



Research into Patients' Views and Expectations of
Chiropractic Care – Final Report from the Study

January 2013

Contents

Chapter	Title	Page no.
	Acknowledgements	4
	Executive Summary	5
1	Chapter 1	11
	Introduction	11
1.1	Background	11
1.2	Structure of the Report	12
2	Chapter 2	13
	Methods	13
2.1	Brief Examination of the Literature	13
2.2	Focus Group and Interviews	13
2.3	Profile of the Patients Interviewed	14
2.4	Patient Survey	15
2.5	Recruiting the Chiropractors and Patients	15
2.6	Profile of the Patients Involved in the Survey	17
3	Chapter 3	19
	Initial Experience of Chiropractic Care	19
3.1	Selecting a Chiropractor	19
3.1.1	Reasons for choosing the current chiropractor	19
3.1.2	Changing Chiropractors	20
3.2	Before Seeing the Chiropractor	21
3.3	At the First Consultation	22
3.3.1	Impressions of the Whole Practice	23
3.3.2	Initial Examinations	23
3.4	Providing Information	24
3.4.1	Adverse Effects/Risks and Managing Expectations	24
3.4.2	Cost of Treatments and Fee Structures	24
3.4.3	The Chiropractor's Knowledge and Experience	25
4	Chapter 4	27
	On-Going Treatment	27
4.1	Treatment Duration and Frequency	27
4.2	Reviewing Progress and Involvement in Decisions about Treatment	28
4.3	Referral to Other Agencies/Access to Other Treatments	29
4.4	Self-Management	30
4.5	The Chiropractor's Approach	31
4.6	Reasons for Ceasing Chiropractic Care	31
5	Chapter 5	33
	Benefits and Adverse Effects	33
5.1	Knowledge and Perceptions of the Benefits of Chiropractic Care	33
5.2	Benefits of Treatment	33
5.2.1	Resolving or Improving Specific Health Problems	34
5.2.2	Reduced Pain and Increased Mobility	35
5.2.3	Prevention	36
5.3	Knowledge and Perceptions of Adverse Effects and 'Risks'	37

5.4	Experience of Adverse Effects	38
5.5	Patient Feedback and Complaints	39
6	Chapter 6	41
	Patients' Views on Fitness to Practise	41
6.1	Assuring Chiropractors are 'Fit to Practise'	41
6.1.1	Views from survey respondents about fitness to practice	41
6.2	Continuing Professional Development	43
6.3	The Use of Patient Feedback	44
7	Chapter 7	46
	Conclusions	46
	Appendix 1 National Survey of Chiropractic Patients	49
	Appendix 2 Topic Guide for Focus Groups and Interviews	53

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Executive Summary

Background

The General Chiropractic Council (GCC) is currently reviewing its approach to the revalidation of registrants, and as part of this process wishes to gain a fuller understanding of patients' views of chiropractic care, in particular people's assessment of the risks and benefits of chiropractic treatment, their expectations of chiropractors, and their experience of them. Firefly Research and Evaluation, in partnership with The Department of Health Sciences at the University of York, has been commissioned to carry-out research on this issue, with fieldwork taking place between May and November 2012.

The GCC set out five questions to inform the research. These are:

1. What do patients of chiropractors see as the benefits of receiving chiropractic care?
2. What do patients see as the potential risks of receiving chiropractic care?
3. Has their perception of benefits and risks changed over time? And if so, how?
4. What has influenced their perceptions of the benefits and risks?
5. Once a chiropractor is on the GCC register, what do patients expect will happen to assure an individual chiropractor's continuing fitness to practise?

The results of the research outlined in this report will inform the work on revalidation and will be considered alongside the findings from a separate consultation being undertaken with registrants and their professional bodies

Methods

The methods for this research include:

- A brief examination of existing research and other information about patients' views and expectations of chiropractic, other manual and complementary therapies
- Telephone interviews with chiropractic patients in three locations across the UK, plus one small focus group, using semi-structured topic guides
- A national survey of a sample of chiropractic patients, undertaken through a questionnaire (available in paper based form or electronically).

Through working with colleagues from the GCC, the three localities selected to help recruit patients to the individual telephone interviews and focus group were Cardiff, the Scottish Borders and Mansfield/ Chesterfield. Thirty patients consented to be involved in the research in this way. The majority preferred to be interviewed, thus only one small focus group took place, in the Mansfield/ Chesterfield area. Two contributed through the focus group and 28 were interviewed over the telephone. Findings from this stage of the research were used to help formulate the national questionnaire.

For the national survey, a random sample of 600 chiropractors (drawn from the GCC's database of registrants) was asked to assist by distributing a questionnaire to 10 of their current and former patients. It was hoped that from this sample of 600 around 25% (150) would agree to be involved. However, despite various means of contacting chiropractors, only 47 agreed to take part. Two further approaches were used to overcome this poor response. First, the practices who had agreed to take part were asked to distribute more than 10 questionnaires. Secondly, we contacted an additional sample of 360 chiropractors and of these 21 agreed to take part. A further two chiropractors volunteered to be involved when the British Chiropractic Association (BCA) sent an email out to its members. This resulted in a total of 70 chiropractors who agreed to help to recruit

patients for the survey by distributing 925 survey forms. This approach generated 368 completed questionnaires.

In addition to these approaches, information about the survey was circulated by email to patients registered with the Care Response¹ initiative. 5167 patients registered with 36 Care Response member chiropractors were emailed and 112 patients completed the survey through this route. The Chiropractic Patients Association also informed its members of the survey.

These methods for distributing the national survey resulted in 544 surveys received and these have been analysed within the report in terms of the demographic information requested from participants, including age, gender, ethnicity, locality (e.g. urban/rural), and qualification (as a proxy for social class).

Initial Experiences of Chiropractic Care

The interviews and focus group were an opportunity to explore how and why people selected their chiropractor. The majority said they had chosen their chiropractor because they were local and/or had been recommended by family, friends or their GP. About a third of people looked at information on-line and a small number did some very detailed research through telephoning around and talking to chiropractors, to try and ensure they approached someone with the experience and knowledge that was important to them. A few people based their decision purely on convenience and the location of the chiropractor.

Around a third of the patients who were surveyed said that they had changed their chiropractor at some point in the past, and the main reasons were linked to the patient moving to a new area, finding a chiropractor at a more convenient location or the chiropractor moving away. Forty nine people said that the approach or manner of the chiropractor did not suit them, or the treatment was not benefiting them, but only nine people highlighted what they perceived as poor treatment as the reason for moving to a different chiropractor.

Those involved in the national survey were asked to rate their knowledge of chiropractic prior to treatment on a scale, and the majority rated it towards the lower end of the scale 'I knew very little'. The survey also explored patients' expectations prior to the first consultation and what they experienced in practice, including: general information about chiropractic and possible reactions; what will happen at the first treatment and how long it will last; costs; consent and provision of GP details. Seven questions relating to these issues focused on what patients expected and what happened before they saw the chiropractor. For all these questions over 80% of patients expected these aspects of care to happen and they did happen, which suggests there was a high level of satisfaction with this stage of the 'patient journey'.

Further to this, patients responding to the survey were asked questions relating to the chiropractors' qualifications, experience and any special interests, plus their registration status with the GCC. Fewer respondents expected the chiropractors' experience or special interest to be available compared to their qualifications and registration, but in all cases expectations were exceeded. People interviewed were largely happy with the information that was provided to them (for example, about chiropractic generally and about fee structures). Those interviewed were generally made aware of the qualifications and experience of the chiropractor, and the length of time someone had been in practice was an important issue for many; however, few had any knowledge about the GCC or about registration requirements. Several expressed the opinion that more should be done to raise public awareness of the GCC and its role.

¹ Care Response is supported and promoted by the College of Chiropractors and is now used by a number of chiropractors, osteopaths and physiotherapists throughout the UK and Ireland as a means of routinely collecting patients' reports of outcome and satisfaction during and after chiropractic care.

Almost all of those interviewed said how much they valued the thorough initial discussion/examination they had experienced with their current chiropractor. People said they were asked to provide a full medical history and many were asked questions about their lifestyle, which they felt was very important. Some described receiving no treatment at their initial consultation, but they were happy with this because they felt that thorough assessment was vital. However, very few of those interviewed remembered potential adverse effects being talked about at this stage.

On-going Treatment

The chiropractor's general approach was of primary importance amongst all of those interviewed: people talked in particular about the chiropractor's air of confidence; of having plenty of time for detailed explanation and opportunity to ask questions, and of a friendly and relaxed approach. For many this extended beyond the individual chiropractor and they talked about the way the whole practice had helped to inspire confidence and trust and helped them to relax; this was achieved through welcoming and informative reception staff, and hygienic, professionally presented premises.

Questions were asked of survey respondents and those individually/through the focus group about on-going treatment processes in relation to: duration and frequency of the treatment; reviewing progress and involvement in decisions; referral to other agencies, and self-management.

Duration and frequency of the treatment: Most interviewed people said that the duration and frequency of the treatment was made clear, and that it tended to be an on-going, evolving process - though a couple said a better indication of the number of sessions should be provided at the beginning. The time allowed for consultations was also an important issue for patients surveyed. 99% of the respondents expected that their chiropractor would allow sufficient time for their consultation and this expectation was largely met, with 97% saying that it had happened.

Reviews and involvement in decisions: The vast majority of survey respondents expected to be given time to talk about how they felt between treatments, and discuss any concerns or changes, and mostly these expectations were met. People responding to the survey had slightly lower expectations relating to the agreement of review points but this may tally with the fact that those interviewed were largely happy to trust the chiropractor's judgement about duration and frequency. The majority of people interviewed said that they felt involved in the treatment process, but this was mainly interpreted as being able to ask questions – some said they did not really expect or want to be involved as they were in the hands of a professional whom they trusted to make the right treatment choices.

Referral to other agencies: Survey respondents did not have particularly high expectations that the chiropractor would refer them to other agencies or contact their GP, should this be needed (86%); a significant percentage said this did not happen (63%), but it is not clear whether this relates to the expectation not being delivered or whether a referral was not required. Nobody who was interviewed expressed any concerns about chiropractors' efforts to communicate with GPs or refer on appropriately, and there were examples where chiropractors had used existing test results supplied by GPs before embarking on any treatment. Several had also recommended that the patient should have an X-Ray or MRI scan, and there were examples where these had revealed important issues.

Self-management: A high percentage of survey respondents expected the chiropractor to provide advice on how to manage problems/symptoms between treatment and this expectation was largely met, with 96% of respondents saying they had been given this type of support. All of those interviewed said that they had been provided with information to support self-management, and this was really valued, not least because it could benefit them, but because for some it helped

develop a sense of trust: “He is making an effort to keep me out of the practice, not in it - he’s not using me as a license to print money.”

Benefits and Adverse effects

Those involved in the national survey were asked to rate their knowledge of the benefits of chiropractic on a scale, and the majority (around 60%) felt that they had some knowledge of the benefits of treatment though a significant percentage said they ‘knew very little’.

The vast majority of patients who were surveyed and interviewed said that they had experienced an improvement in the condition or problem which had initially led to them seeking chiropractic treatment, and benefits included reduced pain; increased mobility/dexterity/flexibility, and confidence to self-manage problems. For some people it was also about the prevention of further problems. There were also a number of additional or unexpected benefits, including, for example, improvement to sleep patterns or reductions in medication.

The national survey also asked patients how much they knew about possible adverse reactions to chiropractic treatment before they first saw a chiropractor, and this showed that overall patients’ knowledge about possible adverse reactions was very low. This was reflected in interviews with patients, where almost two thirds of the patients interviewed said that before seeing a chiropractor, they had little or no knowledge of the possible risks or adverse effects of chiropractic treatment, or did not think there were any significant risks, or hadn’t even thought about risks. A few people said that at the point that they sought help from a chiropractor, they were in such pain and distress that they didn’t want to think about any risks or adverse effects, they just wanted help.

Those patients interviewed who had thought about possible risks raised two main issues. The first was being treated by someone who wasn’t properly trained or a registered chiropractor whose practise was poor. The second was a general concern about the implications of manipulating the spine, neck and joints. However, several patients emphasised the importance of keeping ‘risk’ in perspective, in particular understanding that the likelihood of adverse effects will vary with the part of the body being treated and the nature of the treatment; balancing any possible risks against the likely benefits; and setting the possible adverse effects of chiropractic treatment against the risk of alternative treatments such as back surgery or the long term use of prescription painkillers.

Of those surveyed, around 20% of respondents reported that they had had an unexpected or unpleasant reaction to their treatment (e.g. discomfort immediately after treatment), but in most cases people said this was anticipated and they expressed low levels of concern about it. This was similarly the case with those interviewed. Only a very small number of people surveyed or interviewed said they experienced any unanticipated negative effects, and some of these were not related to chiropractic but to other therapies the chiropractor was employing, such as acupuncture.

Patient feedback systems were also explored, and just over three quarters of patients surveyed expected their chiropractic practice to have a system for confidential feedback but only two thirds said that this was the case in their practice. Patient expectations were also low in relation to being given information about how to complain to the GCC, should they need to. This largely corresponded with responses from those interviewed; some said that they had developed an honest and open relationship with their chiropractor and felt that they could raise any concerns directly. Others said that they would be able to find out about the appropriate ways to raise an issue if and when they needed to. Several people commented that where people were unhappy with standards they generally “*voted with their feet*”.

Patients' Views on Fitness to Practice

Patients involved in the national survey were asked to rate their level of agreement with five statements, relating to possible arrangements for ensuring fitness to practise, covering on-going professional development, peer review, independent reassessment and patient feedback. For all five questions there was strong support from at least half of respondents, with the greatest support for regular independent assessment.

Where people were interviewed, views about systems to support and evidence chiropractors' fitness to practice were quite varied; a few patients did not express any particular concerns about the encouragement and monitoring of on-going professional development, for them what was most important was recommendation and reputation, and their direct experience of a professionally run practice. Most people were concerned that chiropractors were registered with the GCC, but as highlighted through earlier questioning about selecting their chiropractor, many were unclear about the GCC and registration requirements and thought that more should be done to improve public awareness of this. Most people felt it was very important that their chiropractor maintain standards of continued professional development though expectations of the nature and extent of this varied, and in how it should be monitored. Several thought that some sort of direct inspection or observation would be the only way to get a real sense of fitness to practice, plus a few people thought that any inspection regime should apply to the whole practice, not just the individual chiropractor. Gathering of patient comments and suggestions was generally thought to be a good idea, and a range of mechanisms for this were suggested. However, reasons for collecting patient views varied amongst those questioned, for example, whilst the majority linked it to practice development, others linked it monitoring and inspection, and a few saw it as an opportunity for people to hear about patients' experiences and thus help to inform choices about which chiropractor to select.

Some people (both those interviewed and those who made comments on the questionnaire) sounded notes of caution in relation to introducing new regimes of monitoring and inspection. For example, people were concerned that systems should not be overly bureaucratic, and that good practice should be positively encouraged *"from the inside"*; a couple were also mindful that new systems would have a cost, which might be passed on to patients.

Conclusions

The main purpose of the study was *"to 'place' a proposed form of revalidation within the context of patients' views of chiropractic – their assessment of its risks and benefits, their expectations of chiropractors and their experience of them"*. In drawing together our conclusions we have focused on this purpose.

Prior to seeing a chiropractor many patients had some knowledge of the potential benefits of chiropractic care. Where their perceptions and understanding had changed, the overwhelming reason for this was their direct, and largely positive, experience of chiropractic treatment. The two main benefits of chiropractic care were reduced pain and increased mobility resulting from resolving or managing a specific health problem. However, many patients described a range of wider benefits and often these had knock-on effects such as improvements in patient's mental well-being. For some patients chiropractic care was seen as a treatment for a specific health problem. However, many saw it as a form of 'maintenance'.

We were very much aware that some chiropractors felt that the brief for the study placed undue emphasis on the risks of chiropractic care. Whilst most patients start out with a low understanding of the possible adverse reactions, their ability to balance the potential risks matures quite quickly. Patients' perceptions of risk had mainly been shaped by the media or general perceptions in society.

At a macro level patients raised two main issues in relation to 'risk': being treated by someone who wasn't properly trained; being treated by a registered chiropractor whose practise was poor. At an individual level patients emphasised the importance of keeping adverse effects or 'risks' in perspective. They often set the possible adverse effects against the risks of alternative treatment. Only a few had experienced an unpleasant or unexpected reaction to treatment, and the majority of these patients were not unduly concerned about this reaction. Chiropractors recognised the need to discuss these issues with patients, but did not want to concern patients unduly.

The study suggests that patients' expectations were being well met. Of the 33 aspects of care that patients were asked to comment on, there were 18 where more than 90% of patients expected this aspect of care to take place. There were a few areas where there was a slight difference between patients' expectations and experiences and four other areas where patients had relatively high expectations but these were not met for a significant proportion of patients.

Finally, we were aware that there is some sensitivity within the profession about asking patients about fitness to practise and topics related to revalidation. It is not the place of this study to recommend any one course of action in relation to revalidation, and so we have attempted to describe patients' views in a neutral way and draw relevant but unbiased conclusions.

The majority of patients felt that a chiropractor's fitness to practise should be routinely checked, but there were differing views about approaches and frequency. There was support for reassessment by an independent assessor, or enabling chiropractors to review their practice with another chiropractor. However, patients were concerned about the chiropractors' time, costs and bureaucratic complexity. Providing patients with information about on-going training and having a practice-level system for patient feedback would help to reassure them that their chiropractor was keeping their skills and knowledge up to date. Lastly, whilst discussions about 'fitness to practise' focus on the individual chiropractors' skills and knowledge, patients take a broader view with many feeling that it should encompass the whole practice.

Chapter 1

Introduction

This report sets out the main findings from the General Chiropractic Council (GCC) commissioned research into the views and expectations of chiropractic patients. In particular it looks at patients' assessment of the risks and benefits of chiropractic treatment, their expectations of chiropractors, and their experience of them. The GCC is currently reviewing its approach to the revalidation of registrants, and as part of this process wished to gain a fuller understanding of patients' views of the risks, benefits and expectations of chiropractic care. The results of this research will inform this work and will be considered alongside the findings from a separate consultation being undertaken with registrants, their professional bodies and a range of other stakeholders.

The report explores patients' expectations and experiences at different stages in their chiropractic care and treatment 'journey', from selecting a chiropractor to on-going treatment. It describes the benefits which patients feel they have gained from having chiropractic treatment as well as the adverse effects patients may have experienced and considers their attitudes to both risk and benefits. It also examines patients' views about 'fitness to practise' in particular what would reassure them that their chiropractor is keeping their knowledge and skills up to date.

Specifically, the GCC set out five questions to inform the research. These are:

- What do patients of chiropractors see as the benefits of receiving chiropractic care?
- What do patients see as the potential risks of receiving chiropractic care?
- Has their perception of benefits and risks changed over time? And if so, how?
- What has influenced their perceptions of the benefits and risks?
- Once a chiropractor is on the GCC register, what do patients expect will happen to assure an individual chiropractor's continuing fitness to practise?

1.1 Background

There is a growing body of research into patients' expectations and experiences (including adverse effects) of complementary medicines. The OPEn Study² which was funded by the General Osteopathic Council, grouped patients' expectations into five areas: clinic environment; professionalism; treatment; relationship; and outcomes. It found that there was a very high level of satisfaction amongst patients seeing osteopaths working in private practice and most of the most widely held expectations were being delivered well. However, the study did identify some gaps between expectations and delivery of care, which could have a negative effect on outcomes of care and suggested that these gaps could be reduced by improving care and/or managing expectations better.

There has been relatively little work on the expectations of patients of chiropractic. One study conducted in Sweden³ found that whilst patients and chiropractors had similar expectations in relation to key areas such as the chiropractor diagnosing and explaining the nature of the

2 Leach J, Cross V, Fawkes C, Mandy A, Hankins M, Fiske A, Bottomley L, Moore A (2011) *Investigating osteopathic patients' expectations of osteopathic care: the OPEn project*. University of Brighton, Brighton <http://www.osteopathy.org.uk/resources/research/Osteopathic-Patient-Expectations-OPEn-study/>

3 Sigrell H (2002) Expectations of chiropractic treatment: What are the expectations of new patients consulting a chiropractor, and do chiropractors and patients have similar expectations? *Journal of Manipulative & Physiological Therapeutics*. 2002;25: 300-5.

problems to the patients, there were other important areas where expectations differed. In particular, patients were more likely than their chiropractor to expect a rapid (i.e. within one to two treatments) improvement in their condition. They were also more likely to expect to be given advice about how to manage their problem and exercises to do between treatments. Interestingly, the OPEn Study highlighted this as an area where the level of unmet positive expectation was high.

The OPEn Study also explored patients' expectations and experiences in relation to the benefits, risks and side effects of osteopathic treatment. It highlighted a number of priorities for the profession and the regulator to consider. Many of these related to the overall 'customer experience' but others were concerned with the therapeutic process and included the importance of "*informing patients about what to expect in relation to treatment and outcomes including side effects*". Research in the field of acupuncture⁴ has shown that whilst acupuncture treatment is associated with a range of adverse effects these are rarely serious and are not sufficient to prevent most patients seeking further acupuncture. A Dutch study⁵ into the benefits and risks of chiropractic care for neck pain also showed that adverse effects are rarely severe in nature and for most patients the benefits outweighed the risks. Two studies⁶ commissioned by the GCC in 2009/10 brought together information from clinical research about the risks of chiropractic, and examined the possible costs of adverse events and sub-optimal outcomes. They concluded that 'sub-optimal outcomes' were of more concern (and had greater cost implications) than significant adverse events.

Whilst much can be learned from these and other studies, both from their direct work with patients and the wider literature reviews, the GCC identified that a gap remains in relation to UK chiropractic patients' views and expectations.

1.2 Structure of the Report

The report begins with an overview of the methods used (Chapter 2). In Chapter 3 we consider patients' initial experience of chiropractic care, including selecting their chiropractor and the first consultation. Chapter 4 looks at on-going treatment and Chapter 5 discusses the benefits and adverse effects of treatment. In Chapter 6 we consider patients' views on fitness to practice and the conclusions from the research are set out in Chapter 7.

The report draws on both qualitative interviews and one focus group with patients, and a national survey. Throughout we have tried to make clear which source our findings are based on. For brevity, where we refer to the interviews, this includes the findings from the focus group. The report also contains a number of tables showing the results of the national survey. Some patients chose not to answer some questions or indicated that they were not applicable and these are shown in the columns headed 'n/a'.

4 MacPherson H, Scullion A, Thomas KJ, Walters S (2004). Patient reports of adverse events associated with acupuncture treatment: a prospective national survey *Quality and Safety in Health Care* 2004;13:349–355

5 Rubinstein SM, Leboeuf-Yde C, Knol DL, de Koekkoek TE, et al. (2007). The Benefits Outweigh the Risks for Patients Undergoing Chiropractic Care for Neck Pain: A Prospective, Multicenter, Cohort Study. *Journal of Manipulative and Physiological Therapeutics* 30(6):408-418,

6 European Economics for the GCC: (8 February 2010) Report to the General Chiropractic Council and (9 August 2010) Counterfactual for Revalidation – Report to the General Chiropractic Council

Chapter 2

Methods

The study, which began in May 2012 had four main stages:

- A brief examination of existing research and other information about patients' views and expectations of chiropractic, other manual and complementary therapies
- Focus groups and telephone interviews with chiropractic patients in three locations across the UK, using semi-structured topic guides, which took place between May and July
- A national survey of a sample of chiropractic patients, was undertaken after the focus groups and interviews had been completed
- Analysis and preparation of the final report.

It was approved by the University of York, Department of Health Sciences Research Governance Committee.

2.1 Brief Examination of the Literature

Drawing on earlier work by the GCC, the evaluation team undertook a brief examination of existing key research and other information about patients' views and expectations of chiropractic, other manual and complementary therapies. This was used to inform the content of research instruments (e.g. focus group/interview topic guides, the national survey) and how the fieldwork is conducted, and has also been used to set the findings from the proposed research in a wider context (see Chapter 1).

2.2 Focus Group and Interviews

Working with colleagues from the GCC, three areas were chosen for this stage of the study to reflect different types of geography/communities i.e. a rural area (Scottish Borders), town and country (Mansfield and Chesterfield plus surrounding area) and urban (central Cardiff). We then contacted all the chiropractors in Mansfield/Chesterfield and the Scottish Borders, and a sample of chiropractors in Cardiff, to invite them to be involved in the study.

The chiropractors were first contacted by email, the non-responders being followed up by letter two weeks later. Those who did not respond to the letter were then contacted by phone. Even after these steps, the number of responses from Cardiff was particularly low and so we were concerned that urban based practices would be under represented. It was therefore decided to contact a second group of chiropractors in Cardiff and, as an 'insurance policy', contact a sample of chiropractors in North West London. The second group from Cardiff and the London group were only emailed. As the table shows, we received no response at all from 46% (17) and a third (12) declined to take part for a variety of reasons, including a few who were no longer practising. A few explicitly said that their reason for not participating was that they were unhappy with the focus of the study, in particular they were concerned that the terms of reference for the study focused too much on 'risks'.

Table 1 sets out the number of chiropractors contacted and those who agreed to assist the research:

TABLE 1: CHIROPRACTORS CONTACTED/INVOLVED IN EACH AREA

	Number contacted	Agreed to help	Declined	No response
Cardiff	11	3	5	3
Cardiff (2nd group)	9			9
Mansfield/Chesterfield	11	5	2	4
Scottish Borders	6	4	1	1
London	20	2	2	16
Total	37	12	8	17

The chiropractors were asked to assist with the study by inviting up to 10 of their current and former patients (including as far as possible of mixed age, gender, ethnicity and condition or disability) to take part in either a focus group or a telephone/face to face interview. For current patients each chiropractor involved was asked to pass on to the patients the written information about the study at the end of their consultation. They were also asked, if possible, to post information about the study to a few former patients, who ceased treatment at least a month previously. Patients willing to be involved in the study returned their consent/reply form to the research team in a prepaid envelope.

2.3 Profile of the Patients Interviewed

Thirty patients from the initial three areas consented to be involved in the research, the majority of whom preferred to be interviewed. Twenty eight were interviewed over the telephone and two contributed through a small focus group, which took place in the Mansfield/ Chesterfield area. (The Topic Guide for the interviews and Focus Groups is included in Appendix 2). No patients were recruited through the two London practices who agreed to be involved. Table 2 shows that the participants who were involved were fairly evenly spread across the three areas and also across the age ranges and between men and women. The participants described themselves as White British, with the exception of one person of Chinese ethnicity.

TABLE 2: DEMOGRAPHIC PROFILE OF PARTICIPANTS

	female				male			Total
	17	25-50	51-64	65+	25-50	51-64	65+	
Cardiff		2	3		3	1		9
Mansfield/Chesterfield	1	3	1	1		2	1	9
Scottish Borders		2	2	2	1	1	4	12
Grand Total	1	7	6	3	4	4	5	30

Participants were asked if they had used other manual therapies (e.g. physiotherapy, osteopathy) or chiropractic before their recent course of treatment. In answering the question some patients explained that they had also had other types of treatment. Table 3 shows that 60% had had physiotherapy treatment (both NHS and private) and 20% had seen an osteopath. Over a quarter

of participants had gone directly to a chiropractor whilst 43% had had one other type of treatment, 20% two other types of treatment and 10% three other types of treatment.

TABLE 3: OTHER TREATMENTS

Therapy/Intervention	n=
Acupuncture	1
GP consultations	3
Homeopathy	1
Massage	1
Osteopath	6
Physiotherapy	18
Reflexology	1
Sports massage	1

The focus group and interviews were used to explore patients' views and expectations of chiropractic, and their expectations and understanding of how chiropractors maintain their professional knowledge and fitness to practise. They were recorded and transcribed in the form of detailed notes and quotes (rather than verbatim transcription) and then analysed thematically. In addition, the information gained was used to shape the national survey of chiropractic patients.

2.4 Patient Survey

The first draft of the questionnaire to be used in the national survey was developed by drawing on:

- The findings from the interviews and focus group
- Key literature about patients' expectations and experiences of manual therapies
- The GCC Code of Practice and Standard of Proficiency.

The core of the questionnaire focused on patients' expectations and experience of chiropractic care and treatment at different stages in their contact with the chiropractor. However, drawing on the findings from the interviews we also asked patients directly about benefits, adverse effects and what arrangements/systems would reassure them that their chiropractor was keeping their knowledge and skills up to date.

Framing the core questions about expectations and experiences in a way that made sense to patients but did not result in the questionnaire becoming very lengthy was challenging. We tested the first draft of the questionnaire with a small number of patients who had taken part in the interviews and volunteered to assist us in this stage. Building on their comments and following discussions with colleagues at the GCC and within the research team, we developed a second draft of the questionnaire which was then tested with a sample of patients from a local chiropractic practice. Following this second pilot, the final version of the questionnaire was developed and agreed with colleagues at the GCC. A copy of the questionnaire is attached in Appendix A.

2.5 Recruiting the Chiropractors and Patients

The plan for the study envisaged that a random sample of 600 chiropractors, drawn from the GCC's database of registrants, would be asked to assist with the national survey by distributing the questionnaire to 10 of their current and former patients. It was hoped that from the 600 contacted around 25% or approximately 150 chiropractors would agree to be involved. The first sample of 600 chiropractors was initially contacted by post in the hope that this might achieve a

better response rate. This was then followed up with an email reminder ten days later. Of this sample 47 (7.8%) agreed to take part, 15 (2.5%) declined and there was no response from 536 (89.3%).

Two approaches were used to try and overcome this poor response. Firstly the practices who had agreed to take part were asked if they would be willing to distribute more than 10 questionnaires and a number agreed to do so. We then contacted (by email) an additional sample of 360 chiropractors and of these 21 agreed to take part. A further two chiropractors volunteered to be involved when the British Chiropractic Association (BCA) sent an email out to its members. This meant that a total of 70 chiropractors agreed to help to recruit patients for the survey by distributing 925 survey forms. This approach generated 368 completed questionnaires. The information sheet accompanying the survey included a URL link to the internet version and 32 patients completed it this way. After the survey was sent to the chiropractors two informed the study team that they were unwilling to distribute the survey as they were unhappy about the wording or form of some of the questions.

In addition to these two approaches and with the consent of their practices, information about the survey was circulated by email to patients of chiropractors using the Care Response system. Care Response has been developed by chiropractors Jonathan Field and Mark Christensen to assist in the collection of patients' reports of outcome and satisfaction during and after care. It has been used routinely in the Back2Health clinic group since 2002. The system is supported and promoted by the College of Chiropractors and is now used by a number of chiropractors, osteopaths and physiotherapists throughout the UK and Ireland. 3742 patients (46% men, 54% women) registered with 36 chiropractors using Care Response were emailed; 112 patients completed the survey through this route. 22 chiropractors declined to have their patients contacted either because they did not want their patients to be bothered with emails or did not wish to be involved with the study themselves. The Chiropractic Patients Association also informed its members of the survey and 27 completed the internet survey.

Tables 4 shows the outcome of the recruitment in more detail for each of the UK countries.

TABLE 4 RECRUITMENT AND RESPONSE RATES

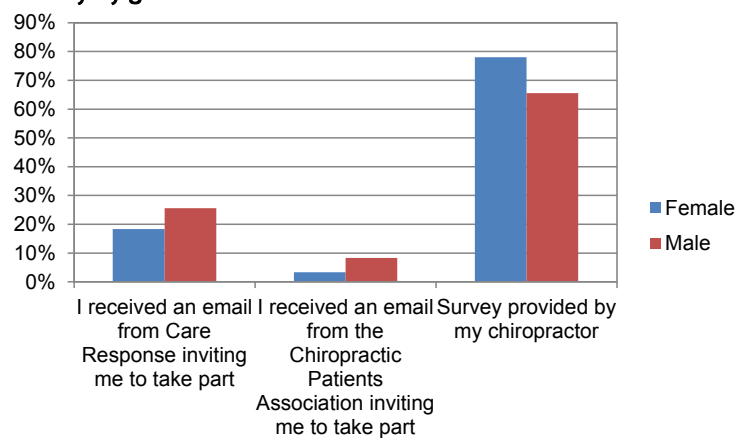
Country	Recruitment				Response		
	All chiroprac's	Sample from Country	Nos. agreeing to be involved	Total qqs circulated	Survey responses via chiroprac's	Survey responses via other routes	Overall
England	2371 (87.1%)	840 (87.4%)	59 (84.3%)	925 (86.0%)	345 (86.0%)	141 (98.6%)	486 (89.3%)
Islands	10 (0.4%)	2 (0.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Northern Ireland	41 (1.5%)	21 (2.2%)	2 (2.9%)	20 (1.9%)	8 (2.0%)	0 (0.0%)	8 (1.5%)
Scotland	168 (6.2%)	56 (5.8%)	3 (4.3%)	50 (4.7%)	12 (3.0%)	1 (0.7%)	13 (2.4%)
Wales	133 (4.9%)	42 (4.4%)	6 (8.6%)	80 (7.4%)	28 (7.0%)	0 (0.0%)	28 (5.1%)
n/a	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	8 (2.0%)	1 (0.7%)	9 (1.7%)
Grand Total	2723	961	70	1075	401	143	544

Note: percentages are of the total in that column of the table.

The response rates from the patients was generally good with overall 37% of the questionnaires sent to chiropractors returned in paper form or on-line. However, it is important to sound a note of caution in terms of how representative the patients involved in this study are of all patients who seek chiropractic care. The nature of this study means that most of the patients who contributed are either currently receiving treatment or have had on-going chiropractic care in the recent past. Those patients who ceased chiropractic care after a small number of treatments, perhaps because they were unhappy with their care may well be under-represented.

Of the 544 surveys received 360 were from women, 180 from men and 4 did not give their gender. Figure 1 shows that a slightly higher proportion of male respondents than female completed the survey on-line.

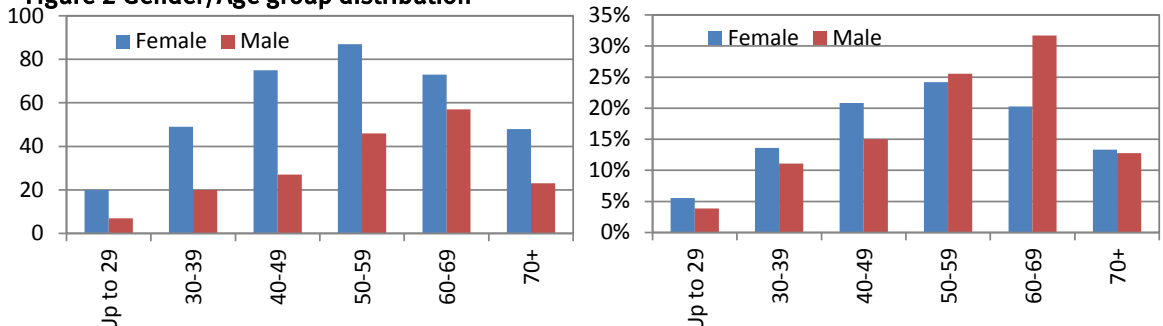
Figure 1 Response to survey by gender



2.6 Profile of the Patients Involved in the Survey

Figure 2 shows the gender and age group breakdown of survey respondents. Twice as many women than men completed the survey. The age profile for women and men is also different, with women following a 'near normal' distribution whilst 70% of the male participants were aged 50 and over. There is some research evidence⁷ that the overall population of chiropractic patients is fairly even split between women and men, and certainly the Care Response database is split 46% men and 54%. It is therefore likely that the higher response from women reflect their greater willingness to complete surveys.

Figure 2 Gender/Age group distribution



⁷ Pedersen P, Breen A C (1994) An overview of European chiropractic practice. *Journal of Manipulative Physiological Therapies*. 1994 May;17(4):228-37.

Although the chiropractors who volunteered to be involved were spread across all four countries of the UK and across cities, towns and rural areas, fewer than 10% of the participants described where they lived as being a City/Urban area (see Table 5). Nearly 50% said they lived in Town or suburb and 40% in a village/rural area. As there is no national data about the geographical spread of chiropractic patients we are unable to judge how representative those completing the survey are of chiropractic patients in general. In relation to ethnicity, less than 5% of respondents described themselves as anything other than 'white British', and only 8% of the respondents said that they had a disability.

TABLE 5 AREAS RESPONDENTS LIVE IN

Description of area participants live in	n=	% of total
City/Urban area	50	9%
Town or suburb	267	49%
Village/Rural area	217	40%
n/a	10	2%
Grand Total	544	

The survey also asked people about their highest level of educational qualification. This question was included as a proxy for social class (as there is a known correlation between level of education and income) but also because a person's level of education may influence the expectations and perceptions. Table 6 shows the highest level of qualification of respondents. As can be seen from the table, 48% of the respondents had either first degrees or second degrees. This compares with 30% of the UK working age population with a first degree or higher⁸; this proportion is likely to be reduced further if those of retirement age were included.

TABLE 6 QUALIFICATIONS

Highest level of academic qualification	n=	% of total
Master's Degree, PhD, Post graduate certificate or NVQ 5	79	15%
BA or BSc degree or equivalent (e.g. NVQ 4, BTEC diploma, City and Guilds level 3+, nursing or teaching qualification)	181	33%
A levels or equivalent (e.g. NVQ 2-3, BTEC certificate, City and Guilds crafts)	104	19%
GCSE or equivalent (e.g. O Level, CSE, NVQ1)	95	17%
Various other qualifications	30	6%
No academic qualifications	38	7%
n/a	17	3%
Grand Total	544	

⁸ Office for National Statistics 2012 Census Population of working age by level of highest qualification, second quarter 2009

Chapter 3

Initial Experience of Chiropractic Care

This chapter looks at the reasons behind people's choice of chiropractor and if they changed chiropractor, why they did so. It also describes patients' initial experiences of chiropractic care, including the information they were given prior to treatment and their first consultation. The individual interviews/focus group and survey explored slightly different questions concerning initial experiences (depending on where a more qualitative or quantitative response was a priority). The source of the findings is made clear in the text.

3.1 Selecting a Chiropractor

There are potentially a number of factors that might influence people's choice of particular chiropractor and so this was explored in the individual interviews. The reasons for changing chiropractor were examined in both the survey and the interviews.

3.1.1 Reasons for choosing the current chiropractor

People involved in the individual interviews were asked to describe the reasons why they selected the chiropractor who is currently treating them. Over half said that it was because they were local and hence easily accessible, and just under half had made the choice following recommendation by various people, including family, friends and their GP. Three participants had deliberately tried various chiropractors before finding one they were happy with and four had investigated different chiropractors via their website or by visiting the practice; only one participant had chosen their chiropractor for price reasons.

A few who did not have access to personal recommendations said it would be helpful if patients' experiences of individual chiropractors could be made available in some way; however, a couple expressed caution about this as it could be distorting or misleading. Some people described how they had to be encouraged to go by others, because they were initially wary:

"I wasn't the greatest believer in it, put it like that....I was a bit sceptical, but I have been very impressed."

Location was a high priority for many patients, with easy access from home or work; however, one person who was seeking a chiropractor with a specific speciality chose to travel 2 hours for their treatments. One person commented that there are 3-4 chiropractors in the same practice and that this gave her more reassurance compared to a lone chiropractor. Two people had selected their chiropractor purely by chance, because they happened to drive or walk past the practice and it sparked their interest.

About a third of people had taken further steps to ascertain chiropractors' qualifications and experience before they made the initial appointment, largely through looking at websites. One person commented that information on the web made it much easier to get a sense of the chiropractor and practice compared to when they selected chiropractors in the past: *"It is not such a leap of faith now."*

A couple of people mentioned that they had checked the chiropractor's GCC registration, though the vast majority had not done this and many said that they were not familiar with the GCC or its role. Several people commented that information about the GCC should be more widely available and that they would have checked about registration had they known.

The interviews suggested that people had a varying understanding of what chiropractic care involved when they opted for this treatment. Some did not really know what to expect:

“I was a bit naïve. I thought it would be a bit along the lines of physiotherapy - maybe a bit more hands on, but it was completely different to what I expected”.

Some said they were conscious that there was some variation in the ‘quality’ of chiropractors and also in the different approaches they use, so they made efforts to phone around and talk to chiropractors in some depth about their qualifications, experience and approach. In one case this initial telephone discussion had made a huge impact, as the chiropractor was aware of the condition the person described, which was relatively rare and had not been recognised by his medical practitioners: *“[On the telephone] he said ‘I know the problem I understand what happens here’. As far as I was concerned I was 50% of the way there.”* In some instances people had done some research on their current chiropractor because they had had negative experiences of chiropractors in the past, but this was largely due to unhappiness with their manner/approach, ineffectiveness or perceived lack of experience and not to any adverse effects. *“It’s not ‘in for 10 minutes, crack you and send you out’ which seems to be the common kind of chiropractor that’s about. His approach is very holistic and so when I read about him I thought I’d like to try him”.*

3.1.2 Changing Chiropractors

Around a third (n=180) of the patients responding to the survey said that they had changed their chiropractor at some point in the past. The reasons they gave for changing are shown in Table 7 (some people provided more than one reason):

TABLE 7 REASONS FOR CHANGING CHIROPRACTOR

Reason/s Given	n=	% of those who changed
Chiropractor moved	54	30%
Patient moved	48	27%
Chiropractor’s approach	36	20%
Convenience	32	18%
No benefit	13	7%
Treatment concern	9	5%
Cost	7	4%
Urgent care needed	4	2%

The table shows that the main reasons were linked to the patient moving to a new area, finding a chiropractor at a more convenient location or the chiropractor moving away. A significant number gave reasons relating to the approach of the chiropractor, and these are summarised as follows:

- 9 did not like the technique employed, for example, finding it too ‘aggressive’.
- 9 expressed a generalised lack of confidence in the chiropractor or did not feel relaxed with them or felt unable to discuss issues fully
- 7 felt that the chiropractor had ‘run out of ideas’ or had too narrow a set of treatment or care options for their particular problem
- 5 people were unhappy with timings/frequency, including being unable to get an appointment urgently; frequent delays to appointment times due to previous patients running overtime; very short appointment times, or too frequent sessions. For the latter two issues these concerns were linked to costs/affordability.

- 1 person said they were linked to a practice where they often saw a different chiropractor, and they did not like the lack of continuity.

Nine people highlighted what they perceived as poor treatment as the reason for moving chiropractor, and this was associated with pain/discomfort.

Some of those interviewed had also changed chiropractor, and, as above, in most of these instances it was because their usual chiropractor had moved away. In a very small number of cases it was because they were not happy with their usual chiropractor, or because they had used a different chiropractor whilst their usual chiropractor was on holiday, and had found the replacement to be more effective.

3.2 Before Seeing the Chiropractor

The national survey asked patients how much they knew (on a scale of 1 to 5) about what chiropractic treatment involved before they first saw a chiropractor. Most patients had little idea of what the treatment involved with around 60% rating their knowledge 1 or 2 and less than 15% saying that they knew a lot or quite a lot (i.e. a rating of 4 or 5)

The survey also explored patients' expectations of a number of important aspects of chiropractic care and what they experienced in practice. Seven questions focused on what they expected and what happened before they saw the chiropractor. For each question patients were asked whether they 'Expected' the service and then 'Did it happen'. Table 8 below summarises the responses. For all the questions over 80% of patients expected these aspects of care to happen and they did so, which suggests there was a high level of satisfaction with this stage of the 'patient journey'. This set of questions also highlighted two areas (completion of a consent form and providing the patient's General Practitioner's name and contact details) where what actually happened exceeded patients' expectations.

TABLE 8 RESPONSES TO 'BEFORE SEEING THE CHIROPRACTOR' QUESTIONS

Questions	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q11. Before Seeing the Chiropractor I expect to be given general information about chiropractic treatment and what it involves	91%	8%	1%	92%	7%	1%
Q12. Before Seeing the Chiropractor I expect to be given general information about possible reactions (both positive and negative) to chiropractic treatment	82%	15%	3%	82%	15%	3%
Q13. Before Seeing the Chiropractor I expect to be given information about what will happen at my first consultation	91%	7%	2%	91%	7%	2%
Q14. Before Seeing the Chiropractor I expect to be told about the cost of treatments	97%	2%	1%	95%	4%	1%
Q15. Before Seeing the Chiropractor I expect to be told how long the first consultation was likely to last	90%	8%	1%	91%	7%	2%
Q16. Before Seeing the Chiropractor I expect to fill-in and sign a consent form for the first consultation	83%	13%	3%	90%	6%	4%
Q17. Before Seeing the Chiropractor I expect to provide my General Practitioner's name and contact details	83%	15%	2%	91%	6%	3%

Amongst those interviewed, a very small number were sent general information about chiropractic care in the post, prior to their initial consultation, but in most cases people were provided with information leaflets at their first visit to the practice.

3.3 At the First Consultation

Ten questions within the national survey explored patients' experience at the first consultation and the responses to these questions are shown in Table 9. Again, in most areas patients' expectations were being met. However, there were a few questions which revealed some modest disparity between what patients expected and what actually happened. In particular, 87% of patients expected that at the first consultation the chiropractor would talk to them about any possible adverse reactions to the treatment but a slightly lower proportion (83%) said this actually occurred. Likewise, 86% of respondents expected their chiropractor to explain what the cost of the agreed treatment plan would be, whereas only 80% said this had happened. A number of patients (14%) did not respond to question 22 (explaining the need for further investigations) or said that it did not occur but many noted that this was because it had not been relevant to their treatment.

TABLE 9 RESPONSES TO 'AT THE FIRST CONSULTATION' QUESTIONS

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q18. At the First Consultation I expect to be given time to tell the chiropractor about my problem and how it was affecting me	99%	0%	1%	99%	0%	1%
Q19. At the First Consultation I expect the chiropractor to take a detailed account of my personal case history	96%	3%	1%	96%	1%	2%
Q20. At the First Consultation I expect to be given a gown and/or towels to cover up if I had to undress	83%	12%	4%	84%	9%	7%
Q21. At the First Consultation I expect to be able to undress and dress in privacy	90%	6%	5%	88%	5%	7%
Q22. At the First Consultation I expect the chiropractor to explain why any further investigations (e.g. X-Rays) were necessary and any risks associated with them	72%	18%	10%	67%	20%	14%
Q23. At the First Consultation I expect the chiropractor to give me a diagnosis or rationale for my care	93%	5%	2%	95%	3%	3%
Q24. At the First Consultation I expect the chiropractor to explain what treatment I will need (e.g. the type, frequency and duration of treatment)	97%	2%	1%	94%	4%	2%
Q25. At the First Consultation I expect the chiropractor to talk to me about any possible adverse reactions to the treatment	87%	9%	3%	83%	13%	3%
Q26. At the First Consultation I expect the chiropractor to talk to me about the likely success of the treatment	93%	6%	2%	91%	7%	2%

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q27. At the First Consultation I expect the chiropractor to explain what the cost of the agreed treatment plan would be	86%	12%	3%	80%	17%	3%
Q28. At the First Consultation I expect the chiropractor to give me time to ask questions about the proposed treatment plan	96%	3%	1%	94%	4%	2%

It was possible through individual interviews and the focus group to gain more detailed descriptions of patients' experience of their first consultations, including impressions of the whole practice, their experience of initial examinations, information provided on potential adverse effects/risks, and their views on treatment costs/fee structures.

3-3.1 Impressions of the Whole Practice

Amongst those interviewed individually or participating in the focus group, several people spoke about how important their initial impression of the practice was, in particular that it was hygienic and had a 'professional' image: *"smart presentation and clean, quality decor."* Peoples' overall impressions were also affected by members of staff other than the chiropractor, and they commented on how much they valued professional and friendly receptionists. A number of people also spoke about the importance of the practice feeling *"friendly"* and this contributed to helping them feel relaxed: *"He just makes you feel like a family friend, he makes you that welcome - which is nice when you go somewhere like that 'cos when you first go you don't know what to expect."* However, there were personal differences in how people wanted this tone to be set, for example one young patient interviewed said how the people at the practice had become *"...my friends as well...Even if you have a problem in your own personal life you go in there and they sit you down and listen to you, and you have a cup of tea or something."* ...where another woman commented on how she valued the practice being *"friendly and pleasant but not over-friendly"*.

3-3.2 Initial Examinations

Almost all of those interviewed said how much they valued the thorough initial examination they had experienced with their current chiropractor. People said they were asked to provide a full medical history/GP contact details and many were asked questions about their lifestyle. Some described receiving no treatment at their initial consultation, but they were happy with this because they felt that thorough assessment was vital. It was frequently noted that the assessment they received was far more detailed than ones experienced through more 'mainstream' medical channels. At this stage in particular people wanted to have an honest discussion with the chiropractor, to be able to ask questions and feel listened to.

"He took time to listen to what I was trying to tell him. I think that was one of the main differences from going to my GP. My GP insisted the pain was such and such and I tried to tell him it wasn't. I think that was one of the best things about it – he actually listened to what I was saying".

People also valued having things clearly explained, and many said how useful it was that the chiropractors used models and/or diagrams to illustrate what was going on in the body:

"His willingness to explain what was going on, what the nature of the problem was and to try and put it in layman's terms".

The general manner of the chiropractor was also commented on as being particularly important at this early stage, in helping people feel at ease and induce relaxation.

“He explained what can happen, how people end up with problems. I explained the sort of work I do and my lifestyle. I found that he had a very quiet way of explaining things that did inspire confidence and I got to know more over time.”

No issues were raised in connection with people feeling they were not treated with dignity and respect.

3.4 Providing Information

3.4.1 Adverse Effects/Risks and Managing Expectations

Whilst the survey suggested that information about possible adverse reactions to the treatment is one of the areas where patients expectations are not being fully met, the interviews reveal that patients' attitudes to being given information on this topic are quite complex. A very small number could recall this being talked about; some people said they could not remember as it was quite a long time ago; others said that it may well have been mentioned in the consent form they signed but they could not recall this. Some said very clearly that they did not think there was any mention of risk by the chiropractor and a few reflected on whether they might have 'forgotten' this because they did not want to hear about it:

“If they did [describe risks] I was not interested in hearing it - I remember now when my chiropractor was dealing with a problem with my neck and he said ‘If you could just stay quiet for a bit, this could be dangerous’. And I thought ‘Ooh, I don’t want to hear that.’ So it might be that they told me [about risks] but that I chose not to hear.”

Some of those interviewed said they would have valued a more open conversation about potential risks in the early stages and have a chance to ask questions about this. People also valued straightforward talking and about what impact the treatment might have: *“We’ll never fix you but we can make your life easier. That’s what I like about him, his honesty.”*

Those in the focus group expressed concern that some people may have unrealistic expectations of chiropractic and expect a 'quick fix', so there should be honest information available making clear that the treatment can take time and may not be effective. They felt that this was especially important as people are paying privately for treatment and may be less motivated to give the treatment a chance to work, because of the cost: *“It should be pointed out that it is a series of treatments....People think that one should be sufficient and it needs to be said that one is not really any good. It may relieve things a bit but it is not going to sort things out.”*

Perceptions and experiences of any adverse effects and risks are explored more fully in Chapter 5.

3.4.2 Cost of Treatments and Fee Structures

The survey suggested that information about the costs of the treatment plan is one of the areas where patients' expectations are not being fully met. By contrast, almost everyone interviewed said the fee structure was clearly explained or described in leaflets. One person said their chiropractor offered an 'affordability' package, which as a young person on a low income she really appreciated.

A few patients described how their chiropractor had an awareness that cost could be an issue for people: for example - one noted that if her chiropractor has a patient with a chronic problem which perhaps needs two short treatments a week for a while, she will often only charge for one treatment; *“The chiropractor suggests when it would be advisable to go back but there seems to be an awareness that financially that might not be feasible for you.”* Another described how on every patient's birthday her chiropractor gives them a £10 off voucher and patients have the option to pay for 6 or 10 treatments in advance and get 10% or 15% off respectively - also, if he feels that he hasn't achieved what he set out to do in a treatment, he will give a free treatment.

Some described what they felt was bad practice, for example, one person talked about their previous experience of a large city practice where he felt that income was the primary concern and this affected the treatment style; *“It was like a meat factory – in the door bang bang....the best practices I’ve been to are laid back but efficient”*. The same person had a friend who had been charged almost £1000 for a lot of treatments in a short period, with only minimal benefit; he emphasised how important it is for chiropractors to treat people as individuals and not just tell everyone that they need a set block of treatments. A couple of people also commented that they did not approve of chiropractors who have people on ‘standing orders’ as they felt that treatment should be more individualised. The issue of costs links to the duration and frequency of treatments and this is described in 4.1.

3.4.3 **The Chiropractor’s Knowledge and Experience**

The patient survey asked three questions related to the availability of information about chiropractors’ knowledge and experience. These covered the chiropractor’s qualifications and registration; their experience; and special interests and additional skills. As Table 10 shows, for all three questions, what happened in practice exceeded patients expectations.

TABLE 10

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q36. I expect that information about the chiropractor's qualifications and registration will be displayed in the clinic/available in leaflets/included on the practice website	90%	8%	2%	95%	4%	2%
Q37. I expect that information about the chiropractor's experience (e.g. length of time in practice) will be displayed in the clinic/available in leaflets/included on the practices website	76%	22%	3%	82%	13%	6%
Q38. I expect that information about the chiropractor's special interests or additional skills (e.g. soft tissue massage) will be displayed in the clinic/available in leaflets/included on the practice website	69%	26%	5%	75%	17%	9%

The majority of those interviewed said that their chiropractor’s qualifications were clearly displayed on the wall of the practice, and some had also noted this on the practice website. The majority said that their chiropractor also told them about their qualifications and experience and for many it was important for them to know that their chiropractor had experience of treating similar problems successfully. *“It’s a type of therapy that can make you feel quite vulnerable and you need to know you are in a safe pair of hands”*. Two people interviewed said that their chiropractor was referred to as ‘Doctor’ or ‘Doctor of Chiropractic’ but they were unclear about what this meant e.g. whether they were medically qualified.

The length of time someone had been in practice was an important issue for a number of people, especially where people had had negative experiences in the past and this had been associated with inexperienced chiropractors. However, there were also examples of more recently qualified chiropractors where patients were very happy with the service they received. A couple of people commented that seeing other patients at the practice and talking to them in the waiting room also helped to build up a sense of confidence in the chiropractor.

Only a very small number of people interviewed could recall that GCC registration was clearly indicated by the chiropractor. A couple of patients commented that chiropractors should be more

proactive about telling people about GCC registration and what this means in practice. Several expressed the opinion that more should be done to raise public awareness of the GCC and its role, and many of those interviewed were unfamiliar with the GCC prior to participating in the research. A couple of people said that there were too many professional bodies and that this could be confusing. Some patients interviewed also seemed unclear about the difference between membership of a professional body and registration with the GCC.

Chapter 4

On-Going Treatment

This chapter explores patients' experiences of on-going treatment in terms of duration and frequency; reviewing progress and involvement in decisions about treatment; referral to other agencies; self-management, and the chiropractors' general approach.

4.1 Treatment Duration and Frequency

In terms of establishing the duration and frequency of treatments, most of those interviewed said that this was an on-going process. The majority regarded this as an understandable and acceptable thing.

"They were very good at explaining – we don't know how long it is going to take but we will do so many sessions and so many times a week and then we will review... until we see how you progress we can't say how long it's going to take - but it will get better."

"Basically after the first treatment she said 'come back in a week to a week and a half and we'll see how it goes from there', which I think was fair enough given the situation."

However, a couple of people said that they would have liked more clarity at the beginning - one described how he would have liked an indication of treatment length at the first or second consultation because it would help him understand the likely cost of treatment plan and the commitment he would need to make as a patient to attending treatments over a number of weeks. He felt the chiropractor should have said something like: *"You'll need at least four treatment and then I'll review the situation."* Another person said: *"He kept saying 'Come back in a week's time' and I was thinking 'Ooh, this is getting very expensive now'.... It would be nice to have that information."*

Several people interviewed had been going to a chiropractor for several years (not always the same one) on a maintenance basis - as one person put it *"for a regular MOT"*. This was generally every few months. However, there were some people interviewed from one practice where there was a different approach to chiropractic treatment: here people are invited to set up a standing order and receive weekly or monthly treatments on an on-going basis. One patient explained that the chiropractor who ran this practice had trained overseas where there was a different approach:

"I see the chiropractor every week....In [country XXX] apparently it's different to here – same as [country YYY]. For chiropractors operating in those countries even for poorer people it's quite normal - like going to the dentist– whereas in this country it's oh I've hurt myself so I'll see one. He's explained that in [country XXX] and [country YYY] it's quite normal to go every month, even every week."

The people interviewed from this practice were all extremely positive about this approach and described a number of benefits beyond their original presenting problem, but many recognised that it could be controversial: *"It's not everyone's cup of tea, I have to admit. I know 3 people I've spoken to who go to other chiropractors and they're not in agreement with how this one operates."*

The survey also asked people about the frequency of their treatment in the past year. Table 11 shows that 80% (n=436) of respondents had monthly or less frequent treatment though a small number (3%, n=15) had very regular treatment, at least once a fortnight.

TABLE 11 FREQUENCY OF TREATMENT

Frequency of treatment	n=	%
None in the past year	21	4
1-6 (Bi-monthly or less frequent)	287	53
7-12 (Bi-monthly to monthly)	149	27
13-26 (up to fortnightly)	65	12
26+ (more than every fortnight)	15	3
n/a	7	1
Grand Total	544	

The time allowed for consultations was also an important issue for patients. 99% of the survey respondents expected that their chiropractor would allow sufficient time for their consultation and this expectation was largely met, with 97% saying that it had happened.

Several of those interviewed also mentioned that they valued not feeling rushed and having plenty of time to ask questions:

“She gives you information as she’s going through it [the treatment] and why she’s doing things as well, so you’re not kept in the dark in any way. Also, not only does she sit you down before you go in and listens to what you’re saying, she does the work with you and then tells you what she’s found, what she’s done and if there is any need for anything else, she’ll tell you”.

This aspect was particularly important for patients who had underlying health problems or disabilities.

4.2 Reviewing Progress and Involvement in Decisions about Treatment

Table 12 shows how the vast majority of survey respondents expected to be given time to talk about how they felt between treatments, and discuss any concerns or changes (Q 29 and 30), and mostly these expectations were met.

TABLE 12 REVIEWING TREATMENT

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q29. I expect to be given time to tell the chiropractor about how I felt after my last treatment, and discuss any problems or concerns	98%	1%	0%	97%	1%	1%
Q30. I expect the chiropractor to ask me if there has been any change in my condition, general health or medication	97%	2%	1%	97%	2%	1%
Q34. I expect the chiropractor to agree with me when my treatment should be reviewed	85%	11%	4%	84%	10%	6%

Several of those interviewed said how much they valued very frequent reviews. For example, one person said that the way their chiropractor started each session was helpful and reassuring, with a review and diagnostic, and establishing alignments, with a summary at the beginning and again at the end.

“I’m quite keen before people start messing you about for somebody to work out what the bloody hell is going on and this was certainly the case with this chiropractor in every session.”

Fewer people responding to the survey expected the chiropractor to agree review points (Q 34), but this may tally with issues concerning frequency of treatment, highlighted in Section 4.1, where people interviewed were largely happy to trust the chiropractor’s judgement about duration and frequency.

In relation to future treatment, 91% of patients expected their chiropractor to talk to them about treatment options but slightly fewer (87%) said this had actually happened (see Table 13).

TABLE 13 FUTURE TREATMENT

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q32. I expect the chiropractor to talk to me about further treatment options	91%	6%	2%	87%	9%	4%
Q33. I expect the chiropractor to allow me time to decide what I wish to do about future treatment	92%	5%	3%	91%	5%	4%

The majority of people interviewed said that they felt involved in the treatment process, but this was mainly interpreted as being able to ask questions. Some people said they did not really expect or want to be involved as they were in the hands of a professional whom they trusted to make the right treatment choices:

“I guess that I just trust that he knows the best thing to do and I’m cringing as I say that as I would never do that with my GP.... It does come down to trust – I don’t always necessarily trust my GP to make a diagnosis and quite often I would expect to be saying what I thought needed to happen – but then I’ve got more knowledge in that field.”

“It’s difficult to be involved because it’s a manipulative therapy that is being done to you and so you can’t be very proactive in the actual treatment – you are essentially giving yourself over to the chiropractor.”

However, a couple said that they would like to be ‘talked through’ the process in more detail during each treatment. In cases where there were complex problems those interviewed generally felt fully involved in considering treatment options including chiropractic and possible referral for tests or other interventions.

4.3 Referral to Other Agencies/Access to Other Treatments

86% of survey respondents expected that their chiropractor would refer them to other agencies or contact their GP, should this be needed, but only 62% said that this had happened. However, 20% of respondents did not complete the second part of this question which may be because an onward referral was not required.

TABLE 14 ONWARD REFERRAL

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q40. I expect that if my problem is not improving with chiropractic treatment and/or I have other health needs, the chiropractor will discuss referral to another healthcare practitioner	86%	8%	6%	62%	18%	20%
Q41. I expect that, if necessary, and with my consent, the chiropractor will contact my GP	87%	10%	4%	62%	20%	18%

Nobody who was interviewed expressed any concerns about chiropractors' efforts to communicate with GPs or refer on appropriately, and there were examples where chiropractors had used existing test results supplied by GPs before embarking on any treatment. Several had also recommended that the patient should have an X-Ray or MRI scan, and there were examples where these had revealed important issues. In a couple of cases the patient had not felt supported or listened to by their GP or NHS practitioner and they had had to self-fund these tests.

At the focus group, one person said that in one of the practices she had used in the past they had the facility to take X-Rays and this had been valuable in checking that she did not have a fracture prior to treatment. In discussion, group members did not feel this facility should be routinely available in chiropractic clinics, as it would be a considerable expense which would have to be passed on to patients and possibly make it unaffordable. They thought that if an X-Ray was really needed then this could be arranged by the GP – however, this then raised questions about whether the GP would be obliged to share the X-Ray with the chiropractor, and they felt that this would be useful to know.

Some people had experienced other forms of therapy provided by the chiropractor, for example acupuncture or massage, and in general these were found to be helpful forms of complementary treatment. One person described how they had been more open to acupuncture because it was provided by the same therapist in whom she had developed trust:

“The first time I went I hadn’t had acupuncture before and probably wasn’t keen on the idea. So she did discuss that with me, you know talked it through....I thought I can’t see the needles as I’m lying on my front so I’ll give it a go because the trust was there. Actually I do feel it’s really beneficial but I needed that kind of explanation and maybe reassurance before trying it.”

However, there was an example where someone said they received a treatment which they felt they did not agree to.

4.4 Self-Management

A high percentage of survey respondents expected the chiropractor to provide advice on how to manage problems/symptoms between treatment and this expectation was largely met, with 96% of respondents saying they had been given this type of support.

Almost all of those interviewed said that their chiropractor had recommended specific exercises to help self-manage their condition or advised that they take up an exercise programme such as Pilates. Many people said they had used these exercises and suggestions and they had proved to be very helpful. This also helped to establish trust for some individuals: *“He is making an effort to keep me out of the practice, not in it - he’s not using me as a license to print money.”* One person said that he asked his chiropractor if there were exercises he could do between treatments,

but he felt that the chiropractor should have instigated this himself, and earlier on in the treatment process.

Some people said that their chiropractor took some trouble to demonstrate to them how to do the self-management exercises, and in some cases they were provided with diagrams and leaflets or directed to videos on websites that they could view at home. One person (who used to be a physiotherapist herself) suggested that chiropractors should frequently check with people whether they are doing self-management exercises and how they are doing them, to help it become more habitual and to ensure people are doing things correctly.

4.5 The Chiropractor's Approach

The chiropractor's manner and general approach was a key factor in people's experience of chiropractic, amongst almost nearly all of those interviewed. People stressed the importance of the chiropractor having good interpersonal skills in order to help people feel relaxed and have confidence in the treatment. As mentioned before, for some people this extended to the whole practice, where they valued an atmosphere of warmth and friendliness. *"It's the whole practice - they give you confidence. They're friendly and if you ask a question they give you loads of information. It's just very good."*

Two people noted that they appreciated the chiropractor talking about things other than the treatment, as this helped to develop the relationship and/or take their mind off things. *"It is very personal. Some moves are very intimate. You've got to be able to get on with them – no, not get on with them, you've got to be able to be comfortable with them."*

One chiropractor holds regular 'drop in' classes at no cost, which patients can attend along with friends or family. These provide information on the body and on the chiropractor's technique and provide an opportunity for family/friends/carers to learn about the process. Patients interviewed valued this: *"You can go any time and you can take anyone you like."*

Some people mentioned that their chiropractor is very accessible (compared to their experience of NHS services), and they valued being able to get an appointment at short notice. There was an example where a chiropractor provides his mobile number and said that he would visit patients at home if required.

4.6 Reasons for Ceasing Chiropractic Care

In the national survey, 135 respondents said that they were not currently receiving treatment. As Table 15 shows, of these nearly 60% said it was because they no longer needed treatment and 36% said that their condition had improved and they were currently able to manage without treatment. A few said that they had ceased treatment because they thought the treatment was not benefitting them or they did not like the chiropractor's approach. The cost of treatment and affordability was noted by a small number of patients.

TABLE 15 REASONS FOR NOT CURRENTLY HAVING CHIROPRACTIC TREATMENT

	n=	% of total (n=135)
The problem the chiropractor was treating improved/got better and I no longer need treatment	80	59.3%
The problem the chiropractor was treating has improved and I am currently able to manage it myself	48	35.6%
I did not feel the treatment was benefiting me	6	4.4%
I was unhappy with the chiropractor's approach/manner	2	1.5%
I had an unpleasant reaction to treatment	0	0.0%
I was unhappy with the cost of treatment	4	3.0%
I am currently unable to afford treatment	7	5.2%
Other health problems have prevented me having chiropractic treatment	1	0.7%

NOTE: responses from Care Response and the Patients Association accounted for two thirds of the patients who were not currently receiving treatment.

A number of other specific reasons were provided for not currently having chiropractic treatment. The majority (5 comments) were from people who felt that they had derived a certain degree of benefit, and they now attend on an ad hoc or maintenance basis. For a couple of others the reasons linked to moving away, and two people said they were now receiving alternative treatments (such as physiotherapy) and did not feel it was appropriate to be receiving both treatments at the same time. For one person the reason was linked to a chiropractor who they said did not use due care when providing acupuncture treatment, and another said they had sought chiropractic for pain relief, which had not delivered the benefits they sought. In another case, the chiropractor had concerns and referred for X rays and scans, which revealed damage requiring hospital treatment.

Chapter 5 Benefits and Adverse Effects

In this chapter we explore patients' knowledge of both the benefits and risks of chiropractic care, and look at the benefits and adverse effects reported in both the interviews and the survey. We also consider patients' views about arrangements for giving patient feedback and making complaints.

5.1 Knowledge and Perceptions of the Benefits of Chiropractic Care

The survey questionnaire asked patients how much they knew about the likely benefits of chiropractic treatment before they first saw a chiropractor. The majority of patients (around 60%) felt that they had some knowledge of the benefits of treatment (i.e. rating 3-5), though a significant percentage (19%) said they 'knew very little' (rating 1).

Patients interviewed were asked about what had influenced their perceptions of the potential benefits of chiropractic, and, as highlighted in 3.1.1, it was often the positive recommendation of a family member or friend who had experienced chiropractic care that had led people to try chiropractic treatment and this had disposed them to think positively. A handful of patients explained that they had previously seen an osteopath and that this had given them a favourable perception of manual therapies in general.

"I had a relatively high level of confidence already. Going on to the chiropractor I thought, 'well you're osteopath on steroids really, aren't you.'"

A few patients said their perception of chiropractic treatment hadn't changed much over time - they had started out with a positive view and it had continued. For those whose perceptions and understanding had changed over the time, the overwhelming reason for this was their direct, and largely positive, experience of chiropractic treatment, and the accompanying information they gained from discussions with their chiropractor. A few had become very interested in the whole field and had taken time to read more about the musculoskeletal system and chiropractic treatment in particular.

5.2 Benefits of Treatment

The patients interviewed for the study described a number of benefits of receiving chiropractic care and treatment (outlined below). This information was used to shape the question in the survey which asked patients to record which, if any, of seven main benefits they had experienced. All except a handful of the survey respondents recorded at least one benefit and the majority - over 80% - highlighted three or more benefits. Table 16 below shows the number and proportion of respondents who recorded the different benefits.

TABLE 16 MAIN BENEFITS OF TREATMENT

	Number	%
It has reduced or removed the pain I was experiencing	503	92%
It has increased my mobility/flexibility	434	80%
It has helped me maintain my general health and wellbeing	344	63%

	Number	%
It is helping to prevent or reduce future problems	297	55%
It has given me a better understanding of my health problem	286	53%
It has increased my ability/confidence to manage my health problem	239	44%
It has enabled me to return to work, sport or other activities	204	38%

The patients responding to the survey were also able to record 'other benefits' and where they did so they were asked to describe these. Many comments reinforced the options provided, but a few additional benefits were highlighted, including:

- Improved mental health/well-being (6)
- Reduced medication (2)
- Improved sleep (2)
- Helped to balance menstrual cycle (1).

As well as informing the survey, the interviews also provided more insight into the ways in which patients experienced the benefits of chiropractic care and treatment, in particular the extent to which it resolved or improved specific health problems, reduced pain or improved mobility, or helped prevent future problems. Each of these is discussed in more depth below.

5.2.1 Resolving or Improving Specific Health Problems

Almost all the patients interviewed said that they had experienced an improvement in the condition or problem which had initially led to them seeking chiropractic treatment. For a number the problem had been completely resolved or the improvement had been much greater than they expected. One patient in her 40's had experienced low back pain most of her adult life. The first chiropractor she saw did provide some pain relief but had not resolved the problem. The second chiropractor she saw was more experienced. He helped her get an MRI scan via her GP, and eventually got to the root cause of her problems.

"I was very anti-chiropractor, I thought 'witch-doctory' and all the rest of it – well, I'm like a reformed alcoholic and – well, I'm still going ... Obviously I still have some twinges but having had back ache for 30 odd years, it's amazing - they say you don't need to be in pain and you don't and it's fabulous."

Others explained that whilst they knew that chiropractic treatment would not 'cure' them, it had significantly improved their condition. Often people had quite complex needs and they greatly appreciated the time their chiropractor had taken to understand their problems and treat them appropriately. One patient explained that she had had polio as a child which had left her with one leg shorter than the other. She also had spondylitis and bursitis in one hip. Despite this she felt that chiropractic care had made a significant difference to her overall wellbeing:

"I actually have a much better quality of life since I've been going to see this particular chiropractor. I mean I'm sailing, kayaking, and I'm walking which I haven't been able to do. I can do things that I haven't been able to do for years and I feel that I've got longer periods of stability than I had before and when I do have problems I find I recover much more quickly when I go to see the chiropractor".

Only one person said that they had not yet seen an improvement in their condition. A number of other patients explained that over the years they had seen more than one chiropractor, and for a

few the main reason for changing chiropractor was that they did not feel the treatment they had been given was effective. However, most had changed due to circumstantial reasons.

Five patients noted that they had sought chiropractic treatment for a particular problem but the chiropractor had then identified other problems which were amenable to chiropractic care. One patient had initially seen his chiropractor about a back problem but the chiropractor noticed that he also had a gait problem. He explained:

“The difference it has made to me is immense.... I feel more agile, more fluid. I can walk better, further, get in and out of cars no problem”.

Another patient explained that she had also originally seen her chiropractor about a back problem but she happened to mention that she suffered from quite severe and frequent migraines, which the chiropractor was able to treat successfully. She described the results as *“life changing”*. Two patients also said that their chiropractor had identified other health issues which were not suitable for chiropractic treatment. Both had been advised to see their GP, with one eventually being referred to an acupuncturist by her chiropractor.

A number of patients had sought NHS treatment before seeing a chiropractor. Some said that whilst NHS physiotherapy had helped, it had not resolved their problem. Others had had more negative experiences ranging from inadequate care to inflexible appointment systems. They saw chiropractic care as more effective and more responsive.

“Someone recommended chiropractic treatment and I've never looked back. I go fairly regular and I know if something's out of place I can lift the phone and nine times out of ten I can see the chiropractor that day. Sometimes I can hardly walk in the door and then I almost run out”.

Patients also reported very mixed experiences of GP care. Some felt they had been *“written off”* by their GP. Others had been told that they would have to use medication (e.g. painkillers, migraine medication) for the rest of their lives. As a result of chiropractic treatment most had been able to stop or at least significantly reduce their use of medication and this was clearly a very important benefit for some people. However, a few patients reported that their GP had actually recommended that they see a chiropractor and one even helped the patient to find a chiropractor with appropriate experience.

One person described how her chiropractor had made very positive statements about the relief the treatment would bring, prior to her going on holiday:

“On the visit [before I was due to travel] she said to me ‘You will not have a significant migraine whilst you are away.’ Now that to me was such a bold statement and I could hardly believe it because I have really suffered and I am very rarely without some sort of symptom, so I said to her ‘Are you serious, are you sure?’ and she said ‘Yes, I am’. And I didn't have one migraine while I was away”.

This really reinforced her trust in the chiropractor. This example does raise interesting questions about the role that autosuggestion could play in the patient's experience – and how that might impact on the way that chiropractors might frame discussions about risk.

5.2.2 **Reduced Pain and Increased Mobility**

Around a third of the patients interviewed highlighted reduced pain as a major benefit and, not surprisingly, this was often accompanied by increased mobility. An older patient who had been a very active sportsman in his younger days explained:

“I've benefitted enormously. I would say she kept me going to be honest....I have one or two old sport injuries that have been interfering with life, as well as osteoarthritis, and

she has been able to keep me extremely comfortable and I have regained the majority of my ability to move around”.

The ability to return to normal activities, get back to work and play sports again (as a result of reduced pain and increased mobility) was highlighted by around a quarter of those interviewed. As one patient put it:

“He allowed me to carry on with my life as it should be, a normal life. I was in a pretty bad state when I went to see him and now I am able to live a proper life... I am almost pain free.”

A few explained that this had also had a positive effect on their general well-being. One patient, who had his own business which involved highly physical work, had damaged his spine in an accident at work. His primary injuries were treated by the NHS but he was left with extreme dizziness which meant he could not work. He was in danger of losing his business and was extremely anxious about the future. He did some research on his condition and eventually found a chiropractor who understood the problem. He explained that the chiropractor had not only treated him, he had encouraged him to think about his general well-being - *“I feel healthier - it's affected everything – my back's a lot better but also my overall health.”*

5.2.3

Prevention

Several patients explained that they see chiropractic care as a form of ‘health maintenance’, helping then to prevent or reduce the likelihood of future problems. This was particularly the case for older patients, as one woman in her late sixties explained:

“It's keeping me mobile – totally – free from pain – I'm reasonably fit and I think I can do pretty much anything I want to do. The initial benefit was freedom from pain. This is why I have the top ups – because as you get older everything starts to seize up.”

What form this took depended very much on the chiropractor's philosophy and treatment style. Some saw their chiropractor a few times a year for a ‘top-up’, whilst others had more frequent but short maintenance treatments. One patient, who saw her chiropractor weekly for prevention/maintenance recognised that this was unusual but felt it worked for her.

“He said that its if he can keep all of that in alignment and adjust it so that [the spine] is in the right shape, so there's no pressure on the system, then everything in your body should function at a better level. And I have to say since I have been going - the place where I go to work there's been viruses and tummy upsets and touch wood I have not had anything at all - nothing - I've not had even half a day off.... I am quite a doubtful person... but I have to say over all this time I have had none of the illness that all of the other staff have had.”

For a number of patients, chiropractic care had also increased their knowledge and understanding of their condition and/or how their bodies worked and this had enabled them to ‘self-manage’ more effectively, as the two quotes below illustrate:

“Basically it teaches you more about bio-mechanics in general and I've applied it and looked at other techniques to improve my running, my cycling, my swimming technique – all things like that. I think it makes you a little bit more aware of how your body should work.”

“The problems I have had with my back have eased considerably. I've become much more aware of posture related issues and how to try and prevent them, and that has come out of my discussions with the chiropractor”.

5.3 Knowledge and Perceptions of Adverse Effects and 'Risks'

The national survey asked patients how much they knew about possible adverse reactions to chiropractic treatment before they first saw a chiropractor. Overall patients' knowledge about possible adverse reactions was very low, with around 70% of patients rating their knowledge 1 or 2, and only 8% rating it 4 or 5.

In the individual interviews and focus group we explored patient's perceptions of possible adverse effects or potential risks and what had influenced these perceptions. Almost two thirds of the patients interviewed said that, before seeing a chiropractor, they had little or no knowledge of the possible risks or adverse effects of chiropractic treatment, did not think there were any significant risks, or hadn't even thought about risks. A few people said that at the point that they sought help from a chiropractor, they were in such pain and distress that they didn't want to think about any risks or adverse effect, they just wanted help.

Those patients who had thought about possible risks raised two main issues. The first was being treated by someone who wasn't properly trained (i.e. someone calling themselves a chiropractor who did not have the appropriate qualifications and registration), or a registered chiropractor whose practise was poor. As one patient put it - *"being treated by a cowboy, someone who doesn't know what they are doing"*. The second was a general concern about the implications of manipulating the spine, neck and joints.

"When you think - what if they slip? Particularly with the spine or neck - what if they do something wrong? I could be paralysed or something – you know it still crosses my mind even now!"

However, several patients emphasised the importance of keeping 'risk' in perspective, in particular understanding that the likelihood of adverse effects will vary with the part of the body being treated and the nature of the treatment; balancing any possible risks against the likely benefits; and setting the possible adverse effects of chiropractic treatment against the risk of alternative treatments such as back surgery or the long term use of prescription painkillers. The three quotes below illustrate these points:

"You don't want to get into risk aversion at any expense.... you can frighten the socks off people. There's a balance to be struck."

"As far I as I was concerned that was minimum risk to the risk of becoming a couch potato – it's a no brainer. There was virtually no risk involved - I believe I was in the hands of an 'extreme' professional who knew his trade inside out and was always learning and developing because he was always saying 'I'm going away on this course I'm going away on that course', so there's someone renewing his trade and keeping current."

"You have to put your faith in it, and there are risks in any treatment."

Where patients interviewed said that before treatment they had some ideas (whether correct or incorrect) about the possible risks or adverse effects of chiropractic treatments, these had mainly been shaped by the media or general perceptions in society, or by the experiences of family and friends.

Some felt that in the general media, chiropractic treatment is often *"lumped together"* with all alternative and complementary therapies. One patient said - *"It's almost like a form of quackery the way that it's portrayed"*, though another said she had the impression that there were now more *"good news"* stories about chiropractic in the magazines that she read. Negative views about chiropractic care had at first deterred some patients from seeking treatment. A handful of patients had done some on-line research about chiropractic care and/or about possible

treatments for their condition. Some had found this helpful but often read things with a slightly sceptical eye - *“you can't believe everything you read, especially on a website.”*

5.4 Experience of Adverse Effects

Of those surveyed, around 20% (n=110) of respondents (n=91/25% of females and n=17/9% of males), reported that they had had an unexpected or unpleasant reaction to their treatment. Table 14 shows the responses to questions regarding the reaction. As Figure 3 shows, the main reactions were extra pain and tiredness or fatigue. 43% (n=46) only had one reaction but the remainder had 2 or more. However, as Table 17 shows most respondents (n=72/67%) had a low (1 or 2) level of concern about their reaction, with only 17% (n=18) reporting high levels of concern (4 or 5) and women slightly more likely to express concern than men. Overall, the reactions most likely to give rise to concern were extra pain and/or radiating pain and tingling/numbness in legs or arms. However, a number of people said that they had anticipated this reaction or their chiropractor had warned them that it might occur. A small number of other reactions were mentioned, including severe neck spasm after treatment (2); pain moving rather than reducing (1); back spasms during acupuncture (1); and bruising (1).

Figure 3

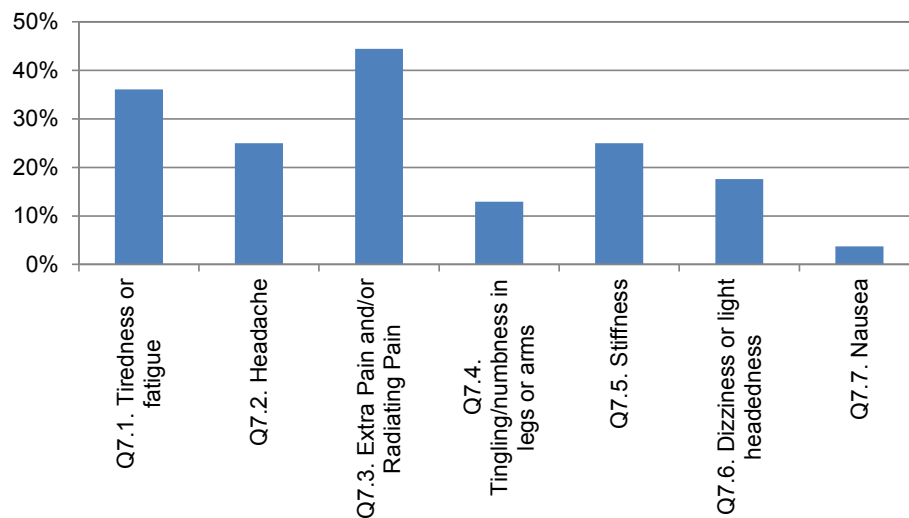


TABLE 17 LEVEL OF PAIN FOR EACH REACTION BY GENDER

Reaction		1/2	3/4/5	n/a
Q7.1. Tiredness or fatigue	Female	33	2	1
	Male	2	0	0
	n/a	1	0	0
Q7.2. Headache	Female	19	4	1
	Male	3	0	0
	n/a	0	0	0
Q7.3. Extra Pain and/or Radiating Pain	Female	21	19	0
	Male	5	2	0
	n/a	0	1	0

Reaction		1/2	3/4/5	n/a
Q7.4. Tingling/numbness in legs or arms	Female	3	9	0
	Male	1	0	0
	n/a	0	1	0
Q7.5. Stiffness	Female	13	7	2
	Male	4	1	0
	n/a	0	0	0
Q7.6. Dizziness or light headedness	Female	13	6	0
	Male	0	0	0
	n/a	0	0	0
Q7.7. Nausea	Female	1	3	0
	Male	0	0	0
	n/a	0	0	0

None of those who were interviewed said they had experienced any significant adverse effects, other than fatigue or aching following treatment, which they had been warned about. The importance of chiropractors attending to and responding to patients' concerns about potential risks (whether they are founded or not) was illustrated by one woman who said she had some concerns about treatment whilst pregnant. She described how the chiropractor wanted her to lie face down on a particular table and reassured her that it was safe, but she was very uncomfortable about this and refused. She said he did not push it and he provided the treatment another way.

“He said the table’s designed for this and immediately started moving the table around to accommodate the bump and I said you know, ‘I don’t want to do this’... but he did take that on board and he responded to that.”

5.5 Patient Feedback and Complaints

Three questions in the survey explored patients' expectations and experiences of systems for confidential feedback and complaints procedures. Table 18 shows that just over three quarters of patients expected their chiropractic practice to have a system for confidential feedback but only two thirds said that this was case in their practice. With regard to patients being given information about complaints procedures, either within the practice or via the GCC, patients' expectations were generally low with only around half of respondents saying they expected to be given this information. In practice only about 40% of patients received this information.

TABLE 18 SYSTEMS FOR FEEDBACK AND COMPLAINTS

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q42. I expect the chiropractic practice to have a clear system to enable me to provide confidential feedback (whether positive or negative)	76%	20%	4%	66%	18%	16%
Q43. I expect to be given information about the practice's complaints procedure	54%	39%	7%	44%	38%	18%
Q44. I expect to be told about my right to refer a complaint to the General Chiropractic Council and be given the GCC's contact details	51%	41%	9%	40%	40%	20%

The information gained from the interviews and focus groups provides some insight into why patients' expectations in relation to this issue were low in comparison to other areas. Very few people interviewed could clearly recall being informed about a complaints procedure. However, most of those who did not think that they had been told were not particularly concerned about this. For some, this was based on the fact that they had developed an honest and open relationship with their chiropractor and felt that they could raise any concerns directly. Many others said that they would be able to find the appropriate ways if and when they needed them. Several people commented that where people were unhappy with standards they generally "*voted with their feet*". Whilst a very small number of people interviewed had had bad experiences of chiropractors in the past, none of these mentioned that they had ever used a complaints procedure that extended beyond complaining to the practice manager.

Chapter 6

Patients' Views on Fitness to Practise

This chapter explores patients' views on assuring chiropractors' fitness to practise, including continuing professional development and the use of patient feedback.

6.1 Assuring Chiropractors are 'Fit to Practise'

The majority of those interviewed felt that a chiropractor's fitness to practise should be routinely checked, but there were differing views regarding the frequency of this and the methods that should be employed. Suggested frequency of reviews of a chiropractors' fitness to practise ranged from one to three years, with the majority saying two or three. For some, they were happy for this to be monitored through a simple self-assessment, with records provided to the GCC, but quite a number of participants thought that there should be some sort of direct inspection or observation by the GCC. Three people felt that this inspection should extend to the whole practice, not just the chiropractor, and include reception staff, hygiene, record keeping, and the general presentation of the practice:

"A bit like OFSTED in schools you know - inspect the whole place. Because I work in a school and when they come it's not just the teaching and the teachers it's the whole thing. Because that makes a good school. So I think with a chiropractor that's what makes a good chiropractor."

However, some people wondered whether direct inspection/observation could be an added cost which might be passed on to patients; others observed that it could be complex to introduce, for example, it might be difficult to gain patient consent for observations, and some suggested that it might be too easy for practices to prepare for inspections, so they are not a helpful indicator of everyday operation. A small number of people suggested that to help overcome this, a 'mystery shopper, or 'undercover boss' method of observation might be a better way of monitoring fitness to practise.

A small number of people (notably those working within health or business environments) stressed how important it is that a commitment to maintaining fitness to practise is encouraged by a supportive regime, not simply imposed. As one person put it - *"It is important that it is not something that is outside of the practice through doing an assessment or an intervention - it has to be supportive and change practice from within."*

The information gained from the interviews was used to shape the questions about maintaining fitness to practise in the survey, and the questions and responses are outlined below.

6.1.1 Views from survey respondents about fitness to practice

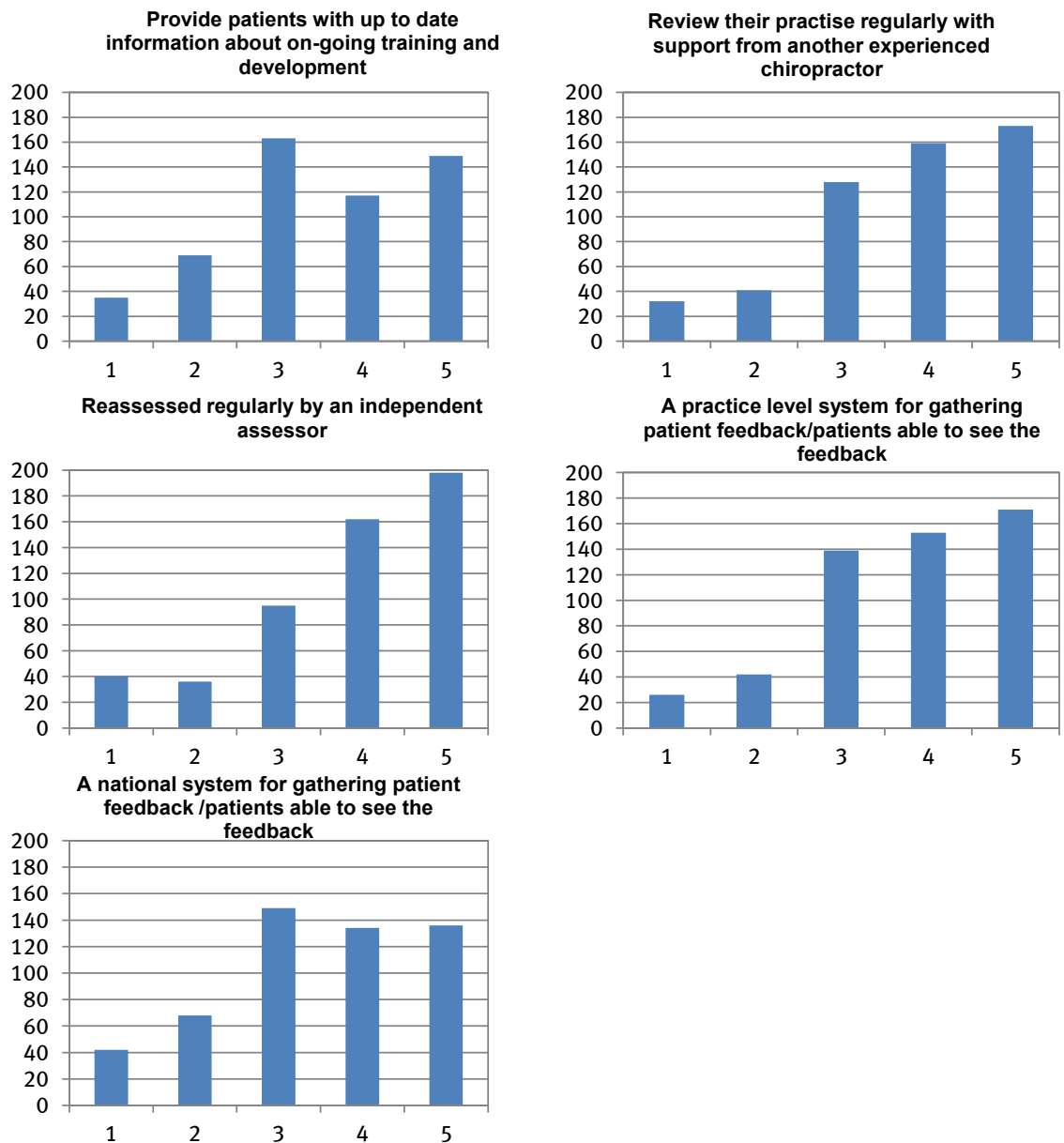
Patients were asked to rate their level of agreement with five statements, each relating to possible arrangements for ensuring fitness to practise. These were:

- The chiropractor should provide patients with up to date information about their on-going training and development
- The chiropractor should review their practise regularly (e.g. every 3 years) with support from another experienced chiropractor
- The chiropractor should be reassessed regularly (e.g. every 3 years) by an independent assessor to ensure they are keeping up to date

- The chiropractor should have a system for gathering patient feedback and patients should be able to see the feedback recorded
- There should be a national system for gathering patient feedback and patients should be able to see the feedback recorded.

The responses to these questions are shown in Figure 4 below, with 1 relating to 'strongly disagree' up to 5 relating to 'strongly agree'.

Figure 4



For all five questions at least half the respondents either agreed or strongly agreed with the questions (85 patients rated all at '5' and only 14 rated all at '1'). The strongest support was for the third question concerning regular independent assessment.

Similar to those interviewed, the respondents were more equivocal about the need for chiropractors to provide patients with information about their training, and about a national system for gathering patient feedback. One survey respondent commented on this, raising concerns about confidentiality:

“Most chiropractors work in small practices where gathering feedback confidentially would be too difficult. Most clients would not want to take part in national surveys. If required they can contact the GCC”

Some respondents added further comments about fitness to practise, the largest number (10) related to concerns that added bureaucracy could risk taking up too much of chiropractors' time. In contrast five people suggested that regulation of chiropractors should be comparable to similar healthcare professions, including GPs.

6.2 Continuing Professional Development

Table 19 below shows that a low number of those surveyed expected to have information about their chiropractor's professional development, though a slightly higher number said this was provided in practice.

TABLE 19 INFORMATION ABOUT CHIROPRACTORS PROFESSIONAL DEVELOPMENT

	Expected			Did it happen		
	Yes	No	n/a	Yes	No	n/a
Q39. I expect that information about how the chiropractor is maintaining/ improving their professional knowledge (e.g. further training) will be displayed in the clinic/included on the practice website	56%	38%	6%	59%	28%	13%

There were some comments from survey respondents concerning on-going training and development, which showed a spectrum of concern about this issue: some people said it was not of great concern to them; others did not feel the need to be informed and trusted their chiropractor to keep up to date, while others felt that on-going professional development was very important and patients should have confidence that this is being undertaken.

The individual interviews provided an opportunity to explore this issue in more depth. Most of those interviewed thought that it was important that chiropractors keep up to date with the latest research, but when prompted there were varying opinions about what form this should take. Some felt that it should not be too prescriptive, but others thought that minimum standards should be set out. Two people said that whilst they recognised the importance of continuing professional development it was not necessarily an indicator of quality:

“If they've got the right attitude then actually putting on strict rules about continuing professional development is unnecessary. I could see the ones who are maybe churning out 15 minute appointments in [large city] might tick the boxes saying 'I've been on two weeks CPD' but that isn't reflected in good practice. There maybe should be more minimum standards.... and even minimum time for appointments would be more reassuring to me.”

One person interviewed who was in the medical profession said that it is the way in which continuing professional development is encouraged that is important, so that it is not just a 'tick box' exercise. He said that in his case he has to undertake 25 hours per year of training, and 10 of these have to be of a 'formal nature' (e.g. conference/specific skills training); doing this allows opportunity to meet other professionals and share practice experience and ideas, and for him this was essential in keeping up to date and promoting enthusiasm for the profession. He said he often worked alone and having this opportunity to meet others was vital, and this was also likely to be the case for chiropractors:

“What I like to see with a professional person is someone who has an enthusiasm for their profession – if I ever thought the chiropractor was doing just another day at the office I would not be particularly happy... The issue is that after a long career you make sure that they're not just doing another day at the office. How do you regenerate yourself? How do you keep interested? How do you challenge yourself? I'm not sure how many practitioners do this and this would be my recommendation.”

Similar to the survey response, a small number of people interviewed said that chiropractor revalidation should be similar to that of people in medical professions, and one person speculated that this might help raise the standing and image of the profession. There were also suggestions that more informal ways for developing practice should be encouraged, for example, through peer review and enabling opportunities for chiropractors to visit each other's practices.

6.3 The Use of Patient Feedback

In Section 5.5, the responses to the survey outlined in table 21 showed that there are relatively low expectations amongst patients about systems for confidential feedback, and even lower expectations concerning information about complaints systems. The responses also suggest that in practice, information about these systems is not routinely provided or that people do not notice/retain it.

The individual interviews and focus group provided an opportunity to explore the issue of patient feedback in more depth, and to reflect on the role it could play in revalidation. Whilst most thought that a system for patient feedback was in principle a good thing, the reasons for this varied. Only a small number linked it to an inspection regime and thought that for this purpose it should be collected independently by the GCC or other independent body. The majority saw patient feedback as an internal matter, to help improve practise.

Some people said that their chiropractor already provides comments/suggestion cards, and patients from one practice said that the chiropractor hands out questionnaires to patients every 6 months. A few respondents said that there should be a wide range of methods for people to feed back their comments, including email, text, and telephone, as well as paper based options. One person reflected on the fact that gathering patients' feedback as a private business was different in nature to the public sector, because people have more choice about the service they purchase:

“I think if they don't [get patient feedback] that is to the detriment to their business – but I think it's quite tricky because they are independent businesses aren't they, and there's an assumption that basically if you're not happy you have a discussion face to face or you go somewhere else. I think it's slightly different to getting patient satisfaction or patient feedback for more general services [NHS] because there isn't an alternative to those general services usually.”

Another warned that patient feedback systems should not become too complex or bureaucratic, and should be locally owned.

A small number of people saw the issue of patient feedback as a mechanism for gathering recommendations, which might influence their selection of a chiropractor. For example, it was suggested that it might be helpful if chiropractors put patient quotes on their websites, or if some kind of star-rating or 'patient referee' system could be developed. However, the people who made these suggestions were often aware of some of the risks associated with such practices, such as bias being introduced. The desire for these mechanisms also underscores the fact that many of those interviewed were very keen to be able to select a chiropractor based on a personal recommendation.

Chapter 7

Conclusions

In its specification for this research the General Chiropractic Council described the main purpose of the study as being *“to ‘place’ a proposed form of revalidation within the context of patients’ views of chiropractic – their assessment of its risks and benefits, their expectations of chiropractors and their experience of them”*. In drawing together our conclusions we have focused on this purpose.

The research suggests that prior to seeing a chiropractor many patients have some knowledge of the potential benefits of chiropractic care, which had developed from discussions with family members or friends who had had chiropractic treatment and benefitted from it. For those whose perceptions and understanding had changed over the time, the overwhelming reason for this was their direct, and largely positive, experience of chiropractic treatment, and the accompanying information they gained from discussions with their chiropractor.

Patients highlighted a range of benefits which they felt had resulted from their chiropractic care. Perhaps not surprisingly, the two main benefits were reduced pain and increased mobility resulting from resolving or managing a specific health problem. However, many patients described wider benefits such as improvements to their general health and wellbeing, prevention of future problems, a better understanding of their health problems and, linked to this, greater confidence in managing their health problems. Often these benefits had knock-on effects such as improvements in patients’ mental well-being or their ability to return to work or sport.

For some patients chiropractic care was seen very straightforwardly as a treatment for a specific health problem, which once resolved would mean that they no longer needed to see a chiropractor. However, many saw chiropractic care as a form of ‘maintenance’ or as a way of preventing problems escalating. This was particularly the case for patients with more complex problems and older patients. A number of patients had had negative experiences of NHS care, in particular the care offered by their GP, and had looked to chiropractic treatment as an alternative to long term use of pain or other medication and/or surgery. Conversely a few patients said that their GP had recommended chiropractic treatment and many patients wanted chiropractic care to be available through the NHS.

As was noted in Chapter 1, in conducting the research we were very much aware that some chiropractors felt that the brief for the study placed undue emphasis on the risks of receiving chiropractic care, and were concerned that asking patients about ‘risks’ might in some way bias their view. In fact the research suggests that whilst most patients start out with a low understanding of the possible adverse reactions to chiropractic treatment, their ability to balance the potential risks (i.e. of adverse effects) against the potential benefits matures quite quickly. Patients’ initial perceptions of risk had mainly been shaped by the media or general perceptions in society, or by the experiences of family and friends. Some felt that in the general media, chiropractic treatment is often bracketed together with all alternative and complementary therapies, whilst others felt that there was more positive reporting of chiropractic care now.

At a macro level, patients raised two main issues in relation to ‘risk’. The first was being treated by someone who wasn’t properly trained (i.e. someone calling themselves a chiropractor who did not have the appropriate qualifications and registration). The survey suggests that the vast majority of the chiropractors covered by this study do display information about their qualifications and registration. However, the interviews revealed a much more mixed understanding of ‘registration’. Many patients were unaware of the GCC and some did not appreciate that chiropractors had to be registered. A few seemed unclear about the difference between membership of a professional body and registration with the GCC.

The second was being treated by a registered chiropractor whose practice was poor. The survey suggests that around a third of the patients who said they had changed their chiropractor in the past had done so because either they were in some way unhappy with the chiropractor's approach or they did not feel they were gaining benefit from the treatment or they felt the treatment they were given was poor. The nature of this study means that most of the patients who contributed are either currently receiving treatment or have had on-going chiropractic care in the recent past. Those patients who ceased chiropractic care after a small number of treatments, perhaps because they were unhappy with their care will be under-represented. Nevertheless, the survey suggests that where patients are unhappy with their treatment this does not necessarily deter them from seeking further treatment from another chiropractor.

At an individual level patients emphasised the importance of keeping adverse effects or 'risks' in perspective. In particular, they highlighted the importance of understanding that the likelihood of adverse effects will vary with the part of the body being treated and the nature of the treatment. They also felt strongly that the low level of risk associated with chiropractic treatment has to be balanced against the likely benefits. Furthermore they often set the possible adverse effects of chiropractic treatment against the risks of alternative treatments such as back surgery or the long term use of prescription painkillers. In fact, only 20 of the survey respondents said that they had experienced an unpleasant or unexpected reaction to treatment, the main reactions being extra pain and tiredness or fatigue. The majority of these patients were not unduly concerned about this reaction, in some cases because their chiropractor had warned them that it might occur. However, the survey also revealed a slight discrepancy between patients' expectations and experiences in relation to their chiropractor talking to them about possible adverse reactions to treatment. Informal contact with chiropractors involved in the study indicates that this is a sensitive area. Whilst the chiropractors recognised the need to discuss these issues with patients, they were also mindful of not wanting to concern patients unduly, especially at their first consultation. Patients also recognised this issue, with a few saying that at the point that they sought help from a chiropractor, they were in such pain and distress that they didn't want to think about any risks or adverse effect, they just wanted help.

In terms of patients' expectations, the study suggests that overall they were being well met. Of the 33 aspects of care that patients were asked to comment on, there were 18 where more than 90% of patients expected this aspect of care to take place. In the majority of these areas patients' expectations were met. There were seven areas where there was a slight difference (2 to 4%) between patients' expectations and experiences. These were:

- Allowing sufficient time for the consultation
- Being told about the cost of treatments
- Having the treatment needed explained
- Being given time to ask questions about the treatment plan
- Being told about the likely success of the treatment
- Being told about further treatment options
- Being able to undress and dress in privacy

There were four other areas where patients had relatively high expectations (i.e. 75% expected an aspect of care to happen) but these were not met for a significant proportion of patients (10 to 25%). These were:

- If necessary and with consent, the chiropractor would contact the patients GP
- If the problem is not improving or the patient has other health needs the chiropractor will discuss referral to another healthcare practitioner

- Having the cost of the treatment plan explained at the first consultation
- The chiropractic practice having a system for patients to provide confidential feedback.

Whilst for the majority of these areas the differences between expectation and experience were very small, the results may suggest areas where the profession and the GCC could focus attention in terms of helping chiropractors improving practice.

Finally, one of the research questions posed by the GCC was *“Once a chiropractor is on the GCC register, what do patients expect will happen to assure an individual chiropractor’s continuing fitness to practise?”*. Again, in conducting the research we were aware that there is some sensitivity within the profession about this issue and about asking patients about fitness to practise and topics related to revalidation. It is not the place of this study to recommend any one course of action in relation to revalidation. Rather we have attempted to describe patients’ views in a neutral way and draw relevant but unbiased conclusions.

The majority of patients contributing to this study felt that a chiropractor’s fitness to practise should be routinely checked, but there were differing views about the approaches that should be used to achieve this and the frequency with which it should occur. Amongst the survey respondents, the highest level of support was for chiropractors to be reassessed regularly by an independent assessor, closely followed by an approach which enabled chiropractors to review their practice on a regular basis with another experienced chiropractor. However, patients were also mindful of the implications of such approaches in terms of the chiropractors’ time; costs both to administer the system and for the individual practices (including a concern that these might be passed on to patients); and bureaucratic complexity. Several also stressed the importance of ensuring that a commitment to maintaining fitness to practise is encouraged by a supportive regime, not simply imposed.

A significant proportion of patients responding to the survey also said that providing patients with information about the chiropractors’ on-going training and development, and having a practice-level system for gathering and showing patient feedback, would help to reassure them that their chiropractor was keeping their skills and knowledge up to date. Several of the patients who were interviewed gave examples of the ways in which their chiropractor had established ways to do both of these things, which they clearly appreciated.

Lastly, it is perhaps important to note that whilst discussions about ‘fitness to practise’ tend to focus on individual chiropractors’ skills and knowledge, this research suggests that patients take a slightly broader view, which included aspects of care which related to the chiropractors’ overall approach. Many felt that it should encompass the whole practice, including things like the clinic environment, practice systems, information, treatment costs and charging arrangements, and indeed it was in some of these areas that there was the greatest discrepancy between patients’ expectations and experiences.

Appendix 1 National Survey of Chiropractic Patients



General
Chiropractic
Council



THE UNIVERSITY of York
Department of Health Sciences

National Survey of Chiropractic Patients

Section A: Your Experience of Chiropractic Treatment

1.	Before you first had chiropractic treatment, how much did you know about: (please circle)	I knew very little					I knew a lot					
	a. What the treatment involved?	1	2	3	4	5						
	b. The likely benefits of the treatment?	1	2	3	4	5						
	c. Possible reactions to the treatment?	1	2	3	4	5						
2.	Approximately how many chiropractic treatments have you had in the last 12 months?											
3.	Are you currently receiving chiropractic treatment? (please circle)						Yes	No				
4.	If No, why did you stop chiropractic treatment? (tick all that apply)											
	The problem being treated improved/got better and I no longer need treatment											
	The problem being treated has improved and I am currently able to manage it myself											
	I did not feel the treatment was benefiting me											
	I was unhappy with the chiropractor's approach/manner											
	I had an unpleasant reaction to treatment											
	I was unhappy with the cost of treatment											
	I am currently unable to afford treatment											
	Other health problems have prevented me having chiropractic treatment											
	Other (please describe)											
5.	For you, what have been the main benefits of chiropractic treatment? (tick all that apply)											
	It has reduced or removed the pain I was experiencing											
	It has increased my mobility/flexibility											
	It has enabled me to return to work, sport or other activities											
	It has helped me maintain my general health and wellbeing											
	It is helping to prevent or reduce future problems											
	It has given me a better understanding of my health problem											
	It has increased my ability/confidence to manage my health problem											
	Other (please describe)											
6.	Have you ever had an unexpected or unpleasant reaction to chiropractic treatment? (please circle)						Yes	No				
7.	If Yes, which reaction/s have you experienced? (tick all that apply)											
	Tiredness or fatigue						Stiffness					
	Headache						Dizziness or light headedness					
	Extra Pain and/or Radiating Pain						Nausea					
	Tingling/numbness in legs or arms						Other (please describe)					
							Not concerned	Very concerned				
8.	How concerned were you by this reaction? (please circle)	1	2	3	4	5						

9.	Have you ever changed chiropractor? (please circle)	Yes	No
10.	If Yes, what was the reason? (please describe)		

Section B: Your experience of chiropractic care and treatment

For each question please circle Yes or No in **BOTH** the 'Expected?' and 'Did it happen?' columns

Before Seeing the Chiropractor		Expected?		Did it happen?	
11.	I expect to be given general information about chiropractic treatment and what it involves	Yes	No	Yes	No
12.	I expect to be given general information about possible reactions (both positive and negative) to chiropractic treatment	Yes	No	Yes	No
13.	I expect to be given information about what will happen at my first consultation	Yes	No	Yes	No
14.	I expect to be told about the cost of treatments	Yes	No	Yes	No
15.	I expect to be told how long the first consultation was likely to last	Yes	No	Yes	No
16.	I expect to fill-in and sign a consent form for the first consultation	Yes	No	Yes	No
17.	I expect to provide my General Practitioner's name and contact details	Yes	No	Yes	No
At the First Consultation		Expected?		Did it happen?	
18.	I expect to be given time to tell the chiropractor about my problem and how it was affecting me	Yes	No	Yes	No
19.	I expect the chiropractor to take a detailed account of my personal case history	Yes	No	Yes	No
20.	I expect to be given a gown and/or towels to cover up if I had to undress	Yes	No	Yes	No
21.	I expect to be able to undress and dress in privacy	Yes	No	Yes	No
22.	I expect the chiropractor to explain why any further investigations (e.g. X-Rays) were necessary and any risks associated with them	Yes	No	Yes	No
23.	I expect the chiropractor to give me a diagnosis or rationale for my care	Yes	No	Yes	No
24.	I expect the chiropractor to explain what treatment I will need (e.g. the type, frequency and duration of treatment)	Yes	No	Yes	No
25.	I expect the chiropractor to talk to me about any possible adverse reactions to the treatment	Yes	No	Yes	No
26.	I expect the chiropractor to talk to me about the likely success of the treatment	Yes	No	Yes	No
27.	I expect the chiropractor to explain what the cost of the agreed treatment plan would be	Yes	No	Yes	No
28.	I expect the chiropractor to give me time to ask questions about the proposed treatment plan	Yes	No	Yes	No

On-Going Treatment		Expected?		Did it happen?	
29.	I expect to be given time to tell the chiropractor about how I felt after my last treatment, and discuss any problems or concerns	Yes	No	Yes	No
30.	I expect the chiropractor to ask me if there has been any change in my condition, general health or medication	Yes	No	Yes	No
31.	I expect the chiropractor to allow sufficient time for the consultation	Yes	No	Yes	No
32.	I expect the chiropractor to talk to me about further treatment options	Yes	No	Yes	No
33.	I expect the chiropractor to allow me time to decide what I wish to do about future treatment	Yes	No	Yes	No
34.	I expect the chiropractor to agree with me when my treatment should be reviewed	Yes	No	Yes	No
35.	I expect the chiropractor to give me advice about how I manage my problem/symptoms between treatments	Yes	No	Yes	No
Chiropractor's Knowledge and Experience		Expected?		Did it happen?	
36.	I expect that information about the chiropractor's qualifications and registration will be displayed in the clinic/available in leaflets/included on the practice website	Yes	No	Yes	No
37.	I expect that information about the chiropractor's experience (e.g. length of time in practice) will be displayed in the clinic/available in leaflets/included on the practices website	Yes	No	Yes	No
38.	I expect that information about the chiropractor's special interests or additional skills (e.g. soft tissue massage) will be displayed in the clinic/available in leaflets/included on the practice website	Yes	No	Yes	No
39.	I expect that information about how the chiropractor is maintaining/improving their professional knowledge (e.g. further training) will be displayed in the clinic/included on the practice website	Yes	No	Yes	No
40.	I expect that if my problem is not improving with chiropractic treatment and/or I have other health needs, the chiropractor will discuss referral to another healthcare practitioner	Yes	No	Yes	No
41.	I expect that, if necessary, and with my consent, the chiropractor will contact my GP	Yes	No	Yes	No
Patient Feedback and Complaints		Expected?		Did it happen?	
42.	I expect the chiropractic practice to have a clear system to enable me to provide confidential feedback (whether positive or negative)	Yes	No	Yes	No
43.	I expect to be given information about the practice's complaints procedure	Yes	No	Yes	No
44.	I expect to be told about my right to refer a complaint to the General Chiropractic Council and be given the GCC's contact details	Yes	No	Yes	No
Further comments					

Section C: Assuring Chiropractors are 'Fit to Practise'

We are interested in what would reassure you that your chiropractor is keeping their knowledge and skills up to date. Please indicate your level of agreement with the following statements		Strongly disagree		Strongly agree		
45.	The chiropractor should provide patients with up to date information about their on-going training and development	1	2	3	4	5
46.	The chiropractor should review their practise regularly (e.g. every 3 years) with support from another experienced chiropractor	1	2	3	4	5
47.	The chiropractor should be reassessed regularly (e.g. every 3 years) by an independent assessor to ensure they are keeping up to date	1	2	3	4	5
48.	The chiropractor should have a system for gathering patient feedback and patients should be able to see the feedback recorded	1	2	3	4	5
49.	There should be a national system for gathering patient feedback and patients should be able to see the feedback recorded	1	2	3	4	5
Further comments:						

Section D: About You

50.	Are you?	Male	Female	
51.	What is your age?			
52.	What is your ethnicity? (please circle or tick one)			
	White	Black or Black British	Asian or Asian British	
	Chinese or Chinese British	Mixed heritage	other ethnic group	
53.	Do you consider yourself to have a disability?	Yes	No	
54.	What is your highest level of academic education/attainment? (please tick)			
	No academic qualifications	GCSE or equivalent (e.g. O Level, CSE, NVQ1)		
	A levels or equivalent (e.g. NVQ 2-3, BTec certificate, City and Guilds crafts)	BA or BSc degree or equivalent (e.g. NVQ 4, BTEC diploma, City and Guilds level 3+, nursing or teaching qualification)		
	Masters Degree, PhD, Post graduate certificate or NVQ 5	Other (please give details)		
55.	How would you describe the area you live in? (please circle or tick one)			
	City/Urban area	Town or suburb	Village/Rural area	
56.	Which of the four UK nations do you live in? (please circle or tick one)			
	England	Scotland	Wales	Northern Ireland

Appendix 2 Topic Guide for Focus Groups and Interviews



General
Chiropractic
Council



THE UNIVERSITY of York
Department of Health Sciences

Expectations of Patients of Chiropractic (EPOCH) Project Topic Guide for Initial Focus Groups and Interviews (Draft 2 11/5/12)

Introductory Comments

- Introduction/Welcome
- Brief overview/reminder of the study:
 - This research has been commissioned by the General Chiropractic Council. The GCC is the UK-wide statutory body which regulates chiropractors. They set standards of chiropractic education, conduct and practice and ensure the development of the profession of chiropractic
 - The GCC is currently looking at how best to ensure that chiropractors are 'fit to practise', and how this might be assessed as part of a *revalidation* process. They are keen to take account of patients' views and expectations as part of this process
 - There are two main parts to the research – i) the focus groups and interviews you are taking part in, and ii) a national survey of chiropractic patients
 - We'll then prepare a report for the GCC.
- Ask participants if they would like to ask any questions
- Reassure participants about confidentiality i.e. no patients will be named; where quotes are used it will be in a way that would not enable individuals to be identified; all names and contact information will be destroyed at the end of the study and patients details will be not shared with anyone outside the research team
- Ground rules for the group - confidentiality (i.e. what is said in the group remains in the group); only one person speaking at a time; fine to ask for a break if needed

Introductory Questions

- 1a. For the focus groups - Ask people to introduce themselves i.e. first name, plus brief information about why they decided to seek treatment from a chiropractor
- 1b. For the interviews – why did you decide to seek treatment from a chiropractor?
2. Had you used other manual therapies (e.g. physiotherapy, osteopathy) or chiropractic before this recent course of treatment?

Choosing Your Chiropractor

3. What made you chose the chiropractor who is treating you now?

Prompts: General reputation e.g. other patients recommended them
Referred or recommended by another healthcare professional
Special interest in their condition/knowledge of their disability
Understanding of my cultural needs
Easy to get to and/or only chiropractor in their area

4. What information (verbal or written) from your chiropractor or from another source (e.g. General Chiropractic Council) reassured you that your chiropractor had the professional knowledge to treat you appropriately?

Prompts: Display of professional qualifications/registration details
Being given a clear chiropractic diagnosis of my problem
Having my treatment plan explained to me, including likely progress and any risk/problem that might occur
An explanation of how the chiropractor will communicate with my GP (or other key health professional) if necessary

Expectations

We are interested in what you expect when you go to see your chiropractor and would like to ask you about three aspects:

5. What do you expect in terms of your experience as a *patient or customer*, for example a pleasant clinic environment, flexible appointment times, value for money, and positive staff attitudes?
6. What do you expect in term of the *treatment or therapeutic process*, for example sufficient explanations of chiropractic, discussion of potential risks and benefits, information about complaints procedures, sufficient time for the treatment, the treatment will impact on symptoms, you will be involved in decisions about your treatment, and given advice about self-management, and provided onward referral if symptoms not improving?
7. What do you expect in terms of the *relationship with your chiropractor*, for example they will understand your symptoms, they will listen and take account of any concerns you have about treatment (e.g. safety, pain, implications for other health problems), they will respect confidentiality, and you feel you can establish a trusting relationship with them?
8. To what extent have your expectations in each of these areas been met, or not, by your current chiropractor or chiropractors you have seen in the past?

Risks and Benefits

9. What have been the main benefits (if any) for you of receiving chiropractic treatment?

Prompt: Explore whether they expected/hoped for these benefit before they had chiropractic treatment or they were unexpected/additional

10. What do you think are the main risks associated with receiving chiropractic treatment?

Prompt: Explore whether they were aware of these risks before deciding to have chiropractic treatment

11. What are the main things that have influenced your perception of the benefits and risks of chiropractic?

Prompts: Their experience of receiving chiropractic
The information provided by their chiropractor
Discussions with patients with similar conditions
Discussion with other health professionals
Articles about chiropractic in the media

Fitness to Practice/Revalidation

12. As a patient, what would reassure you that a chiropractor is 'fit to practise'?

Prompts: The standard of their work is reviewed regularly...
If yes, who by and how often
They work with other chiropractors to compare practice/share learning
They undertake on-going training to keep up to date
They have access to professional advice and support
They belong to a professional association

13. Other comments/thoughts that you would like to add?

Concluding Comments

Thank the group/interviewee for taking part in the research
Explain when the report will go to the GCC
Ask if anyone would like to receive a summary of the main findings
Arrangements for travel expenses
Check if anyone has any final questions

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