

# Consent The Patients' Perspective

**GCC Patient Community: Project Two**



**Basically, consent is permission to treat you, which they should ask every single time. “Are you happy for me to proceed?”**

**GCC Patient Community member**

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## Executive Summary

As part of its [2022-24 Strategy](#) commitments, the General Chiropractic Council (GCC) has established its GCC Patient Community comprising 20 chiropractic patients. Its purpose is to inform the GCC of patient motivators, influences and perceptions on choosing a chiropractor, especially as this healthcare choice has a cost consideration.

The Patient Community will ultimately contribute the 'patient voice' to the GCC's decision-making processes.

### Understanding consent

In October 2022, GCC Patient Community held an online forum focussed on understanding consent within chiropractic care. More specifically, the research set out to explore:

- the principles and key components of consent.
- what, if any, additional information and resources might be required for patients in the [GCC Patient Portal](#) and registrants regarding consent.

### Key findings

- **Patients have a reasonable understanding of consent within the context of chiropractic care**

Members of the Patient Community describe consent as the giving and receiving of information to enable a patient to make an informed decision; with information about immediate and future side effects, risks etc being regarded as key.

Some members consider consent as an individualised process, whereby the chiropractor ensures that information is sufficiently tailored to the individual patient, taking into account a patient's medical history and communication preferences. It is important that patients feel in control and understand they can withdraw consent at any time.

- **Patients believed the consent was broadly similar across a range of different healthcare settings**

Experiences of consent in chiropractic were comparable with other healthcare settings. However, some Patient Community members pointed out that the nature of ongoing consent could be slightly different if patients visited the chiropractor reasonably frequently. In these situations, they anticipated that ongoing consent would be a less formal process or part of an established ongoing dialogue. They believed that this would not be the case within other healthcare professions that patients saw less frequently i.e., dentists.



- **Patients agree with the principles of consent outlined by the GCC**

Members of the Patient Community agreed that consent had to be voluntary; based on sufficient information; part of continuing communication; and, that patients required capacity (although capacity was spontaneously raised, patients soon recognised its importance). Patients also strongly concurred that chiropractors had to obtain specific consent for removing a patient's clothing. It was unclear to some patients how consent was documented by their chiropractor.

- **Patients need a broad range of information in order to give informed consent**

Patients were most animated when talking about the information they required in order to give informed consent. They often highlighted that this information needed to have a broad focus and encompass the wider chiropractic experience as well as the treatment itself.

- **Patients want to be told of significant risks**

When considering risks, patients wanted the chiropractor to be aware of and communicate significant risks. However, in cases where the risk was significant but unlikely, a number of participants took a more pragmatic view, whilst others remained adamant that the patient needed to be able to weigh up all risks before making a decision.

### **Recommendations**

- 1) **For the GCC** to enhance patients' knowledge and understanding of chiropractic treatment in order to feel confident when giving informed consent
- 2) **For Registrants** to recognise and understand the principles of informed consent and have processes in place to obtain consent from patients
- 3) **For Patients** to feel empowered to ask about consent if not raised by their chiropractor

# One: A patient definition of consent

Members of the Patient Community were able to put forward a simple definition of consent within the context of chiropractic care. These definitions highlighted some key points around consent.

## GCC Patient Community:

### 1. Consent as a two-way process

- Some members regarded consent as a two-way process whereby the chiropractor shares information with a patient and, if happy with that information, the patient gives permission to proceed with treatment.

What the Patient Community members said:

“It’s... putting you in a position of making an informed decision so you can make a decision based on the correct information.”

### 2. Consent must be informed

- Some members expected a broad range of information about the treatment itself (and the treatment environment); how they might be expected to feel after the treatment; what the treatment would cost; opportunities for future self-management of the issue.

What the Patient Community members said:

“I think that part of that explanation needs to encapsulate what might come in the next few days and how that might impact you. Because consent in the moment is slightly different than things that have a bit more of a lasting impact. I would kind of expect consent to be, I’m going to do this, it might hurt, but it’s going to work in this way, but you might have some soreness or something that goes on for a few days. I think it’s slightly broader from my understanding of it, than just in the moment of what they’re going to do. It’s kind of what the impact is maybe over a week or so.”

### 3. Consent as an on-going process

- For some members consent was viewed as an on-going process and not a one-off conversation or activity.

What the Patient Community members said:

“Consent is basically permission to treat you, which they should ask every single time. “Are you happy for me to proceed?””

#### 4. Appropriate and tailored consent

- Patients recognised that consent should be appropriate and tailored; recognising that patients have different levels of understanding and experience of chiropractic care; as well as different expectations of their chiropractor.

#### What the Patient Community members said:

“I mean it’s also the kind of cultural angle from that, if you’re a person that has never been to a chiropractor before and you’ve not had any experience at all, what’s going to happen and they are going to need to touch you and put hands on you, so, you know, in some cases that may make people feel uncomfortable. So, it’s just realising that.”

## Two: Patients’ experiences of the consent process

**Members of the Patient Community reported primarily positive experiences of consent processes across the different chiropractors they had seen and were reasonably happy with how consent had been taken.**

#### GCC Patient Community:

##### Positive aspects of the consent process

Based on their experiences, members of the patient community highlighted a number of positive components of what they saw as the consent process.

These include:

- Chiropractors taking a detailed patient history and physical assessment.
- Chiropractors producing a detailed treatment plan, including an outline of the potential number of treatments required and total cost.
- Chiropractors reviewing a patient’s progress at the beginning of each session, ascertaining if anything had changed since the last session and reconfirming that the patient was happy to proceed.
- Chiropractors engaging in dialogue throughout the treatment session, explaining what they were doing and checking that the patient was happy to proceed.

#### What the Patient Community members said:

“When the session started, I was very reluctant, which the chiropractor noticed without me saying anything, and she went way above to talk me through her process, which put me at ease. Her decision to explain her technique made the session go way better than I expected. After that first



time, I booked a follow-up appointment because she had gained my trust by displaying professionalism and knowledge.”

“I have been to two different chiropractors, and both times they’ve done a verbal consultation initially over the telephone to ascertain (i) what my problem was and what they could help with, and (ii) to explain some of the processes they went with.”

### **Negative aspects of the consent process**

However, whilst broadly happy with their experience, some members did identify some issues with the consent process. These issues generally related to the information they were given, such as:

- The generic nature of the treatment plan
- Chiropractors’ use of unfamiliar or ambiguous language
- A limited explanation of what the treatment would involve i.e., no mention of what sounds and sensations the patient should expect
- Limited explanation of what to expect after the treatment i.e., soreness, stiffness.

### **What the Patient Community members said:**

“I got an email of some sort, and they called it a treatment plan, but I felt like it was very basic. It didn’t go into much detail. I felt like it was a printout they already have that they send to multiple people.”

“Well, it’s tricky, because I do feel like I was consenting in an informed way. But I also think some of the terms that they used are a bit woolly and a bit of a catch-all. You know, “I’m going to do this”, or whatever, “You may have this sort of pain going forward.” I know it’s really difficult to be specific because everybody’s body is different, and pain thresholds etc, but it is quite a catch-all thing of, you know, “If I do this you may have pain, but you may not.” You know, it’s not very definite.”

Several patients believed that information was sometimes lacking because chiropractors expected patients to have conducted their own research into chiropractic care before seeking help and, therefore, assumed that patients had a certain baseline understanding.

### **What the Patient Community members said:**

“I kind of knew what was going to happen but that’s because I asked them to detail that for me more. Whereas I think if I didn’t ask, I wouldn’t have got so much information. I think sometimes chiropractors expect people to know what they’re coming there for.”

Indeed, one or two confirmed that they did conduct extensive research and felt informed from the outset, however, this was not the majority. Furthermore, in two instances patients were in severe pain and couldn’t recall how they gave consent and in one case the patient was being treated by a friend who appeared to bypass all consent processes.

## What the Patient Community members said:

“When I met that person, when I met the chiropractor, he didn’t really explain what will be happening but just roughly. I was in pain and the pain was coming back all the time, that I couldn’t do much. And at that time, I was working in care, so I needed to be ready the next day, and with the pain it was even worse. Consent to me is creating a trust, building a trust, because you should trust them before they will do anything with you. So, I based most of the trust into our friendship, because we were friends at the time, and I just trusted that my friend is not going to break me.

### **Mixed experiences of signing for consent**

Some members of the Patient Community did not recall signing anything when visiting a chiropractor for treatment. Although there were some recollections of signing forms they were unable to recall if this included consenting to (and information about) treatment (as opposed to data protection requirements etc).

Some recalled signing forms but admitted that they did not read the information before signing.

## What the Patient Community members said:

“I signed maybe five/six different pieces of paper, and there potentially was a consent form on there.”

“I was given a paper to read, and I can’t remember what it was. I was asked to sign at the bottom. It was like two or three pages. To be honest, I didn’t bother to read that because...it was quite lengthy.”

### **Experiences of consent within other healthcare professions**

The Patient Community reported that their experiences of consent in chiropractic were comparable with other healthcare settings.

However, it was noted that patients seeking chiropractic care were more likely to have conducted their own research prior to seeking an appointment and therefore may need less or be offered less information about chiropractic care than they would in other healthcare settings.

Members also discussed whether the frequency of chiropractic appointments, compared to some other healthcare appointments, might result in a less formal process of ongoing consent over time because they have established a trusted relationship with the chiropractor:

## What the Patient Community members said:

“I’ve had a couple of operations, one emergency and one non-emergency on my back, and it was the same sort of thing. It’s like, ‘Oh you may get, you know, kind

of major bleeding, you may get minor bleeding. This is what to expect with the stitches. This is what you can and can't do.' And that was all run through and then a form to sign at the beginning, you know, in the same sort of area as going to the chiropractor."

"You don't go to see your dentist more frequently than probably twice a year, if you're doing check-ups and stuff like that, whereas you will see your chiropractor more than twice in six months. You could be seeing them every week, you could be seeing them twice a week, you could be seeing them once a month, and so the familiarity would lead to maybe less consent, because there is a perception that you are more familiar, you know what you're doing."

## Three: Exploring key aspects of consent

### Key themes emerging from scenarios and discussions

Patient Community members discussed a number of different facets of consent. To prompt the discussion, members were sometimes asked to respond to specific scenarios (Appendix 2).

#### Voluntary nature of consent

Patient Community members recognised that consent needs to be voluntary with some members pointing out that the principle of consent is voluntary because they had actively sought out a chiropractor. Although there were no experiences of patients being coerced into accepting treatment, one or two members alluded to feeling under pressure to make a subsequent appointment with the chiropractor and carry on with treatment. In these instances, the chiropractor asked the patients when they were next free to attend an appointment, as opposed to asking them if they would like to book another appointment (these same patients seemed less clear about their original treatment plan).

#### What the Patient Community members said:

“They didn’t come to me and say, “I want to do this to you.” I went and said, “This is what my problem is, can you fix it?” So, it was me going to them and saying, “I want you to do this” rather than the other way round”

“So when I was having my treatments, they wanted to book an appointment there and then rather than waiting for you to call them and book another appointment. Like with the GPs they ask you to ring us and book an appointment, whereas with here they just – literally they are there with the calendar, ‘Okay, so you are free this date, this date, this date, this date or next week?’ So that’s like kind of a pressure on you.”

#### Ongoing nature of consent

Patient Community members stressed that chiropractors should establish an ongoing dialogue as a means of building trust and helping patients relax as well as a means of obtaining informal, ongoing consent. The importance of dialogue at the beginning of each appointment was highlighted so that chiropractors could find out about the patients’ experiences in-between appointments. For example, how the patient felt after their last treatment; any unexpected side effects; any new issues to discuss; any more general changes to patient health.

Furthermore, when members of the Patient Community were shown a scenario (Appendix 2) relating to consenting to a new technique, not all of them felt that the use of a new technique required formal and explicit consent unless the technique posed increased risks to the patient and may come as a

shock. In this case members agreed that chiropractors need to talk to patients about what to expect. Some members felt strongly that any treatment that could come as a shock to the patient should be discussed and explicit consent obtained.

### What the Patient Community members said:

“I always seem to have something wrong and when he treats my back it’s always very, very tight and it’s uncomfortable and very scary, because I feel like I’m paralysed after I get a treatment. I’m like stunned for like seconds, which is very invasive. So perhaps out of courtesy he asks, “Are you happy for me to proceed?” I don’t actually fill in forms, I only do it initially, but he asks every time, maybe out of courtesy, to provide assurance.”

“You give that consent at the beginning, they talk you through a treatment plan most of the time – in my case they did – and then during the small interactions I had with them, they generally, because they wanted me to move into different positions, ‘Lie on your back, I’m going to do this.’ So as they were telling me to move, or moving me, they were telling me what they were doing anyway, so I don’t think I needed consent to, ‘Right, do you consent to me turning you onto your back?’ I just think that’s a level that is ridiculous for that.”

### Implied versus explicit consent

Members of the Patient Community believed that simply attending appointments and following a chiropractor’s instructions indicated consent, assuming that the patient had explicitly consented to an initial treatment plan.

Some felt that explicit and more formal consent was only required when the chiropractor was doing a new or different type of treatment. Patients were also quick to point out that explicit consent was required in instances where the chiropractor needed to remove items of clothing or intended to work near particular areas of the body.

### What the Patient Community members said:

“I suppose, using my example, but they told me, for example, “We are going to do this now, please roll over onto your right side.” The sheer fact that I turned over onto my right side, I’m consenting.”

“I think if the patient is there, that in itself is assuming consent because of the situation of who they are as professionals. You know, it’s not like going to a doctor for instance, where you are seeking advice, as opposed to come to a chiropractor, you are going there for a specific reason. So that’s what I think, you know, going there, you have the capacity, you understand it.”

Members of the group who were more anxious required more reassurance from their chiropractor, including the expectation of more frequent consent discussions.

## What the Patient Community members said:

“It calms me. Because he is taking me under his wing and he is like, ‘Are you happy to proceed?’ You know, he is showing that he cares and is making sure that you are prepared for what’s coming.”

“I think in terms of the practice I went to, you only had to give consent for different treatments, just because obviously I went for something else. You would need to know what’s happening with that different treatment.”

However, members were quick to point out that explicit consent was required in instances where the chiropractor needed to remove items of clothing or intended to work near particular areas of the body.

### **Consent to share personal information**

In response to a scenario about the sharing of information (see Appendix 2), Patient Community members agreed that explicit consent is required in relation to data sharing and issues pertaining to confidentiality.

### **Capacity to consent**

Members of the Patient Community did not spontaneously refer to capacity to consent, however, when shown a scenario (see Appendix 2) involving a 15-year-old patient, the majority were surprised that a minor would be deemed to have capacity. It soon became clear that patients saw capacity as integral to informed consent.

## What the Patient Community members said:

“They won’t have the capacity to take on all of the information that they are going to be given for a serious treatment like this.? Kids don’t think about these things – the parents have to be involved in some way. It’s not technically the kid that is giving consent either, it has to be the parents.”

Further discussions touched upon the fact that there may be a role for the GCC in supporting chiropractors’ ability to assess patients’ capacity to consent.

### **When to ask for consent**

Patient Community members discussed the best time to ask patients for consent and whether they should be given an opportunity to reflect on and consider whether they want to go ahead. Whilst members felt that this was a good idea in principle, they were concerned that a lengthy consent process would delay treatment and felt that there needed to be a pragmatic approach to this.

## What the Patient Community members said:

“I think generally, if you’re going for an appointment, it’s an acute issue. You are sore. You are in pain at that time, and so therefore you don’t want to have to wait any longer for the pain or for something to be treated. Unless you’re having an unusual kind of course of action, you’re going because you’re sore, you’re in pain, and you need it treated there and then.”

### **Informed consent**

In discussions about the consent process, members of the Patient Community expressed an interest in information about the wider chiropractic ‘experience’ and a clear indication of ongoing ‘costs’ and future ‘self-management’ options, alongside information about the immediate chiropractic care on offer.

Members felt that for consent within chiropractic care to be truly informed, the information shared with patients should not solely focus on what happens within the chiropractic clinic.

Additional information discussed includes:

- **Managing a condition**

Some members of the Patient Community felt that further information about what they might need to do after their treatment would be helpful in order to manage their condition and prevent it from reoccurring.

## What the Patient Community members said:

“For example, if patients need to do certain exercises, or sit in certain positions, or use certain additional implements that you might not have, such as a different pillow or a posture brace, for instance. They should give that information as well because you are wanting to get the full overview, rather than just what they’re going to provide. If they give you the information for the tools that you can use as well to help make sure it works to its full potential.”

“I agree with the [information on] what to do afterwards, because I think, after having my appointment, obviously a lot of things were suggested that I should do, and I should purchase and buy, such as I needed the posture brace for when I was working on my laptop, for instance. I think just making sure you are aware of that information prior to actually having the appointment, so you’re not in a rush to get them or you’re actually able to get them as well.”

- **The chiropractic environment**

Further information about the setting was also considered useful. For example, what does a treatment room/chiropractic table look like, does the chiropractor treat more than one patient at the same time, will gowns be provided; how long will the appointment take.

#### What the Patient Community members said:

“Maybe a little bit of explanation would help, whether we get a gown or not, because I knew they will ask me to remove my clothing, but I wasn’t sure if they provide a gown or not. But, because it was a lady chiropractor, I didn’t really bother much. But maybe a little bit of information on that one, whether you provide a gown.”

“You should know what the product is, and that’s kind of aside from the medical considerations and the risks and things like that. You should know I’m going to pay this money, and this is what I can expect to get.”

- **Highlighting risks**

Almost all patients wanted and expected information relating to risks (during and beyond the treatment) i.e., what are the side effects, particularly if the risk was well recognised by the profession at large.

Some members of the Patient Community questioned whether it was both possible or desirable to highlight each and every risk, accepting that there were numerous small risks involved in all aspects of life (not just healthcare). They noted that it was not necessarily helpful to a patient or possible for a patient to take on board every single risk and that patients may be deterred from having necessary treatment by the fear of extremely unlikely negative consequences.

#### What the Patient Community members said:

“There are probably a million extremely small risk things that could happen. I just think in practical life you’ve got to make a call and, as the patient, you have to trust your chiropractor. You have to trust them to kind of do what they think and weigh it up, and kind of give you the information so that you can also weigh up. But you can’t weigh everything up all the time.”

“It’s sort of how small of a chance it was and how rare that issue happens. Because otherwise you could be there for hours going through every single risk and potential risk that could happen. You know, how far do they go? If they have to give a list of everything that could go wrong, then how often would a patient really go through the treatment?”

Some members felt that small risks needed to be disclosed so that the patient was in control and able to decide if they were willing to accept the risk.

Members noted that what might be a small risk for one patient could represent a significant risk to another patient. Therefore,



chiropractors should explain risk in a way that is proportionate and enables sufficient understanding. There is a need for chiropractors to ensure that risk is tailored to the individual.

### What the Patient Community members said:

“I think knowledge is important. They need to advise. I mean that’s one of the reasons why I was nervous because I had read up about so many things that could go wrong. But I think it’s important that people are given the knowledge, whether it’s small or large, they need to know.”

“Regardless of its extremely low risk, it should be disclosed and let the patient decide whether they want to give their consent for that treatment or not.”

“I think that’s a right as a patient, you should know everything. As much information as they can provide you if they have the data. You know, you obviously don’t want to be bombarded and I think there is a fine line between knowing too much and giving too much information, but that’s, again, how you present it. Like say the smaller risk, explain those to them and then if they want to read any further, give them access to that information. At least then you’ve given them the choice.”

## Four: The role of the GCC in supporting consent

Members of the Patient Community agreed with the broad principles of consent set out by the GCC and, for the most part, their experiences of chiropractic reflected these principles. Patients were not able to identify any gaps or suggest improvements.

### Supporting chiropractors

Several members suggested that there was scope for the GCC to emphasise the importance of these principles to chiropractors and support chiropractors to deliver against the principles (in a consistent manner) by issuing supporting materials.

#### What the Patient Community members said:

“You know, if these are principles then they need to be underpinned by quite detailed and reasoned kind of next step and possibly the next step beyond that, you know, to form a full framework, rather than just a kind of six-pillars and then you’re on your own, go! You know, so I think that works fine for me, but obviously it needs to also go quite a bit deeper in practice.”

“The capacity certainly would need to be, you know, quite a lot more detailed because there is so many scenarios to it.”

### Supporting patients

Whilst patients did not identify a need to develop materials specifically on consent for the patient portal, there were one or two suggestions relating to how GCC and/or chiropractors could further support patients. In essence, these suggestions related to ensuring that patients had a good understanding of what their chiropractic treatment would involve, rather than focusing on consent per se.

Patients suggested developing a ‘jargon’ buster or glossary of terms so that patients reflecting on proposed treatment plans or conversation with chiropractors could fully understand the terminology being used.

#### What the Patient Community members said:

“I think the language one is a very good one. Obviously, people’s understanding of the language is different. And then, you know, you don’t want a load of medical jargon, although it’s useful to them to be specific to exactly what they’re talking about, in a lot of cases, the wider public don’t generally understand the medical jargon unless they’ve had time to look it up and Google it.”

Another suggestion from members includes further promoting the use of demonstration aids to support a patient’s understanding of which part of the body the chiropractor will be working on and what they will be doing; recognising that this is particularly vital for those who may not have English as a first language or may have difficulty absorbing verbal and written communications.

#### What the Patient Community members said:

“I think demonstration aids is a good one as well, because obviously going back to speaking, you know, words you perhaps don’t get exactly the meaning, whereas if they’ve got, you know, half a spine there and they can say, ‘Well this is what’s happening with yours and this is what I’m going to do, and this is how it’s going to hopefully affect it for the better to help your symptoms.’ So, sort of demonstration aids would be a good one.”

Some members suggested that some generic information could be provided on risks of common treatments and procedures that chiropractors could refer patients to if they were interested in reading further information/evidence.

#### What the Patient Community members said:

“I wouldn’t want to read all of that, but if it was available on the website of each individual practice, or on the General Chiropractic Council’s website, and the patient could be directed to reading it at that point, that information, then it’s available without the sort of overloading.”

## Five: Conclusions

Although the majority of patients had positive experiences of consent within chiropractic care, experiences varied and revealed that there is potential for improvement and/or consistency within consent, such as:

- Ensuring chiropractors are not relying on patients reading (and understanding) consent forms that highlight potential risks – rather the chiropractor needs to verbally communicate all significant (even if only small) risks in a way that does not evoke fear.
- Ensuring that all chiropractors are engaging in an ongoing dialogue and actively checking in with the patients at the beginning of each session. Whilst this was happening in most cases, it was not universal.
- Ensuring that chiropractors are sufficiently tailoring their information to patients and ensuring that it is understood by all patients; taking into account different communication preferences, levels of capacity etc.

The two members of the Patient Community that had the least positive experience of a consent process had taken advantage of a Groupon voucher. Whilst we know from previous research that patients regard themselves as patients rather than customers/consumers, we also know that the two are not mutually exclusive. The question is whether those that err towards behaving as customers (i.e. shopping around, taking advantage of special offers, concerned about value for money) are somehow viewed differently by chiropractors and miss out on a robust process of consent, or if the poorer experiences described by our two participants are unique.

Finally, in terms of potential information for the patient portal, patients requested little beyond a glossary of terms or 'jargon buster'. Instead, they believed that the GCC should focus on supporting chiropractors deliver the established principles of consent providing information and guidance around:

- Determining capacity for consent.
- Tools/techniques/information for ensuring that patients understand treatment and risks involved.

## **Six: Recommendations with explanations**

### **For the GCC to enhance patients' knowledge and understanding of chiropractic treatment in order to feel confident when giving informed consent.**

Although members of the Patient Community did not highlight the need for any specific materials around consent, additional resources could be developed to help patients better understand their treatment and thus ensure they are better placed to provide informed consent. For example, members highlighted a jargon buster to help explain their treatment. In addition, a factsheet to help explain benefits and risks of chiropractic treatment.

These materials could form a patient resource pack, which would be downloaded from the website directly by patients or made available to registrants to provide to patients as part of the obtaining consent process.

### **For Registrants to recognise and understand the principles of informed consent and have processes in place to obtain consent from patients.**

Guidance around consent is already available on the GCC's website but it would be useful to understand how registrants currently obtain patient consent and, specifically, how they ensure this consent is informed. Gathering registrants' views through a short survey would also help to gauge understanding of the principles around consent and identify any gaps in resources that would support registrants' work in obtaining informed consent.

We will develop a toolkit for registrants to provide guidance and tips to obtaining informed consent from patients.

In addition, communications activity, including newsletter articles and social media posts, will serve to remind registrants of the principles around consent and signpost to the available resources on the GCC's website.

### **For Patients to feel empowered to ask about consent if not raised by their chiropractor**

We will engage with patients via our social media channels to reinforce messages around consent and help them feel empowered to ask their chiropractor if the issue of consent is not raised.

# Appendix One

## Background to research

Following extensive stakeholder consultation throughout 2021, the General Chiropractic Council (GCC) published its [GCC Strategy 2022-2024](#), focussing on four aims, each with its own objectives and expected outcomes.

The strategy's first aim, 'To place patients and their care at the centre of all GCC work', would be realised through three objectives, the first being to gain a greater understanding of patient needs and expectations, so these can be reflected in the work of the GCC.

To fulfil this objective, the GCC commissioned Community Research to establish the GCC Patient Community, a panel comprising a cross-section of 20 chiropractic patients. Members of the Patient Community have agreed to take part in a series of qualitative research activities across several subjects over 12 months to:

- Reaffirm, confirm, establish, disprove or refute ideas and beliefs from within chiropractic.
- Develop a clearer picture of patient motivators, influences and perceptions on choosing or continuing to use a chiropractor.
- To bring the patient perspective to the GCC's decision-making processes.

## Research methodology

Community Research conducted a series of 3 online focus groups with patient panel members. Each group was 90 minutes long and comprised 3-6 participants, with 13 out of 20 panel members taking part in total.

A series of scenarios highlighting key issues (Appendix 2) relating to consent were shared with all of the focus groups. However, these were selected based on the preceding discussion and the need to bring out debate which had not emerged spontaneously. As a result, the scenarios were not rotated equally across the groups and some were not used at all. Therefore, views of certain scenarios are based on a particularly small number of participants in some instances.

## Patient Community member quotes

On occasion, quotes from GCC Patient Community members have been edited or amended for grammatical and ease of reading/interpretation reasons. The context and outcomes of all quotes have not been changed in any way. A copy of the original, unedited quotes can be provided upon request.

## GCC Patient Community membership

GCC Patient Community Size	20	
Recency of visit	20	Members had visited a chiropractor at least once in the past six months.
Number of years GCC Patient Community members had sought chiropractic care	4	Less than 12 months
	11	1-3 years
	1	3-5 years
	4	6+ years
Nation	13	England
	2	Northern Ireland
	3	Scotland
	2	Wales
Sex	10	Female
	10	Male
Age	6	Under 35
	11	35-65
	3	65+
Socio-economic group	6	AB
	8	C1C2
	5	DE
Ethnicity	2	Caribbean
	2	Indian
	1	Pakistani
	1	White British: Black Caribbean
	14	White British: English, Irish, Scottish, Welsh, Other
Long-term condition or disability	4	

## Appendix 2 - Consent Scenarios

### **Disclosing Risks**

A chiropractor advises a patient about the risks associated with the treatment they would like to perform (soft tissue massage). Specifically, the main risk is post treatment soreness. Following the treatment, the patient developed significant bruising in the area of treatment (gluteal region). The patient feels the chiropractor should have had advised them of this risk. The chiropractor states they were unaware of bruising being a risk from this treatment type as they were not taught this when they learnt the technique. However, this risk has been established in the profession and a safer practice notice has been issued by the Royal College of Chiropractors.

### Considerations

- Is it reasonable for chiropractors to know all risks of all treatments?
- Should the chiropractor have known this risk and advised the patient?
- Could this information have impacted consent gained from the patient?

### **Disclosing Risks 2**

A chiropractor carries out a treatment technique (manipulation) to the shoulder of a patient. Prior to this the chiropractor thought they had disclosed all relevant and likely risks, benefits, outcomes and alternatives and therefore consent was gained from the patient. Unfortunately during this treatment technique the patient shoulder dislocated which required imaging and medical treatment. There is an extremely small risk of this event occurring, therefore the chiropractor felt they did not need to disclose this, instead they focused on the most common risk i.e. soreness.

### Considerations

- Should chiropractors focus on the most likely or most severe risks?
- If a risk is extremely low, does it need to be disclosed?



### **Alternative Options**

A chiropractor has been treating a patient with hip arthritis over the last 18 months. The patient's condition has not worsened but not really improved. The patient still has significant difficulty in walking for more than five to 10 minutes and requires the use of a walking stick. The chiropractor has always advised the patient of all the risks and benefits associated with the treatment they are performing. The patient eventually sees an orthopaedic surgeon who advises them that a hip replacement is another valid treatment option, in fact the recommendation with the highest evidence behind it. The patient eventually had a hip replacement and achieved a significant improvement. The chiropractor did not disclose to the patient the alternative option of a hip replacement as they felt that chiropractic treatment was the best approach. In particular, it had the lowest risks and therefore they were putting their patients interests first.

#### Considerations

- How important are alternative options as part of consent?
- Was the chiropractors acting in the patients best interests?
- Did the chiropractor truly obtain informed consent?

### **Patient under 16 years old**

A 15 year old patient attends a chiropractic clinic due to low back pain. The patient is alone but states they have their parents' consent to attend to treatment. The chiropractor considers the patient has the capacity to consent as they demonstrate they understand the reason for treatment, the risks, benefits and outcomes as well as alternatives. The chiropractor proceeds with treatment.

#### Considerations

- Is it appropriate to go ahead with treatment?
- How should the chiropractor record this consent?

### **Ongoing consent**

A chiropractor had been treating a patient over the last few months due to neck pain. Prior to treating the neck, the chiropractor would always seek the patient's verbal consent and record this clearly within the notes. The chiropractor had been using a certain technique (Grade 4 Mobilisation) which had been discussed with the patient and informed consent had been gained. The chiropractor decided that a slight modification to the treatment was required (Grade 5 mobilisation). The new treatment had very similar risks and benefits associated with it, however, it is perceived very differently by a patient as it is a quicker treatment technique that can be associated with audible pop/ crack.

#### Considerations

- Does the chiropractor have informed consent for the new treatment as risks, benefits, outcomes and alternatives are comparable?
- Should the chiropractor have notified the patient that the technique will be different?

### **Clothing**

A chiropractor obtained informed consent to carry out acupuncture to the gluteal region of a patient suffering with muscular pain. Although the chiropractor explained that a needle will be placed through the skin into the muscle, the patient did not consider the fact that the chiropractor would have to expose part of the patient gluteal region to perform the treatment. The chiropractor proceeded to lower the patients trousers and underwear without prior warning. The chiropractor felt that because they had explained the procedure, the patient would realise that an item of clothing would have to be lowered, so they get access to the skin.

#### Considerations

- Did the chiropractor obtain informed consent in this scenario?
- How explicit should a chiropractic be when initially describing a technique?
- How important is obtaining additional consent to lower an item of clothing, does this change if the patient is initially aware that this will have to happen?

### **Pressure/ Undue Influence**

A chiropractor assesses the patient, including the use of x rays. The chiropractor explains that the patient has significant degeneration in their spine and will require a package of care to ensure this doesn't get worse. The chiropractor discusses the risks, benefits, outcomes and alternatives. The chiropractor feels that there are giving their professional opinion and seeking to put the interests of their patients first. The patient then consents to have a package of care, which they have over a period of several months. The patient discussed this scenario with a friend of theirs who advises the patient to get a second opinion. The patient sees another chiropractor who reaches a different conclusion and therefore states a different risks, benefits, outcomes and alternatives to treatment. On reflection the patient feels that there was significant pressure to sign up for the package of care offered by the first chiropractor.

#### Considerations

- How can chiropractors ensure that they are not putting pressure or undue influence on patients when decisions are made?

### **Third parties**

A chiropractor has been treating a husband and wife, the couple would always attend together, and one would wait while the chiropractor is treating the other. It is therefore common that health information is discussed in front of each other's spouse. On the next occasion the husband and wife attend separately. The husband attends first and discloses new information about their health status i.e. they require a medical assessment due to new symptoms they are experiencing. When the chiropractor then treats the wife, in conversation he asked about the outcome of the husbands medical assessment. The chiropractor did this because they are concerned and genuinely wanted to know how the patient was doing. The wife then stated she did not know about the medical assessments that chiropractor was referring to and is now worried as the husband had not disclosed this to her.

#### Considerations

- What should a chiropractor do in this situation as they were under the impression that they had consent to disclose personal information to third party i.e. the spouse?
- Is this a breach of confidentiality, does the chiropractor have the patient's consent to disclose this information to their spouse?

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