

# Psychologically Informed Collaborative Conversations (PIC-C): Working in a co-productive way involving patient representatives

[healthinnovationnetwork.com/clinical-themes/mental-health](https://healthinnovationnetwork.com/clinical-themes/mental-health)

April 2021

# Contents

<b>Introduction</b>	<b>3</b>
<b>Chapter 1</b>	<b>4</b>
<b>Co-production: An Overview</b>	<b>4</b>
What is co-production?	4
Why was co-production used for the PIC-C project?	4
How was true co-production met during this project?	4
<b>Chapter 2</b>	<b>7</b>
<b>Patient Representatives Perspectives on Co-production</b>	<b>7</b>
An Overview	7
Inclusion	7
The Patient's Voice	9
Shape Future Care	10
Engaging in Opportunities	10
Challenges in Co-production	17
Next Steps	17
<b>Chapter 3</b>	<b>19</b>
<b>Conclusion</b>	<b>19</b>
<b>Chapter 4</b>	<b>20</b>
<b>Appendix</b>	<b>20</b>
Appendix 1: The Co-Production Ladder	20
Appendix 2: Dear Clinician Letters	21
Appendix 3: Public Journaling	27

# Introduction

The Health Innovation (HIN) was one of four national test sites selected by the Q Improvement Lab (part of the Health Foundation) to test ideas in practice to improve care for people with persistent pain.

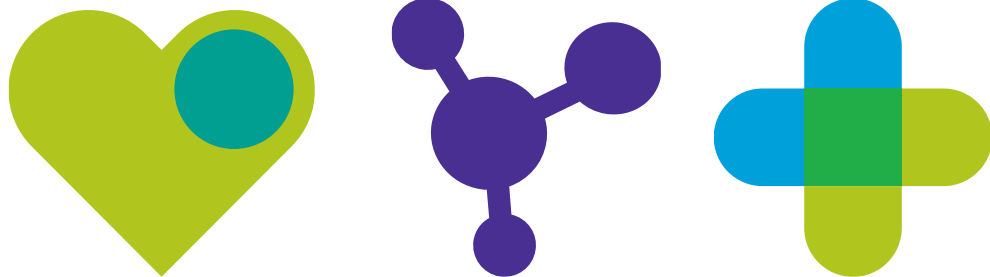
As a result of this work, further funding was awarded from the Health Foundation to progress projects from ideas to practice, and consider how the work can be scaled.

## **Psychologically Informed Collaborative Conversations (PIC-C):**

Working in partnership with the Physiotherapy Pain Association (PPA) and St Georges and Kingston hospital's Chronic Pain Services and MSK teams, we developed a **Psychologically Informed Collaborative Conversations (PIC-C)** training and supervision package for out-patient physiotherapists to:

- increase awareness of the relationship between psychological health and pain,
- increase confidence in starting conversations relating to psychological wellbeing
- establish a mentoring and support structure for complex cases.

The PIC-C programme was co-created with patient representatives. This report highlights the importance of using an integrative co-production methodology and how patient representatives were involved in every aspect of this project, allowing for true co-production to occur.



# Co-production: An Overview

## What is co-production?

Co-production is “A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities”.

## Why was co-production used for the PIC-C project?

Taking time to understand the physical and psychological aspects of a person’s condition helps shape and deliver the best care and services to meet the needs of people using them.

Involving co-production throughout the PIC-C project has allowed for Project Managers, Clinicians and Patients to collaborate to improve research and innovation to inform content development and training delivery, making it more person-centred for the whole population. Co-production in this project was successful due to listening, acting on, collecting, and understanding patients’ thoughts and feelings about the care and their experiences.

## How was true co-production met during this project?

The project team ensured the patient representatives were put at the centre of the project, allowing them to critique and contribute to decisions, and see them as experts, working alongside professionals to ensure the best outcome.

The project team ensured full co-production was met as illustrated by the co-production ladder, by devolving the patient representatives in the project from beginning to end (see appendix 1). The Co-production ladder is a widely recognised model for understanding different forms and degrees of patient and public involvement. Patient and public voice activity on every step of the ladder is valuable, although participation becomes more meaningful at the top of the ladder.

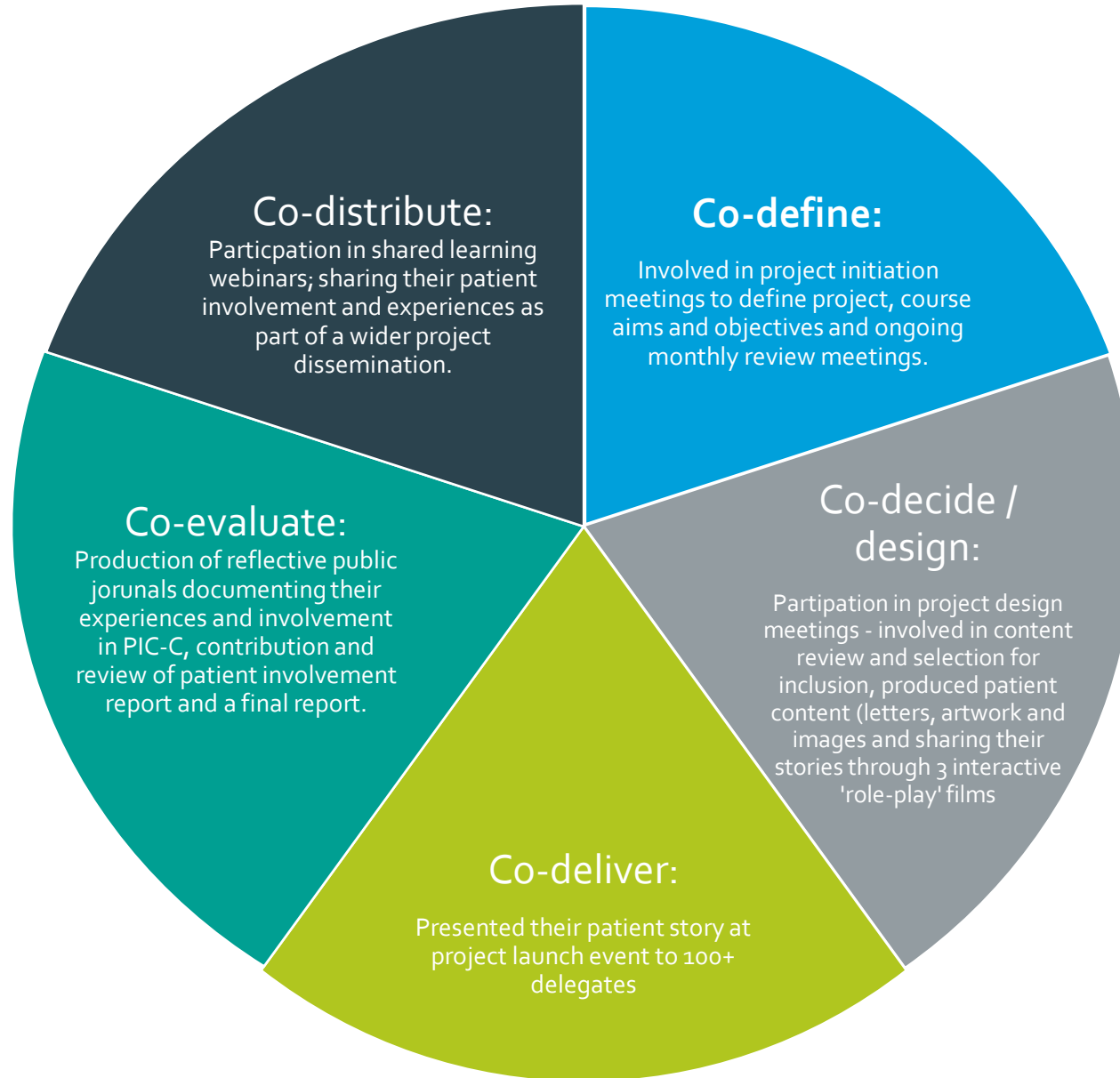
The project team considered patient representatives’ desires, values, personal situations, social circumstances, and lifestyles. Each stage of project development was viewed through the patient representatives’ lenses, seeing them as individuals and team members to develop appropriate solutions.

To ensure a patient centred approach was achieved, the project team followed NICE Guidance ‘Patient experience in adult NHS services: improving the experience of care for people using adult NHS services Clinical Guidance’. NICE Guidance states to consider the following when ensuring a patient centred approach to project delivery and care:

- Develop an understanding of the patient as an individual
- Ensure factors, such as physical or learning disabilities, sight, speech, hearing problems, reading difficulties and understand / speaking English are addressed
- Ask the patient to take into account any factors that may affect their condition, willingness to engage, affect their ability to manage their own care etc.
- Listen to and address concerns / preferences
- Avoid making assumptions
- Take into consideration the requirements of the Equality Act 2010
- Discuss with the patient whether they need any other support

As a result of this approach, patient representatives were devolved in the PIC-C project by ensuring they were involved with co-defining, co-deciding, co-designing, co-delivering, co-evaluating and co-distribution. Figure 1 explains exactly how the patient representatives were involved.

**Figure 1: PIC-C Patient Involvement Co-production Wheel**



# Patient Representatives Perspectives on Co-Production

## An Overview

The patient representatives involved in the PIC-C project expressed their experiences of participating in the project through evaluative semi-structured interviews, by writing public reflective journals and creating blog posts. A thematic analysis to identify themes on patient perspectives on co-production was undertaken by analysing interview transcripts, the journals and blog posts.

The themes identified during the analysis include:

- Inclusion
- Using the patient's voice
- Shaping future care
- Engaging in opportunities
- Challenges in co-production
- Moving forward

1.



## Inclusion:

The patient representatives reported feeling nervous and anxious prior to joining the project group. They worried that they would be surrounded by individuals with existing subject matter expertise and they had not worked in a project based clinical group before.

1.



*"Initially I was obviously a little bit anxious. I do a lot of work anyway at my local hospital, I'm their patient representative, but it tends to be more from my perspective of everything rather than being involved with a clinical group" – PR1*

*"I sort of came in thinking well I have no idea. There are all these people, there is a professor from America and sort of all the heads of departments. But I have to say everybody has been totally easy to work with. I felt that I've been very much a part of it rather than, I suppose initially I thought I'd be very much on the outside [...] and I might just say the odd word." – PR1*

Nonetheless, this was not the case. Patient representatives reported feeling comfortable in voicing their ideas, challenging others, and giving their perspective. They felt their opinions were valued and listened to – a key factor when considering co-production. The patient representatives attributed this to a sense of a flat-structure approach amongst the project team, where the space was open to ask any questions freely and to put forward any ideas and challenges.

*"Firstly, I felt part of the team, I think that has been a really good thing". – PR1*

*"I must confess to initially being a little nervous as the other members of the team were the HIN Project Manager, highly respected clinicians from Kingston and St Georges and one other patient representative who writes blogs on living with pain so I did wonder if my voice would really be heard. However, my nervousness was totally unfounded as the group has been fully inclusive and we have all been treated as equals with our individual views and ideas influencing the content of the package". – PR1*

1.



1.



*"I found it a really good experience. I found that I was accepted as a patient representative, basically as an equal on the team, which were predominantly clinicians. So that was great". – PR2*

*"There was no hierarchy or anything like that, everybody's input was valued and both [the other patient rep] and I felt that we were heard and felt that we were able to make a difference. The team are great – absolutely superb. A lovely bunch of people to work with and I worked with them right from the start on the project". – PR2*

*"The HIN project manager has been absolutely fantastic. She's held us all together, she's made sure that those of us who aren't sort of within the actual network have been so supported and no matter what you asked her, she was there. I just felt that she's really held us all together when at times it must have been difficult, particularly for the clinicians [...] They have my great admiration for just the way it's all been pulled together" – PR1*

Having equality amongst team members allows for true co-production and effective collaboration. An environment where all project members are seen as equal allows for honest conversation, idea sharing and a strong project outcome. Co-production can drive creativity and enthusiasm, and this was felt by the patient representatives involved in the project where they reported buy-in across the project team.

2.



*"Just a big thank you to all of you. Everybody involved in this project has really been super [...] I have felt that everybody's heart and soul has been in this project" – PR1*

*"I think everybody has really tried to pull the whole thing together" – PR1*

*"I think the project was run really well. I think the team showed a great deal of dedication to the project. It was really well led by the Project Manager. Everyone worked well together. We included the patient voice – it was true coproduction. We persevered through the complications of COVID, and we came up with a really powerful training package that will hopefully be utilised going forward." –PR2*

*"I consider that it has been an equal and active partnership with me as a patient representative, clinicians and the HIN". – PR1*

2.



*"My experience was that of true co-production, by all stakeholders, including me as a patient. Impressive!" – PR2*

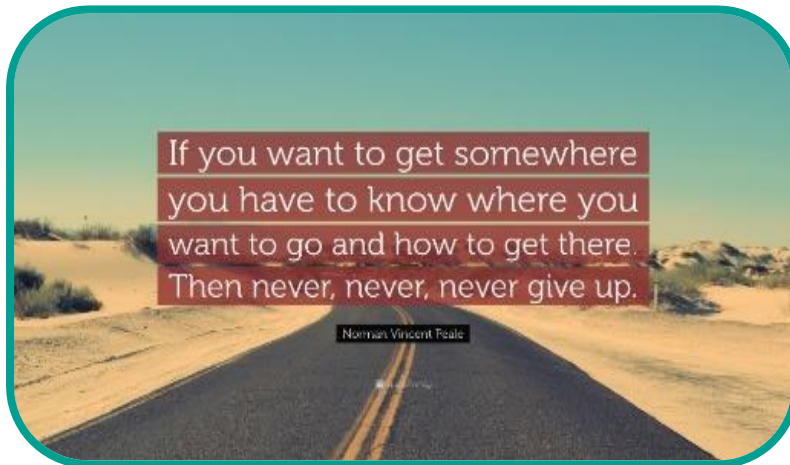
*"I don't know how unique it is to have patients truly co-producing training materials with clinicians, but it is certainly unique for me. Health Innovation Network and the clinicians involved in the project have been amazing to work with. My involvement in this project is something truly value. I hope I have helped make a difference!" – PR2*

Inclusivity into the project group really allowed for the patient representatives to feel involved in every aspect of the project and were able to use their voices to enhance future patient care for the better.



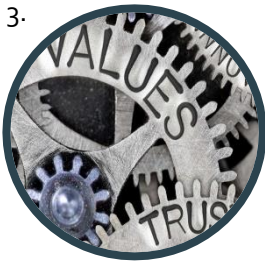
## The Patient's Voice

2.



The patient representatives shared their personal stories and experiences which enabled the project team to understand persistent pain and the psychological impact from a patient's perspective.

3.



*"The patient voice is really important in developing this sort of training. It was really good because both [patient reps] found that we were able to offer a different perspective". – PR2*

Not only did the patient representatives feel comfortable expressing their feelings, stories and emotions, they also felt what they said was listened to by the project group.

*"They have really taken into account the feelings of somebody who has lived now for 24 years with pain – and that's not pain on the odd occasion, my life is pain". – PR1*

*"I think it has been a team that could look at one another's views [...] on the whole I think everybody has listened to everything" – PR1*

*"It is so rewarding to be part of this team and to know that my voice is really being heard and my ideas valued". – PR1*

*"As a patient I was fully included in conversations and decisions. My experience was that of true co-production". – PR2*

*"It's about actually working in a true co-production way and feeling valued". – PR2*

Skills involved in co-production includes listening to the patient voice. The project managers and clinicians listened carefully to the patient representatives throughout this project and took into consideration their views and experiences to ensure the project outcome was positively received by both clinicians utilising it and patients receiving the care.

*"It was really good to have the patient representatives. I was brilliant because we so often design things without actually involving the key stakeholders, which are the patients". – Project Team Member 1*

*"The patient representatives were very direct and very influential in the design of this. There was a leaning towards including the patient voice in the interventions that they developed". – Project Team member 2*

3.



*"It's been really helpful to have the patient representatives throughout. It has given a really useful and different perspective on what our roles are and where we are coming from. They were able to ask some really interesting questions and add comments on the content, our roles and on what the project was aiming to do utilising their fresh perspectives. They were a real benefit in the team." – Project Team member 6*

3.



### Shaping Future Care:

Incorporating the patient voice into this project has allowed for conversations in the clinical space enabling future training to be positively impacted. Without the patient voice, the importance of the need for change in the current care package, would not have been highlighted as greatly.

3.



The patient representatives have been passionate in ensuring the care they and others receive is elevated, compared to what they received as patients in the past.

3.



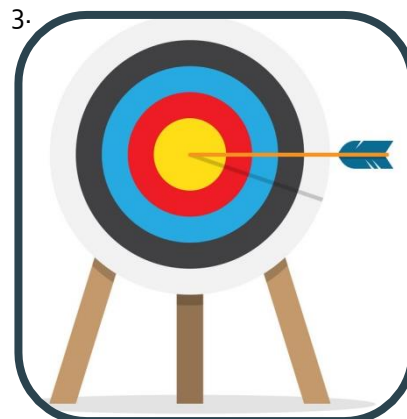
*"Probably being able to voice as a patient some of the things that I can now see are so much further forward than when I was first diagnosed with quite a serious pain complaint". – PR1*

*"I hope now that being part of the team like this that everything we have said will enable people to feel they can talk about their anxieties and the fact that there are psychologists now who will openly ask you how you're feeling [...] I think that's a very important facility and I hope that by talking, other people being able to see me as a patient, saying do talk about it, do have that support – it's there if you ask for it. I believe that physios are far more aware now of what it is like to live with pain. I can't thank them enough" – PR1*

### Engaging in Opportunities:

This project gave the patient representatives opportunities to shape the way training is facilitated in the future. Not only did the patient representatives share a sense of achievement by doing this, they also enjoyed working with the project members and developing a package that would benefit patients.

3.



*"As patients, PR1 and I challenged some ideas, contributed our own and helped ensure the patient voice was both at the centre of our discussions, and the developing training. I am sure we have had an impact on the development of the training, and I am sure the training will be all the better for including our patient voice". – PR2*

*"It has just been great that my experience of living with persistent pain and the way my health care occurred has been able to be utilised to support the development of a training package that will be used to support clinicians and patients going forward. So, yes, I've absolutely loved it." – PR2*

4.



*"But overall it is about producing a training package which actually I am sure will change and improve clinicians' practice and if we can improve clinicians' practice then we are going to improve the care of patients. That will inevitably hopefully lead to more people with persistent pain, like I have, living a better life". – PR2*

*"...everyone involved has shown great motivation to produce on time a high-quality training programme". – PR1*

The patient representatives were involved in developing training material. They filmed vignettes to be used in the training material course. Although there may have been some apprehension around filming, working collaboratively, the project team ensured the patient representatives felt comfortable and at ease. The vignettes have been well received by the project audience.

*"In August, the patient participants were invited to St George's Hospital to film some vignettes to be used as training material for the course. Obviously, I was a little concerned about attending the hospital but was assured that we would be filming in a Covid safe area. The room available was large and airy and the Clinicians had set it up to comply with social distancing requirements. I was their Guinea pig and we experimented with various versions before making the final vignettes. The first vignette highlighted the importance of good communication between the physiotherapist and patient and the second was the psychologist initiating the ability for the patient to speak freely about his/her mental state because of living with pain. I understand that the vignettes have been very well received by the present course participants". – PR1*

4.



5.



*"While we were designing the training, we looked at how some others had produced videos to be used as part of their training. There were some training scenarios that were made up by clinicians, and with clinicians acting as the patients. I questioned why they were doing that, why aren't they using real patients and their real stories? This was taken on board and so that is what we did". – PR2*

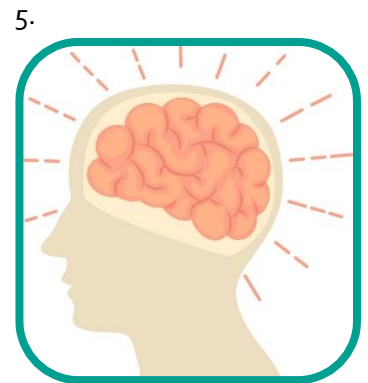




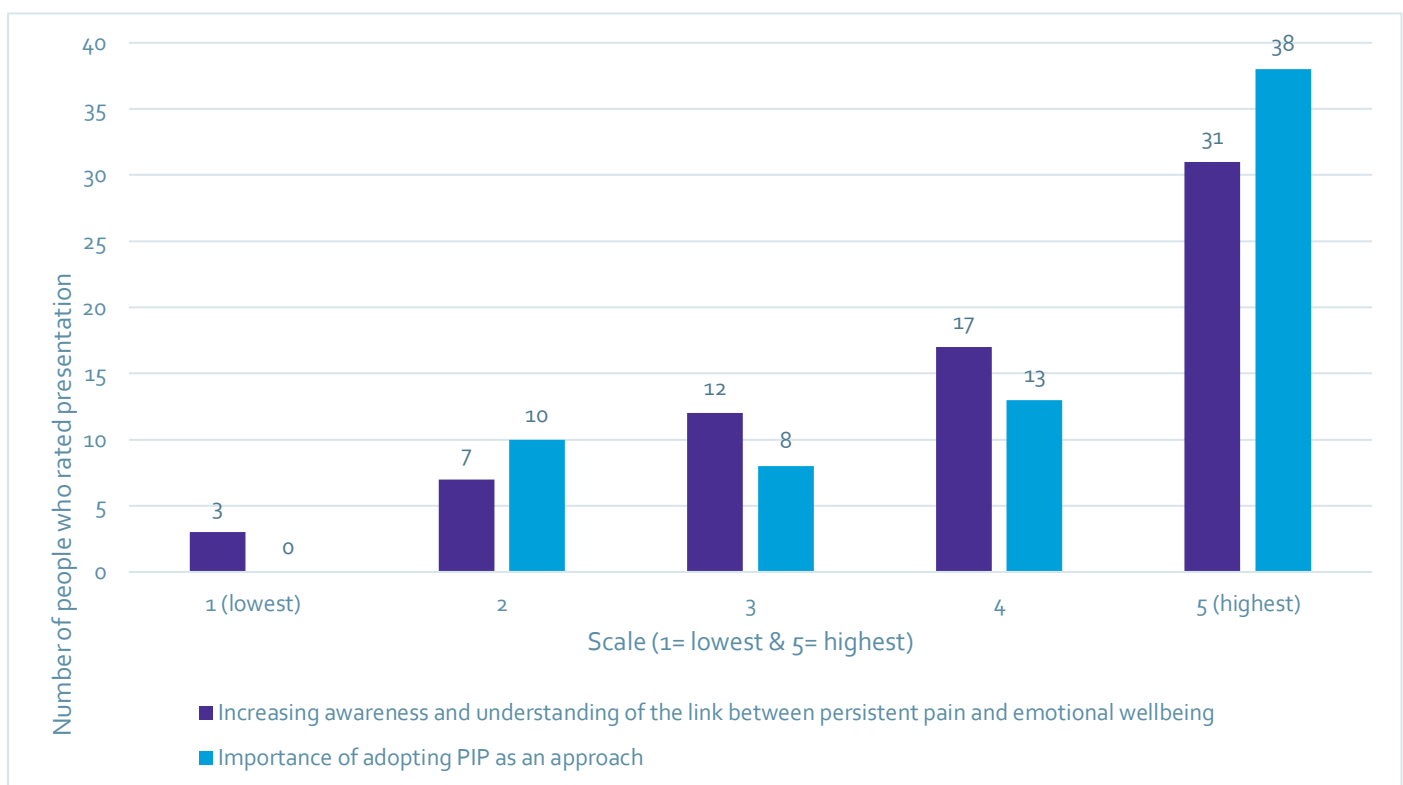
Several other additional opportunities arose from co-production which enriched the project material and resources and encouraged buy in from key stakeholders. Opportunities the patient representatives took part in, included:

- **Public Speaking:**

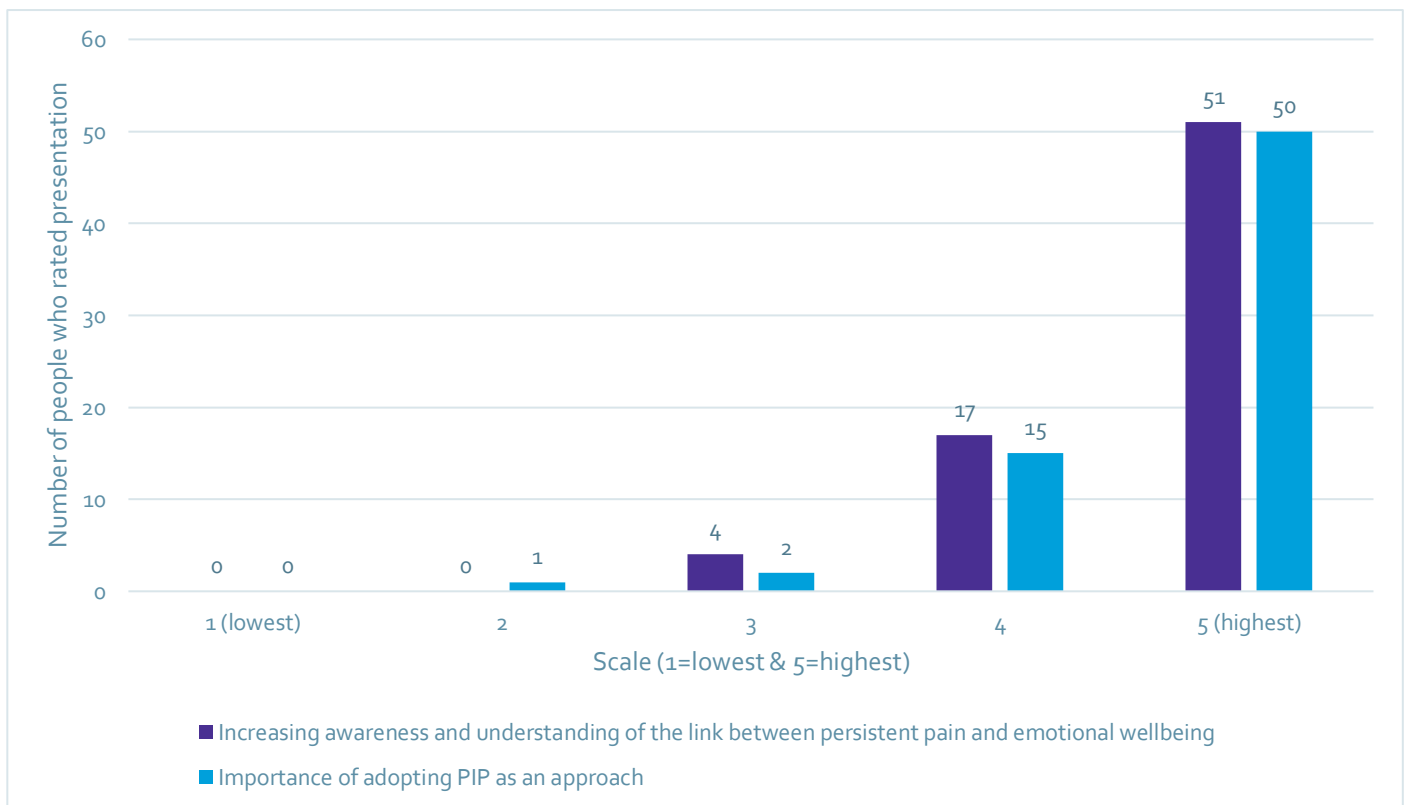
The patient representatives shared their personal stories at the Psychologically Informed Physiotherapist Practice Shared Learning Event on 5<sup>th</sup> March 2020 in Central London. This event hosted 100+ stakeholders nationally, and included physiotherapists, pain clinician's and commissioners. Their stories were highly commended by the audience. See Figure 3 and 4 below.



**Figure 3: A graph to show how useful Patient Representative 1's presentation was in a) Increasing awareness and understanding of the link between persistent pain and emotional wellbeing & b) importance of adopting Psychologically Informed Physiotherapy as an approach**



**Figure 4: A graph to show how useful Patient Representative 2's presentation was in a) Increasing awareness and understanding of the link between persistent pain and emotional wellbeing & b) importance of adopting Psychologically Informed Physiotherapy as an approach**



As well as the audience rating the Patient Representative's personal stories highly, they themselves enjoyed sharing their experiences to change the perspective of clinicians that were in the audience on the day.

*"The day ended with the delegates hearing our patient stories about the effects of living with pain. According to the feedback both stories were very highly rated which was really pleasing". – PR1*



*"We kick started the project with a two-day meeting in London. The format of the course was 'designed' and the way forward planned. In the afternoon of the second day we held a shared learning event for around 100 people, explaining our project and what Psychologically Informed Practice is. Some of us presented, alongside some other invited guests. Scary as it was presenting to a room full of clinicians, I did a 45-minute presentation called 'The need for change: a patient story' and PR1's patient story was also presented. Impressively our patient stories were rated highly by the audience! It was great to put our thoughts across". – PR2*

*"I gave a presentation of my own personal story and it was great to have an impact on both the project and on the clinicians that were in the audience at that time". – PR2*

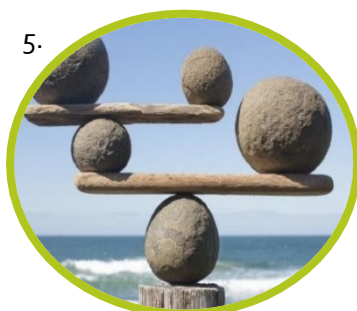


*The PIC-C project team*

- **Written Materials:**

Patient representatives were also proactive in creating material for the project. They wrote Dear Clinician letters that explained their stories and asked Clinician's to reflect whether they would they treat them differently if they knew the psychological impact their persistent pain had on them. The Dear Clinician letters can be found in Appendix 1.

5.



*"It has been a privilege to have actively supported the creation of course materials. I have written some materials for the training course, providing a patient perspective on a range of topics. PR1 and I were involved in the co-production of patient vignettes/case studies which will be used in experiential learning sessions and we hope in the future to be co-delivering some of the training". – PR2*

*"[We] also wrote some materials for the project. We wrote some letters that are being used as course materials. We also filmed a couple of the videos for the training, which was really good. It's mainly just a different perspective being added in." – PR2*

One patient representative set up a blog to highlight their experience collaborating with the Physiotherapy Pain Association (PPA) and their experiences of being involved in the project. You can access the blog [here](#).

6.





- **Artwork:**

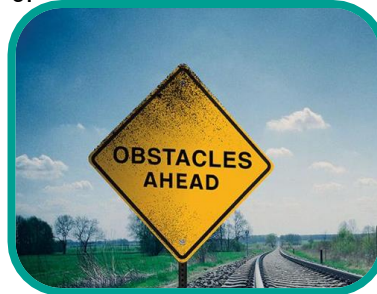
Patient representatives collated artwork and images for the PIC-C training package session slides. Each collation of images and artwork that the patient representatives chose represented the week's theme. The artwork and images have been incorporated throughout this report. Each image has a number assigned to it. This number correlates to the week's session that have been provided below.

- Session 1: PIC-C training package
- Session 2: Adaption Model: Exploring where you are now and how you got here
- Session 3: Exploring Values – Finding your 'why'
- Session 4: Functional Analysis – The ABS of Activity
- Session 5: Behavioural Patterns – Engaging behavioural flexibility
- Session 6: Working with Difficulty – preparing for when things get tricky
- Session 7: Building on progress – Helping changes to stick
- Session 8: Finishing Interactions – The end and the beginning

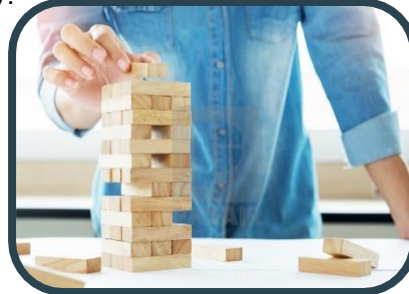
6.



6.



7.



6.



8.



8.



Not only does co-production with patient representatives allow them to bring a patient's perspective to the project, it allows them to understand care from an academic and clinical perspective, as well as learn new skills.

*"COVID was the biggest thing. I've had a great experience, I've learnt something [...] I've learnt to use ZOOM, I've learnt to be able to communicate with seeing all these people in front of me. I'm very much a person to person rather than sit in front of a screen but no I've learnt that". – PR1*

*"It is about collaborating with the other people on the team – there were some really super people on that team who I learned a lot from". – PR2*



## Challenges in Co-production:

Patient representatives felt the only factor that hindered co-production during the PIC-C project was the Covid19 pandemic. All face-to-face contact had to be facilitated utilising digital sources during the pandemic. Patient representatives stated that a mixed course delivery approach, using face-to-face methods and online methods, would be beneficial moving forward to deliver training.

*"Well it would have been nicer to be able to have more, when I say personal contact, I think when you're sitting in a room, the personal contact is much greater than being on a screen. That is very much a personal preference and I think probably in years to come now this is going to be the way forward [...] I feel everybody has put their heart and soul into this project. I honestly do not think [...] that under the circumstances we could have really done much more, and I admire everybody. The entire team has put a great deal of work into it." – PR1*

*"It worked really well but it is a shame that the face-to-face training needed to go due to Covid19. Going forwards, I think there needs to be the option of either online training or face to face training. Unfortunately, we were not able to test out face to face training but that will happen in the future I am sure". – PR2*

## Next Steps:

The patient representatives provided various suggestions and optimistic next steps they would like to see happen following the project's completion. Many of the suggestions revolved around disseminating the good work to other localities and clinicians.

*"I believe that it would be really helpful if nurses, GPs and even consultants if you could get it to that level, to see what it's actually like to be a patient just being bombarded with questions without necessarily having answers they can give easily, whereas I think if you can start explaining to people that if you do gradually talk to people and find out how their life is really affected by whatever it is, it could be cancer, it could be pain, it could be mental problems. Some people just need that little bit of nurturing to get the information out and if in any way we can do that then that has to be a project that would be well worthwhile all over the country not just in small areas". – PR1*

*"I just hope that the training will be delivered far and wide. Having delivered two cycles of it now, there will be things we will have learnt, and things we can improve on. So hopefully we will actually get the opportunity to make those improvements – PR2*

*Hopefully, we will be able to set up a training course so we can train other trainers so the training package can be disseminated widely. I think it should be utilised not just through the UK but internationally as well." – PR*

Other next steps that the patient representatives feel would be beneficial, include accreditation for training completion and to carry on utilising the patient voice.

*"It would be good if we could get some form of accreditation for the training because some clinicians will be looking for that. Accreditation will encourage some clinicians to go on the course". – PR2*

*"The patient voice has been at the heart of the training and has been integral to the production of the training so it would be good if it were integral to promoting it going forward. Hopefully, the patient voice will help make the training more meaningful to clinicians." – PR2*

8.



# Conclusion

Our report demonstrates the value patient representatives added to the PIC-C project. They themselves, feel they represented those living with persistent pain accurately and encouraged physiotherapists to consider the psychological impact of persistent pain on every individual and ensure their care is patient-centred.

*"I have felt that I have brought to it a true representation of what it can be like to live and work with pain". – PR1*

*"So being in something like this you really did feel you could bring it to the fore I suppose" – PR1*

The patient representatives enjoyed their experience being part of the project and feel they contributed considerably to the work produced.

*"Thank you for the invitation to participate as I believe this almost unique partnership of patients and clinicians working together to formulate a training package for health professionals will be beneficial to all concerned". – PR1*

*"I am really enjoying my involvement in this project from the patient perspective and hope my input has been of value to all concerned". – PR1*

The patient representatives would like to continue being involved in future developments of the project:

*"I would very much like to be a part of anything that I feel I can be of help in. It would be good now if we could get this out to not just people that the physios are seeing, perhaps it is something that could be used by GP surgeries". – PR1*

*"I am very happy to support the training going forward. I am happy to lend my patient story and my patient voice to any promotion that's done". – PR2*

**The Health Innovation Network and PIC-C project partners would like to thank the patient representatives involved in the PIC-C project for all their knowledge, wisdom, and enthusiasm.**

# Appendix:

## Appendix 1: The Ladder of Co-Production



## Appendix 2: Dear Clinician Letters

### Patient Representative 1:

Dear Clinician,

This is a difficult letter for me to write to you as it is making me confront in writing the emotions I have kept buried away at the back of my mind for many years. I rarely speak about the emotional impact my condition has had on my life. I often question if it may be of relevance that from a young age, I was a pupil at a prestigious ballet school with every intention of becoming a dancer. My body was stretched and strained in every direction and I do now wonder if I over worked my limbs to achieve my goal and am now paying for the years of hard toil.

If I were sitting in front of you today would you feel uncomfortable if I tell you that I feel totally abandoned by the medical profession? I know you cannot feel my pain; you can only hear my description. You don't know me; you don't know what my life is like and how much I suffer. I can tell you I live every day with pain, not just a fleeting ache but real pain which radiates through my body. It restricts everything I do. If you were one of my clinicians what would be going through your mind? Can you imagine how you would react if you were in a similar situation? Is it because I do not scream and shout or get angry that I am now left to manage my condition without input from anyone? (It is not in my nature to make a fuss). Is it because I do not fit in to a prescribed treatment plan? I pose these questions to make you think but if I am honest, in my heart I know that you would probably all wish to offer me more support and care but you all work in cash strapped NHS which in my opinion really does not have the funding to cope with long term conditions.

I would like you to read this letter and consider if you would treat me differently if I were referred to you today with all the same symptoms. The actual dates below are irrelevant as far as your decisions on treatment and diagnosis are concerned. I am hopeful that 24 years on you will agree that early intervention from a specialist MDT is crucial to reduce the long-term effects of pain which can have a significant impact on the patient affecting all area of their life and that of their family. It is so important to listen carefully to what you are being told by the patient and to understand how the condition is affecting their everyday life. I am sure I would have benefitted from psychological intervention at a much earlier stage, but it was simply not easily available back in 1996.

**At this stage, I will only give you details of my history and symptoms as I would like you to make your own diagnosis. Perhaps by recalling the content of this letter in the future someone referred to you with similar symptoms may receive an earlier diagnosis.**

In 1996 I slipped and fractured my scaphoid which resulted in being in plaster for 6 weeks. When the plaster was removed, I continued to have a considerable amount of discomfort and when my wrist was x-rayed a small tumour was noted and the Consultant decided this needed to be removed with some urgency. The operation was carried out and I was back in plaster for 8 weeks. The plaster was removed just before I was going to Cyprus for 3 weeks. I am still haunted by the image of my fingers which were clawed, a very strange colour, looked rather sausage like and I was unable to move them. It was all very frightening. A pressure garment was made for my hand to control the swelling and off I went on holiday. By the time I next saw the Physiotherapist I was suffering excruciating pain, my fingers were still very red and swollen and I had no movement. This was the start of a long and painful journey to regain the use of my hand. I had physiotherapy and occupational therapy three times a week and carried out exercises at home on a daily basis. I shed many tears from pain and frustration as no-one seemed able to come up with any answers. It was quite bewildering at first as I went from health professional to health professional to try to find the cause of the pain. I was fortunate to find a physiotherapist who took a real interest in my condition and came up with a possible diagnosis. She gave me fantastic support for which I will always be grateful. However, I was no nearer to getting a definitive diagnosis which is what I really wanted.

Time was ticking by, so I decided to do my own research and eventually found a Consultant at Guys Hospital who agreed to see me. At last I had made contact with a knowledgeable person who listened to me and understood my symptoms. It was a relief to be given a name for the condition I was experiencing but you will not be surprised to hear that getting this diagnosis was a bittersweet experience as there was no magic tablet or treatment to cure it. I persevered with months of physiotherapy and occupational therapy. I also had 4 guanethidine blocks plus a

stellate ganglion block and gradually the movement and use of my hand improved. I became quite obsessive about doing my exercises as I was determined to regain the full use of my hand before the birth of my first grandchild. My left hand remains weaker than my right but that is a small price to pay. My assumption was this was just one episode in my journey through life, but this proved not to be the case.

In 2006 I developed reasonably severe pain in my right knee and hobbled around for about 3 years before doing anything about it. I was found to have severe arthritis in my knee joint and a total knee replacement was advised. The surgery was uneventful and once the spinal anaesthetic wore off, I was in the normal post-operative pain which I fully expected. However, about 36 hours later I was certain something was not right. The pain had become much more severe, my knee joint felt very hot and the bandages were causing me considerable discomfort. The physiotherapist who was treating me (it was a specialist hip and knee centre) had no idea what I was talking about when I mentioned the condition I had suffered with previously. I had seen it all before – this time a red swollen knee, shooting pain, stiffness, colour change and the skin was shiny along with sensitivity to touch. By the time I started a course of physiotherapy my knee was stiff and I could not bend it. The neuropathic pain was quite unbearable. This had a huge impact on my life as other than pain I had been unable to drive since the operation and found being reliant on others extremely frustrating. I continued to work full time as I viewed work as my salvation. It kept me busy and didn't give me time to dwell on my altered life.

### **Have you decided upon the diagnosis???**

Once again it was me who searched the internet to find the latest treatments and in October 2009, I secured a place on 2-week intensive rehab programme at the Royal National Hospital for Rheumatic Diseases in Bath where I was diagnosed with classic CRPS. I had daily hydrotherapy, physiotherapy, and occupational therapy along with excellent psychology sessions. I also underwent a manipulation under GA in my local hospital and spent a week on a continuous passive movement machine. As soon as the epidural wore off, I was back to square one. I had four further nerve blocks and have taken part in various research studies including a low-dose immunoglobulin trial carried out at St Thomas@ in 2014. When I last looked on the internet more than 27 countries all over the World are carrying out research into the cause and cure for CRPS.

On good days, I considered myself fortunate as although my condition is life debilitating, it is not considered to be life threatening. I tried to take a philosophical approach but in spite of this there were times when I had suicidal thoughts. Pain is a highly unpleasant physical sensation and it wears you down when you are faced with it every day. It can easily change your mind-set. How I am feeling has an effect on my pain. If I feel sad, angry, depressed, or anxious my pain will seem worse. I am privileged to have a very supportive family, friends, and work colleagues as without them I might not be here today. Sadly, a number of people have committed suicide as they could not come to terms with constant pain whilst others have decided to have the affected limb amputated.

My left knee is in need of a TNR, my left hip is fast wearing out and my right shoulder joint and arm are causing real problems. The Knee Consultant has in his words "grave concerns" about carrying out further surgery, the Shoulder Consultant said that he could operate but was worried I might end up in a worse state and suggested that if I waited for two years it could well heal itself –five years on and no improvement. The only Consultant who has really empathised is the one who first operated on my wrist 24 years ago. At the time he was a newly appointed Orthopaedic Consultant and he remembers me and my history very clearly. He is now a leading Trauma Surgeon. I consulted him privately as I needed time to talk without feeling under the pressure of knowing I was delaying numerous patients waiting outside to see him. He took advice from several of his colleagues to see how to limit the risks of further damage post operation if I decided to go ahead. The suggested plan would involve a week with an epidural in situ before surgery and intensive physiotherapy afterward but there was still quite a high risk and the outcome would not be known until surgery had taken place. Is it worth the risk? I am still considering this 4 years on!



Here we are more than 11 years on since I had knee surgery and 24 years since I first had the fall and my life is still restricted by pain on a daily basis. I have to pace myself and set realistic goals. My walking ability is very limited and I need to use a crutch, but I do now have limited bend in my knee. I dislike filling my body with strong medication as it restricts my ability to drive, and my car is my lifeline. You cannot drive if you suffer drowsiness or dizziness and these are the side effects I suffered from medication such as Pregabalin, Gabapentin, Tramadol and Dihydrocodeine. I now try to restrict myself to Naproxen or just plain simple Paracetamol and provided I take the tablets on a regular basis I can get by.

CRPS has affected me, my husband and family in many ways and it would be all too easy to become completely focussed on pain at the expense of all other aspects of our life. I aim to remain positive. Please never take hope away from anyone. Just reading through this has made me shed more tears than I have for many years. I feel a bit of an emotional wreck, but I will wipe away my tears right now. The sun is shining, I am alive so will go face the World with a smile and get on with life as best I can is my motto!

#### **Patient Representative 2:**

Dear clinician

Do you remember me? I haven't seen you for over 8 years, but I remember you. I was the person who dissolved into tears when I talked about my fears of a future living in pain. I expect you see many people like me.

You told me I had sciatica, and you showed me a model of a spine and explained my problem was a bulging disc, but you didn't explain anything to me about pain, and how complex it is. You didn't help me understand neuropathic pain, and what was going on in my body. You didn't help me understand that who I am and what I do day to day affects my pain. You didn't help me learn to self-manage my pain.

When you first saw me, I was in so much pain that I couldn't sit down in your waiting area. Your receptionist kindly let me lie down on a treatment bed to wait for you. You knew I could barely walk, but you didn't help me get back to walking again. You knew I couldn't sit down without excruciating pain, but you didn't help me work out ways to sit with reduced pain. I desperately needed help to walk and sit down, but you didn't help me. Isn't that part of your role?





Instead you taught me some core exercises and did some manual therapy on me. Do you really think when I was struggling to walk, get dressed and sit-down core exercises were enough? I've often wondered why you taught me core exercises rather than focussing on my function, self-management and understanding. Is it because that is what is 'normally' done with patients who have back pain and sciatica? Was it just what the 'guidelines' and 'research' dictated? But was I really a typical back pain/sciatica patient? Shouldn't I have been treated as the individual that I was?

I came to you after being in hospital for 5 days. They had put me on a range of strong pain killers, including liquid morphine. You asked me what pain medications I was on, and at times you suggested going back to my GP to vary them, but you didn't help me understand the long-term consequences of being on such high levels of opioids. You didn't help me understand that I could self-manage my pain without the use of medications, or at least use less medications. I needed to know that there are other ways of managing pain apart from medications and injections, but you didn't tell me or help me understand. Was I supposed to work this out for myself?

Do you remember showing me my MRI scan, and explaining that a part of my disc had broken away? You showed me where the broken bit was, but you didn't tell me that it would be re-absorbed by my body. For years I worried about what damage this floating bit of disc might be doing in my body as it moved around! You told me that my disc had likely prolapsed because on my MRI you could see that my core muscles were small and weak! Why did you say that? You can't tell that from an MRI! For years I felt guilt and shame that I had caused the pain I was in, and that was having an impact on my work and family life. That it was my fault because I hadn't been fit enough before the accident. Those words stayed with me, and I'm not sure even now when I understand things better that they have left me. Do you not realise how powerful and damaging the words you use can be?



Looking back, I realise how stupid I was going back to my job as a teacher so quickly. I could barely walk, couldn't stand still for long, was in excruciating pain sitting down, on high levels of pain medication (including morphine) and generally in a bad way. I was lucky that I was allowed to work reasonably flexibly, but I would have been even luckier if I had been advised to stay at home a while longer. You told me that research said that if people don't go back to work quickly then they will probably never go back. But that was research about back pain, not sciatica. You told me in such an authoritative way that I believed that would happen to me. I guess you tell all your back pain / sciatica patients the same. You didn't seek to understand me. The fear of a life with no further work was a main factor in me deciding to go back to work quickly. If you had taken the time to get to know me a little better, and how my condition was affecting me a little more, you may well have given me different advice. I was a highly driven individual that needed to put some focus on my health condition rather than work for a while. I wasn't in a fit state to work, but went back to work fearing that if I didn't I never would. I look back now and realise that would never have happened – I would never have not gone back to work. That's just not who I am. Why didn't you take the time to get to know me a little better before telling me such things?



I came to you as a naïve patient. I had experienced very little healthcare before. I am sure I entered your clinic submissively, after all that is what my parents had taught me to do, and society had led me to believe I should do. I thought that as long as I did what you asked me to do then you would 'fix' me. You maintained this imbalance of power. You didn't get to know me as a person, you weren't genuinely curious about who I was and how my condition was affecting me. You didn't empower me to take a less submissive role, and you didn't treat me like an equal partner. Any decisions made were fundamentally yours. Yes, I might have been the person who 'agreed' these decisions, but they weren't really my decisions, they were yours. You didn't give me sufficient, well balanced information to be able to make those decisions. You didn't empower me to be an equal partner in my care.

I appreciate that with the high levels of pain I was presenting with, and sometimes distress, that it must have been difficult to work out what to do with me, but isn't that your job? Why did you keep discharging me to wait for an MRI, or wait for an injection? Why didn't you treat me whilst I was waiting for those things? Why didn't you arrange for some continuity of my care? If you felt you needed to wait for an MRI why didn't you book a follow up appointment with me afterwards? Why did I have to see so many different clinicians, who didn't talk to each other and repeated treatments that hadn't worked for me before? Why didn't someone co-ordinate my care? Why didn't you play your part in making sure someone did?



I've often wondered why I was treated 'conservatively' for 15 months before I was referred to a spinal surgeon. That was clearly far too long. The writing was on the wall that I would need to be offered surgery well before 15 months. Did you play a part in allowing that phase to go on so long? Could you have done something to ensure I was properly reviewed before 15 months? Could you have done more to get me to see a spinal surgeon quicker?

I don't understand why you didn't make it clear to me from the beginning that there may well not be a 'fix', and that I may live in pain for the rest of my life. I don't understand why you didn't teach me to understand my pain condition right from the beginning and support me in learning to self-manage my pain. I don't understand why all the interventions were 'Bio' ones and the 'Psycho-Social' elements were ignored. I don't understand why I wasn't helped to improve my function and independence. I don't understand why you didn't request an OT assessment or talk to any other professionals involved in my care. I don't understand why you gave me 'routine' care, that was probably much the same that you gave to all of your 'sciatica/back pain' patients. I simply don't understand why you didn't treat me as the individual I was.

Do you remember that after a few years I expressed my concern that I was lop-sided and I asked if you could help me do something about it? I was standing leaning on my left leg because of the pain in my right. Whenever I sat down, I leaned across to my left so my right buttock had less contact with the chair. I instinctively knew that continuing to do everything in such a lop-sided manner was going to cause me long term problems, but I didn't know how to resolve it. I know I asked you for help with this because you wrote it down as one of my personal goals, but you then ignored my goals and inserted your own instead. You taught me core exercises again! Why?

At the time I thought you were doing everything you could for me. I liked that you gave me stick pictures of the exercises you were asking me to do. You obviously cared about me and were always pleasant and nice to me. But looking back it wasn't enough. You could, and should, have done much more.



I desperately needed a more person-centred approach. I am convinced that with that approach then even if my nerve damage could not have been avoided, you would have been able to help me to live well, and better manage my pain right from the start. I am sure that you could have helped spare me a great deal of unnecessary suffering, and a lot of medical interventions.

I'm not a 'routine' or 'typical' patient. I do not want to be viewed as part of a 'cohort' of patients with the same diagnostic label, e.g. prolapsed disc, sciatica, or low back pain. There is no patient the same as me in the world, and there have been no research trials carried out on me. I have other co-morbid conditions, and my social, genetic, biological, psychological, and other circumstances are unique to me. There is no research that can give an accurate prediction of my outcomes with any particular treatment option.

I did want research evidence to be utilised as part of the decision-making in my care, but I needed you to consider it in a realistic and balanced way. I needed my narrative to be listened to, and for my individual presentation and circumstances to be centre stage. I needed you to empower me to play my part in genuine shared decision-making with you. I needed good person-centred, evidence-based healthcare. The care you gave me was 'routine'.

After four years of receiving 'routine' care I experienced an episode of better, more 'person centred', evidence-based healthcare from a physiotherapist. He treated me as a unique individual, both in terms of who I am and my presenting medical condition. I was no longer a 'routine' patient with 'routine' care. I'm pleased to say that this person-centred episode of care transformed by ability to live well with my persistent pain condition. But you could have done that!

I will live in daily persistent pain, sometimes severe, for the rest of my life. It is with great sadness that I say I don't know whether some of this could have been avoided if you had given me better, earlier, more person-centred, evidence based, healthcare.

Although I am grateful for the help you gave me, you could have done so much more.

## Appendix 3: Public Journaling

### Patient Representative 1:

#### Public Journal Stage 1: Design

In December 2019 I was invited to be Kingston Hospital's patient representative on a project being funded by the Health Innovation Network to increase awareness of the relationship between persistent pain and mental health. St Georges Hospital and Kingston Hospital Chronic Pain Services are working in collaboration to produce a bespoke package of support aimed at giving clinicians the confidence to openly discuss this problem.

Since my retirement from the NHS I have been involved in working alongside staff at Kingston Hospital on numerous committees supporting the patient voice and views so was very interested to join this project having suffered with pain myself for many years.

I must confess to initially being a little nervous as the other members of the team were the HIN National Project Manager, highly respected clinicians from Kingston and St Georges and one other patient representative who writes blogs on living with pain so I did wonder if my voice would really be heard. However, my nervousness was totally unfounded as the group has been fully inclusive and we have all been treated as equals with our individual views and ideas influencing the content of the package. On the 4<sup>th</sup> and 5<sup>th</sup> of March 2020 we held a very successful team meeting in London. The first day was spent planning and designing the format of the course and on the afternoon of the second day there was a shared learning event when over 100 clinicians joined us to hear the details of the proposed programme from four of the members of the team with the opportunity to give their views and ask questions. Everyone seemed highly enthusiastic and motivated. The day ended with the delegates hearing our patient stories about the effects of living with pain. According to the feedback both stories were very highly rated which was really pleasing.

Covid 19 has obviously changed the way we have to meet at the moment, and this has slowed us down a little, but we are continuing to work hard on the project with regular Zoom meetings – new technology for me! We are now looking at the next stage of the project which will involve preparing patient vignettes etc. and letters written by us to a clinician will be included in the course pack. It is so rewarding to be part of this team and to know that my voice is really being heard and my ideas valued. Thank you for the invitation to participate as I believe this almost unique partnership of patients and clinicians working together to formulate a training package for health professionals will be beneficial to all concerned.

#### Public Journal Stage 2:

Following on from my previous reflections of working with the Health Innovation Initiative on the PIP (Psychologically Informed Practice) training package for MSK physiotherapists.

#### December 2020

The project has continued with all the participants working hard and adapting to new ways of communicating during these challenging times. For me, this has really been an interesting experience as I had never been involved with online Zoom meetings before Covid 19 and was initially concerned that the lack of personal contact with the team members would cause a delay to the completion of the project. However, this has not been the case as everyone involved has shown great motivation to produce on time a high-quality training programme.

I consider that it has been an equal and active partnership with me as a patient representative, clinicians and the HIN.

In August, the patient participants were invited to St George's Hospital to film some vignettes to be used as training material for the course. Obviously, I was a little concerned about attending the hospital but was assured that we would be filming in a Covid safe area. The room available was large and airy and Rebecca and Anna had set it up to comply with social distancing requirements. I was their Guinea pig and we experimented with various versions before making the final vignettes. The first vignette highlighted the importance of good communication between the physiotherapist and patient and the second was the psychologist initiating the ability for the patient to speak freely about his/her mental state because of living with pain. I understand that the vignettes have been very well received by the present course participants.

I am really enjoying my involvement in this project from the patient perspective and hope my input has been of value to all concerned.

## **Patient Representative 2:**

### **Public Journal Stage 1: Design**

In December 2019, I was delighted to be asked to take part as a patient representative in a Health Foundation funded project on persistent pain and mental health. I joined a committee which included physiotherapists, clinical psychologists, and another patient (PR1). As a patient I was fully included in conversations and decisions. My experience was that of true co-production, by all stakeholders, including me as a patient. Impressive!

The aim of the project is to produce and test a 'Psychologically Informed Practice' training package for Tier 2 MSK physiotherapists to:

- increase confidence in delivering and managing psychologically informed physiotherapy interventions,
- improve care and support to patients presenting with both persistent pain and psycho/social needs,
- produce an accredited PIP skills training programme ready for wider spread and adoption.

We kick started the project with a two-day meeting in London. The format of the course was 'designed' and the way forward planned. In the afternoon of the second day we held a shared learning event for around 100 people, explaining our project and what Psychologically Informed Practice is. Some of us presented, alongside some other invited guests. Scary as it was presenting to a room full of clinicians, I did a 45-minute presentation called 'The need for change: a patient story' and PR1's patient story was also presented. Impressively our patient stories were rated highly by the audience! It was great to put our thoughts across.

Two of the group, Rebecca and Anna, took the lead in developing content, but they always kept the rest of the group up to date and fully involved us. As patients PR1 and I challenged some ideas, contributed our own and helped ensure the patient voice was both at the centre of our discussions, and the developing training. I am sure we have had an impact on the development of the training, and I am sure the training will be all the better for including our patient voice.

It has been a privilege to have actively supported the creation of course materials. I have written some materials for the training course, providing a patient perspective on topics. PR1 and I will be involved in the co-production of patient vignettes/case studies which will be used in experiential learning sessions and we will be co-delivering some of the training.

I don't know how unique it is to have patients truly co-producing training materials with clinicians, but it is certainly unique for me. Health Innovation Network and the clinicians involved in the project have been amazing to work with. My involvement in this project is something I truly value. I hope I have helped make a difference!