How engaged are people in their health care?

Findings of a national telephone survey

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Acknowledgements

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making patients' views count

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Contents

Foreword

A high-quality healthcare system is one that puts patients at the centre of the treatment process. Informed, active patients are one half of the partnership approach that underpins effective healthcare. So how comfortable are patients in discussing their care with professionals? What do they understand about their conditions, and the options open to them? How confident are they in managing a chronic condition, monitoring their symptoms, and handling changes and setbacks?

The Health Foundation has, over the past two years, been involved in a comprehensive set of research initiatives exploring different facets of patient engagement as part of our growing body of work on the issue. When we commissioned this research by Angela Coulter and Jo Ellins at Picker Institute Europe we knew it would represent an important contribution to what is known about the state of patient engagement in healthcare in the UK.

Chronic ill health accounts for around two thirds of GP consultations, and the same proportion of hospital admissions. It is of great concern, then, that this research shows that people living with long term conditions are lacking many of the skills and much of the knowledge that will enable them to manage their conditions effectively.

The Patient Activation Measure scores tested by this project have the potential to be much more widely used in the UK. We hope that they will be – and that in time, future studies will reveal that the country's patients are becoming better equipped to handle their health.

Stephen Thornton
Chief Executive
The Health Foundation

Executive Summary

Background

1. There is a growing consensus that patients can, and indeed should, be active partners in their health and healthcare. Evidence shows that patient involvement improves satisfaction with, and the outcomes and appropriateness of care.

2. Patient engagement, and self-care in particular, have been strongly emphasised in the reform of chronic illness care. A new disease management approach is being implemented in the NHS, in which it is envisaged that most cases of chronic illness will be self-managed by the individual or her/his family.

3. Research shows that many patients want more involvement in decisions about their care; better information about health problems and conditions, treatments and lifestyle issues; and greater support from health professionals to practice self-care.

4. While research has investigated public attitudes toward self-care, relatively little is known about the capacity of patients and the public to be successful self-managers of their health and healthcare.

Methods

5. Developed by Judith Hibbard and colleagues at the University of Oregon, the Patient Activation Measure (PAM) assesses people's knowledge, confidence and skills for self-management. This was developed according to a four-stage developmental model of patient activation: *Stage 1*: believing the patient role is important; *Stage 2*: having the confidence and knowledge necessary to take action; *Stage 3*: actually taking action to maintain and improve one's health; *Stage 4*: staying the course even under stress.

6. The PAM is contained within a larger questionnaire probing issues relating to the experience and management of chronic illness, which was used in a national telephone survey of adults aged 45 and above. Three thousand interviews were conducted: 1,000 in England (excluding London), 500 in Wales, 500 in Scotland, 500 in Northern Ireland and 500 in London.

Main findings

7. The majority (72%) of respondents had been diagnosed with at least one chronic condition. The most common condition was arthritis or rheumatism, reported by 30% of respondents, followed by high blood pressure (29%), high cholesterol (19%), chronic pain (18%) and angina or heart problems (12%).

8. Analysis of UK and US PAM scores revealed that there is less variation across the UK population in self-management ability. Nonetheless there were important differences between demographic groups. Lower levels of knowledge, confidence and skills for self-management were observed among respondents who were elderly, from lower social grades, and who had finished their education by the age of 16.

9. Fewer people with chronic conditions had progressed to an advanced level of self-management, in particular those with depression, chronic pain and digestive problems. Of all the groups within the sample, the capacity to self-manage health and healthcare was least evident among people with poor health; only 33% of those with poor health felt able to take and maintain action to improve their health, compared with 60% overall.

10. Chronic illness was found to significantly affect physical and emotional health, as well as daily activities and social interactions. Physical activities were largely or entirely restricted in 20%, and social activities in 17%, of respondents with chronic conditions. Almost a quarter (23%) of the chronically ill had experienced severe physical pain during the previous four weeks, and 62% reported a lack of energy.

11. People with chronic illnesses are already involved in various self-management activities. Eighty one per cent of respondents were self-administering at least one prescription medicine, with most (92%) reporting that they consistently adhered to medication instructions. Self-monitoring was practiced by 79% of people with diabetes, but far lower levels were observed among those with hypertension and lung disease.

12. While 88% of respondents had made health-related lifestyle improvements, not all were able to maintain these on a day-to-day basis or during times of stress. Problems maintaining lifestyle changes were most commonly reported by those with chronic conditions (in particular stroke, depression and digestive problems), poor self-rated health and ethnic minorities.

13. Nearly three quarters (74%) of respondents said they take regular exercise and 72% said that they sometimes or always eat a low fat diet. Women were more likely than men to follow healthy eating practices, and exercise was more frequently reported by people in younger age groups, higher social grades, living in London and with good general health.

14. The majority of those with chronic conditions had received support from a healthcare professional to change their diet (84%) and take regular exercise (82%). The highest levels of support for lifestyle changes were reported by respondents with diabetes, possibly reflecting the commitment to enhancing diabetes self-care as set out in the National Service Framework.

15. Over the previous 12 months, survey respondents had made extensive use of healthcare services. Three-quarters made at least one visit to their general practitioner, with 25% seeing their doctor five times or more, and 15% had visited accident and emergency. Service utilisation was considerably higher among those with chronic conditions.

16. The overwhelming majority (94%) of respondents said they would not wait to be asked before raising concerns with their doctor; a further 66% prepared for consultations by putting together a list of questions or issues they wanted to discuss. However, only 9% indicated that they would ask for further clarification when they did not understand something their doctor had said.

17. There was some interest among respondents in accessing and using information about the quality of healthcare. Forty three per cent said that, before visiting a new doctor, they would try to find out about his or her qualifications. If given a choice of hospital, 67% said that information about hospital safety would be useful in guiding their decision.

18. Overall, respondents demonstrated high levels of knowledge and confidence for self-management. Ninety two per cent understood the nature and causes of their health problems, and 95% said they knew the purpose of their medicines.

19. Among those with chronic conditions, 21% said they did not know the different medical treatment options for their condition, and 13% were not aware of self-treatments. Of respondents without a chronic condition, 91% knew about ways of treating their health problems.

20. Confidence to follow medical recommendations and to perform medical treatments at home was particularly low among ethnic minority respondents and those with poor health. Along with the over 85s, these groups also demonstrated greater uncertainty about the use of their medicines.

21. Skills for self-management also differed according to health status. Fewer people with chronic conditions (above all depression, digestive problems, stroke, chronic pain and bladder problems) and with poorer health felt able to prevent or handle health problems and symptoms on their own at home.

22. Among those with chronic conditions, the most well developed and consistently deployed self-management skills were observed in respondents who were younger, from higher social grades, living in London and with a university-level education.

23. One in five respondents said they were unlikely to seek out information to learn about how to cope with health problems. However, most respondents (93%) expressed confidence in their ability to find trustworthy sources of health and treatment information.

24. When asked about their preferred sources of information, 73% mentioned their doctor. The next most commonly cited sources of health information were health websites (30%), printed materials (23%), nurses and other health professionals (22%) and family and friends (19%). Patient groups were mentioned by only 4% overall, and by only 5% of respondents with chronic conditions.

25. Use of the internet to find health information was most common among respondents from higher social grades, younger age groups, living in London and ethnic minority backgrounds. However, 40% of people from social grades DE but only 29% of ABs expressed an interest in using telephone helplines such as NHS Direct or NHS 24.

Policy implications

26. The Patient Engagement survey has confirmed the importance of initiatives to improve patients' involvement in their health and care. Four in ten people are not regularly taking action to maintain and manage their health, and few of those who are taking action felt confident that they could sustain it on a daily basis.

27. Certain groups will need to be more intensively supported if they are to become active participants in their healthcare. These are the elderly, those from lower social grades, the less educated and the chronically ill. Such groups will benefit from interventions designed to improve the capacity for self-management, through improving knowledge of health issues and building self-confidence.

28. There is an ongoing need for creative and well targeted strategies to deliver health information to patients and the public, and to ensure best use is made of that information. As well as providing information directly to their patients, doctors should be encouraged to act as a conduit to supplementary sources of information and support such as patient groups.

29. Given the variation found among the chronically ill in terms of the impact of their illness and capacity to manage their health problems, a generic approach to self-management education may be of limited success. Patients who are self-managing their chronic condition will continue to need individualised support and guidance from healthcare professionals, including their GP. Particular attention should be paid to people with conditions that were consistently associated with lower self-management ability: namely chronic pain, depression, digestive problems, stroke and bladder problems.

30. In addition to educating patients about monitoring and managing their health problems, 'ownership' of healthcare is encouraged through patients' active involvement in clinical decisions and collaborative relationships with health professionals. Encouraging patients to express their preferences and improving opportunities for shared decision-making will underscore the transition to greater patient self-management.

31. To appropriately and effectively support individual self-management needs, clinicians need information about their patients' capabilities for a more active role in their healthcare. A shortened version of the PAM (PAM-13) has recently been developed for use as clinical assessment tool. Research is needed to establish the feasibility of using PAM-13 in primary care and other health settings in the UK.

1 Introduction

1.1 Patient engagement

In traditional models of healthcare delivery the role of the patient is essentially passive, to be the recipient of medical expertise, services and treatments. However, there is an emerging consensus that patients can, and indeed should, be more involved in their own care. New approaches emphasise that – by providing appropriate opportunities, information and support – patients can act as partners in the delivery and management of healthcare. Patient involvement improves patients' satisfaction with and experience of NHS services. A growing body of evidence also demonstrates that patient engagement in treatment decisions and in managing their own healthcare can improve appropriateness and outcomes of that care.[1]

Patients with chronic conditions are frequent and long-term users of health services, accounting for about 80% of GP consultations, 60% of hospital bed days and two-thirds of emergency admissions.[2] It is now widely recognised that effective management of chronic illness entails an active partnership between healthcare professional and patient, in which education and support for self-care should be a key component. However, little is known about the extent to which patients with these conditions have the skills, knowledge, motivation and confidence to take on a role in their treatment and care.

A measure of 'patient activation' has recently been developed and tested by Judith Hibbard and her colleagues at the University of Oregon.[3] This assesses the extent to which patients are confident 'self-managers' and can be used to identify their information, education and support needs. The questionnaire from which the measure is derived has been used in a national population telephone survey in the United States (US). Picker Institute Europe was funded by The Health Foundation to replicate the survey with a national population in the United Kingdom (UK).

1.2 Policy context

Increasing the flexibility of healthcare services, to encourage greater responsiveness to patients, has been a goal of UK health policy for many years. The drive to design and re-organise services around the needs of patients has intensified under the current Labour government. Published in 2000, *The NHS Plan* set out the government's proposals for creating a "patient-centred service" in which patients (and their representatives) would be fully involved in decisions relating to their care.[4] This, and subsequent policy documents, recognised that the transition to a patient-centred NHS required increased financial investment and reorganisation of services, together with co-ordinated efforts to involve patients in healthcare planning, delivery, assessment and improvement.[5]

The importance of engaging patients and the public was re-stated in 2002 with the publication of the Wanless report, *Securing our Future Health: Taking a Long-Term View*.[6] Wanless concluded that high

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[1] Angela Coulter, *The Autonomous Patient: Ending Paternalism in Medical Care* (London: The Nuffield Trust, 2002).
[2] Department of Health, *Supporting People with Long Term Conditions: An NHS and Social Care Model to Support Local Innovation and Integration* (London: Department of Health, 2005).
[3] Judith Hibbard *et al*, 'Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers' (*Health Services Research*, 39 (4): 1005-1026, 2004).
[4] Department of Health, *The NHS Plan: A Plan for Investment, A Plan for Reform* (London: Department of Health, 2000).
[5] Eg Department of Health, *The NHS Improvement Plan: Putting People at the Heart of Public Services* (London: Department of Health, 2004).
[6] Derek Wanless, *Securing our Future Health: Taking a Long-Term View* (London: Department of Health, 2002).

quality care, and the most productive use of resources, depended on the population's full engagement in health improvement. In this 'fully engaged' scenario, the public is envisaged as taking an active role in maintaining good health and preventing illness, in diagnosing and treating health problems and in making appropriate use of NHS services. In a follow-up report, Wanless re-iterated the importance of self-care to his 'fully engaged' scenario but cautioned that, in order to make healthy decisions, individuals would need to be supported by appropriate information and professional advice.

Patient engagement, and self-care in particular, have been strongly emphasised in the reform of chronic illness care. The growing burden of chronic and long term conditions has exposed significant limitations in traditional models of care delivery which are reactive, curative and focused on acute, episodic illness. Consequently, there has been a move towards implementing a disease management approach, which seeks to co-ordinate services across the health and social care sectors in order to deliver ongoing care. The active participation of people with chronic conditions is integral to this approach, which was recently set out in *Supporting People with Long Term Conditions.*[7] Providing that the right forms of support are available, it is expected that most cases of chronic illness (perhaps as many as 80%) can be self-managed by the individual or by his/her family (Appendix 1).

Various initiatives have been undertaken to encourage and empower people to manage their own chronic conditions on a day-to-day basis. Notable among these is the Expert Patients Programme, a community based education course which aims to equip people with the skills, knowledge and confidence for self-management. Published in 2004, *Better Information, Better Choices, Better Health* outlined a three year programme of action to improve patient and public access to high quality health information.[8] Enhancing communication between professionals and patients, and improving patients' knowledge of their care, is being targeted by the 'Copying Letters to Patients' initiative and the development of patient-accessible electronic medical records.

Although there is a strong focus on *national* strategies for patient engagement and self-management support, the importance of tailoring approaches to meet individual needs and preferences has not been overlooked. Indeed, the NHS chronic care model is underpinned by the principle that "Patients with long term conditions need high-quality care personalised to meet their individual requirements."[9] Our survey explores how the confidence, knowledge and skills for self-management vary across the UK population, to inform a targeted approach to engaging patients in their chronic care.

1.3 Previous research on patient involvement

A number of studies have looked at various aspects of patient engagement in healthcare, although few have specifically examined people's capacity for and attitudes towards self-managing chronic illness. While public opinions vary, there is evidence that some people do want greater involvement in healthcare, including a stronger role in decisions about treatment. For example, surveys of NHS patients in 2004 found that 47% of inpatients, 30% of outpatients, 36% of emergency patients, 32% of primary care patients, 39% of coronary heart disease patients and 59% of mental health patients would have liked more input and choice in decisions about their care.[10] The surveys also identified areas for improvement in the provision of information to patients; these include information on medication side effects, on how to monitor one's condition, and on physical exercise and dietary control. Indeed, research into patients' views and experiences has consistently found that patients want more information about their health and healthcare than they currently receive. Furthermore, there are significant shortcomings in much of the information that is

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[7] Department of Health, *Supporting People with Long Term Conditions* (2005).

[8] Department of Health, *Better Information, Better Choices, Better Health: Putting Information at the Centre of Health* (London: Department of Health, 2004).

[9] Department of Health, *Supporting People with Long Term Conditions* (2005).

[10] Picker Institute Europe, *Is the NHS Getting Better or Worse? An in-depth look at the views of nearly a million patients between 1998 and 2004* (Oxford: Picker Institute Europe, 2005).

currently available to patients and the public including inaccurate and misleading statements; omission of topics of relevance to patients; inadequate or incomplete information about treatment options, risks and side-effects; and a mismatch between the reading level of the materials and reading abilities of the target audience.[11]

Government sponsored research has confirmed the importance of patient engagement, and pointed to a number of factors that can enable people to become more actively involved in their care. The *Health in Partnership* research programme reported that, as well as increasing patient satisfaction, patient involvement can lead to enhanced confidence, reduced anxiety, greater understanding of personal needs, better relationships with professionals and positive health effects.[12] A partnership approach between patients and professionals was advocated, which could be developed and supported through:
- Patient-centred consultations, where the patient is treated as an equal, listened to and properly informed
- The provision of high-quality health information to patients and the public
- Shared decision-making in clinical consultations
- Embedding the principle of patient involvement in professional values and expectations
- Improved professional-patient communication
- Adaptation of patient involvement practices to suit the particular context and individual.

The Department of Health recently commissioned a national survey of public attitudes towards self-care, to assess the impact of recent initiatives and inform future policy development.[13] Published in May 2005, the survey shows that in general the UK public is actively engaged in various self-care activities, and interested in further developing its self-care role. More than half of those surveyed (56%) reported that they had at least one chronic condition and, of these, 48% were interested in playing a more active role in the care of that condition. When asked about barriers to self-care, respondents were most likely to say that time (18%), money (14%) and lack of information and knowledge (8%) deterred them from being more involved in managing their health. Important inter-group differences were highlighted; for example, confidence to practice self-care was lower among the elderly, ethnic minorities and those with poorer health. Various shortcomings in support for self-care were identified, including the relatively low provision of care plans (37%) and written medicine instructions to hospital inpatients during or after their stay (49%). The survey found a mismatch between the important support role that many respondents felt professionals could play, and the actual encouragement for self-care they had received from their GP or practice nurse. Over half (55%) said they did not often receive such encouragement, and 33% said they had never done so. Awareness of other forms of support was low, with only 12% of respondents having heard of self-management education courses (including the Expert Patients Programme) and only 30% knowing of any relevant voluntary groups.

A series of papers has recently been published by The King's Fund, examining various aspects of the experience and care of chronic illness. *Self-Management for Long-Term Conditions* reported research into patients' perspectives on managing their chronic conditions and of the services and support needed for this.[14] To encourage and facilitate patient self-management, service improvements in three key areas were identified:
- Improving health professionals' skills to support self-management
- Improving the provision of information about long-term conditions and the local services available
- Increasing the flexibility of service provision to fit in with patients' other commitments.

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[11] Eg Angela Coulter *et al*, *Informing Patients: an assessment of the quality of patient information materials* (London: King's Fund, 1998); Helen Smith *et al*, 'Evaluation of the Readability and Accuracy of Information Leaflets in General Practice for Patients with Asthma' (*British Medical Journal*, 317 (7153): 264-5, 1998).

[12] Christine Farrell, *Patient and Public Involvement in Health: the evidence for policy implementation* (London: Department of Health, 2004).

[13] Department of Health, *Public Attitudes to Self Care – Baseline survey* (London: Department of Health, 2005).

[14] Sara Corben & Rebecca Rosen, *Self-Management for Long-Term Conditions* (London: King's Fund, 2005).

1.4 Design of the Patient Activation Measure

The Patient Engagement survey was conducted using a measure of 'patient activation' designed by Judith Hibbard, Professor of Health Policy at the University of Oregon.[15] The concept of activation comprises a broad range of elements that patients need in order to successfully manage a chronic illness.[16] Research by Hibbard and her colleagues suggested that activation involves four developmental stages:
- Believing the patient role is important
- Having the confidence and knowledge necessary to take action
- Actually taking action to maintain and improve one's health
- Staying the course even under stress.

According to this model, patients must first recognise the importance of their role and acquire confidence and basic skills in order to actively self-manage, prevent their condition from unduly interfering with their life and interact effectively with healthcare providers. Recently published research has shown that patient activation is strongly correlated with health-related, healthy and self-management behaviours.[17]

A 22 item scale and a shorter 13 item version have been developed, each including items pertaining to the four domains above (Appendix 2). Both scales have been extensively tested and shown to be valid, highly reliable instruments with good psychometric properties. The scales are contained within a longer questionnaire, intended for completion by adults of 45 years and over, which also probes related issues such as information needs and use of prescription medicines. There are separate sections, and versions of the Patient Activation Measure (PAM) scales, for completion by respondents who have chronic conditions and those who do not. The questionnaire also contains specific questions about the self-management of diabetes, arthritis, angina and heart problems, high blood pressure, high cholesterol and lung disease.

By providing an assessment of people's preparedness and capacity to contribute to their healthcare, PAM scores can inform the design and targeting of strategies to enhance self-management.[18] Appropriate strategies will vary in type and intensity, given that individual needs differ at each of the four stages of patient activation. For example, at the early stages there is a need for interventions designed to increase individuals' self-awareness of their role in the care process and their knowledge of their condition and its treatment. At the later stages, support to take and maintain action is required. This might entail interventions to build self-efficacy and improve confidence and skills for different self-management tasks. Judith Hibbard has suggested that, because every stage builds on the achievements of the previous one, individuals must sequentially pass through each of the four stages in order to become effective self-managers.[19]

Prior to commencement of the survey, the questionnaire and PAM scales were adapted for use in a UK population. Pre-testing of the questionnaire was completed using cognitive interviewing techniques which determine whether questions can be clearly understood and accurately answered. Eleven people, matching the survey eligibility criteria, were recruited and interviews were conducted during early May 2005. Generally, few changes were made other than the Anglicisation of key terms and phraseology. Three questions were omitted, and two were added to the final questionnaire. Questions were omitted either because they were found to be too difficult to understand and answer, or were not strongly relevant to a UK context. The new questions addressed preferred sources of health information and use of complementary and alternative therapies.

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[15] Patient Activation Measure; Authors/Creators Judith H. Hibbard, Jean Stockard, and Eldon R. Mahoney; Copyright 2003-2005, University of Oregon. All Rights Reserved.

[16] Judith Hibbard *et al*, 'Development of the Patient Activation Measure (PAM)' (2004).

[17] Jessica Greene *et al*, *How Much Do Health Literacy and Patient Activation Contribute to Older Adults' Ability to Manage Their Health?* (Washington DC: AARP, 2005).

[18] Judith Hibbard *et al*, 'Development of the Patient Activation Measure (PAM)' (2004).

[19] Judith Hibbard *et al*, 'Development and testing of a short form of the patient activation measure' (*Health Services Research*: in press).

2 Study aims and methods

2.1 Aims

The Patient Engagement survey had four main aims:
- To describe the extent to which British patients with chronic conditions feel able to self-manage, to examine differences between population sub-groups, and to identify patients support needs
- To compare self-management knowledge and skills in England, Scotland, Wales and Northern Ireland, and in London
- To provide a baseline for planning The Health Foundation's programme of work on patient engagement and for monitoring progress
- To compare self-management knowledge and skills in the UK with those of a US population.

In addition to these core aims, the survey explored a broader range of topics relating to the experience and management of chronic illness. These included:
- The impact of chronic illness on physical functioning, emotional well-being and social activities
- Exercise and dietary habits
- The use and administration of prescription medicines
- Information needs and information seeking behaviour
- The use of alternative and complementary medical therapies.

2.2 Methods

The telephone survey was conducted by NOP, between May 18 and June 30 2005. A probability sample of the UK population was drawn using a random digit dialling procedure, which took directory phone numbers and changed the final digit at random. This method ensures that ex-directory numbers are included in the survey, thereby reducing the possibility of bias. The sample was cleaned to remove inactive numbers before fieldwork commenced. Where numbers were initially busy or unanswered, a maximum of twelve callbacks were made before the household was categorised as non-contactable. Fax numbers were tried twice, to avoid excluding people with fax and phone on a single line.

Fieldwork was carried out using CATI (computer-assisted telephone interviewing) software. Initial screening established whether the household contained an adult over the age of 45. Where there were two or more qualifying adults, the interviewer asked to speak to the person with the next birthday. If that person was not available, arrangements were made for a follow-up call.

A total of 3,000 interviews were completed; the following regional targets were employed to ensure adequate coverage across the four nations of the UK:
- England (excluding London): 1,000 interviews
- Scotland: 500 interviews
- Wales: 500 interviews
- Northern Ireland: 500 interviews
- London: 500 interviews

Each interview lasted an average of 22 minutes and respondents were *not* offered incentives for their participation.

Prior to analysis, post-stratification weights were applied to the data. This corrects for bias due to unequal probability of selection, bringing the sample in line with the known profile of adults aged 45 and above in the four national populations. The final dataset was weighted by age *within* gender, social grade and region.

2.3 Data presentation

The findings presented below are based on weighted data only. In all tables, an asterisk (*) is used to indicate a value of less than 0.5%. Due to rounding up/down and the acceptance of multiple answers, column percentages may not total 100%.

For many survey questions, respondents were given the option to answer 'not applicable'. Where this was the case, not applicable responses have been excluded, and analysis has been conducted for those participants answering the question only.

2.4 Statistical reliability

A sample of 3,000 provides a relatively high degree of precision for estimates of population values. Table i shows approximate sampling tolerances which apply to the total sample and to the chronic conditions sub-group, at the 95% confidence level. For example, on a question where 50% of the people in the sample responded with a particular answer, there is a sampling error of +/- 1.79 percentage points. So, if the entire population had been asked the same question, we can be 95% certain that their results would fall between 48.21% and 51.79%.

Table i: Approximate 95% confidence intervals applicable to percentages at or near these levels

Size of sample or sub-group	10% or 90% +/-	30% or 70% +/-	50% +/-
3,000 adults	1.07	1.64	1.79
2,157 with chronic conditions	1.27	1.93	2.11

When comparing the findings across various sub-groups, a minimum percentage difference is required for that difference to be deemed statistically significant at the 95% confidence level. Table ii below displays the minimum differences for three major sub-group comparisons: chronically ill vs. non-chronically ill, older vs. younger and social grades AB vs. DE. To illustrate, the difference between the responses of those with and those without chronic conditions must be at least 3.3%–5.49% (depending on the proportion answering the question in a certain way) to be considered statistically significant.

Table ii: Differences required for significance at the 95% confidence level at or near these percentages

Size of sample on which survey result is based	10% or 90%	30% or 70%	50%
Chronically ill (2,157) vs. non-chronically ill (843)	3.3	5.02	5.49
Younger (45-74: 2,589) vs. older (75+: 393)	4.13	6.3	6.87
ABs (571) vs. DEs (1,026)	4.3	6.56	7.16

3 Study sample

3.1 Response rates

A total of 46,197 telephone numbers were loaded into the CATI system. Of those numbers 41% were unobtainable, 3% could not be contacted after 12 attempts and 6% were business or fax lines. In 3% of cases, appointments were made for follow-up calls which did not lead to an interview (for a reason other than refusal). A further 13%, some 6,156 households, were disqualified because they did not contain an adult over the age of 45. Of the remainder 13,094 refused, leaving a net response rate of 18.6%. It should be noted that the true response rate is likely to be higher, as some of those refusing to participate would also have been ineligible.

Table 1: Response rates to the Patient Engagement survey

	No.	%
Total contacts	46,197	100
Completed interviews	3,000	6
Refused	13,094	28
Disqualified	6,156	13
Other*	23,946	52 (41% unobtainable)

* Other includes appointments not leading to interviews (3%), no reply or engaged after 12 attempts (3%), phone number no longer exists/out of order (41%), and business (3%) and fax (3%) lines.

3.2 Age, sex and ethnic background

The survey was completed by adults over the age of 45 only. The majority of respondents (82%) were under the age of 75, which reflects the age composition of the UK population. As Table 2 shows, the age distribution was fairly similar for both sexes.

Table 2: Age of respondents

Age group	All (n=3,000) %	Women (n=1,868) %	Men (n=1,132) %
45-54	32	31	34
55-64	29	27	30
65-74	21	21	21
75-84	14	16	12
85+	3	4	2
Refused	1	1	1

[Base: all respondents]

There was a marked gender difference in response, with approximately two-thirds of the respondents being female (62% female vs. 38% male, unweighted sample). However, as there are many more women than

men in older age groups, this was not unexpected. Indeed, the breakdown of respondents by gender roughly matches the profile of males and females in the pensionable population. Over half of the respondents were married or living with a partner (56%), with the remainder being single (10%), separated or divorced (14%) or widowed (20%).

The majority of respondents (96%) described their ethic background as 'white'. This is similar to, although marginally higher than, the percentage reported in the 2001 UK census (92%). Of the 4% of respondents from ethnic minority groups, half were Asian or Asian British. The ethnic composition of respondents was similar across the four countries of the UK but different in London, where there was a much higher representation of ethnic minorities (Table 3).

Table 3: Ethnic background of respondents

Ethnic background (n=3,000)	All (n=3,000) %	England w/o London (n=1,000) %	London (n=500) %	Wales (n=500) %	Scotland (n=500) %	N. Ireland (n=500) %	2001 Census %
White	96	97	84	97	99	98	92
Mixed	*	*	1	1	*	-	1
Asian or Asian British	2	2	6	*	*	1	4
Black or Black British	1	1	6	*	-	*	2
Chinese	*	*	*	-	*	-	*
Other ethnic group	1	*	2	1	1	*	*
Don't know/refused	1	1	1	*	*	*	n/a

[Base: all respondents]

3.3 Education, income and social grade

Over half of the respondents (52%) had completed their education at secondary level, with the remainder having post-secondary education (23%) or a university degree (22%). Only 5% indicated that they had no formal education.

A household income below the national average of approximately £30,000 was reported by 57% of respondents. However, nearly a quarter of those asked (22%) declined to provide income information. Socio-economic classification was also performed using a measurement of social grade, based on an algorithm developed by the Market Research Society (Appendix 3). As Chart 4 shows, the social grade profile of survey participants was similar to that of the UK population except for some differences in the lower grades D and E. The data were weighted by social grade to correct for this differential response rate.

Chart 4: Social grade of respondents
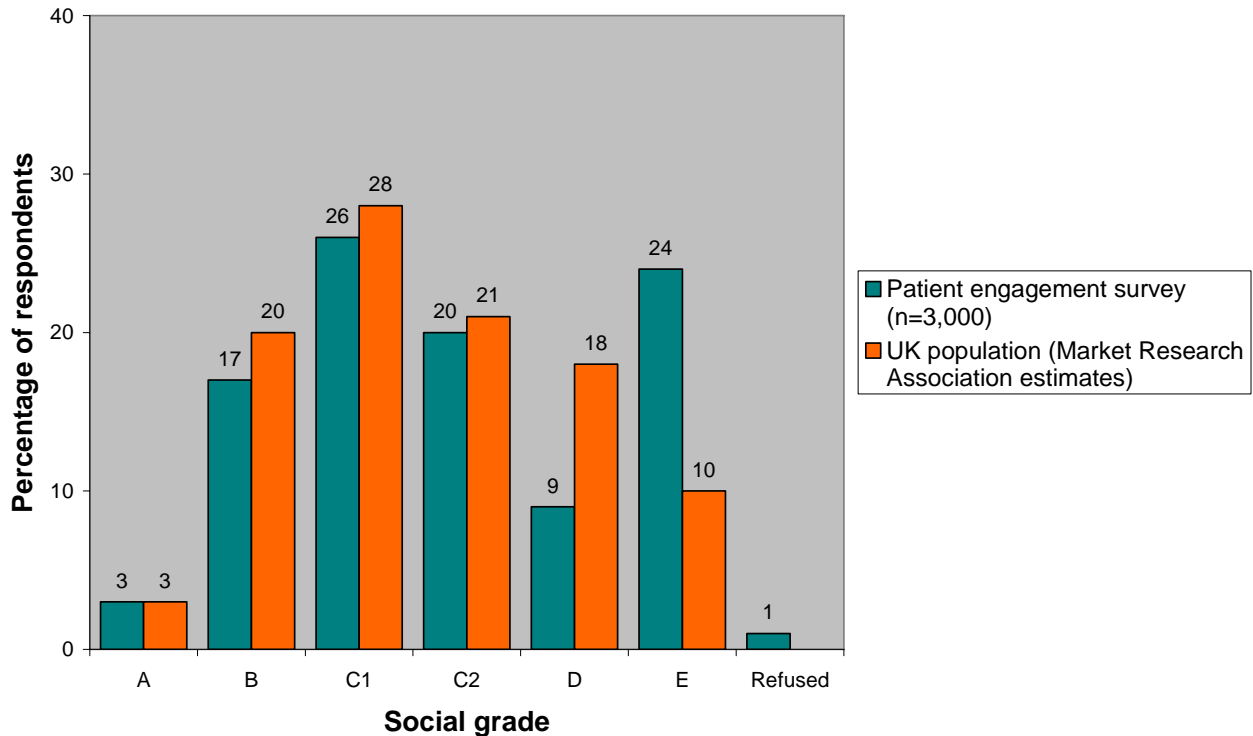
[Base: all respondents]

3.4 Self-assessed health status and chronic conditions

Respondents were asked to rate their general health and their health over the previous four weeks. These were rated as 'excellent' by 14% (general health) and 21% (recent health), as 'very good' by 25% (general) and 28% (recent), as 'good' by 33% (general) and 26% (recent), as 'fair' by 17% (general) and 16% (recent), and as 'poor' by 11% (general) and 9% (recent). There was little difference between the sexes, with women giving marginally lower health ratings than men. By contrast, there were clear associations with the following demographic factors:

- **Age**: ratings declined steadily with age; 21% of those aged over 85 rated their general health as 'poor' compared with only 7% of 45-54 year olds
- **Social grade**: health was rated most favourably by respondents classified as social grade AB, and least positively by those classified as social grade DE; 'excellent' or 'very good' ratings for general health were given by 53% of ABs but only 30% of DEs
- **Household income**: while all income groups were most likely to rate their general health as 'good', it was said to be 'fair' or 'poor' by 40% of those in low-income households compared to just 11% of respondents with the highest household income.

The majority, some 72%, of respondents stated that they had been diagnosed with one or more chronic conditions. Generally, the reported prevalence of chronic illnesses increased with age, or was highest in the 65-74 or 75-84 age groups. The opposite trend was found for depression, with prevalence highest among younger (45-54 year old) respondents. Duration of chronic illness varied substantially: 24% had their longest condition for less than five years, 30% for between 5-10 years, 24% for between 11-20 years, 8% for between 21-30 years and 11% for more than 30 years.[20]

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[20] The remaining 4% did not answer the question.

Respondents were asked if they had been diagnosed with one of 13 major chronic conditions, and also given the opportunity to disclose any other conditions not specifically mentioned. Chart 5 shows the prevalence of conditions reported by participants. The most common condition was arthritis or rheumatism (30%), followed by high blood pressure (29%), high cholesterol (19%) and chronic pain (18%).

Chart 5: Reported incidence of major chronic conditions
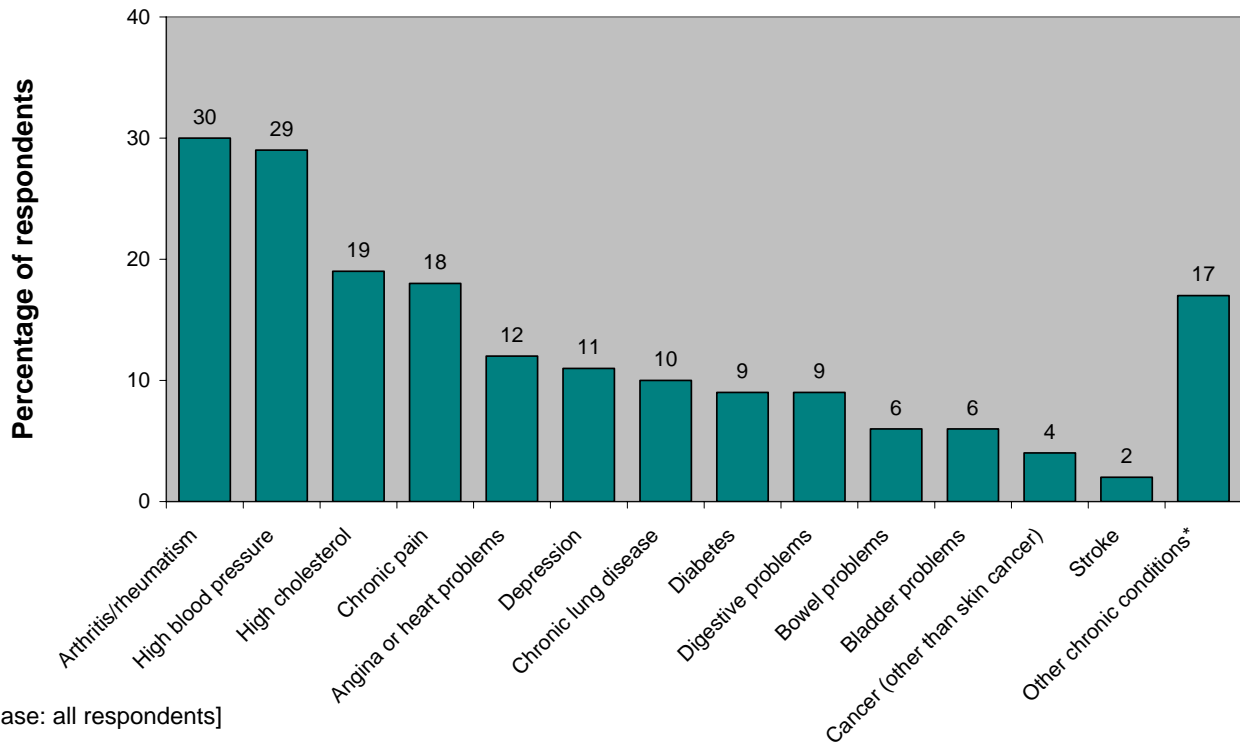
[Base: all respondents]

* Other reported conditions included chronic fatigue/fibromyalgia, hyperthyroid/hypothyroid, menopause, prostate problems, glaucoma, migraine, osteoporosis and allergies.

Respondents with chronic conditions gave much lower ratings of their health, compared to those who did not report any chronic conditions. This pattern was strong and consistent for both general and recent self-rated health (Chart 6). Among those with chronic conditions, poor health was more frequently reported by people with stoke (36%), bladder problems (23%), angina or heart problems (22%) and digestive problems (19%). Very good or excellent health was most common among respondents with hypertension (47%), arthritis (43%) and lung disease (34%).

Chart 6: Self-assessed health status of respondents

General health
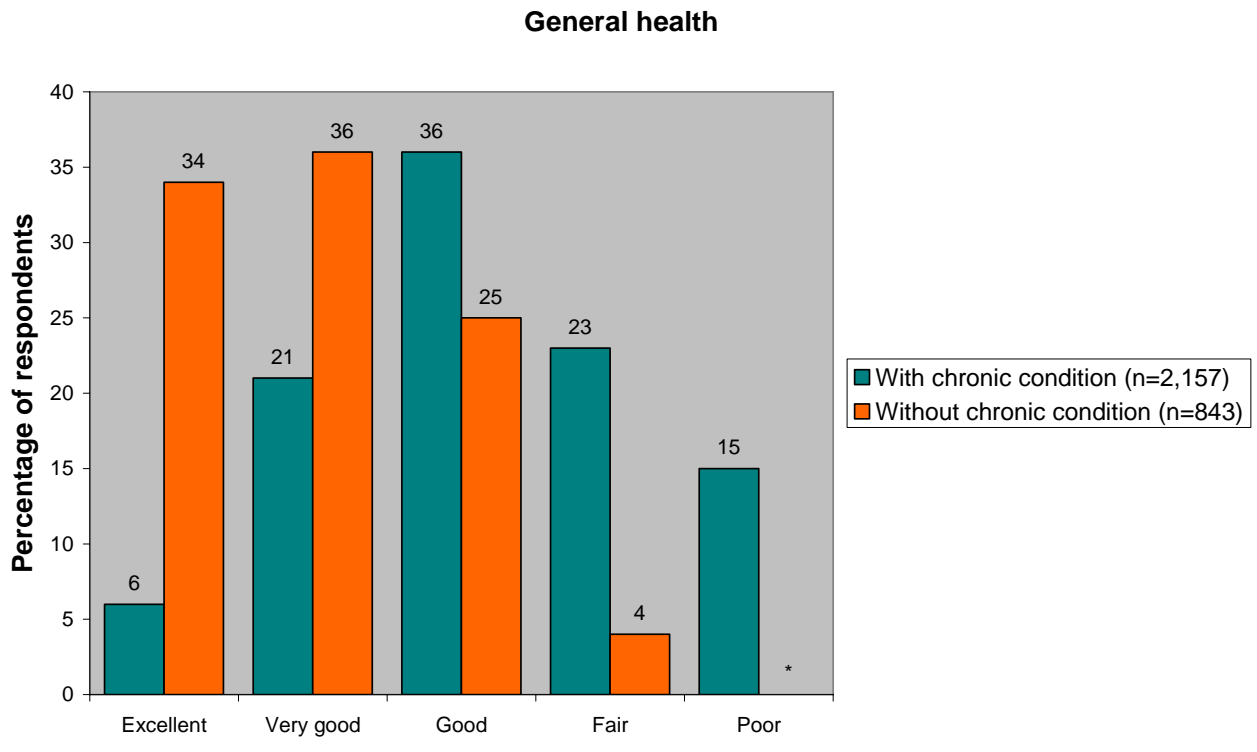
Recent health (last 4 weeks)
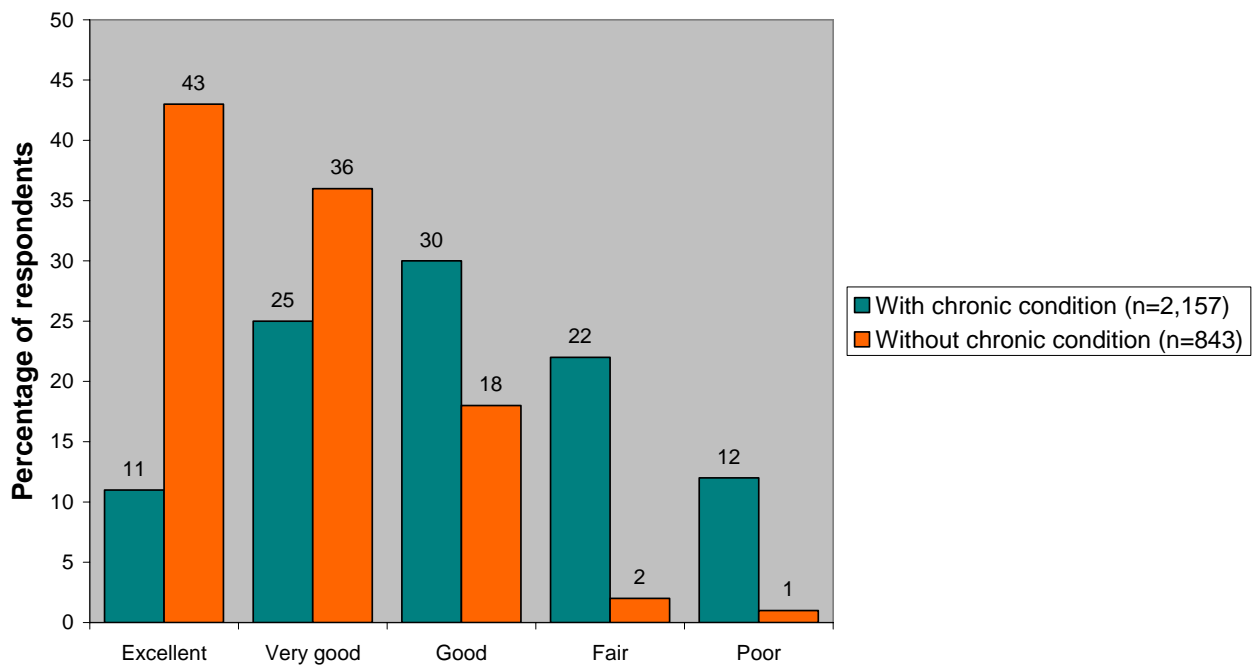
[Bases: all respondents]

4 Survey findings

4.1 Living with chronic illness

Survey participants were asked a series of questions about the impact of health problems on their physical and emotional well-being, day-to-day activities and social interactions. Additionally, they were asked to rate their agreement with the statement: "I am confident I can keep my health problems from interfering with the things I want to do." Overall, the majority of people (82%) either agreed or agreed strongly with this statement. However, far higher levels of disagreement were reported by people with chronic conditions (22%) than those not in this group (7%).

The restrictive effects of chronic illness were confirmed by responses to other survey questions. Both physical and social activities were disrupted to a much greater extent in respondents with chronic illness. Of those respondents, physical activities were largely or entirely restricted in 20%, and social activities in 17% (Table 7). Nearly half (48%) reported difficulty in completing their usual work or household tasks, which was substantial in a third of cases.

Table 7: During the past four weeks, how much did your health limit your usual physical and social activities?

	Physical activities		Social activities	
	With chronic condition (n=2,157) %	Without chronic condition (n=843) %	With chronic condition (n=2,157) %	Without chronic condition (n=843) %
Not at all	54	92	59	89
A little bit	19	4	18	7
Some	8	1	5	*
A lot	17	1	15	2
Entirely	3	1	2	1
Don't know	*	*	*	1

[Base: all respondents]

The chronically ill also had a higher prevalence of emotional problems (45% vs. 24% in non-chronically ill) and were more likely to say that such problems affected their everyday activities (34% vs. 12%). As expected, severe emotional problems were most commonly reported by those suffering from depression (49%), but were also relatively high among people with digestive problems (28%), chronic pain (22%) and bowel problems (20%).

Over half of all respondents reported some level of physical pain and lack of energy over the previous four weeks. Again, however, both these problems were far more common among those who reported having one or more chronic illnesses (Table 8). Almost a quarter (23%) said that they had experienced a high degree of physical pain during the four week period.

Table 8: Over the past four weeks how much i) physical pain and ii) energy did you have?

	Amount of physical pain		Amount of energy	
	With chronic condition (n=2,157) %	Without chronic condition (n=843) %	With chronic condition (n=2,157) %	Without chronic condition (n=843) %
None at all	34	71	5	2
A little bit	28	22	24	7
Some	15	5	33	19
A lot	23	2	37	71
Don't know	*	-	1	1

[Base: all respondents]

The survey found that people with chronic illness are already involved in various self-management activities, although not always consistently. Eighty one per cent of respondents were taking at least one prescription medicine on a regular basis, and nearly a quarter (22%) were taking five or more medicines regularly. There was a high level of self-reported adherence to medication instructions, with 92% of respondents reporting that they always took their medicines as directed. Only 2% stated that they followed instructions only sometimes.

Self-monitoring of blood glucose levels was practiced by 79% of respondents with diabetes, and by 34% on at least a daily basis (Table 9). However, self-testing was not practiced by 20% overall and by 31% of those aged 75 and above. Indeed, the extent and frequency of self-monitoring decreased with age, and was also lower among those from minority ethnic groups (31% reported not self-monitoring compared to 20% of white respondents). While diabetics are advised to check their feet for cracks or calluses on a daily basis, only 35% of respondents with diabetes said that they had checked their feet on each of the previous seven days. Thirty two percent had not done so at all.

Medical self-monitoring was less common among people with hypertension and lung disease. Twenty two per cent of respondents with hypertension have equipment to take their own blood pressure, and just under half (49%) of these reported using the equipment during the previous seven days. Similarly, 38% of people with lung conditions monitor their lung function using a peak flow meter, a little over a third (37%) of whom do so on a regular basis.

Table 9: How often do you test your own glucose level?

	45-54 (n=42) %	55-64 (n=87) %	65-74 (n=81) %	75-84 (n=37) %	85+ (n=7) %
Never	11	10	25	31	27
1-2 times a month	7	9	11	14	-
Weekly	7	10	14	10	18
1-2 times a week	4	9	8	26	-
3-5 times a week	4	18	21	2	36
Daily or more	62	45	21	18	18
Don't know	4	-	-	-	-

[Base: all with diabetes who answered question]

Gentle exercise is recommended for people with arthritis to maintain mobility and flexibility, and strengthen muscles and joints. Almost two-thirds of respondents with arthritis reported that they do exercises to manage their condition; these exercises were regularly undertaken by the majority (65%). A strong age-related pattern was observed, with exercise more frequent among younger age groups (Chart 10). However, we would caution against any simple interpretation of this finding as it is possible that elderly people with arthritis are more severely affected and, therefore, are less able to undertake exercise. Women were more likely than men to report doing exercise to manage their arthritis (67% vs. 59%); however, frequent exercise was most common among male respondents.

Chart 10: Do you do exercises to help manage your arthritis?
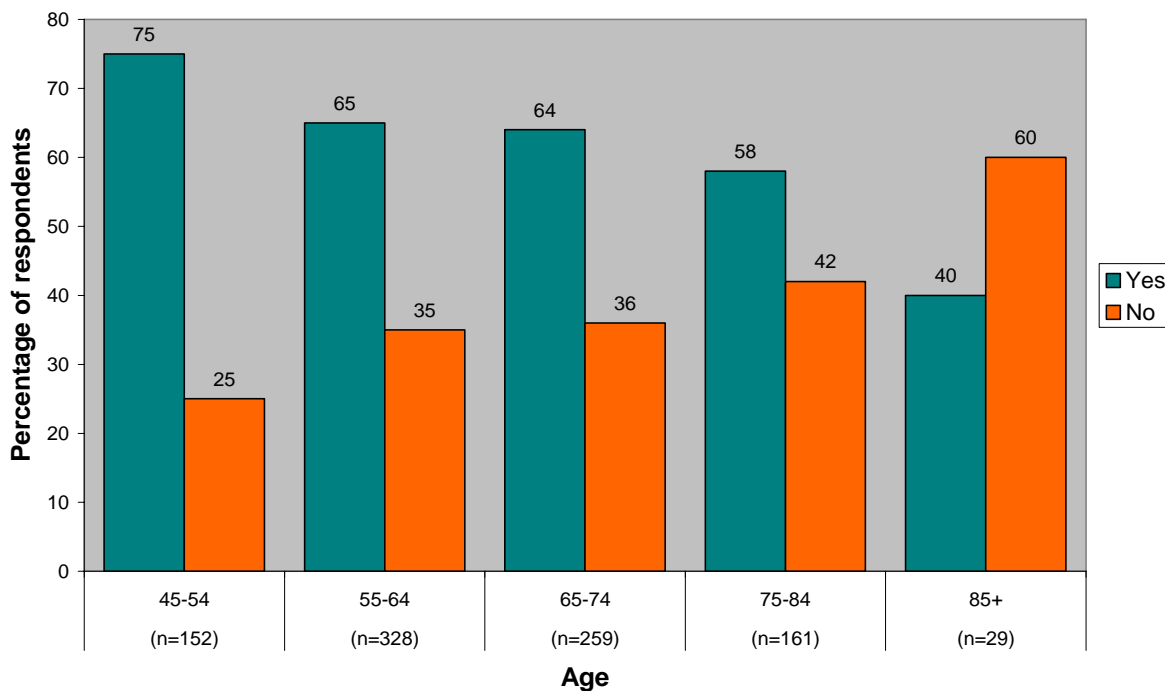
[Base: all respondents with arthritis who answered question]

4.2 Lifestyle and health behaviours

One of the central aims of the survey was to explore the extent to which individuals have adopted lifestyles and behaviours that are beneficial to their health. In addition to questions about making and sustaining lifestyle and behavioural changes, respondents were specifically asked about two particularly important areas: diet and exercise.

The majority of respondents said that they were aware of lifestyle changes that are recommended for their health (95%), and that they had made these changes (88%) (Chart 11). However, what this indicates is that more than one-tenth of people have not made lifestyle changes to safeguard or improve their health, at least some of whom are aware that such changes are recommended. No discernible pattern was found among those who had not made health-related lifestyle improvements; both knowledge of lifestyle changes and efforts to make these were fairly consistent across all groups.

Chart 11: Lifestyle changes recommended for health or health condition – knowledge and action
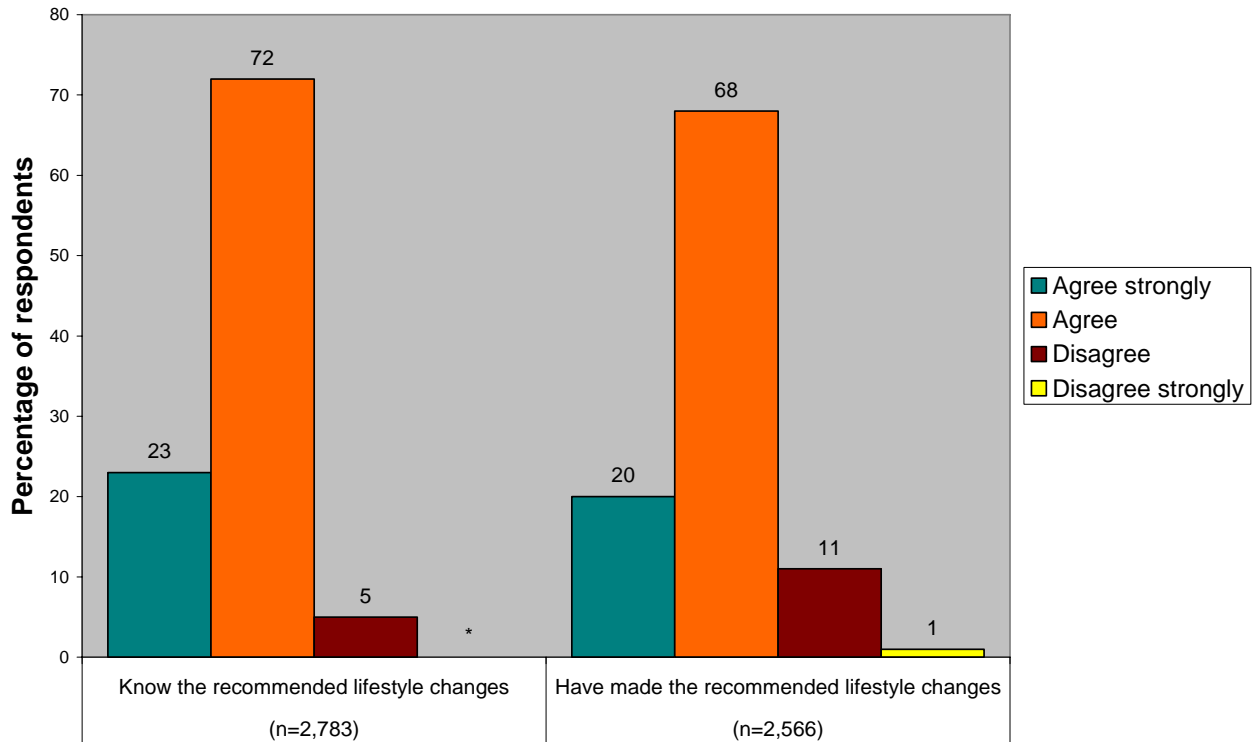
[Base: all respondents who answered question]

While 92% agreed with the statement "I have been able to maintain the lifestyle changes I have made", only 18% reported a strong agreement that may indicate that lifestyle changes are *always* maintained. Indeed, 34% of respondents said they were unable to keep up a healthy lifestyle day-to-day (Table 12). Those reporting having greater difficulty maintaining lifestyle changes on a daily basis were more likely to be living in Scotland (39%), in social grades DE (40%) or from an ethnic minority group (45%). Such difficulty was also most commonly reported by people who had experienced a stroke (46%), and who had digestive problems (44%), bladder problems (43%) or depression (40%).

Table 12: Maintaining the lifestyle changes that are recommended for my health/health condition is too hard to do on a daily basis.

	All (n=2,544) %	England w/o London (n=838) %	London (n=426) %	Wales (n=427) %	Scotland (n=417) %	N. Ireland (n=436) %
Agree strongly	5	5	5	5	4	6
Agree	29	28	31	29	35	31
Disagree	53	55	47	50	48	52
Disagree strongly	13	13	17	16	13	10

[Base: all respondents who answered question]

Health status was also an important factor in being able to maintain lifestyle changes during times of stress. Overall, 12% said that healthy behaviours lapsed during stressful periods; this compared with 32% of respondents with depression, 24% with stroke and 22% with chronic pain or digestive problems. Most strikingly, stress affected only 3% of those with excellent health but 30% of those with poor health (Chart 13).

Chart 13: I am confident that I can maintain lifestyle changes even during times of stress
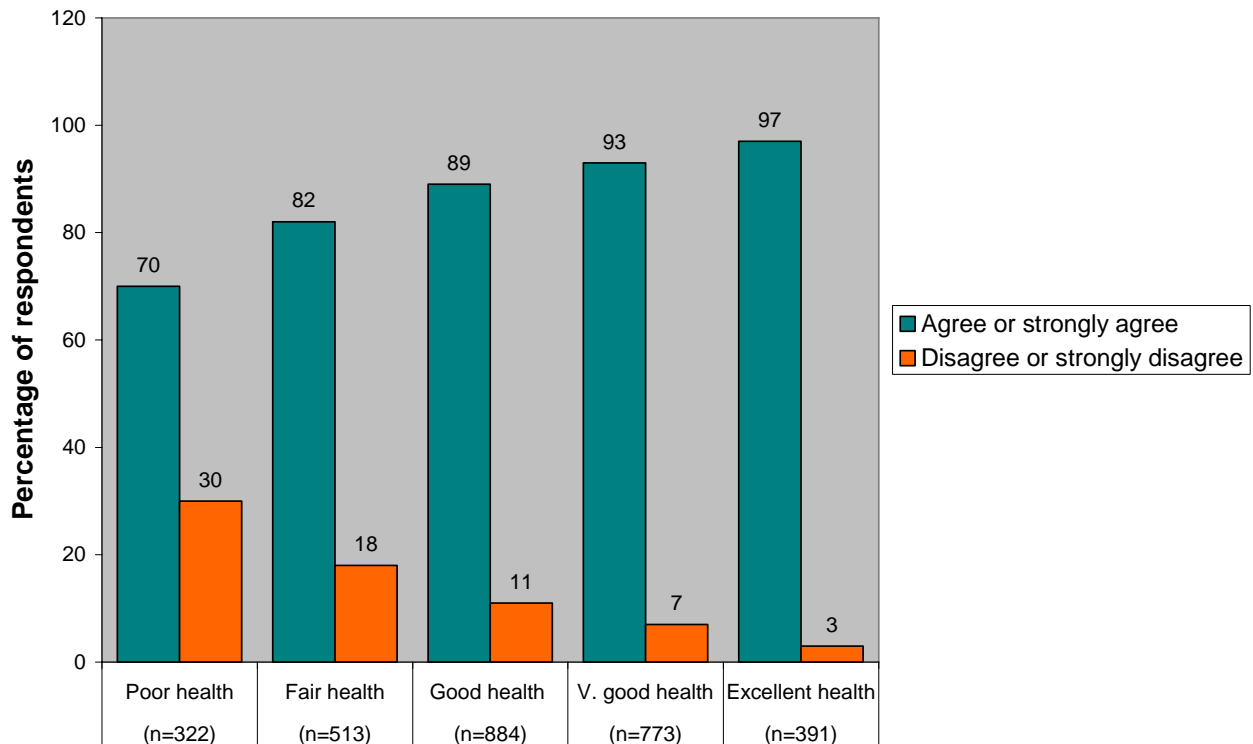
[Base: all respondents who answered question]

Nearly three-quarters (74%) of respondents said that they took regular exercise, which was defined as at least ten minutes of vigorous or moderate activity. Of those who exercise, 83% stated that they do so several times a week or more. Regular exercisers tend to be:

* In younger age groups; 79% of 45-54 year olds take regular exercise compared to 56% of the over 85s
* In higher social grades; 82% of respondents in social grades AB compared to 66% of DEs
* Of good general health; 82% of people who rated their health as excellent, very good or good, compared to 54% of people who rated their health as fair or poor
* Living in London (77%), England (75%) or Scotland (74%), rather than Wales (68%) or Northern Ireland (67%).

Seventy two per cent of respondents said they eat a low fat diet, although in most cases this diet was followed sometimes (22%) or almost always (42%) rather than always (36%). Just over half (53%) manage to eat the recommended five pieces of fruit or vegetables every day or almost every day. However, this amount of fruit and vegetables is eaten once a week at most by 13%, and never by 7%. Gender differences in healthy eating practices were observed; a low fat diet was followed by 78% of women and 64% of men, and the recommended amount of fruit and vegetables was eaten daily or almost daily by 58% of women and 48% of men. Fruit and vegetables were also more regularly eaten by ethnic minority respondents (79% ate the recommended amount four or more days a week, compared to only 66% of white respondents).

There was some evidence of greater dietary self-care among the chronically ill, 76% of whom follow a low fat diet compared to 61% of people who did not report a chronic condition. Eighty four per cent of respondents with a chronic condition had received some help or advice from their doctor about how to improve their diet. A further 82% had been given help or advice about taking regular exercise. Levels of professional support were fairly consistent across the five regions, although marginally higher in Northern Ireland (Table 14). There was some variation according to chronic condition; in particular, people with diabetes received the most professional support in relation to both improving their diet (94%) and taking regular exercise (89%). It

is possible that this finding reflects the existing commitment to enhancing self-care among people with diabetes, as set out in the National Service Framework.

Table 14: When discussing your condition and its treatment, your doctor or nurse …

	All	England w/o London	London	Wales	Scotland	N. Ireland
	%	%	%	%	%	%
Gave you help and advice on improving your diet	(n=2,004)	(n=652)	(n=335)	(n=348)	(n=334)	(n=335)
Agree/strongly agree	84	84	82	83	88	88
Disagree/strongly disagree	15	15	17	16	12	12
Don't know	1	1	2	1	-	-
Gave you help and advice on regular exercise	(n=1,979)	(n=636)	(n=333)	(n=347)	(n=325)	(n=338)
Agree/strongly agree	82	83	75	77	83	85
Disagree/strongly disagree	18	17	25	23	17	15
Don't know	*	*	*	-	-	-

[Base: those with a chronic condition who answered question]

4.3 Use of and attitudes towards healthcare services

The survey found extensive use of healthcare services over the previous 12 months. Three-quarters of respondents had made at least one visit to their general practitioner during the previous year, and 25% had seen their doctor five times or more. Fifteen per cent reported having visited accident and emergency, with 5% making at least two visits. Patterns of doctor and accident and emergency (A&E) visits differed according to health status, with much higher levels of service use among those with chronic conditions (Chart 15). While frequency of A&E visits increased with age, there was no discernable age-related difference in GP consultations. Confirming a broader trend in health service utilisation, GP and A&E services were less widely used by respondents from ethnic minority populations; 33% made no visits to the doctor, and 93% did not attend A&E, compared to 20% and 84% of white respondents.

Chart 15: Doctor and A&E visits by health status

Doctor visits during previous 12 months

A&E visits during previous 12 months
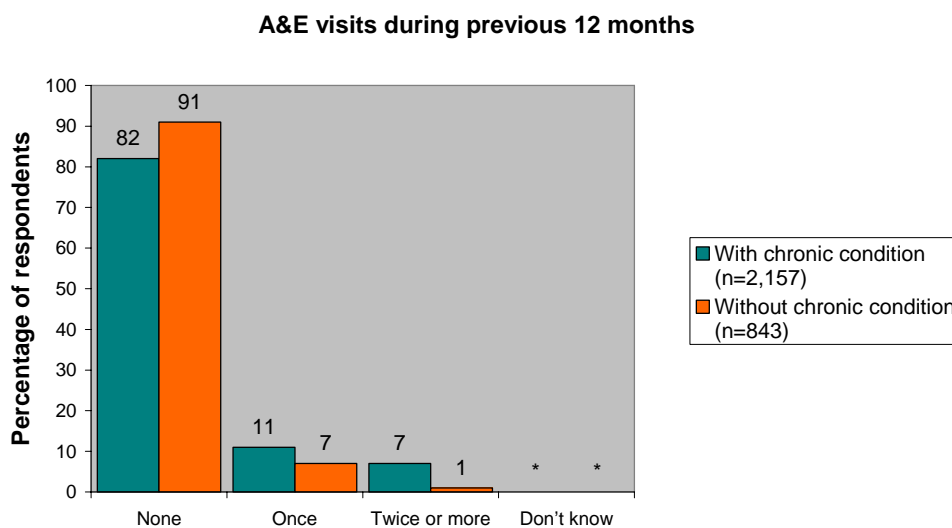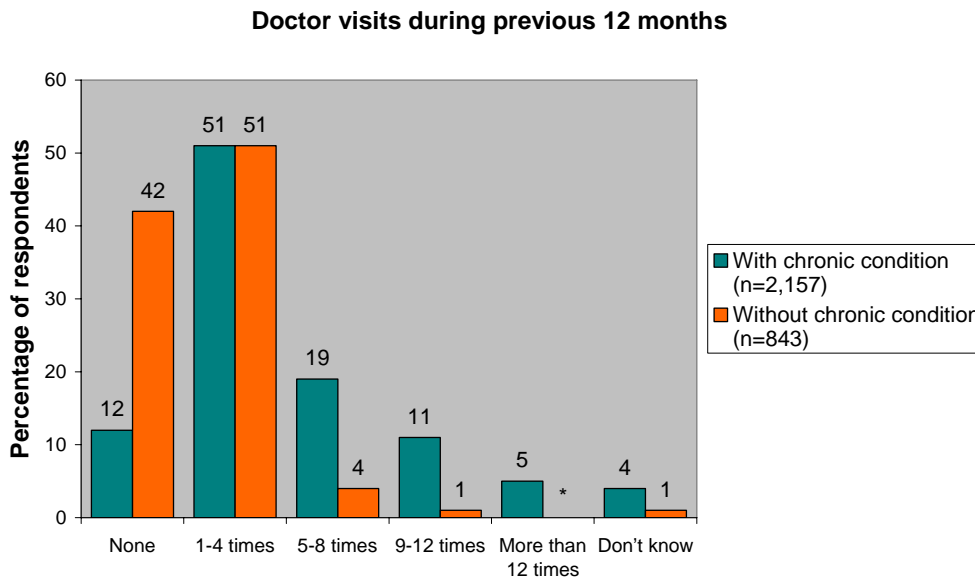
[Bases: all respondents]

A range of questions probed people's attitudes about health professionals and their interactions with them. Encouragingly, 94% said they would not wait to be asked before raising concerns with their doctor (Table 16). Within the chronic conditions group, reluctance to disclose concerns was higher among those with digestive problems (14%) and depression (14%) than with stroke (5%) and cancer (4%). A further 66% indicated that they prepared for consultations by drawing up a list of questions or issues they wanted to discuss with their doctor (Table 17). There was a greater likelihood of such advance preparation in particular groups:

- 57% of the over 75s would take along a list of questions or issues, compared to 67% of 45-74 year olds
- 66% of white respondents, compared to 73% of those from ethnic minorities
- 60% of people in social grades DE, compared to 73% of ABs
- 55% in Northern Ireland and 60% in Scotland, compared to 73% in England, 72% in London and 67% in Wales.

Table 16: I am confident I can tell my doctor concerns I have even when he or she does not ask

	All (n=2,940) %	England w/o London (n=977) %	London (n=492) %	Wales (n=486) %	Scotland (n=489) %	N. Ireland (n=496) %
Strongly agree	28	27	32	29	27	28
Agree	66	67	62	64	65	67
Disagree	5	5	5	6	7	4
Strongly disagree	1	1	1	1	1	1

[Base: all respondents who answered question]

Table 17: How likely are you to bring a list of questions and/or issues you want to cover when you see the doctor?

	All (n=2,933) %	England w/o London (n=973) %	London (n=491) %	Wales (n=492) %	Scotland (n=491) %	N. Ireland (n=486) %
Very likely	27	31	31	30	24	20
Likely	39	42	41	37	36	35
Unlikely	21	16	15	21	21	25
Very unlikely	12	11	11	12	18	19
Don't know	1	1	1	1	1	1

[Base: all respondents who answered question]

Across the entire sample, however, there is evidence that the extent of people's confidence to proactively communicate with their doctor is limited. Only 9% indicated that they would ask their doctor for further explanation when they did not understand something she/he had said. No sub-group stood out as being more willing to persist in asking their doctor for further explanation. Thus, while many people feel comfortable speaking to their doctor and asking them questions, they are far less confident about saying they need further clarification when something has not been explained clearly.

Efforts are underway to make information on the quality of care available to patients, which can be used to make decisions about where and from whom to obtain care. When asked about their interest in accessing and using quality information, responses were mixed. Before visiting a new doctor, 43% said they would try to find out about his or her qualifications (Table 18). People's likelihood of using information about medical errors and preventable deaths was considerably higher. If they were given a choice of hospital, two-thirds (67%) of respondents indicated they would use such safety information to guide their decision (Table 19). For both questions, responses varied according to age; 31% of those over 75 would check out a new doctor's qualifications and 53% would use safety information to choose a hospital, compared to 46% and 70% of 45-74 year olds. Possibly reflecting more deferential attitudes towards the medical profession, there was lower interest in checking doctors' qualifications among women (39% vs. 48% of males), people in social grades DE (33% vs. 51% of ABs) and those with lower educational attainment (39% of people with a secondary education only vs. 52% with a university degree).

Table 18: If I went to a new doctor, I would find out as much as I could about his or her qualifications

	All (n=2,894) %	England w/o London (n=961) %	London (n=486) %	Wales (n=483) %	Scotland (n=486) %	N. Ireland (n=478) %
Strongly agree	6	6	4	5	6	5
Agree	38	37	35	45	43	36
Disagree	38	39	35	35	35	40
Strongly disagree	16	16	21	14	16	16
Don't know	2	4	2	1	3	2

[Base: all respondents who answered question]

Table 19: If you had a choice of hospital, how likely would you be to use a report (comparing rates of medical mistakes and preventable deaths) to do so?

	All (n=2,908) %	England w/o London (n=974) %	London (n=490) %	Wales (n=483) %	Scotland (n=476) %	N. Ireland (n=485) %
Very likely	37	37	43	40	35	33
Likely	39	31	27	26	29	31
Unlikely	18	18	17	19	17	20
Very unlikely	12	11	9	15	15	12
Don't know	3	3	4	1	4	4

[Base: all respondents who answered question]

In addition to questions about conventional medical services, the survey participants were also asked about their use of complementary and alternative medicine (CAM). Overall, only 11% had used CAM during the previous 12 months, but use was higher among females (14%), 45-54 year olds (16%), those living in London (17%) and people in social grades AB (18%). More people reported taking CAM remedies or supplements; 24% said they took these frequently, 9% only sometimes, and 5% rarely. In the majority (61%) of cases, however, these had never been used. Again, usage patterns according to gender, age and social grade were observed. In particular, 40% of women frequently or sometimes used CAM remedies and supplements, compared to 26% of men.

4.4 Knowledge and confidence for self-management

Knowledge and confidence are essential to successful self-management. In order for an individual to take action towards managing their health and care, they need to be able to identify and understand their health problems, choose appropriate strategies for addressing these, and have the confidence to put their skills and knowledge into practice. Analysis of the PAM scores (outlined in Section 4.7) indicates that most people have at least basic knowledge and confidence for self-management. This section examines the nature and extent of these attributes in detail.

Respondents were asked about their knowledge of their health problems or conditions, and of the treatments for these. Only 9% of those with chronic conditions, and 6% of those without, indicated that they did not understand the nature and causes of their health problems (Table 20). Understanding was lowest among the

over 85s (15%), those living in London (12%), people with digestive problems (15%), stroke (15%), chronic pain (14%), depression (12%) and, in particular, respondents from ethnic minority groups (18%).

Table 20: I understand the nature and causes of my health problems/condition

	All (n=2,625) %	England w/o London (n=875) %	London (n=439) %	Wales (n=436) %	Scotland (n=429) %	N. Ireland (n=446) %
Strongly agree	20	19	23	22	21	20
Agree	72	72	65	70	74	71
Disagree	8	7	11	7	5	7
Strongly disagree	1	1	1	1	*	1

[Base: all respondents who answered question]

Among those with chronic conditions, there was a greater awareness of self-treatments than of options for medical treatment (Chart 21). Some 21% said that they did not know the different medical treatments available for their condition, and 13% were not aware of self-treatments. Fewer people with diabetes (11%) and stroke (11%) said they were not aware of medical treatment options, compared to those with depression (29%), lung disease (26%) and chronic pain (24%). Of those respondents who did not report a chronic condition, 91% indicated they knew about ways of self-treating their health problems. Overall, the only factor that was related to variation in knowledge about treatments (both self-initiated and medical) was health status. Compared to only 11% of those who rated their health as excellent, 33% of those with poor health did not know about different medical treatments. Only 9% of respondents with excellent health but 26% of respondents with poor health were unaware of options for self-treatment.

Chart 21: I know about the different medical treatments and self-treatment options for my health problems/condition

Medical treatments
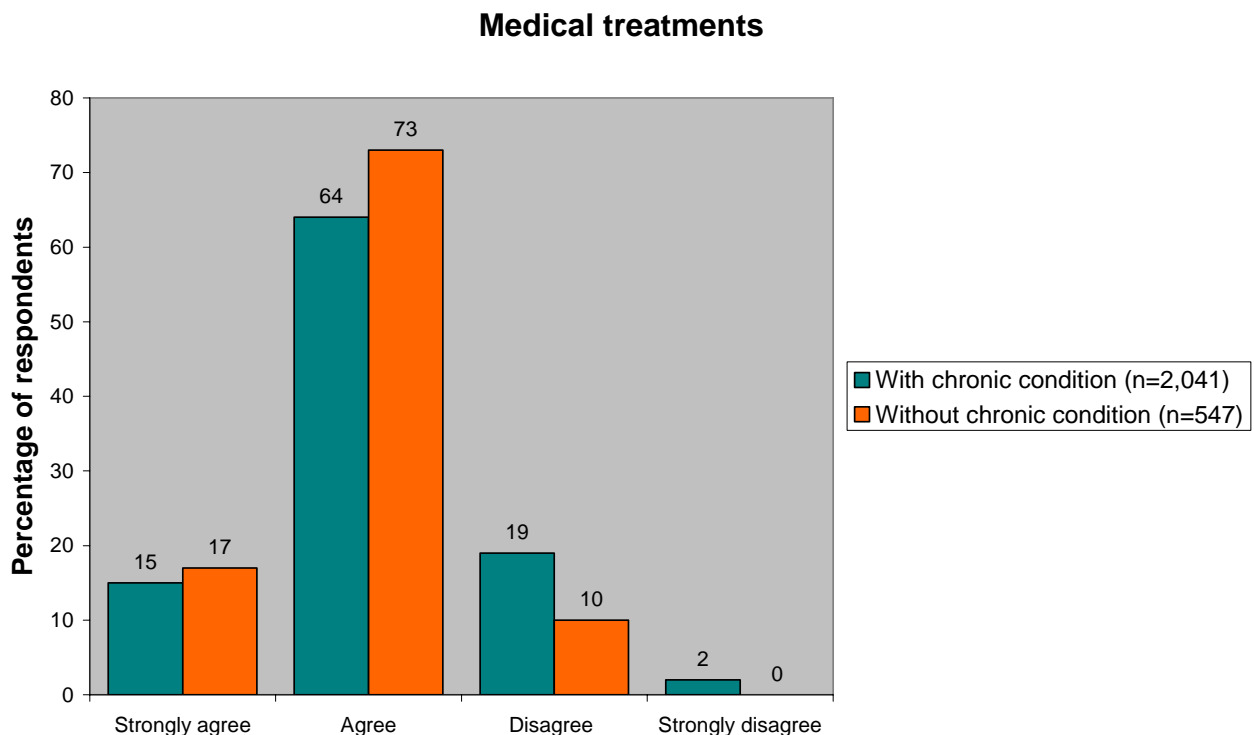
Self-treatments
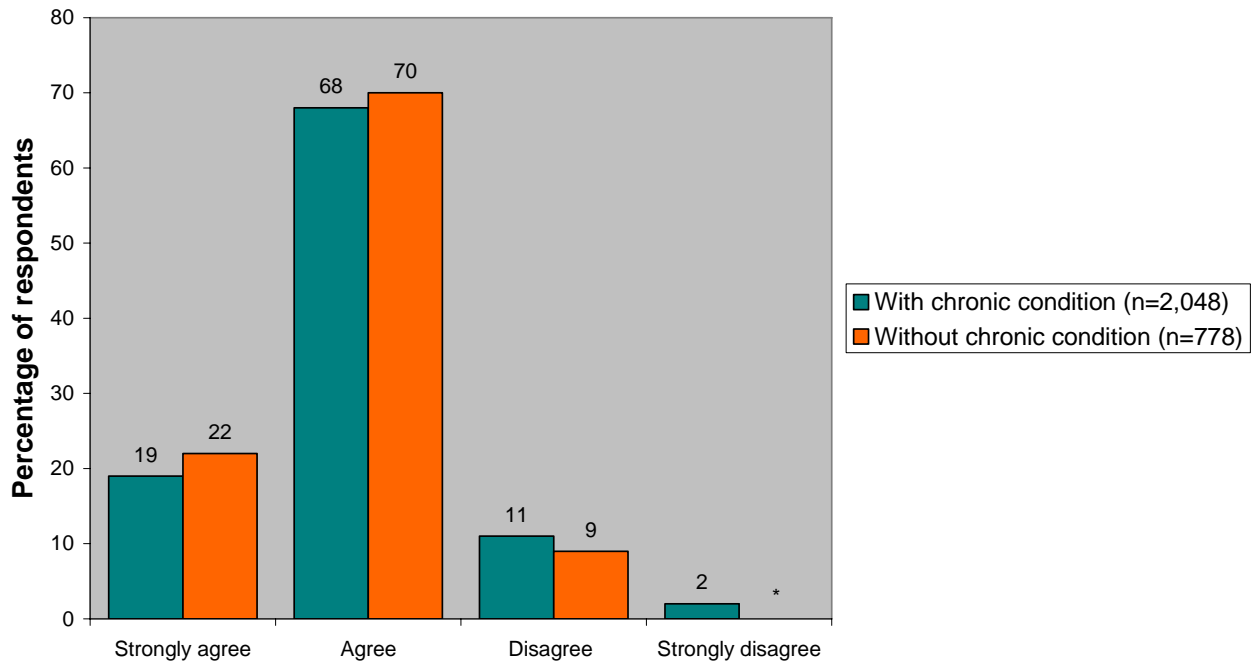
[Bases: all respondents who answered question]

Nearly a fifth (17%) of respondents who did not have a chronic condition, and 81% of the chronically ill, were taking prescription medicines on a regular basis. When given the statement "I know what each of my prescribed medications does", only 5% disagreed overall. However, some groups demonstrated less knowledge about medicines; 18% of the over 85s, 16% of ethnic minority respondents and 11% of those with poor health were uncertain about the use of their medicines. Except for the over 85s, the same groups were also more likely to lack confidence to perform medical treatments at home and to follow medical recommendations (such as making lifestyle changes). Only 4% of the entire sample, but 14% of both people with poor health and ethnic minorities, did not feel confident administering their own treatments. Similarly, 20% of people with poor health and 15% of ethnic minorities were not confident they could follow medical recommendations made by their doctor, compared to 7% overall.

Table 22: I am confident I can follow through on i) medical treatments I need to do at home and ii) medical recommendations my doctor makes

	White %	Non-white %
Medical treatments	(n=2,712)	(n=105)
Agree/agree strongly	96	86
Disagree/disagree strongly	4	14
Medical recommendations	(n=2,704)	(n=103)
Agree/agree strongly	93	85
Disagree/disagree strongly	7	15

[Base: all respondents who answered question]

Even successful self-managers may occasionally need formal medical care. To make appropriate use of healthcare services, the individual must decide whether a problem is minor and can be treated at home, or serious enough to warrant professional attention. Overall, 96% of respondents were confident that they could judge between situations where medical care is necessary and those where it is appropriate to self-treat. With regard to personally addressing health problems, 88% said they were confident they could take action to prevent or minimise problems with their health. However, within this overall figure are some important differences based on health status. A lack of confidence to take remedial or preventive action was reported by 2% of those who did not have chronic conditions, but 12% of people who did. This may reflect the difficulty of self-managing chronic conditions, many of which are complex and often unpredictable. Variation according to condition was also observed. Confidence was particularly lacking among those with stroke (21%), depression (20%), chronic pain (20%), angina or heart problems (19%) and digestive problems (18%) (Table 23). Finally, confidence to take action to prevent or minimise problems was strongly related to self-assessed health status; a lack of confidence was reported by 2% of those with excellent health, 4% with very good health, 8% with good health, 12% with fair health and 29% with poor health.

Table 23: I am confident I can take actions to prevent or minimise problems associated with my health or health condition

	With chronic condition (n=2,082) %	Without chronic condition (n=806) %	Chronic pain (n=587) %	Depression (n=363) %	Angina/ heart problems (n=347) %	Digestive problems (n=285) %	Stroke (n=67) %
Agree/strongly agree	88	98	80	80	82	82	79
Disagree/strongly disagree	12	2	20	20	19	18	21

[Base: all respondents who answered question]

4.5 Active self-management of health and healthcare

Almost all survey participants acknowledged the importance of their own role in managing their health problems and in providing care. Ninety four per cent agreed with the statement "Taking an active role in my own healthcare is the most important factor in determining my health and ability to function." Only 5% said that they were not the person with ultimate responsibility for managing their own health or health condition. However, more people with depression (12%), digestive problems (11%), chronic pain (9%) and bladder problems (9%) did not feel ultimately responsible for managing their health condition, compared to those with cancer (2%) and diabetes (2%).

A core self-management skill is being able to take action to overcome, or at least manage, disruptive symptoms or problems related to living with a chronic condition or other health concern. Indeed, effective self-management is dependent on the ability to identify and solve problems that arise day-to-day. Overall, 89% said they could handle health problems and 88% said they could handle health symptoms on their own at home. Considerable variation in these skills according to self-rated health, and by chronic condition, was observed. Compared to only 5-6% of respondents who did not have a chronic condition, 14% of the chronically ill said they were unable to manage problems and symptoms. Such difficulties were particularly associated with depression and digestive problems, but high levels of difficulty managing illness symptoms were also found in those with chronic pain, diabetes, stoke and bladder problems (Table 24).

Table 24: I am able to handle symptoms (of my health or chronic condition) on my own at home

	With chronic condition (n=2,107) (%)	Without chronic condition (n=782) (%)	Depression (n=370) %	Digestive problems (n=290) %	Chronic pain (n=598) %	Diabetes (n=259) %	Stroke (n=70) %	Bladder problems (n=215) %
Agree/ strongly agree	86	94	74	73	77	80	74	80
Disagree/ strongly disagree	14	6	26	27	23	21	26	20

[Base: all respondents who answered question]

Respondents' answers to two further statements about problem solving also markedly differed according to health status. When given the statement "I am confident I can come up with solutions when new problems arise with my health/health condition", there was an 11% disagreement among those without chronic conditions and a 26% disagreement among the chronically ill (Chart 25). Within the chronic conditions group, confidence to tackle new problems was more common in respondents with excellent health or very good health (88%) than those with good, fair or poor health (70%). Nearly one-fifth (19%) of the chronically ill said they did not know how to prevent problems with their health, compared to only 5% of people who did not have a chronic condition (Chart 26). More respondents with stroke (30%), chronic pain (30%), depression (30%), bowel problems (31%) and digestive problems (32%) reported not knowing how to take preventive action.

Chart 25: I am confident I can come up with solutions when new problems arise with my health/health condition
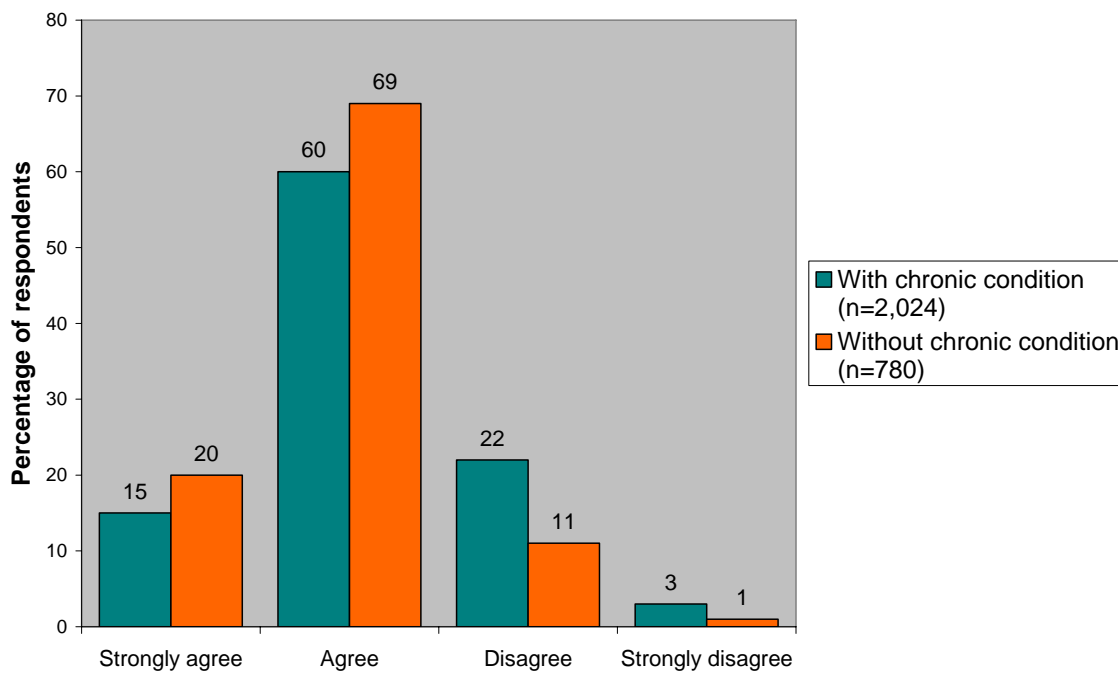
[Base: all respondents who answered question]

Chart 26: I know how to prevent problems with my health/further problems with my health condition
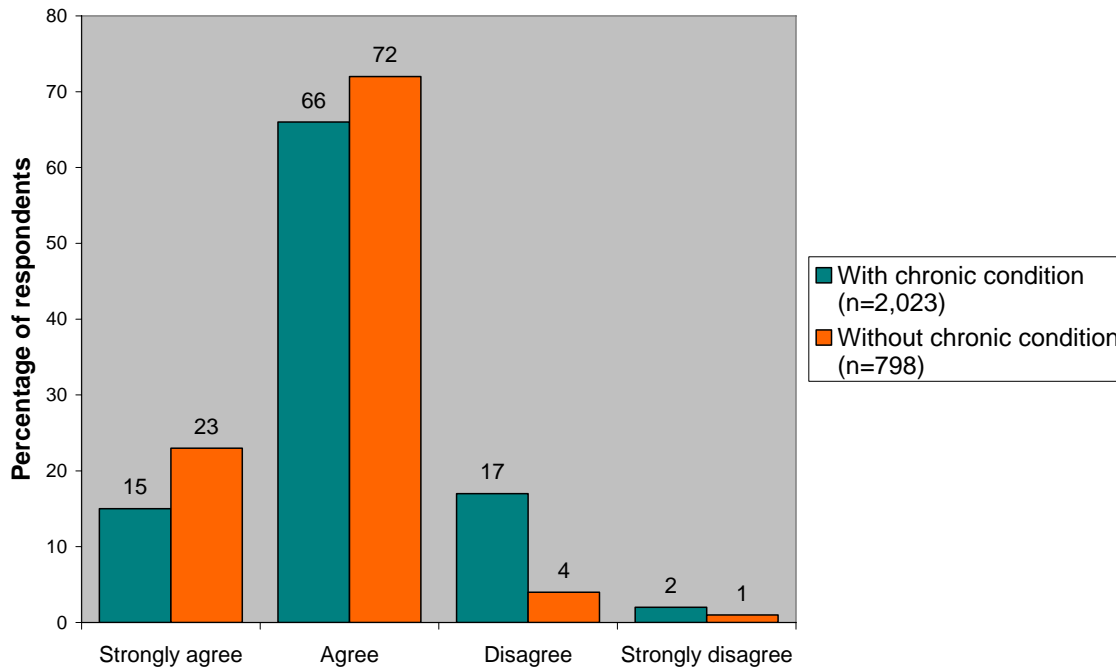
[Base: all respondents who answered question]

Analysis was conducted of respondents from the chronic conditions group only, to explore whether the capacity to take action was related to certain demographic variables. There was no notable difference in terms of the percentage reporting inability to take action to manage their chronic conditions. However, strong agreement with the four relevant statements (handling symptoms, handling problems, coming up with solutions and preventing problems) was greater among respondents who were younger, from higher social grades, living in London and who had a university-level education. This indicates that such groups have self-management skills which are the most well developed and consistently deployed. There were also differences according to ethnic background, but these were not consistent across answers to all four statements.

There are many important ways that healthcare professionals can support and enable people to become active participants in their care. The survey asked all people with chronic conditions whether they had received professional help to self-monitor their condition, and asked those with arthritis if they had been given a pain management plan. Overall, 80% had been shown by their doctor how to monitor their condition to see how well they are doing. Fewer respondents living in London reported receiving support for self-monitoring (73%), compared to those living in England (81%), Wales (81%), Scotland (82%) and Northern Ireland (82%) (Table 27). According to condition, not including diabetes, the percentage receiving such support ranged from 75% (digestive problems) to 81% (cancer, hypertension and high cholesterol); this compared to 91% of those diagnosed with diabetes. Only 35% of people with arthritis had a plan to help manage their pain. Plans were less common among the over 75s (24%).

Table 27: When discussing your condition and its treatment, your doctor or nurse taught you how to monitor your condition

	All (n=1,992) %	England w/o London (n=642) %	London (n=334) %	Wales (n=344) %	Scotland (n=327) %	N. Ireland (n=345) %
Strongly agree	23	23	28	21	21	22
Agree	57	58	45	60	61	60
Disagree	16	16	19	14	15	13
Strongly disagree	3	2	6	4	3	4
Don't know	1	1	3	1	-	2

[Base: those with a chronic condition who answered question]

4.6 Information needs and information seeking behaviour

The role of information in enabling individuals to be actively involved in their health and healthcare cannot be underestimated. Across the health spectrum, people need access to high quality information for knowledge and understanding, to make lifestyle and treatment choices, and to take action to maintain health and manage illness.

The majority of our sample (80%) said that they were likely or very likely to seek out information to learn about how to cope with health problems (Table 28). However, 20% of respondents indicated that were unlikely to access health information for this purpose. Information seeking behaviour varied by age and educational status, with higher levels of interest among 45-54 year olds (84% vs. 64% of the over 85s) and those with a university education (89% vs. 75% of those educated to secondary level only). While concerns have been raised about the quality of health information for patients and the public, most respondents (93%) expressed confidence in their ability to find trustworthy sources of information (Table 29). There were no major differences in confidence between any of the demographic sub-groups, but variation according to chronic condition was observed. More people with diabetes (95%) and cancer (92%) felt confident they could find trustworthy information about their condition, compared to those with bladder problems (85%), digestive problems (84%) and depression (84%).

Table 28: How likely are you to seek out information to learn about how to cope with problems of your health?

	All (n=2,934) %	England w/o London (n=973) %	London (n=492) %	Wales (n=489) %	Scotland (n=487) %	N. Ireland (n=493) %
Very likely	39	38	45	42	36	34
Likely	41	41	39	37	43	43
Unlikely	14	15	11	16	13	14
Very unlikely	6	5	5	5	8	8
Don't know	1	*	1	1	1	1

[Base: all respondents who answered question]

Table 29: I am confident I can find trustworthy sources of information about my health/condition and treatment choices

	All (n=2,916) %	England w/o London (n=967) %	London (n=492) %	Wales (n=484) %	Scotland (n=487) %	N. Ireland (n=486) %
Agree strongly	22	21	25	23	21	19
Agree	71	72	66	68	70	73
Disagree	7	6	8	8	7	7
Disagree strongly	1	*	1	1	2	1

[Base: all respondents who answered question]

Taking along health information to discuss with the doctor can indicate both an interest and desire for active involvement in clinical decision-making. Thirty eight per cent of respondents said they were likely to take to consultations information they had obtained from the newspaper or internet (Table 30). This was more common among women (42%) than men (34%), 45-74 year olds (41%) than those aged 75 and over (25%), people from social grades AB (43%) than those from grades DE (34%), and ethnic minorities (49%) than white respondents (38%).

Table 30: How likely are you to bring to your doctor information from the newspaper or internet when you discuss your care?

	All (n=3,000) %	England w/o London (n=1,000) %	London (n=500) %	Wales (n=500) %	Scotland (n=500) %	N. Ireland (n=500) %
Very likely	12	12	16	14	11	9
Likely	26	26	23	22	27	21
Unlikely	36	37	29	35	32	40
Very unlikely	25	25	24	29	29	28
Don't know	1	1	1	1	1	1

[Base: all respondents]

Nearly three-quarters of people said they sought health information from their doctor; nurses and other health professionals were mentioned by 22% of respondents. After doctors, the next most commonly cited sources of health information were the internet and health websites (30%), printed materials (23%) and family and friends (19%). Newspapers and magazines were listed by 18% of respondents, indicating that the media is also an important source of health information. While patient groups are producing information on various health topics and chronic illnesses, it is of note that they are used by only 4% overall and 5% of the chronically ill. There was little variation according to chronic condition in use of patient groups for health information; moderately higher rates were reported by those with depression (9%) and cancer (8%) and lower rates by those with stroke (1%) and diabetes (4%). Few reported seeking information from television and radio (4%), advertisements (1%) and, most surprisingly, pharmacists (6%).[21] Chart 31 shows the top ten sources of health information.

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[21] In the recent MORI survey of self-care, conducted on behalf on the Department of Health, 13% of respondents indicated that they used pharmacists as a source of information. However, the MORI survey asked specifically about self-care information (rather than health information generally), where pharmacist provision may be seen as more appropriate.

Chart 31: Where or from whom do you look for health information?
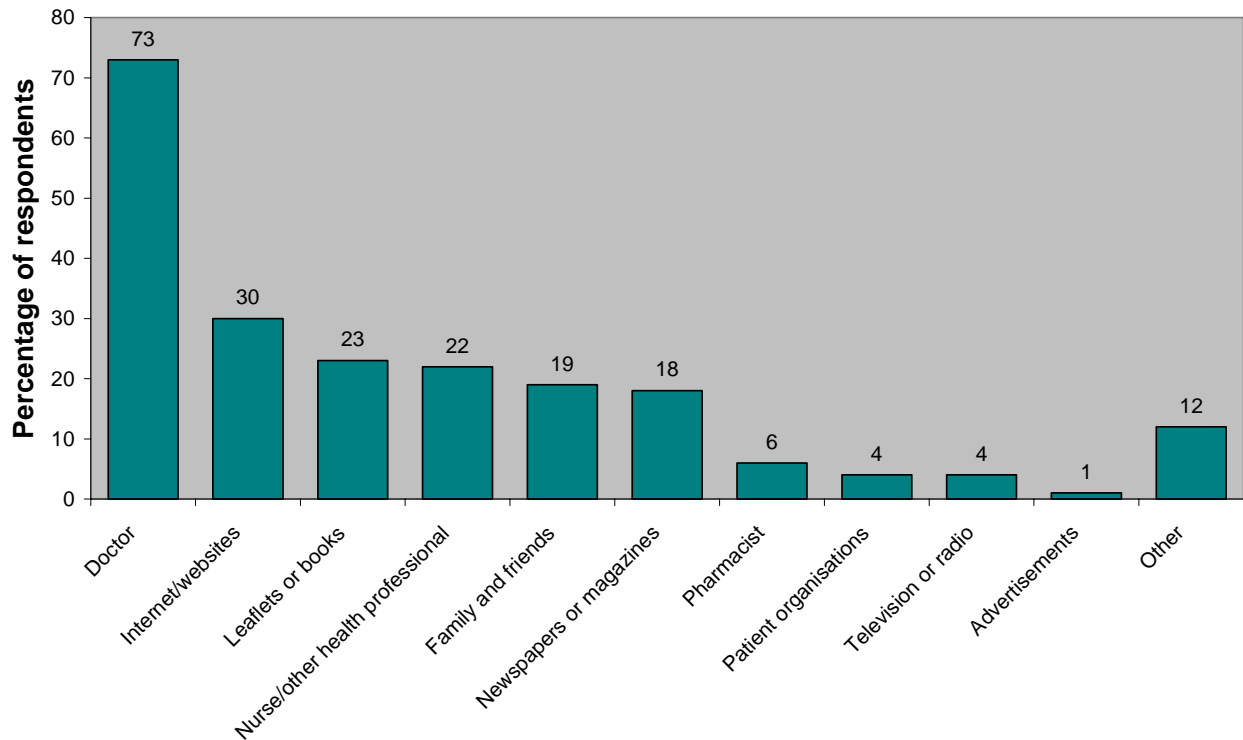
[Base: all respondents]

Within the overall figures on health information sources, there were some interesting differences between groups:

- 21% of women, but only 13% of men, look for health information in newspapers and magazines
- Printed information materials were more likely to be used by those in social grades AB (28% vs. 17% in grades DE) and 45-74 year olds (25% vs. 5% of the over 75s). There was also greater use among people from ethnic minorities (31%) than white respondents (22%)
- Among respondents who did not have a chronic condition, those living in London were less likely to view their doctor as a source of health information (58%) than those in Scotland (71%) and Northern Ireland (74%). There was little regional variation among the chronically ill
- Family and friends were cited by 26% of people in social grades AB, compared to 15% of people in grades DE.

It was in the use of the internet for health information, however, that the most striking differences were seen. Likelihood of using internet health websites declined with age, with only 19% of over 65s indicating probable use compared with 50% of those aged 45-64. There was also a strong correlation with social grade: 50% of ABs but only 22% of DEs said that they were likely or very likely to seek out health information on the internet. Over three-quarters (76%) of respondents from social class DE said that they tended not to make use of the internet (Table 32).

Table 32: When you seek out information how likely are you to look at internet health websites?

	AB (n=548) %	C1 (n=806) %	C2 (n=475) %	DE (n=1,021) %
Very likely	28	24	19	10
Likely	22	25	19	12
Unlikely	21	24	24	30
Very unlikely	28	26	37	47
Don't know	1	*	1	2

[Base: all respondents who answered question]

These above differences are unsurprising given well-documented disparities in access to and confidence in using computer technology. The Department of Health/MORI self-care survey specifically enquired about these issues, and reported that those without internet access were more likely to be older, less affluent and have poorer health. It also found that confidence to use the internet for health information was much lower among those without access.

Lower use of the internet was also reported by respondents from Northern Ireland, only 10% of whom said that they were very likely to seek information via the internet. This compared with 15% of those living in Wales, 18% in Scotland, 20% in England and 24% in London. The internet was also more widely used by respondents from ethnic minorities (46% vs. 38% of white respondents).

Participants were also asked about their use of telephone helplines to access health information. These include the two nurse-led telephone services provided by the NHS: NHS Direct (in England and Wales) and NHS 24 (in Scotland). The majority (62%) said that they were unlikely to seek information via a telephone helpline, and only 10% indicated that they were very likely to use such a service. Likelihood of use varied according to ethnic group, with 'likely' or 'very likely' answers given by 52% of ethnic minority respondents but only 36% of white respondents.

In direct contrast to use of the internet, interest in using telephone helplines was highest among those from the lower social grades (Table 33). Forty per cent of people from grades DE said they were likely or very likely to seek information in this way, compared to 29% of ABs. Also, unlike responses to the internet question, similar levels of interest in telephone helplines were expressed by respondents across all age groups. This suggests that the availability and use of health information is enhanced by offering both internet and telephone access.

Table 33: When you seek out information how likely are you to call a telephone helpline such as NHS Direct or NHS 24?

	AB (n=559) %	C1 (n=855) %	C2 (n=510) %	DE (n=1,005) %
Likely or very likely	29	35	39	40
Unlikely or very unlikely	69	64	59	57
Not available	1	*	*	-
Don't know	1	1	2	5

[Base: all respondents who answered question]

4.7 Patient Activation Measure scores

The extent of people's knowledge, confidence and skills for self-management was assessed using the 22 item version of the Patient Activation Measure (PAM). The measure comprises a number of statements – covering various dimensions of patient involvement in healthcare – to which respondents answer Strongly Agree, Agree, Disagree, Strongly Disagree or Not Applicable. The measure produces activation scores ranging from 0 to 100 (see Appendix 4). It was decided that if 'Not Applicable' answers were given to 8 or more items, PAM scores would not be calculated due to a lack of valid data.

Based on the findings from their national survey, Hibbard and colleagues have identified cut-off points for the four stages of patient activation. These are:

Stage 1: believes patient role important   PAM score 47.0 or lower
Stage 2: confidence and knowledge to take action   PAM score 47.1 to 55.1
Stage 3: taking action   PAM score 55.2 to 67.0
Stage 4: staying the course under stress   PAM score 67.1 and above

This section provides an overview of the general findings – answers to specific PAM items are described in detail in the preceding sections.

The average overall PAM score and averages for each of the demographic and other sub-groups are displayed in Table 34. The sample produced an average of 59.43, with sub-group averages ranging from 55.24 to 66.10. Almost 4% of respondents (3.9%) did not answer a sufficient number of PAM items to calculate a valid score. Chart 35 compares the proportion of UK and US respondents at each of the four stages of activation. This shows that there is a smaller degree of variation in self-management ability across the UK population, with 28.8% at the lowest and highest stages (1 and 4) compared to 34.1% in the US. In both countries, more people achieved higher stage scores than lower ones; 59.6% and 58.8% reached at least stage 3 in the UK and US respectively. However, a significant minority lack the confidence and knowledge to take action to manage their own health and healthcare. Almost 8% in the UK and 12% in the US were at stage 1 only.

Table 34: Average Patient Activation Measure scores

Group	Average PAM score
All	59.43
Gender	
Women	59.22
Men	59.70
Age	
45-54	60.32
55-64	60.34
65-74	59.05
75-84	57.15
85+	55.24
Social grade	
AB	62.71
C1	60.15
C2	58.89

Group	Average PAM score
DE	57.26
Education	
Secondary or less	57.91
Post secondary	60.61
University degree or higher	62.50
Ethnic group	
White	59.49
Other	58.08
Region	
England (w/o London)	59.44
London	60.27
Wales	59.40
Scotland	58.97
N. Ireland	58.21
Self-reported health	
Excellent	66.10
Very good	62.02
Good	58.79
Fair	56.38
Poor	52.54
Chronic conditions	
None	62.04
Hypertension	58.18
Chronic pain	55.60
Arthritis/rheumatism	56.77
Depression	55.14
Diabetes	59.23
Lung disease	56.59
Cancer	57.74
Angina/heart problems	57.32
Bowel problems	58.21
Digestive problems	55.67
Stroke	57.35
High cholesterol	57.82
Bladder problems	55.98

Chart 35: UK and US PAM scores
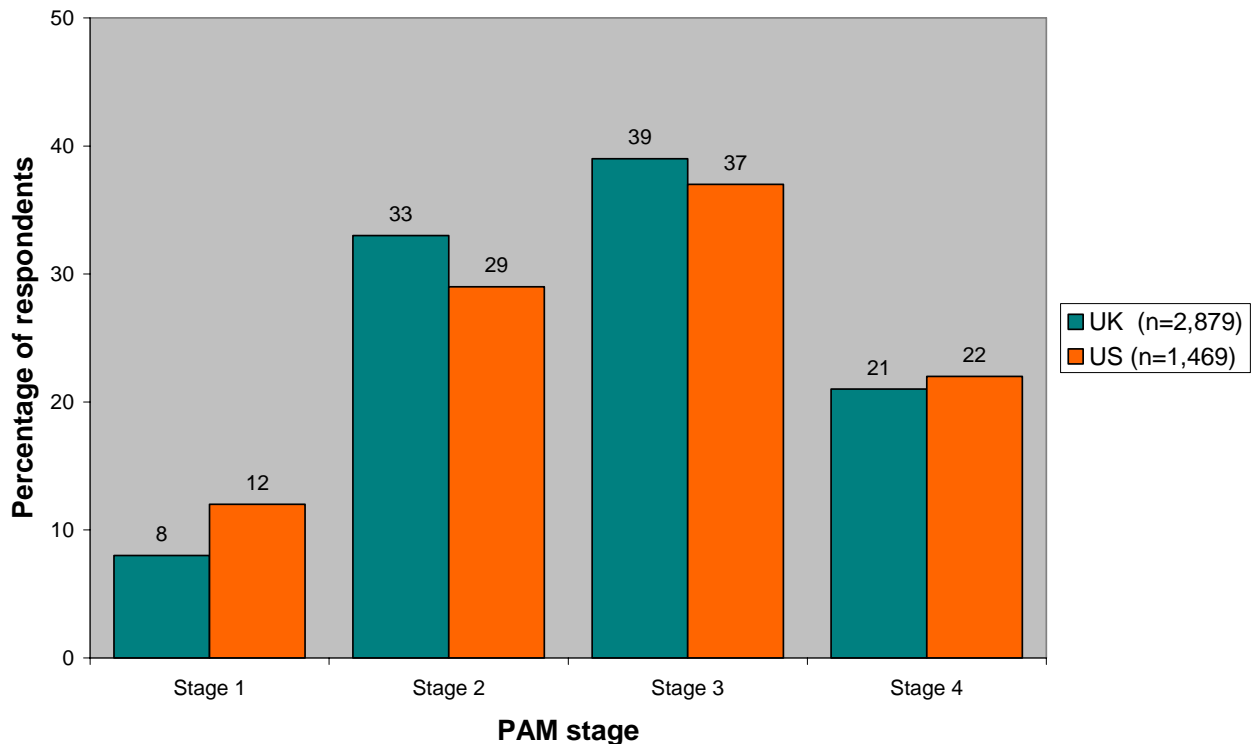
[Base: all respondents with valid PAM scores]

Looking in more detail at the breakdown of PAM scores, important differences between sub-groups can be observed. The US researchers reported that PAM scores were significantly higher in females, younger age groups, the more educated, whites and those with better self-reported health. Some, but not all, of these associations were also observed in the UK. There was little variation in scores by gender. The impact of ethnicity was only evident at the lower end of the scale; compared to 8.2% of white respondents, 14.5% of those from ethnic minority groups were at stage 1. The main difference by region was in the scores for London and Northern Ireland. There was a higher proportion of Londoners at stage 4 (24.8% compared to an average of 20.9%) and people living in Northern Ireland were more likely to be at stage 1 (9.7% compared to an average of 7.9%). Distribution in the middle two stages was roughly equal across all the four UK countries and London.

The largest demographic differences in knowledge, skill and confidence for self-management were related to age, education and social grade. While respondents in older age groups were no more likely to be at stage 1, relatively few achieved scores indicating that they could not only take action but also sustain it during times of stress. Indeed, there was a strong age-related trend in stage 4, which was reached by 9.3% of over 85s, 12.6% of 75-84 year olds, 18.9% of 65-74 year olds, 23.6% of 55-64 year olds and 24.5% of 45-54 year olds (Table 36). Similarly, there was little difference at stage 1 by educational level. However, only 52.8% of respondents who left school by the age of 16 had reached stage 3 or 4, compared to 64.9% of those with post-16 education and 71.9% of those with a university degree or higher (Table 37). The survey found a markedly less well developed self-management role among those from lower social grades. Compared to 5.0% of ABs, 6.3% of C1s and 6.6% of C2s, 11.5% of those in grades DE were at stage 1. Conversely 16.8% of respondents in the lowest social grades, but 28.3% of those from the highest, possessed an advanced (stage 4) capacity for self-management (Table 38).

Table 36: PAM scores by age

PAM Score	45-54 (n=934) %	55-64 (n=933) %	65-74 (n=616) %	75-84 (n=321) %	85+ (n=59) %
Stage 1	9.0	8.4	5.0	9.0	8.1
Stage 2	28.5	27.9	36.8	42.4	43.0
Stage 3	38.1	40.1	39.3	36.0	39.5
Stage 4	24.5	23.6	18.9	12.6	9.3
Average	60.32	60.34	59.05	57.15	55.24

[Base: all respondents with valid PAM scores]

Table 37: PAM scores by education

PAM Score	Secondary or less (n=1,573) %	Post secondary (n=694) %	University degree or higher (n=566) %
Stage 1	7.6	8.4	7.1
Stage 2	39.5	27.1	21.0
Stage 3	36.3	41.4	42.1
Stage 4	16.5	23.5	29.8
Average	57.91	60.61	62.50

[Base: all respondents with valid PAM scores]

Table 38: PAM scores by social grade

PAM Score	AB (n=537) %	C1 (n=828) %	C2 (n=498) %	DE (n=999) %
Stage 1	5.0	6.3	6.6	11.5
Stage 2	25.7	28.7	35.7	38.2
Stage 3	41.0	42.5	39.6	33.4
Stage 4	28.3	22.6	18.2	16.8
Average	62.71	60.15	58.89	57.26

[Base: all respondents with valid PAM scores]

PAM scores were also patterned according to health status. Only 30.2% of respondents who did not have a chronic condition, but 44.5% of those who did, were at stages 1 or 2 (Chart 39). Additionally, fewer chronically ill respondents had reached stage 4 (19.6% vs. 24.0% of the non-chronically ill). There was also variation in capacity for self-management among those with chronic conditions (Table 40). Compared to 44.5% of the overall group, 51.3% of those with bladder problems, 51.4% with arthritis, 57.4% with depression, 58.3% with chronic pain and 59.0% with digestive problems had not reached the stage (stage 3) of being able to take action to manage their health. The highest level of self-management skills was most common among respondents with diabetes (22.7%) and hypertension (20.4%). Conversely, 20.6% of people with depression, 19.9% with digestive problems and 19.8% with chronic pain had not progressed beyond stage 1. Demographic factors may be part of the explanation for this variation according to chronic condition. For example, people with arthritis and bladder problems were more likely to be older and less highly educated compared to the chronic conditions group overall. Conversely, levels of education and social class

background were moderately higher in those diagnosed with diabetes. However, no consistent pattern was found between ability to self-manage chronic conditions and the personal characteristics of respondents, indicating that other non-demographic factors must also be influential.
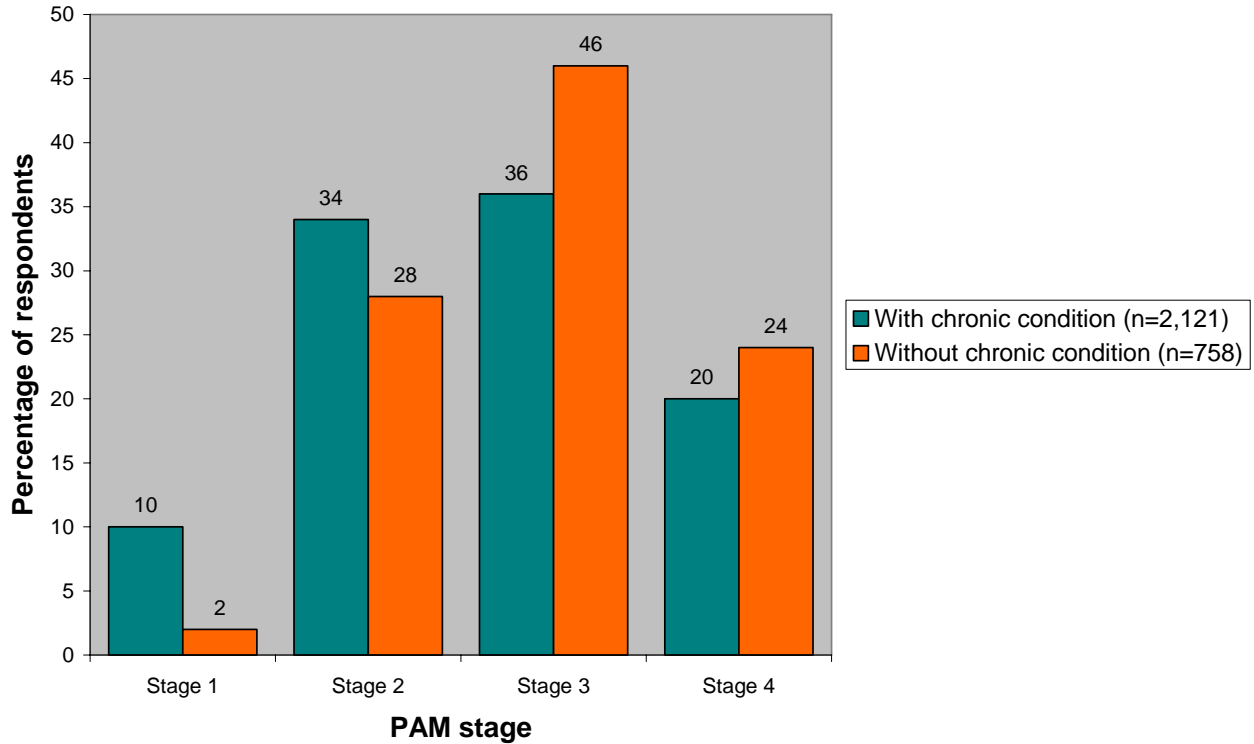
Chart 39: PAM scores by health status

Table 40: PAM scores by chronic condition

PAM score	Arthritis (n=930) %	High blood pressure (n=893) %	High cholesterol (n=607) %	Chronic pain (n=605) %	Angina (n=348) %	Depression (n=376) %	Lung disease (n=314) %
Stage 1	14.2	11.8	13.3	19.8	11.8	20.6	13.5
Stage 2	37.2	33.4	31.1	38.5	35.1	36.8	35.8
Stage 3	32.3	34.3	37.7	26.5	39.9	28.5	36.1
Stage 4	16.3	20.4	18.0	15.2	13.2	14.1	14.5
PAM score	Diabetes (n=260) %	Digestive problems (n=291) %	Bowel problems (n=169) %	Bladder problems (n=213) %	Cancer (n=109) %	Stroke (n=68) %	
Stage 1	8.9	19.9	8.9	15.7	6.3	12.1	
Stage 2	30.5	39.1	39.1	35.6	41.4	32.8	
Stage 3	37.9	25.6	34.3	34.0	35.1	43.1	
Stage 4	22.7	15.4	17.8	14.7	17.1	12.1	

[Base: those with a chronic condition with valid PAM scores]

Of all the groups within the sample, the lowest PAM scores were achieved by people with poor self-rated health (Table 41). A lack of knowledge, confidence and skills for self-management (indicated by a stage 1 score) was demonstrated by 30.8% of those reporting poor health, compared to 10.6% with fair health, 5.4% with good health, 2.7% with very good health and 1.3% with excellent health. Only one-third (33.0%) of respondents with poor health were at stages 3 or 4, but these stages had been reached by 84.0% of those with excellent health. Therefore, individuals whose health is most impaired will need the greatest support to become active self-managers. Interventions to improve knowledge and confidence for self-management should also be primarily targeted towards this group.

Table 41: PAM scores by self-rated health

PAM Score	Poor (n=332) %	Fair (n=518) %	Good (n=899) %	Very good (n=759) %	Excellent (n=371) %
Stage 1	30.8	10.6	5.4	2.7	1.3
Stage 2	36.2	45.6	36.9	25.6	14.7
Stage 3	22.2	30.3	38.6	46.6	48.7
Stage 4	10.8	13.6	19.1	25.1	35.3
Average	52.54	56.38	58.79	62.02	66.10

[Base: all respondents with valid PAM scores]

Notwithstanding the above differences between groups, it is important to note that a relatively small proportion of survey respondents achieved scores in the stage 1 range. Overall, only 7.9% were at the lowest stage of activation. This indicates that most people have some engagement in their care, at least insofar as they recognise the importance of their own role. This is confirmed by the responses to relevant PAM items. Only 6% disagreed with the statement: "Taking an active role in my healthcare is the most important factor in determining my health and ability to function". The overwhelming majority (95%) also indicated that they are the person who is responsible for managing their own health. These achievements will form an important foundation for empowering people towards greater self-management of their health and chronic conditions.

5 Policy implications

The Patient Engagement survey has confirmed the importance of initiatives to improve patients' involvement in their healthcare. We found that four in ten people are not regularly taking action to maintain and manage their health, and only some of those who are taking action are able to sustain it at all times. To guide patients and the public towards effective self-management, support strategies must be implemented which enable the development of appropriate knowledge, confidence and skills, as well as the capacity for perseverance. In particular, strategies must take account of the need to tackle health inequalities, provide accessible health information, transform clinician-patient relationships and promote self-management education.

5.1 Tackling health inequalities

If efforts to engage patients in their own health and healthcare are to succeed, they must be appropriately targeted to meet individual needs and preferences. We have found that there is considerable variation across the UK population in self-management ability. In terms of demographic characteristics, the most striking differences were according to age, educational status and social grade. Certain groups were identified as being less confident and equipped to take on the day-to-day management of their care: namely the elderly, those from lower social grades and the less educated. To a smaller extent, regional and ethnic disparities were also in evidence, with fewer people living in Northern Ireland and from ethnic minority backgrounds having progressed to advanced levels of self-management. While everybody is likely to benefit from encouragement and support from health professionals and other agencies, the above groups will need the greatest assistance to become active self-managers. They will also be more likely to need interventions designed to improve the capacity for action, through improving knowledge of health issues and building self-confidence.

Special attention will need to be paid to the needs of elderly populations in improving self-management. Age-related differences were observed across all issues covered by the survey: from use of health services, through knowledge of health issues, to participation in activities such as medical self-monitoring and physical exercise. People from ethnic minority groups also fare less well in certain areas, in particular knowledge and confidence to self-manage. Efforts are needed to specifically target these groups and to work closely with them to develop age and culturally sensitive support programmes.

Lifestyle and behavioural changes are an important way in which patients can actively contribute to the maintenance of health and management of illness. Our survey confirmed once again that a significant minority of the population does not take regular exercise or follow a healthy diet. Moreover, where health-related lifestyle changes have been made, some people found it difficult to maintain them on a daily basis or during times of stress. There is, therefore, continued need for patient and public education about healthy lifestyles, including the role of diet and exercise. To ensure long-lasting changes, however, strategies to enable people to both make and maintain healthy choices must be implemented. Central to this is the identification and addressing of factors that prevent or discourage health-related lifestyle improvements, which may include time, cost and access to resources.

5.2 Providing health information

Most people are interested in accessing health information, but a significant minority do not do so at present. A better understanding of the barriers (structural, attitudinal etc.) that discourage these groups from accessing and using health information would be valuable. A variety of creative approaches will be required

to meet the information needs of different groups, particularly older people and those from disadvantaged populations.

Older people were less active in seeking and using information about health problems, treatments and the quality of healthcare services. This calls for the provision of appropriate and well targeted information materials to older age groups, and support for these groups to access such materials and make best use of them. As our survey showed, the internet is becoming an increasingly important resource for health information, but the digital divide is still apparent, with younger people and those in higher socio-economic groups being much more likely to seek information on the web. Where new technologies are employed to disseminate health information, provision should be made to ensure accessibility for all groups. This can be achieved either by disseminating information using a range of different methods, or by implementing strategies to support access to and use of internet resources. Our results suggest that telephone helplines have a role to play, particularly for those people who do not have internet access. However, interest in NHS Direct (or NHS 24 in Scotland) was relatively low, suggesting a need for better marketing of this information source.

A strikingly low proportion of survey respondents mentioned patient organisations as an information source. This was surprising in view of the plethora of groups offering support to people with chronic conditions, many of which provide helplines and patient information materials. It raises questions about the capacity of these organisations to connect with those who might benefit from their services and about their marketing ability. Given that most patients look to their doctors first and foremost for information about their health, it suggests that building awareness among doctors and other health professionals about patient information resources and support groups should be a priority. If clinicians are the first port of call, they should be encouraged to provide a more effective conduit for patients looking for supplementary sources of information and support.

5.3 Transforming clinician-patient relationships

To fully engage patients in their healthcare, they need to be seen and treated as equal partners in decisions about their care. In certain situations, people demonstrated trust and ease in communicating with their doctor. However, we also found evidence that patients are not always proactive communicators and doctors are not necessarily sharing treatment decisions with them. More than 20% of the chronically ill were not aware of the different medical treatments available for their condition, which suggests that they were not involved in the decision about how to treat that condition. Furthermore, fewer than one in ten people would ask their doctor to clarify something they had not understood. There is a need for efforts to facilitate the transition towards a partnership approach in clinical consultations. This includes enhancing open and equal communication, and encouraging doctors and empowering patients to share decisions about patient care.

If patients are to become active self-managers, this role must be recognised and developed in their relationships with doctors, nurses and other health professionals, as well as outside the clinical setting (ie at home). In addition to educating people about how to monitor their health and take action to address problems, 'ownership' of healthcare is also encouraged through active involvement in clinical decisions and a collaborative relationship with healthcare providers. Helping to raise standards of health literacy, encouraging patients to express their preferences, helping them to find appropriate health information and giving them the opportunity to participate in decisions are essential preconditions for effective self-management. Clinicians will need training and support to help their patients in this way.

To ensure that chronic care patients are given appropriate forms of support, health professionals will need information about their patient's capabilities for taking on a self-management role. To meet this need, Judith Hibbard and colleagues have recently developed a shortened 13 item version of the PAM for use as a

patient assessment tool.[22] Designed for completion during the clinical consultation, the PAM-13 provides an indication of the patient's current stage of activation. The PAM-13 has been shown to have similar validity and reliability to the 22-item version, and research is underway in the US to test its utility in different clinical populations. Such research could also be conducted in the UK, to evaluate the feasibility of using the PAM-13 to identify patient support needs in primary care and other health settings.

5.4 Promoting self-management education

Compared to day-to-day health problems, particular difficulties arise in living and coping with chronic and long-term illnesses. We found that people with chronic conditions often have a poorer state of health; indeed, most respondents who reported only fair or poor health had at least one chronic condition. The chronically ill were far more likely to have problems of physical functioning, emotional well-being and social interaction. For such individuals, assessing and understanding health problems, and choosing and deploying strategies to overcome them, is an often complicated task. More intensive forms of support, and a focus on developing day-to-day problem-solving skills, are needed to enhance engagement in healthcare among those with chronic conditions.

However, as the survey has clearly shown, 'chronic conditions' can neither be spoken of nor addressed as a homogeneous group. People with chronic conditions vary considerably, both in terms of how their condition affects their daily life and the extent to which they are prepared and able to self-manage. A consistent pattern was found within this variation, with less favourable responses given by those with chronic pain, depression, digestive problems, bladder problems and stroke. Conversely, people with diabetes stood apart as having less difficulty managing their condition and receiving more support to do so. Given the focus on self-care for diabetes as set out in the National Service Framework, this finding may well reflect the success of strategies to target and improve patient self-management of this condition.

This raises questions about the appropriateness of the generic approach to self-management education adopted by the Department of Health's Expert Patients Programme. Established in 2002, the programme is fairly new and, as the MORI survey showed, public awareness of it is still relatively low.[23] Based on the chronic disease self-management programme developed in the US, it relies on group learning led by volunteers with experience of living with chronic conditions. As it develops it is likely to provide useful help to people with a range of chronic conditions, but many patients will continue to look to health professionals as their main source of help and advice. The model adopted for supporting self-management in diabetes appears to be more closely integrated with clinical services through the diabetes clinical networks and the DAFNE and DESMOND patient education programmes.[24] This may possibly account for the more advanced self-management skills among people with diabetes that were apparent in our survey results. Equivalent programmes of action need to be developed and implemented for other chronically affected groups, and above all for those with the five conditions named above.

5.5 Conclusions

Almost all respondents to this survey acknowledged the importance of taking an active role in managing their health problems and many also felt sufficiently confident and knowledgeable to take appropriate action when necessary. However, a significant minority lacked the knowledge, skills and motivation to look after themselves effectively. People recovering from stroke and those with chronic pain, depression, digestive and

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[22] Judith Hibbard *et al*, 'Development and testing of a short form of the patient activation measure' (*Health Services Research*: in press).

[23] Only 12% of respondents to the MORI survey had heard of the Expert Patients Programme, and only 2% had attended courses.

[24] Diabetes UK/Department of Health Patient Education Working Group, *Structured Patient Education in Diabetes* (London: Department of Health, 2005).

bladder problems tended to be less confident self-managers. Around half of the respondents in these groups did not feel able to take effective action to manage their health. These people will require appropriately targeted support to build their knowledge and confidence for effective self-care.

Appendix

1. NHS and social care long term conditions model
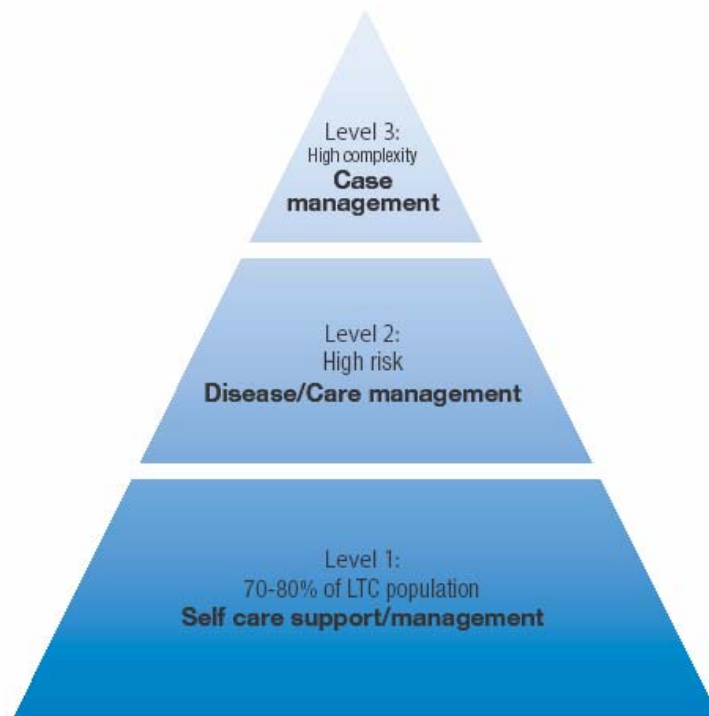
Level 1: Case management – requires the identification of the very high intensity users of unplanned secondary care. Care for these patients is to be managed using a community matron or other professional using a case management approach, to anticipate, coordinate and join up health and social care.

Level 2: Disease-specific case management – this involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways, such as the National Service Framework and Quality and Outcomes Framework.

Level 3: Supported self-care – collaboratively helping individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively.

Source: *Supporting people with long-term conditions* (Department of Health, 2005)

2. Patient Activation Measure (PAM)

The questionnaire used in the Patient Engagement survey contains a 22 item scale that assesses the extent to which people feel confident and able to self-manage their own health and health conditions. The scale consists of a series of statements, with five possible responses:
- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Not applicable.

Separate versions of the scale, with different wording, are intended for those who have chronic conditions and those who do not. Below is the scale for those reporting a chronic condition.

Believes active role is important

1. When all is said and done, I am the person who is responsible for managing my health condition.

2. Taking an active role in my own healthcare is the most important factor in determining my health and ability to function.

Confidence and knowledge to take action

3. I know what each of my prescribed medications does.

4. I am confident I can tell my doctor concerns I have even when he or she does not ask.

5. I am confident that I can tell when I need to get medical care and when I can handle a health problem myself.

6. I know the lifestyle changes like diet and exercise that are recommended for my health condition.

7. I am confident that I can follow through on medical treatments I need to do at home.

8. I am confident that I can take actions to prevent or minimize problems associated with my health condition.

9. I am confident that I can find trustworthy sources of information about my health condition and treatment choices.

10. I am confident that I can follow through on medical recommendations my doctor makes such as changing my diet or doing regular exercise.

11. I understand the nature and causes of my health condition.

12. I know the different medical treatment options available for my health condition.

Taking action

13. I have been able to maintain the lifestyle changes for my health that I have made.

14. I know how to prevent further problems with my health condition.

15. I know about the self-treatments for my health condition.

16. I have made the changes in my lifestyle like diet and exercise that are recommended for my health condition.

17. I am confident I can come up with solutions when new problems arise with my health condition.

18. I am able to handle symptoms of my health condition on my own at home.

Staying the course under stress

19. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress.

20. I am able to handle problems of my health condition on my own at home.

21. I am confident I can keep my health problems from interfering with the things I want to do.

22. Maintaining the lifestyle changes that are recommended for my health condition is too hard to do on a daily basis.

3. Social grade classification

Social grade is a socio-economic classification used by the market research and marketing industries. In the Patient Engagement survey NOP used the standard definitions of social grade, as set out by the Market Research Society.

Social Grade	Description	% of the UK population
A	**Upper middle class** Higher managerial, administrative and professional	3%
B	**Middle class** Intermediate managerial, administrative and professional	20%
C1	**Lower middle class** Supervisory or clerical and junior managerial, administrative and professional	28%
C2	**Skilled working class** Skilled manual workers	21%
D	**Working class** Semi and unskilled manual workers	18%
E	**Those at the lowest levels of subsistence** State pensioners or widows (no other earnings), causal or lowest grade workers	10%

4. Scoring the Patient Activation Measure

To calculate PAM scores, add up the responses to the 22 questions. For each 'Strongly disagree' score the person 1, for each 'Disagree' score 2, for each 'Agree' score 3, and for each 'Strongly Agree' score 4. (The exception to this is question 22, which is scored oppositely).

If respondents have given 'Not Applicable' answers, divide their score by the number of items completed and then multiply by 22. Due to concerns about validity, scores were not calculated for respondents who gave eight or more 'Not Applicable' answers.

The table below converts raw scores into a measure of activation.

Raw Score	Activation	Raw Score	Activation	Raw Score	Activation
22	.0	45	35.0	68	59.4
23	7.9	46	35.7	69	61.1
24	12.5	47	36.4	70	62.7
25	15.4	48	37.1	71	64.1
26	17.5	49	37.8	72	65.5
27	19.2	50	38.5	73	66.8
28	20.7	51	39.2	74	68.1
29	22.0	52	40.0	75	69.4
30	23.1	53	40.7	76	70.6
31	24.2	54	41.5	77	71.8
32	25.1	55	42.4	78	73.1
33	26.0	56	43.2	79	74.3
34	26.9	57	44.1	80	75.6
35	27.7	58	45.1	81	77.0
36	28.5	59	46.1	82	78.5
37	29.3	60	47.2	83	80.1
38	30.1	61	48.4	84	82.0
39	30.8	62	49.7	85	84.3
40	31.5	63	51.1	86	87.3
41	32.2	64	52.6	87	92.1
42	32.9	65	54.2	88	100.0
43	33.6	66	56.0		
44	34.3	67	57.7		

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