁰. The idea underpinning this policy is that everybody will act each day to maintain good health, making informed choices in relation to diet, exercise and lifestyle. Recently the HSE has published its first National Healthcare Quality Reporting System (NHQRS) which outlines a series of quality indicators that reflect the quality and safety of healthcare that patients should receive when they access local health services and hospitals³.

This is a welcome step towards providing the public and patients with relevant information on the quality and safety of care for a range of different services, including indicators relating to chronic conditions. However, there are no indicators that reflect patients' experiences of the care that they receive. While this has been acknowledged by the Minister for Health as a deficit that will be addressed in the near future, it is disappointing that the NHQRS has been enacted without this crucial indicator present. Listening and responding to patients' feedback is essential to providing a patient centred healthcare service.

In this study, there are major discrepancies between the reports of patients and clinicians, with a far greater proportion of clinicians reporting providing patients with written instructions for their care at home or a written list of their medication. In contrast to this is the extent to which patients report these activities as being far lower. GPs and hospital consultants report delays in receiving written reports in relation to care provided. The benefits of patients holding an updated accurate list of their own medication include having this available during unscheduled care episodes and ensuring that the attending clinician is fully informed regarding medication use. In a closely related area, patients rate close communication between hospitals and general practice very highly but all three clinical stakeholders report poor communication and poor co-ordination.

4.6 Barriers to effective chronic disease management and future development of chronic disease management

Successfully addressing the needs of individuals with complex co-morbidities is the single greatest challenge of the Irish healthcare system. It is a huge problem, and it can only be addressed through a variety of different and evolving solutions, devised in a collaborative manner, over the next several decades. Effective solutions will need to be scientifically rigorous, paying close attention to objective outcomes of care, and garnering the experience of key stakeholders in the delivery and development of CDM services. It is therefore vital to identify the barriers to effective care, and alongside this process identify solutions.

In this study, increased workload/lack of time was identified as an extremely important barrier by the greatest proportion of general practitioners and practice nurses. The greatest proportion of hospital consultants identified 'lack of skills and education and the knowledge gap' as an important barrier to chronic disease management. Communication between hospitals and general practice appeared to be the greatest reported barrier to chronic disease management for all clinical stakeholders. Specific payments for patients with a major chronic disease was indicated to have the most support across all stakeholder groups. Despite limited current involvement, there was considerable support indicated by all stakeholder groups for shared care. Lack of appropriate funding and lack of ongoing access to hospital consultants for advice were also identified as extremely important barriers by a majority of general practitioners and practice nurses and as important by a majority of hospital consultants.

Strategic funding directed towards increasing capacity in primary care, extending deployment of robust information technology into acute hospital sectors and regionalised clinical governance structures incorporating primary care and the public's involvement alongside hospital representations appear to be particularly relevant in the context of these findings.

4.7 Strengths of the research

The survey was based upon the Use of Chronic Care Model Elements Survey¹⁵ and included questions from A Survey Of Primary Care Physicians In Eleven Countries⁴⁸, which enables comparisons of data from Ireland with a range of other health systems. This in turn closely reflected the features of the Chronic Care Model (CCM), which is the model currently endorsed by the World Health Organisation for the management of chronic diseases. Thus, there is a consistent and sound conceptual approach throughout each individual stakeholder study, enabling easy comparisons between the four groups. Two further validated survey tools designed specifically for patients were also included within their survey instrument – the Patient Assessment of Chronic Illness Care Survey⁴⁹ and the Assessing Disease Burden- Morbidity Self-Assessment⁵⁰.

The methodology used has resulted in very good response rates throughout each of the four stakeholder groups, which in turn allows confidence in interpreting the results and drawing conclusions likely to be relevant to the Irish healthcare system.

Data presented reflect the insight and experience of individual practitioners who are at the front line of delivering care. Finally, and crucially, this composite report includes the insights and experiences of individuals who themselves have one or more chronic diseases. Their views are directly elicited and not filtered through representative groups.

4.8 Limitations of the research

The important issue of community resources was not included within this programme of research. Community resources are an integral element of CCM which are activities, services and amenities located and operated within the broader community and they include public health policy for community based resources and amenities that can directly improve CDM^{15,18}. Community resources and policy interventions include encouraging patients to participate in community programmes, formation of partnerships with community organisations, advocacy for public policies that improve patient care and utilisation of existing community services. For example, classes run in a local senior citizen centre, or support group meetings run by a patient organisation may be used as part of a treatment plan. Patient information leaflets prepared by a local health department may be used to educate patients. In the current stakeholder analyses we asked questions of all clinical stakeholders about whether they refer patients for education relating to their chronic condition either within or outside of their own service. We asked patients a question relating to whether they had been encouraged to attend an educational class relating to the management of their chronic condition. While the pharmacies that were recruited as data collection sites were purposefully chosen to obtain a good spread of areas of deprivation, we did only recruit pharmacies from the Leinster area. Future research could look at addressing this issue by a more rigorous assessment of community resources in relation to the management of chronic conditions, and also expanding the survey of patients to a national survey covering the four provinces.

This programme of research examines the views of four key stakeholder groups, including three most directly involved in the management of patients with common chronic conditions – general practitioners, hospital consultants, and practice nurses, together with the patients themselves. Other stakeholders could be surveyed, such as practitioners working within the delivery of mental healthcare services, including psychiatry. Further, as matters stand, non-consultant hospital doctors (NCHDs) provide much input in hospital outpatient departments and are involved in the provision of CDM to public patients. The views and experiences of NCHDs should be included in future research.

4.9 Implications for policy

Current and future initiatives on chronic disease should be patient centred and operate within the overall Department of Health policy framework on chronic diseases established in ‘Tackling Chronic Disease’² as well as within existing disease policies. ‘Primary Care – A New Direction’⁶⁸ set out a policy framework within which strategies and programmes should be implemented.

It is acknowledged that chronic diseases and the lifestyle factors that contribute to these are distributed unevenly across the population. The Programme for Government has set out policy measures to prevent illness and promote health across the population. A whole of government approach, as outlined within Healthy Ireland³⁰, is essential in promoting health and reducing the burden of chronic disease in the population. A whole of government approach means that government departments work across portfolio boundaries to achieve a shared goal relating to particular issues, for example, tackling the social determinants that relate to health inequalities.

Universal Health Insurance (UHI) is the Government’s solution to transforming our healthcare service from an unfair two-tiered system to a single system, with access to care based upon clinical need and not on ability to pay⁶⁹. While the significant delays in the implementation of UHI persist, the Government should not lose focus on the continued inequities in the system with regard to access, diagnosis and treatment outlined in this report and the patient report in particular. We are isolated in Europe in not having universal coverage for general practice and primary care. Access to healthcare is a major challenge. Private insurance is used to try to obtain better access but of course excludes those with limited resources. We cannot be regarded as a caring, mature society until access to high quality healthcare is based on need and not means.

4.10 Implications for healthcare services

General practitioners and practice nurses are best placed to deliver on many of the main components of the Government’s reforms, such as better chronic disease management, health promotion and disease prevention strategies, but this is only possible if there is the capacity within the primary care system to meet these challenges. Preparations are underway for a new general practitioner contract. What is planned for the new GP contract includes compulsory cooperation with the primary care team and universal patient registration with a team. For chronic disease management there will be structured reviews, individual care plans, and call and recall systems, along with mechanisms to audit and report on outcomes. The new contract will focus on prevention and health promotion and development of physical and IT infrastructure in general practice. The intention is to plan recruitment in primary care in advance, so that allocation of posts will be governed by a consistent transparent method, to supply staff where most needed and in the most deprived areas. While this is most welcome there is a need to invest in the recruitment of all members of the primary care team, including practice nurses, physiotherapists, speech and language therapists and psychologists. It is highly desirable but by no means certain that there will be meaningful patient representation in the commissioning and governance of this enhanced primary care system.

4.11 Implications for research

This work represents a programme of research to assess key stakeholders' views on the readiness of the Irish healthcare system to deliver effective CDM. This study provides a baseline assessment. Future research should be undertaken to repeat this methodology to determine changes within the healthcare sector as a result of significant reforms within the organisational structure of health service provision and macro level health policy. This would allow close monitoring of any changes over time.

Continuing research into the impact of chronic diseases on the population, the health and social care system, and the economy is required. This research should consider the extent of the burden of these conditions (including financial costs), how they are distributed across the population; how that burden might change in the future and the implications for the health and social care workforce and its training requirements. Alongside patient registers, a system of standardised population prevalence estimates and forecasts (available at national, regional and small area level) should be developed and maintained. These in turn should be incorporated into routine local data collections. A comprehensive and standardised system for monitoring risk factors (overweight, poor nutrition, physical inactivity, smoking, risky alcohol consumption) at the national and small area level should be established and maintained. A minimum dataset, which standardises the reporting of key demographic variables, should be established and agreed by researchers and clinicians, which should be used in all disease registers and national datasets. Relevant data on social determinants of health should be incorporated into clinical, service and public health information systems and used to help plan, deliver and evaluate chronic disease prevention and management programmes.

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Appendix 1: Survey of general practitioners

1. Which of the following statements come closest to expressing your overall view of chronic disease management (CDM) in our health care system?

- On the whole, the health care system works pretty well, and only minor changes are necessary to make CDM work better.
- There are some good things in our health system, but significant changes are needed to make CDM work better.
- Our health care system has so much wrong with it that we need to completely rebuild it for CDM.

2a. How often do your fee paying patients experience the following?

	Often	Sometimes	Rarely	Never
a. Have difficulty paying for medications or other out-of-pocket costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have difficulty getting specialised diagnostic tests (e.g., CT imaging)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Experience long waiting times to see a hospital based specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Experience long waiting times to receive treatment after diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2b. How often do your GMS entitled patients experience the following?

	Often	Sometimes	Rarely	Never
a. Have difficulty paying for medications or other out-of-pocket costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have difficulty getting specialised diagnostic tests (e.g., CT imaging)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Experience long waiting times to see a hospital based specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Experience long waiting times to receive treatment after diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. What out of hours service does your practice utilise (tick all that apply) ?

Local rota Co-op Deputising service No Service (Excluding A&E)

4. Does your practice routinely use written evidence-based treatment guidelines to treat the following conditions?

(e.g., ICGP, NICE, or SIGN Guidelines)

	Yes, Routinely use Guidelines	No, Do Not Routinely Use Guidelines	No Guidelines Available
a. Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Asthma or COPD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. ADHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Do you provide patients, who take multiple medications (e.g. 5 or more) with a written list of their medications ?

Yes, routinely Yes, occasionally No

6. Do you give your patients with chronic diseases written instructions about how to manage their own care at home?

Yes, routinely Yes, occasionally No

7. Have you completed a full Audit Cycle within the last 5 yrs on 1 or more chronic diseases?

Yes No

8. In your own practice, other than doctors, does your practice include any other health care providers?

Practice nurse Psychologist Practice Manager
 Receptionist Dietitian Counsellor
 Administrator Chiropodist Other

9. Please rate the strength of your agreement with the following statements:

1= Strongly disagree 2 =Disagree 3=Neither agree/disagree 4=Agree 5=Strongly agree

I am happy with CDM as it is	1	2	3	4	5
I want to put more time and energy into CDM here in the practice	1	2	3	4	5
Primary care teams will enhance the way chronic disease is managed in my practice	1	2	3	4	5
My local hospital should put more time and energy into CDM	1	2	3	4	5
I am willing to share the CDM workload with my local hospital	1	2	3	4	5
CDM should take place largely at a practice level and delivered largely by GPs	1	2	3	4	5
CDM should take place largely at a practice level by nurses, under GP supervision	1	2	3	4	5
CDM should take place largely at a practice level by nurses working independently of GPs	1	2	3	4	5

10. Is your practice functioning as part of a primary care team?

Yes No

11. Outside of your practice, do your patients have effective local access to the following?

	Private patients	GMS patients
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>
Chiropodist	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>

12a. When your patients have been seen by a hospital specialist, privately, how often do the following occur?

	Always	Often	Sometimes	Rarely	Never
You receive a report from the specialist with all relevant information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information you receive is timely; that is available when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12b. When your patients have been seen by a hospital specialist, publicly, how often do the following occur?

	Always	Often	Sometimes	Rarely	Never
You receive a report from the specialist with all relevant information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information you receive is timely; that is available when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13a. Do you use electronic patient medical records in your practice?

Yes No

13b. If yes, which system?

14. Do you use any of the following technologies in your practice?

	Yes, used routinely	Yes, used occasionally	No
a. Electronic ordering of laboratory tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Electronic access to your patients' laboratory test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Electronic alerts or prompts about ADRs or drug interaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Electronic entry of clinical notes, including medical history and follow-up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Electronic prescribing of medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. How often does your practice communicate with patients by email?

- Often Sometimes Rarely Never

16. How often does your practice communicate with patients by SMS Text ?

- Often Sometimes Rarely Never

17. With the patient medical records system you currently have, how easy would it be to generate the following information about your patients?

	Ease/Difficulty				Is Process Computerised?	
	<i>Easy</i>	<i>Somewhat Difficult</i>	<i>Difficult</i>	<i>Cannot Generate</i>	<i>Yes</i>	<i>No</i>
a. List of patients by diagnosis (e.g. HTN)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. List of patients by lab result (e.g., HbA1C)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Patients due or overdue for (e.g. Flu Vaccine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. List of all medications of a patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Are the following tasks routinely performed in your office practice?

	Yes, using a computerised System	Yes, using a manual System	No
a. Patients are sent reminder notices (e.g., flu vaccine or BP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. All laboratory tests ordered are tracked until results reach clinicians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You receive an alert or prompt to provide patients with test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. You receive a reminder for guideline-based interventions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. How much of a problem, if any, are the following?

	Major Problem	Minor Problem	Not a Problem	Not Applicable
a. Shortage of GPs where you practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Amount of time you or your staff spends on administration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Amount of time you spend coordinating care for your patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. How often do you currently use the following approaches to improving care for patients with diabetes?

1=Never, 2=Rarely, 3=Occasionally, 4=Usually, 5=Always

Use a register to identify and/or track care of your patients	1	2	3	4	5
Use a tracking system to remind patients about needed visits	1	2	3	4	5
Follow up patients between visits by telephone (you or staff)	1	2	3	4	5
Use published practice guidelines as the basis for your management	1	2	3	4	5
Involve office staff in reminding patients in need of follow-up or other services	1	2	3	4	5
Assist patients in setting and attaining self-management goals	1	2	3	4	5
Refer patients to someone within your practice for education about their diabetes	1	2	3	4	5
Refer patients to someone outside your practice for education about their diabetes	1	2	3	4	5
Use flow sheets to track critical elements of care	1	2	3	4	5

21. Please rate the following in terms of your perceived importance as being barriers to the effective management of chronic diseases in your practice:

1=Not important, 2=A little important, 3=Important, 4=Very important, 5=Extremely important

a. Lack of appropriate funding	1	2	3	4	5
b. Lack of skills and education / knowledge gaps	1	2	3	4	5
c. Poor communication between hospital teams and general practitioners	1	2	3	4	5
d. Increased workload / lack of time	1	2	3	4	5
e. Lack of ongoing access to specialists for advice	1	2	3	4	5

22. Please rate the following resources in terms of importance that would allow you to further develop CDM in your practice?

1=Not important, 2=A little important, 3=Important, 4=Very important, 5=Extremely important

a. GP led CDM clinics	1	2	3	4	5
b. Specialist nurse led clinics	1	2	3	4	5
c. Increased practice nurse time for clinics	1	2	3	4	5
d. Targeted funding as in the NHS model	1	2	3	4	5
e. Specific payments for patients with a major chronic disease	1	2	3	4	5

(E.g. COPD, CVD, Diabetes)

23. With regard to Shared Care of chronic disease between general practice and the hospital:

- a. Do you think there is a place for shared care in CDM between General Practice and the hospital? Yes No
- b. Would you support a shared care initiative in CDM between your practice & your local hospital? Yes No
- c. Do you think a shared care initiative between GP & hospital could be run by nurses? Yes No
- d. Are you currently involved in any shared care of a chronic disease? Yes No

24. If you are currently involved in shared care, is it working?

- Yes No Not applicable

PRACTICE PROFILE & DEMOGRAPHIC DATA

25. Where is your practice located?

- City Suburban Small town Rural

26. Your Age Category:

- Under 35 35-49 50-64 65 or older

27. Your Sex:

- Male Female

28. Which of the following describes you practice?

- A single handed practice A two doctor practice A three or more doctor practice

29. Is your practice part of an integrated provider system (e.g. Centric, Touchstone etc.)?

- Yes No

30. About what percentage of your patients are in each of the following categories?

Total can add to more than 100%.

_____ % Full Medical Card

_____ % Doctor Only card

_____ % Private fee paying

_____ % Other (please specify)

31. Is your practice involved in Training?

- Yes No

If yes, are you involved in

Undergraduate

Post-graduate

THANK YOU FOR YOUR TIME & CO-OPERATION

Appendix 2: Survey of hospital consultants

1. Which of the following statements come closest to expressing your overall view of chronic disease management (CDM) in our healthcare system?

- On the whole, the healthcare system works pretty well, and only minor changes are necessary to make CDM work better.
- There are some good things in our health system, but significant changes are needed to make CDM work better.
- Our healthcare system has so much wrong with it that we need to completely rebuild it for CDM.

2a. How often do your fee paying (private) patients experience the following?

	Often	Sometimes	Rarely	Never
a. Have difficulty paying for medications or other out-of-pocket costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have difficulty getting specialised diagnostic tests (e.g., CT imaging)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Experience long waiting times to see a hospital based specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Experience long waiting times to receive treatment after diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2b. How often do your public patients experience the following?

	Often	Sometimes	Rarely	Never
a. Have difficulty paying for medications or other out-of-pocket costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have difficulty getting specialised diagnostic tests (e.g., CT imaging)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Experience long waiting times to see a hospital based specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Experience long waiting times to receive treatment after diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. What is your own clinical involvement with out of hours care (tick all that apply)?

- No clinical involvement
- Usually provide telephone availability
- Sometimes work on site on call
- Regularly provide work on site on call

4. In your Specialty, to what extent do you *routinely* use *written* evidence-based treatment guidelines in the conditions you most commonly treat?

Yes, Routinely use Guidelines	Yes, Sometimes use Guidelines	No, Do Not Routinely Use Guidelines	No Guidelines Available
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Do you provide patients taking multiple medications (e.g. 5 or more) with a *written* list of their medications?
- Yes, routinely Yes, occasionally No
6. Do you give your patients with chronic diseases *written* instructions about how to manage their own care at home?
- Yes, routinely Yes, occasionally No
7. Prior to 2011, had you completed a full Audit Cycle within the last 5 yrs on 1 or more chronic diseases?
- Yes No
8. How often do you systematically advise patients about risk factors relating to their condition?
- Often Sometimes Rarely Never
9. How often do you advise family members of risk factors?
- Often Sometimes Rarely Never
10. Within your own service, other than doctors, does your service include any other healthcare providers?
- Clinical Nurse Specialist Psychologist Team Manager
 Receptionist Dietitian Counsellor
 Administrator Podiatrist Social worker
11. Please rate the strength of your agreement with the following statements:

1= Strongly disagree 2=Disagree 3=Neither agree/disagree 4=Agree 5=Strongly agree

I am happy with CDM as it is	1	2	3	4	5
I want to put more time and energy into CDM here on my service	1	2	3	4	5
Primary care teams will enhance the way chronic disease is managed	1	2	3	4	5
My hospital should put more time and energy into CDM	1	2	3	4	5
I am willing to share the CDM workload with GPs	1	2	3	4	5
CDM should take place largely at a general practice level and delivered largely by GPs	1	2	3	4	5
CDM should take place largely at a general practice level by nurses, under GP supervision	1	2	3	4	5
CDM should take place largely at a practice level by nurses working independently of GPs	1	2	3	4	5
CDM should take place largely in the hospital, delivered by specialist led teams	1	2	3	4	5
CDM should take place largely in the community, by specialist led teams	1	2	3	4	5

12. How well is your service integrated with local GP practices?

Not at all integrated Integrated Well integrated

13. Do your patients have effective local access to the following?

	Private	Public
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>
Podiatrist	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	<input type="checkbox"/>

14a. When patients have been referred to you privately, how often do the following occur?

	Always	Often	Sometimes	Rarely	Never
You receive a referral letter from the GP with all relevant information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information you require is available when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14b. When patients have been referred to you publicly, how often do the following occur?

	Always	Often	Sometimes	Rarely	Never
You receive a referral letter from the GP with all relevant information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information you require is available when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Do you routinely use electronic patient medical records on your service?

Yes No

16. Do you use any of the following technologies in your practice?

	Yes, used routinely	Yes, used occasionally	No
a. Electronic ordering of laboratory tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Electronic access to your patients' laboratory test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Electronic alerts or prompts about ADRs or drug interactions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Electronic entry of clinical notes, including medical history and follow-up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Electronic prescribing of medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. How often does your service communicate with patients by email?

Often Sometimes Rarely Never

18. How often does your service communicate with patients by SMS Text ?

- Often Sometimes Rarely Never

19. With the patient medical records system you *currently* have, how easy would it be to generate the following information about your patients?

					Is Process Computerised?	
	Easy	Somewhat Difficult	Difficult	Cannot Generate	Yes	No
a. List of patients by diagnosis (e.g. HTN)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. List of patients by lab result (e.g., HbA1C)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Patients due or overdue for (e.g. Scope → 3 mths)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. List of all medications of a patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Are the following tasks *routinely* performed on your service?

	Yes, using a computerised System	Yes, using a manual System	No
a. Patients are sent reminder notices (e.g., for routine check ups)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. All laboratory tests ordered are tracked until results reach clinicians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You receive an alert or prompt to provide patients with test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. You receive a reminder for guideline-based interventions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. How much of a problem, if any, are the following?

	Major Problem	Minor Problem	Not a Problem	Not Applicable
a. Shortage of specialist colleagues in your main centre of practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Amount of time you or your staff spends on administration.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Amount of time you spend coordinating care for your patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. How often do you currently use the following approaches to improving care for patients with chronic diseases?

1=Never, 2=Rarely, 3=Occasionally, 4=Usually, 5=Always

Use a register to identify and/or track care of your patients	1	2	3	4	5
Use a tracking system to remind patients about needed visits	1	2	3	4	5
Follow up patients between visits by telephone (you or staff)	1	2	3	4	5
Use published team guidelines as the basis for your management	1	2	3	4	5
Involve office staff in reminding patients in need of follow-up or other services	1	2	3	4	5
Assist patients in setting and attaining self-management goals	1	2	3	4	5
Refer patients to someone within your hospital for education about their condition	1	2	3	4	5
Refer patients to someone outside your hospital for education about their condition	1	2	3	4	5
Use flow sheets to track critical elements of care	1	2	3	4	5

23. Please rate the following in terms of your perceived importance as being barriers to the effective management of chronic diseases on your service:

1=Not important, 2=A little important, 3=Important, 4=Very important, 5=Extremely important

a. Lack of appropriate funding	1	2	3	4	5
b. Lack of skills and education / knowledge gaps	1	2	3	4	5
c. Poor communication between hospital teams and general practitioners	1	2	3	4	5
d. Increased workload / lack of time	1	2	3	4	5
e. Lack of ongoing access to sub specialists for advice	1	2	3	4	5

24. Please rate the following in terms of importance that would allow you to further develop CDM on your service?

1=Not important, 2=A little important, 3=Important, 4=Very important, 5=Extremely important

a. GP led CDM clinics	1	2	3	4	5
b. Specialist nurse led clinics in the community	1	2	3	4	5
c. Increased general practice nurse time for GP led clinics	1	2	3	4	5
d. Targeted funding for GPs as in the NHS model	1	2	3	4	5
e. Specific payments for patients with a major chronic disease	1	2	3	4	5

(E.g. COPD, CVD, Diabetes)

25. With regard to Shared Care of chronic disease between general practice and the hospital:

- a. Do you think there is a place for shared care in CDM between General Practice and the Hospital? Yes No
- b. Would you support a shared care initiative in CDM between your service & local GPs? Yes No
- c. Do you think a shared care initiative between GPs and hospital could be run by nurses? Yes No
- d. Are you currently involved in any shared care of a chronic disease? Yes No

26. If you are currently involved in shared care with GPs, is it working?

- Yes No Not applicable

27. Which of the following best describes your service?

- A single Consultant service
- A two Consultant service
- A three or more Consultant service

28. Where is your service located?

- City
- Suburban
- Small town
- Rural

29. Your age

- Under 35
- 35–49
- 50–64
- 65 or older

30. Your gender:

- Female
- Male

31. Please indicate your Specialty

- Endocrine
- Cardiology
- Respiratory
- Gerontology
- Nephrology
- Neurology
- Rheumatology
- Other

THANK YOU FOR YOUR TIME & CO-OPERATION

Appendix 3: Survey of practice nurses

1. Which of the following statements come closest to expressing your overall view of chronic disease management (CDM) in our healthcare system?

- On the whole, the healthcare system works pretty well, and only minor changes are necessary to make CDM work better.
- There are some good things in our health system, but significant changes are needed to make CDM work better.
- Our healthcare system has so much wrong with it that we need to completely rebuild it for CDM.

2a. How often do your fee paying patients experience the following?

	Often	Sometimes	Rarely	Never
a. Have difficulty paying for medications or other out-of-pocket costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have difficulty getting specialised diagnostic tests (e.g., CT imaging)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Experience long waiting times to see a hospital based specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Experience long waiting times to receive treatment after diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2b. How often do your GMS entitled patients experience the following?

	Often	Sometimes	Rarely	Never
a. Have difficulty paying for medications or other out-of-pocket costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have difficulty getting specialised diagnostic tests (e.g., CT imaging)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Experience long waiting times to see a hospital based specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Experience long waiting times to receive treatment after diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. What out of hours service does your practice utilise (tick all that apply)?

- Local rota
- Co-op
- Deputising service
- No Service (Excluding A&E)

4. Does your practice *routinely* use *written* evidence-based treatment guidelines to treat the following conditions? (e.g., ICGP, NICE, or SIGN Guidelines)

	Yes, Routinely use Guidelines	No, Do Not Routinely Use Guidelines	No Guidelines Available
a. Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Asthma or COPD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. ADHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Do you provide patients taking multiple medications (e.g. 5 or more) with a *written* list of their medications?

Yes, routinely Yes, occasionally No

6. Do you give your patients with chronic diseases *written* instructions about how to manage their own care at home?

Yes, routinely Yes, occasionally No

7. Have you completed a full clinical Audit Cycle within the last 5 yrs on 1 or more chronic diseases?

Yes No

8. In your own practice, other than doctors, does your practice include any other health care providers?

GP	<input type="checkbox"/>	Psychologist	<input type="checkbox"/>	Practice Manager	<input type="checkbox"/>
Receptionist	<input type="checkbox"/>	Dietitian	<input type="checkbox"/>	Counsellor	<input type="checkbox"/>
Administrator	<input type="checkbox"/>	Chiroprapist	<input type="checkbox"/>	Other	<input type="checkbox"/>
Practice Nurse (other than yourself)	<input type="checkbox"/>				

9. Please rate the strength of your agreement with the following statements:

1= Strongly disagree 2 =Disagree 3=Neither agree/disagree 4=Agree 5=Strongly agree

I am happy with CDM as it is	1	2	3	4	5
I want to put more time and energy into CDM here in the practice	1	2	3	4	5
Primary care teams will enhance the way chronic disease is managed in my practice	1	2	3	4	5
My local hospital should put more time and energy into CDM	1	2	3	4	5
I am willing to share the CDM workload with my local hospital	1	2	3	4	5
CDM should take place largely at a practice level and delivered largely by GPs	1	2	3	4	5
CDM should take place largely at a practice level by nurses, under GP supervision	1	2	3	4	5
CDM should take place largely at a practice level by nurses working independently of GPs	1	2	3	4	5
CDM should take place largely in the hospital, delivered by specialist led teams	1	2	3	4	5
CDM should take place largely in the community, by specialist led teams	1	2	3	4	5

10. Is your practice functioning as part of a primary care team? Yes No

11. Outside of your practice, do your patients have effective local access to the following? (tick if yes, leave blank if no)

	Private patients	GMS patients
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>
Chiropodist	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>

12a. When patients from your practice have been seen by a hospital specialist, privately, how often do the following occur?

	Always	Often	Sometimes	Rarely	Never
A report is available from the specialist with <i>all relevant</i> information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information received is timely; and available when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12b. When patients from your practice have been seen by a hospital specialist, publicly, how often do the following occur?

	Always	Often	Sometimes	Rarely	Never
A report is available from the specialist with <i>all relevant</i> information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information received is timely; and available when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13a. Do you use electronic patient medical records in your practice?

Yes No

13b. If yes, which system? _____

14. Do you use any of the following technologies in your practice?

	Yes, used routinely	Yes, used occasionally	No
a. Electronic ordering of laboratory tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Electronic access to your patients' laboratory test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Electronic alerts or prompts about ADRs or drug interaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Electronic entry of clinical notes, including medical history and follow-up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Electronic prescribing of medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. How often does your practice communicate with patients by email?

Often Sometimes Rarely Never

16. How often does your practice communicate with patients by SMS Text ?

- Often Sometimes Rarely Never

17. With the patient medical records system you *currently* have, how easy would it be for you to generate the following information about patients?

	Ease/Difficulty				Is Process Computerised?	
	Easy	Somewhat Difficult	Difficult	Cannot Generate	Yes	No
a. List of patients by diagnosis (e.g. HTN)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. List of patients by lab result (e.g., HbA1C)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Patients due or overdue for (e.g. Flu Vaccine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. List of all medications of a patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Are the following tasks *routinely* performed in your office practice?

	Yes, using a computerised System	Yes, using a manual System	No
a. Patients are sent reminder notices (e.g., flu vaccine or BP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. All laboratory tests ordered are tracked until results reach clinicians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You receive an alert or prompt to provide patients with test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. You receive a reminder for guideline-based interventions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. How much of a problem, if any, are the following?

	Major Problem	Minor Problem	Not a Problem	Not Applicable
a. Shortage of GPs where you practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Amount of time you or your staff spends on administration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Amount of time you spend coordinating care for your patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. How often do you currently use the following approaches to improving care for patients with diabetes? (circle)

1=Never, 2=Rarely, 3=Occasionally, 4=Usually, 5=Always

Use a register to identify and/or track care of your patients	2	3	4	5	
Use a tracking system to remind patients about needed visits	1	2	3	4	5
Follow up patients between visits by telephone (you or staff)	1	2	3	4	5
Use published practice guidelines as the basis for your management	2	3	4	5	
Involve office staff in reminding patients in need of follow-up or other services	1	2	3	4	5
Assist patients in setting and attaining self-management goals	1	2	3	4	5
Refer patients to someone within your practice for education about their diabetes	1	2	3	4	5
Refer patients to someone outside your practice for education about their diabetes	1	2	3	4	5
Use flow sheets to track critical elements of care	1	2	3	4	5

21. Please rate the following in terms of your perceived importance as being barriers to the effective management of chronic diseases in your practice: (circle)

1=Not important, 2=A little important, 3=Important, 4=Very important, 5=Extremely important

a. Lack of appropriate funding	1	2	3	4	5
b. Lack of skills and education / knowledge gaps	1	2	3	4	5
c. Poor communication between hospital teams and general practitioners	1	2	3	4	5
d. Increased workload / lack of time	1	2	3	4	5
e. Lack of ongoing access to specialists for advice	1	2	3	4	5
f. Poor communication between you and the GP(s) in your practice	1	2	3	4	5
g. Patients' not attending for scheduled appointments	1	2	3	4	5

22. Please rate the following resources in terms of importance that would allow you to further develop CDM in your practice?

1=Not important, 2=A little important, 3=Important, 4=Very important, 5=Extremely important

a. GP led CDM clinics	1	2	3	4	5
b. Specialist nurse led clinics	1	2	3	4	5
c. Increased practice nurse time for clinics	1	2	3	4	5
d. Targeted funding as in the NHS model	1	2	3	4	5
e. Specific payments for patients with a major chronic disease	1	2	3	4	5

(E.g. COPD, CVD, Diabetes)

23. With regard to Shared Care of chronic disease between general practice and the hospital:

- a. Do you think there is a place for shared care in CDM between General Practice and the hospital? Yes No
- b. Would you support a shared care initiative in CDM between your practice & your local hospital? Yes No
- c. Do you think a shared care initiative between GP & hospital could be run by nurses? Yes No
- d. Are you currently involved in any shared care of a chronic disease? Yes No

24. If you are currently involved in shared care, is it working?

- Yes No Not applicable

PRACTICE PROFILE & DEMOGRAPHIC DATA

25. Where is your practice located?

- City Suburban Small town Rural

26. Your Age Category:

- Under 35 35-49 50-64 65 or older

27. Your Sex:

- Female Male

28. Which of the following describes your practice?

- A single handed doctor practice
 A two doctor practice
 A three or more doctor practice

29. Is your practice part of an integrated provider system (e.g. Centric, Touchstone etc.)?

- Yes No

**30. About what percentage of your patients are in each of the following categories?
Total can add to more than 100%.**

- _____ % Full Medical Card _____ % Doctor Only card
_____ % Private fee paying _____ % Other (please specify)

31. Is your practice part of an integrated provider system (e.g. Centric, Touchstone etc.)?

- Yes No

If yes, are you involved in Undergraduate Post -graduate

THANK YOU FOR YOUR TIME & CO-OPERATION

Appendix 4: Survey of patients

1. **Your age** Under 35 35-49 50-64 65 or older
2. **Your gender** Female Male
3. **Are you a** Medical Card Patient (including Doctor Visit Card) Private Patient
4. **Which of the following statements come closest to expressing your overall view of chronic disease management (CDM) in our healthcare system?**
 - On the whole, the health care system works pretty well, and only minor changes are necessary to make CDM work better.
 - There are some good things in our health system, but significant changes are needed to make CDM work better.
 - Our health care system has so much wrong with it that we need to completely rebuild it for CDM.
5. **How often do you experience the following?**

	Often	Sometimes	Rarely	Never
a. Difficulty paying for medications or other out-of-pocket costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Difficulty getting specialised diagnostic tests (e.g. CT imaging)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Long waiting times to see a hospital based specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Long waiting times to receive treatment after diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Delay in attending GP because of cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Delay in attending hospital specialist because of cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. **Have you ever been provided with written advice for managing your illness at home?**
Yes or No
7. **Have you ever been given a list by your GP or specialist of the medications you are on?**
Yes or No
8. **Would you be happy for your Doctor to prescribe a generic version of your medicine, if it was guaranteed by the Irish Medicines Board?**
Yes or No

9. In caring for your condition, which of these professionals have you received services from:

- | | | | | | |
|---------------------------|--------------------------|--------------|--------------------------|------------------------|--------------------------|
| Clinical Nurse Specialist | <input type="checkbox"/> | Psychologist | <input type="checkbox"/> | Team Manager | <input type="checkbox"/> |
| Receptionist | <input type="checkbox"/> | Dietician | <input type="checkbox"/> | Counsellor | <input type="checkbox"/> |
| Administrator | <input type="checkbox"/> | Foot Doctor | <input type="checkbox"/> | Social worker | <input type="checkbox"/> |
| GP | <input type="checkbox"/> | Optician | <input type="checkbox"/> | Occupational therapist | <input type="checkbox"/> |
| Hospital based Specialist | <input type="checkbox"/> | | | | |

10. Where do you think your condition should be managed for the most part? (Tick one)

General Practice or Hospital or in the Community led by Specialist teams

11. In your general practice, the person who should look after your chronic illness for the most part should be... (Tick one)

The GP or, the Nurse, under GP supervision or, the Nurse, independent of the GP

12. How important do you think it is to the overall management of your condition that you should have good knowledge about your condition?

Not important a little important important very important extremely important

13. How important do you think it is to the overall management of your condition that there is good communication between the hospitals and GPs?

Not important a little important important very important extremely important

14. Over the past 6 months (or most recent visit to the doctor), when receiving medical care for my chronic illness, I was...

	Almost never	Generally not	Sometimes	Most of the time	Almost always
a) Asked for my ideas when we made a treatment plan.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b) Given choices about treatment to think about.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c) Given a written list of things I should do to improve my health.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d) Satisfied that my care was well organized.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e) Asked to talk about my goals in caring for my illness.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f) Given a copy of my treatment plan.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g) Encouraged to go to a specific group or class to help me cope with my chronic illness.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
h) Asked how my chronic illness affects my life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
i) Referred to a dietician, health educator, or counsellor.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
j) Sure that my doctor or nurse thought about my values and my traditions when they recommended treatments to me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
k) Asked how my visits with other doctors were going.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Thank you

