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The Patients' Perspective A Survey of Chronic Disease Management in Ireland

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Foreword

Mankind has undergone an ‘epidemiological transition’ in terms of what makes us ill and kills us. We used to die of infections, too little food and violence. Now, with better overall health and treatments, we are living longer with diseases such as heart disease, diabetes, cancer and lung disease. Other illnesses such as arthritis and depression may disable us without killing us. These are the “non-communicable chronic diseases” – these illnesses are not infectious but are “chronic” meaning that they are long standing, as opposed to the widely perceived meaning of the term “chronic” as meaning severe – though they may be this as well. To make matters worse, the longer we live, the more likely we are to suffer from several chronic diseases. On the other hand, we are living longer, with more years of good quality life than ever before. We are thus caught in a difficult balancing act – with longer life comes a raft of pressing issues.

These issues pose major challenges to healthcare. Chronic diseases are by definition long standing and are also often complex, requiring a highly sophisticated healthcare system to provide optimal, integrated and comprehensive care. All developed societies face escalating healthcare costs as our populations age. While we know the causes of many chronic diseases, the nirvana of a long healthy life followed by a painless peaceful death remains but a dream for many.

The Adelaide Health Foundation has been systematically examining the opinions of general practitioners, hospital consultants and practice nurses regarding the provision of healthcare for the sufferers of chronic diseases in Ireland and now of the sufferers themselves, the patients. The reports make sobering reading. None of the groups surveyed were satisfied with current systems of chronic disease management although, interestingly, patients appear to be somewhat less dissatisfied than healthcare professionals, but expressed a strong wish for clear communications.

Nevertheless, the shameful inequalities in Irish healthcare persist.

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.

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Summary

- This study provides a baseline of the provision of chronic disease management (CDM) as patients experience it in our health system in 2014.
- It allows for comparisons with previously published views of general practitioners, hospital consultants and general practice nurses.
- The study achieved an 86% response rate.
- 55% of respondents indicated that there are some good things in our healthcare system but that significant changes are needed to make CDM work better.
- Respondents reported inequities in the healthcare system in relation to difficulties paying for and accessing treatment:
 - 67% of private patients reported experiencing difficulties in paying for medications or other out-of-pocket expenses, as did 43% of public patients.
 - 71% of public patients were significantly more likely to report long waiting times to see hospital consultants, compared to 39% of private patients.
 - 63% of public patients expressed difficulty accessing specialist tests, as did 32% of private patients.
 - 52% of public patients reported long waiting times to receive treatment after diagnosis, as did 21% of private patients.
- Private patients are more likely than public patients to delay attending a GP or hospital consultant due to cost. A total of 144 (63%) private patients indicated that they often or sometimes delay attending the GP because of cost, compared with 27 (10%) of public patients surveyed. A total of 156 (68%) private patients indicated that they often or sometime delay attending a hospital consultant because of costs, compared with a total of 93 (36%) public patients.
- 87% of respondents would be happy for their doctor to prescribe a generic version of their medication, if the Irish Medicines Board approved it.
- The most prominently used services noted for the treatment of their chronic conditions included their GP, hospital consultant and clinical nurse specialist services.

- The majority of patients report not being provided with a list of their prescribed medications or written advice on how to manage their chronic illness at home. When the same question was put to the clinical stakeholders, GPs, hospital consultants and practice nurses reported a much higher frequency in the provision of both lists of medications and also written instructions relating to self-management.
- 77% of respondents reported being satisfied most or all of the time with the organisation of their care in the last six months.
 - Despite this high level of satisfaction with care we see that patients are never or generally not asked for their ideas (49.9%, n=251) or their goals (37.6%, n=188) when making a treatment plan.
 - On the other hand, the majority of patients report sometimes, mostly, or always being asked about the impact of their chronic illness on their lives (65.8%, n=332), given treatment choices to think about (62.3%, n=311), and feel that their values and traditions are thought about by nurses and doctors when recommending treatments (72.1%, n=361).
- The majority of respondents believe that it is important for them to have good personal knowledge of their condition and that there should be good communication between hospital teams and GPs in the overall management of their care.
- There was a strong preference for CDM to take place within a general practice setting with 322 (62.9%) in favour of CDM within general practice as opposed to 91 (17.8%) who supported CDM in a hospital setting.

Introduction

According to the World Health Organisation, chronic diseases are an ‘invisible’ epidemic, which account for 85% of deaths and 77% of the disease burden in the European Union¹. They are of long duration and generally slow progression. The four main chronic diseases are cardiovascular diseases (heart attacks and stroke), cancers (particularly breast, prostate and colonic cancer), chronic respiratory diseases (chronic obstructive pulmonary disease and asthma) and diabetes. It is expected that there will be a 40% increase in the number of people in Ireland living with chronic conditions such as hypertension, coronary heart disease, stroke and diabetes by 2020². Poverty, unemployment, the environment, smoking, alcohol consumption, diet, physical inactivity and poor access to services are risk factors for chronic disease and these are distributed unevenly across society³. Here are two examples of typical patient profiles within an Irish context.

Example profiles of typical patients with chronic conditions

Patient 1: Michael is an 81 year old man, living with Claire, his 79 year old wife. They are of modest means. Their care is exclusively provided under the medical card scheme. His diagnoses include diabetes (2004), chronic kidney disease (2009), osteoarthritis (2001), and most recently prostatic carcinoma (2014). He is presently experiencing significant anxiety as a result of adjustment to his own diagnosis of prostatic cancer, and more recently his wife’s increasingly evident dementia. During the last 4 months he has attended his GP on 5 occasions, consulting about the treatment options for his prostatic cancer, making arrangements for his wife should either he or she become unable to live at home, and in relation to detailed end of life care preferences, completing and reflecting on ‘Think Ahead’ with his adult children and his GP (*Think Ahead* is a public awareness initiative aimed at guiding people in discussing and recording their care preferences in the event of an accident or other emergency, serious illness or death). He has visited hospital on three occasions in the same period, twice for urology outpatient appointments, and once for a staging isotope bone scan in relation to his prostatic cancer. He has had blood tests at the practice on two occasions, had his flu vaccine, and he also has had his prescription reviewed twice (he is on 4 long term medicines). Four months previously he was psychologically shocked at his own diagnosis and his wife’s evident deterioration. Now, he is back in a coping mode, on the basis of serial discussions and planning with his family, his GP, and input from his urologist. He understands he is not likely to die in the short term, and that he and his wife are in a complex situation, but they are continuing to cope their way through it together. They are a very loving couple.

In addition to Michael’s own care at the practice, Claire is also herself what is technically described as a ‘high frequency attender,’ in a casual taxonomy which also includes such pejorative terms as ‘bed blocker,’ ‘delayed discharge,’ and ‘geriatric.’

Patient 2: Helen is a 49 year old woman separated from her husband. She now lives on her own, although her adult children sometimes move in with her for brief periods. Her care is exclusively provided under the medical card scheme. Her diagnoses include a brain haemorrhage into her cerebellum (hind brain) 22 years previously. She has chronic intermittent headaches, which are difficult to control. She has a gradually progressive tremor in her right hand and arm, and is “not the best on my feet”, ie is unsteady. She has recurrent bladder infections. She has blood pressure, which is well controlled usually. She has treated anxiety and depression. Despite her medical conditions, she remains a warm and affectionate individual. Despite her own social background of deprivation, and her neurological condition, she is emotionally very intelligent, and has been a very effective mother for her three adult children, who are now all in third level education.

It is likely that her medical condition has impacted on her marriage. Despite the undoubted difficulties in her life, she increasingly understands that she is a very effective and successful mother, and she is helpful with her own ageing parents.

In the last year, she has attended her GP on 12 occasions. She takes 11 regular medications. She has required 4 sets of monitoring blood tests. Because of worsening headaches she required an urgent 24 hour blood pressure monitor; this was provided within one week at her own GP's practice, but was charged for, as it was not covered under the medical card. The waiting time at her local hospital for this service was in the order of 7 months. She has attended neurology outpatients' department twice, the pain clinic twice, respiratory outpatients' department twice (for onset of chronic persistent cough), and has had sleep studies carried out. She has had a gastroscopy carried out as part of a work up for her chronic cough also.

She understands that she will never be well. She and her GP have agreed this, that it is a fact of her life, and they are both comfortable in doing the best they can with the situation as it unfolds.

There is a classic example of a ‘holding relationship’⁴ which is frequent in general practice, but which is objectively difficult to value, measure or fully cost.

Healthcare increasingly needs to address the management of individuals with multiple coexisting diseases, who are now the norm rather than the exception. Multimorbidity can be defined as the simultaneous occurrence of several medical conditions in the same person⁵. In a recent study of 3,309 patients attending general practice in Ireland, the prevalence of multimorbidity was 66.2% in those 50 years of age or older⁶. In a separate study conducted in general practice patients with one or more chronic diseases, healthcare utilisation and cost was significantly increased among patients with multimorbidity⁷, with these patients attending the general practice 10.79 times per year, taking an average of 6.8 regular medications, and attending on average 3.7 different OPD services.

Meeting the complex needs of patients with chronic conditions effectively and safely is the single greatest challenge of the Irish healthcare system.

In Ireland, policy documents such as 'Tackling Chronic Disease'⁸ and 'Healthy Ireland'⁹ recognise that with an ageing population will come a significant increase in chronic diseases, emphasising the need for prevention and cost effective management. Healthy Ireland is the new national framework to improve the future health and wellbeing of the Irish people, which aims to increase the proportion of people who are healthy at all stages of life, and to reduce health inequalities. The Programme for Government¹⁰ prioritises the need to address the inadequate and fragmented services for chronic diseases. This policy recognises the need to implement a model for the prevention and management of chronic diseases, and achieve high quality care through comprehensive and integrated programmes in the community. Clinical Care Programmes, including standardised models for delivering integrated clinical care, are part of on-going reform of our health service. The Clinical Care Programme in the Prevention of Chronic Disease is tasked with developing strategies to prevent chronic diseases such as cardiovascular and chronic respiratory disease, diabetes, obesity and cancer. It modestly aims to reduce the number of people being admitted for treatment for chronic disease by 10% over three years.

The Chronic Care Model (CCM) is an internationally recognised theoretical model, which identifies the essential elements of a healthcare system that encourages high-quality chronic disease care¹¹. According to the CCM, optimal chronic care is achieved when a prepared, proactive healthcare team interacts with an informed, activated patient. In line with this, patients are now seen as partners in managing chronic disease¹². Addressing the burden of chronic diseases is an essential element in transforming the healthcare system within Ireland and a fundamental step for bringing about a healthier population.

More recently, data originating from other healthcare systems underpins the value of placing a strong primary care system in the community, and at the heart of the health system. Evidence from Denmark, New Zealand, the United Kingdom, and increasingly from the United States is persuasive of this approach. The seminal work carried out by Barbara Starfield and Sir Michael Marmot in the 1990s and early 2000s is now underwritten by new data originating from these healthcare systems, most recently the United States, where early outcomes from The Affordable Care Act driving reform have further confirmed the value of this approach. Concepts such as The Patient Centred Medical Home, and the Accountable Care Organisation¹³ are built around an emphasis on the enfranchised individual, with access to personal care, the whole informed by a constant stream of data.

Data relate to key actions, outcomes and costs, made available on a real time basis and delivered by efficient and non-obtrusive use of electronic medical records. Data from specific States (eg Vermont), from early adapter Health Maintenance Organisations (eg Kaiser Permanente) and from particular insured populations (eg Veterans' Health Administration)¹⁴ are informative and encouraging.

Results from previous studies with GPs, hospital consultants and practice nurses clearly indicate that many of the elements necessary for the delivery of high quality primary care based health services are in place in Ireland, yet national outcomes remain unsatisfactory. The opinions of key stakeholders regarding the readiness of the healthcare system to deliver effective CDM are vital to implementing reforms within our health service. We believe that in this context, it is important to understand the beliefs, experiences and attitudes of frontline clinical staff, such as general practitioners and practice nurses working within primary care, and hospital consultants, but most especially patients with chronic multimorbidities. Understanding patients' 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.

Data from this study on patients' insights, concerns and experiences may prove helpful in realising the potential within the Irish healthcare system, and in delivering an improved return on the resources and skills which have been committed to it.

Section One: Rationale, Aims and Objectives

1.1 Rationale

The Irish healthcare system continues to change – reacting to changing socioeconomic circumstances, and consequent on fresh thinking, new policy directions and a realisation that in an era where disease patterns are changing, the approach to healthcare needs to evolve and to use systematic research to inform the choices we are making. The Programme for Government¹⁰ outlined a thorough transformation of the Irish health system from a two-tier service reliant on taxation to a universal healthcare system with compulsory health insurance. Concurrently, Ireland has a rapidly ageing population¹⁵. Over the next 30 years the number of patients over the age of 65 is estimated to almost triple and the number of people with chronic diseases will increase in tandem. It has been estimated that 10% of patients in Ireland consume over 60% of health resources²; a large proportion of this cost is accrued in the final year of life.

Recent research conducted by this project team with general practitioners (GPs)^{16,17}, hospital consultants¹⁸ and practice nurses¹⁹ working within Ireland indicates that when asked directly, the majority of each of these stakeholders report that significant changes are needed in our health system to make chronic disease management (CDM) work better. The Chronic Care Model (CCM)¹¹ is a systematic approach to coordinating healthcare across levels (individual, organisational, local and national). Evidence indicates that this model of ‘person centred care,’ with coordination across care settings and providers is more effective than single disease models or uncoordinated interventions¹. Many countries are engaged in transition to the CCM²⁰. This study refers throughout to the CCM as the standard model of service design and service delivery.

The study seeks to ascertain the opinions of patients regarding critical elements of CDM.

1.2 Aim of Research

The aim of this study is to survey patients with multimorbidities on their perspectives on CDM as they experience it in the Irish healthcare system. Patients’ views are important in planning services and resource allocation in the years ahead, especially should care be transferred from the secondary and tertiary sectors into primary care as per the proposed healthcare reforms. The study examines which elements of the Chronic Care Model are currently perceived by patients to exist, and provides a baseline measure against which future transformations in CDM can be benchmarked. It also provides an opportunity to compare the opinions of patients with those of GPs, hospital consultants and practice nurses, and enables a comparison of Ireland with international data.

Objectives

- To conduct a survey to deliver a baseline measure of CDM.
- To identify strengths and weaknesses of CDM in Irish healthcare services.
- To inform the wider profession and policy makers.
- To examine which elements of the Chronic Care Model are currently in place.
- To compare perceptions of CDM of patients, general practitioners, hospital consultants and practice nurses.

Section Two: Method

2.1 Design

This study used a cross-sectional design with a self-completed patient questionnaire, employing questions from previously used study instruments to allow comparisons across responder groups.

2.2 Sampling

The sample was recruited through pharmacies purposively selected in order to provide good variation in socioeconomic setting. 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

The questionnaire was based upon the GP, hospital consultant and practice nurses' surveys to allow comparisons^{16,18,19}. Two further validated survey tools designed specifically for patients were also included - the Patient Assessment of Chronic Illness Care Survey²¹, and the Assessing Disease Burden- Morbidity Self-Assessment²². This resulted in a fourteen item questionnaire which covered topics such as respondents' perception of CDM, access to care and concerns over out-of-pocket payment costs, acceptability of generic dispensing, evidence of managed care, future development of CDM and demographic details (see Appendix). The questionnaire was piloted for comprehension and ease of completion.

2.4 Procedure

The survey was presented to 600 patients 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 patients and assisted with completion as necessary. A note was taken of all non-responders.

2.5 Analyses

Descriptive statistics, including frequency and percentages were used to report results. Dichotomized variables (e.g., gender) were used in binary logistic regression models investigating impact of the patient's gender on factors associated with CDM. Multiple logistic regression analyses were performed to identify demographic factors such as age, gender and GMS status, and factors associated with patients' perceptions of CDM. Comparisons are made between responses from patients, GPs, hospital consultants and practice nurses. Analyses were performed in SPSS version 18 and in R version 2.12.2.

Section Three: Results

3.1 Response rate

Data collection was conducted between September and December 2013. 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.

3.2 Respondents' profile

This section outlines the age, sex and General Medical Services (GMS) status of respondents.

3.2.1 Age of respondents

In total 54 (10.4%) respondents indicated that their age was less than 35 years, 89 (17.2%) between 35-49 years, 199 (38.5%) between 50-64 years, and 173 (33.5%) 65 years or older. The remaining 2 (0.4%) respondents did not indicate their age.

3.2.2 Gender of respondents

Overall 230 (44.5%) respondents were male, 267 (51.6%) respondents were female. The remaining 20 (3.9%) respondents did not indicate their gender.

3.2.3 GMS status

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

3.2.4 Pharmacy location relating to deprivation index

Level of deprivation was assigned to each pharmacy using the Small Area Health Research Unit (SAHRU) National Deprivation Index where 1 is least deprived and 10 is most deprived. The spread of the level of deprivation in the sample is outlined in Table 1 below. There were no patients from pharmacies within deprivation levels 2, 5 or 7.

Table 1: Level of deprivation attributed to location of recruitment site.

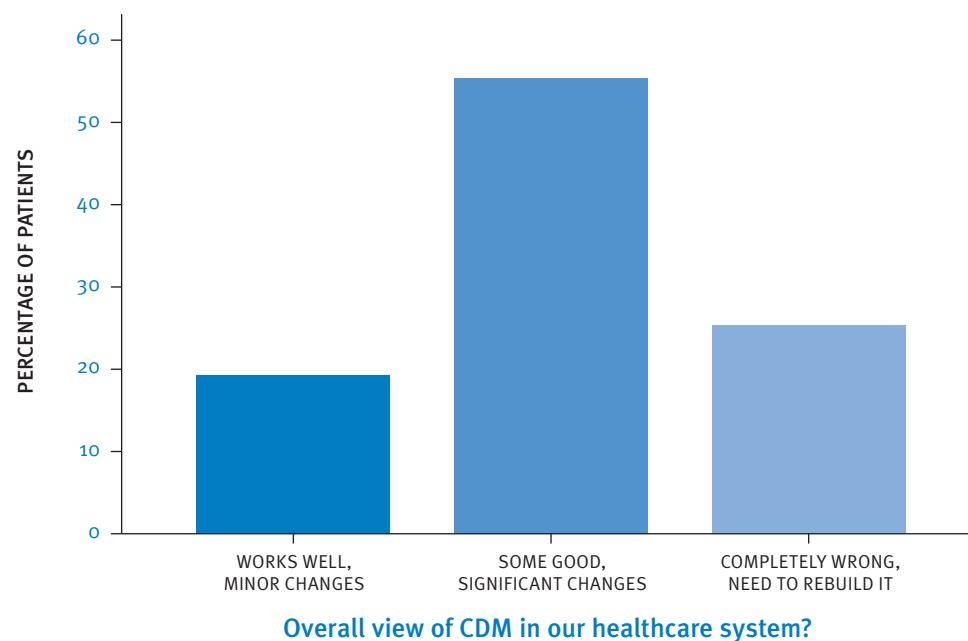
| Level of Deprivation | Number of respondents | % respondents |
|----------------------|-----------------------|---------------|
| 1 (least) | 37 | 7.2 |
| 3 | 30 | 5.8 |
| 4 | 110 | 21.3 |
| 6 | 12 | 2.3 |
| 8 | 104 | 20.1 |
| 9 | 30 | 5.8 |
| 10 (most) | 194 | 37.5 |

3.3 Perception of chronic disease management

This section examines patients' perception of CDM within the Irish healthcare system.

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

Figure 1: Patients' perception of chronic disease management in the Irish healthcare system



A total of 502 (97.1%) respondents answered this question. Missing data = 15 (2.9%)

Overall 97 (19.3%) patients indicated that on the whole, the healthcare system works well, and only minor changes are necessary to make CDM work better. A total of 278 (55.4%) respondents indicated that there are some good things in our health system, but significant changes are needed to make CDM work better. The remaining 127 (25.3%) indicated that our healthcare system has so much wrong with it that we need to completely rebuild it for CDM.

Older patients and private patients were in favour of a greater amount of change. Those in areas with greater deprivation were in favour of the least amount of change. There is no relationship between the gender of the respondent and their perception of CDM.

Table 2: Comparison between patients', GPs', hospital consultants' and practice nurses' perceptions of chronic disease management in the Irish healthcare system.

| | Patients (N=502/517; 97.1%) | General Practitioners (N=368/380; 96.8%) | Hospital Consultants (N=221/227; 97.4%) | Practice Nurses (N=307/341; 90.0%) |
|--|--|---|--|---|
| On the whole the healthcare system works pretty well and only minor changes are necessary to make it work better | 97 (19.3%) | 21 (5.7%) | 10 (4.5%) | 15 (4.9%) |
| There are some good things in our health system, but fundamental changes are needed to make it work better | 278 (55.4%) | 240 (65.2%) | 180 (81.4%) | 251 (81.8%) |
| Our healthcare system has so much wrong with it that we need to completely rebuild it | 127 (25.3%) | 107 (29.1%) | 31 (14%) | 41 (13.4%) |

There is consensus amongst stakeholders with the majority of all groups supporting the need for fundamental change within our healthcare system to facilitate better CDM. A greater proportion of patients advocate for the least level of change with 97 (19.3%) advocating for only minor changes in comparison with 21 (5.7%) GPs, 10 (4.5%) hospital consultants and 15 (4.9%) practice nurses. Older patients, however, are most likely to indicate a preference for fundamental change than younger patients.

3.4 Accessing and paying for healthcare

This section outlines public and private patients' perception of the ease of access that they experience when attempting to access healthcare services, different healthcare providers and ease of paying for out-of-pocket healthcare costs.

How often do you experience the following?

Table 3: Private patients' and public patients' experiences of accessing services and paying for medical costs.

| | Responder | Often | Sometimes | Rarely | Never |
|---|---------------------------------|-------------|-------------|------------|------------|
| Have difficulty paying for medications or other out-of-pocket costs | Private patient (N=231; 100.0%) | 59 (25.5%) | 95 (41.1%) | 36 (15.6%) | 41 (17.7%) |
| | Public patient (N=265; 98.1%) | 39 (14.7%) | 75 (28.3%) | 62 (23.4%) | 89 (33.6%) |
| Experience long waiting times to see a hospital consultant | Private patient (N=230; 99.6%) | 32 (13.9%) | 58 (25.2%) | 77 (33.5%) | 63 (27.4%) |
| | Public patient (N=267; 98.9%) | 112 (41.9%) | 78 (29.2%) | 40 (15.0%) | 37 (13.9%) |
| Have difficulty getting specialised diagnostic tests (e.g., CT imaging) | Private patient (N=230; 99.6%) | 18 (7.8%) | 55 (23.9%) | 69 (30.0%) | 88 (38.3%) |
| | Public patient (N=262; 97.0%) | 55 (21.0%) | 110 (42.0%) | 25 (9.5%) | 72 (27.5%) |
| Experience long waiting times to receive treatment after diagnosis | Private patient (N=227; 98.3%) | 18 (7.9%) | 30 (13.2%) | 86 (37.9%) | 93 (41.0%) |
| | Public patient (N=263; 97.4%) | 52 (19.8%) | 85 (32.3%) | 62 (23.6%) | 64 (24.3%) |

Patients were asked about difficulties paying for and accessing health services. When GMS status was taken into account differences emerged between private and public patients in all questions as illustrated in Table 3. Private patients were significantly more likely to experience difficulties in paying for medications or other out-of-pocket expenses than public patients. Public patients were significantly more likely to report long waiting times to see hospital consultants, difficulty accessing specialist tests and long waiting times to receive treatment after diagnosis.

Older patients were less likely to report difficulties paying for medications and other out-of-pocket costs, difficulties accessing diagnostic tests, long waiting times for consultants and treatment after diagnosis. Those who supported greater level of change to CDM were more likely to report difficulties paying for medications and other out-of-pocket costs, difficulties accessing diagnostic tests, long waiting times for hospital consultants and treatment after diagnosis. Patients from pharmacies in areas with a greater level of deprivation were more likely to indicate difficulties accessing diagnostic tests, long waiting times for hospital consultants and treatment after diagnosis.

The previously and separately reported perceptions of GPs, hospital consultants and practice nurses regarding patient difficulties with access to service and with out-of-pocket expenses is next presented, given its relevance to these issues.

Table 4: 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 |
|--|-------------------------------------|-------------|-------------|-------------|------------|
| *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%) | 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%) |
| *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; 99%) | 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%) |
| *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; 99%) | 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%) |
| *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; 99%) | 76 (20.2%) | 148 (39.4%) | 133 (35.4%) | 19 (5.0%) |
| | 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 patient's experience. Example: 'How often do your private patients experience difficulties in paying for medications or other out-of-pocket costs?'

A total of 154 (66.6%) private patients reported they often or sometimes experience difficulty in paying for medication or other out-of-pocket expenses. The majority of private patients indicated that they rarely or never experience long waiting times to see a hospital consultant (60.9%, n=140), difficulty accessing specialised diagnostic tests (68.3%, n=157) or long waiting times for treatment after a diagnosis (78.9%, n=179) (Table 4).

GPs, hospital consultants and practice nurses were previously asked the same questions in relation to their private patients. There is broad consensus between stakeholders that private patients' experience difficulties paying for medications and other medical costs. There appears to be a trend for hospital consultants and to a slightly greater extent GPs and practice nurses to overestimate the difficulties faced by private patients in accessing hospital consultants, specialist diagnostic tests and treatment after a diagnosis has been made.

Table 5: 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 |
|---|-------------------------------------|-------------|-------------|-------------|------------|
| *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%) | 87 (23.6%) | 92 (25.0%) | 123 (33.4%) | 66 (18.0%) |
| | 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%) |
| *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%) | 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%) |
| *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%) | 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%) |
| *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%) | 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 patient's experience. Example: 'Have your GMS patients had difficulties in paying for medications or other out-of-pocket costs?'

The majority of public patients reported rarely or never experiencing difficulty paying for medications or out-of-pocket medical expenses (57.0%, n=151). As illustrated in Table 5, most public patients indicated often or sometimes experiencing long waiting times for hospital consultants (71.1%, n=190), difficulty accessing diagnostic tests (63.0%, n=165) and long waiting times for treatment after diagnosis (52.1%, n=137).

Similar patterns emerged when GPs, hospital consultants and practice nurses were asked the same questions about their public patients. There is broad consensus between public patients, GPs, hospital consultants and practice nurses about public patients' experiences in accessing and paying for services, diagnostics and treatment. Again GPs, hospital consultants and practice nurses overestimate the difficulties public patients face in accessing and paying for care.

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

| | Responder | Often | Sometimes | Rarely | Never |
|---|--------------------------------|------------|------------|------------|-------------|
| How often have you delayed attending the GP 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 144 (62.6%) private patients indicated that they often or sometimes delay attending the GP because of cost, compared with 27 (10.3%) public patients surveyed. A total of 156 (68.1%) private patients indicated that they often or sometimes delay attending a hospital consultant because of costs, compared with a total of 93 (35.5%) public patients.

Younger patients using pharmacies in less deprived areas and those who feel there is a need for a greater amount of change to CDM in Ireland are more likely to delay attending a GP or hospital consultant.

3.5 Generic medication

This section outlines if patients would be happy to be prescribed generic medication.

Would you be happy for your doctor to prescribe a generic version of medicine if the Irish Medicines Board guaranteed it?

Table 7: Patients' acceptance of generic medicines

| | Yes | No |
|--|-------------|------------|
| Would you be happy for your doctor to prescribe a generic version of your medicine, if the Irish Medicines Board guaranteed it? (N=509; 98.4%) | 442 (86.8%) | 67 (13.2%) |

Patients were asked if they would be happy to be prescribed generic medicines if the Irish Medicines Board approved them. As depicted in Table 7 this suggestion was accepted by a total of 442 (86.8%) patients. There was no relationship between age, gender, GMS status or level of deprivation of pharmacy and acceptability of generic medicine prescribing.

3.6 Resources

This section examines the types of healthcare providers that patients have used for the management of their chronic condition.

In receiving management of your chronic disease which of the following have you accessed?

Table 8: Patients use of services relating to the management of their chronic disease.

| | Yes (private patients) (N= 231; 100.0%) | Yes (public patients) (N= 269; 99.6%) |
|---------------------------|--|--|
| General practitioner | 225 (97.4%) | 253 (94.1%) |
| Hospital consultant | 179 (77.5%) | 208 (77.3%) |
| Clinical nurse specialist | 101 (43.7%) | 129 (48.0%) |
| Optician | 65 (28.1%) | 94 (34.9%) |
| Dietician | 47 (20.3%) | 60 (22.3%) |
| Occupational therapist | 31 (13.4%) | 42 (15.6%) |
| Podiatrist | 22 (9.5%) | 61 (22.7%) |
| Counsellor | 29 (12.6%) | 45 (16.7%) |
| Psychologist | 28 (12.1%) | 29 (10.8%) |
| Social worker | 11 (4.8%) | 30 (11.2%) |

Patients were asked about their use of a variety of services as part of their CDM. The most prominently used services included GP, hospital consultant and clinical nurse specialist services. GMS status was associated with use of podiatry and social work services with public patients using more of both services as depicted in Table 8.

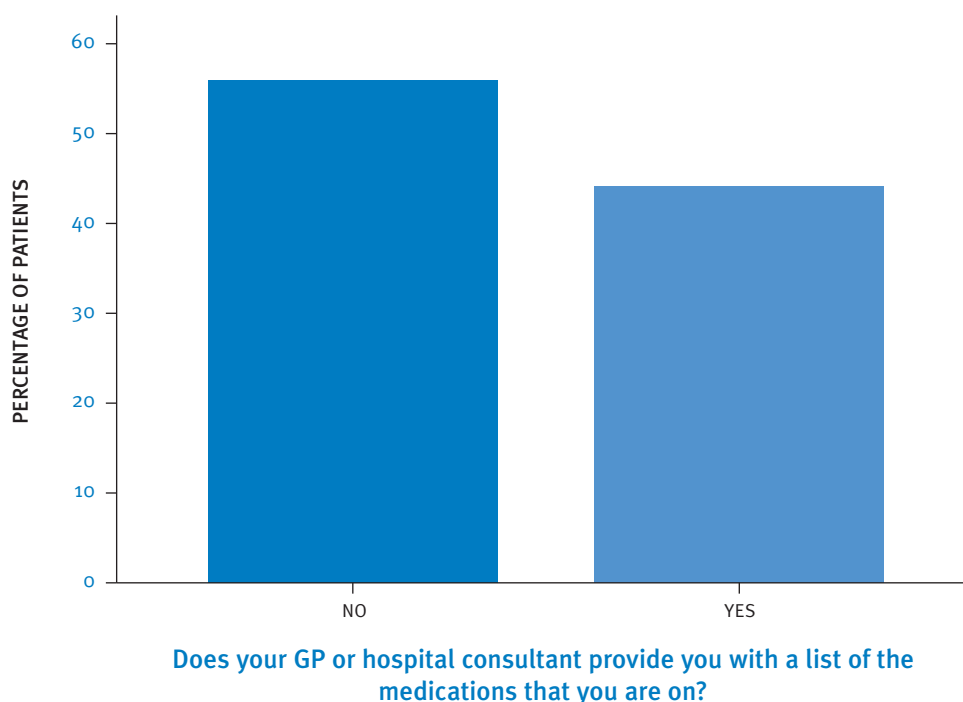
Age had a statistically significant relationship with usage of most services. Younger patients were more likely to use services such as social work, counselling and psychology. Older patients were statistically more likely to have used hospital consultant services, optician and podiatry services. Gender was statistically significantly associated with use of podiatry and dietician services with men being more likely to engage with both services as part of their CDM.

3.7 Evidence of managed care

This section examines the use of strategies for managing common conditions, such as providing patients with a list of their prescription medication, and the provision of advice around risk factors.

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

Figure 2: Percentage of patients provided with a list of their prescribed medication by their GP or hospital consultant



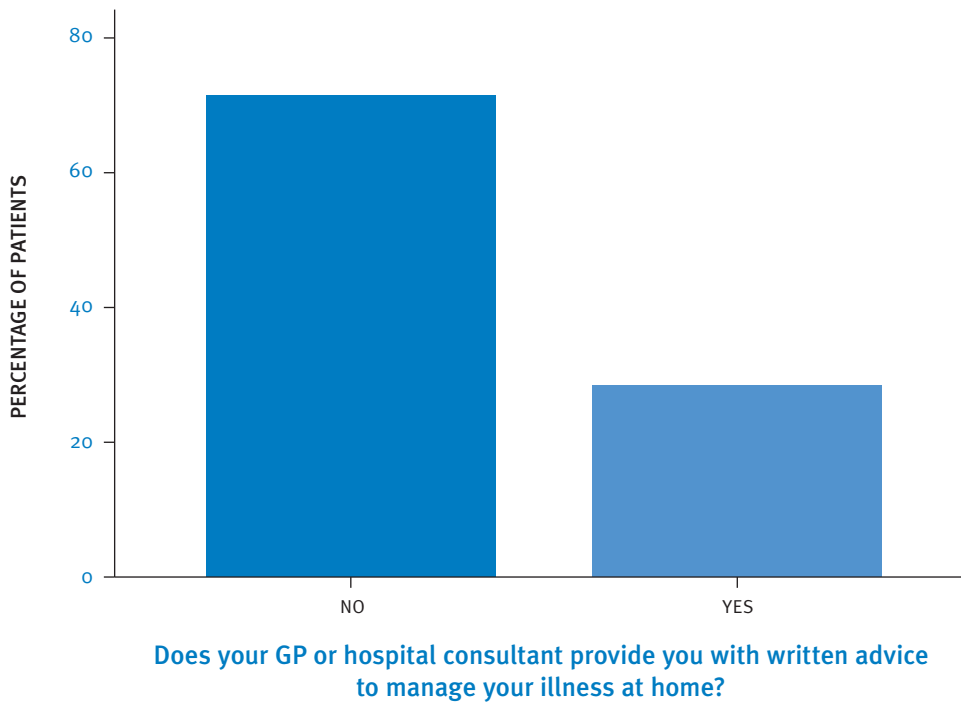
A total of 508 (98.3%) respondents answered this question. Missing data = 9 (1.7%)

Less than half of the patients (44.1%; n=224) reported being provided with a written list of medications by their GP or hospital consultant.

This is in comparison with 272 (72%) GPs, 178 (78.4%) hospital consultants and 224 (66.5%) practice nurses who reported routinely or occasionally providing patients with written lists 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.

Does your GP or hospital consultant provide you with written instructions on how to manage your own care at home?

Figure 3: Percentage of patients provided with written advice to manage their chronic illness at home



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

When 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 145 (28.5%) respondents reported that they were provided with written advice.

The same question was asked of GPs, hospital consultants and practice nurses. A total of 216 (57.0%) GPs, 159 (70.0%) hospital consultants, 238 (70.2%) practice nurses reported routinely or occasionally providing patients with written advice on care at home.

Age or gender did not have any association with provision of written advice, however, similar to written lists of medication, GMS status played a statistically significant role. Private patients were more likely to report receiving written advice on care at home. Those in favour of a greater amount of change in CDM and those who attend pharmacies in more deprived areas were less likely to have received written advice.

3.8 Patient treatment experience in the last 6 months

This section outlines patients' views on their experience of receiving treatment for their chronic condition in the last 6 months, including satisfaction with the organisation of their care, and whether they were encouraged to set goals for treatment.

Table 9: Patient experience of the management of their chronic disease in the last 6 months.

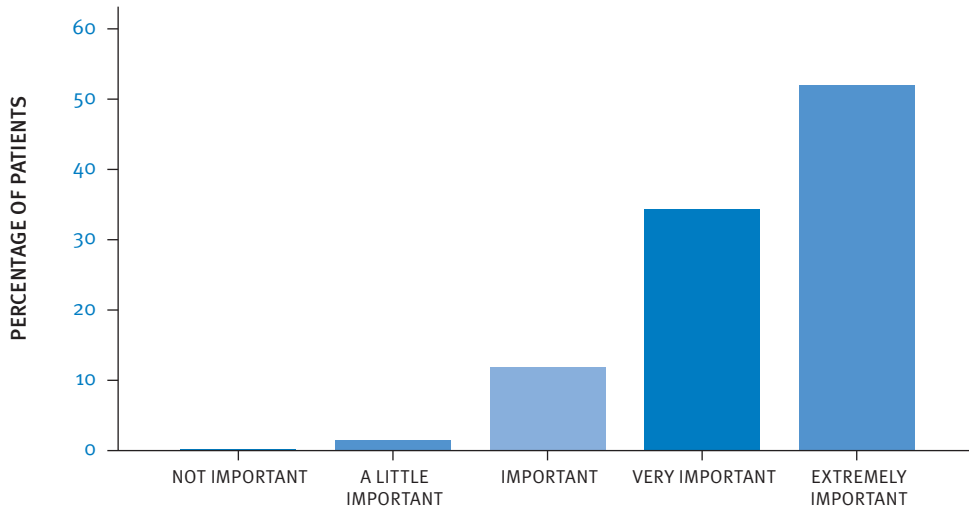
| In the last 6 months I was... | Almost never | Generally not | Sometimes | Most of the time | Almost always |
|--|--------------|---------------|-------------|------------------|---------------|
| ...Asked for my ideas when making a treatment plan (N=503, 97.3%) | 112 (22.3%) | 139 (27.6%) | 135 (26.8%) | 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 (77.1%; n=390) were satisfied most or all of the time with the organisation of their care in the last six months. 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) or their goals (37.6%, n=188) when making a treatment plan. As illustrated in Table 9 this pattern continues with many patients not advised to attend a group or class to cope with their chronic illness (65.9%, n=328) or asked about how their visits were with other doctors (54.6%, n=277). 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), given treatment choices to think about (62.3%, n=311), and feel that their values and traditions are thought about by nurses and doctors when recommending treatments (72.1%, n=361).

There was no relationship between gender and or deprivation and satisfaction of care. Both public patients and older patients indicated a greater level of satisfaction with the organisation of their care in the past 6 months.

Importance of knowledge and communication

Figure 4: Patients' views on the importance of good personal knowledge of their condition in the overall management of their care

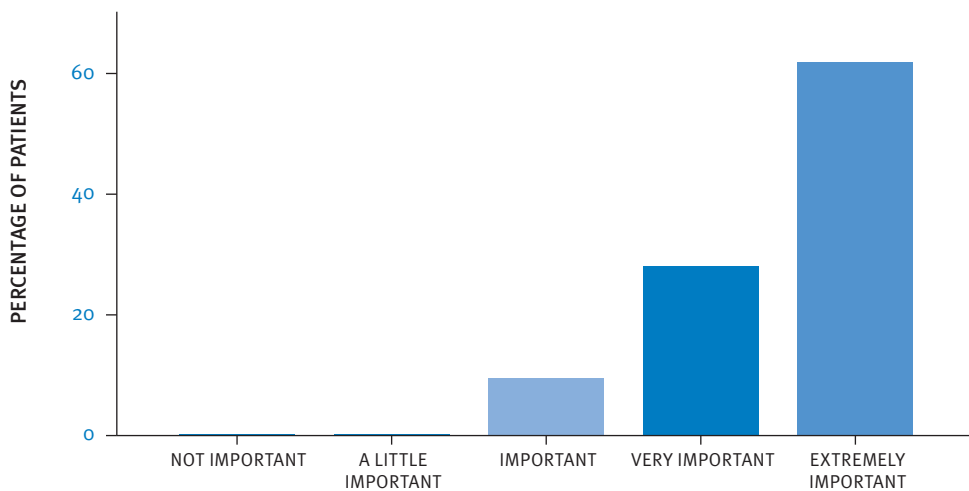


How important is it, in the overall management of your chronic illness, that YOU should have good knowledge of your condition?

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

Patients were asked about the importance of their own personal knowledge about their condition. Good knowledge of their condition was important, very important or extremely important to 503 (98.2%) of patients.

Figure 5: Patients' views on the importance of communication between hospitals and GPs relating to the management of their chronic illness



How important is it, in the overall management of your chronic illness, that there is good communication between hospitals and GPs?

A total of 510 (98.6%) respondents answered this question. Missing data = 7 (1.4%)

Patients were 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 508 (99.6%) patients.

3.8 Future development of chronic disease management

This section examines patients' preferences with regard to the clinical discipline of the person who manages their care (i.e., GP, nurse or hospital consultant) and also whether they prefer their illness to be managed in the community or hospital.

Table 10: Patients' opinions on location of chronic disease management

| | 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%) |

Patients were asked where they felt they should receive CDM. There was a strong preference for CDM to take place within a general practice setting with 322 (62.9%) in favour of CDM within general practice as opposed to 91 (17.8%) who supported CDM in a hospital setting. Within a general practice setting the patients' preference is for care provided by a GP (N=389; 76.3%). Only a minority of respondents favoured care provided by a nurse under the supervision of a GP (N=139; 27.3%) and 10 (2%) respondents were in agreement with CDM care provided by a nurse independent of a GP (Table 10).

Public patients (68.3%, n=183) illustrated a greater level of support for CDM to be managed within general practice than private patients (58.1%, n=133). Age, gender and pharmacy level of deprivation are associated with location of CDM. Those who are older, female and attending a pharmacy in an area with greater deprivation were more likely to be in favour of general practice based CDM.

Section Four: Discussion

This report is the final of four stakeholder studies conducted since 2010 on meeting the challenge of complex multimorbidities within the Irish healthcare system. The studies were undertaken because of the absolute importance of the task for the Irish healthcare system to manage better the burden of chronic illness in an ageing population. There is a need to obtain the insights, concerns and experience of the individuals most intimately concerned, these being GPs, hospital consultants, practice nurses and most importantly patients. Further, these studies are undertaken at a time when there is a strong societal consensus that change in healthcare in Ireland is necessary and imminent.

Obtaining data directly from stakeholders, as opposed to approaching their professional or representative organisations, is important, so that results fully reflect a broad and deep level of unfiltered and original insight.

All four studies have shared a common methodology, with a survey instrument used internationally, and all have achieved high response rates. It is arguable that of the four studies, this study of patients is the most important, in that it reflects the values, beliefs and experiences of those who fund, use and depend most on the Irish healthcare system, and who arguably own the system in a moral and social sense. Further, in considering the generality of the research literature, while there is an overwhelming volume of research on what healthcare professionals do, by comparison, there is remarkably little on what patients believe is important, or on how patients view the services provided.

The methodology was effective in obtaining a high response from a representative and sizeable sample (N = 517) of patients with complex multimorbidities, with a final response rate of 86%. The high response rate reflects a practical and robust approach taken in the study, in surveying patients known to be taking three or more medications on a regular basis, while attending their community pharmacy. Conducting the study in this manner was helpful in reducing the likelihood of response bias (more likely if the study was conducted in general practice or in hospitals for example), and this approach also utilised the valuable resource of pharmacy staff in ensuring a good response rate, where respondents largely completed surveys while awaiting the filling of their prescriptions. It is likely that the high response rate reflects a high level of interest in the subject on the part of these patients. High response rates from a representative sample allow confidence in considering results to be generalisable.

Most patients believe that significant changes are needed to make CDM work better (Figure 1), with almost one in four indicating the system to be ‘completely wrong and in need of a complete rebuild.’ This corresponds with the opinions of the professional stakeholders – GPs, hospital consultants and practice nurses. The extent to which the patients believe this, although substantial, is not as marked as for professional stakeholders. This is perhaps reflective of a more critical approach on the part of professional stakeholders.

The belief in the need for change is greatest among older patients, who have the highest disease burden. In the longer term this is an important result, and represents a direct challenge to policy makers, administrators and clinicians to improve the healthcare system for patients with complex multimorbidities, who are arguably the most vulnerable patient sub-group.

Patients clearly view communication between hospitals and GPs as being important for their care, and they believe that good communication is essential between primary and secondary care. Their belief in this regard must be considered against the deficiencies known to exist within the system²³. Patient expectations regarding good communication, and their low reported levels of receiving written material, particularly care plans and medication lists from their professional caregivers, is remarkable. Fewer than one in four indicated they received written care plans, and less than half of these patients, taking three or more regular medications, report receiving written medication lists from their professional caregivers. These rates are further remarkable given the marked discrepancies between patients' reported rates for these activities and the higher self reported rates by professional caregivers.

Elsewhere in results, it is noted that over half of patients rate the importance of good knowledge of their condition as 'extremely important' (Figure 4). Based on the chronic care model, these values and related activities are central to good chronic disease management, and should be considered valuable activities by professionals. Given the absolute need to achieve best outcomes for the management of complex comorbidities, provision and communication of clear goals, desirable outcomes and effective management of medication risk are important, and require to be agreed clearly, and consistently implemented by all individual stakeholders. While web based modalities may support these features of good care at some time in the future, at present, results here indicate inconsistent and sporadic provision of written treatment plans and medication lists by Irish healthcare professionals. Inadequate provision in these areas increases likelihood of poor compliance, ambiguity in care objectives, and sub optimal management of medication risk within a patient group at high risk of both excessive and unsafe medicines administration, and of preventable morbidity and mortality from their long term medical conditions. From the perspective of process analysis, failure consistently to provide written care plans and medication lists reflects a classic failure of the stressed system, where important but non-urgent tasks are preferentially neglected over tasks perceived as being urgent.

These results are lent further emphasis by the approach outlined in Healthy Ireland⁹, which in turn strongly promotes autonomy, self care and prevention among patients, and challenges healthcare professionals to modify their actions to reflect more closely societal preference and national policy than is evident from data emerging from this study. Patients clearly believe that they themselves should have good knowledge of their condition – this is important, as 'self-care' for CDM and for seeing patients as active partners in their own treatment, are important elements of the CCM.

The inequitable Irish two tiered health system continues to feature. Private patients have more difficulties paying for medication costs and out-of-pocket expenses. A high proportion report consistently delaying in attending their GP because of cost. Ireland is markedly anomalous within Europe in still not having universal coverage for GP and primary care services²⁴. This seems increasingly remarkable in the context of a society which now views itself as recovering from the 2007 downturn, socially progressive and 'smart.' Data presented here (particularly Tables 3, 4, 5, and 6) clearly indicate that public and private patients are exposed to the hazards of both systems. 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 delay in seeing their GP because of costs. Both private and public patients report delaying seeing a hospital consultant because of costs.

Regarding medicines, it is evident from the data that patients are open to achieving potential health spending savings on better medicines management, with high acceptability for generic medications (86.5%) among the sample. This is important, and is thrown into sharp focus given the annual absolute cost of medicines within Ireland, and the relatively high cost of medicines paid by individual citizens and by the Irish Exchequer, the latter two both being high in a European context. Irish prescribers, dispensers and healthcare administrators collectively continue to expose Irish taxpayers and Irish patients to unduly excessive medication costs.

Patients express some satisfaction regarding certain aspects of how their care is organised (Table 9). This is evident where they are asked about their goals in relation to their illnesses, how their illness affects their life, and the extent to which they believe that their clinical teams are aware of their personal values and traditions when recommending treatment.

Patients are less positive regarding being given choices for treatment, or being asked for ideas when making treatment plans, nor do they feel encouraged to attend a group or class about their illness, or being asked about how their visits with other doctors are going. Once again, these results may indicate a stressed system where important tasks not perceived as being medically urgent are neglected systematically, and / or a system which has historically reflected the values of an acute system of care geared to management of crises as opposed to a system more properly focused on longer term best outcomes.

It is clear that patients overwhelmingly view general practice as the optimal setting for most of their CDM, which is closely aligned with current government policy (Table 10). Patients views are not concordant with those of professional caregivers in so far as they clearly have misgivings regarding having most of their CDM delivered under a GP led but practice nurse delivered model, which approach has high support among professional care givers, is that favoured in the chronic care model, and is in keeping with the process of delivering services in the most cost effective manner. However, patients do not yet appear ready for practice nurses to take a more active role in their care, and this issue requires to be addressed as part of change management within the Irish healthcare system. This finding is thrown into sharper focus based on a result from a study of chronic disease management in Irish general practice¹⁷, where it was observed that the average number of GP visits for each patient with co-morbidities was 9.2 consultations per year, whereas the average number of practice nurse consultations for each patient was only 1.6 per year. These data indicate that there is a clear need for consultation and communication with patients should the proposed changes be instituted.

Used correctly, data presented here, and in the previous stakeholder studies, will be helpful in guiding and implementing policy and managing change, for political representatives, administrators, and clinical staff. Results will also provide benchmarks against which the extent of proposed changes can be measured. While much of the public commentary regarding the healthcare service in Irish society has been negative, and especially so since 2007, results from this and the previous studies within this series provide clear and reliable direction towards a more effective healthcare system.

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Appendix: Survey Instrument

Department of Public Health & Primary Care, Trinity College Dublin

National Survey of the Management of Chronic Disease – Patients’ Perspectives

Thank you for assisting with this study. It looks at how your medical care is provided, and in what way you might like to see this changed in the future. It is a confidential study, and your responses will only be included as part of overall results. The study is being carried out by Trinity College (TCD HSE GP Training Scheme), and results will be helpful in planning future changes to our healthcare system.

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

