

Institute of Advanced Studies Workshop Transcript

Chronic Pain in the UK: Medical, Academic and Political Perspectives

OPENING REMARKS & WELCOME ADDRESS

[00:00:05] Dr. Alicia Spencer-Hall: Well I'm delighted to welcome you to our Chronic Pain Workshop, something that has been in the works for months and months and months, and it's so great to see all of you here today.

I'm going to start off with some boring but essential logistical information. Basically, just look at your conference programme. Everything is in there: toilets, refreshments, what we're doing today.

I'd like to note a few changes to the programme just very quickly. Dr Alex Lee will now be moderating panel three, and unfortunately Dr Francis Ryan cannot be with us today but she has given us a hard copy of her paper, so we'll circulate that and you can read that, and we can discuss that in the Open Forum.

In terms of A/V today, we are having a livestream, which is very exciting, so people will be watching along with us remotely. So if you're in the front rows, the back of your heads might be visible, just so you know. So if you don't want that broadcast, please move back.

Also in the Q&A, your question will obviously be recorded so it can be heard, but your face won't be on screen. So if you're interested, the camera is there [points towards camera with mic hand] just in the corner. So people stood up here are on screen, but anyone in the audience is not actually going to be visible on screen.

We will also have a dedicated 'Live Tweeter' and so we have on the wall here our hashtag for the day, which is #CertainPain. So if you want to live tweet with us please do so, I know a lot of people on Twitter are saying they're excited to be with us today, and we are hopefully going to be taking questions from Twitter in our Q&A's for panels and in our Open Forum.

Feel free to snack when you need to, to move about when you need to. Today is about a productive community discussion. It is not super formal. So please, eat fruit. I ordered a *lot* of fruit, please eat some fruit. There is tea and coffee all day, water, and we're going to be having some very tasty Pret A Manger lunch. If there are any problems or anything, come and speak to me, or, if there are tech things, Jennifer Shearman, who is just here in the front row. We will sort you out.

In terms of breaks, there are breaks all the way through the programme, but if you feel like you want to get up and you need a break, please do so. Like I said it's informal: do what you need to do to enjoy today.

We also have a quiet room at our disposal, which is the door literally opposite this room. In there you'll find blankets, gluten-free and dairy-free snacks, water, eye-masks, earplugs, anything you need if you need a break and some time out, please do use it, it's there for us all to enjoy.

Guidelines for questions: we really want to hear from you guys in the audience, so speak back to panellists, and obviously also for our Open Forum, that's just a conversation for us all together. However, please note we're limited for time, and so keep questions as on-point as you can. And remember, you can always button-hole people in our many, many coffee breaks.

So finally, I just want to say I'm so thankful for all of the people who volunteered their time, [who've] taken time out from family life today as it is a Saturday in Summer, and academics are normally very much not in the office right now. So it's great to see so many UCL academics with us.

[00:03:25] And with all these logistical practicalities now announced, and without further ado from me, I'd like to introduce James Wilson who will be giving our welcome address for us all today. James Wilson is a Senior Lecturer in Philosophy and Vice-Dean for Arts & Humanities at UCL. He is Co-Director of the UCL Health Humanities Centre, Director of the MA in Philosophy, Politics, Economics of Health, and Co-Director of the MA in Health Humanities. How he does it, I don't know – that's a packed schedule! His research integrates Philosophy with other relevant disciplines such as Epidemiology, Economics and Political Theory, to explore conceptual and practical challenges in the sustainable and equitable improvement of human wellbeing. So, over to James.

[00:04:18] **Dr. James Wilson:** So it's a very great pleasure to be able to welcome you to this conference. One of the things I do here is that I am the Joint Director of our Health Humanities Centre. UCL itself has immense strength in biomedical medicine. There are two or three thousand researchers involved in biomedical medicine at UCL. But at the same time, a really important thing from the perspective of the institution is to be able to connect all that massive expertise in biomedical medicine with things that matter to human beings, whether that's literature, music, art and so on. That's a lot of what we do in the Health Humanities Centre, almost, as it were, to think about the lived experience of illness, the stories people tell about their illness, the way in which people can express their illnesses affected by power, stigma, and various other sorts of social phenomena of that sort. So it's a great honour and a pleasure for me to be with you today.

I also wanted to say a little bit in the introduction about the Institute of Advanced Studies. You're sitting in the Institute of Advanced Studies here. It's a very new thing for UCL. It's only been going for two years. One of the points of designing the Institute of Advanced Studies was that UCL was well-known to have enormous strengths in biomedical medicine but we wanted to do something for arts and humanities and social sciences. So this is an Institute of Advanced Studies, as it were, for Arts and Humanities and Social Sciences where the Arts, Humanities and Social Sciences people at UCL, as it were, lead massive interdisciplinary projects to get UCL thinking as a community about how we can improve the world through art, literature and social science, to put it very broadly.

And each year the IAS sets UCL as a whole a challenge as something to think about, and one of the things it set as a challenge this year was 'Sense and Sensation' as a topic for thinking about. As part of that, each year, we bring in Junior Research Fellows to help us think and to get the community engaged in a particular problem, and we're delighted that our research fellow, Alicia Spencer-Hall, who has organised this fabulous conference, is one of our Junior Research Fellows for the year. Her

research is mostly about chronic pain in medieval literature. The way she's brought this together with such a community of people is fantastic.

One of the things about the work we do at UCL is—obviously you know—we're a lot of academics and a lot of students, but we think of what our remit is as not just about academics talking to one another but academics working together with communities to bring about beneficial change. So I think one of the things that is really fantastic about today is that it's not just a day of academics, it's a day of community. I think that I'm hoping towards the end of today we'll be able to think more broadly about possibilities of social change, how everybody can work together to think about chronic pain, bringing together the biological, sociological, personal, political approaches in order to change the narrative overall.

I guess that just leaves me to say it's going to be a fantastic day and welcome again. Let's get started!

PANEL 1 – MEDICAL APPROACHES

[00:08:04] Nicole Brown (Chair): Thank you very much. My name is Nicole Brown and I'm chairing this first session. I would like to invite Professor John Wood to come up to the front please.

[00:08:44] Professor John Wood is the Director of the Molecular Nociception Group and Professor of Molecular Neurobiology at University College London and SNU Korea. In recent work John has focused on the wiring of the peripheral nervous system and the function of subsets of sensory neurons in distinct pain syndromes, and today he'll be talking about new insights into pain mechanisms. Can I pass you over the microphone and would you like to speak?

[00:09:17] Professor John Wood: Thank you so much. Okay, I'll try to speak quickly. Well we've heard what an immense problem chronic pain is this morning. We're very keen to treat it, if we possibly can. It's been a disaster in terms of drug development over the last thirty or forty years. Really nothing has come through. So we really do need new insights into pain mechanisms, and I've got a wonderfully talented group here at UCL who are carrying out a lot of experiments in this area. I really don't have time to go into their wonderful work, but I just want to mention the fact that the Wellcome Trust just across the road have funded most of our work and have been incredibly helpful.

We're all aware that pain is a giant problem, but you may be shocked at the numbers. This is an analysis of pain in the United States—I think in 2012—and what you see is actually more than half of the population have got a pain problem. Unbelievable. So about a quarter of them have a little bit of pain on some days, but more than 14 million people have a lot of pain, all the time, and this is debilitating in every respect. It destroys their ability to work and their family lives, and they get depressed. As a clinical problem I would say that pain is the greatest challenge of the age, far eclipsing in number things like dementia, which are so fashionable to discuss at the moment.

How can we treat pain? Where do we perceive pain in the brain? There are hundreds of papers published using functional imaging. This is a technique where blood flow through the brain is measured in terms of the amount of haemoglobin passing around neurons and is an indirect measure of neuronal activity. There are bits of the brain like the thalamus and the somatosensory cortex, and a bit called the anterior cingulate, that light up when people are feeling pain. I think there are 400-odd papers on this, and people tend to suggest that this is where we perceive pain.

[00:11:14] We got a couple of people who are totally pain free, who have never felt pain in their lives, a male and a female, and we did the same experiments in a magnet with them. And you can see that they have exactly the same responses as normal people. So we don't have the faintest idea where pain is perceived in the brain. That's still a work in progress. And so to attempt to focus drugs on these kind of targets in the brain is pretty much doomed to failure. This is correlatively interesting, but doesn't seem to have any major mechanistic significance.

If you look at the nerve innervate, the skin, muscle and viscera though—that is, the peripheral nervous system—there is really hope. Here's a man who's got neuropathic pain. That's pain caused by nerve damage in his foot. So if you brush his foot it's exquisitely painful. If you treat this man with the kind of drugs you have at the dentist, drugs like lidocaine, that block peripheral nerves, you can completely block the pain sensation. And this is true of almost all pain conditions.

And even more amazingly, here's somebody with phantom limb pain. They've had a limb amputated and many people that have amputations feel pain in the missing limb. If you apply the same drugs like lidocaine to the sensory neurons that innervated the leg that isn't there any more, again, you can get almost 100% pain relief, even in phantom limb pain. So it's this drive from the peripheral nerves into the central nervous system that's required for pain. So that's the place to try to develop drugs.

One direct route to doing this is to find families that have got inherited pain syndromes and to map the genes that are responsible for them. And, again, it's very striking. We've been involved in a number of these studies and all the genes that we've found that are involved in pain are expressed in the peripheral nerves, the nerves that innervate the body, rather than the central nervous system. Within the central nervous system it's all wiring and signalling through a neurotransmitter called glutamate, but in the peripheral nervous system there are specific pain-related targets. So there's a channel called TRIP8 1. This is a family in Colombia. When they get cold or tired they have excruciating thoracic pain. The women say it's worse than childbirth, and this maps to peripheral nerves. There are some sodium channels as well. There's something called Paroxysmal Extreme Pain Disorder that people get when they have mechanical stimulation. There's something called Erythromelalgia which is a continuing kind of inflammatory pain condition that's inherited. And most excitingly of all, there are some people who have mutations in sodium pain channels that are completely pain free. So that's the place to look if you want to get hold of some useful drug targets.

[00:13:58] So this is—I'm sorry to be too technical, but this is the structure of a sodium channel. These are the things that allow electrical signalling throughout the nervous system and in muscle and you can see they have a lot of these bits of protein that cross the membrane. We have three different human pain conditions that map to this one channel Nav1.7. Two of them give rise to ongoing pain, and in some very rare people that don't have this channel, they're totally pain free.

Actually I think I'll skip all the mechanistic stuff, what do you think? I wasn't quite sure of what the audience would look like and I'm sure you're not too interested in this.

But just as an aside, nerves release neurotransmitters and we find that in people without [Nav]1.7 or mouse models, the mice that don't have [Nav]1.7, they don't release neurotransmitter any more. That's very surprising.

So the drug industry went crazy. This was all done ten years ago, and they made a whole load of extremely potent Nav1.7 blockers. And you can see that if you induce pain with a specific drug that activates [Nav]1.7 these blockers work very well. But if you look at normal pain and add the blocker of [Nav]1.7, you don't get any analgesia at all. How come?

[00:15:11] Well, it turns out that in the mouse that doesn't have the channel, you have a massive increased expression of opioid peptides. And so in male and female mice, you get more of these small molecules which are the things which make you analgesic, a little bit like morphine does. So there's an antagonist of morphine-like signalling called Naloxone, and here's a mouse that's analgesic. If we give it Naloxone, it starts to feel pain. These are different measures. It's true in both male and female mice.

Most importantly of all, we have a friend in Stoke Newington who is totally pain free. She has never felt pain. We give her this drug that blocks opioid action and you can see she starts to be able to feel pain [for the] first time in her life. And here are my poor post-docs in the lab who've done the same experiment as controls, and they feel pain all the time. So this suggests that the opioids are important as a contributory factor to the analgesia with the loss of this sodium channel.

And what's interesting is that we can change the concentrations of sodium in the cell and we can mimic the effects of deleting the channel. So if we increase the sodium, opioids go down. If we block sodium going in, opioids go up. And we've discovered that the channel is stuck to opioid receptors through a protein which is called GPRIN1, and as a result of this—again sorry if it's a little bit technical—drugs like Fentanyl, very potent opioids, are much more effective in the absence of the sodium channel than in normal mice.

This would suggest if you add these [Nav]1.7 blockers that don't work to a bit of opioid, then maybe you'll get fantastic analgesia. And this actually was shown with the drug lidocaine almost 20 years ago by Gabriel Pasternak in the United States. So here's a little bit of lidocaine and a little bit of opioid: if you put them together, you get fantastic analgesia. So we've taken [Nav]1.7 blockers, which don't seem to do anything, and very low doses of opioids, put them together, and we get inhibition of pain in a variety of models of inflammatory pain and these are models of nerve damage pain. So that's very exciting.

[00:17:30] Do you remember that I just showed you that there was a drug that didn't work at all? Well here it is. These are people in Australia who don't believe anything that we publish and fortunately they found exactly the same thing. So here's some of the [Nav]1.7 blocker that doesn't do anything, some opioid that doesn't do anything: if you put them together you get fantastic analgesia.

So we're now trying to take this into the clinic to do proof of concept studies with human volunteers. But what's very exciting about this is it works for many, many different sorts of pain. Nav1.7 is a sodium channel that's found in peripheral neurons. If you take it out in a mouse, the mouse becomes pain free. If people don't have it, they are pain free. And interestingly, this thing somehow regulates the expression of opioid peptides and also sensitises the receptors that respond to opioid peptides. So if you put opioids and [Nav]1.7 blockers together we get fantastic analgesia in many models. We don't get it to work in osteoarthritis, and we don't know why that doesn't work, and we don't get it to work very well in bone cancer pain, but in everything else we've tried it works very well.

So, UCL Business are trying to help us get the show on the road, giving us £1 million to do proof of concept studies. It's extremely difficult to persuade Pharma to take on any projects because they've lost so much money in the pain field. They can make loads of money out of cancer because they make monoclonal antibodies to various cancer-specific products and they're very effective, but the pain field in Pharma has sort of collapsed. So we're trying to gee it up again with this kind of story, and I hope if we have a meeting in, say, five years' time, we'll be able to tell you whether this approach has been successful or not. But we're optimistic.

[Applause]

[00:19:20] **Nicole Brown (Chair):** Thank you very much Professor Wood. Would you like to sit down on the side there? The idea is – the idea is we have all the panellists present and then have joint questions afterwards.

[00:19:41] Are there any questions for Professor Wood please?

[00:19:46] [Inaudible question asked by audience-member off-microphone]

[00:19:54] **Professor Wood:** That's a very interesting question. So what I find really extraordinary is, our friend in Stoke Newington—our female 1.7 mutant who is totally pain free—if you treat her with an opioid antagonist she starts to feel pain. So that means that for forty-five years of her life she has had opioid mediated analgesia without side-effect with the endogenous opioid system. So if you look at the way Pharma carry on, they make increasingly potent opioid drugs, or drugs that have a long half-life, and maybe many of the problems that are associated with opioids in the clinic now are to do with the fact that they're so potent, and lead to desensitisation so you need increasing doses. If we can exploit this 1.7 blocker to spare the level of opioids, I think it would be fantastically useful. You may not know this but in the United States last year more people died of opioid overdoses than were killed in car crashes, because there's been a massive explosion of prescribing opioids and many people get hooked and then they buy drugs on the street and have overdoses. So, you know, opioid-sparing approaches such as this could be very handy.

[00:21:04] **Questioner 2:** Yes. Could you say a little about the side-effects of the drugs that alleviate the pain?

[00:21:12] **Professor Wood:** We don't know anything about what would happen in humans, but we know that people without the 1.7 channel are completely normal. And so this is the exciting element to this, that if we have a specific blocker that blocks Nav1.7, there shouldn't be any side effects. You know, sodium channel blockers are very, very good analgesics, but the problem is that that there's a narrow therapeutic window so they can kill you at higher doses. But the human data suggests that a Nav1.7 blocker would have no side effects at all. So it looks good.

[00:21:49] **Questioner 3:** Thanks. I was wondering, how confident are you that, in case of chronic pain, as opposed to acute pain, because of the complexity, as I understand it, of the number of systems that interact to produce that pain, do you think it actually is possible to produce a drug? Because I'm not a doctor, but all the doctors I've worked with have always believed it's almost impossible, because there are so many other factors playing into that experience of pain and intensifying it, which your drug isn't going to control. So how do you see the drug interacting with other—?

[00:22:20] **Professor Wood:** I mean that's a little pessimistic because we've all taken aspirin-like drugs which are quite effective. I mean opioids are actually very effective. The problem is the side-effects that are associated with opioids because they kill you if you take too much. So I don't think you should be so negative. We just don't know yet until we get this thing in the clinic, and we might have a horrible shock that it doesn't work very well at all, but all of the animal data, and all of the genetic data in people, suggests that, you know, it's a very positive scenario for a drug development.

[00:22:52] **Questioner 3:** [inaudible, off-microphone]

[00:22:57] **Professor Wood:** I don't... I just think we're, you know, sort of, tall mice, that's my primitive view. I think there's lots of social interactions in mice, you know. I mean it's extraordinary how different their pain thresholds are over the day, and whether they're with other groups and so on, so it's a very, very useful model. Obviously we can't do experiments on people, but I think most of the pain system in animals and humans is pretty similar, you know.

[00:23:32] **Questioner 4:** Hi I'm Dr. Krishnamoorthy, one of the Pain Management Consultants from Wigan. Thank you, this is very interesting research and lecture. I've got a lot of patients in my care, you know, who don't respond, you know, to even massive doses of opioids. But, so from your research, do you think, you know, adding a small amount of this Nav1.7 blocker will help? You know, which is... like... lidocaine is one of those things isn't it? So—

[00:24:04] **Professor Wood:** Yup, lidocaine is very broadly acting on a whole range of sodium channels so the side effect issue is more likely to be problematic, but you know, at low doses, it's fine, and I know Dr Lu in the back row uses lidocaine infusions on a large number of chronic pain patients.

[00:24:18] **Questioner 4:** Yes I do use lidocaine infusions for fibromyalgia and things like that. People do get relief. Not all of them respond, but some of them. But I have a group of patients where opioids are not responding and they are on a huge dose of opioids, so adding a little bit of lidocaine infusion to those group of people would benefit, I think. Is that right?

[00:24:38] **Professor Wood:** Yes. It would be very nice if we could talk to you about this in the clinic one day. I would love to see that. I mean obviously I'm presenting quite a simple picture here, and there are many painful conditions—for example, migraine: if you take opioids it tends to antagonise triptans and can actually make the headache worse—so there very many different mechanisms of pain. But these people seem not to have any acute, any inflammatory or neuropathic pain problems, so things like post-surgical pain and so on, probably wouldn't happen for these people. So, you know, it's a fairly broad target for many pain conditions.

[00:25:16] **Questioner 4:** Thank you.

[00:25:17] **Chair:** [off-microphone] We've got time for one more question I think?

[00:25:22] **Questioner 5:** Hi there. What is your opinion on Donald Trump declaring a national emergency on opioid abuse?

[00:25:28] **Professor Wood:** Sorry?

[00:25:29] **Questioner 5:** What is your opinion on Donald Trump—

[00:25:32] **Professor Wood:** Ah. Well I think he should put his money where his mouth is and fund our clinical trial. Do you want to write him a tweet? [Laughs] It would be good if something good came out of Donald Trump, yes.

[00:25:43] **Nicole Brown (Chair):** Thank you very much. I would suggest that if people have more questions they get in touch with you. Thank you very much. Thank you.

[Applause]

[00:25:56] Paula Bronson, please, would you like to come to the front? Our next speaker is Paula Bronson. She is employed as the Physiotherapy Lead with the persistent pain service at Bart's Health National Health Services Trust, where she works with a predominantly Bengali patient population in East London. But she is also currently a PhD in Social Anthropology at UCL and as part of that she is studying persistent pain in Nepal. And today Paula is going to present on the topic of understanding persistent pain in the clinic, and she is going to talk about social and cultural perspectives. I suggest that we stick to what we had planned, so that Paula is presenting for ten minutes, and then after that it will be Dr Walker presenting for ten minutes, and the questions will be combined after the two speakers.

[00:27:06] **Paula Bronson:** My apologies, I was running late this morning so didn't quite have the chance to set up.

[00:28:04] Good morning everybody. Apologies for the slow start. So again, I work as a Pain Specialist Physiotherapist, and what my aims are today is to really talk about—more, to kind of take a bit of a diversion. I realise this is a medical panel but as an anthropologist I have to get my social aspect in, and looking at the introduction in terms of people living with pain it's their social, lived experience that I'm going to focus on today. And as a clinician again, this is sometimes often what we don't really, really hone in on, and we have so much to learn in terms of listening. Now I'm going to frame this within a study that was actually done in our department through Atlantic Commission, and taking up the recommendations and applying it to my clinic as well as my patients.

Okay, so what do we even do? We're a multi-disciplinary group. We take a biopsychosocial approach, and this is pretty much the gold standard within the medical community. So we have pain consultants, clinical psychologists specialising in pain as well as physiotherapists like myself who specialise. And again, this will probably come up again later today, but just to frame it within the definition of the International Association of Pain's Definition (and I'll just go ahead and read this for you): it's "an unpleasant sensory and emotional experience"—and I have highlighted the 'experience'—"associated with actual or potential tissue damage or described in terms of such damage." Okay I know that's a bit of a mouthful but it will make more sense as we start to talk.

This is Tower Hamlets; this is where I work. Predominantly, I would say, through a clinic day, probably 95% of my patients are Bengali-speaking only or Sylheti-speaking patients. And so, again, looking from the biological grounding that we take, and looking at the previous presenter, it's grounded in a biological approach as pain being an output. So what we mean by an 'output' is everything all together: what you see and the way it's expressed is an output. And what Lorimer Moseley, who is a researcher in Australia, what he looks at is it's essentially a reaction to a perceived threat. So 'perceived' is also a key word. You might have, you know, a train barrelling down the tracks, or you might feel that there is. And again, listening and legitimising the pain experience is very important. So the same expression, the same output, is there in people's lives, regardless of what's actually going on biologically, and of course we completely legitimise that things are going on biologically.

[00:31:16] So framing this within culture, it's in a socio-cultural context. But what is culture? Medicine in itself is a culture. It's obvious that in terms of our clinic, we're taking a Western biomedical approach, and this is it down here in the corner, but this is not the dominant medical system within the States – within the States?! Within the world, sorry!

I did a pilot research project in Bhutan and these are just some pictures, quickly, in terms of framing things within a religious context. In the equivalent of the National Healthcare System there, there's a choice for patients to either go to their traditional doctors or to a biomedical doctor. These treatments are a bit different. And the Draktsho will say mantras to the medicine Buddha, heat up golden needles, and apply those to the back, causing scarring, but again this is a pain treatment that is very much accepted and is seen as efficacious. Unfortunately there's many places in the world that still continue to do animal sacrifices; this is in Cuba. And again, faith-based [practices] in Ukraine up top.

So trying to—again there's very many different definitions of culture, certainly within anthropology, but framing it within this study: “the shared overt and covert”—and again, ‘covert’ I'd like to emphasise here – “understandings that constitute conventions and practices, and the idea, symbols and concrete artefacts that sustain conventions and practices, and make them meaningful.”

Okay, so, there are three areas that this study looked at: cultural competence, health inequalities and communities of care. And I'm going to focus just on two because this is what I see pertains more to my patients.

[00:33:11] Medicine should accommodate the cultural construction of wellbeing. What is wellbeing? Something completely different, maybe, within a Bengali community, even family, person, or myself and my experience, or even my team. Agency should be better understood with respect to culture.

So the findings. The first one: again, explanatory models. I frequently ask people, “So why do you feel you've had pain for so long?” Again, maybe no one's ever asked them this before, and it might be anything. I had a patient that ate a Jackfruit and felt that that might have been it. Someone else fell off the bed as an infant twenty-five years ago. Other people [say], “I hurt my back at work”.

Knowing your own explanatory models and beliefs is very important. Again, as physiotherapists we're taught very structurally: so there's a ligament pulled in the back, something like that. That's fine, but just know the way that you understand pain to exist. Again, one doesn't expect from a cultural competence or social construction of meaning that we know all of the practices and customs of other people that we work with. And again, this isn't necessarily culture.

Looking at where most of the patients come from is a Muslim community in Sylhet, the language being a non-written language dialect called Sylheti. And this just makes reference to some studies, again, in looking at certain cultures we can just completely oversimplify, attendance being a big thing in medical appointments. Why do some people never show up? Well what a lot of studies have found in terms of interviews is that people might just not have the bus money. Okay. And this is across the board. And this is... this is across the board.

Again, quality of life. And this is what we do in the clinic: it's to help people negotiate how to improve their quality of life living with pain, for year after year after year. Diet, gender roles, [are] very important and very different within an individual context and what my expectations are and the way that I was taught 30 years ago that I'm going to change people and somehow make them better.

[00:35:21] This is just very quickly looking at traditional South Eastern medical systems. What again, going back for our definition, it might be covert, people don't know necessarily that that's what some of their belief systems are based on, and it's very, very common within the world, looking at balances in the system. Too much bad blood. My patients will frequently talk about, not about nerves, there's no such word in Sylhet for 'nerve'. They talk about blood—"too much blood in my leg"—things like that. Again, when you're going to explain what's going on in a diagnosis, to start talking about nerves—sorry Professor Wood [laughs]—this doesn't fit within the Sylheti community. Balance is very important. Again, they're not necessarily looking at a scientific explanation. Exercise, as a physiotherapist, isn't necessarily seen as something that's going to make a big change. And again, this is about, you know, the balance system and causing weakness in some people, whereas we see it as being strong.

Now I did want to ground this in—I did a qualitative study and asked questions in terms of, again, based on belief systems and why people feel they have pain, and some of the difficulties, the second finding being agency. Often my patients feel that they're not part of the family. They can't contribute. Their role as the mother or the grandmother is completely lost. They feel very disconnected.

It's very common for people to want the pain to go away. Again that's a loss of agency not even particular to the Bengali community. And again, people frame things using metaphors that they know in their everyday life. This woman felt that there was a fish bone stuck in her throat. Obviously she knew that there wasn't one there, but feeling that there was nothing anybody could see or pull out, so she felt completely helpless.

[00:37:27] How do you cope with your own pain? This was a bit more positive. Some people did feel, instead, using the word 'fresh'. I see this a lot: "I feel 'fresh' when I go out, when I start to walk." So feeling that they can make some changes, and again, tapping into that and listening to people. Often people speak in terms of agency, and this is something which, if you listen to people, certainly within my patient community, the influence of Jinn is quite predominant. And this is again just a belief system that there, again, is an outside influence that can largely contribute to changing people's lives. This is a patient that I interviewed at length who had quite an interest and knowledge, and again, he felt what we would see as some of maybe more troubling depressive symptoms he saw was attributed to Jinn. Faith healing is very, very common. How the pain is situated. Again, loss of agency in terms of feeling like they can do nothing about it.

So in conclusion, culture is always in a constant state of change. Trying to keep up with it is very, very difficult. But we can, in listening and understanding, certainly help people to better motivate and maybe make some changes in terms of quality of life. Thank you.

[Applause]

[00:39:04] Nicole Brown (Chair): Thank you very much. We'll save questions for later. If you'd just like to sit down on the side there.

And I would like to invite Dr Walker to the front. Dr Walker is currently the Reader and Consultant in Paediatric Anaesthesia and pain medicine at UCL GOSH, Institute of Child Health at Great Ormond Street London. Dr Walker trained as a Paediatric Anaesthetist and Pain Specialist in Australia and moved to London in 2000 to pursue developmental pain research. Today she is talking about chronic pain in children.

[00:40:00] Dr Suellen Walker: Thanks very much. So I'm very pleased to be here and particularly because we're including the issues of pain in children in the programme, because I think this is something that, if we think about what we hear or what we understand, we're often just dealing with the tip of the iceberg. Because pain in children is very common. It can vary obviously in the type and severity but it does increase throughout childhood and adolescence and increasingly becomes more common in females as they get older. It has a significant impact on function, and we'll hear a lot about this today: on children being able to go to school, which is their main functional outcome that we're interested in; also on their physical function, as we've just been hearing; and impacts on mood and family.

Importantly it has a very big economic burden, which I think under-recognised and which, I think, is really an important trigger for realising that we need more resources in this field. Because it's not just the healthcare costs that are important: it's the families having to take time off work to take their children to various appointments or stay at home with them that has a much bigger impact than we may actually realise.

And importantly as well, there's much more research now showing associations between, particularly early life stress, but also pain in childhood having a much longer term impact on persistent pain in adulthood. So what's happening early on is having a long term effect throughout the life span.

We've heard already mentioned this idea of a biopsychosocial model and that's something that we use in paediatric management as well. If we think about the traditional medical model of history and examination, investigations and treatment, that certainly has a role; but in terms of treatment we're thinking much more about a more global approach to management with a multi-disciplinary team.

[00:42:11] So again, we've heard mention of neuropathic pain and this is an area of particular interest and research for us at Great Ormond Street. Nerves normally will signal an acute danger associated with pain and then we'd expect, as healing occurs, for that pain to go away. But if there's an injury or a disease to these fibres that normally carry pain, we can actually upset the balance. So rather than this acute warning system, the pain persists, and even though there may not be an obvious injury there can be ongoing pain.

For us the issue is that this is often very severe and it's often very difficult to treat. But it is a high proportion of our patients. We actually get more than many other clinics because we have a specific interest. This nerve injury type pain can occur after surgery or after trauma. It can be associated with various diseases like neurological disease, and also after treatments, particularly chemotherapy.

But for us, we always have to remember that we're dealing with a very broad range of children across different ages and different developmental stages and that obviously has an impact on how we assess pain. But it also has an effect on how the nervous system responds to injury. So we may see diseases and effects that we don't see after the same injury in adults, and we can also see variability in the response to treatment.

So if we're thinking about assessment, we do begin with a classic pain history. We have specific tools for children of different ages that we can assess the intensity of their pain, but we're also interested in what's aggravating their pain and what's relieving it. One of the big issues with neuropathic pain is it's not like a broken leg which will be worse when you move it. The pain can actually come on out of the blue without a clear trigger and that can be very difficult for people to understand.

[00:44:20] There are specific descriptors as well that are often associated with this type of pain. Professor Wood has already mentioned phantom limb pain. This is something that does occur in children as well. And so the pain may be described as burning or feelings of pins and needles or electric shock, those sharp, sudden onset types of pain. But obviously in younger children it's much harder for them to understand and describe the pain in those terms.

We often also ask children to draw their pain, not from a figurative point of view, but just really so we have an understanding of where their pain is and how severe. And it's a little hard to see but this boy has got abdominal pain which he is rating at four of ten. He's got also burning pain in his hands which is five or six out of ten. And then very severe burning pain in his feet which he's rating at eight out of ten. And so we can use that to assess the distribution of pain and also see how it changes with time.

One of the other things that we do is always keep an eye on the adult literature and see ways we can adapt different techniques. One of those is quantitative sensory testing, and we can measure thresholds to look at alterations in sensitivity to a lot of different sensations: so, temperature; different forms of touch and pressure; and as well as that we can map areas of altered sensitivity. So things that—again, just a plain brush across the skin—which most of us would actually feel was pleasant—or moving a cool roller across the skin—as we move towards the area that's painful, we may see that in children that stimulus starts to feel uncomfortable or noxious, and so, as I say, we can map areas of altered sensitivity. Importantly it's the overall pattern that we're looking at. It's not just are they more or less sensitive. I think that's something that's often quite difficult. People will talk about having a high pain threshold or a low pain threshold and it's just not that simple.

[00:46:31] If we think about temperature pressure thresholds, these are experiments I did in children when they were eleven or twelve and again at nineteen or twenty years of age. We put a thermode on the hand. It starts at 32 degrees and the child presses the button as soon as it starts to feel uncomfortable. And what you can see is there's huge variability here. That's despite the fact that I did all of these measures with the same equipment in the same room using the same instructions. And it's not just that these are random results, it's just that there's a lot of individual variability. What we need to do is to try to understand what contributes to that.

And so, obviously, age is an important factor. You can see that the younger children are much more sensitive than at an older age. Sex and gender again becomes increasingly important later in adolescence. Obviously there will be factors related to medical conditions, previous experience—

really important for pain in children as well as adults—anxiety and coping style will influence this. And again, interactions with the environment and also genetic factors. And as Professor Wood has mentioned, as I'm sure many of you are aware, there's a lot of interest in genetic analysis here at UCL and also across the UK and so this may help us to understand individual differences and variability and allow us to better predict those at risk of persistent pain and perhaps tailor treatment more specifically. But at the moment my particular interest is that there are genetic conditions that are specifically associated with and often with symptoms that begin in childhood, and so we need to recognise these conditions as early as possible: Erythromelalgia, which Professor Wood has mentioned; another metabolic disease called Fabry disease often actually presents first with pain. And so we need to ensure that children are included in specific research studies, and there has been one specifically recently about neuropathic pain and we did recruit children to that, because this can help us in the diagnosis and specific management of some conditions.

[00:48:52] Identifying new treatments, again, Professor Wood has mentioned, and that's really important because at the moment we're really just extrapolating from what works in adults and we don't have good evidence for what works well in children. There's a number of trials from the Cochrane Library which brings together all the evidence, really just highlighting the need for more specific paediatric trials.

But clearly pain is not just about medications, and we work very closely with psychologists both in assessment and treatment, looking at effects on quality of sleep, mood, sleep, and the child's coping style. Physiotherapy we've heard mentioned and, again, [is] very important for us in a paediatric clinic. And going beyond, this is a very severe pain condition associated with inability to walk on that leg so physio is very important from that. But also just improving the physical strength and capabilities of the children and getting them back to school, as I mentioned, which is really important not just for their education but also for their social function and for the family. The range of costs that are associated with chronic pain goes much beyond just a pain score in the child.

So clearly pain is a very complex experience in children, as it is in adults, and we need a team. That's a big team with a lot of different people with different skills. And, clearly that needs a lot of resources. At the moment there are relatively few commissioned, or NHS commissioned, paediatric pain services throughout the UK. And, I would also argue that we need more research in education.

Just to finish, to come back to the point I made at the beginning, chronic pain is not just an issue about the child. It does influence their pain and health outcomes throughout adulthood. That's both in males and in females, and we know a lot more about differences in males and females in pain now. And so this is really reflected in the mission statement of the Institute of Child Health where it's not just the health and wellbeing of the child that we're focusing on but also on the adults that they will become.

Thank you very much.

[Applause]

[00:51:19] **Nicole Brown (Chair):** [off-microphone] Thank you very much... Do you have any questions for either Paula Bronson or Dr Walker?

[00:51:44] Thank you. They were both very, very interesting presentations and I really enjoyed listening to both of you. I was just wondering, you were both talking about the biopsychosocial model. Obviously in research and in your work, this is something that is quite important. The question for me is how is that practicable if we're looking into the actual situation in a clinic? Do people, like yourselves, have enough time to evaluate the social environment of a child or of somebody? And that's one of the questions from me is, yes, I understand the concept of it, but how practicable is it in reality?

[00:52:26] **Dr Walker:** I'll start. So when a child comes to see us in the pain clinic they come and see a whole team. And so in the room there will be a pain physician, there will be a psychologist, there will be a physiotherapist, there will be a clinical nurse specialist, and so everyone is involved in the assessment. As well as that we do a range of validated outcomes and we have the results of those when the child comes. And so we're looking very broadly at those issues. And it's important, particularly important for parents and for children, that psychology doesn't mean that we think that the pain is not real, that it's in their head. It's a part of the management, and that's a really important factor, because we can't manage pain in isolation from all of these other factors. And so, you know, I think it's important that everyone sees that we do have a team approach. They meet the whole team and then depending on their individual needs they'll be followed up by different members of the team.

[00:53:34] **Paula Bronson:** Likewise, very much so. Pain clinics, being multi-disciplinary, meaning 'from assessment'. Certainly I always sit in with a psychologist or likewise have meetings afterwards with the consultant. Patients are always involved in terms of then making decisions, groups, all kinds of taster days, so it's an ongoing almost kind of evolving system based on the individual needs.

[00:54:14] **Questioner 6:** Thank you. I was just wondering if any work is being done with the power of imagination, of mind, [on] placebo response with children or indeed with different cultures who might have different attitudes as to where the pain is coming from. I can't remember the exact details but I know of work done in Oxford where patients were being analysed by fMRI as burning pain was applied to their legs and they had a line administering—I don't know, morphine or some opioid or something—and they were told that the pain control was beginning and stopping and so on, and they responded to *that*, because they weren't changing it. And the effect was huge. So I don't know whether kids have the power of placebo the same as adults, or different cultures will have different indoctrinations which is going to affect their mental mind, imagination, attitudes.

[00:55:22] **Paula Bronson:** There has been quite a lot of research on placebo, and again sometimes it has a negative connotation. Actually we always use it to our benefit and, certainly, everyone uses it to their benefit. It has sometimes accounted for up to 20 to 30% of pain management or control. So again, it's very difficult. It's very individual. But in looking at the context and as a patient experience, that is what you bring as a person to your experience of pain. So I can't really cite specific studies regarding placebo and culture but... [Microphone cuts out]. Okay so I'll pass this over. [Laughter].

[00:56:19] **Dr Walker:** Yes, and I think, as you say, the idea that placebo has a negative connotation is not something that we would work with as well. I mean everyone has very good endogenous systems for managing and coping with pain and that's really what we're trying to tap into. Children are very good with distraction and hypnosis, and that doesn't mean that the pain isn't there. It's just that they're dealing with it a different way. And in fact, you know, the endogenous systems that

Professor Wood mentioned with opioids and various other neurotransmitters can actually be activated by psychological techniques and by distraction and hypnosis. So there's a biological as well as a more social construct, and I think, particularly for children, as well—I'm sure it's the same in adults—you know, having some control and being able to feel that you can do something to help yourself is often incredibly important. Again, that's something the psychologists work with a lot.

[00:57:17] **Nicole Brown (Chair):** Thank you very much. We've got time for one more question.

[00:57:19] **Questioner 7 (Dr James Wilson):** It's a shame, in many ways, that Professor Wood had to go early. I wanted to really ask you to reflect on his talk. He gave us a vision of the future of pain management where it seemed to be very much the 'bio' end of the biopsychosocial model. So it seems to be that, well, if we can just get the right pain receptors and twiddle things, then almost we can control pain and just think of human beings as tall mice, he said at one point. Do you think there's a possibility of actually making genuine progress just with new drugs or do you think that culture is always going to be at the very heart of the way we think about chronic pain?

[00:57:54] **Dr Walker:** I mean I think pain will always be an individual experience. I think if we can recognise it and improve treatments early, you know, I think we can reduce some of the other factors that build up over time. And so I definitely agree that we haven't had any advances and we definitely need better pharmacological treatments particularly for neuropathic pain because the drugs that we use really aren't specific and have a lot of side effects. So there's a definite role for improved management and also for earlier recognition and treatment. But at this stage, you know, we will still be needing to work as a team.

[00:58:36] **Paula Bronson:** Again I agree. And looking at if there's better pain relief or control early on, often the social, cultural or more compounded factors that unfortunately can create a downward spiral in people's lives, year after year, can be stopped short. But again, I think it's always going to be, you know, very multi-factorial and multi-disciplinary.

[00:59:06] **Nicole Brown (Chair):** Thank you. We've got one more question at the back here, this is the last question before we take a break.

[00:59:13] **Questioner 8:** Dr Walker, you—reasonably enough—have been researching and treating children, and you said at one point you have extrapolated from adult experience. To what extent has your work thrown up insights which would apply to older people as well, particularly perhaps as children, being younger and less sophisticated and distorted by life, may be fresher in what they communicate?

[00:57:48] **Dr Walker:** I think, you know, as well as the nervous system being more vulnerable in some situations, it also has a better recovery, and so from a biological point of view that can help us. But we do know, certainly from our laboratory research and also from a large number of epidemiological studies, as I say, that that early experience can have a much greater effect throughout adulthood. And so I think it is important in an adult chronic pain clinic, to be asking about those early life events that may have had a longer term impact and that, you know, again for us, has influenced how we've looked and tried to do longer longitudinal studies to see whether changing that early experience can actually improve the longer term outcomes.

[01:00:02] **Nicole Brown (Chair)**: Thank you very much Dr Walker and Paula Bronson. I would like to ask you to kindly thank them formally with a round of applause.

[Applause].

Thank you. We are taking a break and there are teas and coffees at the back of the room.

PANEL 2 – INSIGHTS FROM ACADEMIA

[01:30:34] Dr Emma Sheppard (Chair): Okay, hello everyone! Can everyone hear me? Ian, can you hear me at the back? Brilliant. Okay. Hi, I'm Emma and I'm going to be moderating the second panel on insights from academia. Our first speaker is Alex Haagaard who is speaking to us remotely through Skype, so if there are any technical issues please do hold on. They are currently watching through the livestream, and if you have any questions for Alex please use Twitter or grab my attention and I can tweet them, because they are not able to be on Skype after they're speaking. It gets a bit complicated somehow.

Alex is a disabled artist, researcher and activist, and they have lived with chronic pain for approximately twenty-five years, although their experience of pain remains emergent involving practices of reading, writing, documenting and discussing. Alex is a co-founder of the #CripTheVoteUK movement and is currently working on The Invisible Project, or the In/Visible Project, documenting experiences of shifting visibility within disabled experience.

[01:32:19] Alex Haagaard: Hi there! How are you? Okay great. Oh apparently my computer has conflict. Good! Oh, okay, sorry. Alright. And are you able to see my screen? Okay, sorry. Alright so I will share my screen with you. So are you now able to see the presentation? Oh dear. [Laughing] Thank you. Let's try that. Is that... you'll be able to see your selves now! And presentation? Okay, awesome! So I think probably you've lost me now, but that's okay, you can look at the much more interesting slide presentation.

[01:33:35] So, just to give myself a little bit of an additional introduction, I am an artist, a sociologist and someone who deals with chronic pain—someone who is chronically pained myself—and so I come at my research from a very auto-ethnographic point of view. So that's sort of very much where this particular paper is coming from, a place of considering the significance of my own experience of chronic pain, in the context of my construction of my own illness and my identity in relation to my own illness.

That being said, my ideas have also coalesced as I've had discussions with other members of the chronic pain community and have found that my experiences have been echoed. Because of course, one of the issues that I'll talk about is that you sort of become very uncertain as someone who is chronically and invisibly pained about what you are experiencing that is in fact real and valid and what is not necessarily [real and valid].

So we'll begin with the way that pain has typically been treated in philosophical, literary critical canon, and of course the major literary philosophical study of pain is Elaine Scarry's *The Body In Pain*, which crucially posits that pain is a phenomenon that lacks an object and therefore resists expression in language. But this is a theme that is echoed within a lot of other philosophers, including Husserl and Merleau-Ponty, who almost take pain as the sort of emblem of the state of being unable to enter another person's mind. So it does become almost a symbol or signifier of that very fundamental metaphysical problem which is solipsism.

[01:35:54] So this is a really crucial quote from *The Body in Pain*, which says:

So for the person in pain, so incontestably and unnegotiably present is it that 'having pain' may come to be thought of as the most vibrant example of what it is to 'have certainty', while for the other person it is so elusive that hearing about pain may exist as the primary model of what it is 'to have doubt'.

This comes very early in the book and it signals to me a crucial problem with the way this study has been conducted and with the way a lot of philosophical approaches to ontology and to phenomenology have, which is that they exclude disabled voices, and don't even consider the possibility that disabled voices may be fundamentally different and that our experiences of being and of consciousness and our experiences of experiencing may in fact be fundamentally different.

So this is taken very much as a given in current mainstream philosophical approaches to pain, this idea that you know you have pain and you are able to know it certainly and in its entirety and that someone else cannot possibly know what you're experiencing. So there is that disjoint between the inner self and the exterior world; so again that referencing of solipsism.

[01:37:28] And so then she progresses from there and suggests that as a function of this, pain resists expression in language. And we do see this at a clinical level: that patients often do have difficulty expressing their pain in a way that clinicians are able to understand what it is that they're experiencing. And this is something I've encountered multiple times, particularly when I was a child and was chronically ill even as a child, and I think this is an experience for a lot of people who were ill or disabled as children because of course their vocabulary and their understanding of what they're experiencing differs a great deal from that of an adult and so it leads to these communications breakdowns and these resistances to language.

But the argument that Scarry puts forth is that pain not only resists language but actively destroys it because it is the only phenomenon known to human experience that lacks an object. So there's another really crucial early on in her book, which says:

Contemporary philosophers have habituated us to the recognition that our interior states of consciousness are regularly accompanied by objects in the external world, that we do not simply have feelings that we have feelings for somebody or something, that love is love of X, fear is fear of Y, ambivalence is ambivalence about Z. If one were to move through all the emotional, perceptual and somatic states that take an object, hatred-for, seeing-of, being-hungry-for, the list would become a very long one. And though it would alternate between states we are thankful for and those we dislike it would be throughout its entirety consistent affirmation of a human being's capacity to move out beyond the boundaries of his or her own body into the external, shareable world.

[01:39:24] Skipping over, because it's quite a long segment, but:

...this list and its implicit affirmation would, however, be suddenly interrupted when moving through the human interior when it last reached physical pain. For physical pain, unlike any other state of consciousness, has no referential content. It is not of, or for, anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language.

So this is the key argument that actually I am going to be challenging with this paper.

But from there she progresses to the idea that we are unable to express pain accurately in language, but then also attempt to express pain using what she calls the language of agency. So metaphors—the pain as weapon or as wound—are actually deployed in very strategic ways, for instance in campaigns of war and torture, but also efforts to get people to sympathise with those experiencing pain, so for instance the work of Amnesty International.

She does some really excellent analysis of these literary instances and approaches to pain. However I think the crucial thing that is missed is that there is a separate category of pain and this particular category, the way in which it's experienced, really challenges the way all of the other pain is conceptualised.

And this isn't necessarily a flaw of her analysis because this has to do very much with the social approaches of an abled society to pain. So this is very much the way the wider world is interpreting and working with pain, but when you actually approach pain from the subjective perspective of someone who is a chronically invisibly paine person it undermines those approaches.

[01:41:39] So I'm going to take a little bit of a look at what it means to be in pain when you are a chronically paine person and, so, the really crucial thinking going back to that initial quote from Scarry's book is that she states that to have pain is to have certainty, whereas to hear about someone else's pain is to have doubt. But this is very much not my experience with pain. I have been experiencing... so this is the thing, I have not been experiencing pain, I have been experiencing phenomena that should be painful since I was about four years old. I complained about them for a little while as a child, was told they were just growing pains, was told they were normal, was told, "Oh your knapsack is too heavy and you're out of shape." So eventually I learned, yes, these are just normal parts of human experience, and I forgot them, and I did not realise they were painful.

And then very suddenly, this quote off to the side here, is a blog post that I wrote shortly after being finally diagnosed or recognised clinically as having chronic pain and it was a very sudden realisation one evening that I was experiencing what is very characteristic neuropathic pain, which up until that point, I was in patient groups for narcolepsy which I also have, and a number of people in the groups have fibromyalgia as well and would be discussing it, and I sort of always dismissed the possibility that I could have it despite having some other systemic symptoms of it, because I did not experience that key symptom of allodynia, which is a neuropathic pain generally localised to the skin.

[01:43:38] And then very suddenly one evening while watching a movie I realised that actually I was experiencing that and that I had been experiencing it for years. And as I've embarked on a diagnostic journey over the past year—I'm actually about to go see the Ehler-Danlos clinic in Toronto on Monday for my first appointment which will hopefully finally conclusively diagnose all of these issues that I've been having since I was about four years old. And so as I've embarked on this diagnostic journey this year, I have come to realise all of these physical experiences that I never realised I was having.

So the notion that to have pain is to have certainty is often very much not reflective of what it often is to experience chronic pain, particularly what it is to experience chronic pain as someone who is femme, feminine-labelled, at the level of the clinic, someone who is maybe racialized, because after

a certain point—and I think this also particularly applies to those who have experienced chronic pain or who have experienced phenomena related to chronic pain since childhood, because it is at that point that you learn it is normal, and then stop consciously experiencing it.

[01:45:05] In my discussions with other people in the chronic pain community I have noticed a very sharp divide between those who began experiencing chronic pain in adulthood and their cognisance and experiences with it, and those who have experienced pain-related issues since childhood. Almost invariably those who have experienced these issues since childhood and were taught that they were normal, whether explicitly or implicitly, because they had family members who were always pained as well and they never knew another normal, very much for all of us there has been this process of epiphany where we realise, “Oh these things are pain!” Whereas those who have experienced chronic pain as adults, either because of an adult-onset condition or following an injury, they are very much more aware of their pain.

I think that’s a crucial caveat when framing this particular experience of pain. And so this is what I’ve been referring to and it’s a very common theme among rare and invisible patients, and I mean I have a running joke with my best friend that I will be describing something to him and he’s like, “Yeah that’s pretty weird,” and I’ll be like, “Oh is that not normal” and he’s like, “No, that’s another incredibly weird thing about you.” And similarly with my parents, I’m constantly going up to them and say, “Oh, are you able to do this? Or are you experiencing this particular physical sensation?” They’re like, “No, that is not remotely normal.” So there’s this process of discovery that goes on that is quite interesting in terms of conceptualising pain.

[01:47:00] Actually, speaking of Professor Wood’s presentation on lidocaine, this [slide] is me after having had some lidocaine shots for chronic migraine.

But it’s also worth noting that the idea that pain is resistant to language is not uniformly accurate either because we have very different languages that we use to describe pain as chronic, invisible patients. So we tend to use what Scarry terms the *language of agency*, essentially using metaphors to describe pain, talking about pain in terms of wounds, in terms of trauma, in terms of weapons sometimes, often when speaking with clinicians, persons who have different kinds of chronic pain (so may not be grounded in the particular kind of embodied experience we have) or speaking to laypersons without pain.

So the first example is a little bit more technical language, the way I might describe the pain in my shoulder to a clinician, whereas below is how I might explain it to a stranger without chronic pain and then, notably, below, is how I would speak about this to someone else who has Ehler-Danlos. I would use much more referential language, talking about—still talking about an injury—but talking about the particular mechanics of what is going on in my body.

And I think this is key, because Scarry’s assertion that pain is object-less is actually really not accurate, and this process of discovery that chronic invisible patients tend to go through is very much contingent upon us objectifying our pain, upon realising the source or the direction of our pain.

[01:48:54] So it was once I had the language and framework of fibromyalgia that I finally realised, “Oh yes that is precisely what I’m experiencing.” And similarly when I first asked my doctor, my GP,

about the possibility that I might have Ehler-Danlos last year, she said, “Well have you ever experienced dislocations?” and I said no, I don’t think so, and then I began to realise I experience them about ten, fifteen times a day, to varying degrees of pain. But the language actually needs to exist before you can consciously experience it, so I think that’s a key reframing that needs to happen in our approaches to pain.

And so, in relation to this, what I call ‘textualisation’ plays a major role in the way that invisibly chronic ill people enact their own illnesses. This can take the form of social media, blogging, selfies, and hashtags. ‘Painsomnia’ is a really big and significant one. And it enables people not only to document their own experiences but to place them in a context and in a language in relation to others with similar experiences, and that contextualisation is really key to validating and therefore incorporating the experience into their consciousness. But then beyond that we have other forms of textualisation, so tracking, documentation of signs, clinical signs, for personal and clinical use, and of course increasingly now, quantified-self technologies.

[01:50:30] And so this is significant because it has ontological implications for how chronic invisibly ill patients experience their own body, and very frequently we experience our bodies and our symptoms as separate from ourselves, basically an object body that is distinct from the subject identity. And often when we talk about our bodies, when I’m talk about my body when I’m talking about it with my fellow chronically ill people, we’ll say, “Oh yeah, my muscles are acting up today,” or “Oh, my brain is doing this or that.” We very much distinguish ourselves from our body and sort of, fragment our body in the way we talk about it.

And there is some resonance to this practice with the idea of, Bhabha’s concept of ‘hybridity’ and DuBois’s ‘double consciousness’ so that we have adapted to this clinical, mechanical, objective language of the clinic—whoops, okay!—and basically my suggestion is that the language dependence of our experiences of pain actually links this experience of dualism to the unique character of our particular pains. Alright, so we’ll skip over the last slide, it was sort of tangentially related anyway, so thank you very much! ... Thank you! Sorry? Okay! Sounds good. Perfect, sounds good. Thanks.

[01:52:28] Dr Emma Sheppard (Chair): Okay so our next speaker is Dr Deborah Padfield. Deborah is a visual artist specialising in lens-based media and interdisciplinary practice and research within fine arts and medicine. She is currently a Teaching Fellow and Honorary Research Associate at the Slade School of Fine Art at UCL.

[01:52:52] Dr Deborah Padfield: I want to use this session to just give a quick overview of two fine art and medical collaborations at UCL and UCLH which argue that images can be one way of improving, sort of facilitating improved communication of pain, particularly in medical pain encounters.

So *Perceptions of Pain* was a three-year interdisciplinary project at UCL and it explored the value of images and image-making processes to the diagnosis and management of chronic pain, and it brought together a multi-disciplinary team to analyse material which was generated during the face-to-face project.

Face 2 Face is a collaboration between myself as an artist and Professor Joanna Zakrzewska, who is a facial pain specialist from UCLH. In turn, it built on an earlier project at St Thomas’s Hospital, *Perceptions of Pain*.

Both these projects researched whether and how photographic images of pain, co-created with patients, can expand the dialogue around pain in the consulting room and improve mutual understanding.

[01:54:13] Pain equals evil. Evil equals darkness. Darkness equals pain. So how do you constrict that type of sentiment into a number from one to ten, as patients are so routinely asked to do? And the sort of sense of hopelessness of isolation, the sort of multifaceted nature of pain, with its linguistic roots in Western culture anyway, of retribution derived from the Latin word *poena*, meaning punishment; none of these things can be adequately conveyed through a number. And not only is a number unlikely to capture the complexity and the intensity of pain, but that number itself is dependent on the social context in which it's sought.

To go back to the *Face 2 Face* project, facial pain has got all the difficulties associated with musculoskeletal pain, as well as additional ones specific to the face. So much of our social activity, for example, involves the face. If we go out for a coffee, or we kiss, like the lovers might be about to do in the background of the image, for most of us we take that for granted. For people with facial pain, they are really worried that it's going to trigger off another intense episode of pain and so are likely to avoid it. Similarly with having a cold drink, or biting into a piece of fresh fruit.

So the project had many strands. There were workshops for clinicians and patients to attend together. There was an artist's film that looks at intersects and disconnects between patient and clinician narratives. But the central strand was the co-creation of photographs with patients which reflected their unique experience of pain. And that these images were co-created was really important, so as not to re-appropriate their experience again, after having been on the receiving end of so many medical imagining processes.

[01:56:10] And I thought what was interesting, was that in both *Face 2 Face* and *Perceptions of Pain* some of the same themes seem to have appeared in the images. For example, this one was very much to do with the disintegration of the self, or negative process. And there's a similar theme within this one—I'm really sorry you can't see them, they're really vivid, they're being a bit bleached—but this person described himself as having pain that was really intense at the centre of his being, like an apple that was rotten at the core, but no one could see it, and it was only when it worked its way to the outside that people could actually see it.

And the same themes also came up again and again, which was medication as a really contested issue, which is quite interesting in relation to the conversations we've had earlier, where she described herself as feeling like a rubbish dump and asked me to go and photograph a rubbish dump, which was more like the first theme, but then when I brought it to the session, the patient had actually got large bottles of medication packets which she then placed on top of the photograph and we re-photographed it. So when you've got that sort of difference in scale, it's the medication that really comes out, and it was that medication that was what she wanted to talk about, that she'd just got the medication settled and then someone would come along and change it and her whole world would start toppling again. Likewise in *Face 2 Face* there were many images that were to do contested medication.

So in the project I worked with patients at three points during their treatment: there was before treatment; during it; and afterwards. This is one the images that someone made before surgery, where the knife there is sort of standing in both for a metaphor of pain itself, but it's also perhaps standing in for the, sort of, looking forward to the surgeon's knife as a possible healer of pain. So I think there is something about the ambiguity which is facilitated through photographs which may be important.

[01:58:01] And then this is an example of the image she made actually post-surgery, where she has used the strawberry metaphor again but that icon has been transformed into a pin cushion, and with all the other icons of illness identity, they are now trapped. It is those that are within the barrier, not her, and she is allowed to release it and let it go.

And it's also important to say that the images didn't really necessarily follow progression of high intensity to low intensity of pain with everyone. For some people the images literally spiralled around issues associated with their pain. And this is particularly true of this person who described herself as feeling like a 'shadow sandwich', which is a really beautiful but a really challenging metaphor to give a visual form to, and it has negative and maybe positive connotations as well. In fact, I think the shadow could be seen as a perfect metaphor for pain. And again, this was the bread that she brought to the session. She propagated it in her room to make the sandwich. And again, you've got this sense of disintegration. In addition you've got perhaps this sort of sense of being muffled and unable to speak, unable to get out through the texture of the bread. And here is our final shot of the shadow sandwich.

So in the final strand of the project what we did is put a selection of the images from *Perceptions of Pain*, and a selection from *Face 2 Face* together, and actually created a pack of 54 laminated cards, which you're really welcome to have a look at later. Ten different clinicians from UCH offered to pilot these in their consultations and they had two consultations each with the patients using the images, and two consultations not using the images, and these were new patients to their clinic every time and they were in exactly the same conditions and the primary goal for all of them was pain assessment, so they were real consultations. It wasn't a set up. And the patients hadn't been involved in making the images.

So they were given the images to look through about twenty minutes before their consultation, asked to pick out any cards that resonated for them, take them into their consultation and see if it helped them to talk about their pain or act as a trigger in any other way, and then we wanted to look at what the impact on doctor-patient interaction was. We filmed the consultations and we also asked clinicians and patients to complete post-consultation questionnaires. I think this material makes up a unique body that we were lucky enough to have a fantastic multi-disciplinary team come together to analyse from their different perspectives, and this slide I think gives you a sense of the range of disciplines and expertise and methodologies that they all brought.

[02:00:42] These analyses are still going on and so far they have been written up in the *Lancet*, *The British Journal of Pain*, and they're about to be brought together in a new volume to be published by UCL Press next year, so please look out for it, it's called *Encountering Pain*.

And I thought I'd just run through, really briefly, a few of the analyses to give you an idea of the ways in which we seem to be discovering that images can actually impact on doctor-patient interaction.

So overall, the images seem to have one main effect: patients speak more. And Professor Elena Semino, who is actually just sitting here, and so I'm sure she would be happy for you to talk to her in more detail about it afterwards, carried out a linguistic analysis, and she was able to show really clearly that patients spoke proportionately more when the cards were being used. And then using computer aided software she was also able to explore what kind of language actually happens around the cards, and she identifies specific words and domain areas appearing more in the with-image consultations than the without. In particular she found that 'feels like' and other similar terms suggested more metaphoric language. There were a lot of emotional words coming up, and there were also, interestingly, more personal pronouns such as 'I', which perhaps some empowerment by the patient to take control of the consultation at that particular point.

[02:02:04] When I did a thematic narrative analysis myself I also looked at the language and found that, for me, it became much richer, and much less generic, than the normal language in the clinic. And here's a few examples, because it seemed that patients seemed able to project their own feelings and their own experiences onto the image whatever the original experience of that image had been. So I think the fact that images are open to different interpretations actually worked in our favour here. And it gives—I think that someone was talking about agency—I think that gives a patient agency to talk about issues which are really troubling them.

So I'll give you a few examples. This one, the patient had put these images on the desk between her and her clinician, and then she pointed at this image, and she said, "This is about my self-identity, because that person's face is burning off." And the image could just as easily have been used to describe the physical character of the pain, such as 'hot' and 'burning sensations', but she chose to interpret it as something that was altering and erasing her identity, so that for her was obviously a very important part of her chronic pain experience.

Similarly here, this image was originally made with someone with back pain, so the chain stood in for the vertebra, with the sort of gap in it. But there was an older woman who had brought these cards in, and she had actually chosen lots of images, and when she pointed to it she said, really tearfully, "I feel a gap. My family. Not all of them are going to come for Christmas."

And then lastly, having, again, laid the tables between him and the consultant, there was a young man who actually traced his finger over the cards and said, "Simply, the word 'loss'." And then later in the consultation the clinician returned to the same theme saying, "The issue of loss. You picked out that card. Why was that?" And the patient responded by saying, "There are things that are missing in one's life. I mean this has an enormous impact. And there are things, aren't there – I'm kind of avoiding those issues." And then a conversation developed about the way he had adapted his life and his relationships to cope with the pain, and with loss. And actually this card is one that has been picked up really frequently, and it has elicited many discussions such as, "I have lost my way of live my life," "I have lost my identity," etc.

[02:04:28] So in some ways, the image, you can see, is actually bringing pain directly into the consultation, in a really physical way. And from my own observation it seemed that when the images are not being used, the patient and clinician sit usually on one-third of the frame, and the space between them is pretty empty. It's pretty dead. When the images are used, inevitably there's a sort of dance of limbs and arms and legs between that space and that space between them becomes very animated, and something quite negotiated happens. And what the hope is, is that sense of

negotiation can actually continue on into the rest of the consultation and continue into the relationship and the language.

So Dr Amanda Williams has led a section of the team exploring the impact of the cards on the non-verbal interaction, and their findings seem to support that hope. So they took slices of the video footage from both the control and the study group using the images, and they took one minute out of every six minutes and analysed that, looking at behaviours drawn from the literature which indicate rapport, affiliation, dominance and correspondence. And they investigated what impact each of those had because of the cards. And their analyses were happily able to demonstrate that when the pain images were present, clinicians used more affiliation behaviour. There was greater correspondence between patient and clinician affiliation behaviour, and patient clinician rapport was enhanced. The interesting part of that is that actually clinician behaviour showed more change than patients, and that was something we didn't expect and will probably look at later.

[02:06:09] In an interview for my latest film, *Pain Under the Microscope*, psychologist Dr Amanda Williams said: "It is hard to think about what people need to communicate, without saying that to do so there must be someone who listens. And not just one person who listens, but a listening world. And I don't think that listening, understanding world is there." So this throws the focus back on all of us to help improve the understanding between those with, and those witnessing, pain. And I would argue images are one step toward creating that listening world, and perhaps today is another step in creating that listening, understanding world.

And I'm sorry I've gone so fast I've got it in early! So I'm really sorry... [Laughs]

[Applause]

And there's some publications.

[02:07:07] Dr Emma Sheppard (Chair): Okay. Thank you very much Deborah. And our last speaker on the panel today is Nicole Brown, who is talking about 'Learning about Academics' Pain'. Nicole is a Lecturer in Education at UCL Institute of Education and is a Doctoral Researcher at the University of Kent. Her research interests relate to identity and body work, physical and material representations of metaphors, generation of knowledge, and advancing learning and teaching within higher education.

[02:07:41] Nicole Brown: Thank you very much. It's quite difficult to follow on from these interesting talks, to be honest. In a way it's quite a logical way forward. Deborah was just talking about the relationship between doctors and patients, and using visual representations to help that conversation. I'm using a similar approach but for research purposes. Today I'd like to talk about academics' pain, and my research is into the academic identity and how that is impacted by fibromyalgia.

Now, fibromyalgia is quite a complex condition. It's characterised by chronic widespread pain, fatigue, sleep disturbances, increased sensitivity, and actually we've heard earlier Alex talk about some of these aspects. Now, these are visual representations of what people feel the pain is like, but it's actually not visible. But then there is also another quite substantial influence of fibromyalgia and that's 'brain fog'. What people call 'brain fog' is a cognitive dysfunction, it's where suddenly your

brain just doesn't process the information any more. And often that brain fog is quite difficult to cope with for people, more so than pain. Typically fibromyalgia symptoms wax and wane and change and move, within days, even within hours. So it could be that you're meeting somebody who looks perfectly healthy one minute and next minute can hardly walk. And that obviously is quite a difficult concept for people to understand.

[02:09:27] At the same time the cause of fibromyalgia is not known at this point in time, and the diagnosis literally just depends on excluding everything else. And that is what makes the condition itself quite contested, even within the medical profession. Amongst the general public there are about 1 to 10 per cent of people suffering from fibromyalgia. In pain clinics, the percentage seen of fibromyalgia patients is a lot higher. And also there are related conditions such as Chronic Fatigue Syndrome, where there is a high prevalence amongst medical staff, students, teachers and nurses.

And this is why my interest lies really, is why is it that all fibromyalgia research, or most fibromyalgia research focuses on people that are from lower socio-economic backgrounds and women in their fifties and onwards? This is why I'm focusing my work slightly differently.

The approach that I'm taking is quite complex. If you look at the themes that I'm covering, obviously I'm covering things like fibromyalgia itself but I'm also looking at related conditions and issues, illness narratives, embodiment, identity, academic identity, the changing higher education and how that impacts academic identity. So as you can see it's quite a wide field of literature that I'm engaging with. In terms of the actual research approach that I'm taking, I'm very much focusing on the metaphors we live by. And this taps into what Deborah has done with her work. I do believe that the way we live is we express metaphors, often unconsciously, and I'm tapping into that by asking the participants to produce metaphors for me. So it's my idea to try and get as close as possible to the experience. We've heard before that pain is often quite difficult to describe and to place, and we've had the pain scales and we've had the numbers, and yet, you know, when I'm saying 'burning pain', is that the same burning pain that you experience? We don't know. So therefore I'm trying to get as close as possible. I'm using metaphors and representations. I'm asking my participants to produce timelines, and then what I call identity boxes. And these identity boxes are boxes where I'm asking a question but rather than getting an answer, I'm asking people to find an object to represent that answer and put it into the box. And after several weeks we then have a conversation. So it's not so much an interview, as an 'inter-view': the interaction between the interviewer and the participant that creates new meanings and makes it possible to discuss what the participant's experiences are like.

[02:12:37] I don't want to focus too much on how I'm analysing the data because that's quite complex, but suffice to say that I'm looking at the individual objects in isolation, and then looking at the boxes and how they evolve over the few weeks, and then I'm looking at the interviews in isolation and then actually combine the two. So in the interviews, for example, I will ask people, you know, "Why did you place this particular object in? Where did you place it? Why did you place it? Where are you placed it?" And these kind of conversations will then obviously create new meanings and descriptions. I'm also looking at different levels, so the descriptive level, the linguistic level, and organisational elements within the boxes.

Once the themes have been identified I can obviously probe a little bit more deeply with the participants. I have recruited participants through advertising at a range of different conferences and

through social media and through email universities' Disability and Support Services directly. Obviously it's not very easy to recruit academics. You can't just go around and say, "Have you got fibromyalgia?" So it's quite difficult, that process, to get to those people.

In the end, I have secured the participation of 20 academics. Several academics have said that they would be interested but can't, for whatever reason, which I'll come to later. The 20 academics are 19 women and one man, which is quite telling. And they are literally from all areas of academia, so early-, mid-career, and late-career academics. Their positions reflect the wide range of positions available within academia, so there are PhD students, Research Fellows, Lecturers, Support Officers, Professors, and the participants' age ranges are between 31 and 62, with a mean age of 47.

[02:14:40] So in the second half of my short presentation, I really would like to tap into some of the data and what the data actually says and some of the stories that I have heard. So here are examples from three different participants. This one is actually the male participant who decided to create his timeline like this. And as you can see, the story that he's got to tell, I mean I know I haven't focused on it too much, but you can see there is an issue of recovery, there is limping on, so there is this "adjusting?" And then he left it at that. But actually when he sent it to me, he said, "At the end of the day I don't think I have adjusted, I don't think I have accepted any of this." So his story, although it looks quite nice and neat on here, is a lot more complex in the conversations that I've been having with him.

This here is one of the identity boxes. And as you can see, there are things like, this person is obviously like a family person, she has got children, she likes sewing and any kind of handcraft, but finds it difficult because of the pain. So this why it's sort of hanging halfway out of her box, because it's something that she wants to do but isn't able to do all of the time, or not as much as she would like to. And then at the top here, all of this is to do with her medical records. So the experience, the thing that she is telling us about, is that her life is mainly covered, or largely covered, by all of these medical interventions and medical processes that she has to go through. So this is obviously quite a big part, and it covers up her normal identity, if you like. And I then put in this one here, which I thought was quite a telling story, a telling picture, that's from somebody who is doing a PhD. She has been trying to do her PhD for a while. She abandoned it and then got back to it again. Again, this is all due to her health conditions, and obviously, in the end, she says, "I don't want to die without a voice." She doesn't necessarily have any suicidal feelings, she doesn't think that she's going to die of fibromyalgia, which she knows she won't, but at the same time, she feels like she has got a story to tell and she has got so much to bring to the world and yet fibromyalgia holds her back and she is feeling like she is losing out on being able to tell her story.

[02:17:24] In the next picture, this is a concoction of four pictures from one particular person. This is Kate. This is not her real name, by the way, but it's just making them easier for me to remember who these people are! Kate is in her mid-forties and she is an established academic working as a Disability Advisor, and her images demonstrate her experiences with fibromyalgia. But what's interesting is she actually, in her conversations, focuses on—and this is the part that I really want to hone in on for this particular presentation—she focuses on her health experiences, or her illness experiences, of other illnesses and other conditions *more* than fibromyalgia. So for example she has got this back rest which helps her at work. And at work she had declared scoliosis, so she has some kind of hip misalignment and that structural problem of her hip being misaligned means that she often gets back aches but it also means that one foot is quite considerably longer than the other so she has to

have special soles on her feet as well. And she very much focuses on that structural pain and that structural condition rather than the fibromyalgia experience, although in reality it's the fibromyalgia that actually affects her more.

For example, this here is a sign of how cold she feels. It's one of the symptoms of fibromyalgia is that you've got rather odd feelings of warm and cold, so sometimes people feel very, very, hot, almost like they're menopausal in a way, they get hot flushes, and then in the next minute they are really, really, cold, absolutely freezing. So clearly this is a big part of her life. There are so many pictures where she has got her feet covered up and her duvets on, etc., etc., so this is obviously a big part of her life, and yet at work she doesn't disclose that. And I think that's crucial in our understanding of pain, is that at the moment, it looks like society is quite accepting of chronic pain and certain pain conditions, but doesn't look at the wider picture.

Now fibromyalgia, as we've heard earlier, also included cognitive dysfunctions, and actually the cognitive dysfunctions or the things like feeling cold, etc., could actually affect the individual a lot more. And in the stories that I've heard from the participants, it's certainly that aspect of the illness that affects them a lot more in their identity, especially the cognitive dysfunctions. It's their personal pain, it's an emotional pain that they feel, of not being able to talk to somebody else without actually asking three times what is it that you've actually said, because you couldn't process the information.

[02:20:26] This is obviously quite a shocking picture here, as well, where she's talking about how much money she is actually spending on all sorts of additional treatments, and again, the pain treatments, you know, like painkillers like we've heard earlier, all sorts of different painkillers being used, that aspect seems to be quite commonly accepted, but at the same time, fibromyalgia patients feel that they can't take those painkillers all the time, simply because the pain is there one minute and the next minute it's not, so what's the point in taking painkillers if it's not actually there all the time?

So therefore a lot of these people are resorting to alternative methods, in this case supplements or creams, which are obviously quite expensive and may not necessarily help much either. The other thing is also, with Kate, just to point out she has disclosed her fibromyalgia to certain colleagues at work, and that's, again, quite a typical story. A lot of the academics that I'm talking to are disclosing it to some colleagues, because obviously some colleagues will realise when suddenly you go blank and you can't actually finish the conversation, so in a way you are forced to disclose it, but at the same time there is a little bit of an element of a taboo issue there, saying as an academic that your brain doesn't work, or saying that you have got mental health issues related to that, for example depression.

I'd like to mention here Holly, who is in her late thirties. She is a Research Fellow who is also currently doing a PhD, and she has been on benefits because of her mental health issues and depression.

So these are all stories that are all real, connected to pain, but often not really talked about. The narrative tends to be about the pain itself and not whatever else is affecting individuals.

[02:22:24] I'd like to finish with Divya. This is her real name; she has asked to be named. She is a Professor in Scotland, in the University of Edinburgh. This is a poem that she has written. I have

edited out a little part, but this is just to let you know some of the stories, some of the feelings, that people have in relation to fibromyalgia. She is using fibromyalgia... Sorry, she is using her position as a Professor to try and raise awareness for fibromyalgia. She has got a website where she is trying to relay the experiences of people, so for her it's very important. She has obviously fully disclosed it.

But what's telling is that people that are in their early or mid-careers are not as willing to disclose the condition as those that are very, very, well established, and in this case, Professors. So generally I would like to say that the issue with fibromyalgia is that it's not just a pain condition, and that perhaps our view of fibromyalgia as a pain condition needs to change, and at the same time we need to look at how people's experiences of pain aren't just a pain experience by themselves, but actually go into their psychological wellbeing overall. Thank you.

[Applause]

[02:24:08] Dr Emma Sheppard (Chair): [referring to microphone] Yay, I made it work! Deborah, if you'd like to come up and if we have any questions, and Alex is available on Twitter, I believe, so they are also able to talk to us as well. So can I get any questions for anyone on the panel please? There was a question on Twitter, sorry, if I can just dig it out...

[02:24:37] Deborah Padfield: There's one over there...

[02:24:38] Dr Emma Sheppard (Chair): Oops, sorry, there we go. Wonderful. I missed you.

[02:24:44] Questioner 9: Thanks. Hi! Just about the art cards thing, which I think is a brilliant concept actually to make it easier to communicate with consultants about the abstractness of pain. But obviously it's quite a long journey, and obviously this is a new project. Are you thinking that you might be able to evolve it and take it down to the step lower to GPs? Because obviously to get through the gate-keeper with chronic pain conditions at GP level is quite difficult, and obviously GPs have got five minutes. They don't actually necessarily want to hear about the longer story or the impact. They're just doing diagnostic protocols. Do you think bringing something in that would take away from the number scale or whatever might be an easier method for them and do you think that is something that could be developed?

[02:25:31] Deborah Padfield: Yes. I think it's got the challenge of the time constraints, because I think my GP has ten minutes. Maybe I'm just lucky! But I think a lot of them do. But what I think I would argue is that bringing the images in at an early stage means that you elicit much earlier the sort of complexity of the full picture, maybe the most troubling issues around it. So that particular consultation may take a little longer but actually it will speed up things in the future. And also the context in which that pain management is happening in, because as you've said, it's not happening in isolation. It's happening in someone's life and someone's community within other relationships as well. And actually when we did the study—because one of the things that a lot of the clinicians had expected would be that the images would make the consultation take longer—but actually in our study, they weren't, they were very slightly shorter. So there was no significant difference, and using the images was a little bit quicker, so it was really negligible. So I think there are worries about it taking longer. I think what they're more worried about is that it will open up some sort of Pandora's Box of emotions and they won't necessarily have the time to close it down. But maybe they need to be opened up and heard and then they can actually be addressed more quickly.

[02:26:37] **Nicole Brown:** My idea of the identity boxes I have actually presented to Pete Moore, who is the Pain Toolkit person, and he is one of the big pain managers and his programme is being used in pain management courses within the NHS. And he is also quite strongly of the opinion that things like these will actually help people to cope with their pain better because they are able to express what they experience and they feel like they are heard, so absolutely.

[02:27:08] **Questioner 10:** This is one more related question. Would you be able to share these photos to other clinics in the rest of the country? Because even if it's not helping the patients, it will at least help the NHS managers to understand what pain is. You know, because that's the main difficulty I face, to convince NHS managers that pain is real.

[02:27:30] **Deborah Padfield:** That's a brilliant question. It's what we're trying to do. There's one thing – I do do sessions with training junior doctors and with training GPs, using the cards, so I think there's definitely an argument for, with the team and working with Joana Zakrzewski doing sort of joint training sessions. But what we're really hoping to is actually make the cards available, but like always it's funding, so at the moment I'm completely not funded. The funding ended last year. So we're trying to get the next grant in order to either make it more available or to actually publish them and make them available. And then the other thing we're trying to look at is also looking at could we make or co-create images in different cultures and look at is it possible to create a cross-cultural pack of cards. I'd love to get them more widely available. So if you've got any suggestions, please email me.

[02:28:20] [Inaudible question is asked off-mic] [02:28:24] Yes! I'm so not a business woman, I think that's my problem! [Laughter] I was quite interested when someone said UCL Business earlier but I suppose we also want to keep some sense of how the cards are used, but yes, I desperately want to get funding to make them available freely. Yes?

[02:28:40] **Questioner 10:** How about putting them on the website? Because that's going to be easily available for us in the pain clinic.

[02:28:48] **Deborah Padfield:** Because it's taken me about ten years to make the images for which I've got very little remuneration. The only remuneration I've had is through different academic positions. I need to actually have something to keep this going, to sustain it. At the moment I don't think I want to just make them available. And I also want to keep them... I want to keep some control over how they're used, like the set, how the set is used. And I think there's something also to do with the physical handling of them, because people have talked about maybe applying for grants to get digital versions, which would be cheaper, and we thought about maybe if we can protect them in some way, that patients have an iPad with digital versions so they can look at them at home, so it's not taking too much time in the waiting room or the clinic, but then they choose the numbered card, because they're all numbered on the back. But in the clinic you are physically handling physical objects, because I think there's something to do with that physical interaction that changes, it changes the interaction so the nonverbal then impacts on the verbal, I think. I wouldn't want to take that physicality out. I think you're almost bringing pain in a very physical, concrete way, into the consultation, but it's led then by the patient. But we've been thinking about it, we've been thinking about how we can do it.

[02:29:58] **Questioner 10:** Maybe a limited number of it? It's possibly a funding issue, isn't it? But you can get funding for websites potentially.

[02:30:05] **Deborah Padfield:** You can... Yes. Or just – I need funding though.

[02:30:08] **Questioner 10:** But it's difficult, I know.

[02:30:10] **Deborah Padfield:** I wouldn't mind putting a limited number out, because there's loads of them out there anyway, but I would probably want to think very carefully about the format we produce them in. I mean Elena is actually part of the team I'm working with, so if you've got any ideas, which I know you have. [Elena responds off-mic]. Yes I suppose that would be okay for the clinics. But ideally if I get a grant I can make them available for clinics and patients so I think, ideally, that is what I'd like to do, but it may just be because I don't have a business head.

[02:30:48] **Questioner 11:** Have you looked at using the cards to track pain over time?

[02:30:53] **Deborah Padfield:** That's quite interesting. We haven't done a longitudinal study, except that in this last project I did work with people, sort of before their management, during it, and afterwards, so in that sense the images have changed. So there are some more positive images now coming into the cards. When I did the first set it was just the before management ones mainly. So with the individual people I've worked with, yes it tracks changes, but we haven't looked at, say, the longitudinal effect on people being offered the cards in their consultations, and that could be another study. I think Joana was also suggesting also maybe looking at the clinician's language in the referral letters. Does that change when you're using images? Does it bring in more of the patient's actual language, rather than the generic language that I always object to like 'complains', and you think, "I haven't been complaining." It would be nice if you could bring patient language in there.

[02:31:47] **Unknown voice:** Or 'comply'.

[02:31:46] **Deborah Padfield:** Yes! And you probably haven't been complying either! [Laughter]

[02:31:56] **Questioner 12:** I have a question about... I always apologise for being a linguist. I'm a linguist. I have a question about the way in which people talk about, or worry about, pain "being all in my head," as you have in the poem, and whether that is ever challenged. Because the 'all in my head' assumes an opposition between subjectivity in your head that is not real and is kind of your problem to deal with and then objective reality that is out there and is recognised. And it kind of flies in the face of the definition of pain, which is what is experienced and described as such. But it carries all these negative associations, 'all in my head'. So what I would always want to say is it may be in your head and it is *entirely real* and legitimate and to be dealt with. So as part of these various projects, and especially as you interact with these academics, or anyone else, is that assumption ever explicitly challenged? Does anybody ever explicitly challenge it in order to get beyond the position that is expressed in this poem?

[02:33:02] **Nicole Brown:** It's absolutely that problem. People find that people don't accept fibromyalgia pain. Fibromyalgia itself, it's because it is recognised that there is a link between stress and anxiety and pain. So it's even more, "Oh well, you're just a bit anxious, you know, just be a little bit less stressed and all the pain will go away." So there is that aspect of it. And what therefore

people do is that, they don't say truthfully what ails them. That's what it comes down to, you know. The bottom line is that they will say things like, for example, we have seen Kate earlier who says that she's got a hip misalignment. So she's blaming—but this is something that's structural and people can relate to it. So therefore, well, you know, there is clearly, I can prove on my x-ray there is something wrong, therefore it is not in my head. And it's that that people relate to. So the other person that I spoke to, Holly, she has got Ehler-Danlos syndrome, which is a hypermobility syndrome, again that's something that can be proven with biomedical tests. And therefore people resolve to those things and ultimately the ones that haven't got something physical won't disclose the issue at all. They would disclose it to me, they will speak to me, but not at their workplace, not in public. And there's one person in particular who said to me, "I want to be part of this research. My story must be told. It must get out there. But I don't want anybody to find out that it's me." So that's a quite a telling—I don't think you will be ever, at this point in time, I don't think we will ever be able to overcome that challenge of people thinking it's only in their head.

[02:34:52] Dr Emma Sheppard (Chair): Just wanted to add, actually, Alex has just been able to weigh in on Twitter, and they have said that—I think this speaks to what Nicole has just been saying—talking about issues of funding and that. They've said, funding is absolutely an issue, but they also think that an even greater challenge entails the institutional and epistemic structures, so it's not just about the money, it's about changing people's mind about what is a valid and a reasonable thing to look at when it comes pain.

[02:35:33] Questioner 13: About the cards. Say you did get the funding, approximately how long would it take for it get into the clinics, do you think?

[02:35:44] Deborah Padfield: I don't know. For the cards where they are now, it wouldn't necessarily take that long. If we're actually going to look at doing cards, either with paediatric patients, or doing cards cross-culturally, then it would take another probably three years to develop those and then look at whether the images can resonate cross-culturally or not. But they're almost ready to go, so yes it wouldn't take that long to get them out. I think what we'd want to do if we do make them available to the clinics is do a training session with clinicians who will be using them, so that they feel really comfortable with listening to people talking about the images and not feel, in a way, that they have to lead the discussion on the images, or they have to lead the interpretation. That interpretation is left entirely to the patients, because that is what you're trying to elicit, is what... people will project all sorts of things onto them, so they need to feel comfortable with that, I think. And so we'd do some sort of introduction of how they've been developed, and possible ways—because Joanna uses them in a lot of different ways. But one of the nice things is she's said also that since doing the project she's become really aware of the space between her and her patients. So it's lovely actually hearing the impact on clinicians using them already. But yes. I think that's what we'd do to tie it in.

[02:37:09] Dr Emma Sheppard (Chair): I just wanted to add one more thing that Alex had brought up, is the difference between something that Alex wasn't able to speak about in their presentation but also talking about the difference between speaking of pain, and also being heard and a willingness, not necessarily a conscious willingness, to listen to discussions of pain and encounter those ideas and how that can kind of be around—sorry, here goes, blank mind—lack of phenomenological experience and the experience divide. And I really suggest, if you're a Twitter user, having a quick look at the hashtag [#CertainPain] because there's been some really interesting conversations

around that going on. But as it is now just about five to one, let's call lunch, and lunch will now run – I'm sorry I've just been given a message as well that lunch will run until two o'clock. So the last panel will start at two o'clock. Okay, wonderful. Thank you very much!

[Applause]

[02:38:20]

PANEL 3 – POLITICS OF CHRONIC PAIN

[03:43:24] Dr Alex Lee (Chair): Welcome back now to our third panel of the day. I'm Alex. I'm going to be chairing the panel. Unfortunately as you'll have heard this morning Dr. Frances Ryan can't be with us. I have copies of her paper here which I'll hand out at the end of the session so you can read what she was going to say. And because we've only got two speakers, each of our speakers is now going to speak for fifteen minutes and we're going to hear both papers and then have questions at the end.

So our first speaker is Ian Semmons, who is going to talk on 'Going Nowhere'. Ian has lived with chronic pain for over twenty-seven years and founded the charity Action on Pain in 1998. He has served on many key NHS and Department of Health project teams and spent eleven years as a lay member of the fitness to practice panels at the General Medical Council. He is a Director on the North Norfolk Railway and has been responsible for securing several sizeable grants enabling the railway to develop its facilities. Over to you, Ian.

[03:44:28] Ian Semmons: Thank you and good afternoon, and yes, I am an anorak and quite proud to be so too. Thanks for inviting me here. I see we haven't sold many tickets for the circle up there, but we've got a good audience here. I'm going to talk to you about the politics of pain, and the title of my talk is 'Going Nowhere', which might sound awfully negative but hopefully at the end of my talk negativity will be replaced with reality. It's quite a harsh message at times because the politics of pain is an awful mess. Pain has no real profile within central government or indeed local government, which is quite a difficulty. We've been doing this now for twenty years, lobbying quite hard within central government, going to interviews with numerous health secretaries—can anyone remember Frank Dobson?—through to, today, Jeremy Hunt. And the message is basically just the same: that pain just does not have a profile.

Why does it not have a profile? Well, there are other conditions that, some might say quite rightly take priority. You know, cancer pain or cancer, heart conditions, diabetes, obesity coming into play now. And pain could be linked to all of those conditions but rarely gets mentioned. There's a frustration there, certainly. When you look at national government and their attitude towards chronic pain, and not just in England, across the border in Scotland—I'll come on to that in just a moment—there doesn't seem to be any impetus or drive to do anything about the eight million people in this country that have chronic pain. It is a very, very low priority. You talk to Department of Health people, who change on a regular basis. The last one I spoke to came from the Probation Service so knew an awful lot about chronic pain. This is what we're up against; this is the barrier. And there is no drive to change it. Pain is not seen as a sexy subject. It is not a vote-winner. And that is the reality.

[03:46:57] Let me give you real examples of that. I mentioned Jeremy Hunt. I had a really good meeting with him for about half an hour a couple of years ago and, he's quite a decent chap actually, forget what the press say, but he is quite a decent chap. And he holds some of his surgeries in Sainsbury's in Farnham. Now, I live in Norfolk. Good old Norfolk. And I said to him: you know, on my way home from Farnham, because I've got friends in Farnham, going back to Norfolk, I go through eight counties. I go through numerous Care Commissioning Groups [CCG's]. Each of them has a different approach to pain management: what they will fund, what they won't fund, etc. In Norfolk we have five CCG's. It makes no sense at all. I said, "What is the consistent thing though, Jeremy, on that journey? Because I have pointed out the inconsistencies. What is the consistent thing?" And he

looked a bit bemused. And I said, “Well, the consistent thing is my pain. It doesn’t change remarkably as I go across the country border or into another CCG. That pain is still the same. So why is there not a national guideline that CCG’s have to have in terms of delivering pain management services?” He said, “Well the CCG’s know best.” I tried not to laugh. He had really no concept of that, and I went on to explain to him that in the pain clinic that my wife works in—she’s a specialist pain physiotherapist—it serves three counties: Cambridgeshire, Lincolnshire, and Norfolk. The patients coming in from those different counties cannot all be treated the same, because the CCG’s won’t fund the particular treatment. Does that make any sense? It doesn’t. But there is no political will at either the national level or in the local scrutiny committees to change it.

[03:49:07] The CCG’s generally are fairly ignorant about pain management. Let me give you a clear example of that. And that example is this. In the pain clinic my wife works at, there is a long waiting list. Quite common I suspect. Now, the CCG’s cure to this was, “We will suspend the waiting list. We won’t put anybody else on it.” We gently explained to them that if they did that, as soon as they opened it again it would be overwhelmed. You’d be back where you started. Their second idea is: “We will fund one consultation with a consultant and then one treatment with a physio or occupational health.” One treatment? We advised them again that that really wouldn’t work and all that would happen is that the GP would send them back in again and the list would grow, etc., etc. The other barrier that you have is that the pain consultant will put in a particular course of treatment for that patient, writes to the GP, the GP says, “No, I’m not going to pay for that.” So we’re getting nowhere. And we’re getting nowhere because there isn’t the central will, within government, to change it.

To give you an idea of where chronic pain sits in the wider community, one of my colleagues has done a bit of research. In the last six months, media coverage of transgender issues has had more coverage than chronic pain has in eleven years. Now why is that? One of the reasons is that unfortunately we’ve actually diluted chronic pain. We now use the words ‘persistent pain’, which really hasn’t done us any good in media terms. Only last week I had a journalist from Associated Press in the States ringing me up talking about opioid dependency in this country, and she said, “What is the difference between chronic and persistent pain?” She had no idea. And that hasn’t helped. To give you an illustration of where that hasn’t helped is that a few years ago, our sister charity in Ireland changed their name to Chronic Pain Ireland. Their media coverage has just rocketed. They have got an awareness. They have got a brand. And that’s important. So I would urge everybody who uses the word ‘persistent’, please, get away from it, because you aren’t doing a lot of good to the wider pain community.

[03:51:58] We need to get pain into the media. We need to get it into [the awareness of] politicians. We need the impact in there. But there’s a wider problem too. As I was talking to somebody, a pain consultant, regarding the Faculty of Pain Medicine. And there’s a number of places available on there. And only a third of them have been taken up. We have an ageing working population in pain management, and people aren’t coming through, and that’s a worry as well. Now surely if that was more into the media side of things—the chronic pain, the value of chronic pain services, what you guys do on a daily basis, was made more aware, if the politicians were made more aware, then there would be a change.

At the moment it is not going to happen. There is absolutely no interest in Parliament. We have the British Pain Society who, sadly, are politically naïve. We have the Chronic Pain Policy Coalition, who

come out with the same old thing again, “Oh let’s have a meeting at the House of Commons” and they value success by six politicians turning up. How many Lords are there? How many politicians are there? And it’s the same old thing and they’ve been doing that for twenty years. We don’t go anymore because it is a total waste of time.

[03:53:28] Equally, what is a barrier too with politicians, is most of these initiatives are funded by pharma companies, and that does put politicians off, if you like, you know, it’s the reality. We would like to see the money that pharma companies put in, put into front-line services, providing equipment, etc., etc. It ain’t going to happen, but we’d love to see that happen. Good example: in Malta just recently there was a Societal Impact of Pain meeting that’s been going on for quite some time over the years in different European locations. It costs about £400,000 to put on, funded by a pharma company. I won’t tell you which one, but most of you probably know. Where could that money have been spent? It achieves nothing.

I mentioned about Scotland. Scotland Pain Services are in an absolute mess. The Scottish government’s answer is to set up yet another—the third—steering group in five years to look at pain services and what the problems are. We already know what the problems are, and we have told them. And when you see the brief of this Steering Group, it is just going to be a talking shop. And that’s unfortunate. So I stress about going nowhere. But there’s a responsibility for everybody in this room to change that. I’d like you to go away today and think about what you could do to raise the profile of chronic pain. How are you going to do it? It’s a thought, isn’t it?

[03:55:14] We have changed our tack completely. We don’t go to, say, the Chronic Pain Coalition meetings, etc. As I say, they’re a waste of time. What we’ve been doing is we’ve been approaching and getting a lot of success approaching employers, to give them a greater understanding of the impact of pain management and how they can enable their employee to stay in work. And that’s had a great success, that really has worked very, very well, and for the last three years we’ve been doing Health and Wellbeing Primary Care Exhibitions at the NEC. Tremendously successful. And we’ve had companies like Waitrose, British Gas, etc., really signing up to what we’re doing. And that makes a real difference. Innovation.

On the public side, eight million people out there with chronic pain. But it’s bigger than that, isn’t it? It’s a lot bigger. How about the families? The relatives? The friends? How do they get to understand the impact of chronic pain? The reality of chronic pain? Well we’re addressing that as well, albeit in a small way, because we’re only a little organisation, totally volunteer run. But we have a mobile information unit which we’re told is the only one for chronic pain in the world. Which is great. And that will go out to various locations like, say, set up in a Morrison’s car park, and we sit there. And you would absolutely be amazed at the take-up. On Bank Holiday Monday we’ll be at the Aylsham Show in Norfolk. Seventeen thousand people show up. We get overwhelmed. And the benefit there is that we talk to the relatives, the friends, the carers, employers. It’s raising the profile. We also manage to attract politicians at things like the Aylsham show because they like to come and strut around and see what’s going on. It’s a nice show. If you’re up that way, do go. And we’ve been able to certainly talk to some local politicians about what’s going on in pain management, even to the extent of some coming into pain clinics to see what it’s all about.

[03:57:33] One of the Health Secretaries I haven’t mentioned, but in the journey along, said to me in the House of Commons, “I know everything about chronic pain.” Oh right, one of the few. He said, “I broke my finger and I went across to St Thomas’s and they put it right for me. It was only a few

weeks. Gone. Excellent.” You had to think, do you really know what chronic pain was? I won’t say which party but it’s not the one that’s in power at the moment. Got to get some equality there!

So there’s a situation there, isn’t there. The political side ain’t good. And there’s nothing on the surface at the moment that implies that it’s going to change. But what can you do to change it? What can you do in your own domain to change that? How many of you invite your local politicians in, and your national politicians in, to your clinics to what you do? Anybody? Not a soul.

You’ve got to market yourself. It’s a competitive world in health, today. The reality is there.

Thank you. Times up, how about that. Fifteen minutes went really quick. I will take questions later, and if you have been, because I know it’s after lunch, thank you for listening.

[Applause]

[03:59:04] Alex: Thank you very much Ian. Our next speaker is Dr. Emma Sheppard, whose talk is called, ‘Crippling Pain’. Emma has a PhD in Social Sciences and her thesis explores experiences of chronic pain from a disability standpoint. Her wider research interests encompass Crip Theory, embodiment and sexuality, and she lives with chronic pain.

[03:59:34] Dr Emma Sheppard: Brilliant. There we go. Yay, I’ve got it. Okay. Sorry, I’m going to sit on the table. Ian had the right idea, it’s quite comfy. So my talk is coming from a slightly different standpoint. I am going to talk very briefly about a slightly more theoretical approach, about the idea of Crip Theory, and Queer Theory—which is influenced by Queer Theory, I should say. So it’s from a sociological standpoint, but also how this ties into more political ideas around pain, particularly around chronic pain. And some of it will cross over quite a bit with what Alex was saying in the earlier panel.

So, very, very briefly, a quick and dirty account of Crip Theory, to start with. Crip Theory is, as I said, rooted in Queer Theory, so it’s concerned with how this idea of what we call *compulsory ablebodymindedness*, which is a really good mouthful of a word, but [is] basically the way in which the world is constructed for a particular person, a particular human that we have in mind when we say ‘people’: what that person is capable of, what that person looks like, acts like, even sounds like or maybe even how they dress.

[04:01:16] So we can think about things like, for example, stairs. We think of stairs as a pretty important, pretty normal, average thing that we have. This means that the ‘normal’ human should be able to use stairs. So with *compulsory ablebodymindedness* that might include stairs, but it can also include not being in pain.

So ‘normal’ becomes, instead of just being a way of perceiving, is what we think of as ‘ideal’. So ‘becoming normal’, ‘being normal’ is *ideal*: it’s something that we want to be, and something that we *should be*, and we should try our best to ‘be normal’.

So normal people have able bodyminds: i.e., they have no limitations on their bodily movement; they have no mental illness; and they have ‘normal’ cognitive development. And they must maintain this. So if we think about all the work that many people put in in going to the gym, not to be faster or

stronger, but just to be healthy. So if we think about ideas around health and the capacities that our bodies have this assumption of a capacity is reflected in how the world and society is constructed.

To give you a really broad definition of what I'm working with, disabled persons [with] a disabled bodymind, are those that fail to perform to perform heteronormative, flexible, independent ablebodymindedness at the right time and in the right amount of time. So we can also think around how the world is constructed for straight people, for people who have 'normal' sex, all of these things.

[04:03:11] But at the same time this leads to a construction of what we think disability looks like, and people living with chronic pain don't always fit into that paradigm of what 'disabled' is. This is quite often where people with chronic pain fall into the gaps—why it's not sexy, as Ian says—because on the rest of it we don't necessarily look like disabled people. We're not visibly impaired. And on top of that, for some people who live with chronic pain, that pain isn't always a fixed experience. It isn't something that is the same every day. So it can be quite hard to deal with on that level as well.

So to 'crip' pain, to look at it through a Crip Theory standpoint, we can look at all the ways in which we have very normal ideas, our normal pain ideas come running along and come into each other. So what I'm saying is that these ideas we have of what pain is, and what pain isn't, affect then how we go on to treat pain, how we go on to treat people who live with pain. And so there are several—and they're very broad, when I categorise these—there are several ways in which pain is understood.

First of all, not feeling pain is abnormal. So the talk we had, the first talk where the gentleman whose name I've forgotten was talking about using and working with people who didn't experience pain, and the genetics of not experiencing pain as a way to look at how to cure and treat pain. I found that quite interesting because not feeling pain... Excuse me again [coughs repeatedly] Sorry I've been teaching all week and my voice has started to go a bit croaky.

[04:05:29] So we think about not feeling pain as normal. Your average normal body doesn't wake up in pain. But at the same time, an inability to feel pain, so a lack of capacity to feel pain is in itself a disability. So pain kind of sits in this very awkward space where it's very much normal, in that you should be able to feel it, but is also very not normal in that feeling pain is bad.

Normal people should be able to talk about their pain, is the next one on the list. We should be able to talk about what we are experiencing. We should be able to say that we are in pain, for example. Describing pain and ascribing source and meaning becomes very important. Then on top of that, and this is often the one that comes in around medicine and medical care: pain is a sign of damage, i.e., if you are in pain, something is wrong. But pain only has meaning in that sense as a diagnostic tool, as an ability to tell you what is wrong or where there is a problem. And in this sense, after a while, chronic pain becomes meaningless. It's just a repetition.

[04:07:26] Then, and this is the third one that I've come across: pain is inherently negative, i.e., we don't like pain. We shouldn't want pain. And when we are in pain, we should want to get rid of it. Fiona Kumari-Campbell talks about disability as an ontological impossibility, i.e., something that we don't want and we are almost incapable of imagining ourselves as. So we are incapable of imagining ourselves as disabled people if we are not disabled. If we are not in pain, we are incapable of

imagining ourselves in pain, particularly chronic pain, pain that doesn't have a fixed boundary, and as a researcher that's what I've been looking at.

So being in pain is negative. And because of this unimaginability it becomes something that's quite difficult to talk about. And not only difficult to talk about, but difficult to listen to. We don't like to listen to other people talking about being in pain. Lots of people don't like watching TV shows or films where people are shown being in pain, and it's that kind of thing. It's that deep discomfort with pain. So being in pain becomes a state in which is unsustainable, not just because of the experience of being in pain, but of all the social pressures of other people saying, "I don't like you being in pain." That's not necessarily to do with the fact that they want for you not to experience pain. It's as much to do with the discomfort that the body in pain causes them.

[04:09:19] So, to reduce it down, experiencing pain makes us human, but being in pain makes us inhuman. It makes us an abject other, if you want to go all sociological terms on us, and it makes us almost unwanted and monstrous.

So, suffering. Suffering is great. I have a massive issue with the phrase, 'chronic pain sufferers', and any moment when I hear the phrase, 'people suffering from chronic pain', because it just...Oh It's really irritating. I'm not quite sure why. But this [is the] idea that pain is abnormal and pain is distressing, and pain is an ontological impossibility. Suffering means that it's everything. So if we 'suffer from' chronic pain, it becomes our whole world, and there is an assumption that those who are in pain, that that pain that they experience is everything. And that's why, as Nicole was talking about earlier, you know, with people living with fibromyalgia, actually their chronic pain may not be the thing that impacts their identity the most, or maybe is one of the many things that have impacted their identity. But the assumption is the minute you say 'pain', it almost pushes aside everything else, when the lived reality of people living with chronic pain is actually that there's lots of other things going on too. Calling them 'chronic pain sufferers' erases all those other things and reduces them down to pain, and that's where this discomfort comes back in because we don't like pain.

[04:11:04] So what does this add up to? There are a huge range of rehabilitation practices available, some of which are ones that are available on the NHS and have lots of research saying that they might be quite good. Others are endorsed by random strangers we meet on the street, such as the person who advised me to try yoga the other week (like I haven't tried!). So we can think of rehabilitation practices as everything from pain medication to cutting out certain types of fruit juice, or Coca-Cola, or whatever it is this week that causes chronic pain. But they're all focused on going back to normal. And this emphasis on cure and treatment pushes responsibility for ending pain onto the person living with pain, because it's not a case of 'the pain treatment doesn't work', it's a case of 'they've not tried the next one'. And this demand of keeping up with trying all of these things has a massive impact.

And this is where I think the political aspects of chronic pain come in, because it's not just about living with chronic pain, it's this constant pressure to try something else. If this doesn't work try the next thing, try the next thing. Well maybe you haven't tried that for long enough? Maybe you need to give it six months instead of three months? Or maybe you need to give it a year? Or maybe you've just not wanted it enough?

But at the same time we live in a political situation where these ‘cures’, and I use the term very loosely, these rehabilitative practices, are profitable. They make money. There’s a huge amount of money to be made in diet, for example, and diet has become a big thing around chronic pain and managing chronic pain by ‘eating clean’ and all of these things.

[04:13:10] So whenever one thing kind of makes you feel a bit better you’ve got to try the next thing, to get closer and closer to this idea of normal. But it’s the individual that is marked as the failure, and not wider life. It’s not wider life that is doing them wrong. It is they aren’t keeping up with it. So pain becomes a personal failure. And while chronic pain must be lived with, and normality must be performed, this means that the person living with chronic pain must engage in stigma-management, must try and behave as though they are not in pain.

To finish off, alternatives. And these are very loose, because some of these ideas around what we mean by ‘normal’ and ‘chronic pain’ and ‘disabled’ are very, very deeply interwoven into the whole way we live and our whole conception of what it means to be people. So one of the biggest things, I think, is saying that chronic pain can be awful, but it isn’t always totally awful all of the time. And living with chronic pain, the key bit is the *living*, not the chronic pain. Stepping away from rehabilitative practices can be useful for some people, and accepting when others do or do not engage with rehabilitative practices. So this is not just for people who don’t live with chronic pain, but also those who do. Embracing lives as disabled, as cripp; as saying, “I’m in chronic pain and that’s okay.” And acknowledging slow and unreliable lives, and valuing how disabled bodies and subjectivities experience and reproduce the world.

And that’s where I’m going to finish because I’m going to go and have another coughing session.

[Applause]

[4:15:15] Dr. Alex Lee (Chair): Thanks very much Emma. So now I would like to invite both of our speakers back up to the front and I’ll open up the discussion to the audience. Are there any questions?

[4:15:44] Questioner 14: Hello. That was fascinating because it seemed to me that you’re almost saying fairly opposite things, if I’ve sort of understood you, because you’re saying that chronic pain is something we need to try to reduce, and you’re almost saying that it’s okay to have chronic pain. I’m just wondering if that is a very Westernised approach, because in some settings, in some cultures, I wouldn’t say that being without pain is normal. Actually almost having pain is part of human life, what it means, in fact. Joanna Burke talks about having pain is part of what it means to be human. So is it focusing on a very Western perspective and are there other things we can learn from other cultures? To both of you really.

[4:16:31] Dr. Emma Sheppard: Yes, to answer that, yes it is. This is a very Western view of things. This is not to say that in other cultures there isn’t an expectation that pain is negative. I would say that pain being bad, on some level, is quite a broad concept. What I’m saying more is that there is such pressure to stop pain that actually it becomes a pressure to stop everything until pain is stopped. It’s almost like because you’re in pain you can’t be anything else. Whereas instead there needs to be a greater and wider acceptance that people in pain still live brilliant, fulfilling lives, and actually being in pain doesn’t prevent them, it is a part of that brilliant and fulfilling life, if that makes sense. So

rather than focusing solely on a cure, and solely on stopping pain, we also need to focus on the fact that it's okay to be disabled, and that's not a bad thing in itself.

[4:17:48] Ian Semmons: Yes I'm in some ways quite opposed to that. I don't think the issue is as great as Emma is making out, from our experience over the years. I think broadly within families chronic pain is accepted when those folks understand what the implications are, and it is also down to the attitude of the person with the chronic pain. You know, are you going to sink or swim? Possibly one of the biggest steps is to accept, firstly, that you've got it. And once you do that then you can start to say, well, how am I going to deal with this? Is it going to be the key player in my life or is it going to be something that I get on with and I find ways of handling it. Not necessarily medication. It could be all sorts of things. You know, relaxation. And yes there are loads of quackery in all things, you can buy all sorts of things, but I've survived twenty-seven years without all those and from our experience when we talk to people face to face is that most of them, when they understand where they're going with it, and sometimes healthcare professionals are a bit reluctant to tell it as it is, once they understand that, then they can start to move forward. And their families understand. I can't stress that enough, you know, family support, where it's there, is absolutely invaluable.

[4:19:34] Questioner 15: Thank you very much. I was quite intrigued by both presentations. I have come across the Crip Theory before as well, but I was just wondering, how does this fit with today's society where, for example, from my own experience with the research that I'm doing, people are reluctant to disclose their issues in the first place, and that's, you know, with both of your positions, how can we make changes to the politics, for example, of pain if actually people can't disclose it, and at the same time they can't disclose it because they too worried about losing their jobs for example, or not getting jobs, as we can see with the academics that I'm working with. So the question for me is, how do you see how we can move on from that position that we're in if society doesn't accept pain in that sense?

[4:20:29] Dr. Emma Sheppard: So to start with I would say that's where the idea of stigma-management comes in. Being in pain is hugely stigmatised. And I think we need to talk more about the fact that being in pain is stigmatised and people who treat people who are in pain—and not just people who are in pain, but people who talk about being in pain, badly, because that's the key part, because if you don't talk about being in pain, you're not necessarily treated badly because you're in pain. You might be treated badly because of other people's perception of what you're doing or not doing, but it's not known why you do those things or you don't do those things. So for me there's two parts: there's acknowledging the stigma of being in chronic pain, and challenging people, but then also challenging this idea that pain is awful, because the first thing when I talk about my chronic pain is people want to say how bad it is, or about this time they were in pain too. So there's a sympathy there, and there is an urge to sympathise and empathise, and to say well actually, that's fine, but it's not all awful all the time, and we need to let people live with their pain in the way that suits them best, but also to say that, to essentially to normalise pain, if that makes sense. Because I think that's part of what the stigma is, it's the fact that it's seen as this awful, terrible thing that we can't talk about. Or that people don't like to listen to.

[4:22:09] Ian Semmons: Yes, again, I'm in disagreement with that because I find more and more now over the years, people are quite happy to talk about it. In terms of how you deal with an employer, one of the ways we deal with it is that we ask, when the person with the pain sees the healthcare professional, they get as much information from them as they can, and hopefully they will get some

really good information. With GPs that can be difficult because they don't get much training in pain management, which is unfortunate. But we also produce a booklet called 'Understanding and Managing Chronic Pain', and we urge them to take that into their employer and say, "Have a read of that." And do you know, it works a lot of the time. Not all the time. But it works. Because bear in mind, that employer hasn't got a clue! Or you'll have an employer who's got a family member or friend who's got chronic pain, and will relate to it. So it's sort of thinking out of the box a bit. In all my years I've never come across anybody who has ever seen chronic pain as a stigma. I've found people who were very frustrated with it, with their own situation. And it is frustrating. We've all been there. And that's not going to change. But I've never seen it as a stigma. There's far worse things out there that attract more attention, and my fellow trustees would say exactly the same.

[4:23:54] Dr. Emma Sheppard: I just wanted to add to that, that at the same time, when addressing employers, we do have to be aware that for others living with chronic pain they may also be existing in states of, for example, precarious employment, where they don't feel capable of talking to their employer because they're very aware that the minute they raise anything, they could lose their job. Or that they may have their hours cut because their employer goes, "Well, if you can't cope, we'll scale it back." And it becomes—so I would say there is a stigma there. That's what I would mean by a stigma. It's something that is perceived of as a negative quality in a person, and that they are treated differently, and they are treated less well because of that. So yes there are a whole range of issues and chronic pain is not just around an individual bodymind, it's around wider social and political issues. And that's why I think it is a political issue. It's because we don't just have to look at it as chronic pain. We have to look at it as issues of, for example, labour precarity and gender roles and availability of medication and whether going for biopsychosocial or Crip Theory or what model of disability we're looking at, they all tie into each other.

[4:25:20] Dr Alex Lee (Chair): Okay so we have a question from Twitter from Alex who spoke earlier. They've asked: Do you think there is a role for diagnosis or diagnostic labels distinct from a pursuit of treatment or a cure?

[4:25:56] Dr. Emma Sheppard: So, yes and no? To be one of those people. Diagnostic labels can be awfully useful. They are particularly useful when it comes to accessing, for example, accessibility service. It can be really, really hard to access things, as we're in a university, like the Disabled Student Services if you don't have a diagnosis. Diagnosis can be very useful for identity and knowing what's wrong can be very useful. It's been nearly ten years now but I remember getting my diagnosis and going, "Ah, okay. This is something I can deal with." Outside of cure, rehabilitation, yes and no. But again, because I do think we focus on, "This is your impairment or disability or whatever, this is what you must do." Whereas sometimes I think we should perhaps focus on, "This is how it impacts your life, let's look at the impact and address it that way," rather than looking at the name that you've got on your file of what you've got. Ian?

[4:27:18] Ian Semmons: Yeah I think I'd sum that up very shortly that you regard everybody as an individual and you respond to their individual needs. It's very easy to tick-box, and it's being able to listen to the needs of that person affected by chronic pain and tailoring the support you give to that particular need. The key to what I've just said is listening and individuality. It's absolutely critical.

[4:27:52] Dr. Alex Lee (Chair): I think we're going to have to stop there now. If you've got any more questions I'm sure our panellists will be happy to talk to you over the break. So we have a break now

until 3.15pm, so there's tea and coffee at the back, and I have copies of Frances's paper here and I'll hand some out, but come and pick one up if I don't manage to get one to you. And let's thank our speakers one more time.

[Applause]