

PAIN MATTERS

THE MAGAZINE OF PAIN CONCERN | painconcern.org.uk

ISSUE 80

WHAT TREATMENTS REALLY WORK

**Describing
neuropathic
pain**

**The impact of
adverse childhood
experiences**

**How we think about pain
and how we research it**



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WELCOME

Dear Reader,

Funding for pain research is absolutely essential in order to move towards a healthcare system with improved outcomes, where quality of patient care is better informed by science and led by the needs of the patients. With that in mind, we are pleased to announce that this edition of **Pain Matters** is guest-edited by Lesley Colvin, co-lead of the University of Dundee Chronic Pain Research Group along with David Walsh, the Director of the Advanced Pain Discovery Platform (APDP).

The Advanced Pain Discovery Platform is a four-year initiative which has received a massive £24m in funding. On the APDP website it is stated that 'The aim of this programme is to deliver a consortium-based platform of national scale that will break through the complexity of pain and reveal potential new treatment approaches to address a wide spectrum of chronic and debilitating the clinical conditions'. Partners of the APDP initiative include Medical Research Council (MRC), Economic and Social Research Council (ESRC), Biotechnology and Biological Sciences Research Council (BBSRC), Versus Arthritis, Eli Lilly, and the Medical Research Foundation. So, it's safe to say this an ambitious project that will propel the advancement of pain research in Scotland and beyond, bringing together a wealth of expertise. Importantly, people living with chronic pain have been involved with this initiative from the start and will continue to help shape the research and there are opportunities for people with chronic pain to get involved, to find out more please visit hdruk.ac.uk/helping-with-health-data/health-data-research-hubs.

Jennifer Bowey, Managing Editor

MESSAGE FROM OUR GUEST EDITORS

THE ADVANCED PAIN DISCOVERY PLATFORM (APDP)

Despite world leading research, the problem of pain still blights the lives of far too many people in the UK. In this issue we introduce the Advanced Pain Discovery Platform and tell how this will revolutionise research and benefit patients

The United Kingdom has been in the forefront of pain research. Experts in universities and industry have driven the creation of new and robust techniques that uncover genes and molecules, brain structure and function, psychological and social mechanisms, drug and non-drug treatments. People who suffer from pain have driven this national collaboration, ensuring research that is relevant to their needs. So why does pain remain such a big problem?

Our understanding of pain continues to improve: we know much more now than in the past about the genetics of pain. We know better which treatments do and don't work. We are understanding how brain regions connect to determine the lived experience of pain. However, pain is as complex as the people who experience it. How can we bring together the experience of pain and what we can discover about body chemistry or how the brain works? How much more could we learn using all the



information and blood samples from those tens-of-thousands of people with chronic pain who participate in research? How could we all work together to ensure changes in the lives of people in pain?

The APDP is a new, unique partnership that has developed from a vision shared by government, charities and the private sector. This is a long term initiative that has been funded by the UK government and Versus Arthritis who have shared a £24 million initial investment, with the American Pharmaceutical company, Eli Lilly, giving additional support. The Medical Research Foundation is also on board with additional funding for much needed research into pain in children and adolescents. The partners in APDP hope that it will have international impact leading to scientific discoveries that will finally break through the complexities of pain and so lead to new approaches that address the wide spectrum of chronic and debilitating conditions causing pain. We believe this new funding and approach will transform people's understanding of the many variations and unpredictability of pain. It will uncover shared mechanisms and break down inconsistencies in diagnosis and treatment. It will discover new ways of diagnosing and treating pain. The APDP brings together people with lived experience of pain and excellence in chronic pain research across diagnoses, disciplines, academic, clinical and commercial communities.

The APDP is a new, unique partnership that has developed from a shared vision

Articles in this edition of **Pain Matters** highlight how this new, unique partnership includes people with lived experience of pain alongside research experts and how this new phase of collaborative partnership will make significant changes that ultimately will lessen the impact of pain on individuals and society.

David Andrew Walsh, Director of the Advanced Pain Discovery Platform, Co-director of Pain Centre Versus Arthritis, Professor of Rheumatology, University of Nottingham and Honorary Consultant Rheumatologist, Sherwood Forest Hospitals NHS Foundation Trust.

Lesley A Colvin, Professor of Pain Medicine, University of Dundee, Hon Consultant in Anaesthesia & Pain Medicine, NHS Tayside, Clinical Lead of NHS Research Scotland Pain Area/ Scottish Pain Research Community (SPaRC).



David Andrew Walsh Lesley A Colvin

THE IMPORTANCE OF PATIENT INVOLVEMENT IN PAIN RESEARCH



By Carolyn Cooper,
Antony Chuter & Dr Gillian Craig

The Advanced Pain Discovery Platform (APDP) is a new research initiative that is combining expertise across the UK to undertake innovative pain research. Over one hundred pain clinicians, psychologists, researchers, charity partners and, most importantly, patient partners have come together to address important issues in pain.

Involving people who have experience of living with pain is of fundamental importance in the design and development of APDP pain research. The projects within the platform have patients involved at every point in the research process. Patient involvement is different to patient participation in research: involvement is where research is performed 'with' patients rather than 'to' patients. Patients involved in research are treated as equal partners within the research team. This article has been developed by patient partners within the platform to highlight the importance of patient involvement in pain research.

Living with pain is a very personal and emotional journey. People living with pain often feel isolated if their family, friends or medical professionals do not understand or believe their pain or the impact their

pain has on them. It is very difficult for researchers to understand the wide-reaching impact that pain has on many aspects of people's lives, such as daily activities, personal and professional relationships, finances and mental health. Only people living with pain can express their perspectives on the impact of pain and issues that are important to them. Therefore, it is vitally important that people living with pain and their experiences are embedded throughout the creation and execution of pain research.

Patient involvement is inviting patients to the research table and asking 'what is important to you?' and 'how can we do this better?' Patient involvement in pain research can give us a voice and the opportunity to be heard. When researchers say: 'oh, we hadn't thought of that', we feel valued, listened to and, most importantly, believed. People living with pain have unique and valuable perspectives that can have a significant impact on the direction research takes and can improve the quality of the research. Involvement can also make research more accessible to patients by ensuring that care pathways are patient-friendly and that patient documents are understandable.

The image of an outstretched hand of someone living with pain demonstrates the hope that this research brings for people living with pain. Artists, Emma Rankin and Angela Gillies are Masters students in Art, Science & Visual Thinking at the University of Dundee. They created the image in this article, and they are working with the PAINSTORM team to create artwork for the project.



Our experience of being patient partners is that we have a purpose and a sense of feeling valued when our perspectives are listened to and implemented. Our input can improve the experience of research participants, not to mention the impact the research can have on future patients. Sharing our experiences within a patient group can make us aware that we are not alone and that there are a lot of people with similar experiences. Living with pain can cause people to feel like they're losing their identity, but we feel that being involved in research ignites a passion within us to be a force for positive change.

Patient involvement can be a rewarding and productive process for both researchers and patient partners. We encourage people living with pain to become involved in research that they are passionate about. We hope that by working together we can develop a better understanding of pain conditions and improve future management guidance and treatments.

Antony Chuter is a patient partner on the Alleviate project and Carolyn Cooper is a patient partner on the CAPE project. They have both lived with pain for over thirty years and have developed this article together.

Dr Gillian Craig is a Patient and Public Involvement Manager and is supporting patient involvement across several of the APDP projects.



Antony Chuter



Carolyn Cooper



Dr Gillian Craig

CALL THE PAIN CONCERN HELPLINE



Information, support or a listening ear for anyone wanting to talk about their own pain or that of someone they care for.

The helpline is open:

Monday 14:00 - 16:00

Wednesday 18:00 - 20:00

Call 0300 123 0789 or email help@painconcern.org.uk anytime.



ALLEVIATE DATA HUB: AN OPPORTUNITY FOR PATIENT ENGAGEMENT

By: Antony Chuter, Jillian Beggs, Gillian Craig & Jenni Harrison

Chronic pain research is vital in order to understand the causes of chronic pain and to improve the management and treatment of pain conditions. Although chronic pain is routinely researched, the data from these investigations are often held in isolation. The aim of the data hub is to combine data from chronic pain research being undertaken across the UK, to maximise the value and use of this data.

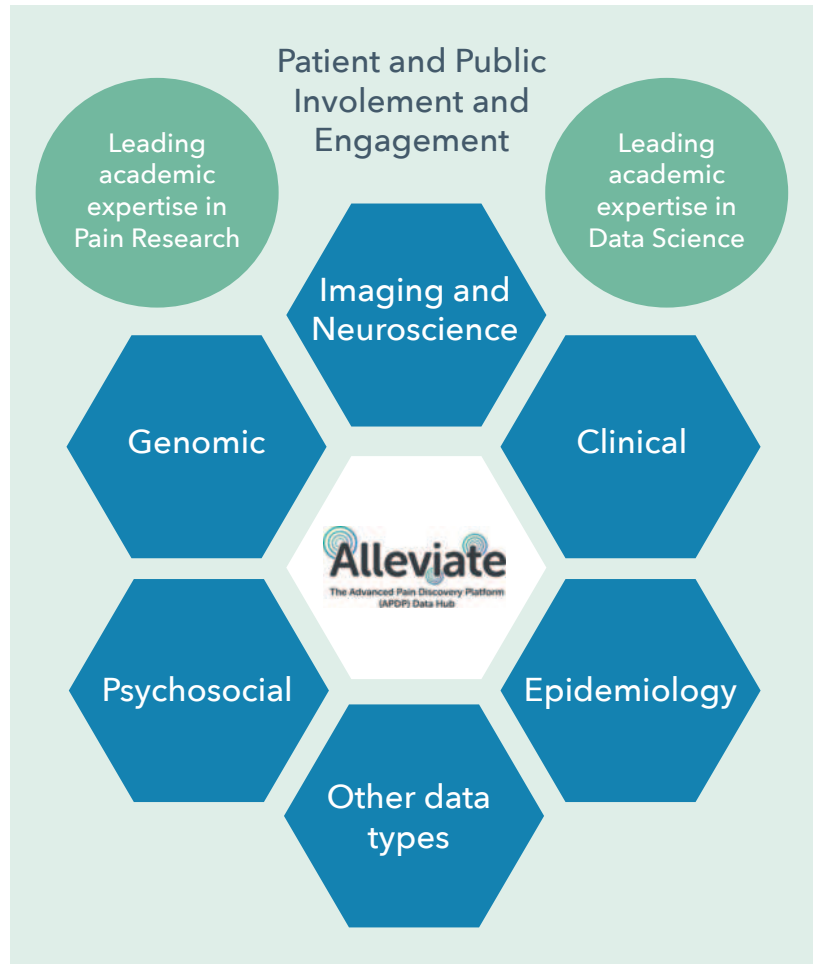
Alleviate is a data hub which will technically support the Advanced Pain Discovery Platform (APDP). Alleviate is also part of an established network of nine Health Data Research Hubs, led by HDR UK (<https://www.hdruk.ac.uk/helping-with-health-data/health-data-research-hubs/>). Health Data Research Hubs are centres of excellence with expertise, tools, knowledge and ways of working to maximise the insights and innovations developed from the health data.

Alleviate will make pain research data FAIR: Findable, Accessible, Interpretable and Reusable. This will provide a national approach to chronic pain research, with the potential to uncover new knowledge of chronic pain and provide new treatments to improve patient care. Alleviate is funded by UKRI and Versus Arthritis.

The Alleviate lead patient partners, Antony and Jillian, have shared their thoughts and experiences of being

involved in this project. Jillian believes that Alleviate is an exciting development for all people living with pain and those who support them. The project creates the opportunity for researchers and healthcare professionals to quickly and easily share anonymous research information that could provide new treatments. More importantly the project is shaped by patients, with a lived experience of pain at its heart.

Having patient partners within the Alleviate project team ensures that the researchers always consider the impact of their decisions on patients at every point. The patient partners are equal members of the research team, which ensures that the development of the project and the results shared are relevant to those living with pain. Patient partners in Alleviate will also share ideas and opportunities with other pain-related research projects, creating a community of patient voices relevant to pain research.



After living with pain for more than thirty years, Anthony shared that he, and perhaps many others, have only dreamt of a project like this. A project which brings together data on pain and on people living with pain. 'I am excited and slightly daunted about being involved in this project, as it is important for so many people who live with pain. I cannot wait to participate in building the community of people living with pain, who will help guide and influence this important work. My analogy is "you have to put books in the library to enhance knowledge"', he says. The Alleviate data hub will create a powerful resource that will be informed by what matters to people living with chronic pain.

Patient and public involvement is integrated throughout the data hub development. We will create a community of engaged patients living with chronic

The Alleviate data hub will create a powerful resource that will be informed by what matters to people living with chronic pain.

pain to guide the project. If you live with pain, and would like to join the Alleviate Pain Community, please register your interest at <https://www.hdruc.ac.uk/helping-with-health-data/health-data-research-hubs>.

Anthony Chuter is a patient partner on the Alleviate project and has lived with pain for over thirty years.

Jillian Beggs is a patient partner on the Alleviate project.

Dr Gillian Craig is a Patient and Public Involvement Manager and is supporting patient involvement across several of the APDP projects.

Dr Jenni Harrison is the Deputy Director of the Alleviate Data Hub project, based in the Health Informatics Centre at the University of Dundee.



Anthony Chuter



Jillian Beggs



Dr Gillian Craig



Dr Jenni Harrison

THE IMPACT OF ADVERSE CHILDHOOD EXPERIENCES ON CHRONIC PAIN

CONSORTIUM AGAINST PAIN INEQUALITY

By Tim Hales and Sam Singleton

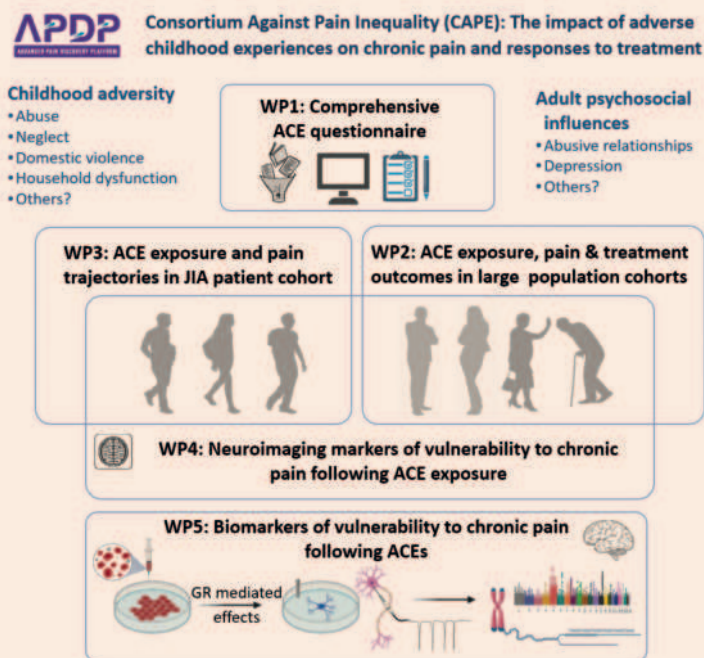
Adverse childhood experiences (ACEs), which include physical and emotional abuse, neglect and household dysfunction, are the most common and intense childhood stressors. Although exposure to at least one ACE is common, occurring in around half of children, experiencing multiple events can have an impact on health in later life.

One possible impact is an increased risk of chronic pain in adulthood. Unfortunately, current pain treatments have limited effectiveness in addressing pain following ACEs, consequently the number of people living with chronic pain is increasing.

While there is good evidence that ACEs increase pain vulnerability, there are no effective methods to identify those at greatest risk. One reason for this is our poor understanding of factors that increase the risk of pain following ACEs. Therefore, the Consortium Against Pain Inequality (CAPE) aims to better understand the relationship between childhood adversity and chronic pain. CAPE also aims to investigate why some people with pain respond well to pain killers while others do not.

By working with patient partners, scientists and clinical health researchers, CAPE is developing a questionnaire to assess exposure to ACEs and the associated impact. Through the use of this questionnaire, CAPE aims to better understand links between adversities, pain and treatment outcomes. Alongside this, the project will study brain images and genetic markers to identify what factors are associated with poor pain outcomes and poor treatment outcomes in people with ACEs.

Through understanding how ACEs are linked to health inequalities in later life, we hope to reduce the burden of chronic pain by identifying those at greatest risk and developing personalised treatments.



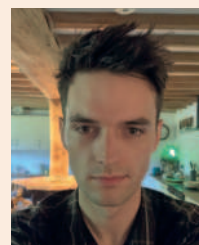
The figure depicts the five CAPE work packages (WPs). The acronyms JIA and GR are juvenile idiopathic arthritis and glucocorticoid receptor, respectively. The project is funded by the Advanced Pain Discovery Platform (APDP) a collaboration between Versus Arthritis, UK research Institutes and Eli Lilly.

Tim Hales is Professor of Anaesthesia, Associate Dean in the University of Dundee School of Medicine and Principal Investigator of CAPE.

Sam Singleton is a member of Professor Tim Hales' group and recruited by CAPE as a research assistant to investigate potential biological markers linking childhood adversities to chronic pain.



Tim Hales



Sam Singleton

More about CAPE and the Advanced Pain Discovery Platform:

www.dundee.ac.uk/stories/major-funding-success-research-chronic-pain

www.ukri.org/news/new-data-hub-and-research-into-chronic-pain

www.versusarthritis.org/news/2021/may/how-will-our-research-help-people-living-with-chronic-pain

RESPECTED, INVOLVED AND EMPOWERED



Janine Rennie

Janine Rennie shares her experience

Patient partners have been involved from the design stage and the project development has been informed by lived experience. We have established a Chronic Pain Advisory Group (CPAG) and members are keen to be involved in the hope that the evidence linking ACEs to chronic pain will be better understood. However, it's important to note that discussions about experiences could trigger traumatic memories. CAPE takes the wellbeing of those individuals supporting the research very seriously. I am included as part of the team, rather than in a tokenistic way. I feel my views and input are listened to, as are points raised by others in CPAG.

Being a Patient Partner has been extremely important to me. I have felt respected, involved and empowered by the process and the way colleagues have worked with me. I feel that I'm part of a project that can enact change for people who have experienced ACEs and who live with pain. The project will ensure healthcare professionals and others gain a greater understanding of the links between ACEs and chronic pain, ensuring that the experiences of patients are not dismissed. I feel that the CAPE project should be identified as a model of good practice for patient involvement, because those with lived experience have been involved from the outset of the project, throughout both design and delivery. I am very excited to see the results and I feel proud to be part of this project and work with inspiring people.

I experience significant pain every day and I welcome a future where we understand how my past has contributed to my present experience of day-to-day life. I believe it will contribute to breaking down the stigma that I, and others, face and ensure we are treated with dignity and respect.

Janine is CAPE's lead patient partner and is CEO of Wellbeing Scotland, a charity who work with survivors of childhood trauma. Janine has been supporting people who have experienced ACEs for fifteen years and also has lived experience.

ADVANTAGE CONSORTIUM LEADS PIONEERING RESEARCH INTO VISCERAL PAIN

By Professor Geoff Woods, Professor Amanda Williams, Ms Tess Harris

Visceral pain is pain arising from diseases of the abdominal and chest organs. The ADVANTAGE consortium aims to improve pain management for people with visceral disease. Our focus is to understand pain and how it affects people - rather than the underlying visceral organ disease.

During this pioneering programme we will establish a national visceral pain data archive for use by all pain researchers. At the end of the four-year grant we want to leave a collaboration of people to continue this work.

One in twenty individuals in the UK is disabled by visceral pain, often constant pain, plus unpredictable pain 'flare-ups' that may require hospital admission.

'Pain is a constant unwanted companion in my life. Accompanied by chronic fatigue and general malaise, it has a psychological impact that demands I change aspects of my daily life. Pain is a very discontented companion vying for pole position with my ulcerative colitis, complex and exhausting at times.'
Inflammatory Bowel Disease patient.

We know surprisingly little about visceral pain. No one has systematically studied how pain is connected to underlying visceral disease, to other health problems or how it affects people's psychological and social wellbeing.

continued on page 10

'I had to give up working because of the pain, leading to the loss of my business and twenty people being made redundant. This had a major psychological impact on me and put me in a difficult financial position for the future.'
Polycystic Kidney Disease patient

ADVANTAGE will establish a UK-wide database of visceral pain patients. Detailed assessments (clinical, psychological and genetic) of 1000 people with visceral pain will occur in clinical hubs in Edinburgh and Cambridge.

The types of pain we will study are from endometriosis, Crohn's disease and ulcerative colitis, polycystic kidney disease (PKD), pancreatitis, chest/pleura pain, painful bladder syndrome and high vaginal pain after MESH surgery. We will include chronic and 'flare-up' pain, analyse sexes separately and determine the usefulness of wearable technology in pain assessment. In particular, we need to find people with severe pain but little disease and vice versa, as both teach us different things about pain.

We will also define the specialist nerves of inner organs that pass pain information to the brain, as they are different to the usual nerves that sense pain in skin and in bones but are not yet well identified. Finally, we will seek to learn what drives differences in visceral pain across psychology, autoantibodies and genetics.

ADVANTAGE includes patient representatives with lived experience of visceral pain and charities including Bowel Research UK, Crohn's & Colitis UK, Endometriosis UK, Pelvic Pain Support Network and PKD Charity.

Professor Geoff Woods, NHS Clinical Geneticist and Mendelian pain researcher

Professor Amanda Williams, Professor of Clinical Health Psychology, active in research and clinical work in persistent pain

Ms Tess Harris, CEO PKD Charity and patient partner



Professor Geoff Woods



Professor Amanda Williams



Tess Harris

INVESTIGATING NEUROPATHIC PAIN

David Bennett and Kathryn Martin explain the Painstorm Project



Professor David Bennet



Dr Kathryn R Martin

Neuropathic pain affects 8% of the population and is caused by damage to the sensory nervous system. This damage changes the way the body deals with messages from the nerves. It is often caused by common conditions such as diabetes and HIV, as well as cancer chemotherapy. Many people living with neuropathic pain report that it can negatively impact on their quality of life.

The PAINSTORM project seeks to understand what causes neuropathic pain. We will engage with people at risk of developing neuropathic pain and follow their progress over time. We will use innovative technologies including brain, spinal cord and nerve imaging to explore what causes neuropathic pain.

One of our key questions is, why are some people severely impacted by neuropathic pain while others with a similar pattern of nerve damage are not? To investigate this question we examine the role factors like age, gender, ethnicity, genetics, environment and medical history might have on the risk of developing neuropathic pain.

We are working with patient partners on this project to understand what outcomes are important to all people living with neuropathic pain. We want to improve existing treatments and develop new treatments, based on the views of our patient partners. The PAINSTORM project brings together patients, clinicians and researchers from many different backgrounds. Ultimately, we aim to transform lives by improving the understanding and management of neuropathic pain.

Professor David Bennett is Head of the Division of Clinical Neurology at the University of Oxford.

Dr Kathryn R Martin is a Lecturer at the University of Aberdeen. Within PAINSTORM, she is lead for PPI Patient and Public Involvement.

DESCRIBING PAIN

By Fiona Talkington

When I tell people that I live with neuropathic pain the responses are varied: 'have you tried meditation?', 'but you're not in pain now though?' or simply a blank stare, at worst, ridicule. If I explain that it is something that developed after chemotherapy, and other treatments, for breast cancer - the 'debris on the beach' as I like to put it - the responses I get are likely to be along the lines of 'at least you're cancer free'. It's hard to explain that this invisible pain in my legs, feet and hands has caused major disruption to my life. It's an unwanted soundtrack and I can't turn the volume down.

My own search to find doctors who understood me, even if I could just be useful for research, took me down a path which has arrived at the PAINSTORM team. This team brings together other people with lived experience, clinicians with immense experience and highly skilled researchers. PAINSTORM has the potential to change lives and increase understanding and awareness, which could improve quality of life for people with pain.

I am struck by the dedication and determination of the PAINSTORM team who not only bring such great expertise, but who show real empathy and understanding towards people living with neuropathic pain. There is real openness of communication at every level in this quest for answers, for treatments and for greater understanding - a real drive to broaden communication so that patients feel listened to at every possible level. It's immensely moving to be part of this team and to feel the energy which will make breakthroughs, which will improve awareness so that I, and so many others, stop being met with blank stares or worse.

Fiona Talkington is a PAINSTORM patient partner. Fiona is a presenter on BBC Radio 3, a writer and curator working in music and the arts in the UK and abroad.



Fiona Talkington

Describing neuropathic pain, any pain, is challenging. On a scale of 1-10 just doesn't cut it. Pictures, music, writing can have an impact and these have already rippled through some of the PAINSTORM team. I'll leave you with mine:

They call it pain
I call it a burning knife
I call it despair
I call it being suffocated

I call it a burning knife
They call it by a name I can't even spell
I call it being suffocated
I call it the sharp beaked bird that took my life away

They call it by a name I can't even spell
I call it the splinters of tears that pour down my face
I call it the sharp beaked bird that took my life away
I call it drowning

I call
I call it despair
I call them
They call it pain

© Fiona Talkington

PAINSTORM stands for **P**artnership for **A**ssessment and **I**nvestigation of **N**europathic Pain:
Studies **T**racking **O**utcomes, **R**isks and **M**echanisms.



THE IMPACT OF SOCIETY AND OUR MINDS ON THE WORKINGS OF CHRONIC PAIN

By Noreen Shivji, Colin Wilkinson, Candy McCabe, Carolyn A. Chew-Graham, Lisa Austin, Edmund Keog

Alongside biological factors, psychological factors such as thoughts and feelings, and social factors including personal relationships and lifestyle, can also affect chronic pain. However, we don't know which of these factors is most important, or how they combine to affect people's experiences of pain.

To further investigate these factors, the Consortium to Research Individual, Interpersonal and Social influences in Pain (CRIISP) will focus on how people think and feel about pain, how relationships with others affect their pain and consider the wider social and environmental influences on pain.

People with pain participate in our work at all stages, to ensure our work is guided by the way pain affects people's lives. We will start by exploring the existing

evidence (previous research) to identify the things that have the greatest effect on pain and what measures and methods best reflect lived experience. We will ask people with pain which factors are most important to them and test those factors in existing large datasets. We will then carry out new studies on a selection of psychological and social factors, explore how they contribute to pain and observe how people live with pain.

Our consortium gives us an opportunity to change how we think about pain and how we research it

Our consortium gives us an opportunity to change how we think about pain and how we research it. We will make everything we learn and the tools we develop available to pain researchers. Through our work we will seek to open new areas of pain research that will develop better ways to help people live well with pain.

REFLECTION FROM PATIENT PARTNER COLIN WILKINSON

I got involved in the CRIISP consortium because I was excited by the opportunity to participate in a major piece of research into the psychosocial aspects of pain. This is an area that I was unfamiliar with but interested in. Particularly as I have learnt of the benefits of distraction, positive attitude and various other techniques through my own experiences of chronic pain and my involvement in a previous project.

The journey of getting to know the members of the consortium, putting together the consortium application and beginning work has been fascinating. Seeing different perspectives on the same problem come together is part of why I got involved in research. Being part of the team means I can bring my perspective to bear on equal terms with those of the scientists. I am a science geek, so getting to sit down with real scientific experts to solve a problem together is my dream job. It is very important to me that the voices of people with pain are placed at the forefront of pain research. If these consortia do not see pain through the lens of our experience, they may be focussing on the wrong problems or addressing them in the wrong way. The Advanced Pain Discovery

Platform (APDP) represents a once-in-a-generation opportunity to address the challenges of pain and the largest single investment into pain research in Europe. It's our job, whatever our role is, to make sure we don't waste this opportunity.

Dr Noureen Shivji is a Research Associate in Health Services Research at the School of Medicine, Keele University

Mr Colin Wilkinson is a Patient and Public Involvement and Engagement representative, at The University of Bath

Professor Candy McCabe is a Professor of Clinical Research and Practice School of Health and Social Wellbeing, Faculty of Health and Applied Sciences at the University of the West of England, Bristol. Her other roles are: Head of Education & Research, Dorothy House Hospice, Winsley (half time), Director of the Chronic Pain Health Integration Team, Bristol Health Partners

Professor Carolyn Chew-Graham is Professor of General Practice Research, at the School of Medicine, Keele University. She is a GP in Manchester. Her other roles are: Honorary Professor of Primary Care Mental, University of Manchester and Visiting Professor, University of York. She is the current Chair Society for Academic Primary Care (SAPC)

Dr Lisa Austin is a Research Manager BSW Research Hub and Research Design Service, University of Bath

Professor Edmund Keogh is a Professor in the Department of Psychology, Centre for Pain Research, University of Bath.



Dr Noureen Shivji



Colin Wilkinson



Professor Candy McCabe



Professor Carolyn Chew-Graham



Dr Lisa Austin



Professor Edmund Keogh

WHERE'S THE EVIDENCE: WHAT TREATMENTS REALLY WORK?

By Amanda C de C Williams

It can be so hard to identify cause and effect in one's life, whether to do with changes in pain, general wellbeing or mood. What makes sense one day doesn't seem to apply the next day; many patients find that analgesics work for their pain only occasionally, enough to keep trying but not enough to rely on. Exactly the same problems face researchers on pain and its treatment. Only by establishing clear cause and effect relationships can those who treat pain be sure of the advice and treatments they offer. So how can they achieve that?

TOO MUCH RESEARCH?

The amount of research in pain, as in other areas, is overwhelming and increasing every year. While this should offer better prospects for people with pain it is, of course, not so straightforward. What stops research results turning into better practice in treating pain?

One is the amount of time it would take just to read it all, assuming it were easily accessible which it isn't for many clinicians. Another is that it takes careful reading to distinguish the good from the middling and the bad quality research. Yet another barrier is that, like all of us, clinicians tend to find it easier to read and incorporate research which seems to fit with what they already believe.

MAKING SENSE OF THE EVIDENCE: THE COCHRANE COLLABORATION

It is in this climate that evidence-based medicine has developed. There are ways of judging the standard of any piece of research and ways of combining the results of many studies on the same problem to produce a result which is far more trustworthy than that of any single study. This leads to summaries combining all the 'good' studies up to that point in a particular form and using particular rules to give as true an answer as possible. When that works, it saves everyone a huge amount of work and sets a new standard for future studies to achieve or exceed. It also provides insights which could never have been achieved from any single study. The clinician still has the task of applying this new knowledge to each individual to whom it may be relevant, but they at least can be confident in their knowledge.

The movement which incorporates this practice of summarising is called the Cochrane Collaboration:

a worldwide association of people and their work following these principles. The summaries are called 'systematic reviews' and 'meta-analyses' (the statistical bit). All reviews provide a lay summary which is easily accessible through <http://summaries.cochrane.org/>.

SCIENCE OR ART?

There has, of course, been a backlash against evidence-based medicine. Some people like to think of clinical skills (medical, psychological, physiotherapeutic and so on) as more of an art than a science, built up with experience in ways which cannot be captured by strictly conducted studies. It's true that experience can capture some important truths which are hard to study by these methods and it may well bring to attention things which need testing. However, it's not enough on its own: it's rare that clinical experience can distinguish cause and effect clearly enough for us to have complete confidence.

Of course, it's far easier to study some treatments than others. For example, if we need to know if a drug is effective to reduce pain we try it, at several dosage levels, against a placebo (a harmless inactive substance) on groups of people with pain. We then measure the effect of the drug on pain and any unwanted effects. This sort of model works quite well for analgesic pain killers (for instance, for postoperative pain), but not quite so well for chronic pain.

RANDOMISATION AND PLACEBOS

There are strict ethical conditions to ensure that people entering trials get reasonable treatment. In fact, they usually get very good quality treatment, better than in everyday practice. However, it's important to make sure that if a study shows

differences in the results of different treatments, that they are due to those differences in treatment, not to the fact that there were differences between the people. There are alternatives to randomisation, but unfortunately letting people choose is not one of them if you want to be able to draw firm conclusions.

Placebo is a bit of a dirty word because it's seen as a way of fooling people, but in fact it is about attempting to mobilise the body's own healing without drug intervention. surgery is rare but when it has been allowed (making an incision and sewing it up, under anaesthetic - you can see the ethical problems) it's remarkably successful, not just on how patients feel overall but on other specific symptoms which the patient has no conscious control over. It's a very real effect, but not one we can make work for us at will. We need to believe in what is being done to or for us.

So, it's important that when trying out a new treatment, particularly something with a lot of hype about it (e.g., cannabis for pain), that there's a convincing placebo so that patients really can't guess whether they're getting the real thing or the placebo and nor can those treating them. So, placebos are used to show that a treatment gives a genuinely better effect than the body's own efforts.

ASKING THE RIGHT QUESTIONS

In order to judge the effects of a treatment, these effects need to be clearly spelled out at the beginning of the study (or treatment). In chronic pain, treatments often aim to make the patient feel better in general, rather than targeting pain itself. Unfortunately, it's all too common for a clinician to promise benefit to the hopeful patient but to be unable to back it up with evidence. Patients can be part of changing

this by asking about the evidence. If there are studies in the research literature or a systematic review, the crucial questions are:

- Were the patients like me and their problem like mine?
- Was the treatment in the study like the one I'm being offered?
- What were the benefits of treatment, and for what proportion of patients?
- What were the disadvantages or risks of treatment, and for what proportion of patients?

Eventually, it will be possible to combine information about treatments with all sorts of information about ourselves (biological, psychological and more) to get a personalised profile of the likely benefits and risks of all the treatments offered. Meanwhile, if there's been a Cochrane systematic review and meta-analysis, the answers to the questions above will be available. If not, and you're told that the treatment is recommended on 'clinical wisdom' or 'experience', then you need to be aware that there is a wide margin of error around the promised benefits and the risks may not be clearly recognised. Any treatment which can change things for the good can also do harm, not least raising your hopes and then disappointing you. If the practitioner is selling you something directly, whether a substance or a device or a service, his or her offer of treatment may not be entirely unbiased and healthy scepticism is in order.

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PRODUCTION OF PAIN MATTERS

THANKS GO TO

Our guest editorial team, the volunteers on Pain Concern's Listeners and Readers Panel, Amanda Williams, Fiona Talkington.

MANAGING EDITOR Jennifer Bowey

EDITORIAL TEAM Rebecca Blyth, Georgia Gaffney, Bernardo Rodriguez

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DESIGNERS

Creative Link, www.creativelink.tv

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