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Abstract

This thesis contributes to our understanding of the moral dimensions of using self-management technologies in general practice. Through qualitative interviews with general practitioners (GPs) and patients with experience in home blood pressure monitoring (HBPM) utilization, it examines the influences of HBPM on the general practitioner-patient relationship, patient responsibility for their health and patient autonomy.

The first part of this thesis provides an account of the ethical implications of self-management technologies and their related practices for the doctor-patient relationship (DPR), patients’ responsibility for their health and patient autonomy. This account is contrasted with models of the DPR drawn from the bioethics and clinical literature, and with the conceptions of patient responsibility and patient autonomy that inform these models. Self-management technologies and their related practices have the potential to be more ethically robust than ordinary care. They may be able to influence patients’ health agency by promoting their cognitive and emotional abilities and, through this, change health outcomes for chronically-ill patients. However, there are a number of pertinent ethical issues concerning mutual trust in the DPR, patient responsibility and patient autonomy that need further empirical clarification.

Building upon the theoretical material covered in the first part of the thesis, the second half describes an empirical study, which consisted of a series of interviews with GPs (n = 13) and patients (n = 19). HBPM was used as a case study for self-management technologies. The interviews focused on participants’ experiences with HBPM as a means to collect experiential narrative material relevant to answer the research questions.

The findings are presented across two domains: the GP-patient relationship and patients’ responsibility for their health. GPs’ and patients’ views of these ethical notions are presented comparatively. Mutual trust in the DPR plays an important role in promoting patients’ motivation to maintain their health, which in turn, underpins all dimensions of patients’ responsibility for their health.

In the final part of the thesis, these two themes from the empirical findings are drawn together with the theoretical material. I emphasize the significance of these findings for the bioethics literature concerning the DPR, patient responsibility and
patient autonomy and for the conceptual base of self-management technologies. The implications of these conclusions for bioethics, general practice and public health are then considered.
Statement

This work contains no material which has been accepted for the award of any other degree or diploma in any university or tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except when due reference has been done in the text.

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Liviu Oprea, Candidate

Date: _____________________
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May, 2012
## List of abbreviations

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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>BP</td>
<td>Blood pressure</td>
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<tr>
<td>CCM</td>
<td>Chronic Care Model</td>
</tr>
<tr>
<td>CDSMP</td>
<td>The Stanford University Chronic Disease Self-Management Program</td>
</tr>
<tr>
<td>CM-DPR</td>
<td>The collaborative model of DPR</td>
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<tr>
<td>DPR</td>
<td>Doctor-Patient Relationship</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<td>HIV</td>
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<td>HBPM</td>
<td>Home Blood Pressure Monitoring</td>
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<td>NR</td>
<td>Negative Reinforcement</td>
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<td>NR-GPs</td>
<td>GPs who used negative reinforcement communication style</td>
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<tr>
<td>PCC</td>
<td>Patient Centred Care</td>
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<td>PR</td>
<td>Positive Reinforcement</td>
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<td>RCC</td>
<td>Relationship Centred Care</td>
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Chapter 1: Introduction

Chronic diseases are pervasive globally and their prevalence is increasing worldwide.\textsuperscript{1} Chronic diseases now represent a major health burden in most advanced societies, at an estimated 46\% of global burden of disease and 59\% of mortality.\textsuperscript{2} In Australia chronic disease represent 70\% of the total burden of ill-health, as measured by disability-adjusted life-years, and it is expected to increase to 80\% by 2012.\textsuperscript{3,4} Heart disease, stroke, diabetes, depression and cancer are the major contributors. Individuals with chronic diseases have a poorer quality of life and decreased life expectancy.\textsuperscript{1} There is also an impact on their economic security through the direct costs of their medical care and indirectly due to reduced workdays and employment opportunities. Societies are affected directly through increasing health care costs and indirectly through a negative impact on economic development due to decreased productivity.\textsuperscript{1,5,6}

Significant scientific advances regarding the prevention, diagnosis, monitoring and treatment of chronic disease have been made.\textsuperscript{1,7,8} Although these scientific advances have proven effective to improve the health outcomes of chronically-ill patients, the quality of health care still lags behind these achievements.\textsuperscript{9} Multiple studies have shown that evidence-based health care for chronic conditions is not the norm in most health care systems and, frequently, patients do not get the care they want or need.\textsuperscript{1,7,8} It has been argued that the implementation of self-management technologies at the level of primary care may improve health outcomes for chronically ill patients and decrease the associated health care costs because they may increase patients’ adherence to evidence-based therapeutic approaches and doctors’ adherence to clinical guidelines.\textsuperscript{10}

In the last thirty years there has been an increasing trend to introduce self-management technologies for the management of chronic diseases, such as the utilization of glucometers for self-adjusting insulin therapy, or peak flow meters for self-monitoring of asthma, or the utilization of information technologies for self-monitoring of chronic diseases.\textsuperscript{11-13} These technologies are part of self-management plans incorporating diagnostic, monitoring and treatment components. They have begun to replace the traditional approaches, where health care professionals control technologies and patients are under the close supervision of their doctors for their treatment plans.

These technological developments have been accompanied by conceptual developments of treatment models that aim to facilitate the implementation of these
technologies in medical practice. The most significant conceptual development has been the Chronic Care Model (CCM) - a multipronged evidence-based policy (figure 1) that aims to improve health outcomes for chronically ill patients.\textsuperscript{1,7,10} It has been implemented, partially or as a whole, in a large number of health care organizations in the United States, the United Kingdom, Sweden and some developing countries.\textsuperscript{14-18} The World Health Organization (WHO) has recommended CCM for health care systems worldwide.\textsuperscript{1,18}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{Fig1.png}
\caption{Chronic Care Model}\label{fig:CCM}
\end{figure}

Amongst its components, the support for self-management component of CCM\textsuperscript{19,20} aims to increase patients’ involvement in medical care, by focusing on patients becoming their own primary care givers. This component of CCM includes two components: (1) the Stanford University Chronic Disease Self-Management Program (CDSMP), which is an educational intervention that aims to develop patients’ self-management skills;\textsuperscript{14} and (2) the collaborative model of doctor-patient relationship (CM-DPR), which is a new paradigm of the doctor-patient relationship (DPR) developed to promote self-management approaches in chronic diseases by increasing patients’ medical expertise and decreasing the power asymmetry in this relationship.\textsuperscript{14,15,17,21,22}
Self-management technologies are as much moral as technical interventions. These technologies and their related conceptual developments have the potential to change the interaction in the DPR and, through this, can have an impact on the nature and quality of the DPR. They also have the potential to influence patients’ sense of responsibility for their own health and their autonomy through a significant transfer of expertise and responsibility from health care professionals to patients.

Despite this important moral dimension, self-management technologies have not yet been comprehensively assessed from an ethical point of view. This thesis focuses on understanding and describing:

1. What doctors and patients’ accounts of their experiences with home blood pressure monitoring reveal about the pathways and mechanisms through which self-management technologies may influence the doctor-patient relationship?; and

2. How do doctors and patients build and maintain the notion of patients' responsibility for their own health and patient autonomy and understand the influences of self-management technologies on patient responsibility and patient autonomy?

This thesis makes a contribution towards our understanding of the moral dimensions of self-management technologies by focusing on how these technologies influence the DPR, patients’ sense of responsibility for their health and patient autonomy. Empirical data from general practitioners and patients are used firstly to describe the ethical features of the DPR and GPs’ and patients’ understandings of their personal responsibility for their health in the context of chronic illnesses. Secondly, the data are used to analyse the influences of self-management technologies on how these ethical concepts are interpreted by doctors and patients. On the basis of these findings, the thesis suggests new ways to understand the DPR and, in particular, doctors’ and patients’ responsibilities with respect to patient health and health care that are more appropriate for the management of chronic diseases.

In the second chapter, I begin an analysis of self-management technologies using an ethical lens to set the scene for the rest of this thesis. First, I describe the concept of self-management technologies, the roles of different self-management technologies in improving patients’ health and the evidence for their effectiveness in improving patients’ health. I then argue that there is a need for an ethical analysis of the pathways and mechanisms through which these technologies may influence patients’ health. Second, I identify the ethical issues raised by self-management technologies in relation to the DPR. I describe the goals of the Chronic Disease Self-Management Programs (CDSMP) and of the collaborative model of the doctor-patient relationship (CM-DPR) and then argue that
these interventions are not clear about how self-management technologies, mutual trust in
the DPR and patients’ responsibility for self-care interrelate. Third, I suggest that CDSMP
and CM-DPR are intended to increase patients’ responsibility for self-care by promoting
patients’ agency. I describe the communication patterns that characterize these
interventions and suggest a number of ways in which these interventions may promote
patients’ agency. I then analyse these communication patterns and argue that they may
prevent self-management technologies from reaching their expected outcomes.

The third chapter is concerned with the analysis of the ethical issues associated with
the implementation of the collaborative model of doctor-patient relationship by comparing
it with models of the DPR found in the bioethics and clinical literature. First, the
contractual\textsuperscript{23,24} and relational\textsuperscript{25-27} models of the DPR (drawn from the bioethics literature)
and the patient-centred care (PCC)\textsuperscript{28,29} and relationship-centred care (RCC)\textsuperscript{30} models
(from the clinical literature) - are briefly reviewed. I describe their goals, the conceptions
of patient autonomy and patients’ responsibility for their own health on which these
models rely and the communication processes in DPR advocated by these models through
which their goals might be reached. Second, I show that CM-DPR combines features, in
terms of building mutual trust in DPR, conceptions of patient autonomy and of patients’
personal responsibility for their health from both the contractual and relational models of
DPR. I argue that these features appear to be conceptually inconsistent, which raises
questions about the capacity of CM-DPR to both promote mutual trust and patients’ self-
efficacy. I also argue that there is a need for further research to understand the relationship
between patient responsibility for their health, patient autonomy and mutual trust in the
DPR in the context of self-management approaches in chronic diseases.

In chapter four, I shift from theoretical concepts associated with self-management
technologies to their practical aspects by reviewing what we have learnt from qualitative
studies on the influences of self-management technologies on mutual trust in the DPR,
patient autonomy and patients’ responsibility for their health. To date there has been
relatively little work in these areas; a review of the qualitative studies reveals only a small
number of papers concerned specifically with the relationship between self-management
technologies and mutual trust in the DPR, patient responsibility for health and patient
autonomy. I argue that there is a need to further understand and describe: (1) the pathways
and mechanisms, through which self-management technologies may influence interactions
and mutual trust in the DPR, (2) how GPs and patients build and maintain the notion of
patients’ responsibility for their own health and the influences of self-management
technologies on patient responsibility and patient autonomy.
Chapter five focuses on the methodological aspects of the empirical component of this thesis and describes the techniques employed in designing, collecting and analysing the data. Home blood pressure monitoring (HBPM) in general practice is used as a case study for self-management technologies. I chose HBPM as a case study for understanding the ethical dimension of self-management technologies for several reasons. First, HBPM is used frequently to self-monitor the blood pressure of hypertensive patients. Second, hypertension is a common condition in general practice that is encountered either as an isolated risk factor in otherwise healthy individuals or in association with multiple chronic conditions such as diabetes or angina. These features facilitated recruitment of research participants because general practitioners frequently encounter this condition in practice. It also helped me to study different types of interactions between doctors and patients depending on the various health needs of the patients who used HBPM.

The empirical data consist of transcripts from thirty-two semi-structured interviews with thirteen general practitioners and nineteen patients who had experience with HBPM utilization. The interviews focused on participants’ experiences with HBPM as means to explore and collect experiential narrative material to develop an understanding of: (1) the ethical features of the DPR; and (2) patients’ sense of responsibility for their health; and, then, to explore how HBPM influenced DPR and patients’ responsibility for their health. The transcribed interviews were analysed by using the constant comparative method with the findings focused around two domains: the GP-patient relationship and patients’ responsibility for their health, all in the context of HBPM utilization.

The results of this analysis are presented in the next three chapters. Chapter six and seven provide an account of GPs’ and patients’ views of the GP-patient relationship in the context of HBPM. Chapter six reports GPs’ views and chapter seven compares patients’ views with those of the GPs’. This involves an exploration of how GPs and patients understood, justified and developed the GP-patient relationship in the context of HBPM, and how HBPM contributed to this relationship. First, I demonstrate that, from the GPs’ and patients’ point of view, the main function of HBPM was to facilitate collaborative approaches between patients and GPs, focused on improving the technical certainty of clinical activities associated with the management of hypertension. In addition, GPs used HBPM to motivate their patients to maintain their health by engaging them in their care and patients used HBPM to increase their control over their own health. Although all GPs used HBPM for similar goals, their accounts of the impact of HBPM on patients’ motivations to maintain their health varied. In addition, patients’ engagement in their own
care arose as a result of a GP-patient relationship characterised by trust rather than an initial expectation of HBPM.

Second, I describe how the GPs and patients in this study experienced and understood communication and the influences of HBPM on communication. Based on the data from the GPs and patients, I identify two styles of communication between GP and patient, which I label: *positive reinforcement* (PR) and *negative reinforcement* (NR). There were two groups of GPs, those who wanted to motivate their patients to maintain their health by promoting their health agency (PR-GPs) and those who wanted to motivate their patients by making patients worried about their health (NR-GPs). With the PR style, GPs and patients used HBPM to build mutual trust between them, whereas the NR style was used by GPs to assess whether patients could be trusted with HBPM. The GPs were about equally divided between those who used a PR style and those who supported the NR style. Patients, by contrast, all tended to adhere to a PR style. I also show that the PR communication style occurred within a relational model of the DPR whereas the NR communication style was associated with a contractual type of DPR. These two types of relationships had differing influences upon patients’ confidence in their abilities to manage their blood pressure and their illnesses more generally, due to their differential effects on the promotion of mutual trust in the GP-patient relationship.

In chapter eight, I describe GPs’ and patients’ views of personal responsibility for health in the context of HBPM. I focus on the relationship between patients’ motivation to maintain their health and patients’ sense of responsibility for their health. First, I demonstrate that GPs and patients associated patients’ responsibility for their health with the idea that patients had a duty to maintain their health by carrying out practical activities. Second, I describe the beliefs and values that underpinned patient responsibility and show that both GPs and patients associated patient responsibility for their health with: (a) patients’ capacity to deliberate effectively; and (b) patients’ control over health care decisions and over their own lives more broadly. I demonstrate that patients’ motivation to maintain their health was built into all these notions of patient responsibility. I also show that PR-GPs, NR-GPs and patients understood these notions of patient responsibility differently. These different understandings were significant, in the context of HBPM utilization, because they were associated with different approaches with respect to patients’ motivation. HBPM influenced patients’ control over health care decisions and patients’ capacity to deliberate effectively because it influenced patients’ motivation to maintain their health. However, HBPM did not appear to influence significantly patients’ capacity to control their lives.
In chapter nine, I draw together the findings of this study with the theoretical material presented in the first part of this thesis to discuss their significance for self-management approaches and to build an account of the GP-patient relationship, patient responsibility and patient autonomy in the context of the use of self-management technologies. Mutual trust in the DPR plays an important role in promoting patients’ motivation to maintain their health, which in turn, underpins all dimensions of patients’ responsibility for their own health. The implications of these outcomes for the bioethics literature concerning the theoretical models of DPR, patient responsibility for health and patient autonomy as well as for the literature concerning the conceptual base of self-management approaches in the context of chronic diseases are discussed throughout the text of this chapter.

In chapter ten, I summarize how I have answered the research questions of this thesis. I also discuss the limitations of this research and suggest questions for further research.

In summary, this multi-disciplinary research study draws on bioethics and the qualitative social sciences to explore the relationship between the conceptual basis of self-management technologies and the ethical issues associated with the implementation of these technologies. It aims to offer a contribution for clinical ethicists, general practitioners and public health practitioners.
Chapter 2: Ethical issues associated with the utilization of self-management technologies

2.1 Introduction

My intent in this review is to begin an analysis of self-management technologies using an ethical lens in order to set the scene for the rest of this thesis. The chapter has three sections. In the first section, I begin with a description of the concept of self-management technologies, the roles of different self-management technologies in improving patients’ health and the evidence for their effectiveness in improving patients’ health. I then argue that there is a need for an ethical analysis of the pathways and mechanisms through which these technologies may influence patients’ health. In the second section, I identify the ethical issues raised by self-management technologies in relation to the DPR. I describe the goals of the Chronic Disease Self-Management Programs (CDSMP) and of the collaborative model of the doctor-patient relationship (CM-DPR) and then argue that these interventions are not clear with respect to how self-management technologies, mutual trust in the DPR and patients’ responsibility for self-care interrelate. In the third section, I suggest that CDSMP and CM-DPR are intended to increase patients’ responsibility for self-care by promoting patients’ agency. I describe the communication patterns that characterize these interventions and suggest a number of ways in which these interventions may promote patients’ agency. I then analyse these communication patterns and argue that they may prevent self-management technologies from reaching their expected outcomes. I conclude by suggesting that, while these arguments are potentially persuasive, they are only theoretical and we require empirical evidence to assess their acceptability more fully.

2.2 Self-Management Technologies

In this review the term ‘self-management technology’ is defined as both a technical device used by patients for self-measurement of biologic parameters and the self-management plans patients follow. I use this definition because the technical devices devoted to self-monitoring patients’ health conditions do not act directly on patients’ health. However, they may increase doctors’ adherence to clinical guidelines and patients’
adherence to therapeutic recommendations. These technologies aim to respond to the gap between significant scientific advances regarding the prevention, diagnosis, monitoring and treatment of chronic diseases and health outcomes for patients. Despite effective therapies for chronic conditions and proven benefits, only about half of all patients with chronic conditions such as hypertension, diabetes or asthma have their biologic parameters controlled and maintained to target goals as developed by scientific evidence.

This evidence-practice gap has been attributed to broad socio-economic factors as well as to individual doctor and patient factors. First, there is evidence that the utilisation and the process of health care are highly influenced by socioeconomic status. For instance, lower socioeconomic status is associated with less preventive care, less ambulatory specialist care and less hospital care. The pathways through which socioeconomic status influence the process and utilization of health care described in the literature have included health care affordability, transportation, education, knowledge, level of literacy, patients’ self-management skills, as well as competing interests such as caring for others or work demands. Second, at an individual level this evidence-practice gap has been attributed to two factors: doctor’s inertia to adjust therapy when the treatment goals are unmet, and patient factors such as denial and lack of motivation to follow therapeutic recommendations. In addition, patients’ lack of adherence to treatments has been attributed to lack of trust between patients and doctors. For instance, low levels of health literacy are associated with lower trust in health care providers and, thus, with lower adherence to therapeutic plans.

As most of the social determinants of health reside outside of health care systems and self-management technologies’ interventions stop at the practice door, I will focus my attention to their influence on individual doctor and patient factors. Self-management technologies aim to influence patients’ motivation to maintain their health and thus to promote patients’ self-management behaviour and concordance with a prescribed treatment regimen. These technologies are usually associated with self-management plans and educational interventions designed to encourage frequent home measurements to engage the patients in their own care. In addition, these plans encourage closer communication between patients and clinicians and generally are driven by clinical guidelines. Therefore an analysis of the technical devices together with their associated self-management interventions may help us understand the pathways and mechanisms through which these technologies can influence patients’ health.

Historically, the first reference to self-management technologies dates back to 1961 and was linked with the utilization of self-monitoring of blood glucose by patients with
diabetes type 1. Patients adjusted their insulin doses in response to changing blood glucose concentrations. The main expectation was that patients would maintain their blood glucose within a normal range, and this was shown to be associated with better health outcomes and less long term complications for patients with diabetes type 1. In addition, it was expected that self-management would reinforce concordance with beneficial lifestyle behaviours by increasing patients’ understanding of the effect of diet and exercise on capillary blood sugars.

Since 1961, self-management plans, including the use of diagnostic and therapeutic techniques by patients, have increasingly become an important component of their management to improve the outcomes for chronically ill patients. Asthma, diabetes mellitus type 2 and hypertension are chronic conditions in which self-management plans, involving diagnostic, monitoring and therapeutic components, have become an essential component of the treatment. Glucometers have increasingly been used for self-monitoring of blood glucose in diabetes type 2 patients. Similarly, asthma patients have used peak flow metres for measuring their lung volumes and, to some extent, they use these measurements to make therapeutic decisions. Home blood pressure monitoring has been used increasingly for diagnostic and monitoring purposes in hypertensive patients in general practice. All of these technologies are associated with educational interventions that aim to increase patients’ literacy with respect to their illnesses and technology utilization and their motivation to adhere to therapeutic plans.

In addition, information technologies have been implemented as a means to facilitate doctor-patient communication and self-monitoring of patients’ health states. For instance, electronic pre-visit forms allow patients to describe their problems. Such forms can take into account patients’ specific circumstances and can give primary care doctors access to an extended informational base about the various personal, cultural, social and psychological needs of their patients. Internet technologies have also been used to support patients to self-monitor their health status, or to learn self-management skills. All of these technologies aim to provide alternatives to current models of care that are essentially only reactive to patients’ immediate needs. They aim to optimise quality improvement by focusing clinical decision making on long-term prevention through productive doctor-patient interactions enhanced by motivated patients and proactive clinicians. Proponents of these technologies have argued that these productive interactions will improve the clinical and functional outcomes for chronically ill patients.
However, the evidence on the effectiveness of different self-management technologies is not yet convincing. For example, blood pressure in hypertensive patients who self-monitor their blood pressure,\textsuperscript{75,76} and HbA1c in diabetes type 2 patients who self-monitor their blood glucose have been assessed\textsuperscript{69,77} and studies on their effectiveness carried out in different environments have shown contradictory outcomes. The utilization of self-monitoring of blood glucose by patients with diabetes type 2 has been found in some studies to be effective in improving physiological parameters in diabetic patients,\textsuperscript{77} whereas in others it has been found to be ineffective and has been associated with increased anxiety or depression amongst patients.\textsuperscript{56} Similarly, although most studies on the effectiveness of home blood pressure monitoring to improve blood pressure in hypertensive patients have shown positive outcomes, there are also studies that have shown opposite outcomes.\textsuperscript{75,76,78}

This variation in the effectiveness of self-management technologies has been attributed in part to selection bias in the patients enrolled in these studies.\textsuperscript{53} Not all the patients enrolled in these studies have had the same experience with self-management of their chronic illnesses and the same psychological abilities to make use of these technologies. Arguments\textsuperscript{53} have been made that studies showing a positive impact of self-management technologies on patients’ health have included patients with an already increased level of literacy and motivation to maintain their health. Therefore, patients’ improved health outcomes may be a marker of the generally beneficial self-management behaviour of these patients, rather than the impact of the self-monitoring per se.\textsuperscript{53} For instance, studies showing that self-monitoring of blood glucose improved HbA1c in patients with diabetes type 2 were carried out in patients with established diabetes type 2 who were already self-monitoring their blood glucose at the time of enrolment in these studies.\textsuperscript{53} Patients with long term experience in self-managing their illnesses who opted for self-monitoring had better knowledge and were more motivated to assume increased responsibility for self-care as compared with other groups of patients such as newly diagnosed patients with diabetes type 2.\textsuperscript{53}

Similarly, arguments have been made that studies showing a positive impact of self-management technologies on patients’ health have enrolled patients with high socio-economic status.\textsuperscript{70} For instance, in a study that showed significant improvement of patients’ blood pressure values as a result of an intervention that combined home blood pressure monitoring, web-based services for doctor-patient communication and pharmacist care,\textsuperscript{69} the study population had a higher socio-economic status and was better educated compared with the general population. It has been argued that the increased level of health
literacy and better psychological abilities of these patients enabled them to make better use of these technologies, and were responsible for patients’ improved health outcomes. All of these individual and social patient factors are significant because they imply that the findings of these studies cannot be extrapolated to the general population.

As a response to this selection bias, some authors have proposed that studies on the effectiveness of these technologies should be carried out in homogeneous groups of patients from the point of view of health literacy and motivation for self-management. This approach would control for the beneficial effect of self-management behaviour on patient’s health from that of the self-management technology per se. For instance, some studies have focused either on newly diagnosed patients with diabetes type 2, or on patients with an already established diagnosis of diabetes type 2. In addition, these studies have excluded patients already motivated to assume increased responsibility for their own care such as patients who currently monitor or have previously monitored their blood glucose. Some of these studies have shown negative outcomes. For instance, O’Kane has shown in a study on the effectiveness of self-monitoring of blood glucose in newly diagnosed patients with diabetes type 2 that self-monitoring has not improved patients’ HBA1c. In addition, patients developed either anxiety or depression. Similarly, Farmer et al have shown that self-monitoring of blood glucose has not had a positive impact on HBA1c of the patients already diagnosed with diabetes type 2 whose diabetes was reasonably well controlled and who did not self-monitor their blood glucose before their enrolment in these studies.

However, this approach, which attempts to dissociate the impact of patients’ motivation for self-care from that of self-monitoring technologies per se on patients’ health, has limits. First, these studies cannot explain whether these negative outcomes could be attributed to self-monitoring per se or to the lack of effectiveness of the educational interventions that are usually associated with the utilization of self-management technologies. For instance, O’Kane concluded that self-monitoring promoted anxiety due to the enforced discipline of regular monitoring without any tangible gain. By contrast, Franciosi et al have shown that self-monitoring of blood glucose could have an important role in improving the metabolic control of patients with diabetes type 2 if it is part of a larger educational strategy devoted to promoting patients’ autonomous behaviour in the context of self-monitoring. Patients who were less knowledgeable and experienced with the self-management of their illnesses were more likely to develop anxiety and depression.
Second, an approach that attempts to separate the impact of patients’ motivation for self-care from that of self-monitoring technologies on patients’ health cannot identify whether or not self-management technologies can influence the individual and social factors that shape patients’ cognitive and affective abilities required to self-manage their chronic illnesses. This is a significant issue because these technologies were developed to improve patients’ health through this pathway.\textsuperscript{10,83}

In addition to these patient factors, some authors\textsuperscript{70} have also suggested that the variation in the effectiveness of self-management technologies may be explained by the quality of doctor-patient relationships, which could also influence patients’ engagement with their own care. For instance, the study conducted by Green et al\textsuperscript{69} has shown that home blood pressure monitoring (HBPM) combined with web-services for facilitating doctor-patient communication and pharmacist care has produced the highest level of positive impact on patients’ blood pressure compared with HBPM alone or combined with web services for doctor-patient communication. This paper argued that frequent patient contact with the pharmacist stimulated patients’ interactions with their doctors via a website and ultimately patients’ engagement in their care.\textsuperscript{70} Patients receiving the Web service, HBPM plus pharmacist care had significantly more web interchanges with their doctors relative to the other 2 groups.\textsuperscript{69} It has been argued that this enhanced medical interaction promoted patients’ engagement in their care and improved health outcomes for these patients.

This argument suggests that the impact of self-management technologies on patients’ health is also related to interpersonal communication. Moreover, self-management technologies may also change the ways in which doctors and patients make health care decisions together and, through this, could have an impact on the nature and quality of the doctor-patient relationship. Because the DPR is the medium through which medical care is delivered, changes in the nature of this relationship may influence the effectiveness of these technologies as well. Although it has been argued that these technologies have the capacity to improve patients’ health by promoting productive interactions between motivated patients and proactive professionals,\textsuperscript{10} the nature of these interactions has not yet been described. Furthermore, the evidence for the capacity of self-management technologies to influence these interactions is indirect. The studies on the effectiveness of self-management technologies assess the quality of care or patients’ health outcomes, rather than evaluating the doctor-patient relationship itself.

The review above not only points to the contested nature of the evidence surrounding self-management technologies; it also suggests that self-management technologies are
interesting from an ethical point of view. They are as much moral as technical interventions, because they are contingent on patients’ motivation to assume responsibility for self-care, without actually evaluating whether this is an ethically acceptable approach. These technologies are also closely linked to the quality of the DPR, which is also a phenomenon which can be assessed ethically.

It is likely to be helpful to analyse the educational interventions and the specific models of DPR that usually accompany the implementation of self-management technologies. This may also help us understand the pathways and the mechanisms through which self-management technologies may act on patients’ agency and health. In the next sections, I analyse the pathways through which the Chronic Diseases Self-Management Program and the collaborative model of the DPR that were developed for self-management of chronic illnesses attempt to influence the DPR and patients’ health agency. I pay some attention to the ethical concepts that are at stake here, but the ethical analysis is developed more fully later in the thesis.

2.3 Self-Management Technologies and the Doctor-Patient Relationship

I have already noted in the introduction that the self-management component of the chronic care model has two parts: the Stanford University Chronic Diseases Self-Management Program and the collaborative model of DPR.\textsuperscript{1,10,34} In this section I analyse the pathways through which these two interventions aim to influence interaction in the DPR.

The Stanford University Chronic Diseases Self-Management Program (CDSMP) is an educational program that aims to develop patients’ self-management abilities.\textsuperscript{14} The main expectation in the CDSMP is that patients will assume an increased responsibility for their own health.\textsuperscript{15} This intervention aims at developing patients’ cognitive and affective abilities so that they can act as their own primary caregivers,\textsuperscript{14,84,85} and at increasing their internal motivation to follow healthy behaviours.\textsuperscript{14} The argument behind these approaches is that chronic diseases are likely to be life-long and, therefore, patients need to engage continuously in different health care practices.\textsuperscript{84} CDSMP attempts to develop patients’ self-efficacy – one’s confidence that one can acquire the knowledge, skills and attitudes to achieve therapeutic goals.\textsuperscript{85} During these educational programs patients learn problem solving skills and use action plans to address their own medical, social and emotional problems.\textsuperscript{14,15,22} These educational programs aim to develop patients’ health literacy and
self-management abilities, and to improve doctor-patient communication to promote patients’ healthy behaviours and health outcomes.\textsuperscript{49}

In addition, the collaborative model of DPR (CM-DPR) changes the role of primary care doctors from gate-keepers to coordinators of care to support patients’ self-efficacy.\textsuperscript{86} It has been argued that these new roles on the patients’ part require a different kind of partnership between patients and doctors.\textsuperscript{84} CM-DPR seeks to promote mutual trust in DPRs. When primary care doctors act as gatekeepers, this is often perceived in a negative way and associated with judging, meeting or denying patients’ requests.\textsuperscript{86} In contrast, when primary care doctors act as coordinators, they can help patients navigate their way through complicated and potentially dangerous specialist care.\textsuperscript{87} This change in doctor-patient interaction can promote mutual trust,\textsuperscript{86,88} which has been shown to be associated with better health outcomes.\textsuperscript{49,50}

It is possible that mutual trust between doctors and patients lies at the core of the interactions through which self-management technologies aim to improve patients’ health outcomes. First, these interactions may imply doctors’ trust in their patients. Self-management technologies involve doctors empowering their patients by transferring to them expertise and responsibility. Such expertise is not only a matter of knowledge and skills, but also includes the ability to use knowledge and skills to manage uncertain situations.\textsuperscript{89} There is a discretionary element in managing such uncertainty, and this requires that doctors trust their patients sufficiently to be confident in transferring this discretionary responsibility to patients. Failing to trust patients may decrease patients’ self-efficacy and responsibility for their own health.

Second, these interactions may entail patients’ trust in their doctors. The transfer of significant roles and responsibilities from doctors to their patients, as happens in self-management approaches, may require patients’ trust that this transfer is indeed in their best interests because these tasks were traditionally viewed as doctor’s job. Failing to trust doctors may decrease patients’ self-efficacy and responsibility for their own health by decreasing their adherence to self-management approaches. There is some evidence that higher patient trust in doctors is associated with reduced difficulty in accomplishing self-management tasks by patients.\textsuperscript{48}

However, despite the potential value of these two interventions of the self-management component of the chronic care model, they do not make explicit the relation between mutual trust in the DPR, professionals’ responsibility for health care, and patients’ personal responsibility for their own health. Presumably, these interventions promote patients’ capacity to assume responsibility for their own health by enhancing both
patients’ self-efficacy and mutual trust in doctor-patient relationships. Yet the foundations of self-efficacy and mutual trust between doctors and patients appear to be conceptually divergent. Self-management education programs emphasize the central responsibility of chronically-ill patients for the management of their diseases, whereas a focus on mutual trust may suggest reliance of patients on doctors’ health care decisions. In addition, there is no evidence that self-management technologies actually promote trusting doctor-patient relationships. In the third chapter of this thesis I will compare the CM-DPR with different bioethical models of the DPR and clinical methods of care to analyse in details the ethical issues associated with this relationship between mutual trust in the DPR and professional and personal responsibility for health.

In summary, I have suggested that self-management technologies may have an impact on the DPR. The self-management interventions associated with self-management technologies are supposed to promote a collaborative model of the DPR, which in turn foster mutual trust between doctors and patients. I have suggested that mutual trust may lie at the core of the interactions between doctors and patients through which self-management approaches aim to promote patients’ health. However, the model does not make explicit how mutual trust and professionals’ and patients’ responsibility for health care interrelate. In the next section, I analyse the mechanisms through which self-management technologies and their related practices could act on human agency in order to identify the ethical issues that self-management technologies may raise in relation to patients’ human agency.

2.4 Self-Management Technologies and Human Agency

In this section, I suggest that self-management technologies and their related interventions are intended to promote patients’ responsibility for their own health by enhancing their agency. I begin by describing the philosophical underpinnings of and the communication patterns that characterize the Stanford Chronic Disease Self-Management Program (CDSMP) and the collaborative model of DPR (CM-DPR). Then I suggest a number of ways in which these interventions may influence human agency and argue that the communication patterns that characterize these interventions may prevent them from reaching their expected outcomes. Finally, I suggest that these theoretical arguments require further empirical analysis.

Therapeutic approaches in chronic diseases can be seen on a continuum. At one end of this continuum there are full self-management approaches, for instance, an expectation
that diabetes patients will adjust their doses of insulin based on their own readings. At the other end of this continuum are doctor-centred approaches. In between there are “half-way” approaches, as in the case of HBPM where patients monitor their blood pressure, but they do not adjust their treatment plans. To understand whether this continuum could be seen as a full range of options from which patients can choose based on their preferences and particular needs, or a general shift from professionally led approaches to patients led ones, it may be useful to overview CDSMP and the CM-DPR that have been associated with these technologies.

Chronic Disease Self-Management Programs and the collaborative model of doctor-patient relationship are built on the social cognitive theory of Bandura. In social cognitive theory the meaning of personal responsibility for health is response ability or, in other words, the capacity of individuals to build on their strengths and respond to their personal needs and the challenges posed by the environment. This theory holds that people do not live completely autonomously, as their lives are complex and interdependent and their choices depend on the context of their lives. People both produce and are produced by their environments. Yet, our capacity for agency and the exercise of control over nature and our quality of life is the essence of humanness. A central part of human agency is the control of one’s own thought processes, motivation, and action.

At the core of his theory Bandura places the psychological concept of perceived self-efficacy - personal confidence in reaching one’s desired goals - which acts on motivational, cognitive, affective and decisional processes. Presumably, Bandura understands this psychological trait as shaping the scope and extent of people’s autonomous behaviour. Thus, if perceived self-efficacy is high, people expand the range of opportunities and choices that they will consider, and face adversity better through emotional self-regulation, resilience and enhanced perseverance. By contrast, people with low self-efficacy have low resilience and perseverance in case of adversity and are more prone to depression or anxiety.

Based on Bandura’s self-efficacy theory, Kate Lorig has developed the CDSMP. This intervention relies on four communication patterns: information-giving; feedback; negotiation and contracting; and verbal persuasion. CDSMP is a group educational intervention led by lay instructors. It aims at developing patients’ self-efficacy by promoting healthy behavioural changes, such as losing weight or increasing the level of physical activity, in chronically-ill patients through a four phases intervention. The first phase aims to prompt the adoption of the new behaviour. First, an information-giving
session aims at providing patients with relevant physiologic and psychological information about the activity to be mastered. Second, communication focused on negotiating a short-term action plan to acquire the skills required by the activity aims at tailoring the level of performance in accordance with patients’ capacity and desire to change in a particular stage. Third, a communication session focused on giving patients weekly feedback with respect to their achieved performance aims at modelling patients’ self-management behaviours. In the second phase – behavioural contracting – patients document their willingness to change their behaviour in writing. The third phase aims at maintaining the desired changes. It seeks to create a supportive environment in which more experienced chronically ill patients and the instructor use persuasive communication for less experienced patients to maintain the new behaviour. The fourth phase is characterized by information-giving communication aiming at teaching participants how to prevent behaviour relapse and to manage negative feelings such as anxiety and guilt associated with behavioural relapse.

The CM-DPR developed by Bodenheimer et al.\textsuperscript{14-16} that accompanies CDSMPs uses the same communication sessions. CM-DPR seeks to change the traditional model of patient compliance with doctors’ recommendations,\textsuperscript{14,16,57} where patients’ therapeutic motivation is shaped by external factors, such as pleasing doctors, to an internal motivation to follow healthy behaviours through improved health literacy and self-efficacy.\textsuperscript{14} This model of the DPR focuses on developing short term action plans with respect to management of chronic disease based on an assessment of patients’ needs.\textsuperscript{16} An action plan is an agreement between a patient and a doctor that the patient will make a specific behavioural change relevant to her medical condition.\textsuperscript{14,23} First, there is a communication session focused on information-giving aimed at improving patients’ health literacy by providing them with relevant medical instructions tailored to their particular health needs. Second, a communication session focused on giving feedback seeks to promote patients’ comprehension by asking patients to restate doctors’ medical instructions is used. Third, there is a communication session focused on negotiating specific health goals and on contracting with patients, sometimes by acknowledging in writing specific short term actions to improve the medical condition or to achieve a specific behavioural change.\textsuperscript{23} Patients have to define their own health goals and develop short-term action plans, periodically re-evaluated and changed accordingly to achieved outcomes.\textsuperscript{14,21} Finally, a communication session focused on persuading and encouraging patients seeks to maintain patients’ achievements or to prevent departures from their action plans.\textsuperscript{23,100}
Self-management interventions seek to promote human agency and thus patients’ capacity to respond to their health needs in a range of ways. The first way is by strengthening patients’ level of control over their health care decisions. In the bioethics literature individual control over health care decisions is understood in terms of voluntariness and intentionality. Voluntary decisions occur in the absence of coercion, while knowledge about the medical intervention makes it intentional. Self-management interventions appear to promote both voluntariness and intentionality of patients’ health care decisions. They attempt to change the interaction between doctors and patients from bargaining for power to collaborative relations. They seek to change the role of primary care doctors from gate-keepers to coordinators of care, to promote mutual trust and decreased power asymmetry in DPR.

Such interventions also attempt to promote partnerships between doctors and patients focused on developing common therapeutic goals. The use of self-management technologies appears to increase the transfer of valuable clinical information between doctors and patients to the benefit of both parties. Doctors are intended to contribute to patients’ agency by improving patients’ health literacy and internal motivation to follow healthy behaviours. In turn, better-educated patients with improved self-management skills may be able to enhance the clinical performance of their doctors by strengthening the doctor’s capacities to provide evidence-based care. Porter has argued that an approach such as this focused on promoting shared values changes the interaction between individuals from bargaining for power to collaborative relations where individuals add value for each other.

The second way through which self-management interventions aim to promote patients’ agency is by enhancing patients’ capacity to deliberate effectively with respect to their health decisions. In the bioethics literature, responsible deliberation is defined as actions taken where a person believes that he or she is in a situation calling for a decision, is aware of the alternatives and the consequences of the alternatives, evaluated both, and chooses an action based on that evaluation. In addition, patients’ choices should be the result of a self-reflective process rather than a reflection of factors outside individual control. Self-management interventions attempt to make patients’ choices more robust by improving patients’ health literacy, increasing the trust in health care professionals, decreasing power asymmetry in the DPR and by improving patients’ psychological abilities to cope with their medical conditions.

The third way through which self-management interventions attempt to influence patients’ autonomy is by promoting patients’ control over their life goals. Put another way,
self-management interventions aim to promote actions that are consistent with patients’ attitudes, values, dispositions, and life plans.\textsuperscript{7,104-108} Self-management interventions redefine patients’ medical interests in terms of their broader life goals and adjust medical care to fit with patients’ life goals. To illustrate this, Bodenheimer et al give the example of twin brothers, both with hypertension and diabetes.\textsuperscript{14} One of them has a happy life and comfortable income, and is concerned to preserve his long-term health as much as possible. He self-monitors his blood glucose and blood pressure to maintain them continuously within normal range and to prevent later complications. The second brother is divorced and has a disabled child with behavioural problems. His main concern is to care for his child. He is afraid of hypoglycaemic episodes that may prevent him from caring for his child and is less concerned with kidney failure that may occur later in his life. These two men need different self-management plans. The proponents of self-management interventions argue that we need to adjust therapeutic plans to patients’ life goals and commitments because, without this adjustment, people will not develop the internal motivation and self-efficacy necessary to pursue those health goals.

However, these communication patterns raise a number of ethical concerns in relation to their capacity to promote patients’ agency. First, the relationship between the communication patterns promoted by this model does not necessarily promote mutual trust in the doctor–patient relationship. Collaborative care aims to decrease power asymmetry between doctors and patients and develop patients’ health literacy and self-efficacy, thereby supporting patients’ internal motivation to follow healthy behaviours. However, the emphasis on negotiation and on making a contract with patients (sometimes in writing) is at odds with the notion of trust, and can suggest that doctors do not trust that patients will develop the necessary internal motivation. Second, persuasive communication patterns and contractual approaches suggest that the model attempts to produce behavioural changes by using the doctor–patient relationship to exert psychological pressure on patients. This may be perceived by patients as external coercion threatening their internal motivation to maintain their health. These communication patterns appear conceptually divergent from the goals of self-management technologies of promoting mutual trust in the doctor–patient relationship and of enhancing patient internal motivation.

Third, self-management interventions reconfigure the role of DPR from improving patients’ health outcomes to promoting their life goals. This leads to decreased asymmetry in terms of expertise and responsibility between doctors and patients. The expected outcomes of this model are empowered patients, with their own therapeutic goals, acting
as their own primary care givers and developing self-efficacy to reach their health goals. On this view, in the collaborative model there is a paradigm shift in the definition of therapeutic goals, treatments and health outcomes away from a focus on morbidity and mortality and toward patients’ enhanced ability to pursue their life plans and commitments. However, none of the communication patterns that characterize this model suggest that self-management interventions may promote patients’ life goals. In addition, the pathways through which promoting patients’ health choices can shape their internal motivation to follow healthy behaviours in the long run are not explained.

There is some evidence that both the CDSMP and the CM-DPR produce only short-term improvements of patients’ adherence to their therapeutic approaches and lifestyle changes followed by relapses. This evidence suggests that the communication patterns that characterize these interventions may not have the anticipated impact on patients’ agency. This is a significant issue because these communication patterns are the mechanisms through which self-management interventions attempt to influence patients’ health.

However, all of these ethical arguments are theoretical rather than supported by empirical evidence on self-management interventions’ capacity to promote these expected outcomes. There is no empirical evidence that the communication patterns that characterize self-management interventions actually do influence patients’ health agency and mutual trust in DPR. A further understanding of how these communication patterns may influence mutual trust in DPR is necessary because mutual trust in the DPR is presumably at the core of the productive interactions through which self-management technologies and the related self-management interventions may influence patients’ health.

2.5 Conclusion

Self-management technologies have received considerable attention, principally because they may be able to influence patients’ cognitive and emotional abilities and, through this, change health outcomes for chronically ill patients. I have suggested in this chapter that there is a need for a broader ethical analysis of the impact of self-management technologies on DPR and patients’ health agency. These include the patterns through which mutual trust influences patients’ responsibility for health care, the role of self-management interventions in promoting human agency, and the kinds of communication patterns likely to support this. I have also suggested that further empirical work in this
area is needed. In the next chapter, I will analyse the ethical issues associated with the implementation of CM-DPR by comparing it with models of the DPR found in the bioethics and clinical literature.
Chapter 3: Self-Management Technologies and Doctor-Patient Relationship

3.1 Introduction

This chapter is concerned with models of the doctor-patient relationship (DPR). It analyses the ethical issues associated with the collaborative model of the doctor-patient relationship (CM-DPR) by comparing this model with models of the DPR found in the bioethics and clinical literature. The first part of the chapter describes a number of different models of the DPR - the contractual\textsuperscript{24,111} and relational\textsuperscript{25,26,111} models of the DPR (drawn from the bioethics literature) and the patient-centred care (PCC)\textsuperscript{28} and relationship-centred care (RCC)\textsuperscript{30} models of primary care (from the clinical literature). I describe the goals of these models, the conceptions of patient autonomy and patients’ responsibility for their own health on which the models rely and the communication processes that the models advocate. To connect this analysis with my second chapter, I also show how these models aim to promote mutual trust in the DPR.

Second, I compare the CM-DPR with bioethics models of the DPR and with clinical models of primary care. Firstly, I compare the collaborative model of DPR with bioethics models of the DPR and show that the CM-DPR combines features, in terms of building mutual trust in the DPR, conceptions of patient autonomy and of patients’ personal responsibility for their health, from both the contractual and relational models of the DPR. I argue that these features appear conceptually inconsistent, which raises questions about the capacity of the CM-DPR to both promote a partnership between doctors and patients and mutual trust in the DPR. Secondly, I compare the CM-DPR with clinical models of primary care and show that there is a need for further research to understand the relationship between patient responsibility for their health, patient autonomy and mutual trust and the communication patterns in the DPR in the context of self-management approaches in chronic diseases.

3.2 Bioethics Models of Doctor-Patient Relationship

The bioethics literature on the doctor-patient relationship is characterized by a continuing debate over the moral superiority of different models of DPR ranging from
paternalist models\textsuperscript{112} – where doctors are in absolute control over health decision making, based on the argument that doctors’ are medical experts and know best patients’ health interests - to informative or consumerist models\textsuperscript{112} that emphasize patients’ absolute control over health care decisions. Between these two extremes are shared decision-making models, and the contractual and relational models of the DPR are two examples of models which promote shared decision-making between doctors and patients. (I limit this review only to shared decision-making models because the collaborative model of the DPR developed for self-management has this approach.) I describe the goals and communication patterns through which these models aim to reach their goals. I also analyse the communication patterns of these models and argue that these models are normative and prescriptive in nature and the communication patterns through which they aim to reach their goals have not been assessed empirically.

3.2.1 Contractual Models of the Doctor-Patient Relationship

The notion of contract used in the contractual model, although it draws on legal language, is not that of a legal contract.\textsuperscript{113-115} Rather, the model builds on a more symbolic form of contract as in the traditional religious or marriage "contract" to interpret the relationship between doctors and patients as an interaction between two equal moral agents, both parties having responsibilities and expecting benefits.\textsuperscript{27,115} It recognises that between doctors and patients there is not a full mutuality of interests and, therefore, set of rights and duties will protect the trust and confidence that are at the core of the contract. Fried\textsuperscript{116-118} has argued that, once a patient has been accepted by a doctor, that patient is entitled to four rights of personal care: lucidity (the right to have access to relevant information); autonomy; fidelity (the right to continuing service aimed toward the patient’s own interests); and humanity (the right to be treated with compassion and respect). In the same vein, Veatch\textsuperscript{115} has described the contractual approach as being the only framework that allows a true sharing of authority and responsibility. He describes a larger set of norms that should underpin a contract such as: (a) protecting good and avoiding harm; (b) protecting individual freedom; (c) preserving individual dignity; (d) truth-telling and promise-keeping; and (e) maintaining and restoring justice. Once trust and confidence are broken, the contract is broken.\textsuperscript{24,115}

In this model of the DPR the primary goal is to promote patient autonomy. It starts from the presumption that doctors are responsible for technical decisions, for which they are specifically trained, and patients are responsible for significant decisions that involve
moral values and life-style preferences that they are expected to know better than their doctors. This model assumes a significant amount of information exchanged between doctors and patients to establish the ethical values underlying health care interventions as well as a negotiation process over these values to set a contract that will regulate their relationship. In case of intractable conflicts between doctor’s and patient’s values there will be no contract and the patient will be referred to another doctor. Once this framework is established and the underlying ethical values agreed on the decisions will be made by doctors based on patients’ values. Thus, Veatch has argued that a contractual model promotes both autonomy and patients’ health.

At the level of the clinical encounter two versions of the contractual model, namely the interpretative and the deliberative model of DPR have been described. Although both versions have the same aims, these two models promote different conceptions of patient autonomy and, therefore, different communication patterns.

3.2.1.1 The interpretative model

The interpretative model aims to elucidate patient values and what the patient actually wants to know to help her select an appropriate medical intervention. The aim of elucidating the patients’ values is to support them in their autonomous choices. The interpretative model understands patient autonomy as control over their lives. That is, an action is autonomous when that action is consistent with a person’s attitudes, values, dispositions, and life plans even though these values are not fixed and may sometimes conflict when applied to specific circumstances. Consequently, the doctor must explore patients’ values and help the patient to understand her values and aspirations. The doctor will provide the patient with relevant information about the nature of her medical illness and about the risks and benefits of the available therapeutic options. In addition, the doctor will help the patient to understand which medical interventions will align best with the patients’ own values. The final decision will be made by the patient who will decide which courses of action best fit her values and aspirations.

The interpretative model has been criticized mainly for its subjective interpretation of patients’ best interests. First, it rejects any possibility on a doctor’s part to assess in an objective way the best interests of their patients and the best course of action for a medical condition. Arguments have been made that doctors have to contribute to health care decisions because their expertise lies in understanding the biological effects of medical interventions and they need to use this expertise to guide the process of decision-
making.\textsuperscript{112} In addition, Savulescu\textsuperscript{122} has argued that patients’ best interests can be achieved only through rational discussions between doctors and patients based on relevant information. He has suggested that patients’ decisions are shaped not only by their values but, to some extent, by their emotions associated with their illnesses. This emotional bias, which is irrational, may preclude them from making the best decisions for themselves. Therefore, doctors owe a duty to support patients through rational deliberations that can promote patients’ rational beliefs and, therefore, their best interests. In the same vein, other authors\textsuperscript{25} have argued that doctors develop understanding of the patient’s life goals from their long-term relationships with patients and can assist them in determining their best interests.

### 3.2.1.2 The Deliberative Model of Doctor-Patient Relationship

Emanuel and Emanuel\textsuperscript{112} have argued for a deliberative model of the DPR, which in their view can tackle the pitfalls of the interpretative model. The goal of the DPR is to help the patient determine and choose the health-related values that can be realized in a clinical situation. The Emanuels\textsuperscript{112} have argued that the conception of patient autonomy on which this model relies is moral reflection. It means that the patient is empowered to reflect on the moral values related to different therapeutic alternatives.\textsuperscript{7,105,123} Doctors act in the clinical encounter as teachers or friends. This approach implies that doctors will: provide patients with all relevant information regarding the available therapeutic options; help patients elucidate the values embodied in health interventions at hand; and suggest why certain health-related values are more worthy and should be aspired to. In the deliberative model doctors do not aim to do anything more than try to persuade their patients with respect to the health care intervention they should receive. Ultimately, patients decide what a valuable health care choice is for them and will select what they want.

This model is also a prescriptive model of the DPR, stems from the same contractual model of the DPR and is based on the same societal shared values as the contractual model.\textsuperscript{124} First, it embodies the ideal of personal autonomy specific for pluralist and liberal societies. It allows a person to select a preferred course of action unrestricted by coercion, ignorance and physical interference. Second, it promotes an image of a caring doctor which is in line with the ideal DPR in society. It allows doctors to provide recommendations and to persuade patients to accept them. Third, Emanuel and Emanuel argue that this model does not promote disguised paternalism. Rather, a deliberative process allows doctors to learn from suffering and to educate their patients. Finally, this
model allows patients and doctors to know each others’ values, which is important for patients in the process of selecting their doctors.

The Emanuels themselves have criticised this model. First, it is not clear whether it is proper for doctors to judge the values of their patients. The model implies that doctors can judge health related values better than their patients. In addition, the model can be a vehicle for promoting the values of particular doctors. An emphasis on doctor as counsellor, advisor or friend gives doctors more power in the relationship. That power can be easily abused. However, Brody has argued that, instead of depriving people of relationships that people may find helpful and supportive, a better approach would be to watch carefully for the various ways and circumstances in which doctors may abuse power at a system level to prevent those abuses.

The contractual model as a whole has been criticized as being based on incorrect assumptions. Several authors have argued that doctors and patients do not begin their relationship by explicitly negotiating a contract of any sort. Rather, their expectations are mutual and implicit. In addition, arguments have been made that this model focuses on only one moral value - namely patients’ autonomy - ignoring other important moral values such as duties and responsibilities.

3.2.2 Relational Models of Doctor-Patient Relationship

The most prominent version of a relational model of the DPR stems from Brody’s narrative ethics. The DPR is viewed as a narrative, unfolding during episodes of ill-health that occur over time. This model is seen as specific to general practice. Although it takes the DPR to be instrumental for patients’ autonomy, the relationship has an intrinsic value. That is, the relationship per se adds something to expected outcomes as opposed to relative contributions of doctors and patients to their relationship.

This model shares similarities and differences compared with contractual models of the DPR. Similar to contractual models of the DPR, this model starts from the presumption that a duty to contribute to shared decision-making, on the part of both doctors and patients, is a prerequisite for the functionality of this model. On the other hand, the model departs from contractual models in the sense that it does not emphasize that potential tensions between doctors’ and patients’ interests can be regulated through external rules. Rather, it describes a partnership between doctors and patients focused on...
common therapeutic goals of doctors and their patients achieved through an open dialogue over time.27

This dialogue is characterized by doctors engaging in informing patients about therapeutic options, including their benefits and risks, and an exploration of both patients’ and doctors’ values and experiences. Brody has suggested that a useful way to integrate the scientific practice of medicine with the art of medicine is for doctors and patients to see themselves as co-authors of the illness experience.127,128 This approach suggests that this model promotes a relational type of autonomy; put another way, a free, self-governing agent is also socially constituted and defines her basic value commitments in terms of interpersonal relations and mutual dependencies.129 “Thinking through patients’ stories of illness” facilitates common meaning for doctors and patients.26 Common meaning is built through an open dialogue between doctors and patients that leads to shared decisions and common therapeutic goals. Finally, similar to the Emanuels’ deliberative model,112 doctors offers recommendations based on both sets of values and experiences. Quill and Brody27 have argued that an open dialogue where doctors assume and frankly reveal their biases will result in enhanced autonomy.27

This model does not deny the power imbalance in the DPR and recognizes that occasionally it may lapse into unintended paternalism.27 However, by accepting doctors’ power to offer recommendations it enhances patients’ competence and power. The active exchange of ideas and the negotiation of differences between doctors and patients that characterize the relational model of DPR can lead to power sharing between doctors and patients. Doctors’ recommendations can enhance the collaboration between patients and doctors, and facilitate patients to make autonomous choices that are informed by both medical facts and the doctors’ experience.27 For instance, if a doctor believes that a patient makes an irrational health care decision, which is discrepant with that patient’s life narrative, there is no reason to maintain neutrality. Rather, through an open dialogue doctors and patients may come to innovative solutions that can solve the problem. By using their powers to assist patients and not to control them, doctors promote mutual trust in the DPR.27

In summary, all these bioethics models of the DPR are theoretical attempts to promote patients’ autonomy. The contractual models of the doctor-patient relationship describe a DPR based on rules external to individual relationships. These rules, which are derived from higher societal norms, aim to create the premises for trust in the relationship by protecting patients’ autonomy. By contrast, the relational model of the DPR focuses on the role of individual relationships in promoting patients’ autonomy. Most of these models
also describe processes through which their goals might be reached. I also described the conceptions of patient autonomy, patient responsibility, mutual trust and the communication patterns through which their goals can be reached.

One of the weaknesses of all of these models is that their characteristics are derived from philosophical reflection, rather than from empirical studies of doctors’ and patients’ behaviours. The models tell us little about their effectiveness in promoting patients’ health or patients’ autonomy. In the next section, I analyse clinical models of primary care with the aim of identifying those processes in the DPR, which are effective in promoting mutual trust in the DPR, patients’ autonomy and/or patients’ health.

3.3 Clinical Models of Primary Care

Since their inception more than fifty years ago through the early work of Balint clinical methods of care have gained a high profile in general practice and are considered a central feature of quality practice. In this section, I analyse, through an ethical lens, the concepts and ideas that are commonly described and empirically studied in the literature on clinical models of primary care. I argue that clinical models of primary care, similarly to bioethical models of the DPR, are prescriptive and normative in nature. First, I describe and analyse from an ethical point of view the patient-centred care (PCC) model of care. I show that some of the ethical interpretations of the different dimensions of this model are not made clear by its proponents. Second, I describe the relationship-centred care (RCC) model of care and empirical research on this model. I focus on the communication patterns that characterize the RCC and outline empirical research on their effectiveness to promote patients’ health and patients’ autonomy. I show that there is some evidence that the communication patterns which characterize the relationship-centred model of care can promote both patient health and patient autonomy.

3.3.1 Patient-Centred Care

Patient-centred care (PCC) has its roots in the early work of Balint. This model of primary care was originally developed by Balint to express his belief that every patient has to be understood as a unique human being. In Balint’s view, respect for persons at the level of the clinical encounter is generally good for patients’ health. He argued that patients’ tendency to seek medical care cannot be explained entirely in an objective way,
because it heavily depends on individuals’ psychological and social circumstances. He claimed that illnesses are as much psychological phenomena as biological ones and he encouraged general practitioners to explore patients’ health problems not only from a biological point of view, but also to focus on patients’ unique psychological and social circumstances to understand the “real reasons” for medical encounters. Based on this understanding he developed the concept of ‘doctor as a drug’, arguing that the most powerful therapeutic tool in a doctors’ hand was the doctor herself. This ‘drug’ acts via the doctor-patient relationship. Thus, there is a need for a “mutual investment” in this relationship which, over time and through multiple consultations, may result in mutual trust that influences patients’ health in a positive way.

The literature that developed out of this early model has depicted PCC in various ways. Acknowledging this wide variation in the definition of PCC, in a review of the empirical literature, Mead and Bower have proposed five key dimensions for this model, which they identified by analysing the main themes encountered in the literature concerning this subject. The main dimensions of this model are: (a) biopsychosocial - the doctors’ ability to have a perspective on illnesses that includes consideration of social, psychological and biological factors associated with diseases; (b) “the patient as a person”, which concerns doctors’ capacity to understand the meanings of the illness in individual patients; (c) sharing power and responsibility, seen as doctors’ sensitivity to patients’ preferences for information and sharing decision making; (d) the therapeutic alliance, regarded as developing common therapeutic goals and enhancing the bond between the physician and patient; and (e) “doctor as a person” or the awareness of individual characteristics and qualities of a doctor for the practice of medicine.

Although the language of patient-centred care belongs to the fields of psychology and sociology, this model also has moral underpinnings. Its first two dimensions, the “biopsychosocial” and “patient as a person”, aim to promote patient autonomy understood as patients’ control over the entire range of experiences in their lives. I treat these dimensions together because they strongly interrelate in the sense that there is a need for biopsychosocial knowledge and skills on the part of doctors so that they can explore patients’ personhood and psychological and social dimensions of patients’ illnesses. These components require a doctor to elicit and interpret patients’ stories of illness to understand the meaning of illness for each patient, under the presumption that in this way a doctor will be able to design a course of therapeutic action concordant with the patient’s unique preferences, experiences, goals, and needs. Inherently, this approach suggests respect for persons because it treats each person as a unique human being.
The third component “sharing power and responsibility” requires doctors to encourage patients to become active participants in health care decisions. It aims to promote patient control over health care decisions. It departs from Parson’s biomedical model, which describes an ideal model of the DPR, where doctors provide the best medical care they can give and patients do everything in their control to get well. Patients give up some of their usual responsibilities such as going to work and follow doctors’ therapeutic recommendations. This model assumes that asymmetry in the DPR would be in the benefit of both doctors and patients. By contrast, the meaning of patient responsibility in PCC is patient ability to respond to their own health needs. Most papers referring to this component suggest that the negotiation between doctors and patients to set common therapeutic goals is the main communication pattern. The aim of this communication pattern is to accommodate the preferences of both parties, aiming at a unanimous decision of which both parties are rationally convinced. This component has been promoted because there is evidence that patients’ lack of adherence to therapeutic recommendations is associated with doctors’ failure to regard patients as experts in their own illnesses, their failure to explain their approach and an inability to reach consensus care.

However, the literature concerning patient-centred care is not clear about the meaning of the “sharing power and responsibility” component. Some authors have criticized PCC because it forces patients to become active participants in their own care, even if they would prefer not to be involved in health care decisions. If this happens, the approach might be in dissonance with the “patient as person” component which requires treating each patient as a unique human being. Thus, it is not clear whether sharing power and responsibility means a transfer of responsibility from doctors to patients to create a more equal relationship or gathering doctors’ and patients’ powers to achieve common therapeutic goals as the “therapeutic alliance” component may suggest.

The fourth component “therapeutic alliance” gives consequentialist value to the DPR. Patient-centred care suggests that the DPR has a moral value because the relationship can improve patients’ health outcomes. For instance, empirical evidence has shown that a friendly and empathetic relationship is associated with patients’ increased adherence to therapeutic recommendations. In addition, there is some evidence that the doctor-patient relationship has a direct influence on patients’ health via the so-called placebo effect. Thus this model of care differs compared with contractual models by emphasizing that the bond between doctors and patients depends on communication in the DPR, rather than on external rules. However, the architects of PCC do not make clear how this affective bond
between doctors and patients is created and how it may be influenced by doctors’ and patients’ responsibilities.

The fifth component “doctor as a person” is probably the least developed component of this model. It suggests the need for moral capacity for self-awareness and self-criticism by the doctor. As opposed to biomedical models where doctors bring only objective knowledge, in PCC doctors also bring their own personal perceptions from their experiences. Therefore subjectivity is pervasive in clinical practice as doctors and patients continuously influence each other. These subjective factors may have either positive influences via empathy or negative influences via certain biases against some patients. When these influences are harmful they need to be corrected and the doctor needs a moral capacity for self-awareness to develop positive affective relationships with patients.

Unlike bioethics models of the DPR, there is a whole body of empirical research on the effect of patient-centred care model on health care outcomes. For instance, there is evidence that different dimensions of patient-centeredness can improve patients’ health outcomes. In addition, there is evidence that good communication techniques result in patients’ increased adherence to therapy, trust in health care providers, healthy behavioural changes, greater patient satisfaction with the outcomes of health care, improved health, and improved functional and psychological outcomes. However, this research has been criticized mainly because it has analysed the impact of different components of PCC in isolation. Evaluating the different dimensions of PCC in isolation may not be appropriate as each dimension contributes to others and a change in one dimension may alter the characteristics of other dimensions, potentially leading to invalid outcomes of research. This argument is supported by Mead and Bower who have noted that there is lack of information with respect to the interdependence of different dimensions of patient-centeredness.

3.3.2 Relationship-Centred Care

A relationship-centred care (RCC) model of primary care has been developed by the Pew-Fetzer Task Force on Advancing Psychosocial Health Education to overcome at least in part the critiques of the PCC model of the DPR. This method of care is also theory driven and prescriptive in nature, being based on four principles: (a) relationships in health care ought to include dimensions of personhood as well as roles of all actors at the level of
health care; (b) affect and emotions are important components of relationships in health care; (c) all relationships occur in the context of reciprocal influence. Thus, the smallest unit of measurement in this method is an interactional exchange, and (d) relationship-centred care has a moral foundation.

These principles shed some light on the philosophical and ethical bases of this method. The ethics of RCC stems from its philosophical stance. RCC is built on a symbolic interactionist theoretical perspective that starts from the presumption that relationships - abstractions that symbolize the interaction between individuals - provide the context for many important functions and activities in health care. That is, in health care, information is exchanged, resources allocated, diagnoses made, treatment chosen and outcomes evaluated within various relationships. The first principle of RCC makes clear that, in the clinical encounter, both the clinician and the patient are individuals who enter into a relationship with their individual set of experiences, values and perspectives. That subjectivity is pervasive in general practice. These interactions, although subjective in nature, have a symbolic value for doctors and patients, and lack of respect for and understanding of personal interpretations in doctor-patient interactions influence the doctor-patient relationship, personhood and, ultimately, patients’ health via emotional stress. Thus in RCC the borders between subjective and objective stances blur, and respect for persons becomes an objective need for therapeutic relationships.

Whereas the meaning of “sharing power and responsibilities” in PCC is not very clear, in RCC the relationship between doctors and patients is instrumental for both patients’ and clinicians’ autonomy. This is made explicit in the third principle of relationship centred care, which states that health and related practices do not occur in isolation, but are related to one another in time, space, and content. As such, doctors benefit by the opportunity to know their patients, and RCC encourages clinicians to be influenced as a result. While achievement of the patient’s goals and the maintenance of health are obviously the focus of any doctor-patient encounter, allowing a patient to have an impact on the clinician is a way to honour that patient and her experience. In this model doctors do not turn control over to patients. During the decision-making process doctors show respect to patients, find out about patient’s values, expectations, preferences, and background, tailor their therapeutic approaches to the patient based on knowledge of patient, help patients get their story across, listen nonjudgmentally, provide emotional support to their patients, manifest empathy and compassion, and support them to make autonomous decisions. The proponents of RCC argue that these behaviours on
doctors’ part contribute to the development of trust by patients and their doctors and permit accommodation of different degrees of patients’ autonomy.

The last principle of this model of the DPR explicitly emphasizes the moral value of DPR. The moral foundation of RCC stems from its proponents’ belief, consistent with a relational ethics approach,\textsuperscript{153} that the formation of genuine personal relationships has an intrinsic moral value, because such relationships tend to make those involved more committed to each other, and to supporting each other’s autonomy.\textsuperscript{30,148,149} In RCC, respect for patients’ autonomy implies autonomy-support. To illustrate the concept of “autonomy support” the proponents of RCC give the example of counselling about smoking cessation to contrast an autonomy-supportive doctor with a controlling one.\textsuperscript{154} A controlling doctor pressures a patient to stop smoking. By contrast, an autonomy-supportive doctor would elicit the patient’s feelings and opinions about smoking and would encourage the patient to decide whether to stop or continue to smoke. Of course, the autonomy-supportive doctor would inform the patient that stopping smoking is good for her long-term health, but he would respect the patient’s decision. In the view of the architects of RCC, this approach is important to motivate patients to maintain their own health.\textsuperscript{154} Autonomous patients feel willing and able to engage in health-relevant behaviour because they have fully accepted its importance. In contrast, controlled patients behave in a specific way because they feel pressured by some interpersonal (e.g. doctor, family or others) or intrapsychic force.

Relationship-centred care has also pursued empirical validation. This research has been focused on: (a) identifying what kind of communication styles favour a RCC,\textsuperscript{144} and (b) their relation with patients’ outcomes. Thus, the process in RCC has been developed by analysing the empirical studies,\textsuperscript{155} rather than by the philosophical and ethical assumptions of its proponents. In a literature review, Roter\textsuperscript{156} has identified five categories of communication that characterize RCC. The first category is information-giving, which means informative exchange that includes biomedical and psychosocial (broader social, psychological) dimensions. The way in which language is used plays an important role, suggesting or proposing being considered relationship-centred as compared to giving specific instructions. The second category is information-seeking and refers to asking questions across biological, psychological, emotional and social categories. The third category is partnership building where doctors facilitate patient participation in the medical care. Less dominant and controlling language is considered relationship-centred promoting an equalization of participants’ statuses. The fourth category is rapport building that explicitly conveys emotional content verbally and nonverbally. This category differs
from the first two, because it explicitly emphasises expression of feelings and emotions such as statements about worries and concerns. The fifth category relates to socio-emotional behaviours. RCC is characterized by positive atmosphere; positive nonverbal behaviour such as nods, smiles, or eye contact; and social conversation that convey friendliness and personal regard.

The effectiveness of these processes in RCC on the promotion of patients’ trust in their doctors and on patients’ health has been evaluated. This research suggests that medical encounters characterized by communication focused on building rapport with patients, open discussion, gathering information, understanding the patient’s perspective, sharing information and reaching agreement on problems and plans are associated with developing trust in their doctors and greater adherence to treatments. In addition, complex and compassionate DPRs can be good for patients’ health. There is evidence that, when doctors promote an information exchange that has these characteristics, psychological distress is reduced, symptoms mitigated and biological outcomes improved. Furthermore, participatory clinical encounters contribute to the development of active partnerships that, subsequently, produce better health outcomes. For instance, there is a positive association between asking patients questions with respect to their understanding of a problem, their concerns, and their symptoms’ resolution, reduction in anxiety, and physical limitations in chronic diseases. Similarly, consultations that are responsive to patients’ emotional status such as doctors expressing empathy and support are associated with symptoms’ resolution and decreased psychological distress associated with their illnesses. Consultations which are facilitative in terms of helping patients telling their story and eliciting their full spectrum of emotions and concerns, and which are autonomy-supportive, improve patients’ general health and health status.

In summary, in this section I have suggested that clinical models in primary care, in a similar way as bioethics models of the DPR, are normative and prescriptive in nature. In patient-centred care the ethical meaning of the “sharing power and responsibility” dimension of this method is not made clear. Relationship-centred care has the same goals as patient centred care, but it is clearer about the meaning of sharing power and responsibility. In RCC doctors and patients join their powers to reach their therapeutic goals. Thus, this model may permit the accommodation of different degrees of patients’ autonomy. I also described the conceptions of patient autonomy on which these two methods rely and the communication patterns through which they aim to promote patient autonomy and mutual trust in the DPR. Finally, I suggested that there is some evidence that the communication patterns in relationship-centred care are effective in promoting
patients’ health. In the next section, I compare the collaborative model of the DPR in the context of self-management technologies with the bioethics and primary care clinical methods to identify potential ethical concerns with the collaborative model of doctor-patient relationship.

3.4 Ethical Issues with the Collaborative Model of the Doctor-Patient Relationship

In this section I show that the collaborative model of DPR combines features, in terms of building mutual trust in the DPR, conceptions of patient autonomy and of patients’ personal responsibility for their health from both the contractual and relational models of the DPR. I argue that this may be conceptually inconsistent. Second, I compare the CM-DPR with the patient-centred care and relationship-centred care models of care and show that there is a need for further research with respect to the relationship between patient responsibility for their health, patient autonomy and mutual trust in the DPR in the context of self-management of chronic diseases.

In the bioethics literature the relationship between mutual trust in the DPR and patient autonomy is acknowledged. The significance of patients’ trust in their doctors is well recognized and it is associated with patients’ willingness to seek care, to disclose symptoms and to be compliant with therapeutic recommendations. Patient trust is taken to mean that patients perceive that their doctors are professionally competent and bear good will towards them. Although doctors’ trust in their patients is less discussed in the bioethics literature, in the second chapter I argued that self-management may require doctors to trust their patients in order to transfer to them significant responsibilities associated with self-management technologies. Doctors’ trust in their patients depends on three domains: (a) doctors need to trust that patients are genuinely seeking medical care; (b) patients’ honesty; and (c) patients’ competence to understand information and to cooperate with management. A willingness to trust patients is a significant ethical step in recognizing the patient as a person with agency rather than merely a passive recipient of care. This recognition of patients’ agency is part of part of respect for patient autonomy as well as for patients’ capacity to assume responsibility for their health. In what follows I analyse the relationship between patient responsibility for their health, patient autonomy and mutual trust by comparing the CM-DPR with the bioethics models of DPR and with clinical methods in primary care.
3.4.1 Comparison between CM-DPR and the Bioethics Models of DPR

First, the collaborative model of the DPR (CM-DPR) shares similarities as well as significant differences with contractual models of the DPR. Both models start from the presumption that doctors and patients are equal moral agents, who have to enter into their relationship with a set of responsibilities and expected benefits. In addition, both models aim to promote patient responsibility and mutual trust by enhancing patients’ autonomy. In chapter two I argued that mutual trust may be important for the capacity of the CM-DPR to promote patients’ responsibility for their own health, which is the core value of self-management approaches. In addition, both models aim to provide patients with relevant information about the benefits and risks of the available therapeutic alternatives.

There are also differences between the models. The collaborative model of the DPR and the contractual models of the DPR are based on different conceptions of patient autonomy. The CM-DPR aims to promote behavioural change in patients by integrating therapeutic recommendations with patients’ aspirations and life goals, whereas the interpretative version of the contractual model aims to promote patients’ values, aspirations and life goals. Although both approaches may suggest to patients that their doctors are well intentioned and respect them as persons, these different goals also imply differing communication approaches, which, in turn, may have differing influences on mutual trust in the DPR. The communications pattern through which the CM-DPR aims to integrate therapeutic approaches with patients’ life circumstances is focused on negotiating specific health goals and on contracting with patients in taking specific-short term actions to improve their medical condition or to achieve a specific behavioural change, whereas in the interpretative model communication in the DPR is focused on interpreting patients’ values and life goals. There is no empirical evidence with respect to how these communication patterns influence patients’ control over their lives and/or mutual trust in the DPR.

Another point of difference is that the collaborative model of the DPR aims to promote patients’ capacity to deliberate effectively, whereas the deliberative version of the contractual model aims to promote patients’ moral reflection. Autonomy as moral reflection requires that people question the values on which they base their choices in a deliberation, and this differs from effective deliberation in the sense that people can deliberate effectively without questioning their underlying values. These different conceptions of patient autonomy also imply differing communication patterns. In the deliberative model persuasive communication aims to promote patients’ reflection by
empowering the patient to reflect on the moral values behind different therapeutic alternatives, whereas in the CM-DPR it aims to develop patients’ capacity to deliberate effectively by promoting their self-efficacy. This is a significant issue since the CM-DPR focuses on developing the cognitive and affective abilities patients need to reach a therapeutic goal rather than on patients’ moral self-development. It is not clear how persuasive communication may influence mutual trust in the DPR, especially in those cases where doctors and patients do not share the same values or opinions. There is some evidence that persuasive communication, especially when it is not associated with a detailed description of all the available therapeutic options, is associated with distrust in DPR being perceived as manipulation.\textsuperscript{167} However, this is clearly an area in which more research is necessary.

Second, the CM-DPR shares similarities with Brody’s\textsuperscript{25,26} relational model of the DPR. Both models describe the DPR as a partnership between doctors and patients. In addition, both models aim to promote patients’ responsibility for their own health by enhancing patient autonomy. However, the relational model of the DPR promotes a relational type of autonomy, whereas the CM-DPR promotes autonomy understood as control over health care decisions, effective deliberation and control over one’s own life goals. Although the basic value of autonomy, namely control over one’s actions, is preserved in both models, the CM-DPR places the locus of control at an individual level, whereas Brody’s relational model places it at an interpersonal level.

By combining contractual and relational features, the CM-DPR may be conceptually inconsistent because these different approaches suggest differing communication patterns. In the CM-DPR, doctor-patient communication is focused on changing patients’ behaviour (negotiation of an agreed action plan and persuading patients to follow that plan), whereas in the relational model the communication is focused on the DPR (open dialogue focused on developing common therapeutic goals). These different communication patterns may also have different capacities to promote partnerships between doctors and patients. This is a significant issue for the CM-DPR because self-management approaches imply that doctors and patients work together and have to rely on each other. In addition, bioethics models do not provide empirical evidence with respect to which conceptions of patient autonomy promote better a partnership between doctors and patients. In the next subsection, I compare the CM-DPR with clinical methods of primary care to identify which communication patterns and conceptions of patient autonomy are effective in promoting mutual trust in the DPR.
3.4.2 Comparison between CM-DPR and Clinical Models in Primary Care

The collaborative model of DPR (CM-DPR) shares similarities and significant differences with the patient-centred care model of DPR (PCC). Both the CM-DPR and PCC aim to promote patients control over their health care decisions and over their own lives. In addition, the CM-DPR is not clear with respect to the relationship between the sharing of power and responsibility between doctors and patients and mutual trust in the DPR. The CM-DPR does not make explicit whether the bond between doctors and patients stems from a negotiated contract between doctors and patients or from their mutual trust. In ways that are similar to PCC, the CM-DPR does not make clear how communication patterns focused on contracting a negotiated action plan by patients influence the affective bond between doctors and patients. This is a significant issue because mutual trust can alter the power imbalance in the DPR by creating opportunities for patients to exercise autonomy and to assume responsibility for their care.\textsuperscript{158}

The CM-DPR differs from PCC in that PCC aims to promote patients’ control over health care decisions and over their lives by promoting biopsychosocial communication and through negotiation between doctors and patients to set common therapeutic goals, whereas the CM-DPR aims to do this through an information exchange with respect to the benefits and risks of different therapeutic approaches and by negotiating with patients a short-term action plan. Neither model makes clear how communication influences patients’ perceptions that their doctors are professionally competent and well-intentioned and doctors’ perceptions that their patients are honest and competent to cooperate with the management of their diseases. This issue may be relevant for the capacity of both models to promote mutual trust, as well as for patients’ capacity to negotiate their health care. There is evidence that patients with lower levels of health literacy engage less in negotiating their health care with their doctors and trust their doctors less.\textsuperscript{168,169}

The CM-DPR shares similarities with relationship-centred model of care (RCC). Both the RCC model of care and the CM-DPR are described as partnerships between doctors and patients.\textsuperscript{14} In addition, both share the same symbolic interactionist stance. They aim to improve patients’ health outcomes through productive interactions between doctors and patients.\textsuperscript{83}

By contrast, as is the case for Brody’s relational model, RCC promotes a relational type of autonomy, whereas the CM-DPR promotes an individualist understanding of patient autonomy. This also suggests different communication patterns. In the CM-DPR doctor-patient communication is focused on negotiating an agreed short-term action plan
and on persuading patients to follow that health care choice, whereas in RCC doctors and patients develop an open and emotionally-rich dialogue that promotes support for patients’ decisions. Previously I have shown that there is some evidence that the communication patterns in RCC promote patients’ trust in their doctors and to some extent patients’ health.\textsuperscript{155} Mutual trust in the DPR can promote a partnership between doctors and patients. In addition, these differences in the doctor-patient communication may also have different influences on the capacity of these two types of relationships to promote patients’ self-efficacy.

However, it is not clear how this autonomy-supportive stance adopted by the relationship-centred care influences doctors’ trust in their patients, especially in those cases when patients do not want or are not prepared to assume increased responsibility for their health. Further research is necessary to understand those conceptions of patient autonomy, which are consistent with a partnership between doctors and patients in the context of self-management of chronic diseases. In addition, more research is needed to understand the relationship between patient responsibility for their health, different conceptions of patient autonomy, mutual trust in the DPR and patients’ perceptions of self-efficacy. This issue is especially significant in the context of self-management technologies where there is an expectation that patients will assume an increased responsibility for their own health and health care.

In this section, I have suggested that the CM-DPR shares similarities in terms of conceptions of patient autonomy and patient responsibility for their health with contractual and relational models of the DPR. This combination of features appears to be conceptually inconsistent. I have also argued that there is a need for further research to understand the relationship between patient responsibility for their health, patient autonomy and mutual trust and the communication patterns in the DPR in the context of self-management approaches in chronic diseases.

3.5 Conclusion

In this chapter, I have reviewed bioethics and clinical models of the DPR and compared them with the collaborative model of the DPR in the context of self-management in chronic diseases. First, I reviewed bioethics contractual and relational models of the DPR and clinical patient-centred care and relationship-centred care methods of care. I described their goals, the conceptions of patient autonomy and patient
responsibility on which these models rely and the communication processes they advocate. I also showed how these models aim to promote mutual trust in the DPR. Second, I showed that the CM-DPR combines features, in terms of building mutual trust in DPR, conceptions of patient autonomy and of patients’ personal responsibility for their health from both the contractual and relational models of the DPR. I suggested that these features may be conceptually inconsistent, which raises questions about the capacity of the CM-DPR to both promote mutual trust and patients’ self-efficacy. I also compared the CM-DPR with clinical methods in primary care and argued that there is a need for further research to understand the relationship between patient responsibility for their health, patient autonomy and mutual trust and the communication patterns in the DPR in the context of self-management of chronic diseases. In the next chapter, I review qualitative research on the impact of self-management technologies on the doctor-patient relationship, patient responsibility for their health and patient autonomy.
Chapter 4: Self-Management Technologies and Empirical Ethics

4.1 Introduction

This chapter draws on existing qualitative research literature on self-management technologies to describe and explain the pathways through which self-management technologies can shape mutual trust in the doctor-patient relationship, patient autonomy and patients’ sense of responsibility for their own health. I focus on qualitative studies because the ethical concerns associated with self-management technologies and their associated practices described in chapters two and three of this thesis stem, in part, from limited theoretical understanding of the pathways through which self-management technologies may influence the goals of and the processes in doctor-patient interaction. Explaining pathways and generating theory is a particular strength of qualitative research.¹⁷⁰⁻¹⁷²

I show that studies on self-management technologies do not clarify the ethical concerns raised in previous chapters. Although these studies give valuable information with respect to the impact of self-management technologies on patient autonomy, patient responsibility and doctor-patient communication in the context of self-management technologies, they do not describe how the interaction in the DPR may influence these outcomes. This is a significant issue because interaction in the DPR is the vehicle through which self-management technologies may influence these outcomes. This research does not explain the pathways through which mutual trust in the DPR, patient autonomy and patients’ responsibility for their health interrelate in the context of self-management technologies.

4.2 Review of Qualitative Research on Self-Management Technologies

In this section, I review the literature on qualitative research on self-management technologies. First, I describe the strategies that I have used to identify qualitative studies on the impact of self-management technologies on doctor-patient relationship. I also describe the inclusion and exclusion criteria for studies reviewed in this chapter and the outcomes of my search strategy. Second, I describe the methodological approaches and the
aims of these studies and argue that they have not adopted the conceptual basis of the collaborative model of doctor-patient relationship in the context of self-management technologies. That is, the smallest unit to be explored and analysed is the doctor-patient interaction in the context of self-management technologies. By contrast, most of these studies are exploratory in nature, aiming to identify patients’ experiences with different self-management technologies. Third, I review the findings of this research and argue that, although they suggest that mutual trust in the doctor-patient relationship is relevant for patient autonomy, patients’ responsibility for their health and patients’ motivation to maintain their health, they do not explain how patients’ responsibility, patient autonomy and mutual trust in the DPR interrelate in the context of self-management technologies.

4.2.1 Searching Strategies and Outcomes

Studies on qualitative research concerning the impact of self-management technologies on doctor-patient relationship were identified in PubMed by using the following searching strategies:

- English language Medline search from the last ten years (2001-2011) using the search terms (ethical OR ethics OR moral) AND (self-management OR monitoring) AND (technology OR device OR equipment) AND (qualitative study OR research);
- English language Medline search from the last ten years (2001-2011) using search terms (self-management OR monitoring) AND (technology OR device OR equipment) AND (doctor OR physician OR general practitioner OR family practitioner and patient OR client AND (relationship OR interaction OR interpersonal OR communication) and (qualitative study OR research);
- English language Medline search from the last ten years (2001-2011) using search terms (self-management OR monitoring) AND (technology OR device OR equipment) AND (doctor OR physician OR general practitioner OR family practitioner) AND (patient OR client) AND experiences AND (qualitative study OR research);
- English language Medline search from the last ten years (2001-2011) using search terms (self-management OR monitoring) AND (technology OR device OR equipment) AND (trust/mutual trust) AND (qualitative study OR research);
English language Medline search from the last ten years (2001-2011) using search terms (self-management OR monitoring) AND (technology OR device OR equipment) AND (professional OR doctor OR physician OR provider OR general practitioner OR family practitioner AND (patient OR client) AND (responsibility OR accountability) AND (qualitative study OR research);

- English language Medline search from the last ten years (2001-2011) using search terms (self-management OR monitoring) AND (technology OR device OR equipment) AND (patient OR client) AND (autonomy OR control) AND (qualitative study OR research).

- A review of the bibliographies of the articles that I deemed relevant after the assessment of all the articles identified by previous searching strategies.

The inclusion criteria of studies analysed in this review were: (a) studies on medical devices or technologies operated by chronically ill patients and (b) self-management technologies used by patients for self-monitoring of their health states. Two hundred and thirty six articles were identified through these search strategies. I examined their abstracts and thirty seven full text articles were selected for further analysis. Twenty-seven articles were repeatedly identified and they met the inclusion criteria. These studies form the basis of this literature review. The remaining articles were excluded from this review because either they were not reports on qualitative studies, or the studies did not focus on a self-management technology. All the articles selected as a basis for this literature review fulfilled the inclusion criteria.

All of these qualitative studies were exploratory and descriptive in nature. A multitude of self-management technologies, ranging from internet-based tools for self-monitoring of disease states to complex equipment such as home haemodialysis, were studied. The studies aimed to describe patients’ experiences and, sometimes, professionals’ experiences with the utilization of self-management technologies. Table 3.1 briefly describes the self-management technologies studied, the aims of these studies and their methodological approaches.

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<thead>
<tr>
<th>Author and date</th>
<th>Technology</th>
<th>Methodology</th>
<th>Objectives</th>
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<tr>
<td>Anhoj, J. and</td>
<td>Website to self-monitor asthma</td>
<td>In-depth semi-structured interviews</td>
<td>To describe patients' and health-care</td>
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<td>Nielsen, L.</td>
<td></td>
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<tr>
<td>Year</td>
<td>Authors</td>
<td>Study Title</td>
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<tr>
<td>2004</td>
<td>Ballangrud et al.</td>
<td>In-depth interviews with patients. Social constructivist approach</td>
<td>To understand how clients experience living with home mechanical ventilation and how they experience care and supervision of health care personnel.</td>
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<td>2003</td>
<td>Berit L. et al.</td>
<td>Home ventilator</td>
<td>Phenomenological approach</td>
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<tr>
<td>2004</td>
<td>Chou, M. H. et al.</td>
<td>Multimedia education program in depression</td>
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<td>2007</td>
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<td>2004</td>
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<td>Reference</td>
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<tr>
<td>Fex, A et al 2009 (^{179})</td>
<td>Advanced medical technology (from ventilators to oxygen therapy)</td>
<td>In-depth interviews</td>
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<tr>
<td>Fex, A, et al 2011 (^{180})</td>
<td>Advanced medical technology (from ventilators to oxygen therapy)</td>
<td>In-depth interviews with patients</td>
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<td>Fonda, S J. et al 2010 (^{181})</td>
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<td>Focus-groups conducted to obtain feedback on the PHA</td>
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<td>Giles, S. 2003 (^{182})</td>
<td>Home haemodialysis</td>
<td>In-depth interviews with patients</td>
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<tr>
<td>Greenhalgh, T. et al 2008 (^{183})</td>
<td>a personal health organiser accessible through the internet from which people can view their</td>
<td>Focus groups and short semi-structured interviews with patients</td>
<td>The philosophical approach</td>
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<tr>
<td>Study Authors</td>
<td>Methodology</td>
<td>Data Collection Tool</td>
<td>Data Source</td>
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<tr>
<td>Hedberg-Kristensson, E. et al 2007</td>
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<tr>
<td>Horton, K. 2008</td>
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<td>Lehoux et al 2004</td>
<td>Antibiotic intravenous therapy, parenteral nutrition, peritoneal dialysis and oxygen therapy.</td>
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<td>Antibiotic intravenous therapy, parenteral nutrition, peritoneal dialysis and oxygen therapy.</td>
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<tr>
<td>Li, J. et al 2007</td>
<td>Information technology to support hypertension care</td>
<td>Focus groups with African-American hypertensive patients</td>
<td>Information technology to support hypertension care</td>
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<td>Logan, K.</td>
<td>intermittent self-</td>
<td>In-depth interviews</td>
<td>intermittent self-</td>
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<td>et al, 2008&lt;sup&gt;188&lt;/sup&gt;</td>
<td>catheterization with patients Social constructivist</td>
<td>experiences of learning to carry out clean intermittent self-catheterization and user views of service provision.</td>
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<tr>
<td>Marziali E, 2009&lt;sup&gt;189&lt;/sup&gt;</td>
<td>Computer Internet-based videoconferencing healthcare support program In-depth interviews Social constructivism</td>
<td>To examine the feasibility and benefits of a computer Internet-based videoconferencing healthcare support program for community-dwelling older adults with chronic disease.</td>
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<tr>
<td>McCarthy, A, et al, 2010&lt;sup&gt;190&lt;/sup&gt;</td>
<td>Peritoneal dialysis In-depth interviews that explored social constructivism</td>
<td>To understand the concept of compliance with PD from the patient’s perspective.</td>
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<tr>
<td>Mol, A, 2000&lt;sup&gt;191&lt;/sup&gt;</td>
<td>Glucometers Interviews; direct observation and text analysis empirical philosophy</td>
<td>To explore patients’ experiences with glucometers</td>
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<td>Neville, R. G. et al, 2006&lt;sup&gt;192&lt;/sup&gt;</td>
<td>Electronic communication media In-depth interviews with doctors and patients</td>
<td>To explore patient and health care professional (HCP) views towards the use of multi-agent computer systems in their GP practice.</td>
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<tr>
<td>Peel, E. et. al, 2004&lt;sup&gt;193&lt;/sup&gt;</td>
<td>Glucometers In-depth interviews</td>
<td>To explore the pros and cons of glucose monitoring from the</td>
<td></td>
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<tr>
<td>Study Authors</td>
<td>Technology &amp; Methodology</td>
<td>Research Design</td>
<td>Purpose</td>
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<tr>
<td>Pinnock, H. et. al, 2007&lt;sup&gt;194&lt;/sup&gt;</td>
<td>Mobile phone-based monitoring on asthma self-management</td>
<td>Focus group and in-depth interviews with patients and doctors in primary care</td>
<td>To explore the opinions and concerns of people with asthma and primary care clinicians on the potential role of mobile phone monitoring technology</td>
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<td>Rickerby, J. Woodward, J. 2003&lt;sup&gt;195&lt;/sup&gt;</td>
<td>Home blood pressure monitoring</td>
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<td>Winkelman, W. J. et. al 2005&lt;sup&gt;196&lt;/sup&gt;</td>
<td>Online electronic medical records</td>
<td>Exploratory, descriptive study using in-depth interviews and focus groups with patients Social constructivism</td>
<td>To discover how patients living with chronic inflammatory bowel disease value Internet-based patient access to electronic patient records.</td>
</tr>
<tr>
<td>Wong, J. et. al 2009&lt;sup&gt;197&lt;/sup&gt;</td>
<td>Nocturnal home haemodialysis</td>
<td>Semi-structured interviews and focus group Social constructivism</td>
<td>To explore patient training experiences related to the self-administration of haemodialysis at home.</td>
</tr>
</tbody>
</table>

Table 4.1 - Characteristics of studies on self-management technologies

None of these studies investigated the impact of self-management technologies on the doctor-patient relationship or doctor-patient communication. There is, therefore, a mismatch between the focus of these studies and the aims and approach of self-management technologies. This body of research does not align with the collaborative care rationale which is espoused for self-management technologies. In the previous chapters, I have shown that self-management technologies, at least conceptually, aim to promote...
patients’ health via productive interactions between doctors and patients. Mutual trust in the DPR is at the centre of these interactions and a change in the interaction of doctors and patients in the context of self-management technologies may have a significant impact on patients’ wellbeing and self-efficacy. These factors would suggest that the smallest unit that has to be explored and analysed is the interaction in the DPR in the context of self-management technologies.

Despite these deficiencies, these studies do shed some light on how patients understand and experience being responsible for their health and being autonomous. They also inform our understanding of the impact of doctor-patient communication on these ethical concepts in the context of self-management technologies. In the next subsection, I analyse, with an ethical lens, the significance of these studies.

4.2.2 Research Findings on Self-Management Technologies

In this subsection, I describe the implications of these qualitative studies for patient responsibility, patient autonomy and mutual trust in the DPR. Although these studies generally use psychological and sociological frameworks, their findings are relevant for conceptions of patient responsibility and patient autonomy in the context of self-management technologies as well as for mutual trust in DPR. I argue that, because these studies do not focus on how self-management technologies shape communication in the DPR, they do not capture how patient responsibility, patient autonomy and mutual trust interrelate in the context of self-management technologies. In what follows, I analyse the patient responsibility and patient autonomy in the context of self-management technologies and discuss the relevance of this research for the collaborative model of DPR (CM-DPR) developed for self-management approaches.

4.2.2.1 Self-Management Technologies and Patients’ Sense of Responsibility for their Health

Several studies in this review provide an insight into the impact of self-management technologies on patients’ sense of responsibility for their own health. In these studies, patient responsibility is understood either as (a) patients’ duty of self-care; or (b) patients’ ability to respond to their health needs. First, there are several studies in which research participants associated patients’ responsibility for their health with the idea that patients
had a duty to maintain their health by carrying out practical activities. They showed that personal responsibility understood in this way sometimes could undermine self-care. For instance, Peel et al., in a study on patients’ experiences with self-monitoring of blood glucose, found that this technology could have contradictory influences. Generally self-monitoring was associated with an increased awareness amongst patients of the impact of lifestyle and dietary choices on blood glucose levels in ways that promoted patients’ self-care. It also enhanced patients’ sense of accountability. However, an enhanced sense of accountability could work both ways with respect to responsibility for self-care. It could amplify patients’ sense of “success”, giving them reassurance and comfort in case of lower blood glucose values. By contrast, in cases when blood glucose remained high despite patients’ efforts to manage their illnesses correctly, this enhanced sense of accountability could also amplify the sense of “failure” about self-management, often resulting in anxiety, self-blame and, in some patients, to abandonment of their diabetic regimen. In a similar way, Wong et al. in a study on home haemodialysis, have described how the transfer of responsibility and accountability from doctors to patients was associated with increased anxiety amongst patients because they feared using the technology and worried about the shift of medical responsibility from practitioner to patient.

Although these two studies acknowledged that health care professionals should play a role by clarifying misunderstandings and ensuring that patients understand their responsibilities, they did not focus on how different interactions in the DPR could influence patients’ perceptions of responsibility in the context of self-management technologies. However, it is not clear whether these perceptions were the result of the direct impact of utilization of self-management technologies on patients’ sense of responsibility or whether communication also played a role in promoting these perceptions. The relationship between mutual trust in the DPR and these outcomes was also not covered in these two studies.

In addition, there are three studies which suggest that patients’ sense of responsibility is influenced by mutual trust in the DPR and by doctor-patient communication. Mutual trust in the DPR influences patients’ willingness to use self-management technologies. For instance, Neville et al., in a study which explored patient and health care professional views towards the use of multi-agent computer systems in GP practices, have shown that patients’ trust in doctors appeared to extend to trust in their doctors’ decision to introduce and offer novel technological methods of consulting. The communication between doctor and patient also influenced patients’ willingness to use self-management
technologies. For example, Fex et al.\textsuperscript{179} in a study of the impact of a range of advanced medical technology (from ventilators to oxygen therapy) used by patients at home, have shown that the positive impact of the utilization of these technologies depended on professional technical support that was individually tailored in terms of knowledge and on professional emotional support. This influenced patients’ positive attitudes towards their health.\textsuperscript{179} Similarly, Logan et al.\textsuperscript{188}, in a study on the utilization of intermittent self-catheterization, have shown that patients’ experiences of using this technology depended on effective doctor-patient communication. Information giving with respect to and explanations of this technology promoted patients’ motivation to comply with tasks by increasing patients’ retention of knowledge and confidence to use the technology.\textsuperscript{188} However, none of these studies explored patient responsibility, understood as patients’ capacity to respond to health needs, which is the main conception of patient responsibility in self-management approaches. This is also a significant issue because patients’ capacity to carry out self-management activities may depend on their capacity to respond to their own health needs.

There is only one study which does define patient responsibility in terms of patients’ capacity to respond to health needs. In a study of the lived experiences of patients with chronic inflammatory bowel disease which focused on the impact of internet-based patient access to electronic patient records\textsuperscript{196}, it was shown that appropriate information technology promoted and supported illness ownership or, in other words, enhanced the capacity of a patient to act on his or her own behalf to directly influence his or her illness trajectory. This capacity depended on patients’ awareness of their illness, whether or not they wished to change and to be involved in their own care and on communication that affirmed that patients own their illnesses. This kind of communication changed the DPR from one of passive dependency and expectation to one of interdependency, mutual appreciation, mutual support, and shared problem solving. Mutual trust in the DPR was also transferred to a patient-accessible electronic medical record system when trusted physicians supported such a system.

Even in this study, the communication patterns that characterize patient-driven communication and how they actually influence mutual trust in the DPR were not made explicit. These research studies do not clarify how interaction, patient responsibility and mutual trust in the DPR interrelate in the context of self-management technologies. In the next subsection, I analyse the significance of these studies for different conceptions of patient autonomy.
4.2.2.2 Self-Management Technologies and Patient Autonomy

Studies which concern the relationship between self-management technologies and autonomy can be divided into three groups. First, there are several studies, \(^1\) that focus on patient autonomy defined as patient control over health care decisions. These studies have found that self-management technologies can promote patients’ intentionality by enhancing patients’ awareness of their illnesses. This helps patients to take positive actions with respect to their health. For instance, patients who used an internet based personal health application for diabetes receive timely, readily available information on how diabetes-related domains interact, how their behaviours affect them, and they can use this to plan future activities.\(^1\) Similarly, patients who used home blood pressure monitoring become aware of the consequences of hypertension and may want to take further measurements, and to consider adjusting their treatment in the light of these measurements.

Self-management technologies can also have negative impacts on patient control over decision-making. For instance, Pinnock et al, \(^1\) in a study, which explored the views of people with asthma and general practitioners on the potential role of mobile phone monitoring technology, have shown that technology increased patients’ perceptions of dependence on their GPs and feelings of anxiety when technology did not work well. In addition, Rickerby et al, \(^1\) in their study on HBPM, have shown that some patients showed less knowledge and enthusiasm in using HBPM, and considered the management of hypertension to be the doctor’s job. Nonetheless, there is some information that suggests that self-management technologies’ capacity to promote patient control over decision-making depends on the extent to which the technology interferes with patients’ daily activities. Anhøj et al, in their study which explored patients’ and health-care providers’ use of a website devoted to self-monitoring of asthma, showed that most patients stopped using the website because it was not integrated with their own lives. Although most patients found the website useful none of them used it as intended. The website protocol required patients to enter diary values immediately after measuring the morning peak flow. However, because patients didn’t have immediate access to internet, they entered the values whenever possible rather than every morning. This resulted in suboptimal utilization of the website because patients were not able to introduce the values every day, and in turn, this affected the adjustment of medication based on peak flow morning values. In addition, most GPs in this study found it difficult to fully instruct the patients in the system because they were not confident computer users. In turn, when the
patients received from GPs therapeutic recommendations that they didn’t understand or which contradicted their past experiences, the patients reacted with disbelief and none of them took the prescribed action. Presumably patients did not follow GPs’ therapeutic recommendations because they did not perceive the GPs to be professionally competent. In chapter two, I have shown that patients’ trust in their doctors is taken to mean that doctors are professionally competent and bear good will towards them. In addition, I have shown that patients’ trust in their doctors is significant for patients’ adherence to doctors’ recommendations. These findings suggest that there is a relationship between patient control over decision-making, mutual trust in the DPR, patients’ confidence in using self-management technologies, and doctor-patient communication. However, the study does not make explicit how these ethical dimensions might relate to each other. More generally, none of these studies have shown how different patterns of doctor-patient communication can influence mutual trust in the DPR and patients’ control over decision-making. Although the studies do describe how some communication patterns influence patients’ control over decision-making in a positive way, there is no information related to the impact of doctor-patient communication on the utilization of different self-management technologies in those circumstances in which the technologies produce negative impacts on patient control over decision-making.

Second, there are several studies\textsuperscript{176,178,185} that focus on patient autonomy, defined as patient capacity to deliberate effectively. Chou et al\textsuperscript{176} in a study which explored the self-learning experiences of depressed patients through an interactive multimedia education program have shown that this technology had a positive impact on patients’ motivation to learn. The program increased their understanding of depression and their self-awareness by integrating new knowledge with their previous experiences of ill health and this helped them to change their behaviour. In addition, Horton\textsuperscript{185} in a study which examined whether a tele-monitoring system using fall detectors could reduce fear of falling among community-dwelling older people who had recurrent falls, showed that this technology improved patients’ self-efficacy by promoting feelings of security.\textsuperscript{185}

In previous chapters I have defined responsible deliberation as actions taken where a person is aware of the alternatives, the consequences of these alternatives, evaluates both, and chooses an action based on that evaluation.\textsuperscript{7} Patients’ choices should be the result of a self-reflective process rather than a reflection of factors outside individual control.\textsuperscript{24} Although the findings of these studies suggest that self-management technologies can promote patients’ self-awareness and their motivation to change their behaviour, none of the studies show how self-management technologies can promote patients’ capacity to
evaluate different therapeutic approaches. In addition, these studies do not describe how communication between doctor and patient may influence patients’ capacity to deliberate effectively. This is significant for self-management approaches, because the CM-DPR aims to promote patients’ capacity to deliberate effectively via persuasive communication. Further research is necessary to understand how self-management technologies may influence patients’ capacity to deliberate effectively.

Third, there are several studies, which focus on patient autonomy defined as patients’ control over their lives. For instance, Ballangrud et al., in a study on the utilization of home ventilators in patients with respiratory failure, have described how patients who used home ventilators felt in control over their own situation and that this enabled them to live a normal and active life. Similarly, Giles, in a study on patients’ experiences with home haemodialysis, showed that end stage renal disease who were able to use correctly home haemodialysis were able to live a normal life. Although these findings are relevant, they are from studies where patients have serious illnesses, such as end stage renal disease or respiratory failure. By contrast, in patients with less debilitating conditions such as diabetes or infections, self-management technologies appeared to have the opposite impact on patients’ control over their lives. In these studies, although self-management technologies can improve health status, there are significant burdens for patients’ lives.

In addition, there is only one study which has shown that doctor-patient communication may have an impact on patients’ capacity to control their lives in the context of self-management technologies’ utilization. Lehoux et al., in a study which explored from the patient's perspective how the level of user-friendliness of medical technology influences its integration into the private and social lives of patients, have shown that the biomedical discourse made patients feel that they do not owe their own body and private space. Further research is necessary to understand the communication patterns through which self-management technologies may influence patients’ control over their lives.

There are several problems with respect to the impact of self-management technologies on patients’ control over their lives that are not clarified in these studies. First, these studies rely on a limited understanding of patient capacity to control their lives as compared with the bioethics conception of this ethical notion. These studies understand patients’ control over their lives as control over patients’ actual life circumstances whereas in the bioethics literature patients’ control over their lives is understood as actions that are consistent with patients’ attitudes, values, dispositions, and
life plans. Therefore, an account on the impact of self-management technologies on patients’ capacity to live their lives would imply a future-oriented perspective on patients’ capacity to live the kinds of lives they want to lead, rather than one focused on patients’ capacity to control their actual circumstances as these studies suggest. Second, the relative role of self-management technologies and patients’ perceptions of health risks on patient capacity to control their lives is not explained. Clearly, more research is needed to understand the relationship between patients’ responsibility for their health and their control over own lives.

In summary, in this section I have shown that qualitative studies on self-management technologies, although they suggest that patient responsibility, patient autonomy, mutual trust and doctor-patient communication are important, do not explain the pathways through which these ethical conceptions interrelate.

4.3 Conclusion

In this chapter, I have identified the research gaps with respect to how self-management technologies can influence interaction in the doctor-patient relationship. My literature review of qualitative studies on self-management technologies has shown that these studies do not explain clearly the relationship between doctor-patient interaction, patients’ sense of responsibility for their own health, patient autonomy and mutual trust in the DPR. In addition, there is a lack of information with respect to how self-management technologies influence communication in the doctor-patient relationship and the impact of different patterns of communication in the doctor-patient relationship on the utilization of self-management technologies. This review, therefore, provides a basis for the research questions that I asked in my own empirical work. In the next chapter I will describe the objectives of my study and its methodology.
Chapter 5: Methodology

5.1 Introduction

This thesis is concerned with describing the moral dimension of self-management technologies and their related self-management practices at the level of general practice. Qualitative methods have been selected because understanding and describing the pathways and mechanisms, through which self-management technologies may influence interactions and mutual trust in the DPR, patients’ responsibility for their own health and patients’ autonomy, will require data rich in detail and embedded in the lived experiences of chronically ill patients and their general practitioners, explored them through dialogue and reflection.

The aim of this chapter is to provide a detailed description of the evolution, design and execution of the empirical part of the research for this thesis. First, the study objectives and the research questions of this study will be described. Second, the theoretical stance within which this research study took place will be briefly presented and justified. I argue that this study adopted a symbolic interactionist stance because it fits with the theoretical basis of self-management approaches and it is suitable for realizing the objectives of this study. Third, the techniques employed in designing, collecting and analysing the data for the empirical part of this thesis are presented.

5.2 Study Objectives and Research Questions

The objectives of the empirical components of this study matched those of the study overall and were to describe and explain:

(1) The pathways and mechanisms through which self-management technologies may influence mutual trust in the DPR; and

(2) How GPs and patients interpret the notions of patient responsibility for their health and the influences of self-management technologies on how doctors and patients interpret these ethical notions.

The research questions explored in this research project are:

(1) How do doctors and patients describe the pathways and mechanisms, through which self-management technologies may influence the doctor-patient relationship?; and
(2) How do doctors and patients build and maintain the notion of patients’ responsibility for their health and patient autonomy and how do doctors and patients describe the influences of self-management technologies on patient responsibility and patient autonomy?

I used the following detailed questions to expand on the main objectives and research questions. The first set of detailed questions was linked with the first objective and the second set to the second research objective:

1.1 What are the goals of doctor-patient relationship in the context of HBPM?
1.2 What are the patterns through which HBPM contributes to these goals?
1.3 How do doctors and patients understand and describe each others’ meanings?
1.4 What does it mean a trustful doctor-patient relationship for hypertensive patients and their GPs?
1.5 How, and through which processes, HBPM could influence the interaction in doctor-patient relationship?
1.6 What are the patterns through which HBPM influences mutual trust in the doctor-patient relationship?
1.7 How does mutual trust in the DPR influence, if at all, patients’ perceptions of self-efficacy?

2.1 What is the meaning of patients’ personal responsibility for health for hypertensive patients and GPs?
2.2 What are the differences between GPs’ and patients’ perceptions of the patient’s personal responsibility for health?
2.3 How do respondents’ perceptions of patient responsibility for health using self-management technologies differ from concepts of patient responsibility used in other models of doctor-patient responsibility?
2.4 What are the processes through which HBPM influences the meanings of and consequences on personal responsibility for health care and health?
2.5 What are the processes through which HBPM influences the GPs’ and patients’ perceptions of patient autonomy?
2.6 What is the relationship between mutual trust in the DPR, patient autonomy and patient personal responsibility for health care and health in the context of HBPM utilization?
5.3 Methodology

The realisation of the aims of this study requires research methods compatible with describing GPs’ and patients’ experiences with self-management technologies, as it is through this process that I might describe the pathways and mechanisms, through which self-management technologies may influence interactions and mutual trust in the DPR, patients’ responsibility for their own health and patient autonomy. Such methods must be holistic, and aim to capture the data from the perspective of those involved. These are features of qualitative research. First, qualitative research is based on the presumption that reality is multiple and socially constructed. Second, qualitative research is based on the notion that context is essential for understanding human behaviour and it resists the positivist stance that truth is out there and waits to be discovered. Therefore, researchers must meet participants where they are, in the field, so that data collection occurs where people engage in their everyday practices. Research conducted in the field allows investigators to capture participants’ experiences in an effort to obtain a more complete understanding of the phenomenon under investigation. Third, qualitative research is an inductive and emergent process where researchers build upon and ground their findings in the data collected. The process of conducting qualitative research, including study design, emerges from experiences in the field while an investigator is actively engaged in inquiry because human phenomena and action cannot be predicted. Thus, what they learn in the field will influence and promote changes to a study’s design.

From a methodological point of view the research study adopts a symbolic interactionist stance. Blumer, based on previous work of Mead, first coined the term symbolic interactionism. Symbolic interactionism incorporates two concepts: symbol and interaction. A symbol refers to any social object (e.g. objects, gestures, or words) that stands in place of or represents something else. Symbolic interactionists argued that symbols are a human creation because only human beings have the ability to arbitrarily assign meaning or, in other words, to make something into a social object. Interaction underscores the significance of interpersonal communication in transmitting the meaning of symbols. Through interaction, culture develops. Interactionists understand culture as the ideas, objects, and practices that constitute everyday life. On the one hand, culture pre-exists actual individuals and, therefore, structures people’s lives. On the other hand, people have human agency and interpretive skills and, thus, the ability to negotiate, modify and accept or reject the meanings they learn. In this
way people are active creators of symbols and culture.\textsuperscript{198,204} Therefore, symbolic interactionists see meanings as being social products formed through the activities of people interacting. Meanings arise neither from the intrinsic characteristics of the things nor through psychological elements between people.\textsuperscript{201} Rather meanings develop out of the ways in which other persons act toward the person with respect to the thing. Meanings allow people to produce various realities that constitute the so-called real world, but because these realities are related to how people create meanings, reality becomes an interpretation of various definitional options.\textsuperscript{198,201}

I have adopted this theoretical stance because it fits with the conceptual base of self-management technologies and their related practices. In the second chapter of this thesis, I have shown that Stanford University Chronic Disease Self-management Program (CDSMP) and the collaborative model of DPR (CM-DPR) that were developed for self-management purposes rely on Bandura’s social cognitive theory.\textsuperscript{166} This theory shares significant similarities with this philosophical stance. In a similar way to symbolic interactionists, Bandura\textsuperscript{91,93} claims that people both produce and are produced by their environments. The vehicle through which CDSMP and CM-DPR aim to promote patients’ autonomy and their responsibility for self-care is human interaction.\textsuperscript{85,97} These interventions aim to promote patient autonomy and patient responsibility through interpersonal communication.\textsuperscript{14,16,95,96,206,207} In addition, in the third chapter, I showed that CM-DPR shares significant similarities with the relationship-centred model of DPR that relies on a symbolic interactionist stance.\textsuperscript{30} This stance is also compatible with the realization of the aims of my study. The core task of symbolic interactionists as researchers is to capture the essence of the studied phenomenon by getting insight into the inter-subjective construction of reality through interpretation.\textsuperscript{171,198,200}

5.4 Study Evolution and Design

In this section, I describe the evolution of the questions, the research design and the ethical clearance of this research project.

5.4.1 Evolution of the Questions

In this subsection, I describe the sources of the major assumptions in this research study. First, I show that my interest for this study grew out from my medical experience
and from my interest in medical ethics. Second, I show that the second source of assumptions in this research are the common ideas and concepts described in the literature with respect to self-management technologies and related practices in the context of chronic illnesses’ management.

I am trained as general practitioner and I also have formal education in bioethics. My pre-understandings with respect to the topic of this study were influenced by my medical background. I have cared for chronically ill patients for more than ten years as a general practitioner and I perceived that patients’ health status depended on patients’ capacity to assume responsibility for their own care. Patients are under medical observation only once in several months and, they have to be engaged in self-care for most of the time by making health care decisions according to the changing conditions of their illnesses and their lives. However, I discovered in practice that patients make trade-offs between their health interests and other life priorities. For instance, in many situations, hypertensive patients tried to adjust their medicines such a way to promote their wellbeing and life interests, rather than to decrease their blood pressure values to normal levels as dictated by clinical guidelines and scientific evidence.

This created a discrepancy between my expectations as a general practitioner concerned about treating medical conditions according to scientific evidence, and patients’ expectations of being helped to maintain control over their lives. During my medical training I had been taught that doctors are medical experts with a special responsibility for patients’ health. However, situations when there were conflicts between patients’ capacity to take care of their health due to their life priorities and my responsibility for their health, made me aware that the medical model in which I was socialized during my medical training did not provide clear solutions to solve this conflict.

In 2004 I undertook a Master program in Bioethics, at Case Western Reserve University in Cleveland, Ohio in the US. During this program I spent several hundreds of hours in hospitals participating in clinical ethics consultations. This process made me understand that patients are interested in negotiating their treatments in such a way that their life’s interests will be preserved and enhanced. In addition, I was influenced by the theory of critical interests as described by Ronald Dworkin,208 which also shaped my understandings of self-management technologies and related practices. However, it was not clear to me how promoting patients’ life interests into the health care context might influence patients’ internal motivation in a positive way.15,16 I started to read in the area, but I found little to specifically address this question.
Once I had developed an interest in this area of research I started to reflect and list all the things that influenced me and possibly could continue to influence me while conducting this research. First, I had a strong belief that we as doctors owe a special duty to promote patients’ responsibility for their health. That was, I had the perception that we as doctors should persuade patients to choose the best alternative therapeutic approach that might improve their health status. Second, I had a strong belief that we should respect patient autonomy in the context of health care. That was, I thought that we as doctors have to provide enough medical information for patients to allow them to make sound therapeutic decisions, but finally patients had to decide what was the best therapeutic decision for themselves. At times these two assumptions appeared to be in conflict and I became aware that both medicine and medical ethics could not provide clear solutions to solve this conflict in such a way as to promote both patient autonomy and patient responsibility for their health. I began to think that I might get answers to these questions through dialog with general practitioners and patients experienced with self-management approaches in the context of chronic illness management.

The second major source of assumptions in my research were the common ideas and concepts that are described in the literature with respect to self-management technologies and related practices in the context of chronic illnesses’ management. In the second chapter, I argued that mutual trust in DPR might be relevant for patient autonomy and patient responsibility for self-care in the context of self-management technologies’ utilization. In the third chapter, I argued that the collaborative model of DPR described in the context of self-management technologies combines features from different bioethics and clinical models of DPR that appear conceptually inconsistent. These raised questions about the capacity of this model to both promote mutual trust and patients’ self-efficacy. I also found as mentioned in chapter four that there was little work with respect to the influences of self-management technologies on mutual trust in GP-patient relationship, patients’ autonomy and patients’ responsibility for their health.

Study Design

The empirical part of this study consisted of a series of semi-structured interviews with general practitioners and patients experienced with HBPM utilization. The interviews were focused on participants’ experiences with HBPM as means to explore and collect experiential narrative material to develop an understanding
of: (1) the ethical features of the DPR; (2) patients’ sense of responsibility for their health; and (3) patient autonomy; and, then, to explore how HBPM influenced DPR, patients’ responsibility for their health and patient autonomy. This focus on patients’ and GPs’ experiences with HBPM functioned to ground the research in the practice. In addition, by interviewing both GPs and patients my account was informed by the perspectives of all involved parties and allowed me to compare their views in order to and to provide a holistic and thick description of the studied phenomena.

When choosing the methods for this study I was guided by the need to understand GPs’ and patients’ perspectives on the studied phenomena. Understanding meanings and describing patterns are accessible through language and, therefore, as noted above I have chosen qualitative methods. I also chose semi-structured interviews for this study. Interviews are a useful method to collect data from a range of research participants in a short period of time, especially when the studied phenomena could not be directly observed. Engaging in observation would not have provided the kind of information I sought. The literature review suggested that patient responsibility and patient autonomy were related to patients’ beliefs and intentions and their emotional responses to technology utilization. However, we cannot observe feelings, thoughts and intentions and we cannot observe experiences that took place at some previous point of time or situations that preclude the presence of the observer. Therefore, I decided to ask people questions about these things.

The literature on qualitative research describes three kinds of interviews: (a) informal conversational interview; (b) semi-structured interviews; and (c) standardized open ended interview. I have chosen semi-structured interviews, which involved the implementation of a number of predetermined questions and specific topics. I developed questions around themes and asked all participants about them. This type of interview allowed me to consistently cover all the areas of the studied phenomena in all interviews. This approach facilitated gathering more comprehensive data from research participants than a conversational interview would have done. However, the wording and the sequence of the questions was not predetermined, which allowed me to follow the flow of the conversation and to adjust it to specific circumstances.

The focus of the interviews was on patients’ and GPs’ experiences with home blood pressure monitoring (HBPM). The interviews were focused on discussing real management cases with general practitioners and patients rather than on focusing on discussing the conceptual features related to my research questions. In the interviews with general practitioners, I asked them to tell me about one of their patients who use or have
used HBPM. Then I asked them how that patient differs compared with other patients who use HBPM. Similarly, in the interviews with patients, I asked them to tell me about different experiences they had with HBPM. This approach allowed me to examine in detail the practices related to self-management approaches and to better understand through comparison the influences of contextual factors on this practice and on the studied phenomena.

The study design also included developing strategies to address potential bias. A first potential source of bias stemmed from my a priori assumptions that I have already described. I have dealt with them in two ways. First, data were collected over a period of several months, and data analysis was ongoing. This approach allowed me to identify new questions from the emerging theory\textsuperscript{214} that were added to interviews with the remaining participants.\textsuperscript{214} Second, during the interviews I used active listening.\textsuperscript{198,199,213,215} I shared my understandings with the research participants to obtain a collaborative interpretation and description of the findings. I used the information from research participants to paraphrase or summarize it,\textsuperscript{198,215} but tried to do not change the meaning. I asked the research participants whether or not I correctly understood what they have said. My attitude was: “I want to understand, so I’m going to try to repeat back to you what I think you said”. This approach helped me to seek confirmability\textsuperscript{198,216,217} or, in other words, to verify whether or not I understood a phenomenon from the perspective of the research participants and to check whether or not I understood the meanings people gave to their experiences.

A second source of potential bias was related to selection of the patients that I interviewed. I selected patients through their general practitioners. A detailed description of the recruitment methods will follow later in this chapter. General practitioners tended to select patients whom they trusted and who trusted their GPs. All the patients in this study described trustworthy relationships with their GPs. I dealt with this potential selection bias\textsuperscript{172} by asking patients how their actual general practitioners differed compared with other general practitioners they consult in the present or they had consulted in the past. GPs also tended to describe experiences with patients that confirmed their opinions with respect to HBPM. That is, GPs who were proactive with HBPM tended to emphasize their positive experiences with HBPM, whereas GPs who were reluctant to use HBPM tended to tell their negative experiences. In all these cases, I asked GPs how other patients who used HBPM differed as compared with those they mentioned. This approach helped me to get a comprehensive understanding of GPs’ and patients’ views of a trusty relationship in
the context of self-management technologies as well as to understand the factors that influenced HBPM utilization.

A third source of potential bias was my medical background. Both general practitioners and patients were aware that I was trained as a general practitioner. This could have influenced patients’ responses to my questions so that the patients tailored their responses to what a doctor might want to hear. I dealt with this problem in a number of ways. First, whenever it was possible, interviews were carried out in patients’ homes. This approach helped to create an informal atmosphere and to build rapport with patients. Second, I emphasized that my role in this study was as a researcher. This approach helped me to avoid therapeutic misunderstandings. Third, I assured patients that the interviews could remain confidential and that their general practitioners will not be informed about the issues they have discussed with me. The fact that I was from overseas might have helped this as well.

I had a similar approach with general practitioners. In situations when GPs appealed to my medical knowledge or experiences during their answers, I asked them to explain me more what they want to say. I paid special attention to shortcuts in conversation through expressions such as “you know”. In these situations my attitude was: “I know that some of the questions I am asking may sound simplistic to you, but I am really interested to know your opinions”. This approach helped me to engage an explanatory stance.

5.4.2 Ethical Clearance

Approval for this project was sought from the University of Adelaide Human Research Ethics Committee. The project was granted approval following a submission of an application containing a detailed description of the project including the recruitment methods, copies of information sheets for patients and general practitioners that were used in this project, consent forms and letters of invitation to enrol in the study for GPs and patients.

Informed consent was obtained prior to participation and confidentiality was maintained throughout the research process. Appendix I contains copies of information sheets for patient (I.A) and GP participants (I.B). Permission to record interviews was obtained, and participants advised that transcripts and audiotapes will be kept locked in researcher’s office. I was also aware of the sensitive nature of this research and avoided intrusive questioning that may interfere with participants’ integrity and personal
Participants were fully informed of the sensitive nature of the study prior to consent being obtained.

5.5 The Interview Study

5.5.1 Participants’ Recruitment and Responses

The research was conducted around Adelaide and was focused on general practitioners with experience in HBPM and hypertensive patients who used HBPM for the management of their medical condition. Access to research participants was gained through the Discipline of General Practice at the University of Adelaide. This was largely a pragmatic decision because I did not have any other means to access general practitioners.

A total of 13 GPs were interviewed in this study. The recruitment of general practitioners took place in two rounds. First, a formal letter of invitation, explaining the purposes of this project has been sent to all general practitioners in the existing database of the Department of General Practice. Five hundred and eighty-four letters were sent to general practitioners. Six general practitioners with experience in HBPM subsequently expressed an interest in participating in the study. I contacted these general practitioners via telephone and explained the project in detail. All of these GPs accepted to be enrolled in this research study and appointments for interviews were established.

However, this first round of recruitment proceeded very slowly and did not secure enough research participants. This suggested a need to change the recruitment strategy. Therefore, the project was advertised in a GP meeting of a geographically defined network of general practitioners, which was affiliated with the Department of General Practice at the University of Adelaide. In this second round, another seven general practitioners experienced in HBPM utilization were recruited and interviewed. The recruitment of general practitioners stopped when the point of saturation was reached. That means that I stopped recruiting and interviewing GPs when newly recruited GPs continued reporting essentially the same ideas as the previous ones and collecting new data would have not collected any novel results.

The hypertensive patients were recruited through their general practitioners. A total of nineteen patients were interviewed in this study. As with GPs, patients’ recruitment took place in two rounds. Two strategies guided the recruitment process. First, maximum variation sampling was used, to secure participants from a range of gender, age, and socio-economic background. I asked GP participants to recruit three hypertensive patients.
in three categories: (a) patients using this technology who were interested in monitoring their illness; (b) hypertensive patients using this technology who were reluctant to manage their illness; and (c) hypertensive patients who had used this technology in the past and abandoned it. I also included patients diagnosed only with hypertension and patients who had developed cardiovascular diseases. This helped me to explore how comorbidities influenced the meanings I sought to understand and describe. GPs were provided copies with the detailed description of the project and information sheets for patients. In this first round, 12 patients expressed their interest to participate in this study. I contacted them via telephone and explained the project in detail. All of these patients were enrolled in the project and interviewed.

At this stage the ongoing data analysis suggested that all the patients enrolled in the study had a trustworthy relationship with their general practitioners. This suggested a potential selection bias. This was a significant issue since data analysis also suggested that mutual trust in GP-patient relationship significantly influenced HBPM utilization. Therefore, I decided that there was a need to change the recruitment strategy. The second round of recruitment was done also through general practitioners, but it did not use a direct patient recruitment by GPs. One practice agreed to advertise the project directly to all practice patients who use or have used HBPM. Interested patients contacted me directly. Another seven patients expressed their interest to participate in this study and, after explaining the project to them in detail, they accepted to enrol. This approach attracted also patients from general practitioners who were not interviewed in this study. Despite these differences in recruitment this second approach did not significantly influence the data. All the patients recruited in this second stage also had trustworthy relationships with their GPs. Interviews continued until theoretical saturation had occurred.221

**Interview Themes**

The general practitioner interview started with an invitation for the participants to tell me about their experiences with HBPM. The discussion covered any topic raised by the interviewee. This was supplemented by questions regarding the factors that influenced them to start using HBPM and expectations from HBPM utilization. This discussion was followed by an invitation to discuss one of their patients who uses or who had used HBPM. Similarly, the discussion covered any topic raised by the interviewee. In addition, I asked general practitioners about the decision-making process, patient responsibility and
doctor-patient relationship in the context of HBPM utilization. As a general rule I first explored how GPs built the notions of decision-making process, patient responsibility and GP-patient relationship and then asked them how HBPM influenced their views of these notions. Then, I asked the interviewees how that individual patient differed compared with other patients who use HBPM. As a general rule I asked about differences for each topic raised by the general practitioner in the first part of the interview. The interview ended with an invitation for the interviewees to tell me about their professional background. The general practitioner interview schedule is presented in appendix II A.

The patient interview also started with an invitation for the interviewees to tell me about their experiences with HBPM. The discussion covered any topic raised by the interviewees supplemented by questions regarding the circumstances when they started to self-monitor their blood pressure and expectations from HBPM utilization. In addition, I asked patients about the decision-making process, patient responsibility for self-care and the GP-patient relationship in the context of HBPM. I followed the same general rule as with GP interviews of exploring first how patients built these notions and then how HBPM influenced patients’ views of these notions. Then I asked patients about how their experiences with HBPM in the context of the relationship with their current GP differed compared with their experiences with other GPs. I explored the differences for each topic raised by patients in the first part of the interview. I ended the interview with an invitation to tell me anything they consider relevant, but that they had not had the opportunity to discuss during the interview. The patient interview schedule is presented in the appendix II B.

5.5.2 Participants’ characteristics

I interviewed 13 general practitioners. Table 2 describes GP participants’ characteristics. The names of the GP participants are pseudonyms. A short biography of each of the GP participants is included in appendix IIIA. Table 5.1 briefly describes the characteristics of the GP participants. The table provides socio-demographic data (GPs’ age and gender), the practice characteristics (GP experience and the type of practice – solo/group) and the pattern of HBPM recommendation. I have classified HBPM recommendation into three categories based upon participants’ responses. Totally patient driven meant that the GP adopted a neutral position with respect to HBPM. Whenever a patient wanted to self-monitor her blood pressure, that GP accepted and encouraged the patient to self-monitor, but the GP did not instigate self-monitoring. Long-term utilization
meant that the GP adopted a proactive attitude towards HBPM and recommended hypertensive patients to self-monitor their blood pressure at least before the periodic clinical encounters and whenever patients experienced high blood pressure values. Short-term utilization meant that GPs recommended HBPM only to exclude white coat phenomenon in which case GPs lent blood pressure machines to their patients and asked them to self-monitor their blood pressure for a period of up to a week.

<table>
<thead>
<tr>
<th>GP name</th>
<th>Age</th>
<th>Gender</th>
<th>Years in General Practice</th>
<th>HBPM Recommendation</th>
<th>Type of Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>34</td>
<td>Male</td>
<td>3 years</td>
<td>Totally patient driven</td>
<td>Group practice</td>
</tr>
<tr>
<td>Amanda</td>
<td>41</td>
<td>Female</td>
<td>12 years</td>
<td>Long term utilization</td>
<td>Group practice</td>
</tr>
<tr>
<td>Christian</td>
<td>46</td>
<td>Male</td>
<td>10 years</td>
<td>Long term utilization</td>
<td>Group practice</td>
</tr>
<tr>
<td>Christopher</td>
<td>51</td>
<td>Male</td>
<td>20 years</td>
<td>Short term utilization and reluctant to long term utilization</td>
<td>Group practice</td>
</tr>
<tr>
<td>Francis (GP)</td>
<td>59</td>
<td>Male</td>
<td>25 years</td>
<td>Long term utilization</td>
<td>Group Practice</td>
</tr>
<tr>
<td>Frederick</td>
<td>48</td>
<td>Male</td>
<td>17 years</td>
<td>Long term utilization</td>
<td>Group practice</td>
</tr>
<tr>
<td>Gram</td>
<td>31</td>
<td>Male</td>
<td>1 year</td>
<td>Long term utilization</td>
<td>Group practice</td>
</tr>
<tr>
<td>Gregory</td>
<td>47</td>
<td>Male</td>
<td>20 years</td>
<td>Totally patient driven</td>
<td>Group practice</td>
</tr>
<tr>
<td>Harold</td>
<td>53</td>
<td>Male</td>
<td>23 years</td>
<td>Long term utilization</td>
<td>Solo practice</td>
</tr>
<tr>
<td>Joann</td>
<td>52</td>
<td>Female</td>
<td>17 years</td>
<td>Long term utilization</td>
<td>Group practice</td>
</tr>
<tr>
<td>Laurence</td>
<td>54</td>
<td>Male</td>
<td>25 years</td>
<td>Long term utilization</td>
<td>Group Practice</td>
</tr>
<tr>
<td>Neil</td>
<td>63</td>
<td>Male</td>
<td>31 years</td>
<td>Long term utilization</td>
<td>Group practice</td>
</tr>
<tr>
<td>Ralph</td>
<td>46</td>
<td>Male</td>
<td>17 years</td>
<td>Totally patient driven</td>
<td>Group Practice</td>
</tr>
</tbody>
</table>

Table 5.1 – GP participants’ characteristics
I also interviewed 19 patients with experience in HBPM. The characteristics of patient participants are briefly described in table 3. The names of patient participants are pseudonyms. A short biography of each of the patient participants is included in appendix III.B. The table 5.2 provides socio-demographic data (patients’ age, gender, level of education and employment status), the relationships between patients’ participants and the pattern of HBPM utilization. I have classified HBPM utilization by patients into two categories based upon their interview responses. Long-term utilization meant that the patient adopted a proactive attitude towards HBPM and used it to self-monitor his or her blood pressure periodically and before the clinical encounters as well as whenever he or she experienced high blood pressure values. Intermittent utilization meant that the patient used HBPM either for short periods of time before the clinical encounters or at the request of his or her GP for periods of up to a week to exclude the white coat phenomenon.

<table>
<thead>
<tr>
<th>Patient Name</th>
<th>Gender</th>
<th>Age</th>
<th>Employment status</th>
<th>Education level</th>
<th>HBPM utilization</th>
<th>Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anna</td>
<td>Female</td>
<td>55</td>
<td>Home duties</td>
<td>Tertiary</td>
<td>Intermittent use</td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>Female</td>
<td>58</td>
<td>Nurse</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>George</td>
<td>Male</td>
<td>64</td>
<td>Engineer</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td>Mary’s husband</td>
</tr>
<tr>
<td>Gerry</td>
<td>Male</td>
<td>72</td>
<td>Retired (working part-time as driver)</td>
<td>High school</td>
<td>Intermittent use</td>
<td></td>
</tr>
<tr>
<td>Gertrude</td>
<td>Female</td>
<td>69</td>
<td>Retired</td>
<td>High school</td>
<td>Intermittent utilization Abandoned</td>
<td></td>
</tr>
<tr>
<td>Jacqueline</td>
<td>Female</td>
<td>55</td>
<td>Teacher</td>
<td>Tertiary</td>
<td>Intermittent use</td>
<td></td>
</tr>
<tr>
<td>Jane</td>
<td>Female</td>
<td>60</td>
<td>Home duties</td>
<td>High school</td>
<td>No. Instigated her husband to use HBPM</td>
<td>Stephan’s wife</td>
</tr>
<tr>
<td>Larry</td>
<td>Male</td>
<td>60</td>
<td>Plumber</td>
<td>High school</td>
<td>Intermittent use</td>
<td></td>
</tr>
<tr>
<td>Laura</td>
<td>Female</td>
<td>69</td>
<td>Retired</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>Occupation</td>
<td>Highest Education</td>
<td>Utilization</td>
<td>Additional Information</td>
</tr>
<tr>
<td>------------</td>
<td>--------</td>
<td>-----</td>
<td>------------------------------------------------</td>
<td>-------------------</td>
<td>---------------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>Malcolm</td>
<td>Male</td>
<td>79</td>
<td>Retired (still working as sharebroker)</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>Mark</td>
<td>Male</td>
<td>71</td>
<td>Retired</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>Mary</td>
<td>Female</td>
<td>63</td>
<td>Home duties</td>
<td>High school</td>
<td>Long term utilization</td>
<td>George’s wife</td>
</tr>
<tr>
<td>Rick</td>
<td>Male</td>
<td>52</td>
<td>Teacher</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>Rose</td>
<td>Female</td>
<td>64</td>
<td>Retired</td>
<td>High school</td>
<td>Intermittent use</td>
<td></td>
</tr>
<tr>
<td>Russel</td>
<td>Male</td>
<td>41</td>
<td>Engineer</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>Sam</td>
<td>Male</td>
<td>71</td>
<td>Retired</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>Sandra</td>
<td>Female</td>
<td>68</td>
<td>Retired</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
<tr>
<td>Stephan</td>
<td>Male</td>
<td>65</td>
<td>Retired</td>
<td>High school</td>
<td>Intermittent use</td>
<td>Jane’s husband</td>
</tr>
<tr>
<td>Stuart</td>
<td>Male</td>
<td>53</td>
<td>University Lecturer</td>
<td>Tertiary</td>
<td>Long term utilization</td>
<td></td>
</tr>
</tbody>
</table>

Table 5.2 – Patient participants characteristics

5.5.3 Data Gathering and Handling Procedures

The final data set comprised thirteen interviews with general practitioners and nineteen interviews with patients. Eleven general practitioners preferred to be interviewed in their offices and two were interviewed in the meeting room of the Discipline of Public Health. Sixteen patients preferred to be interviewed in their homes and three selected to be interviewed in the meeting room of the Discipline of Public Health. All the interviews were audiotaped and the transcripts were stored in my personal computer. The duration of the GP interviews varied from 50 minutes to 108 minutes. The duration of patient interviews varied from 47 minutes to 129 minutes. All the interviews were transcribed verbatim. During the transcription all the real names were erased and replaced with pseudonyms. The transcripts were checked for accuracy several times and necessary corrections were made.
5.5.4 Data Analysis

Analysis of collected data was ongoing and it was assisted by the computer software QSR NVivo. I transcribed all the interviews during the process of data collection and then they were analysed. Data analysis involved multiple readings of both the transcripts and summaries of the transcripts, developing codes from these readings and then applying the codes to the transcribed interviews. This process was repeated until the final list of code captured all of the phenomena identified by the multiple readings.

Codes were inductively generated and grounded in the participants’ descriptions of their past and present experiences with HBPM. I started with an open coding approach to capture any ideas and concepts of interest from data. I developed summary sheets listing all the main issues, events, and variables addressed by the interviewees and noted any new avenue for investigation raised by the research participants. Linked to this, I paid attention to all empirical instances that seem to be related to the research questions, to develop an intuitive sense of what was significant for answering the research questions. Particularly, I looked to those empirical instances that could be relevant to discover the meanings that my research participants gave to such notions as therapeutic goals, therapies, health outcomes, common ground for treatment and responsibility for health care; the attributes they gave to these notions; and the way they identified these dimensions. As new codes emerged in later interviews, previous interviews were reread and re-coded. Once I developed a final list of codes I have re-coded all the transcripts.

At this stage I used the software to carefully examine the material held at different codes. This helped me to provide thick descriptions for the studied phenomena. I used this approach for two purposes. First, I wanted to increase the transferability of the data, which sought that the results of the study could be transferred to other situations or other contexts beyond the scope of the study. It is from this thick description that the audience could determine if the findings might be transferred to their environment.

Second, I used this thick description to analyse connections and patterns between codes. The data were interpreted using the constant comparative method. I sought for negative cases and alternative explanations to challenge the patterns that seemed apparent. The alternative understandings were described and tested. Further questions and possible routes of inquiry were developed to answer the questions that emerged. This helped me to group codes into categories and then in core categories.
Three major themes were apparent from the patient and GP data: (1) building rapport; (2) taking care of one’s health; and (3) control over things. At this stage of data analysis I moved towards developing concepts or relating my findings to existing concepts in the literature. I compared the major themes identified during the data analysis with the theoretical concepts from the literature and established the final core categories: (1) GP-patient relationship; and (2) Patient responsibility for their health in the context of HBPM utilization. However, at this stage the connections between the core categories were not evident. Therefore, I went back to data checking for connections. The final step involved reviewing the data to compare and contrast patients’ and general practitioners’ perspective of the same phenomenon.

5.6 Conclusions

In this chapter, I described the methodology employed in this study. First, I described and justified the philosophical stance within which this study has developed. Second, I described the evolution of the research questions and study design. Finally, I presented the execution of this study including participants’ recruitment and responses, interview themes, data collection, participants’ characteristics and data analysis. In the next three chapters, I will describe the core categories of this study: (1) GP-patient relationship; and (2) Patient responsibility for their health.
Chapter 6: General Practitioners’ Views of GP-Patient Relationship in the Context of Home Blood Pressure Monitoring (HBPM)

6.1 Introduction

In this chapter, I describe general practitioners’ views of the GP-patient relationship in the context of home blood pressure monitoring (HBPM). The purpose of this chapter is to describe how home blood pressure monitoring influenced the GP-patient relationship. This chapter has two sections. In the first section, I describe GPs’ reasons for using HBPM. I show that GPs used HBPM to improve the technical certainty of clinical activities and to motivate their patients to maintain their own health. I also note that, although all GPs used HBPM for similar goals, their account of the impact of HBPM on patients’ motivation to maintain their health varied.

In the second section, I show that the impact of HBPM on patients’ motivation to maintain their own health depended on the type of approach the GP brought to communicating with their patients. Based on the data from the GPs, I identify two types of GP-patient approaches to communication in GP-patient relationship in the context of HBPM utilization, which I label - based on their orientation towards patients’ motivation to maintain their health - positive reinforcement style (PR) and negative reinforcement style (NR). GPs who used PR communication aimed at developing in patients a positive feeling that they could influence their health status, whereas GPs who used NR communication aimed at promoting patients’ worries for and, to some degree, anxiety about their health. I describe the characteristics of these two types of communication and demonstrate that they were associated with two types of relationships. PR communication style was associated with a relational type of DPR where GPs and patients built mutual trust and NR communication approaches promoted a contractual model of the DPR where GPs assessed patients’ capacity to be responsible in the context of HBPM. In chapter nine I will return to these findings to explore their significance for self-management and for the impact of a self-management technology on the doctor-patient relationship (DPR).
6.2 Why Did the GPs in this Study Use HBPM?

For all GPs in this study “building partnership with their patients” was seen as the vehicle for maintaining and improving the health of their patients. Through this they aimed at engaging their patients in their own care, which they saw as a prerequisite for improving their patients’ health. They considered that patients had to make changes in their lives if they were to maintain and improve their health.

“Maintain the patients' health, make sure they are involved in the management of their condition, and with chronic conditions is highly important that the patient is involved because they have to change things in their lifestyle in their life to manage their condition. So if they are not involved they are unlikely to do that. So that implies to have a partnership with the patient that's the most important.”

(Joann)

The GPs used HBPM to help this partnership to promote their patients’ best interests in two ways. First, HBPM improved the technical certainty of clinical activities. Second, HBPM was used as a motivator for enhancing patients’ engagement in their own care. In this section, I describe these two functions.

6.2.1 HBPM and Better Blood Pressure Control

In this study, GPs used the relationship with the patient to secure better control of blood pressure values which, in turn, enhanced both patients’ health and life goals and GPs’ professional goals. HBPM provided a vehicle for GPs and their patients to focus on creating greater technical certainty in the management of hypertension. It did this in three ways. First, all GPs used HBPM for diagnosis purposes. They tried to deal with the white coat phenomenon - a transient increase in blood pressure triggered by the sight of medical personnel. This phenomenon decreased the accuracy of patients’ blood pressure values recorded in the surgery, undermining GPs’ capacities to diagnose and treat hypertension. Most GPs in this study lent blood pressure machines, owned by the surgery, to their patients and then allowed patients to monitor their own blood pressure recordings over a short period of time of up to two weeks. Information was transferred from patients to their GPs to improve diagnostic accuracy and the adequacy of GPs’ therapeutic recommendations.
“…my advice generally to patients is that, if they consistently measure high blood pressure in the surgery, rather than starting the medication straight away, we need to make sure if they don’t have that white coat hypertension, which in fact 20 to 30% of people will do, but we can’t say what 20 to 30% of people it is. So I tend to prefer to use the little portable machines, which for most of the patients are fairly reliable. So we send them off with the machines. I tell them to take a measurement first thing in the morning, last thing in the night and two roughly random times during middle of the day ... and tell them to record that for a week and also to write whatever the machine records for them basically and they then come back with a sheet of paper, we look at the average of what they wrote and if they have 120 over 70 at home than fantastic, they don’t need medication.”

(Gram)

Second, most GPs used HBPM for long term monitoring of hypertension. They recommended HBPM to provide greater confidence for the long-term management of hypertension. In this case HBPM allowed GPs and their patients to improve the long-term monitoring of hypertension, by monitoring the pattern of the blood pressure so that abnormal patterns could be detected early. Isolated recordings in the surgery might not give an accurate understanding of patients’ blood pressure, because blood pressure could have large variations across time. Therefore, GPs recommended HBPM to get a better understanding of patients’ blood pressure patterns. For example, by using patients’ records they expected to gain an understanding of blood pressure values that took into account diurnal variation in blood pressure. They also thought they could have early warning of a sustained rise in blood pressure values that might not be captured by the routine follow-ups. This broader understanding of patients’ pattern of blood pressure improved the diagnosis and treatment of hypertension.

“When they present to a general practice you choose the day and you get a snapshot whereas we can do those three figures over a space of time and I think more data you have the better it is. I think that in this sense home blood pressure monitoring is a good thing as gives you more information. And I guess I also would like to see the dienal variations during the day time because we get figures only they are at us. This helps us with diagnosis and treatment.”

(Amanda)
“I don’t set down any strict responsibilities, just they report to me when it’s high. I usually give them my target and if it’s over 150, you know, for a sustained period of time, I will give medication.”

(Christopher)

Third, GPs used HBPM to tailor their recommendations to patients’ life circumstances. For instance, there were situations when patients did not have access to health care services due to professional or geographical reasons and some GPs in this study recommended HBPM to increase patients’ access to care.

“...And maybe if they have trouble accessing us, if there is a hundred and twenty hours a week flying interstate accountant maybe we give them a blood pressure monitor so that they can do it themselves or suggest that they buy themselves and use it.”

(Harold)

Likewise, patients’ working conditions sometimes interfered with their treatments and some GPs recommended HBPM to enhance patients’ control over their treatment, suggesting that they were prepared to accommodate their recommendations to patients’ working circumstances.

“This is a person who is old, a person who lives in the country. So I don’t see him that often and he basically has his own machine and keeps an eye on blood pressure. I see him once in six months I see how he is going. The other thing is he, I don’t remember exactly where he lives, he works in a very hot environment and is prone to postural hypotension so if the blood pressure looks to be particularly low or it is particularly hot I tell him to skip one or more medications.”

(Francis)

This is not to say that, through this individualization of the therapeutic approaches to patients’ life circumstances, GPs focused exclusively on reaching normal blood pressure values for maximizing patients’ health. Although all the GPs in this study accepted the goal of maintaining ‘normal’ blood pressure values (as dictated by scientific studies or expert bodies), the focus of their practice was rather on promoting patients’ wellbeing and life interests, which, in their view, would enhance patients’ capacity to adopt healthy
behaviours in the long term. These understandings led the GPs to try to maintain “midlevel” or “reasonable” blood pressure values to the extent this was possible given patients’ life circumstances.

“Well a good doctor will try to meet the best golden standards with all these conditions to get to them as close as possible. But also a good doctor will not just slavishly put someone on three different antihypertensive and say the blood pressure is perfect, but the people don’t enjoy life because of the side effects of the medication. You should get the balance right, which means what the experts say the targets are and what is realistically possible. And is always … because I think I understand if they decrease the blood pressure from 180 to 160 is still good even if they do not get 140. So reasonable targets … well you try to attain the gold standard and recommended targets set by National Heart Foundation and that stuff but you tell a patient this is what the target is and we’ll see how we go and if he needs three medications and can’t afford or they have side effects from that I think they won’t care about the targets if they feel like crap.”

(Christopher)

In summary, the GPs used HBPM to improve the long-term management of hypertension. However, they did not slavishly pursue the best possible blood pressure measurements as defined by scientific evidence. Rather, they focused on promoting patients’ wellbeing and interests.

6.2.2 HBPM and Promoting Patients’ Motivation to Maintain their own Health

For the GPs in this study, the second function of HBPM was to enhance patients’ motivation to maintain their own health by engaging patients in their own care. The GPs thought that there were times in the long-term management of hypertension when patients were not motivated to take care of themselves. This was so because hypertension was not associated with symptoms and patients’ didn’t perceive that they were ill.

“I think that, try to remember back. First time I’ve seen him he was very reluctant to start treatment, but after a while he decided that he needs to be treated and this happened probably because hypertension is very invisible. It is not like a cough or cold where it’s happened something wrong with you something visibly wrong with you. With blood pressure is nothing visibly wrong with you so you manage with something invisible.”

(Francis)
In situations such as these, GPs in this study used HBPM to increase patients’ involvement in their own care. This then provided the GP with opportunities to discuss more general health issues with patients.

“I think that most patients we have recommended are those with whom we have difficulties either with compliance or willingness or difficulty in medication or starting a reasonable medication or very high readings in surgery. It might give them a sense of control, of responsibility and again it could be a small component of the treatment. I guess in terms of engaging them in talking about risk factors and suggesting to them that they will go and deal with that risk factor, at least measure it, their engagement increases and that provides us with the knowledge and an opportunity to discuss this change. So it’s another level of engagement.”

(Adam)

Although all GPs used HBPM for similar goals, their views about how well HBPM worked to promote patients’ motivation to maintain their own health and health varied. This was so because some patients developed anxiety when they measured abnormal blood pressure values.

“I: what advantages and disadvantages do you think home blood pressure measurement has?
R: The only disadvantage I actually have found is that some people become quite obsessive about it and this raises their level of anxiety.”

(Ralph)

However, in the long run GPs described different impacts of HBPM on patient anxiety. Six out of the thirteen GPs interviewed said that HBPM was useful because in long run it decreased patient anxiety. In a win-win situation GPs had better control of hypertension and patients were reassured by having access to information regarding their blood pressure. This increased patients’ engagement in their own care.

“To me it’s a win-win situation because his blood pressure is too high we can do things to bring it back to normal and he can double check and reassure himself, so in the end rather than being anxious it will give him certainty once he is on treatment. So he will help us to make the diagnosis we will help him work out that he is getting right. And on the long run
he will be reassured so rather than being anxious about what is his blood pressure he would say: “Look I know my blood pressure is right, in good safe levels. I am not at risk of stroke or heart attack.”

(Cristian)

By contrast, the other general practitioners said that HBPM increased patients’ anxiety.

“I think it increases her anxiety but gives a sense of control for this particular lady. She knows what’s going on but this makes her anxious.”

(Neil)

Some GPs in this group also said that HBPM was not useful to build patient motivation with anxious patients. This was so because these patients were already obsessive about their health.

“I: And how do you think that home blood pressure monitoring influenced their motivation?
C: No I don’t think. The patients who get the blood pressure machines they are pretty well motivated through their obsessiveness already. They are the kind of patients you tell them to do something and they will do it. So home blood pressure monitoring does not help to motivate patients. They are already pre-selected. They go and buy the machines they are a kind of neurotic persons.”

(Christopher)

In summary, in this section, I have shown that HBPM did not change the goals of DPR, but helped the GP and patient in jointly realising their goals. GPs perceived that HBPM helped them to improve the long-term management of hypertension. In addition, I have shown that GPs in this study used HBPM to enhance patients’ motivation to maintain their own health. When patients lost their motivation to follow GPs’ recommendations, GPs employed HBPM to engage patients in their own care. Some GPs thought that HBPM increased patients’ motivation by decreasing their anxiety. By contrast, a second group of GPs described different outcomes. In the next section, I analyse the influence of HBPM on process in the GP-patient relationship.
6.3 GPs’ Views of the Process of GP-Patient Relationship in the Context of HBPM

In this section, I demonstrate that the impact of HBPM on patients’ motivation to maintain their health depended on the capacity of the GP-patient relationship to promote mutual trust. In turn, this capacity to promote mutual trust depended on the characteristics of communication in the GP-patient relationship. During the data analysis, it became apparent that there was an association between GPs’ views about the influence of HBPM on patients’ motivation to maintain their own health and the communication patterns between these GPs and their patients. I identified two communication approaches that I labelled (a) positive reinforcement style (PR) and (b) negative reinforcement style (NR), based on their orientation towards patient motivation to maintain their health. Six out of the thirteen GPs interviewed in this study described a positive reinforcement communication style that was focused on developing in patients a positive feeling that they can influence their health status and the remaining seven GPs described a negative reinforcement communication that was focused on developing in patients a concern for their own health.

The general practitioners in this study gave no indication that they used different communication styles (PR or NR) with different patients. My questioning strategy allowed me to exclude this possibility because in the first part of the interviews I invited GPs to discuss one of their patients, who use or who had used HBPM. The discussion covered any topic raised by the interviewee as well as the decision-making process and doctor-patient relationship in the context of HBPM utilization. Then, I asked the interviewees how that individual patient differed compared with other patients who use HBPM. As a general rule I asked about differences for each topic raised by the general practitioner in the first part of the interview. All GPs interviewed described the same communication styles with all their patients. Table 6.1 briefly describes the GPs’ views of the characteristics of the process in the GP-patient relationship.

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<td>Patients have increased confidence that they can manage their illnesses (Quote - q.13)</td>
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</tr>
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Type of GP-patient relationship associated with the communication style | Relational type of DPR (Quotes - q.2, q.16, q.17) | Contractual type of DPR (Quotes - q.20,

Table 6.1 GPs’ views of the characteristics of the process in GP-patient relationship

In what follows, I describe these two communication approaches and show that the PR style was associated with a relational type of DPR, whereas the NR style was associated with a contractual type of DPR. First, I describe PR communication and demonstrate that this style reinforced a bidirectional relationship between patients’ personal responsibility for their own care and mutual trust and, through this, it promoted both the GPs’ confidence that their patients could manage their illnesses correctly and the patients’ confidence that they were able to manage their own illnesses. This communication approach promoted trust because it accommodated all sorts of patients’ desires and capacities to be involved in their own care. Second, I describe the NR style and demonstrate that it focused on assessing patients’ capacity to be responsible in the context of HBPM utilization. This approach promoted GPs’ reliance on their patients and patients’ confidence that they were able to manage their own illnesses only if GPs and patients shared similar opinions. In cases of discordance between patients and their GPs, this communication style involved GPs in trying persuade their patients to change. This led to distrust in the GP-patient relationship.

6.3.1 Positive Reinforcement Style

The GPs who used the PR communication style suggested a mechanism to increase patients’ motivation by promoting “a positive feeling that they could influence their health status”. They also described that HBPM contributed to this feeling by increasing patients’ engagement in their own care.

q.1 “I think it [HBPM] helps. I think it helps the management of their condition and gives them some feeling of ownership if you want to put it like that. Then it is a benefit for both of us. I mean ownership over their condition or power edge or whatever. In fact some
control. They can feel they can influence their health status I guess by doing something about it, even it is not treating by themselves, but measuring their blood pressure or something else give them more information so they can feel they do more instead of seeing the doctor once a month for their condition who will tell them do this take this or that.”

(Harold)

HBPM utilization facilitated a partnership between GPs and patients. The GPs said that HBPM moved their relationship with patients towards a partnership where both parties were active and aimed at the same goals.

q.2 “I: And how did home blood pressure measurement influence your relationship with this patient?
R: I am not sure. He may be in a better position to answer that than me. But I think that it was something positive because we are a team, both aiming at the same goal. I was changing his medication and he was monitoring the blood pressure and medication to see whether he achieved the outcome that he wanted.

(Ralph)

PR communication was the vehicle through which these common therapeutic goals were established and it had the further benefit of also building mutual trust in the GP-patient relationship. PR communication created an open dialogue between doctors and patients that led to the establishment of common therapeutic goals. It had four characteristics: (1) building partnership; (2) biopsychosocial communication; (3) GPs sought and provided information that was relevant for patients’ health in their social context; and (4) the communication was non-judgemental and autonomy-supportive. Following I describe these communication characteristics and show how they contributed to mutual trust in the GP-patient relationship and to patients’ motivation to maintain their own health.

Building partnerships:

First, communication in the PR style focused on building partnerships with patients to promote trust in the GP. This resulted in patients feeling respected as competent persons. The GPs provided patients with relevant information with respect to how they could be involved in their own care.
q.3 “Well I give them advice, I give them information, and we talk about the best options and then together we make a decision on what to do, whether to increase the treatment stuff or by changing lifestyle, and how they can help that for instance by monitoring their condition. For instance, for diabetes they can help by monitoring blood sugar, for hypertension by monitoring their blood pressure.”

(Joann)

In the views of some of these GPs, this approach promoted mutual trust. Patients trusted their GPs more because the GP respected them as competent persons. The utilization of HBPM implied that patients were able to take responsibility for their own care and this reinforced for patients that their GPs treated them as intelligent persons. In addition, GPs trusted their patients more when patients took responsibility for their own care.

q.4 “I: So you say that giving them control increase their trust?
J: I think it is so. Why? I realized that doctors treating them in this way you say we are treating an intelligent person that can take responsibility for their condition. I think most people appreciate that. And they tend to give more trust to the doctor and we trust them as well.
I: Has home blood pressure monitoring played any role in this?
J: That's one way to let them take control and responsibility. They can see what's going on and they can monitor their own condition. So I think that's a part of the whole idea.”

(Joann)

Biopsychosocial communication:

Second, the PR approach used a biopsychosocial communication pattern, which explored the impact of patients’ illnesses on their lives as well as of their lifestyle on their illnesses. HBPM facilitated this communication pattern by allowing the doctors and patients to discuss patients’ recordings in varied circumstances.

q.5 “Instead they will tell us my blood pressure was high before going to the meeting or riding, and perhaps we can look on different angles of their blood pressure management such as stress time, and how other risk factors are coming into that. And we understand how every part of their life is influencing their health, from the interaction with me to their
desire to improve their health. I mean we understand all those factors that influence their health and desire for health.”

(Harold)

The underlying process of this communication pattern was a negotiation between GPs and their patients focused on harmonising GPs’ therapeutic recommendations with patients’ life circumstances. HBPM helped GPs and patients to understand blood pressure patterns in different circumstances through an exchange of their interpretations. In this way, GPs understood how patients’ life circumstances influenced their health and the views of their patients with respect to their desire and capacity to change relevant risk factors. GPs could tailor therapeutic recommendations based on patients’ suggestions and this in turn increased patients’ engagement in care and adherence to therapeutic recommendations.

q.6 “I have a particular lens or view of his situation which is very narrow. So he could come to some agreement about the way I view his health, but that does not necessarily translate on how he [patient] views. I have a gentleman in his late fifties, I think, a low income earner who’s a heavy smoker, with type 2 diabetes, who has had elevated office readings or certainly above what I consider acceptable for a diabetic. And this patient had already his sphygmomanometer at home and came with his figures. So we discussed lifestyle issues and quitting smoking is important. So if [there] would be little or no cost involved in the decision to give up smoking so probably we easily agree. But given he is addicted to nicotine and smoking is an important part of his social life, there is a high cost to him to give up smoking and so there is resistance to give up smoking. Or if I say I am concerned about your blood sugar we should add some medication that it will help reduce it, which I did, the cost in taking more tablets, financial costs and potential side effects and this is something we can talk about it so I think the cost to him is lower. So although objectively there are two or three risk factors which have equal impact on your health, or some more than others, and here are my priorities to change, some will be a lot easier for him to participating just because he approximated his lifestyle already, the circumstances might be already encouraging him already to change whereas some others gets the grain … So I think part of understanding is that where people are coming from is important and not everything we tell people is acceptable for them.”

(Adam)
Most GPs in this group perceived that this process of going along with patients was good for patients’ engagement in their own care. Going along with patients, even when patients’ and doctors’ therapeutic options were at odds, promoted patients’ trust in their GPs because patients felt that they were taken seriously as persons.

q.7 “I feel that [respecting her suggestions] she feels that she’s taken seriously and that her opinion is valued, and that her suggestions are not dismissed out of hand. I think that if you discourage people they are less likely to engage [in care] and if you encourage them they are more likely to engage.”
(Frederick)

Seeking and providing information:

Third, the PR approach focused on seeking and giving information that was relevant for patients’ health. The underlying process was feedback between GPs and their patients that helped clarify the differences between doctors’ and patients’ views and expectations with respect to management of patients’ illnesses. For instance, GPs and patients worked together to check the reliability of patients’ machines. This resulted in GPs trusting patients’ recordings because they learnt that patients’ blood pressure machines were accurate and that patients used them correctly.

q.8 “And how have you decided whether their measurements are accurate?
C: By telling them to bring it [blood pressure machine] in and do it simultaneously. So I check their machines and if they’ve done it in a while and their readings are really different with mine, I would say the next appointment bring the machine and will see how accurate they are and how closely they relate to each other.”
(Christian)

q.9 “I told him to bring the machine to look at it to see whether he is using it correctly and get some idea whether the machine is accurate and compare to our own machines.”
(Ralph)

In addition, HBPM also facilitated feedback from patients that helped GPs to clarify the differences between their and their patients’ interpretations with respect to the significance of the blood pressure pattern. This approach helped GPs to plan future therapeutic actions that could promote patients’ capacity to manage their illnesses more successfully because they understood the concepts behind the management of their diseases.
q.10 “I think it [home blood pressure monitoring] improves it [communication] because it gives extra points to talk about it and it’s a good way of understanding what they understand about their problems because we talk about their blood pressure how they relate to it how they record it. It’s a good way of getting feedback from them about how the messages I’ve given to them about blood pressure are coming back. If they talk to me in a well-educated way then they obviously understood what is about if they don’t understand and they come back with the blood pressure machine or write it funny or don’t know what to do with the machine then there is a simple rule of life ...maybe they didn’t understand what I told them. So it’s a good way of getting feedback on that or whether they understand the concept or not. This helps us to know what we have to do next.”

(Christian)

Through this process GPs developed their own confidence that patients had the required knowledge and skills to manage their own illnesses.

q.11 “I: How has home blood pressure monitoring influenced the trust you have in this patient?
R: It influenced me because I know he understands the concepts, I know he understands what he is looking for, so that means I am happy that when we treat it and when he monitors that he will have a safe understanding of the implications of the high blood pressure and is more likely that he will take the medication appropriately because he will check whether he is doing well or not.”

(Ralph)

q.12 “I trust him to do the machine and to give me the correct readings because I think he realizes that if he gives me wrong readings he will harm himself as well. And I trust him that he takes care of his condition as well. And he has a good control over it.”

(Joann)

In addition, GPs said that, through the same process, patients developed their own confidence that they could manage their illnesses. This confidence was, in part, the result of HBPM utilization because in this way patients had information about their illnesses that allowed them to understand if they were on the right track. This confidence was also enhanced by GPs who reassured patients that they trusted them and that they would take
seriously their blood pressure values measured at home. In GPs’ views this decreased patients’ anxiety and increased patients’ capacity to reflect on their illnesses.

q.13 “I think he worries less rather than more because last time when we had a problem with his back and his hip and he was here, he worried more and more about his blood pressure whereas I think that we can reassure him that he can check the things and see if everything is alright. He will balance his response so we can keep him less anxious so I think he will be less anxious about it because he has some way of checking it. Is an extra tool to have him think about the illness and rather than worrying, I think it’s more about supporting him to be autonomous and independent and to be looking more after himself. So it’s more about him caring and me helping rather than me running his blood pressure. So he understands that under different circumstances his blood pressure might be higher, but at home might be lower. And in the end I am happy with all his readings and I don’t need to do more checking on the fact that he is actually accurately reporting them.”

(Christian)

Non-judgmental communication:

Fourth, the PR style used nonjudgmental and autonomy-supportive responses to engage patients in HBPM. This communication pattern was characterized by exploring patients’ desire to be involved in their care.

q.14 “I: What does it mean he is involved?
J: They can see themselves that their blood pressure is under control and if it goes higher than they can come in and discuss it. So they know what their blood pressure is, gives them some more control over it. Rather than monitoring every now and then in the surgery.
I: What has been your role in the decision making process?
J: I discussed with him first told him what's available and explored his feelings towards this to see if it is agreeable and then I've gone.”

(Joann)

These GPs recommended HBPM to all their hypertensive patients, but were not overly directive. There were some patients who did not want or were not prepared to be involved in their own care by monitoring their blood pressure. In cases when patients were not
willing to self-monitor their blood pressure, GPs supported open dialogue by suggesting to their patients that they could discuss this again in the future if patients changed their mind.

q.15 “F: I think that to anyone who is not motivated to look after their blood pressure I give usually some reasons to as how I think that blood pressure would be better managed, indicate that we can help with their blood pressure, but further it is their choice to choose and, that we will be happy to help them out in the future and that we are ready manage the blood pressure.”
(Frederick)

These GPs were open about tailoring the GP-patient relationship to patients’ various desires of being involved in their care. A non-judgmental stance helped these GPs to do this.

q.16 “I always had the view that I am an adviser I can be the resource, but I can’t tell people what to do. They have to choose what to do. So more often you tell someone so they can make an educated decision and do a risk analysis and the pros and cons of this then more they would be in the position to decide what they want to do. There are some people who want that I do the decisions and then they will follow them blindly and I am ok with that, but I do think that it is important to involve the people that they make the choices they want to do it.”
(Ralph)

These GPs thought that this nonjudgmental characteristic of communication increased patients’ trust in their GPs because it avoided confrontation and enhanced collaboration. HBPM helped this by allowing doctors and patients to establish a relational type of DPR, by which they meant a partnership between GPs and patients where both parties worked together by co-authoring common therapeutic goals.

q.17 “How did home blood pressure measurement influence the trust he has in you? I guess in several ways. One is because of the way we are doing it. Two is because he checks what I am saying to him and is not just me saying something which is not true he can go and check by himself. And so I think it gives us a common starting point to discuss the pro and cons of medication and gives us information to talk about. Sometimes people you talk them about them they feel threat or feel the criticism, whereas when we talk about
blood pressure it means we both talk about management and gives us a chance to be both of the same side and is about getting it right instead of I am talking to you because it is not right. So it means we work together.”

(Christian)

In summary, I have showed that GPs adopting the PR style to the DPR aimed at developing in patients a positive feeling that they could influence their health status. This occurred within a relational type of GP-patient relationship, described by GPs as a partnership where both parties worked together to co-author common therapeutic goals. The PR style was characterised by: (1) building partnerships with patients; (2) biopsychosocial communication; (3) seeking and providing information that was relevant for patients’ health in their social context; and (4) communicating in a non-judgemental and autonomy-supportive way.

6.3.2 Negative Reinforcement Style

In this section, I describe the NR style and compare it with PR communication. I show that GPs who used the NR approach aimed at motivating their patients by making them worried about their own health. The main expected outcome was to promote patients’ compliance with GPs’ recommendations by developing patients’ sense of responsibility for their health outcomes. I describe the characteristics of communication in the NR style and show that it was associated with an assessment of patients’ capacity to be responsible in the context of HBPM utilization. This was consistent with a contractual model of the DPR where patients’ engagement in their own care depended on patients’ sense of responsibility and capacity to comply with GPs’ recommendations. In cases where patients and GPs shared similar opinions or affiliations, GPs developed a partnership that promoted patients’ confidence that they could manage their illnesses. In cases of discordance, GPs tried to persuade patients to change their behaviours. This type of relationship increased confrontation and distrust and GPs who used the NR approach restricted the recommendations for HBPM only to patients whom they relied on.

The general practitioners involved in NR style aimed at motivating their patients by making them concerned about their own health.
q.18 “I aim to shape in them the awareness of the possible consequences of under-management or suboptimal management, which I guess plays on the concern for avoiding future complications or adverse effects of high blood pressure or diabetes or whatever it is. So that’s a combination of being aware of the problem and relation to other problems that could be reduced through good management.”

(Gregory)

Similar to GPs who used the PR approach to communication, GPs who used the NR style aimed at increasing patients’ responsibility for their own health. However, GPs who used the PR style understood responsibility as role responsibility or patients’ capacity to control their health. By contrast, GPs who used the NR approach aimed at increasing patients’ sense of responsibility for their own health. The main expected outcome of NR style was to increase patients’ compliance with GPs’ therapeutic recommendations. In cases when patients were not compliant with GPs’ recommendations, these GPs tried to persuade their patients that an ‘admirable’ health care decision might influence their health and life outcomes in a positive way.

q.19 “We can’t think anything more than giving the information and resources and the advice. But still we can motivate them they can find the right hook it’s the way I think ... If you want to see your grandchildren you will change things for better ... If you want keep playing bowls you’ll do better if you will lose weight. So it’s a way to say that your blood pressure will be better if you lose weight. So motivation is very important for life style changes but also for compliance with medication ... I try to use that to motivate them, it’s a bit of emotional blackmail sometimes. It’s a technique. So if you want to see your grandchildren grown up, you want to lose weight or you do not want to go blind and that sort of things.”

(Christopher - GP)

The NR approach was associated with a contractual model of the DPR. GPs needed to trust and to be trusted by their patients to recommend HBPM to them. However, whereas for PR-GPs mutual trust was associated with GPs’ confidence that patients had the required abilities to manage their illnesses, for NR-GPs mutual trust was associated with GPs’ confidence that patients will follow their instructions. This was so because these GPs perceived that using HBPM implied a transfer of responsibility from doctors to their patients.
q.20 “I: What is the significance of this mutual trust?
F: I think it works both ways. If the practitioner doesn’t trust the patient then the practitioner shouldn’t put any responsibility to the patient, if you don’t trust him at all I think. Vice versa if the patient doesn’t trust the practitioner, then you worry about compliance, you got compliance issues. You cannot use the blood pressure monitoring as a determinant for medication, if you don’t trust the patient. That person should comply with what you say.”
(Francis)

By contrast with PR-GPs who said that patients felt that they were treated as intelligent persons when GPs involved them in their own care, the NR-GPs said that, in the context of HBPM, patients’ capacity to be responsible implied certain personality traits on patients’ part. For example, these GPs perceived that patients needed to be intelligent enough to understand the concepts behind HBPM utilization and had to have the required psychological abilities to monitor their blood pressure by themselves.

q.21 “I: What factors have influenced you to recommend home blood pressure monitoring to this patient?
G: I think his education. I also think he is a reasonably intelligent person. Yee education and intelligence does help. He has a biology background. It is not medical but it is a biology background. ... There are also some people trying to do that and then they’ve given up because they got too stressed by doing it. So his contribution is that he can do it without being stressed by doing it.”
(Gregory)

The GPs who used the NR approach used communication to evaluate patients’ capacity to be responsible in the context of HBPM utilization. This communication was patient-centred, in the sense that GPs used it to identify patients’ personality traits that could indicate compliance. This communication process was characterized by three factors: (1) biopsychosocial communication; (2) communication pattern focused on biomedical issues and on providing patients with standardized guidelines; and (3) communication focused on persuading patients to follow GPs’ therapeutic recommendations. HBPM facilitated and enhanced the characteristics of this communication style. Following I describe the characteristics of this communication style,
the role of HBPM and show how the characteristics of this communication approach related to mutual trust in the GP-patient relationship.

**Biopsychosocial communication:**

First, the GPs using the NR style communicated in a way that focused on biopsychosocial issues. Although this communication characteristic was described by both GPs who used PR and NR styles, GPs in these two groups used it in different ways. Whereas GPs using the PR style used biopsychosocial communication to integrate their therapeutic recommendations into patients’ specific life circumstances, GPs using the NR style used it to identify the commonalities between them and their patients. Similar interests and affiliations of GPs and patients could promote a sense of reliance on each other.

**Q.22** “I: What kind of factors or circumstances shapes your trust in him?
F: I think respect for each other in his area of expertise. He is a wine maker and I trust he makes good wine and I am a doctor and he trusts that I do the right thing for medical matters.”
(Francis)

**Q.23** “I: And how did home blood pressure measurement influence the trust he has in you?
L: Some of that trust might be because he knows my interest in computing as a hobby and he knows what I can do with the speed stick. This can make him to think that we have some similar interests or that I am up to date doctor that I can do things most doctors don’t know to do with this [speed stick]. So in that sense is a kind of rapport building and maybe the benefit.”
(Laurence)

Similarly, a nursing or medical background of their patients or of family members encouraged GPs to think that they could rely on patients’ ability to monitor their blood pressure in a reliable way and that patients would be compliant.

**Q.24** “The advantage [of home blood pressure monitoring] will be that he would be alerted that he could have a problem. The disadvantage is that he might kid himself that he might have good blood pressure at home if he had good results and he may ignore the
higher ones, but I would suspect that he might not do this because he is tempted to seek advice and because his son is a doctor he will take it seriously.”

(Amanda)

Seeking and providing information focused on biomedical issues:

Second, GPs using the NR style focused on seeking and giving relevant information, just as the PR-GPs did. However, GPs using the NR approach used information transfer to assess patients’ personality traits, whereas GPs using PR style used it to build trust in patients. For instance, NR-GPs gave standardized instructions with respect to HBPM utilization and then used the information that came back from their patients to assess whether patients had the required abilities to comply with their instructions.

q.25 “… what I tend to do is, if a patient has blood pressure that’s above the range we will be treating in the surgery as long as it is not stupidly high blood pressure measurement … if it is say the sort of 150 over 90 I’ll send home. Next time he will come to me; we will check it again and, if it is still high we will send him at home to measure, explain him, tell him a bit about the procedure then they come back and if they have high blood pressure then you explain exactly the procedure tell them the sort of table we want them to draw up and then leave them to draw up their own table because it’s a good indication of how aware they are, of organizational matters, and also how much responsibility are they prepared to take. Some people come with excel spread sheets …then you will get to be a good patient a nicely compliant patient. But if you come with something scratched on a piece of paper that means that won't be able to follow any instructions.”

(Gram)

Obtaining patients’ compliance with GPs’ therapeutic recommendations implied that patients trusted their GPs. Compared with the previous group of GPs, who promoted trust by harmonizing therapeutic recommendations with patients’ life circumstances, this group focused on explaining their therapeutic recommendations to patients. When the GPs felt that patients did not rely on their recommendations they used HBPM to facilitate a “second opinion” to reinforce patients’ trust. This also promoted patients’ confidence that they were able to manage their illnesses by reassuring them that they were on the right track with the management of their illnesses.
q.26 “So we talk about trust, so some may not trust. Look again I have a lady patient who has what we call labile blood pressure, who is very medically savvy, who monitors her home blood pressure so she can avoid taking any medication and I think her blood pressure has been reassuring for her. She also has some degree of asthma and some chest pains, which have been perhaps reflux in origin, so we have somebody, who was a little bit more anxious maybe because she is so well educated and good in her verbal communication and is very hard to presume that we are right and I think home blood pressure monitoring was good for her to reassuring her that her blood pressure was not that bad and that the treatment she has is satisfactory.”

(Gregory)

**Persuading patients to change:**

Third, GPs using the NR style tried to persuade patients to change their behaviours around HBPM. For instance, most GPs in this group considered that HBPM was not suitable for anxious patients who measured their blood pressure very often and became obsessed with variations. This often resulted in higher blood pressure values.

q.27 “The disadvantage [with home blood pressure monitoring] is that sometime they become a little obsessed with respect to their blood pressure. ... well, the obsession often I think probably results in a higher blood pressure but ...and you hear that when they have a headache they hook their blood pressure machine on them and they start to obsess about getting their BP down or that sort of things”

(Gram)

In these circumstances the GPs persuaded patients to change their behaviour by monitoring their blood pressure less and discouraged patients from using HBPM if they anticipated that patients’ anxiety was likely to increase by using HBPM.

q.28 “N: I have an obsessive man who comes in with a meticulously recorded three times a day recordings and I have told him that he has to do it two or three times a week because I don't want him to remain obsessed so I have some concern about the selection of the patients.

I: What happen with those patients who are not suitable for home blood pressure monitoring?
N: I think we just continue to ... first of all I make no suggestion that they buy an instrument. If they express an interest in it, I just tell that this cost money and they just can pop in have the sister checking their blood pressure or in the shopping centre and that's good enough. Or I generally discourage them in any other way.”
(Neil)

Despite their efforts, most GPs in this group also mentioned that this strategy was not successful in motivating patients to follow GPs’ recommendations.

q.29 “Other aspects of that interaction would often mean that you have your neurotic well patients measuring their blood pressure at home whenever they feel unwell and presenting you a list of figures, which is dreadful, which probably don’t represent their full spectrum of blood pressure readings. That's another gentleman here [looking to his notes] who was going to show me page after page with blood pressure records four to six times a day and eventually I couldn't stop him.”
(Gregory)

The discordance between GPs’ and patients’ views with respect to management of hypertension or the utilization of HBPM often led to conflicts which influenced the GP-patient relationship in a negative way. Some GPs in this group associated anxious patients’ behaviour with an inability on the patients’ part to trust GPs’ decisions. That further enhanced the conflict in the GP-patient relationship, because GPs felt that their decisions were not valued.

q.30 “F: Again I think that their [anxious patients] behaviour reflects that they don’t trust you as much. They want to see for themselves and vice versa they don’t trust me that much how can I trust you that you will take the medication I am asking to take?
I: And how home blood pressure monitoring influence mutual trust in this specific group of patients?
F: I think it wasn’t particularly helpful. I think they go and buy a machine come back with readings and I explain to them that all the readings are in the range of normality and they drop off the machine saying: “If I am normal why should I measure it?” If you really feel that somebody does not trust you, simply say “why monitor your blood pressure simply stop the medication and see what happen.”
(Francis)
Because of all these factors, these GPs recommended HBPM only to patients whom they trusted.

q.31 “But you do this [home blood pressure monitoring] with the right sort of patients that you do really trust you have a good relationship you know what I mean and don’t do this with all the patients ... you have to have a long relationship with him to know he is intelligent enough to handle that sort of things you put some written action plan some guidelines.”

(Christopher)

In summary, I have shown that GPs who used the NR style aimed at motivating their patients by making them concerned about their health. The expected outcome was to develop patients’ sense of responsibility for their health outcomes. The GPs aimed to persuade patients that an ‘admirable’ health care choice could influence their health outcomes in a positive way. This communication approach was consistent with a contractual type of DPR. The characteristics of that communication - its biopsychosocial orientation, focus on seeking and giving relevant information to assess patients’ compliance and restricting HBPM only to patients whom GPs trusted – could be successful by promoting mutual trust and patients’ confidence that they could manage their illnesses, but it could also lead to distrust and confrontation in DPR.

6.4 Conclusion

In this chapter, I have considered the ways in which GPs’ goals for HBPM related to their approaches to communicating with patients. I have shown that GPs used HBPM to facilitate collaborative approaches with their patients devoted to promoting patients’ health. HBPM both improved blood pressure control and enhanced patients’ motivation to maintain their own health. Although GPs used HBPM for similar goals, their views of the potential of HBPM to enhance patients’ motivation to maintain their health varied.

In the second section of this chapter, I showed that this variation depended on characteristics of the communication process in GP-patient relationship. I identified two types of communication approaches: positive reinforcement and negative reinforcement. GPs who used the PR approach aimed to develop in patients a positive feeling that they could influence their health status, whereas GPs who used the NR approach aimed to
promote in patients’ a concern for their health. The PR approach was consistent with a relational model of DPR whereas the NR approach followed a contractual model. In both these relationships, HBPM enhanced and facilitated the communication patterns of these relationships. In addition, the utilization of HBPM in PR relationships facilitated mutual trust and patients’ confidence that they could manage their illnesses, whereas its utilization in NR promoted GPs’ reliance on their patients and patients’ confidence only to the extent patients and GPs agreed on therapeutic goals. These are partial views of HBPM and its role in shaping the DPR. In the next chapter I will discuss the patient perspective on HBPM and its role in shaping the DPR.
Chapter 7: Patients’ Views of GP-Patient Relationship in the Context of Home Blood Pressure Monitoring (HBPM)

7.1 Introduction

In this chapter, I continue to investigate the role of HBPM and its impact on doctor-patient relationship by describing patients’ views of the GP-patient relationship in the context of HBPM and comparing their views with GPs’ views. The chapter has two sections. In the first section, I describe how patients understood, justified and built the goals of the GP-patient relationship in the context of HBPM, and the functions of HBPM in relation to these goals. Throughout I compare patients’ account of the goals of doctor-patient relationship (DPR) with GPs’ understandings. I demonstrate that, from the patients’ point of view, the main function of HBPM was to facilitate collaborative approaches between patients and GPs, focused on improving the technical certainty of clinical activities associated with the management of hypertension. In addition, patients used HBPM to increase their control over their own health through engaging in their care. However, patients’ engagement in their own care arose as a result of a trusting GP-patient relationship rather than an initial expectation of HBPM.

In the second section of this chapter, I describe patients’ views about the communication process in the GP-patient relationship and the influences of HBPM on this process. The two communication patterns were the same as those I have identified for the GPs: one pattern that focused on positive reinforcement (PR) and a second that focused on negative reinforcement (NR) of patients’ health agency. Patients with higher engagement in their own care were involved in GP-patient relationships characterized by a PR communication style, whereas patients with narrower engagement were involved in GP-patient relationships characterized by a NR communication style. The type of approach they took depended on whether they thought that their GPs were interested in them as individuals. In chapter nine I will return to these findings to explore their significance for self-management and for the impact of a self-management technology on the DPR.
7.1 Why Did the Patients in this Study Use HBPM?

All the patients in this study described collaborative relationships with their GPs in the context of HBPM. All patients said that these approaches with their GPs were prompted by their perceptions of their responsibility for their own health, by which they meant their duty to maintain their health.

“Sort of a lot is common sense. You have to be sensible with your health, don’t you? Everybody with their health should be sensible if you got something you should not really neglect it.”

(Laura)

This understanding of personal responsibility promoted a therapeutic alliance between patients and GPs that was good for patients’ health. This was so because it encouraged patients and doctors to help each other to control patients’ blood pressure values. Patients used HBPM as a tool to help themselves and their GPs. In turn, patients perceived that their GPs were able to individualize their therapeutic recommendations to patients’ biological and, sometimes, psychological needs.

“Well I first took it on because my doctor, he examined me for many years, and at Christmas time before the end of December last year, my blood pressure changed and went high, and it’s never been and he gave me some tablets to take which was frightening. And I thought, I have a machine and I’ll do a check for myself, and that could help, because I was in the ambulance business, and I bought one and what I actually do with this machine is for his benefit and myself. And that’s the main reason of having a machine is just to have some check for his benefit, as well as, I know if I need to see a doctor.”

(Mark)

Similar to their GPs, patients used HBPM to help this partnership to promote their best interests in two ways. First, HBPM improved the technical certainty of blood pressure measurement. Second, HBPM was used as a means to increase their control over their own health. In this section, I describe these two functions.
7.1.1 HBPM and Better Blood Pressure Control

Patients used the relationship with the GP to secure better control of their blood pressure which, in turn, enhanced both patients’ health and life goals and GPs’ professional goals. HBPM provided a vehicle for patients and their GPs to focus on creating greater technical certainty in the management of hypertension. However, HBPM did not change the goals of the partnership between GPs and patients. Rather, it helped this partnership to reach its goals. Patients helped GPs in three ways.

Firstly, GPs could not accurately diagnose and initiate effective treatment without patients’ help. For instance, isolated measurements taken in the surgery might not be sufficient for GPs to understand the pattern of patients’ blood pressure. Therefore, patients used HBPM as a tool to help their GPs to acquire better knowledge with respect to their blood pressure. Patients felt that by using HBPM they increased the capacity of their GPs to monitor their blood pressure and adjust their medication appropriately.

“Every time I went to the doctor my blood pressure seemed to be up quite a bit and we just discussed whether it might be the white coat syndrome and so I think it might have been his idea in the beginning that perhaps I could try to monitor at home and that’s what I have been doing for quite some time. So, I think that possibly by taking my measurements at home he could see that it was down a bit from when I go to see him and I suppose that’s my personality which makes blood pressure go up when I am confronted with the doctor, although we know him and he is a friend. I do feel that this was a help in him being able to prescribe the medication. So that’s probably the reason why ...in first place because I have this sort of white coat syndrome that made me have blood pressure taken at home.”

(Sara)

“Well she [her general practitioner] would do it [blood pressure measurement] anyway, but because I was doing that homework for her, research at home for myself, it gave her a lot more material to work with when I came back... I showed her a lot more numbers that she couldn’t afford to do. She couldn’t live with me and check my blood pressure every couple of hours every day.”

(Anna)

Second, patients assisted their GPs in establishing optimal treatment. Patients were aware that establishing a hypertension medication plan was individual-specific, “a trial
and error” process. By monitoring their blood pressure at home, they increased their doctors’ capacity to individualize their treatment.

“That’s the problem he said, we do by trial and errors. “Because” he said: “everybody’s system acts or reacts to tablets in different ways. What’s good for you may not be good for others.” What’s good for me could be good for me and makes the next person ill. What I think it [home blood pressure monitoring] gave him a better guide on what was taking place. Because as I said with that Avopro being at 150 it was alright for a few days, more than few days, probably a couple of weeks, and then all of a sudden went high again and he had to change it. So by me monitoring my blood pressure he was able to change it.”

(Mark)

Third, patients assisted their GPs to better understand the pattern of their blood pressure by measuring their blood pressure in environments and circumstances that were otherwise unavailable to the GP. Thus, they wanted to allow their GPs to see how their life circumstances influenced their health so that their GPs could optimize their treatments.

“Well, I think my doctor recommended it [home blood pressure monitoring] to me probably to help him more so than to help me, because he was the one who was giving me medication. So it must have some effect on the doctor to know to treat the patient. Isn’t it? So to me, how can a doctor help you, if he does not know what’s going in 24 hours or when are at home. They don’t know what happen when you are digging your garden or when you are under a lot of stress or worry or get family problems, a lot of stress you might have, you may not have a good relationship in your marriage. It can affect all people”

(Emily)

However, this is not to say that by helping doctors to individualize therapy to their life circumstances, patients’ only aims were to reach normal blood pressure values. In the same way as the GPs, the fact that patients could individualise their therapy helped patients to realise their life interests. For patients, achieving a state of health was a means to reach other valued ends in their lives. In the context of HBPM, taking care of their own health meant reaching the target values of blood pressure in order to maintain their lifestyles.
“At that stage I finished going back to my doctor, saying that I was having dizzy spills. When I was getting up it was no blood in the head and I had to stop. It was no pain, but I had to stop and wait for two or three seconds for blood to catch up and then to go away. Now he immediately suggested that it was because I was on too large a dose of medication and it could be cut back. So we had a discussion about my blood performance and we came to the conclusion, and I agreed with him, that around 140 for a man, aged seventy, is probably not really bad. So if we can keep it around that level then we think that is a good management we should achieve. There is no point in getting it down at 120 because it means that I have to take tablets and medication to bring it down twenty ranges what is going to achieve? I don’t want dizziness, I am quite happy with my life with the way it goes, I am reasonably fit and I think that managing in this way is the best way to go, rather than trying to make it become what is theoretically almost an impossibility at my stage. Because I can live at my age I am reasonably fit. I drink half bottle red wine a day along with my wife. I play tennis. I play golf. And generally I keep fit by working in this garden I’ve got, which is quite demanding.”
(Sam)

In summary, the patients used HBPM to improve the long-term management of their hypertension. However, they did not pursue the best possible blood pressure measurements as guideline defined blood pressure targets. Rather, as discussed in more detail in the next section, they focused on optimizing their own wellbeing and interests and their control over their health.

7.1.2 HBPM and Promoting Patients’ Control over their Own Health

For the patients in this study, the second function of HBPM was to enhance their control over their own health through an increased engagement in their own care. Most patients described how HBPM helped them to take a more active role in managing their health. However, this engagement in care varied. There were two groups of patients identified in the data analysis. The first group of patients said that HBPM helped them to identify when they needed to consult general practitioners because of abnormal blood pressure values.
“You might not go to the doctor for months and in the meantime I wouldn’t have known that it was up and the need for medication to be controlled. So I think it’s, if your blood pressure is irregular and does go higher, I think it’s at least an informed thing, when you go along to the doctor and take the records with you.”

(Gertrude)

The second group of patients described a higher degree of engagement in their own care. They said that HBPM helped them to understand the link between their lifestyles and blood pressure status, enabling them to make behaviour changes thereafter.

“I am curious ... and I thought: “oh that would be a great opportunity instead of a one day for the doctor for one minute, I can check it up for a week and get some insight into why it goes up or when it goes up or maybe when I am at risk and was very high at the time. But by understanding probably I can get carried away in the garden and I might stay there for an hour instead of staying there for five hours and come back and have lunch have a drink when I am very tired, very satisfied but very exhausted. So I may say myself: “Right, have a drink, have something to eat, have some rest and go back again later”

(Anna)

Although most patients said that HBPM made them feel in control of their health, and helped them to understand the consequences of their behaviour on their blood pressure, these were the consequence of their interaction with their GPs, rather than an explicit initial expectation.

“M: I’m in control to do it [measure blood pressure] when I want to do it, which is really good thing to me.
G [her husband]: But I guess in the first instance you were told to do it by the doctor.
M: I haven’t been told to do it.
G: You wouldn’t have done it without your doctor saying to do it.
M: Oh, I wouldn’t have done it! I wouldn’t have said: “Oh, that’s a pretty blood pressure machine, let’s take it home”. No I wouldn’t have done that.”

(Conversation between Mary and George)

In addition to these perceived benefits, all the patients in this study reported that they used HBPM because they trusted their GPs.
“I didn’t have any expectations at all. I was concerned about my health, because I’m getting older, and I want to be around for long time, so, I thought it would be a good idea. I didn’t have any expectations. I am completely comfortable with and trust the doctors at the surgery where we go, especially Mary [her general practitioner]. You know if she tells me to do something because it is good for my health, I would do so. So, I really have no expectations at all.”
(Sandy)

“I have a very strong trust in him [her general practitioner]. If he is saying that I should be doing these things [monitoring blood pressure] then I am more than likely to do them. Perhaps not without questions, but eventually if I satisfy myself that what I have to do and why I have to do it then I am quite happy to do it.”
(Sam)

In summary, I have suggested that HBPM did not change the goals of DPR, but helped the patient and GP in jointly realising their goals. Patients used HBPM to help their doctors to improve the long-term management of hypertension. In addition, patients used HBPM to promote their health and lifestyle interests by increasing their control over their health through an increased engagement in their own care. However, this engagement varied. In addition, all patients in this study said that this engagement was a consequence of trusting relationships with their GPs, rather than an expectation from using HBPM. In the next section, I describe the processes through which mutual trust in GP-patient relationship was built and how HBPM influenced this.

7.2 Patients’ Views of Process in the GP-Patient Relationship in the Context of HBPM

7.2.1 Introduction

In this section, I show that patients’ engagement in their own care depended on the capacity of the GP-patient relationship to promote mutual trust which, in turn, rested on the characteristics of the GP-patient communication. During the analysis it became apparent that there was an association between the degree of patients’ engagement in their
own care and the communication process in the GP-patient relationship. The two groups of patients with different degrees of engagement also described different communication characteristics within the GP-patient relationship. The two communication styles described by patients mapped onto those I have identified for the GPs: one style that focused on positive reinforcement (PR) of patients’ health agency and a second that focused on negative reinforcement (NR) of patients’ health agency. Patients with higher engagement in their own care were involved in GP-patient relationships characterized by PR communication, whereas patients with narrower engagement were involved in GP-patient relationships characterized by NR communication. The type of approach they took depended on whether they thought that their GPs were interested in them as individuals and whether they had been able to find a GP who took this interest in them. Table 7.1 briefly describes patients’ views on these two types of communication styles as described by patients.

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<td>Assesses patients’ and GPs’ trustworthiness (Quotes - q.16, q.17, q.18, q.21)</td>
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<td>Patients’ confidence that they could manage their illnesses</td>
<td>Patients’ increased confidence that they could manage their illnesses (Quotes - q.1, q.14)</td>
<td>Patients’ increased confidence that they could manage their illnesses to the extent they shared similar values with their GPs (Quotes - q.16, q.17) Distrust in cases of discordance between GPs and patients. (Quote - q.24)</td>
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<tr>
<td>Type of GP-patient relationship associated with the communication style</td>
<td>Relationship-centred type of DPR (Quote - q.13)</td>
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Table 7.1 Patients’ views about the characteristics of the process in the GP-patient relationship

In this section, I analyse the influences of these two communication styles on mutual trust in the GP-patient relationship and compare patients’ accounts with GPs’ accounts of the communication process in DPR. In the same way as in the previous chapter, I show that the PR style occurred within a relational type of DPR, whereas the NR communication style was associated with a contractual type of DPR. I show that these two relationships had different capacities to promote patients’ confidence because the communication processes that characterized them had different capacities for promoting mutual trust in the GP-patient relationship. In what follows, I describe patients’ views about the relative impact of these two communication patterns and HBPM on mutual trust and patients’ confidence that they were able to manage their illnesses.
7.2.2 Positive Reinforcement Style

Patients involved in PR communication style described an engagement with their care that focused on fostering the patients’ adherence to their medical treatments and promoting lifestyle changes that could help them to improve their health. Patients in this group attributed this engagement to their perception that HBPM helped them to develop cognitive and psychological skills to manage their illnesses.

(q.1) “The only time when you ever found out what it [blood pressure] was is when you went to your doctor. So by doing it at home you keep an eye on it to see what exactly happens. You understand your lifestyle. If you drink too much in the night when you wake up next morning you know it’s high, if you don’t, you know, it’s pretty reasonable. If you drink too much, next morning you think you should not drink overly much. Also you know it gets down over the day and it’s not that high over the twenty four hours period. And that’s good because I am worried about if it is getting too high I might have a stroke. You also understand that when you get stressed your blood pressure gets up too. So you want to control that. So you know when you are stressed that your blood pressure goes through the roof, so you try to take it easy and calm down yourself and get it down again. So you wouldn’t be able to do that if you wouldn’t measure your blood pressure. You know when it’s high when you’re stressed so you try to calm down and do things differently. And it does work. And also you take your tablets.” (Gerry)

The positive reinforcement communication style was the vehicle through which HBPM supported patients’ engagement in their own care. This was so because this communication style increased patients’ confidence so that they were able to manage their illnesses. The pathway through which this communication pattern influenced patients’ confidence was mutual trust between GP and patient. It had four characteristics: (1) building partnership; (2) information giving and seeking; (3) communication that was non-judgemental and autonomy-supportive and (4) biopsychosocial communication. I will now present patients’ descriptions of these communication characteristics and show how they contributed to mutual trust in the GP-patient relationship and to patients’ confidence so that they were able to manage their illnesses.

Building partnership
Firstly, when GPs focused on building partnerships with patients, this promoted trust in the GP. Similar to the GPs, patients perceived that their problems were taken seriously by their GPs when they recommended HBPM. In addition, patients described their satisfaction at being recommended HBPM by their GPs, as this showed them how they could be involved in their care and could help their GPs.

(q.2) “So he wanted to go to the bottom line of this thing [making an accurate diagnosis] and that’s the feeling of so much satisfaction, but also accepting the fact that maybe the doctor needs a bit of help sometimes and that’s the way you can help.”
(Stephan)

Information giving and seeking

Secondly, when GPs provided relevant information about their health and encouraged their proactive involvement in conveying health information, this promoted mutual trust in the GP-patient relationship. Both ways of communicating underscored the GPs’ professional competence and the patients’ competence in managing their illnesses and this built mutual respect. The underlying process of these communication patterns was feedback between patients and their GPs. HBPM facilitated this feedback which, in turn, contributed to building or reinforcing mutual trust.

This feedback had a number of facets. First, a transfer of biomedical information from patients to their GPs helped the GPs to understand patients’ medical conditions and to arrive at correct diagnoses and offer reasonable treatment plans. Thus, HBPM created opportunities for patients to promote GPs’ trust in the patients’ own expertise in managing their illnesses. In addition, GPs became more confident that their therapeutic approaches were on the right track.

(q.3) “The doctor now can say, he could quite easily say, “This guy’s blood pressure is under control”, we know it’s a hundred and forty without having to rely on one reading every six months or three months which is not good enough. And I think more people should monitor their blood pressure. So that when they may go to the doctor with a problem and, everybody has to go to the doctor with a problem at some stage, you go to the doctor with the problem and you say: “Right, here is my blood pressure this is what is running at”, so immediately the blood pressure issue is gonna go away, or it’s gonna be highlighted that this is perhaps the problem. I think it helps the doctor immediately to
understand if blood pressure was a problem. And that’s because you provide him information. That’s information on me going to him.”

(Sam)

Second, HBPM helped doctors and patients to get to know one another characters or to confirm what they already knew about each other. Patients’ knowledge about doctors’ characters and doctors’ knowledge about patients’ characters were significant for mutual trust in GP-patient relationship because this promoted respect for persons. A full exchange of information between patients and doctors, which included both factual and emotional information that could inform patients’ health decisions and doctors’ professional decisions, was associated with honesty. By contrast, an interaction characterized by a limited exchange of information was usually characterized as unsatisfactory and sometimes led to confrontation in the GP-patient relationship.

(q.4) “I: What circumstances shaped your trust in your doctor?
R: I think the thoroughness of the treatment and the determination and that sort of stuff. And the fact that he will tell me what possible alternatives I have, why he is sending me for a blood test, or whatever he wants me to do and that sort of stuff. I think this shapes the level of trust I have and probably he knew when I came, first saw him, I was honest and I told that I came for a second opinion and that I have a disagreement with my previous doctor that I wasn’t happy with my doctor and I didn’t argue with my own doctor about that. But I did and so actually he said: “So go to a different doctor”. So I was honest with him with why I am there and probably that influenced the way he responded. But the fact that it was a very thorough investigation what have happened and we also talked a lot. I’ve not been misdiagnosed by my previous doctor, but the symptoms I had in the next few weeks haven’t been explained. So when it was a sudden change and I went back to my previous doctor he didn’t explained what actually was. And I wasn’t really happy with that. But the fact that I’ve learnt what is likely to happen, then I was satisfied because I had a better explanation from my actual doctor and this is why I stay with him as my permanent own GP.”

(Rick)

The increased transfer of information between patients and their GPs promoted patients’ trust in their GPs because it suggested that GPs were professionally competent as well as indicating that GPs were interested in patients as individuals.
"I: And how did home blood pressure monitoring influence your relationship with him?
R: I don’t think it influenced it. I think it’s something that underlined what an excellent doctor he is and how knowledgeable he is about these matters. He seems to be, he does care and I think I am very happy to go back to him because I know that I am talking with somebody who knows what he is doing. That’s not always the case.”
(Russel)

Third, these communication characteristics promoted respect for persons by increasing doctors’ and patients’ capacity to exchange relevant health information and their capacities to rely on each other’s judgements. For most patients, GPs’ knowledge about their character was linked with respect for themselves as competent persons. The patients thought that there was a need on the doctors’ part to understand their honesty. HBPM created opportunities for patients to learn that their GPs understood their character. They felt that their GPs perceived their honesty when the doctor used the patient’s readings for clinical judgement. GPs’ trust in their readings promoted respect for persons because patients’ felt that they were valued as competent persons.

"I: And how do you think he trusts you?
S: Well, I would like to think that he feels that I am, when I am talking to him, that I am honest and the reason I’m coming to him is because I need his help and that I expect to get it. So I would think that he would, I hope, not think that I am an idiot.
I: And how, if at all, do you think that home blood pressure monitoring has influenced his trust in you?
S: Yes, I think so. I mean when I was the first time or two times at him. I think I showed him a list of takings and I did an average a mean and we sort of talk about the average. I took out the highest ones, I took out the lowest ones, I crack in the middle and now when I go to him I say these are the readings and I am not cheating myself so he needs to understand, and I think he understands. I mean if I have a problem what’s the point to saying him it’s a 140 when there is a 150. And he is using these figures and we discuss the levels.”
(Sam)

In turn, patients perceived that their feelings that they were valued as competent and honest persons promoted comfort in the GP-patient interaction and encouraged patients to
seek more medical information. This in turn built GPs’ confidence in patients and increased the amount of information they transferred to patients.

(q.7) “I: How would you describe the trust she has in you?
S: Well she always takes my blood pressure readings and says that it is ok. So she has trust in me because, you know, I told her about how I’ve found monitoring my blood pressure at home and she was very interested. Well, hopefully she will think that I am very intelligent, who knows. Because I tell her what I found perhaps and then she told me what has been found in research and I felt quite comfortable in asking her any question and probably, because of that she may trust me to be interested in my health and to be able to choose for me, not more than everybody else, but you know she does … she’s able to tell me things because I am trying to understand what she is saying.”
(Sandra)

The patients’ account of this feedback was different from that of the GPs. For GPs, this feedback was the result of an open dialogue that focused on factual information with respect to management of hypertension. By contrast, patients described this feedback as the result of a dialogue beyond words that revealed doctors’ and patients’ characters. This kind of interaction required listening skills on the GPs’ part that indicated a communication beyond words.

(q.8) “She takes the time to listen to you, to listen to what to what you’re saying. And listens to what you want to say. You know you not be saying out in the words but she, to me, she listens to what you maybe mean to say, if you can understand what I am saying. She’s a very compassionate doctor.”
(Emily)

Non-judgmental communication

Thirdly, non-judgmental and autonomy-supportive communication promoted mutual trust in GP-patient relationships. Most patients in this study said that they wanted to improve their health to the extent the doctor suggested, so long as reaching this goal did not undermine their ability to do other valued things in their own lives. Patients who matched the PR style said that general practitioners were willing to tailor their therapeutic recommendations with patients’ lifestyles and desires.
I: Seems that you try to match your blood pressure to your lifestyle somehow...
S: Yes.
I: Did you discuss these things with your doctor?
S: Yes I did and he was of this opinion. I basically came to the opinion that I didn’t want 120 over sixty. I was happy with 140 over sixty. And then when I went to see my doctor and we talked about this and I put it to him that wasn’t really necessary. It’s not affecting me and you have to die of something at some stage and at seventy year of age you’re getting closer to that time. So that’s no point in upsetting your life equilibrium to the point where it becomes ... well living becomes a pain. And I don’t want that, I don’t need that.
I: So to understand better, a good treatment to you means to adjust your health to your lifestyle.
S: Yes. To keep the things under control, but to keep them in a medium where everything still goes on.
I: What thought your doctor about this understanding of a good treatment?
S: Well he was all for it. He believed that what I suggested, I think it was my suggestion might be his, but I think it was mine, so it was good. And we both agreed that this was in my case the way to go.”
(Sam)

Patients who described this autonomy-supportive and non-judgmental communication pattern suggested that their GPs trusted them. For instance, a patient ‘played doctor’ and changed her medical treatment without consulting her GP after monitoring her blood pressure. The fact that her doctor accepted her decision without being judgemental suggested to her that the doctor trusted her and valued her as competent person.

(q.10) “... And all of a sudden in the last two months it went up crazy to 200 over 120. Now when I was at 200, I was on a lot of medication. Now I weigh only fifty kilos and that medication was sending me, you know, crazy. I was strange, I felt detached and so I played doctor, which is a thing that a person shouldn’t do, but I did. I cut my drugs back gradually. Because I was monitoring my blood pressure so, therefore, I knew that I could do this. I told to my doctor some of the things I had done. ... Well, I think he must have a fair bit of trust in me, because he sort of knows what I do, and when I say to him “Look I did such and such”, he’s quite happy with what I do and discusses these things with me. So, I suppose if he didn’t, he wouldn’t sort of, you know, say ... like I said I cut back on blah, blah, you know, the drug, and he said: “that’s fine”, you know, and he’s quite happy
with what I’ve done. Another doctor, you know, would raise his arms in the air and say: “This is what I’ve prescribed; this is what you should take”. But home blood pressure monitoring has influenced the trust he has in me because as I said, it helps them to know what’s going on.”

(Laura)

**Biopsychosocial communication**

Finally, a broad biopsychosocial communication that focused on discussing patients’ worries and concerns about their illnesses was instrumental for building rapport. This was particularly illustrative in cases when patients used HBPM as a tool in the long-term management of their illness. Some patients developed anxiety when they recorded high blood pressure values or a sudden change in the pattern of their blood pressure. This was often associated with negative emotional feelings such as anxiety or “becoming worried about their own health” because patients did not know how to interpret the pattern of their blood pressure. In addition, patients’ perceptions that their doctors showed a concern for their emotions made them feeling valued as competent persons.

(q.11) “Well they probably think that you were sensible, I suppose, in some ways. When I came back to my doctor some months ago I suppose, I felt so ill. This was after I was treated for the very, very high blood pressure, and I took it one day and it was still say 180 over a hundred and something and I felt ill. I phoned him and he nearly got me and saw me, even if he was fully booked up. So he was great. But I think that anybody who has a blood pressure machine you have got to discipline yourself, so you don’t become a sort of a “Oh, I have to take my blood pressure this morning” or in the night: “I better check my blood pressure” Because if I take my blood pressure say now and it was 120 over 80, and I might have taken it tonight and could be 160 over 90, and you think: “Oh gee, this is not good” So people sort of panic about it whereas with me I do not, but I do worry when it’s 200 over 100 and you feel terrible. But my doctor understands me. If you call or leave a message he always calls you back. He is a very caring person.”

(Laura)

In addition, a communication pattern focused on broad biopsychosocial issues was perceived as reassuring. For instance, a patient who had a trusting relationship with her GP developed a feeling of guilt because she neglected her health by being the carer for her mother. She felt that, by giving a lower priority to her health interests as compared with
her responsibilities towards her mother, she did not respect her obligations towards her GP. An open dialogue with respect to this issue helped her to feel reassured because she perceived that her GP understood her circumstances.

(q.12) “A: No, the monitor didn’t give me moral support; she gave me moral support because she cared for my mother, and my mother was not an easy person to look after. And she said: “I can understand you are under stress, maybe your blood pressure is high because you have to care about an elderly person especially when it is your mother that woman”. And it wasn’t that bad, but at least she understood what it means to be a carer. You know, a very full time job. You can’t disappear for too long, and I was doing a master degree at that time, and I had to go at lectures at night, and I was worried while I was away if she [her mother] gets food, and probably she thought I shouldn’t be going to uni, and you know the blood pressure went up.

I: And how does this relate to your ability to take care of your health?
A: Maybe she [her GP] understands me. Because when you have this special relationship and you abuse yourself you feel very guilty. And when you go to the doctor with the problem and you think “Oh, maybe I did it to myself”, you really threaten that respect because she would expect you to help her in her job, just the way I expect her to help with my health like a mutual obligation.”

(Anna)

This communication style occurred within a relational type of GP-patient relationship. This was a partnership between patients and their GPs where both parties actively worked together. This partnership enhanced patients’ interest in taking care of their own health.

(q.13) “I: And how did home blood pressure monitoring influence the relationship with your doctor?
R: It makes a much more positive relationship.
I: In what sense?
R: In the sense ... Umm ... Kind of working together, rather than ... I am searching for the right term ... but ... yea ... like he’s expert and we share information and I can question things, that sort of stuff, which I didn’t do beforehand and tend to explain what’s wrong and do what doctor told me to do. But now sort of I am more inclined to question perhaps being a bit more pre-emptive with my health. And I think that’s sort the influence it has.”

(Rick)
Mutual trust in the GP-patient relationship, built through all these characteristics of the PR communication approach, promoted patients’ trust in themselves and increased their confidence that they had the required cognitive and psychological abilities to manage their illnesses.

(q.14) “I: What you said means that your honesty with him influenced his attitude towards you?  
R: Yes and again his honesty worked back to me the same way for me to feel confident in what he is doing and again the trust with the blood pressure that I could measure properly and that I could keep records on it and that I wasn’t fooling around with that, because I know people who stopped medication trying to get anti-cholesterol tablets. And I know people doing that. So that’s a level of trust that what I am doing is correct. So my honesty with him returned my trust in me.”  
(Rick)

In summary, I have shown that patients involved in the GP-patient relationships characterized by a PR communication style described a bidirectional influence between the process of communication in the GP-patient relationship and HBPM utilisation that built mutual trust. Mutual trust was built through a complex verbal communication style that made patients feel valued as competent and honest persons. This positive emotional interaction was perceived by patients as autonomy-supportive because it suggested that GPs valued them as individuals and, in turn, enhanced patients’ confidence that they had the cognitive and psychological abilities to manage their own illnesses. HBPM facilitated and enhanced the characteristics of this communication style. The patients’ accounts suggested that PR communication occurred within a relational type of interactions, where patients and their GPs promoted each other’s agencies.

7.2.3 Negative Reinforcement Style

Patients who were involved in GP-patient relationships characterised by NR communication style described a narrower engagement in their own care. This engagement was limited to adhering to their medical treatments and to consulting their GPs when their blood pressure was abnormal.
“I: How do you think that home blood pressure monitoring has influenced your health?

M: I don’t think so. I don’t think it influenced my health at all. It’s like smoking, everybody say, you know: ”Do you feel better now that you gave up smoking? Oh, no I don’t feel any different.” The blood pressure monitor, the blood pressure tablets, I don’t think I feel any different. The blood pressure monitor is that I am aware now that I have high blood pressure.

I: And what’s the significance of the fact that you are aware that you have high blood pressure?

M: Now I am aware of the fact that I have to take tablets to lower my blood pressure and see my doctor if it’s high. That would be probably all I can say about it.”

(Mary)

These patients described similar communication characteristics to those described by NR-GPs: biopsychosocial, biomedical and persuasive communication. I describe these communication styles and discuss how these characteristics influenced mutual trust in the GP-patient relationship in the context of HBPM.

Biopsychosocial communication

Firstly, patients described a biopsychosocial communication pattern that focused on retrospectively evaluating patients’ sense of responsibility. Patients described the GP-patient relationship in the context of HBPM as a transaction that depended on their sense of responsibility. Patients with a GP who had a NR communication style said that GPs perceived patients’ sense of responsibility as a personal value that contributed to building mutual trust in GP-patient relationship. “Being a responsible person” was associated with a higher capacity on the patient’s part to follow GPs’ medical and lifestyle recommendations. Patients in this group said that their compliance with GPs’ recommendations promoted GPs’ trust in them.

“I: How do you think that your general practitioner trusts you?

S: Ah, I that's comes in ... I guess I can say he respects me as being a responsible person for my health.

I: When you say that he respects you as a person responsible for your health, what do you mean?
S: I think he sees me as a person who fits with his suggestions and that I will follow those suggestions which may improve things. I guess. That I will react at his suggestions that may help me whereas I guess some patients would rely on doctor just to give them some medication and that may not have an effect if they don’t change their lifestyle or something like that. I perceive him as seeing me as being a person who is prepared to change my lifestyle and habits if it is of benefit to me.”

(Stuart)

Patients said that, in the context of HBPM, being a responsible person was important because using HBPM implied that they had the required competence to follow GPs’ instructions and provide GPs with accurate readings. In addition, patients needed to have the psychological capacity to cope with HBPM without developing anxiety. Most patients in this group said that they acted as responsible persons in other environments such as in their work and that they had the necessary cognitive and psychological abilities to use HBPM. In cases of concordance between patients’ and GPs’ opinions, this approach fostered a trusted partnership where patients followed GPs’ instructions.

(q.17) “I: And how, if at all, has home blood pressure monitoring influenced the trust your GP has in you?
M: Oh, I think he does, very sincerely he puts full trust in what I do, because of the way I lay out the records for him, he said to me: “The way you’ve got it, you are not going up there and getting it out to have it [the monitor] on the table and every five minutes bumping. And you are not panicking. And he said: “well if you gonna do this you should not have the machine”. I think myself that he was very pleased to know that what I was doing and that it was being done in the same manner he was asking. I think that he was quite happy that I was running at home as they would at the actual surgery. And it was recorded in a manner correctly so that when you read the readings you get a true record of what is going to taking place. And I think that he was very happy about the fact that I did such recordings in a professional manner. But I told him that’s coming from running an office with the traffic signals where you cannot start to worry about the jobs they give you there. I’ve been always in a procedure where you have to make a decision and you have to stick by have it done without panic. To have the job done and that’s the same as a job.”

(Mark)
In addition, similar with NR-GPs patients said that similar affiliations promoted GPs’ trust in their patients.

(q.18) “I think he probably respects me because I was a professional, a registered nurse, but I am retired now.”
(Gertrude)

Biomedical communication

Secondly, the NR communication pattern focused on biomedical issues and on providing patients with standardized guidelines promoted a contractual approach, where patients evaluated GPs’ professional responsibility. Patients described the relationship with their GPs as a transaction where they paid for professionalism and knowledge with respect to their illnesses.

(q.19)“G: I think I agree with Mary that I expect a level of professionalism and knowledge, that’s what we pay after all.”
(George)

As opposed to the ‘information giving and seeking’ characteristic of the PR communication style with its complex verbal and emotionally-rich dialogue, the NR style restricted communication to discussing biomedical issues associated with the utilization of HBPM.

(q.20) “I: How did you decide to measure your blood pressure at home?
M: The doctor just asked me to. He said: “have the machine and take it just four times a day for a record of it.
I: And what did you discuss with your doctor that home blood pressure monitoring would involve?
M: Didn’t discuss any, just asked me to do it. Just to keep an eye on it. That’s all.”
(Mark)

This communication focused on biomedical issues prompted patients to have an evaluative approach with respect to GPs’ therapeutic recommendations. Establishing common therapeutic goals with their doctors, in the context of HBPM, was the result of
seeking and sharing information in multiple relationships: the doctor-patient relationship, family relationships and sometimes with friends and other people in the community. Thus, patients sought and compared relevant medical information from a variety of sources. For instance, the process through which Mark has accepted the “target values”, at which he aimed and monitored at home, was based on a comparison of the target values of blood pressure recommended by his own GP with the ones recommended by another doctor to his wife and with the information from the leaflets that accompanied his blood pressure machine.

(q.21) “It was just mainly to record for my doctor to be able to give me the tablets, medication correct. Because those leaflets, which came with the machine, show that what it is recommended is 140 over 80. And Dr. Johnson together with other doctors on the medical board decided that they have medical decisions that they try to give other doctors a guideline and as I showed you on the top of that [pointing to his record sheet], the top of that reading of the report, that’s the readings he would like to see me at, which is a lot lower, it’s 110 against 140 and that’s 70 against 80. So one comes down 10 and the other one comes down 30. But in the same complex is Dr Marshall. He saw my wife and gave her a check out for a driving license and that, and her blood pressure was 140 over 80 and he said fine. But Dr. Johnson would prefer to see it there. You see that difference between doctors and you don’t know whether that’s right, but the doctors on that board seem to think that is a lower reading, not ridiculously low, but in that range, that is more beneficial for the actual patient.”

(Mark)

This evaluative approach lacked the positive emotional interaction seen in the relational type of GP-patient relationship. The lack of positive emotional interaction encouraged a contractual approach on patients’ part because patients thought that GPs did not have an interest in them as individuals. In addition, the contractual approach was influenced by patients’ perceptions of decreased social opportunity to develop trust in the relationship.

(q.22) “G: I think, it’s a fair comment to say that it is very difficult to find a health professional that has an interest in what happen.

M: Exactly.
G: I mean in us, in individuals not. It’s seemingly more like you go and see your accountant and it’s no emotions towards what is done.
M: Yes
G: I mean is here are the numbers and I think that some of the doctors have worked that way too.
I: You mean it’s not that kind of trustful relationship you have with your own doctor?
G: That’s correct.
M: With an accountant you don’t have this kind of relationship. No.
I: But this is what you expect from your doctor?
G: Yes
M: Well, this is really what you expect from everybody but you don’t get it.
G: And because of that we become very independent I think. And, therefore, we’ve got the machinery like the home monitoring that allows us to be more independent.”
(Conversation with George and Mary)

This perceived lack of interest on the part of their doctors implied that patients used HBPM to get a “second opinion” with respect to their blood pressure as compared with the readings taken in the surgery. This approach promoted mutual trust on pragmatic grounds. That is, patients thought that HBPM would be useful for their GPs and indirectly for them. In turn, they felt their GPs trusted their readings because it was ultimately in the patients’ interests to take them correctly. This kind of instrumental trust promoted patients’ awareness that they had hypertension and needed to take their medication.

(q.23) “I: How, if at all, has home blood pressure monitoring influenced the trust you have in your doctor?
G: No, I didn’t think it’s influenced the trust I have in my doctor, other than I suppose that ... I think it was Jackie who introduced me to the machine in the first place and it didn’t hurt, so I still trust her [laugh]. So I suppose it’s an element of trust, which says to me, take this machine at home and use it twice a day. And I think well, you know, it’s not much hurt but must be useful. And I trust her that it would be useful to her and therefore I give it my best to get the numbers right, by trying to use it properly. Because automatically it’s gonna be beneficial to me. And I am not too sure that she has trust in me other than as a patient. If I enter there and tell her something I mean she believes it. But again that’s for my ultimate benefit, so, there’s no sense to me to going there with a wrong reading of numbers and I don’t see any point in that, and I suspect that the doctor would expect the
same thing that there is no point in me taking wrong numbers or telling her something that’s not the case.

I: Several times you’ve told me that having an illness could influence you emotionally. How has home blood pressure monitoring influenced, if at all, this component?

G: No other than the sense of satisfying a curiosity. I don’t think it has a big influence on me. I suppose other than the, well, not only the curiosity but getting a second opinion I suppose you could say. The doctor in the surgery with the machine is one opinion, if you know what I mean, and then this [monitoring] is a second opinion. I don’t think it fixed me mentally or emotionally.

I: And how has home blood pressure monitoring influenced you to take care of your health?

G: Only in the sense that I take a tablet instead of half, and that’s all.”

(George)

Persuading to change

Thirdly, patients who were involved in the relationships characterized by NR communication described how their GPs tried to persuade them to change their behaviour. In the context of HBPM, the main source of discordance between patients and GPs concerned the potential of HBPM to produce anxiety. Patients said that GPs believed that, in some patients, usually labelled hypochondriacs, HBPM per se could produce anxiety due to patients’ decreased psychological abilities to cope emotionally with their illnesses. However, patients said that it was their lack of knowledge with respect to interpreting their high blood pressure values that caused their anxiety. In circumstances when there was discordance between patients’ and GPs’ opinions, patients said that GPs persuaded their patients to stop HBPM because anxiety could be the cause of their high blood pressure values. Unlike the communication patterns in PR style, from the patients’ point of views, GPs did not support patients’ own health care decisions and did not provide patients with moral support. Patients said that this communication pattern promoted neither their trust in GPs nor their compliance with GPs’ recommendations. This was so because patients felt devalued as persons.

(q.24) “well this is an instant. I do not want to mention any names. This was with other doctor I saw because John was on holiday. He told me to put the blood pressure machine away. And not take it, because it was so high. He said: “Come down to the doctors and say to Mary the sister to take it. And I said: “Well, I felt that it wasn’t taking blood
pressure that was worrying me because it was so high, because I didn’t take it in weeks. That proves the point that I haven’t taken it in weeks. So it wasn’t taking it that worries me, it was that I didn’t know what it was ... so that’s the difference in there. He was thinking that I was worrying about it. That I panicked. Whereas my own doctor knows that I don’t. Well you’re concerned but he never said to me: “Put it away! Don’t take it!” So that’s the difference. But this doctor didn’t know me. So this other doctor, he is a very good doctor, very thorough with everything, but said put the blood pressure machine away because you’re worrying about it. I said: “No, I am not”. Because he didn’t know me, ok? It was the first time I’ve ever been there. He thought oh that’s a woman who takes her blood pressure every day and she is panicking, whereas my doctor is just the opposite. And that’s because he knows me. And he knows what sort of person I am, I suppose, and he made this in several years. But home blood pressure monitoring helped us to build this rapport and understand better each other.”

(Rose)

Thus far, I have shown that the PR communication style occurred within a relational type of GP-patient relationship, where patients and GPs built mutual trust through complex verbal and emotionally-rich communication. By contrast, the NR communication style reflected a contractual type of relationship, where patients and GPs evaluated each other’s sense of responsibility. These two types of relationships had different effects on patients’ confidence in their cognitive and psychological abilities to manage their illnesses. This was so because they had varied effects on trust in the GP-patient relationship which, in turn, influenced patients’ confidence. The PR style developed mutual trust in all patients and promoted patients’ confidence in their psychological and cognitive skills to manage their illnesses because patients felt respected as competent and honest persons. The NR communication style promoted mutual trust and patients’ confidence in GPs’ illness management when GPs and patients shared similar opinions, values and affiliation, but it promoted distrust in cases of opinion discordance.

7.3 Conclusion

In this chapter, I have considered the ways in which patients’ goals for HBPM related to their approaches to communicating with GPs. I have demonstrated that patients used HBPM to facilitate collaborative approaches with their GPs devoted to promoting the technical certainty of blood pressure monitoring and as a means to increase their control
over their own health. HBPM both improved blood pressure control and enhanced patients’ control over their health by increasing patients’ engagement in their care. I have also shown that HBPM promoted various degrees of patient engagement in their own care. Patient engagement in their own care was the result of patients’ trust in their GPs, rather than an initial expectation of using HBPM.

Second, I identified the two communication styles that were described by both patients and GPs: a positive reinforcement style and a negative reinforcement style. I have shown that these two styles impacted in different ways upon patients’ confidence in their abilities to manage their blood pressure. The PR style occurred within a relational type of DPR, whereas the NR communication style reflected a contractual type of relationship. These two types of relationships had differing influences upon patients’ confidence in their abilities to manage their illnesses, due to their differential effects on promoting mutual trust in GP-patient relationship. In the next chapter, I will describe and analyse GPs’ and patients’ perceptions of the influences of HBPM on responsibility for their own health, which was the main outcome or determinant of the GP-patient relationship in the context of HBPM.
Chapter 8: GPs’ and Patients’ Views of Personal Responsibility for Health in the Context of HBPM

8.1 Introduction

In this chapter, I describe GPs’ and patients’ views of personal responsibility for health in the context of HBPM. I focus on the relationship between patients’ motivation to maintain their health and patient’s responsibility for their health. In chapter six, I identified the characteristics of two groups of general practitioners: those who wanted to motivate their patients to maintain their health by positive reinforcement of their health agency (PR-GPs) and those who wanted to motivate their patients by making them worried about their own health (NR-GPs). These two groups of GPs described different impacts of HBPM on patients’ motivation to maintain their health and on patients’ health status. During the analysis it became apparent that the views of these two groups of GPs and the views of patients about how and to what extent patients could be responsible for their health shared similarities as well as significant differences. In this chapter, I describe these similarities and differences and analyse the significance of these different understandings.

The chapter has two sections. In the first section, I show that GPs and patients associated patients’ responsibility for their own health with the idea that patients had a duty to maintain their own health by carrying out practical activities. In the second section, I describe the beliefs and values that underpinned patient responsibility and show that both GPs and patients associated patient responsibility for their own health with: (a) patients’ capacity to deliberate effectively; and (b) patients’ control over health care decisions and over their own lives more broadly. I show how patients’ motivation to maintain their health underpinned all these notions of patient responsibility. I also discuss the significance of these notions of patient responsibility in the context of HBPM. I show that HBPM could promote all these notions of patient responsibility for their health by influencing patients’ motivation to maintain their health. However, its impact on patients’ capacity to control their lives was not significant. In chapter nine I will return to these findings to explore their significance for self-management and for the impact of a self-management technology on patient autonomy and on patient responsibility for their own health.
8.2 Patient Responsibility for their Health as Practical Activities

General practitioners and patients in this study described patients’ responsibility for their own health in terms of patients’ duties to maintain their health. In the GPs’ view, in the context of chronic disease this duty implied that patients had to pursue certain practical tasks directed toward maintaining their health. Patients were expected to understand their medical conditions, the consequences of sub-optimal treatment of their illnesses, and the potential negative health outcomes. In addition, patients were supposed to make lifestyle changes in accordance with their health needs, adhere to treatments, monitor their illness and seek medical help for routine and acute care, when required.

“I: What responsibilities does this patient have for his health?
G: He is responsible for understanding that he has a medical condition or medical problem, what the consequences could be if his blood pressure is sub-optimally controlled. So, the importance of control and then for himself he is responsible regarding his lifestyle measures to help maintain his health, compliance with medications to maintain his health, to seek help if he feels there is a deterioration of his health or a problem with his health and to, I guess just to ensure sort of periodic follow-ups as a maintenance procedure. So, the awareness of his health has to be guided by us here in the process, so to understand that these are his problems and to be able to do this. Some people need more encouragement to do this but he is under control from my perspective“ (Gregory – NR-GP)

“I: What responsibilities do you think this patient has with respect to managing his illnesses?
A: Well I guess he carries the most of the responsibilities for his health in very practical ways. So I can see myself as a consultant so my responsibility is providing education and motivation support whatever, but his responsibility is still there in terms of turning up, seeking appointments seeking the advice chose whether he follows that advice and coming to that he has a financial responsibility to pay for any management or any medication and lifestyle.”.
(Adam – PR-GP)

Similarly, patients described personal responsibility in terms of a duty to do things for themselves. This duty implied that patients were supposed to pursue practical tasks such
as monitoring their blood pressure, making lifestyle changes in accordance with their health needs and adhere to their medical treatments.

“I: What responsibilities do you think you have for your health?
M: Well I am a lovely person I am going to look after me, somebody else can look after me, but I can look after me better. If I do the homework I get the prize. So, monitoring my blood pressure, taking my tablets, that’s with the blood pressure, that’s my responsibility now. Yes blood pressure is one of the things that I check now. I try to make sure I have plenty sleep. I try to make sure that we eat healthy and that’s no reason to worry. I walk more, I’m out more. I’m retired, I can do what I like I think. And that’s all I do.”
(Mary – involved in NR communication with her GP)

In addition, patients associated their responsibility for self-care with activities such as meditation or spending quality time with their friends.

“I: What responsibilities do you think you have with respect to managing your hypertension?
G: Only through relaxing probably doing meditation and things like that more than actually taking the medication in itself because I am not very happy with taking medication. If I can avoid it through a healthy way than having to take medication I am happy.”
(Gertrude - involved in NR communication with her GP)

“I: What responsibilities do you think you have for your own health?
M: Ah, I relax, take things easy, don’t rush around, don’t go and run crazy here and there; if want to do something do it and then have a bit of a rest. Go and say hello to one of the neighbours. In general don’t rush around. I mean hard”
(Mark - involved in NR communication with his GP)

These activities were justified because patients thought that stress could make their blood pressure go up.

“Now the doctor said that a lot of blood pressure is caused through stress, which was always with me and I knew that stress can cause it.”
(Emily involved in PR communication with her GP)
In the specific context of HBPM, both GPs and patients said that patients should pursue specific tasks such as measuring their blood pressure in accordance with GPs’ instructions and recording their blood pressure values. They had to do this so that GPs could understand blood pressure patterns and to assess treatments effectiveness.

“I: What responsibilities do you have with respect with home blood pressure monitoring?
R: Just to measure it [blood pressure] on a daily basis following the instructions and I make a note with what the measurements were. I didn’t change the medication or anything like that. Basically we discussed when I should do, what times of the day and that sort of situations. And I think I’m guessing this is a level of assessing how well he’s doing as well, so, to see how much to rely on medication.”
(Rick involved in PR communication with his GP)

“I: What have you discussed that home blood pressure monitoring would involve?
S: Purchasing the machine and measuring the blood pressure at least three times a week. And that's he did it, measuring three times in a row and taken both the three readings and also the time when he has to do it, morning afternoon and night.”
(Joann – PR-GP)

In addition, GPs and patients both associated patient responsibility for self-care with a rational utilization of HBPM. Most GPs and patients in this study said that in cases of stabilized hypertension a rational utilization of HBPM would imply that patients should not measure their blood pressure values too often. Most of them mentioned that a reasonable period of time for monitoring blood pressure was between once per week to once or twice per month. Monitoring blood pressure at reasonable periods of time was significant, because some patients panicked when they measured abnormal blood pressure values. At times this led to obsessional behaviour, with patients measuring their blood pressure values very frequently. This led to patient anxiety that could make patients’ blood pressure values go up.

“That group of patients falls into the more anxious group of people and people who are very concerned about their blood pressure and record the numbers and fear that there is a health threat if they measure slightly high blood pressure values. I have an obsessive man who comes in with a meticulously recorded three times a day recordings and I have told
him that he has to do it two or three times a week because I don't want him to remain obsessed. Sometimes this may lead to anxiety and high blood pressure”.
(Neil – NR-GP)

“And I thought, I have a machine and I’ll do a check for myself, and that could help because I was in the ambulance business and I bought one and what I actually do with this machine for his benefit and myself, I don’t panic to go every five minutes to get the machine. That is silly. When I am going to see him for an examination for maybe a week I take the reading for that purpose of having a record of how the procedure is, to give him some idea of what my blood pressure is. Well I think when you get your medication and get stabilized then you can start leading a reasonably normal life and therefore you don’t have to take it every day. Until they can get it stabilized I had to take it. But once is stabilized there is no need to take it every day. Otherwise you just become obsessed with blood pressure”
(Mark involved in NR communication with his GP)

All the patients in this study experienced negative emotions during HBPM. However, they said that they had a responsibility to learn to control their negative emotional responses associated with HBPM.

“And that’s part of my responsibility for health to learn and discipline myself. I did discuss that with my doctor, but he didn’t say much on this he tried to juggle my medication. You know what should you take, how many to take, or whatever. This is the way things were I suppose. But I think that anybody who has a blood pressure machine you have got to discipline yourself, so you don’t become a sort of a “Oh, I have to take my blood pressure this morning” or in the night: “I better check my blood pressure” Because if I take my blood pressure say now and it was 120 over 80, and I might have taken it tonight and could be 160 over 90, and you think: “Oh gee, this is not good” So people sort of panic about it, whereas with me I do not worry. Well, I do worry when it’s 200 over 100, and you feel terrible.”
(Emily involved in PR communication with her GP)

In summary, in this section I have shown that GPs and patients associated patient responsibility for their health with practical activities directed towards maintaining their
In the next section, I will describe the values, beliefs and ideas that GPs and patients associated with what it meant to be a responsible person.

8.3 The Meanings of Patient Responsibility for Health

In the previous section I suggested that GPs and patients both described responsibility for health in terms of actions one might take to show that one was being responsible. Underneath these actions were a set of beliefs, values and ideas about what being responsible meant. In this section, I show that there were at least two different and interrelated views amongst GPs and patients about what responsibility is and what underpins it: (1) patients’ capacity to deliberate effectively; and (2) patients’ control over health care choices and over their lives more broadly. Following I describe these understandings of patient responsibility. Throughout the text I compare the views of the GPs with patients’ views and describe the significance of these differences in the context of HBPM.

8.3.1 Patients’ Capacity to Deliberate Effectively

First, GPs and patients associated patient responsibility with rational deliberation. By reflecting on their health, patients became more conscious of their own health and, therefore, could take positive actions that could prevent ill health. There were three dimensions to patients’ capacity to deliberate effectively. First, patients’ capacity to deliberate effectively had an experiential dimension. Both GPs and patients said that patients’ self-awareness of their health status was often determined by patients’ personal and family experiences of ill health. Patients who had experienced ill health in themselves or their relatives made a connection between unhealthy behaviours and poor health outcomes. In some patients making this causal connection increased their responsibility for their own health by prompting them to do things that might avert ill-health / complications.

“\textit{I: What factors do you think shaped her interest for her own health?}\n\textit{N: Often these patients have had a parent or a sibling who have died of a stroke or have been crippled by stroke and I think there is a line between a healthy concern and obsession which is sometimes difficult to draw. And I think that if they had heart disease,}
if they had a transitory ischemic attack, if they had certain blood pressure related problem they are more likely to want to avoid catastrophic complications.”
(Neil –NR-GP)

“I: Are other things that shaped your responsibility for your health?
S: My father had a heart attack, when he was sixty five, which I thought he was reasonably young, and I felt in a way that perhaps if he would have been a little bit more conscious that perhaps at times he may have avoided this by being fully responsible and maybe he would be here today perhaps. But since when I was in my late forties I was responsible. I suppose it was also my grandfather who had a stroke at fifty-nine. He lived up to 89 or 91 like that, but he never had full coordination on his right hand side after that stroke so I think that’s another thing that affected my consciousness of trying to keep me healthy.”
(Stuart – involved in NR communication with his GP)

Second, most patients described a psychological dimension that influenced their capacity to deliberate effectively. This dimension was described only by patients. Patients were confident that they had the psychological abilities to manage their illnesses and make positive health choices. Patients described this confidence as “positive thinking” or a “positive frame of mind” and discussed its effects as enhancing their capacity to make positive choices with respect to their health because it decreased their negative emotions. This positive frame of mind helped patients to be proactive with respect to the management of their chronic illnesses and to make positive health choices focused on maintaining their health.

“I: What responsibilities do you think you have for your health?
R: I think that’s me where the ultimate responsibility is. There are things you can do, and things that if you don’t do it’s helpful, in terms of what you ingest and activity you take part in, as well a positive frame of mind.
I: When you say a positive frame of mind what do you mean?
R: Well, that’s no matter whatever happens not to despair, really. Sort of, ok that’s the situation we can do this, we can take some positive actions, rather than despairing about things.
I: And what is the significance of this positive frame of mind?
R: I think it’s an important factor actually. You know it’s to do, you know, with what essentially quality of life is about. It’s about not being a victim it’s about positively taking small choices. Everything is making small choices basically, and if you make small choice in a positive direction that’s good.”
(Russel involved in PR communication with his GP)

These patients said that HBPM helped them to feel reassured, which increased their confidence. HBPM decreased the level of uncertainty associated with the management of chronic diseases, which, in turn, decreased patients’ negative emotions. This impacted positively on patients’ mental wellbeing.

“I: And how did, if at all, home blood pressure monitoring influence your emotions?
S: Well I suppose it gives me perhaps more confidence. Yea it gives me additional confidence.
I: In what sense gives you additional confidence?
S: I relax perhaps. I feel more relaxed that I know and see what is happening. The doctor is no longer that person who straps my arm and takes my blood pressure. And you don’t know what is happening and you look at his face and you don’t know and you try to anticipate from his face what the reading is going to be. I no longer need that.
I: What significance has this confidence for you?
S: I guess if would have other health problems and would worry. I guess is something I never thought about it. I feel more reassured perhaps that’s the word to use. It’s about known and unknown. If you know you can handle it with fewer emotions I think. It’s always a difference between known and the unknown, which I think it’s a big boost to your confidence and wellbeing for sure. And I guess if would have known that the readings went up I would approach my doctor very quickly.”
(Stuart – involved in NR communication with his GP)

However, the impact of HBPM on this psychological dimension also depended on GP-patient communication. In chapter seven, I showed that PR communication style through its biopsychosocial characteristic helped patients to decrease their negative emotions associated with HBPM utilization and increased their confidence.

Third, patients’ capacity to deliberate had a time dimension. This notion of a time dimension was also described only by patients. It had two senses: (1) time to think about their health and (2) time of life. First, self-reflection about health required time. Most
patients in this study associated periods when they were busy with decreased capacity to reflect on their health. Second, the time of life was associated with patients’ willingness to assume responsibility for their own health. Time of life was associated with an awareness of their mortality, and their awareness of this generally began around the age of forty. From this point on, patients appeared to think that they should assume more responsibility for their own health.

“I: What kinds of circumstances or factors have shaped your responsibility for your own health?

L: probably I was that busy in those days that I wouldn’t be thinking about my own health. I wouldn’t go to the doctor except something was wrong. So I really feel that probably that by being asked to buy the monitor made me more aware about my health. Because at the time when my dad lived with us and we were four kids and we were busy with all the things a family involves and we hadn’t time to think about this. If you got the flu it stopped you for a while but with having the blood pressure monitor is just generally makes you more aware of general health. And something is that you get older you are more aware of mortality as you were young and just think about you full of energy and catching around and I think age has something to do with responsibility because you are more aware of your health and things that go wrong with you. I think my cholesterol readings are good your blood pressure is fine than that’s good but they are only fine because you are on medication. So you are responsible, makes you aware, makes you responsible. Well makes me responsible.”

(Laura – involved in PR communication with her GP)

HBPM influenced the time dimension of patients’ capacity to deliberate effectively. It helped these patients to understand their health more deeply by becoming aware of their aging process. This enhanced self-awareness made these patients become self-reflective about their health, which, in turn, led to becoming more proactive and making positive health choices such as adhering to their medical treatments and changing their lifestyles in accordance with their health needs.

“I: How has home blood pressure monitoring influenced, if at all, your responsibility for your health?
“A: Probably made me a little bit more self-aware of the fact that I am getting older and I am not young anymore and I do need to pace myself to be a little bit more realistic about the things I do because I am very hands on and work hard.

I: Could you please give an example of how home blood pressure monitoring helped you to become more self-aware of these things?

A: Yes because high blood pressure is not a good thing, and strokes are not good things and I probably could see that if I keep working as hard and as long and not looking after my body then I could probably have a stroke and then, I couldn’t look after my mother. So it made me more responsible I think.

I: What happened next?

A: I went on the medication and that seem to take me out of the risk area. What else? I haven’t stop smoking, haven’t stop drinking, and there are probably more things that I should do, but I have now a very, very good diet, probably the best I know of. So I grow my own food and know where it comes from. I am more aware of my physical activity and haven’t pushed myself hard.”

(Anna – involved in PR communication with her GP)

### 8.3.2 Patients’ Control over Health Care Decisions and over their Lives

All general practitioners and patients associated patient responsibility with the extent to which patients took control over their own health care decisions. The GPs said that patients’ responsibility for their own health stemmed from patients’ freedom to make health care decisions and to pursue their health care choices.

“I: What responsibilities do you think this patient have with respect to management of his illness?

R: Well I think it is his responsibility entirely really. It’s his life, it’s his choice.

I: Could you please elaborate a little bit more on this?

S: Well it’s totally up to him whether he wants to manage his hypertension or not. I can only advise him and giving my opinion, whether he actually wants to follow that is totally up to him.”

(Ralph – PR-GP)

Similarly, all patients associated their responsibility for their health with their control over their health care decisions. Patients wanted to be in control of themselves because they thought that when they were in control they took better care of their health. In addition,
they perceived that taking responsibility for self-care would minimise the suffering associated with their chronic illnesses.

“M: I might want to be in control of me. If I am not in control of me who is? You know, I can’t expect my husband to look after me, if I don’t look after myself. I can’t expect my doctor as a professional to look after me, if she says to me: “you should be taking these tablets” and I’m not gonna take them. Well you know that’s me who’s gonna suffer.”
(Mary – involved in NR communication with her GP)

Patients’ control over their health care decisions depended on their knowledge and on their attitudes towards self-care. First, GPs and patients said that patients’ control over their own health care choices depended on the patients’ capacity to seek out information and try to understand their illnesses. This capacity increased patients’ awareness of their own health and, thus, patients’ intentions to follow healthy behaviours. This awareness helped patients to manage their illnesses better.

“L: what allows them to feel more in control? I suppose that essentially more information about everything. Clearly more information gives people more ability to understand what is happening and then to make their own decisions about what they want to do.”
(Laurence – NR-GP)

“I: What factors did influence his sense of responsibility?  
C: Knowledge as usually and talking to other people. Once you have facts you tend to act on. When he is aware of a problem he would tend to track it down to found out what it means. I think knowing that someone else in his family is having high blood pressure is making him understanding the management.”
(Christian – PR-GP)

Similarly, patients said that their capacity to make sound health care choices depended on their awareness of their own health. This awareness promoted patients’ responsibility for self-care by helping them to take positive actions that could maintain their health.

“I: Before you have told me that you see yourself as a responsible person for his health. Could you please tell me more about this?
S: Well I guess I am not obsessive ... When I went to the doctor I saw articles which he reads through and point out that you should not be overweight or eating the wrong food because these may cause diabetes or cancer or things like that. And I guess I’ve read those articles and think that ok, that this aspect of my lifestyle maybe I should change that, maybe I shouldn’t be eating these foods, or drinking that much alcohol or something like that. I am very lucky that I am a very physically fit person, that I enjoy a good active lifestyle, and keep that going.”

(Stuart involved in NR communication with his GP)

In general, patients described less individualistic approaches with respect to their control over their health care decisions. They considered that their capacity to make sound health care decisions had a relational component. Although patients said that they wanted to be in control of themselves, they did not set boundaries between them and significant others. Rather, patients became aware of their own health and made health care decisions in the context of their relationships with significant others such as their family members, friends and their GPs.

“J: Sometimes there is a problem and men will not see it. So I think yes, most women would say that they feel responsible for their husbands’ health because most husbands: “I’ll be right” that’s the attitude. And I think you have to kick to the back sides to get to the doctors and I feel that becomes a woman’s responsibility because in most cases men don’t go to the doctors like woman do. Women say I will go to the doctor today I don’t feel well, whereas men will say I will do it tomorrow. So that’s my responsibility.

S: I think as well my doctor would say to me: “You are ok Stephan” and I would think “Oh, great thing that’s good” I will get home and she [Jane] says: ”oh did you say this?” and I would say: “He didn’t ask” so most times we go to the doctors Jane comes with me because two minds are better than one. I don’t need to know the figures and I don’t remember the figures unless I wrote them down, whereas Jane asks the doctor and he responds to her, so now I have used my wife coming alone with me. I feel like my secretary is coming along with me. She can take the notes. [Laugh] and she will have several questions to ask. Well it is a shared responsibility.

I: What factors shaped this shared responsibility?

J: We love and trust each other.”

(Conversation with Stephan and Jane – involved in PR communication with their GP)

“I: We discussed about your own responsibility for your health, your doctors responsibility for health. Who else’s is responsible for your health?
L: Well, if you thought about it you belong to a family. Family is caring. You would like ...
Well three years ago I’ve got flu and I was so sick that I went to bed. So my husband cooked tea, my son came to me and said: “Look mummy you look terrible” and he said: “I think I will ring the doctor”, I said: “No you cannot do this because dr. Neil lives in that direction and the surgery is in the other side”. But he did and within an hour Dr Neil was at my place. So, I think family has some responsibility to observe that you are not well and you may die. And myself with my husband think the same. I said to him: “You better go and see about that.” So families I feel should be responsible if love them. But even people you don’t know and they are not well you can say: “I think you should go and see the doctor.” I think human beings should care enough one to another to say about someone's health or suggest to go and see a doctor. I don’t think you have to be in a relation to do this, but it is especially when you know someone.”
(Laura – involved in PR communication with her GP)

This relational component of patient responsibility was significant. Some patients started to use HBPM on the recommendation of their family members or friends. In addition, some patients were able to understand and to identify their health problems by talking with significant others.

“It was George [her husband] who started to bring home the blood pressure thing, and I just took one for fun. And it was a little on the high side. I've got to Mary [her GP] and she said I had white coat syndrome. It’s only been in the last three months that I had problems, real problems with my blood pressure. And we’ve brought one at home; I’ve started taking it in morning and night and found that one of the numbers is higher than it should be. Mary put me on something to take one of the numbers down, and I ended up getting ringing in my ears at night times. The first time that I had it I woke up in the middle of the night and it was that big bumping in my ears that I couldn’t understand why George couldn’t hear it, because it was so loud that woke me up. I eventually said to George: “What the hell is that because you didn’t hear anything” and then I realized it was in my ears. So it was a couple days later and you know it continued every night. So, I saw one of the other doctors down there and sitting up and asked what’s with this and this should be the cause of why I’m having the noise in my ears. He changed the medication and the noise is gone now.”
(Mary – involved in NR communication with her GP)

“And most of my friends have got it [blood pressure machine]. We had some friends who are older than us, that never had blood pressure when they suddenly went to the doctor
“Oh you got blood pressure”. So they will buy a blood pressure monitor. The doctor didn’t recommended it, but I spoke to them yesterday and I’ve said: “If you got a machine you know what’s running all the time when you go to the doctor, because they’re not sure at the moment whether they should be on medication or not. Well if it is higher all the times perhaps they should be.”

(Emily – involved in PR communication with her GP)

Similarly, in their interactions with GPs, patients did not focus on setting boundaries between themselves and their GPs. First, patients perceived that they had a duty to help their GPs, because in this way they could promote GPs’ capacities to help them. They perceived that by doing so they promoted their health interests.

“I think that it [home blood pressure monitoring] is just one of those things that you do or you don’t do. If you gonna say I don’t want to take this I think his [general practitioner’s] responsibility is more. He needs to look at you more, at why you don’t want to take that. I shouldn’t put the doctor in that situation. He makes the suggestion that you take the thing [blood pressure machine] to go along with and try and, then his responsibility towards you is satisfying to him because you’ve done what he asked you to do. I think people have to take on board what their responsibilities are. And their responsibilities are to help the doctor because then he can help you.”

(Stephan – involved in PR communication with his GP)

In addition, patients wanted to rely on GPs.

“S: I just felt from day one when I had a first consultation with him [his GP], which is probably three four years ago I felt a rapport that I haven’t normally felt with my general practitioner that I have seen in the past.
I: When you say a rapport what do you mean?
S: Well it means that we get along. I trust him from the first day, which I think it was really good. And that’s built on through the all the other experiences that I had with him. And that means that I am quite happy to embrace his suggestions. Because I thought well if he’s suggesting something than I am happy to do that.”

(Sam involved in PR communication with his GP)
In chapter seven, I showed that mutual trust in GP-patient relationship was significant for patient engagement in their own care. Patients who collaborated with PR-GPs described a higher engagement in their own care as compared with those who collaborated with NR-GPs.

Second, GPs and patients said that patients’ control over health care choices depended on the patients’ attitudes towards self-care and, specifically, their motivation to maintain their health. Patient motivation to maintain their health related more broadly to how people thought about control over their lives. Control influenced patients’ motivation to take care of their own health. NR-GPs had an individualistic understanding of the locus of control, whereas PR-GPs and all the patients placed the locus of control both in the social context and at the individual level. However, all the participants in this study said that HBPM could not significantly influence patients’ control over their lives.

NR-GPs said that patient responsibility was just a matter of patients’ personal preferences for controlling their lives.

“I: What do you think that made him a responsible person?
L: It’s a personal attribute really I would say. I mean every person ... you know, there is a lot of psychological theory about the locus of control and when people feel in control of their lives or something else is controlling them ... so different people feel in different ways. I suppose that one can say that is implicitly accepting his responsibility for his condition and looking after it, so one would take it as a sign of autonomy that he wants to be actively involved in his care other than he is taking tablets.”
(Laurence – NR-GP)

These GPs perceived that patients’ preferences were influenced by patients’ personal cognitive abilities such as their intelligence.

“I: And what do you think about this?
L: I think that’s reasonable again depending on patients’ intelligence. Motivation may not be something reasonable to expect in all patients, but he is a mechanically oriented person and he has a reasonable understanding. I don’t know if he knows a lot about hypertension, but at least he understands what he is trying to achieve.”
(Laurence – NR-GP)
“I: You've told me that he was interested in controlling his blood pressure. What factors have influenced his interest for this?

A: He is an elderly man who’s a retired engineer, who is very smart and likes to record his own figures. I think intelligence and education matter a lot.”

(Amanda – NR-GP)

NR-GPs used patients’ cognitive skills as a criterion to select patients for HBPM utilization.

“But you do this [recommend home blood pressure monitoring] with the right sort of patients that you do really trust you have a good relationship you know what I mean and don’t do this with all the patients ... you have to have a long relationship with him to know he is intelligent enough to handle that sort of things.”

(Christopher – NR-GP)

This understanding was also significant in the context of HBPM. In chapter six, I showed that these GPs tried to promote patients’ control over their health decisions by using biomedical communication to achieve patients’ compliance with their therapeutic recommendations. This increased patients’ motivation to be involved in their care only if patients and GPs shared the same opinions. In cases of discordance between GPs and patients, NR-GPs used persuasive communication focused on promoting patients’ worries about their own health. Sometimes this approach produced distrust and decreased patients’ capacity to assume responsibility for self-care.

By contrast, PR-GPs and all the patients said that patients’ health decisions were not simply free choices because patients had to make health decisions in conjunction with other life constraints such as work commitments or caring for sick members of their families. They had to balance these competing interests and, when patients assigned higher priority to other life interests, this could decrease their motivation to maintain their health. This was not to say that these less motivated patients did not have a sense of responsibility for their own health. Rather, they had decreased capacity to respond to their health needs.

“I think some people are more motivated than others in terms of caring for their own health. This is not to say that they don’t care, but there are people who have some overriding priorities such as they work or they care for other sick members of the family and then they tend to neglect their own health. So, for example if you got someone who
had high blood pressure, but you know they are very busy because of work commitments or because they’re caring for sick members or whatever, then they are occupied and they don’t look after themselves as much as they would if they wouldn’t have all those other worries. If they put their other worries such as work or caring for others over and above their own health then we can see that their health will suffer.”
(Ralph – PR-GP)

These GPs associated patients’ control over their lives with patients’ capacity to live the kind of lives they wanted. PR-GPs said that patients’ negative prospects to live the kind of life they wanted could decrease their motivation to live and subsequently, their capacity to assume responsibility for their own health. For instance, a hypertensive patient whose husband died decided to forego her treatment and to die because she found, in this circumstance, her life was not worth living.

“Brings me to mind a patient who actually has died and her blood pressure went up when her husband has died. And I couldn’t get it out why she died and recently I saw the son of this person and he said: “Look I think my mother wanted to die after my father died because she didn’t have in life anything to care about anymore. And he said “I think she wasn’t taking the medication and that’s why her blood pressure was high and she died.” She basically wanted to die because of her husband. Probably committing suicide was not an option so she simply forgot to take the medication.”
(Christian – PR-GP)

Similarly, patients’ negative financial circumstances or adverse social and personal factors could influence their capacity to live the kind of life they valued and this could decrease their motivation to maintain their own health.

“I: What do you think that are your responsibilities for your health?
S: I’ve gone from someone who was not a big man but strong, into something that’s not left too much in it and that’s only a year of retirement. I had a job which was great, but I no longer have that prospect and we haven’t grandchildren and that garden don’t take a lot of time and we really have to walk along the beach to spend our time. That’s the thing. If you are very wealthy than you can say: “let us go and travel, let us go and do this, let us go and do that”. But we are not and I can tell you, you work with your hands like myself and, they don’t pay so much for your hands. But the bottom line is that all these happened
in the short space of time of our son being ill me finishing work, and it’s drawing a
different dynamics of the whole thing really. And when things like these happen than it
will be an anxious time. What I want to say is if you want to save your health from this
point than you go to say: “Well there’s no point in being an idiot and doing a bloody
Joann job and then you can’t sit down for two months or lie down because you have so
much pain.” But your motivation is lower than would be otherwise. If someone can meet
me tomorrow and say: “your son has no longer cancer” then lifts the spirit like that. But
your spirit gets down with things like that.
I: How has this influenced your health?
S: I’ll be right that’s the attitude. If I don’t feel well I wouldn’t go to the doctor. I will say
I will do it tomorrow.
J [his wife]: Tomorrow might be too late.”
(Conversation with Stephan and Jane – involved in PR communication with their GP)

By contrast, patients who had positive views about the future had a greater motivation
to maintain their own health and an increased capacity to assume responsibility for self-
care. For instance, patients with higher socio-economic status appeared to be able to live
an easier life. This increased patients’ capacity to assume responsibility for self-care
because they wanted to enjoy their lives as much as they could.

“And most people, fortunately in this area most people are prepared to take responsibility
for their own health because they ...maybe it is not very politically correct, but there are
slightly more affluent bunch of folks with decent lifestyle and they want to protect their
lives as much as they can to enjoy their lives as much as they can ...and then follows
naturally that they are prepared to take a little more responsibility for things.”
(Frederick – PR-GP)

“I: What circumstances shaped your interest in health?
M: Well, I think also that I like living and I like doing the things. So if you don’t have
reasonable health you don’t do what you like. We’ve done a trip this year. Hopefully we’ll
do something next year. We’re looking either South Africa or South America and these are
the things to look forward to ... As I said we’ve done most of Europe, United States, parts
of Canada. We like these cruise ships because you go on a cruise ship for two weeks you
don’t have to pack and unpack, but you can stop there for two days and there for other
two days. Yee that’s what we like to do and we’re able to do.”
(Malcolm involved in NR communication with his GP)
Patients’ capacities to live the kind of lives they valued were also significant in the context of HBPM utilization. Most PR-GPs said HBPM was used mainly by people with higher socio-economic status who were highly motivated to maintain their health and had a higher degree of personal autonomy. However, they said that GPs were not able to influence these social determinants of patients’ responsibility.

“I: What kinds of patients are suitable for home blood pressure measurement?
A: I think higher socio-economic groups are choosing more often I think they are more likely to have a sphygmomanometer at home or someone in the family has one. I think education level and empowerment level or that sort of thing does influence the decision to use. These people are highly motivated in their health care and concerned about their health care and they are more likely to choose it. It does require a degree of autonomy on the patient behalf.
I: To what extent can you influence these factors?
A: We don't have a huge amount of control on that. We can teach people and build rapport with people. That’s a philosophical question really I guess hopefully government is responsible in providing safe living conditions, basic living conditions food water shelter, make sure to fit individually the patient in the population.”
(Adam – PR-GP)

Patients also described an association between their sense of control over their lives and HBPM utilization. People with positive prospects to live the kind of life they valued were motivated to maintain their health. Their past positive experiences as well as their positive prospects for the future both supported and enhanced their positive thinking. This motivation prompted them to use HBPM.

“I: and what kind of things shapes this positive thinking?
S: I think it’s all those years of competitive sport. I’ve played terribly aggressive football and in my mind is that the only thing that’s worse that no winning is losing. So I had that sort of push, which is inbuilt in me. And I think also that you really don’t want to become vegetable. You want to be able to do things when you want to do. And that’s I want to be. So I need to be as fit as I can be to do things I want to do. And at the moment I can do all those things.
I: So you say that you need to control your health to be able to live the kind of life you want to live.
S: Yes.
I: What role, if at all, has played home blood pressure monitoring in this understanding?
S: Actually I have used home blood pressure monitoring because I had this understanding to start with. And I aim this for years ago and I aim to be reasonably fit.”
(Sam – involved in PR communication with his GP)

However, this is not say that patients’ life and health choices were simply determined by patients’ social chances to live the kind of life they valued and that their personal capacity to influence their lives were not significant. Rather, GPs suggested that HBPM might allow patients to prioritise other issues above their health. For instance, one GP said that HBPM helped patients understand the risks associated with having hypertension. Thus, patients were able to balance the long-term risks of having hypertension with other health and social problems. Although this meant that patients with low health risks assigned less priority to their health interests as compared with other life interests they had, HBPM increased patient autonomy more generally and allowed patients to exercise control.

“I think she knows that high blood pressure is a risk. I discussed that with her several times, but she weights the risk of hypertension and the difficulty of treatment of her hypertension against many other concerns in her life; whether she can cope with her husband and cope with her mood changes and her anxiety, and I guess she’s made a decision to forego treatment in short, because it was a small risk in the longer term ...oh.. Forego any further treatment on the basis of that her life will be ... she would have greater autonomy in her life and greater ability to cope with her anxiety and husband and that sort of things in her life. And I guess the home monitoring was coming to the equation and we come to a point where she is making decisions on her own behalf to have treated or have not treated based on her knowledge of risk that I’ve conveyed to her and her experience of trying new drugs in past.”
(Frederick –PR-GP)

There were also several patients who described how HBPM had an impact on their capacity to control their lives. This group of patients perceived greater risks associated with their health.
“It [home blood pressure monitoring] also make me, it actually did make me more aware that for a long while I had chest pain a not real major pain. Chest pain and neck pain it did me to go to the doctor and discuss that which was checked up and actually was angina pains. So I guess it made me more responsible for that as well in the sense of not ignoring something but actually acting on it.”

(Rick involved in PR communication with his GP)

These patients said that HBPM helped them to improve their psychological abilities to cope with adverse life events. For instance, a patient described how HBPM helped him control his professional life. He had experienced difficulties in his professional environment and the frustration associated having abnormal blood pressure values overlapped with the frustration about his professional environment. HBPM helped this patient to understand the negative impact of his professional situation on his health. Thus, he increased his control over his own life by assigning a higher priority to his health needs and, ultimately, changing his job.

“I: How has home blood pressure monitoring influenced your life?
R: Oh, what it did do I actually changed my job at one point. Not within teaching I've taken a job we could relief teaching when teachers are away and they will give me work when they are away and I had to allocate lessons to other teachers or bring an extra teacher for a day and allocate lessons to them. I've done that for a number of years at my previous school, and I changed schools. It was just so frustrating and I actually stopped doing that. Much annoyance with the principal, but that's not the matter, but I related that to my health. That was when I've started doing the home monitoring. Oh just didn't think at that time when I’ve started the home monitoring that I will be frustrated and angry and that sort of stuff. But when I did the morning measurements will be always up in the morning and that sort of stuff. It will be better at night but you cannot go at school during the night. And teaching can be frustrating at times, you actually don't have a level of control of what happens and when. As a teacher you cannot set the agenda. Other people set your agenda. And it was very frustrating at that point. So actually I changed part of my role in school and I've also changed actually stopped teaching extra stuff keeping only long terms commitments. And again I probably drop some other commitments next year.”

(Rick – involved in PR communication with his GP)
In summary, in this section I have demonstrated that patients’ responsibility for their own health depended on: (1) patients’ capacity to deliberate effectively; and (2) patients’ control over their health care decisions and over their lives more broadly. Patients’ motivation to maintain their health was inbuilt in all these notions of patient responsibility. I showed that PR-GPs, NR-GPs and patients understood these notions of patient responsibility differently. Table 3 briefly describes PR-GPs, NR-GPs and patients views of what does patient responsibility mean.

<table>
<thead>
<tr>
<th>What does patient responsibility mean?</th>
<th>PR-GPs</th>
<th>NR-GPs</th>
<th>Patients</th>
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<tbody>
<tr>
<td>Capacity to deliberate effectively</td>
<td>Influences patients’ capacity to assume responsibility. Promoted by patients’ self-awareness of own health mediated by patients’ personal experiences of ill health</td>
<td>Influences patients’ capacity to assume responsibility. Promoted by patients’ self-awareness of own health mediated by patients’ personal experiences of ill health</td>
<td>Experiential dimension - patients’ awareness of their own health mediated by their personal and family experiences of ill health Psychological dimension – patients’ positive frame of mind Time dimension</td>
</tr>
<tr>
<td>Control over health care decisions and over their lives more broadly</td>
<td>Determines patients’ duty for their own health. Depended on patients’ capacity to seek out information and try to understand their illnesses.</td>
<td>Determines patients’ duty for their own health. Depended on patients’ capacity to seek out information and try to understand their illnesses.</td>
<td>Bi-directional relationship between control over decision making and patient responsibility Depended on patients’ awareness of their own health Had a relational component that depended on mutual</td>
</tr>
</tbody>
</table>
Influenced by patients’ life constraints that shaped patients’ motivation to maintain their health.

Influenced by the strength of patients’ free will and their cognitive abilities.

Influenced by patients’ life constraints that shaped patients’ motivation to maintain their health.

Table 8.1 – GPs’ and patients’ views of what does patient responsibility mean

These different understandings were significant in the context of HBPM utilization because they prompted different approaches with respect to patients’ motivation. I have shown that HBPM could influence patients’ control over health care decisions and patients’ capacity to deliberate effectively because it influenced patients’ motivation to maintain their health. However, HBPM could not influence significantly patients’ capacity to control their lives.

8.4 Conclusions

In this chapter, I described GPs’ and patients’ views of personal responsibility for health in the context of HBPM. I focused on the relationship between patients’ motivation to maintain their health and patient’s responsibility for their health. I also demonstrated that the views of PR-GPs, NR-GPs and the views of patients about patient responsibility for health shared significant similarities and differences. I have also showed the significance of these different understandings in the context of HBPM. In the first section of this chapter I showed that GPs and patients described patients’ responsibility for their health in terms of practical activities focused on maintaining patients’ health. I also described these practical activities.

In the second section, I described the values, beliefs and ideas that GPs and patients associated with what it meant to be a responsible person. I demonstrated that patients’ responsibility for their own health depended on: (1) patients’ capacity to deliberate effectively; and (2) patients’ control over their health care decisions and over their lives.
Patients’ motivation to maintain their health underpinned all these notions of patient responsibility. I showed that PR-GPs, NR-GPs and patients understood differently these notions of patient responsibility. These different understandings were significant in the context of HBPM utilization because they prompted different approaches with respect to patients’ motivation. I showed that HBPM could influence patients’ control over health care decisions and patients’ capacity to deliberate effectively because it influenced patients’ motivation to maintain their health. However, HBPM could not influence significantly patients’ capacity to control their lives. In the next chapter, I will draw together the findings of this study with the theoretical material presented in the first part of this thesis to discuss their significance for self-management approaches and to build an account of the GP-patient relationship, patient responsibility and patient autonomy in the context of the use of self-management technologies.
Chapter 9: Discussion

9.1 Introduction

This study has examined: (a) how self-management technologies influence the doctor-patient relationship; and, (b) to what extent doctors and patients build and maintain the notion of patients' responsibility for their own health and patient autonomy through the use of self-management technologies. Following a critical examination of the key concepts in the literature concerning the conceptual base of self-management approaches in the context of chronic diseases, the bioethics literature with respect to the doctor-patient relationship and empirical ethics related to self-management technologies, I then collected and analysed my data to provide a detailed description of the pathways and mechanisms through which self-management technologies can shape the doctor-patient relationship and patients’ agency. Data analysis resulted in two categories: the GP-patient relationship and patients’ responsibility for their health, all in the context of HBPM utilization.

In this chapter, I draw together the findings of this study with the theoretical material presented in the first part of this thesis to discuss their significance for self-management approaches and to build an account of the GP-patient relationship, patient responsibility and patient autonomy in the context of the use of self-management technologies. I show that mutual trust in the doctor-patient relationship plays an important role in developing patients’ motivation to maintain their health, which, in turn, underpins all dimensions of patients’ responsibility for their health. Throughout the text, I discuss the implications of these outcomes for the bioethics literature on models of the DPR, patient responsibility for personal health and patient autonomy as well as for the literature concerning the conceptual base of self-management approaches.

9.2 Self-Management Technologies and the General Practitioner – Patient Relationship

This study has a number of implications for the doctor-patient relationship. First, this study shows that mutual trust in the DPR plays an important role in GP-patient interactions, and that a change in the interaction of doctors and patients, for example through the use of self-management technologies, has a significant impact on patients’ self-efficacy or, in other words, patients’ confidence that they have the cognitive and affective abilities to manage their illnesses. In chapter six and seven, I have shown that,
for the participants in this study, the main function of HBPM was to facilitate collaborative approaches between patients and GPs, focused around improving the technical certainty of accuracy of the blood pressure recordings associated with the management of hypertension. HBPM was also used by GPs to motivate their patients to maintain their health and by patients to increase their control over their health. Patients’ engagement in their own care depended on the capacity of the GP-patient relationship to promote mutual trust in the DPR, which, in turn, rested on the characteristics of the GP-patient communication. I have shown that the positive reinforcement (PR) communication style occurred within a relational model of the DPR, whereas the negative reinforcement (NR) communication style was associated with a contractual type of DPR. These two types of relationships had differing influences upon patients’ confidence in their cognitive and affective abilities to manage their blood pressure and their illnesses more generally, due to their different effects on the promotion of mutual trust in the GP-patient relationship.

Second, this study indicates that a self-management technology is likely to have a greater impact on patients’ engagement in their own care and patients’ self-efficacy when it is used within a relational model of the DPR. Along the same lines as Brody’s relational model of DPR25,126,127 and the relationship-centred model of care (RCC),30,148-151 the relational model of the GP-patient relationship described in this study was a partnership between patients and their GPs where both parties actively worked together. This partnership helped patients to engage with their care in ways that fostered the patients’ adherence to their medical treatments and promoted lifestyle changes that could help patients to improve their health. The findings are consistent with those of other studies,14,84,85 which show that patients’ engagement depends on patients’ self-efficacy. In addition, I have also shown that a positive reinforcement communication style contributed to patients’ engagement in their own care.

Consistent with the above finding is the finding that a contractual type of relationship of GP-patient relationship has less impact upon patients’ engagement in their care. As with contractual models of the DPR in the bioethics literature,24,111 the contractual type of relationship described in this study was perceived as a transaction that depended on GPs’ and patients’ sense of responsibility. This type of relationship promoted a degree of engagement of patients with their care; however, this engagement was limited only to fostering patients’ adherence to their medical treatments and to consulting doctors in case of high blood pressure values. It was also associated with a negative reinforcement communication (NR) style. Patients’ engagement in their own care and patients’ confidence that they had the cognitive and
affective abilities to manage their illnesses developed only to the extent that GPs and patients shared the same opinions with respect to therapeutic recommendations.

Third, the findings of this study show that mutual trust between doctor and patient is crucial to patients’ self-efficacy. This is a significant issue in the context of self-management technologies because it emphasises how much mutual trust and self-efficacy are interrelated. At the core of the PR communication style was mutual respect between doctors and patients. This communication style, through its characteristics, (of building partnership, seeking and giving information that was relevant for patients’ health in their social context, nonjudgmental and autonomy supportive and biopsychosocial communication) promoted mutual respect; it underscored GPs’ professional competence, patients’ competence to manage their illnesses, and GPs’ and patients’ honesty. This increased GPs’ and patients’ capacity to rely on each others’ judgments, which, in turn, increased the transfer of emotional and factual information about the patient’s health. More information also promoted patients’ awareness of their hypertension and the need to adjust their lifestyle to their health needs. Mutual respect also promoted patients’ trust in themselves and increased their confidence that they could manage their illnesses.

These findings are also significant because they show that GPs’ trust in their patients and patients’ trust in their GPs influence each other. In chapter three, I showed that doctors’ trust in their patients is not well acknowledged in the bioethics literature. My findings show that the affective bond between doctors and patients enhanced mutual trust in the DPR. In chapter seven, I showed that PR-GPs and patients described the PR communication style slightly differently. Despite these differences, the positive emotional interaction described by patients underscored GPs’ and patients’ characters and honesty. This helped to build rapport between GPs and patients and promoted mutual trust. It also helped reassure patients that they were on the right track with the management of their illnesses when they developed anxiety during HBPM. This is also significant for the PCC method of care, as it supports the notion that the affective bond between GPs and patients resides in mutual trust and not from a negotiated contract. This is a contribution to our understanding of the PCC method of care, as I showed in chapter two that the PCC method of care does not make it clear whether the bond between doctors and patients stems from a negotiated contract between doctors and patients or from their mutual trust.

Fourth, the findings of this study have implications for the collaborative model of the DPR (CM-DPR) developed by Bodenheimer et al14-16 upon which Chronic Diseases Self-Management Programs are based. The CM-DPR is similar to the contractual model of the GP-patient relationship described in this study. It aims to promote patients’ control over their health
by providing patients with relevant medical instructions tailored to their particular health needs and it also uses persuasive communication to change patients’ health behaviour.

To the extent that the CM-DPR is similar to the contractual model of the GP-patient relationship, my findings suggest that the CM-DPR will not necessarily promote a trustworthy partnership between patients and GPs and it may not succeed in enhancing patients’ self-efficacy. The NR communication style in this model of the GP-patient relationship did not have the positive emotional interaction that developed in the PR communication style. This lack of positive emotional interaction prompted an evaluative process in which both patients and GPs evaluated each other’s sense of responsibility. Patients evaluated GPs’ professional competence and GPs’ evaluated patients’ cognitive and affective abilities to follow doctors’ recommendations. This evaluation meant that patients’ lifestyles did not necessarily change; where it did, this was limited to those cases when GPs and patients shared the same opinions.

This finding raises a significant issue for the CM-DPR, because it implies that the CM-DPR may not achieve its aim of promoting behavioural changes, such as losing weight or increasing the level of physical activity, in chronically-ill patients.95-99 The findings with respect to biomedical communication are also significant for the contractual models of DPR, as they suggest that these models may have a limited impact in promoting patients’ control over their health. By contrast, seeking and giving information within the PR communication style appeared to enhance patients’ control over their health because it promoted a bidirectional transfer of information between patients and GPs.

In addition, the findings of this study raise questions about the ways in which persuasive communication may influence patients’ capacity to deliberate effectively. This study shows that persuasive communication promoted neither mutual trust in GP-patient relationship nor patients’ self-efficacy. Persuasive communication was unsuccessful because patients felt devalued as persons and GPs felt that their patients did not trust their decisions. In cases where patients were not compliant with NR-GPs’ recommendations, these GPs tried to persuade their patients that an ‘admirable’ health care decision might improve their health and life outcomes. This approach promoted distrust and increased confrontation in the GP-patient relationship. By contrast, the PR communication style promoted patients’ capacity to reflect on their health.

Notwithstanding these criticisms, the findings of this study do highlight some strengths of the CM-DPR. In chapter one, I described how the CM-DPR aims to promote patients’ control over their lives through communication focused on negotiating specific health goals and on contracting with patients to undertake specific short-term actions that could
improve their medical condition or achieve a specific behavioural change.\textsuperscript{14-16} Although neither the PR nor NR communication style had this communication pattern, the findings of this study show that biopsychosocial communication and seeking and giving information communication patterns do encourage patients to integrate therapeutic recommendations into their life goals and aspirations. This is also significant for the interpretative version of contractual models. Neither the PR nor NR communication style had a communication pattern focused on interpreting patients’ values and life goals,\textsuperscript{112,123} as the interpretative model of DPR does. However, the GPs and patients in this study did want an integration of therapeutic recommendations with patients’ aspirations and life goals.\textsuperscript{112,123}

In summary, my study demonstrates that the contractual model of the DPR fails to really provide an effective basis for the relationship between the GP and patient in the context of self-management of chronic diseases. In addition, my findings suggest that there is a need to focus on the relational model of DPR and on the PR style of communication, which has the potential to promote mutual trust in the DPR and patient self-efficacy.

9.3 Self-Management Technologies and Human Agency

In this section, I discuss the implications of this study for patients’ personal responsibility for their own health and for patient autonomy. I explain the pathways through which patients’ responsibility for their health and patients’ autonomy interrelate. I show that, in my study, patient responsibility for their health was influenced by patient autonomy. I show that, in the context of HBPM, patients’ responsibility for their own health and patient autonomy was partly influenced by GP-patient communication and partly by technology utilization.

This study has shown how patient responsibility and patient autonomy interrelate in the context of self-management technologies. Consistent with other studies,\textsuperscript{90,179,188,192,197} this study has identified that patients’ responsibility for their health was interpreted as patients’ duty for self-care. In chapter eight, I showed that both GPs and patients described patients’ duty to maintain their health in terms of practical tasks. Patients had a duty: to understand their medical conditions, to make lifestyle changes in accordance with their health needs, to adhere to treatments, and to monitor their illness and seek medical help for routine and acute care. In the specific context of hypertension, GPs’ and patients’ expectations were that patients would measure and record their blood pressure in accordance with GPs’ instructions and would use HBPM in a rational way. Rational utilization of HBPM meant
that patients had to monitor their blood pressure at reasonable periods of time, because some patients panicked when they measured abnormal blood pressure values. Patients in this study also said that it was their duty to learn to control negative emotional responses associated with HBPM.

As with other studies that have focused on the impact of self-management technologies on patients’ duty for self-care, this study identified contradictory effects of HBPM on patients’ responsibility for self-care. In some patients HBPM promoted an engagement with their care that focused on fostering the patients’ adherence to their medical treatments and promoting lifestyle changes, whereas in others it produced a lower level of patients’ engagement that was limited only to adhering to medical treatments and to consulting doctors when it was necessary. In addition, in some patients HBPM produced anxiety and decreased responsibility for self-care. Some patients stopped using HBPM.

Consistent with Bandura’s social cognitive theory, this study found that patients’ responsibility to maintain their health included a capacity to build on their strengths and respond to their personal needs and the challenges posed by the environment. Patients’ responsibility for their own health was partly influenced by communication with their GP and partly by their use of technology. HBPM encouraged patients to maintain their health.

Although GPs and patients in this study did not talk explicitly about patient autonomy, the findings of this study show that their understanding of patient responsibility was related to the main conceptions of patient autonomy. First, my study links patient responsibility with patients’ capacity to deliberate effectively. These findings provide indications of a more positive definition of patients’ capacity to deliberate effectively compared with the definition of effective deliberation found in the bioethics literature. GPs and patients in this study associated responsible deliberation with a reflective process through which patients became more conscious of their own health and, therefore, could take positive actions that could prevent ill health. By contrast, in the bioethics literature, responsible deliberation was perceived as being more neutral, meaning actions taken where a person believes that he or she is in a situation calling for a decision, is aware of the alternatives and the consequences of the alternatives, evaluated both, and chooses an action based on that evaluation. This difference may be explained by the fact that patients and GPs in this study considered that patients’ responsibility for their health is a value per se and patients aimed at following healthy behaviours whenever their life circumstances allowed them to do so.
My findings also shed light on the mechanisms through which patients’ capacity to deliberate effectively is related to personal responsibility for health. In chapter eight, I showed that patients’ personal and family experiences of ill-health prompted them to make a connection between unhealthy behaviours and poor health and this increased their sense of responsibility. Patients’ confidence that they had the psychological abilities to manage their illnesses and to make positive health choices also made them more proactive with respect to their health. All of these things, however, required time for patients to think about their health. Such time appeared to be more available to patients who were older. These findings may be important for the theoretical understanding of effective deliberation. For example, in chapter two, I discussed how effective deliberation implied that patients’ choices should be the result of a self-reflective process rather than a result of factors outside individual control.4

In contrast with other studies176,178,185 that focused on patients’ autonomy understood as patients’ capacity to deliberate effectively, this study revealed patients’ capacity to deliberate was also influenced in part by how they used technology and by communication with the GP. HBPM acted on patients’ capacity to deliberate effectively through all these dimensions. It influenced the experiential dimension of patients’ capacity to deliberate effectively by increasing patients’ awareness of their own health. It also gave them the confidence to manage their illnesses. HBPM helped patients to feel reassured and decreased the level of uncertainty which, in turn, decreased patients’ negative emotions. This impacted positively on patients’ mental wellbeing. By contrast, persuasive communication in the NR communication style decreased patients’ self-efficacy and increased their level of anxiety.

Second, this study also shows that patients’ ability to respond to their health needs was influenced by their control over their health and over their lives more generally. Consistent with the bioethics literature, the GPs and the patients in this study interpreted individual control over health care decisions to be therapeutic decisions that are voluntary and intentional.7 Patients’ control over their own health care choices depended on their capacity to seek out information and to try to understand their illnesses. Patients with this capacity were more aware of their own health, better able to follow healthy behaviours and in a better position to manage their illnesses.

A relational model of autonomy has a greater capacity to enhance patients’ control over their health due to its capacity to promote mutual trust in the DPR. In the third chapter I have shown that relational autonomy depicts a free, self-governing agent as socially constituted and one who defines her basic value commitments in terms of
interpersonal relations and mutual dependencies. In a similar way, the patients in this study described a relational component to their capacity to make sound health care decisions. Although they wanted to be in control of themselves, they did not set boundaries between themselves and significant others. Rather, they became aware of their own health and made health care decisions in the context of their relationships with significant others such as family members, friends and their GPs. In addition, patients thought they had a duty to help their GPs because this increased the GP’s capacity to help them. This in turn helped patients to understand and to detect their health problems. This is a significant issue in the context of self-management approaches because it points to the centrality of relational autonomy for a trustworthy partnership between GPs and patients. This is also significant for the collaborative model of DPR, because its individualistic understanding of patient autonomy will not promote a partnership between GPs and patients.

This study has also shown that patients’ sense of responsibility for their health depended, to some degree, on their capacity to control their lives. Their control over their lives and their decision making were interdependent. In chapter eight, I showed that patients’ control over their health care decisions also depended on their motivation to maintain their health, which related more broadly to how people thought about control over their lives. Perceptions about control influenced patients’ motivation to take care of their own health.

In addition, I found in this study that NR-GPs had an individualistic understanding of the locus of patients’ control over their lives, whereas PR-GPs and all the patients placed the locus of control both in the social context and at the individual level. NR-GPs associated responsibility with patients’ preferences to control their lives and they considered that these preferences were influenced by patients’ personal cognitive abilities such as their intelligence. By contrast, PR-GPs and all the patients associated patients’ control over their lives with patients’ capacity to live the kind of lives they wanted. This capacity was largely influenced by socio-economic determinants. Patients’ negative views of their future could decrease their motivation to live and their capacity to assume responsibility for their own health. In contrast, patients who had positive views about the future had a greater motivation to maintain their own health and an increased capacity to assume responsibility for self-care.

Patients exercised control by balancing their competing interests when they had to make life and health decisions. Patients’ perceptions of high health risks increased their motivation to maintain their health, prompting them to take control over their lives and to make positive health choices. Despite the fact that NR-GPs, PR-GPs and patients placed
the locus of control at different levels, all of them agreed that HBPM did not seem to directly influence patients’ capacity to control their lives.

In contrast with other studies \(^{174,175,180,182,186,189,191}\) that have focused on the impact of self-management technologies on patient autonomy, this study has found that HBPM has a minimal impact on patients’ capacity to control their lives. These other studies have focused on evaluating self-management technologies for patients with serious illnesses, such as end stage renal disease or respiratory failure, whereas my study focused on a much less debilitating condition. Perhaps this is why I found a bidirectional relationship between patients’ capacity to live the kind of lives they wanted and HBPM utilization. This may be the case for a number of reasons. First, socio-economic status was relevant to HBPM utilization. HBPM was used mainly by people of higher socio-economic status who were highly motivated to maintain their health and had a higher degree of personal autonomy. In addition, patients’ positive past experiences and positive prospects for the future enhanced their self-efficacy, which, in turn, prompted them to use HBPM. Second, HBPM helped patients to exercise control over their lives by balancing health interests with other competing life interests. In patients with higher health risks, HBPM promoted patients’ motivation to maintain their health and to take control over their life by making positive health choices.

In summary, in this section I have discussed the significance of my study for the ethical conceptions of patients’ responsibility for their health and patients’ autonomy. I have shown that HBPM had an effect on patients’ control over health care decisions and patients’ capacity to deliberate effectively because it influenced patients’ motivation to maintain their health. However, HBPM did not seem to directly influence patients’ capacity to control their lives.

### 9.4 Conclusion

In this chapter, I have drawn together the findings of this study with the theoretical material presented in the first part of this thesis and discussed the significance of these findings for the GP-patient relationship, patient responsibility and patient autonomy. First, I discussed the implications of my study for the GP-patient relationship. My findings suggest that mutual trust in the GP-patient relationship is at the core of the productive interactions between patients and their GPs and that changing these interactions can influence patients’ self-efficacy. In addition, I explained that a self-management technology has a higher
impact on patients’ engagement in their care and on patients’ self-efficacy when it is placed in
the context of a relational model of DPR. I also discussed the significance of this study for the
CM-DPR, suggesting that such a model would not promote a trustworthy partnership and
patients’ self-efficacy. The combination of relational and contractual features of the CM-DPR
thus appears to be conceptually inconsistent.

Second, I have explained the pathways and mechanisms through which patient
responsibility and patient autonomy interrelate in the context of self-management
technologies. I have shown that self-management technologies can promote patients’
responsibility for their health, because they can enhance patients’ motivation to maintain
their health. However, HBPM did not seem to directly influence patients’ capacity to
control their lives.
Chapter 10: Conclusions

This thesis contributes to our understanding of the moral dimensions of using self-management technologies in general practice. I started with an appraisal of the ethical implications of self-management technologies and related self-management practices for the doctor-patient relationship (DPR), patients’ responsibility for their own health and patient autonomy. I showed that self-management technologies have received considerable attention, principally because they may be able to influence patients’ cognitive and emotional abilities and, through this, change health outcomes for chronically ill patients. Despite these potential benefits, I suggested that there is a need for a broader ethical analysis of the impact of self-management technologies on the doctor-patient relationship (DPR). I argued that such an analysis should investigate the patterns through which mutual trust influences patients’ responsibility for health care, the role of self-management interventions in promoting human agency, and the kinds of communication patterns likely to support this.

I then contrasted this account with models of the DPR drawn from the bioethics and clinical literature, and with the conceptions of patient responsibility and patient autonomy that inform these models. I showed that the collaborative model of the DPR developed for self-management approaches combines features from both the contractual and relational models of the DPR, such as building mutual trust, and conceptions of patient autonomy and patients’ personal responsibility for their health. I suggested that these features may be conceptually inconsistent, which raises questions about the capacity of the CM-DPR to promote both mutual trust and patients’ self-efficacy. I also compared the CM-DPR with clinical methods in primary care and argued that there is a need for further research to understand the relationship between patients’ responsibility for their health, patient autonomy, mutual trust and communication patterns in the DPR characteristic of chronic disease self-management.

This was followed by a review focused on findings from qualitative research about the influences of self-management technologies on mutual trust in the DPR, patient autonomy and on patients’ responsibility for their health. This review showed that these studies do not explain clearly the relationship between doctor-patient interactions, patients’ sense of responsibility for their own health, patient autonomy and mutual trust in the DPR. In addition, it revealed a lack of information with respect to how self-management technologies influence communication in the DPR and the impact of different patterns of communication in the DPR on the utilization of self-management
technologies. Accordingly, the aims of the empirical part of this thesis were to describe and explain: (1) doctors’ and patients’ perceptions of the pathways and mechanisms through which self-management technologies can influence mutual trust in the DPR; and (2) how GPs and patients interpret the notion of patient responsibility for health status and outcomes and whether self-management technologies influence how doctors and patients interpret these ethical notions.

The empirical part of the research consisted of collecting data from general practitioners (n = 13) and patients (n = 19). Home blood pressure monitoring was used as a case study for self-management technologies. I used in-depth semi-structured interviews focused on participants’ experiences with HBPM as a means to explore and collect experiential narrative material to develop an understanding of participants’ views about: (1) the ethical features of the DPR; (2) patients’ sense of responsibility for their health; and (3) patient autonomy; and, then, to explore the influence of HBPM on these. Analysis of these data revealed two core categories for this study: (1) the GP-patient relationship; and (2) Patients’ responsibility for their health. The findings of the qualitative study revealed that, in relation to HBPM, mutual trust in the DPR plays an important role in promoting patients’ motivation to maintain their health, which in turn, underpins all dimensions of patients’ responsibility for their health.

Finally, I discussed the implications of these outcomes for the doctor-patient relationship and human agency in the context of self-management of chronic diseases. I argued that self-management technologies have a greater impact on patients’ engagement in their care and self-efficacy in the context of a relational model of DPR compared with a contractual one because the relational model of the DPR promotes mutual trust. I explained the mechanisms through which mutual trust and self-efficacy interrelate in the context of HBPM. I then discussed the implications of this study for the collaborative model of the DPR, showing that, due to its communication patterns, the CM-DPR is unlikely to promote self-efficacy and mutual trust in the DPR. In addition, I showed that greater levels of patient autonomy enhance patients’ motivation to maintain their health, which in turn, promotes patients’ capacity to assume responsibility for their health. I also discussed the implications of these outcomes for theoretical conceptions of patient autonomy and responsibility for health. I showed that, in the context of self-management technologies, patient responsibility and patient autonomy is partly influenced by the utilization of technology and partly by GP-patient communication.
10.1 Significance of this Research

This study has practical and theoretical implications for general practice, bioethics and public health ethics. First, on a practical level this study suggests that general practitioners should be taught how to build mutual trust in the GP-patient relationship. This is linked to the communication styles of general practitioners, in particular the ability to listen to and appreciate the patient’s account and to integrate therapeutic recommendations with patients’ life goals and aspirations. In addition, GPs should learn to trust in the capacities of patients to determine aspects of their medical care. This is particularly significant in the context of self-management of chronic disease because GPs’ trust in their patients significantly influences patients’ self-efficacy. The responsibility to build trust rests with patients as well as with their GPs. This study thereby suggests that self-management education programs need to develop, on the one hand, patients’ self-efficacy and, on the other hand, patients’ communication skills so that they will be able to build mutual trust with their GPs. This is especially significant in the context of self-management technologies where GPs have to transfer significant roles and responsibilities to their patients and both patients and GPs have to rely on each other’s judgments.

With regard to the theoretical basis of general practice, this research has found a potentially fruitful link between the relationship-centred model of care and ethical theory. As previously discussed, the relationship-centred method provides a framework within which doctors are more likely to recognise patient expertise and to demonstrate the requisite relational skills. This study provides an insight into the meanings of negotiated therapeutic goals, therapies, and common ground for treatment, as well as of their associated clinical and ethical practices in the context of self-management technologies. It clarifies the relation between mutual trust in doctor-patient relationships and patients’ sense of responsibility for health care and health. The findings of this study also give us a deeper understanding of the meaning of a trusting relationship and of the communication patterns through which a self-management technology can contribute to building trustworthy doctor-patient relationships in the context of self-management of chronic illness.

Second, this study is significant for bioethics with respect to the doctor-patient relationship and for the ethical conceptions of patient autonomy and personal responsibility for health. The discipline of bioethics has to date relied more on theory than on empirical research. Earlier in this thesis, I argued that one of the weaknesses of bioethical models of DPR is that their characteristics are derived from philosophical
reflection, rather than from empirical studies of doctors’ and patients’ behaviours. The models tell us little about their effectiveness in promoting patients’ personal responsibility for their health and autonomy. This thesis represents one such attempt in which research questions informed by bioethical theory have examined these ethical conceptions in the context of real life utilization of self-management technologies in general practice. This research has highlighted the importance of mutual trust in bioethical conceptions of the doctor-patient relationship. In addition, it has revealed the mechanisms through which communication in the DPR influences mutual trust as well as patients’ autonomy and responsibility for their health. My findings have enriched our understanding of ethical conceptions of patient autonomy and responsibility by explaining the pathways and mechanisms through which these ethical conceptions interrelate.

Third, this study may also contribute to public health and policy ethics. The outcomes of this study with respect to the meaning of individual responsibility for health care and health could help public health practitioners and policy makers to shape policy on chronic care self-management in accordance with patients’ and general practitioners’ needs and capacities. In addition, the findings of this research study are significant for the evaluation of self-management technologies from an effectiveness point of view. Earlier in the thesis, I showed that the evidence on the effectiveness of self-management technologies is contradictory. My findings indicate that these contradictions could be the result of varying prevalence of contractual and relational types of DPR in different settings. My study showed that HBPM had a higher impact on patients’ self-efficacy in the context of a relational as compared with a contractual type of DPR, due to differing capacities of these two types of relationships to promote mutual trust. In addition, I have shown that mutual trust in the DPR plays an important role in GP-patient interactions, such that a change in the interaction of doctors and patients in the context of self-management technologies may have a significant impact on patients’ self-efficacy. Although these DPR interactions are the pathway through which self-management technologies act on patients’ self-efficacy, these studies do not consider them when the effectiveness of self-management technologies is evaluated.

10.2 Limitations of this Research

This study was limited to a small number of GPs located in largely urban practices in South Australia, and to patients recruited by those GPs. Despite my efforts to recruit a full
range of patients who used HBPM, all the patients interviewed described their relationships with their GPs as trustworthy. This means that the patient group was potentially biased towards patients who had particularly friendly relationships with their GPs and thus was not representative of the full range of patient attitudes and experiences. In addition, this study was limited to patients who had experience with HBPM utilization. Therefore, it did not capture the views of patients who might have an indication for HBPM utilization but were not yet using it, or of patients using other kinds of self-monitoring technologies. Nonetheless, it did not capture the views of patients who abandoned HBPM. I have interviewed only one patient who abandoned HBPM.

In addition, the total number of participants in this study was too small to allow for any meaningful numerical analysis, or to make generalisations about the relative frequencies of participants across the range of attitudes found. This study has provided a detailed account of general practitioners’ and patients’ perceptions of the doctor-patient relationship, patients’ responsibility for their health and their autonomy in the context of HBPM utilisation in general practice; research of different design is required to provide generalizable data about the population that uses HBPM.

Nonetheless, some of the findings of this study may have limited relevance for treatment delivery self-management technologies. This study has employed HBPM, which is a self-monitoring technology, as a case study for self-management technologies. Treatment delivery self-management technologies, such as self-adjustment of insulin doses in diabetes type I patients who self-monitor their blood glucose, may entail a different kind of doctor-patient interaction compared with that associated with self-monitoring technologies. This could be so because the level of uncertainty associated with patients self-adjusting their therapies is higher compared to situations where patients only self-monitor biological parameters, but still rely on doctors to change their therapies. For instance, doctors may need higher levels of trust to rely on their patients’ expertise and skills to manipulate therapies by themselves. In addition, patients’ fear and anxiety due to this higher level of responsibility may be more significant compared to self-monitoring alone. The different requirements of self-management may entail, at least in part, different communication characteristics and have different effects on mutual trust in the DPR and on patients’ self-efficacy. In addition, this study suggested that HBPM does not have a significant impact on patients’ control over their lives. By contrast, treatment delivery technologies may have a significant impact on patients’ capacity to control their lives. For instance, type I diabetic patients by self-adjusting their insulin dosages to their day to day health needs may increase their capacity to control their lives.
10.3 Future Directions

There is a need to understand how GPs’ professional responsibility for patients’ health, GPs’ own self-efficacy, and mutual trust in the DPR interrelate. In addition, there is a need to understand the interrelationship between GPs’ professional responsibility and patients’ responsibility for their health. In the second chapter of this thesis I showed that self-management technologies aim to optimise health care outcomes by focusing clinical decision making on long-term prevention through productive doctor-patient interactions enhanced by motivated patients and proactive clinicians. It is likely that GPs’ professional responsibility is influenced by patients’ responsibility for their health and that the relationship between these ethical notions may have an impact on GPs’ proactivity and, through this, on interaction in the GP-patient relationship.

These insights into the importance of mutual trust in the DPR may help to inform evaluations of the effectiveness of self-management technologies. Current studies on the effectiveness of these technologies do not consider the interactions in GP-patient relationship, which is the pathway through which they act on patients’ self-efficacy and presumably on patients’ health.

10.4 Concluding Remarks

This thesis started with an account of the ethical implications of self-management technologies for the doctor-patient relationship, patients’ responsibility for their health and patient autonomy. I showed that these technologies may be able to influence patients’ health agency by promoting their cognitive and affective abilities and, through this, change health outcomes for chronically-ill patients. However, there are a number of pertinent ethical issues concerning mutual trust in the DPR, patient responsibility and patient autonomy that need further empirical clarification. Through qualitative interviews with GPs and patients with experience in HBPM utilization, this study examined the influences of HBPM on the GP-patient relationship, patient responsibility for their health and patient autonomy. It is the conclusion of this thesis that, in the context of self-management technologies, mutual trust in the DPR plays an important role in promoting patients’ motivation to maintain their health, which in turn, underpins all dimensions of patients’ responsibility for their health.
APPENDICES
Appendix 1 A: Information sheet for patients

The purpose of this study is to explore what people who measure their blood pressure at home think about this. We want to understand how measuring your blood pressure at home influences your relationship with your doctor, your ideas about health and your illness, your responsibility for your health care and the responsibility your doctor have to provide care. We will also like to understand how measuring blood pressure at home is influencing your ideas about your personal responsibility.

There will be two groups of participants in this study: (a) general practitioners and, (b) patients. If you will accept to participate in this study you will be asked to take part in up to three interviews lasting approximately 90 minutes each. These three interviews will be over a period of several months. In the first interview we will ask you how you come to use home blood pressure monitoring and what has that been like. In addition we may ask you how and what did you discuss with your doctor when you decided to take your blood pressure at home; what were your expectations; how taking your blood pressure at home influenced your life and your responsibility for your medical care; and how does it influence your relationship with your doctor.

In the second interview, based on your previous answers you will be asked to tell us what you actually think about taking your blood pressure at home. We will try to understand how and what you understand by treatment, health results, you and your doctor’s responsibility for medical care, and what factors shaped your understandings. In the last interview you will be asked to check if what we have understood from your interviews is what you wanted to say.

Additionally, we will ask you permission to let us observe a consultation with your doctor related to home blood pressure measurement. The consultation will be audio recorded if you will agree.

There will not be direct benefits for you participating in this study. A payment of 50 dollars per encounter will be provided you as a remedy for your lost time and other costs.

There are no major risks related to this study, excepting the possible discomfort associated with interviewing. The frequency of our visits might affect your comfort, and therefore we are open to any arrangement convenient for you.

Your participation in this research study is voluntary. Refusing to participate will not alter your usual health care or involve any penalty or loss of benefits to which you are
otherwise entitled. If you decide to join this study, you may withdraw at any time and for any reason without penalty or loss of benefits. If information generated from this study is published or presented, your identity will not be revealed.

The information obtained as a result of this study will remain confidential, stored in a locked file at the University of Adelaide – Discipline of Public Health, and will not be disclosed others outside of the study team except with your permission or as may be required by law. All study results of this study will be collected in a computer or data registry at the Discipline of Public Health – University of Adelaide. These data will be shared with study team members. All interviews obtained from you during this study will be coded with a unique identification number, in place of personally identifying information.

If you have additional questions or concerns with respect to your participation in this study feel free to contact:

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Appendix 1 B: Information sheet for General Practitioners

The purpose of this study is to explore the moral aspects of the care of chronically ill patients in general practice in the context of self-management technologies. We want to understand how measuring home blood pressure at home influenced your meaning of therapeutic goal, treatment, health results, individual and professional responsibility for health care and your relationship with hypertensive patients.

There will be two groups of participants in this study: (a) general practitioners and, (b) patients. If you will accept to participate in this study, you will be asked to take part in two interviews lasting approximately 90 minutes each. These two interviews will be over a period of several months. In the first interview we will ask you how you come to recommend home blood pressure measurement to your patients. In addition we may ask you how and what you discussed with your patients when you decided to recommend home blood pressure measurement; what were your expectations; how do you think that taking blood pressure at home influenced your patients’ lives and your responsibility for your medical care; and how does it influence your relationship with your patients. In the second interview you will be asked to check if what we have understood from your interviews is what you wanted to say.

In addition, you will be asked to help us to recruit three of your patients diagnosed with hypertension. They should be diagnosed with hypertension and using home blood pressure measurement for at least six months. These patients should fall into three categories of interest for this study: (a) patients using this technology and being interested to monitor their illness; (b) hypertensive patients using this technology and being reluctant to manage their illness; and (c) hypertensive patients who used in the past this technology and abandoned it. Additionally, we will ask you permission to let us observe up to three consultations with your patients related to home blood pressure measurement. The consultation will be audio recorded if you will agree.

There will not be direct benefits for you by participating in this study. The participation in this study will help researchers better understand how home blood pressure measurement can shape the meaning of therapeutic goal, therapy, health outcomes, common ground for treatment and personal and professional responsibility for
healthcare for general practitioners and their hypertensive patients using this technology. However, a payment of 150 dollars per encounter will be paid to you.

There are no major risks related to this study, excepting the possible discomfort associated with interviewing. The frequency of our visits might affect your comfort, and therefore we are open to any arrangement convenient for you.

Your participation in this research study is voluntary. If you decide to join the study, you may withdraw at any time and for any reason. If information generated from this study is published or presented, your identity will not be revealed.

The information obtained as a result of this study will remain confidential, stored in a locked file at the University of Adelaide – Discipline of Public Health, and will not be disclosed others outside of the study team except with your permission or as may be required by law. All study results of this study will be collected in a computer or data registry at the Discipline of Public Health – University of Adelaide. These data will be shared with study team members. All interviews obtained from you during this study will be coded with a unique identification number, in place of personally identifying information.

If you have additional questions or concerns with respect to your participation in this study feel free to contact:

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Appendix 2 A: Interview schedule (General Practitioners)

1) Could you please tell me about your experience with home blood pressure measurement?
   1.1 For how long have you been noticed that your patients use home blood pressure measurement?
   1.2 What factors did influence your attitude with respect to home blood pressure measurement?
   1.3 What were your expectations from HBPM with respect to your patients’ health needs?

2) Please tell me about one of your patients who uses or have used home blood pressure measurement.
   2.1 What did you discuss with this patient with respect to home blood pressure measurement?
   2.1.1 What did you tell to this patient home blood pressure measurement would involve?
   2.1.2 What was your role in taking this decision?
   2.1.3 What factors did influence your decision to recommend HBPM to this patient?
   2.1.4 Why do you think that HBPM is suitable for this patient?
   2.1.5 What was the role of this patient in taking the decision to measure his/her blood pressure at home?
   2.1.6 Why do you think has he/she chosen to measure his/her BP at home?
   2.1.7 How did she/he take this decision?
   2.1.8 How do you think that his/her personal circumstances shaped his/her choice for HBPM?
   2.1.9 To what extent do you agree with the way this person manage her illness?
      Why?
   2.1.10 How HBPM did influence this level of agreement? In what ways?

2.2 What responsibilities do you think this patient has with respect to managing her illness?
2.2.1 How did his/her illness or illnesses influence his/her life?
2.2.2 How is this person managing his/her illnesses?
2.2.3 What factors influence the ability of this person to manage his/her illness?
2.2.4 To what extent do you think this patient can control these circumstances? Why do you say this?
2.2.5 How did home blood pressure measurement influence his/her ability to manage her/his illness?
2.2.6 How did home blood pressure measurement influence his / her health status?
2.2.7 How did HBPM influence his/her personal, family or social life?
2.2.8 How did home blood pressure measurement influence the emotional status associated with his/her illness?
2.2.9 How did HBPM influence her ability to control her health?
2.2.10 How do you think that home blood pressure measurement influenced the responsibility for health of this patient?
2.2.11 Why do you say this?
2.3 How did home blood pressure measurement influence your relationship with this patient?
2.3.1 How would you describe the trust you have in this patient?
2.3.2 What factors shaped the trust you have in this patient?
2.3.3 How, if at all, the trust you have in this patient did influence his/her ability to manage her illness? In what ways?
2.3.4 How would you describe the trust this patient has in you?
2.3.5 What factors do you think have influenced the trust she/he has in you?
2.3.6 How, if at all, HBPM did influence your mutual trust?

3) How do other patients with hypertension differ as compared to this one?
3.1 How the role you have in the decision making process has differed in other hypertensive patients as compared to this one?
3.2 How does the concordance between you and patients regarding their therapeutic recommendations differ in other patients as compared to this one? Why?
3.3 What kinds of patients are suitable for home blood pressure measurement? (or would choose to measure their blood pressure at home) ?
3.4 What shapes their motivation?
3.5 What kinds of patients would choose to do not measure their blood pressure at home?
3.6 What circumstances influence their ability to manage their illnesses?
3.7 What happen with these patients?
3.8 To what extent do you think these patients can fulfil their responsibilities with respect to their illnesses?
3.9 To what extant do you think they can control these circumstances? Why do you say this?
3.10 How would you describe their ability to control their own health?
3.11 How would this influence their responsibility for their own health?
3.12 How would you describe your trust in them?
3.13 How would you describe their trust on you?
3.14 What role do you think that self-management technologies (home blood pressure measurement) could influence this?

4) What does it mean to be a good doctor with respect to chronic diseases?
4.1 What does it mean to practice a scientifically accurate medicine?
4.2 What does it mean communicate well with your patients?
4.3 What does it mean to avoid medical errors?
4.4 What does it mean to respect the interests of your patients?
4.5 How, if at all, different circumstances influence a good clinical practice with respect to chronic diseases?
4.6 What factors related to patients influence a good clinical practice with respect to chronic diseases?
4.7 What other circumstances influence a good clinical practice with respect to chronic diseases?
4.8 What where your expectations from home blood pressure measurement?
4.9 How did HBPM influence your clinical practice with respect to hypertension?
4.10 How did home blood pressure measurement influence your ability to practice a scientifically accurate medicine?
4.11 How did HBPM influence your ability to communicate with your patients?
4.12 How did HBPM influence your ability to respect the interests of your patients?
4.2 How does HBPM influence your ability to be a good doctor?
   4.2.1 What responsibilities do you have for your patients’ health?
4.2.2 What factors do shape your responsibility for your patients’ health?
4.2.3 How did home blood pressure measurement influence your responsibility for the health of your patients?

5. In the end of this interview, could you please tell me about your professional background?
5.1 How has your professional background influenced your attitude towards HBPM?
Appendix 2 B: Interview schedule (Patients)

1) Could you please tell me about your experience with home blood pressure monitoring?
   1.1 For how long have you been measuring your blood pressure at home?
   1.2 Why did you begin to measure your blood pressure at home?
      1.2.1 What circumstances did influence your decision to begin measuring your blood pressure at home? Could you please give me an example?
   1.3 How did you use the blood pressure machine since then?
   1.4 What were your expectations from measuring your blood pressure at home?

2) What did you discuss in the beginning with your doctor about home blood pressure measurement?
   2.1 What did your doctor tell you that home blood pressure measurement would involve?
   2.2 What was your role in taking this decision to use the blood pressure machine at home?
   2.3 What factors did influence your decision to start measuring your blood pressure at home?
   2.4 Why did you think that HBPM is suitable for you?
   2.5 What was the role of your doctor in taking the decision to measure your blood pressure at home?
   2.6 Why do you think he/she has chosen to recommend you to measure your blood pressure at home?
   2.7 What kind of factors / circumstances do you think he considered when he recommended you to measure your blood pressure at home?
   2.8 What do you think about the recommendations of your doctor?
   2.9 To what extent do you think your doctor agree with your approaches with respect to your illness?
   2.10 What circumstances have influenced this level of agreement?
   2.11 What roles, if at all, has home blood pressure measurement played in reaching this agreement?
   2.12 How did HBPM influence this level of agreement? Could you please give me an example?
   2.13 What do you think about how you manage your illness?
   2.14 How did your illnesses influence your life?
2.15 How do you manage your illnesses?
2.16 What do you think about how you take care of your health?
2.17 What circumstances do influence your ability to manage your illnesses?
2.18 What circumstances do influence your ability to take care of your health? Could you give an example?
2.19 How did home blood pressure monitoring influence your ability to manage your illness?
2.20 How do you think that home blood pressure measurement has influenced your health?
2.21 How did HBPM influence your personal, family or social life?
2.22 How did home blood pressure measurement influence your emotions associated with your illness? Could you give me an example?
2.23 How did HBPM influence your ability to control your health?
2.24 What responsibilities do you think you have with respect to managing your illness?
2.25 What responsibilities do you think you have with respect to your health?
2.26 To what extent can you comply with the responsibilities you mentioned? Why?
2.27 How did home blood pressure measurement influence your relationship with your doctor?
2.28 How would you describe the relationship you have with your GP?
2.29 How would you describe the trust you have in your doctor?
2.30 What factors shaped the trust you have in your doctor?
2.31 How, if at all, the trust you have in your GP did influence your ability to manage your illness? Why do you say this?
2.32 How would you describe the trust your GP has in you?
2.33 What circumstances do you think have influenced the trust your doctor has in you?
2.34 How, if at all, the trust you have in your GP did influence the trust she has in you?
2.35 How, if at all, HBPM did influence your mutual trust?

3) How do other doctors you have consulted differ as compared to this one?
3.1 How the role you have in the decision making process has differed when you have consulted other doctors for your actual illness?
3.2 How the concordance between you and other doctors regarding their therapeutic recommendations has differed when you have consulted other doctors?
3.3 Why do you think about this?
3.4 What roles, if at all, did home blood pressure measurement played in your relationship with other doctors? Could you give me an example?
3.5 How would you describe the trust you have in other doctors you have consulted for your illness?

3.6 What circumstances did influence the trust you have in them?

3.7 How would you describe the trust they have in you?

3.8 What circumstances did influence the trust they have in you?

3.9 To what extent do you think these circumstances could be controlled?

4) What does it mean you a good doctor with respect to chronic illness?

4.1 What does it mean to practice a scientifically accurate medicine?

4.2 What does it mean communicate well with your patients?

4.3 What does it mean to respect the interests of your patients?

4.4 What does it mean to engage you in the therapeutic recommendations?

4.5 What makes a good doctor with respect to chronic diseases?

4.6 What circumstances influence the ability of a doctor to have a good clinical practice?

4.7 How did HBPM influence the practice of your doctor?

4.8 How did home blood pressure measurement influence the ability of your GP to practice a scientifically accurate medicine?

4.9 How did home blood pressure measurement influence the ability to communicate with you?

4.10 How did home blood pressure measurement influence the ability of your GP to respect your interests?

4.11 How does HBPM influence the ability of your GP to be a good doctor?

4.12 How would you define the responsibility of your GP for your health?

4.13 What circumstances influence his responsibility for your health?

4.14 How did home blood pressure measurement influence his responsibilities for your health?

4.15 What roles did home blood pressure measurement have played?

4.16 Who else is responsible for your health?

5) In the end of this interview, could you please tell me about your background?
Appendix 3 A: GP participant biography

Adam is local medical graduate who practices as general practitioner for about three years. In this period of time he practiced only in urban areas and now he practices as general practitioner in a practice with a special interest in HIV medicine. By caring seriously ill patients, he developed a special interest for self-management. He noticed that patients who are engaged in with the self-management of their illnesses had a better health status compared with patients who are not engaged in their own care and are at risk to die. He was not proactive with home blood pressure monitoring because the management of hypertensive patients was a marginal activity in his practice. However, he never opposed to patients’ intentions of self-monitoring their blood pressure.

Amanda is local medical graduate who did her GP training in several hospitals around Adelaide. She practiced as general practitioner in the suburbs of Adelaide for about twelve years. Amanda attributed her interest for self-management and home blood pressure monitoring to the characteristics of her practice. That was, her practice was characterized by patients belonging to middle class who were highly motivated to maintain their health and interested to receive more health information.

Christian is a local medical graduate who did his GP training in several hospitals around Adelaide. He practiced as general practitioner for about ten years. Christian was involved in politics where he promoted several projects devoted to implementing coordinated care and self-management in general practice. He was also involved in research projects in general practice. These activities made him to believe that it is doctors’ job to motivate patients to be involved in their own care. Christian recommended home blood pressure monitoring to all his hypertensive patients.

Christopher is a medical local graduate. He did his training in general practice in several hospitals in Adelaide. He practices as general practitioner in Adelaide for about twenty years. He was also interested in research and was proactive by participating in most research concerning general practice. His interest for home blood pressure monitoring developed as a result of participating in a research project which demonstrated that patients’ blood pressure values in the surgery differed considerably compared with patients’ blood pressure values measured at home. However, he considered that home
blood pressure monitoring was useful only to diagnose white coat phenomenon and not for long-term monitoring of hypertension. This was so, because he considered that long-term monitoring induced patients’ anxiety.

**Francis** is a local medical graduate who did his GP training in several hospitals around Adelaide. He practiced as general practitioner for about twenty-five years. He is very interested in medical technology. He recommended home blood pressure monitoring since the blood pressure machines were available and attributed his interest to home blood pressure monitoring to the availability and quality of blood pressure machines. In addition, he mentioned that his views towards self-management and doctor-patient relationship came from his practice.

**Frederick** is a local medical graduate who did his GP training in several hospitals around Adelaide. He practiced for about seventeen years in the suburbs around Adelaide. Frederick was also involved in research projects about the effectiveness of self-management in general practice. These research projects made him to become interested in home blood pressure monitoring. He recommended home blood pressure monitoring to all his hypertensive patients being convinced that this is a tool that could engage patients in their own care.

**Gram** is an overseas medical graduate who did his GP training in Adelaide. He finished his GP training a year ago and practiced as fully qualified GP since then. Although he was interested in home blood pressure monitoring, he mentioned that his experience with HBPM was limited to several cases. This was so because most of his patients were younger and healthier compared with what an average GP had.

**Gregory** is a local medical graduate who did his GP training in several hospitals around Adelaide. He practiced as general practitioner for about 20 years. Gregory spent eight years in rural general practice. Since 1999 he practiced in Adelaide in several suburbs around Adelaide. He was not proactive with home blood pressure monitoring. That was, he never recommended home blood pressure monitoring but never opposed when patients wanted to self-monitor their blood pressure.

**Harold** is an overseas medical graduate who did his entire medical training abroad. After his GP training he practiced as General Practitioner in several countries. He moved to Australia ten years ago, and practiced in almost all the states in both urban and rural communities. He recommended home blood pressure monitoring in all hypertensive
patients. He was not sure what circumstances made him interested in home blood pressure monitoring.

Joann is a local medical graduate who did her GP training in a hospital around Adelaide. She practiced as general practitioner for about 17 years. Her interest for home blood pressure monitoring came for her practice because one of her main duties was to monitor chronically ill patients. In addition, she linked her interest for self-management with her human nature. That was, she liked patients who took control over their own care because she liked to be always in control of herself.

Laurence is a local medical graduate and practiced as general practitioner for all his working life in the suburbs of Adelaide. He attributed his interest for self-management and particularly for home blood pressure monitoring to his interest for prevention and for informatics. This was so, because he perceived home blood pressure monitoring as a tool that could significantly help patients to prevent the complications of hypertension.

Neill was a local medical graduate and practiced as general practitioner for 31 years. He practiced as general practitioner in both urban and rural areas. In addition to the practice, Neil acted also as counsellor for different professional bodies. He was also involved in research projects in general practice. He attributed his views about self-management and home blood pressure monitoring to both his practice and policy activities.

Ralph graduated from the medical school in New South Wales and did his GP training in several hospitals in Adelaide. He practiced as general practitioner in Adelaide for seventeen years. Ralph developed a special interest for the doctor-patient interaction and for meeting and knowing people. He sees himself as an advisor. He attributed his attitude towards patients to his family tradition of being general practice. He was the third generation general practitioner in his family.
Appendix 3B: Patient Biographies

Anna is a 55 year old lady living alone in a suburb of Adelaide. She was a real estate agent and now she is retired. She started to self-monitor her blood pressure at the request of her doctor. She does not have her own blood pressure machine and self-monitors her blood pressure once or twice a year for a period of a week by using a blood pressure machine borrowed from the surgery.

Emily is a 58 year old lady living together with her husband Ross in a suburb around Adelaide. She worked all her life for a pharmaceutical company. She started to self-monitor her blood pressure almost twenty years ago, when she was diagnosed with hypertension. Her work in the pharmaceutical company made her reluctant to take medicines. This prompted her to use the blood pressure machine to adjust her medical treatment to minimal doses. Emily is now retired and uses home blood pressure monitoring on a regular basis.

George is a 64 year old man living with his wife Mary. He is an engineer who was very interested in any kind of technologies. He belongs to a family with a history of hypertension and was diagnosed with hypertension 15 years ago. He started to self-monitor his blood pressure four years ago at the request of his doctor who lent him a blood pressure machine. However, after a period of time he bought his own blood pressure machine and started to self-monitor his blood pressure on a regular basis.

Gerry is a 72 year old man living alone in a suburb around Adelaide. He worked his entire life as a professional truck driver. Although he is now retired he still works as a driver for local fire service. He started to self-monitor his blood pressure when he was accidentally diagnosed with hypertension during a medical check-up. His doctor asked him to self-monitor his blood pressure for a week. Since then Gerry self-monitors his blood pressure occasionally when his doctor asks him to do so.

Gertrude is a 69 year old lady who lives together with her husband Herman. They emigrated to South Australia from Europe almost forty years ago. Gertrude started to self-monitor her blood pressure at the recommendation of her chiropractor. In addition, her husband who had self-monitored his blood pressure for more than ten years taught her how to use the blood pressure machine. However, she self-monitored her blood pressure for only three months and then stopped because she developed anxiety.
Jacqueline is a 55 year old lady who lives alone in suburb around Adelaide. She is a teacher of French language at a private school in Adelaide. She was diagnosed with hypertension ten years ago when she divorced of her husband. Jacqueline started to self-monitor her blood pressure at the request of her doctor with who she has a trusting relationship. She self-monitors her blood pressure once or twice a year for a period of several days.

Jane is a 60 year old lady living with her husband Stephan. She does not have hypertension and does not self-monitor her blood pressure. However, Jane is very concerned because Stephan has hypertension and anxiety. She took care of his health in the sense that she goes together with Stephan when he has to consult a GP and help him to self-monitor his blood pressure.

Larry is a 60 year old man living alone in a suburb of Adelaide. He is divorced. Larry is a plumber. He started to self-monitor his blood pressure at the request of his doctor. He self-monitors his blood pressure only when his doctor asks him to do so.

Laura is a 69 year old lady who lives together with her husband Harry. She was a registered nurse and now she is retired. Laura started to self-monitor her blood pressure nine years ago at the request of her doctor. Since then she self-monitored her blood pressure regularly. She attributed her interest for self-monitoring to her professional background.

Malcolm is a 79 year old man living together with his wife Helen. He was a sharebroker and now he is retired. He suffered many surgical interventions and he has a significant interest in medical technology mainly because he thought that he was still alive because of technical advances. He started to self-monitor his blood pressure values at the request of his doctor. However, his trust in medical technology played as well a role in self-monitoring. He self-monitors his blood pressure on a regular basis.

Mark is a 71 year old man living together with his wife in a suburb around Adelaide. He worked as police officer for twenty years and then as ambulance officer for another fifteen years. Mark started to self-monitor his blood pressure at the request of his doctor. He self-monitored his blood pressure regularly.

Mary is a 63 year old lady living together with her husband in a suburb around Adelaide. She was diagnosed with breast cancer. This experience made her aware that she had to assume responsibility for her health. She started to self-monitor her blood pressure at the
request of her doctor. However, her husband played a major role in stimulating and teaching her to self-monitor her blood pressure.

Rick is a 52 year old man living together with his partner in a suburb around Adelaide. He is a mathematics teacher and he is very interested in his work. He was diagnosed with hypertension more than ten years ago and recently he developed angina pectoris. He started to self-monitor his blood pressure at the request of his doctor. Rick self-monitors his blood pressure on a regular basis.

Rose is a 64 year old lady living with her husband Yen in a suburb around Adelaide. She worked as a secretary and she is now retired. She started to self-monitor her blood pressure ten years ago at the request of her doctor. Rose self-monitors her blood pressure on an occasional basis when her doctor asks her to do so. She does not have her own blood pressure machine.

Russel is a 41 year old engineer. He is single and lives together with his mother in a suburb in Adelaide. He became interested to self-monitor his blood pressure a year ago when his father died because of a stroke. He also attributed his interest in home blood pressure monitoring to his education.

Sam is a 71 year old man living together with his wife. Sam is now retired. He was a practicing accountant. In addition, he was a professional football player. When he retired from professional sport he continued to do sport to maintain his physical condition. These sport activities made him to be particularly interested in his health. He started to self-monitor his blood pressure at the request of his doctor.

Sandra is a 68 year old lady living together with her husband in a suburb of Adelaide. She was a registered nurse and now she is retired. She had a long experience with monitoring blood pressure because she used to monitor the blood pressure of her husband who suffered a stroke. Later when she was diagnosed with hypertension she started to self-monitor her blood pressure.

Stephan is a 65 year old man living together with his wife Jane in a suburb around Adelaide. He worked all his life as self-employed roofer and now he retired. He started to self-monitor his blood pressure at his wife’s suggestion. This happened during a panic attack Stephan suffered when he found that his son has cancer. Stephan monitors his blood pressure only occasionally and do not have his own blood pressure machine.
Stuart is a 53 year old man who lives together with his wife in a suburb around Adelaide. He is a university lecturer who is very interested in his work. He started to self-monitor his blood pressure four years ago at the request of his doctor.
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