

VERSUS ARTHRITIS



We want to work with the TV and film industry to change the way chronic pain is depicted in TV shows and films, and to make sure it is portrayed more often – to reflect both the reality of pain and just how prevalent it is in our society.

That's why we've produced this guide on portraying chronic pain in productions and storylines. It includes:

- The views, stories and lived experiences of some of the 18 million people living in chronic pain in the UK
- The reasons why depicting pain in TV and film storylines is so important
- Suggestions on how chronic pain should be depicted, and the difference doing so could make

Working together, we can make sure more people understand what it's like to experience chronic pain – so those living with it get the help and support they desperately need.

Who is this guide is for?

This Versus Arthritis guide is for anyone who influences the way chronic pain is portrayed in TV and film storylines and productions, including:

- TV and film broadcasters and commissioners
- Actors, playwrights, directors, scriptwriters and programme makers
- People who work in relevant roles in the wider sector, such as at universities, regulatory bodies, associations and membership bodies.

Acknowledgements

We would like to thank all of the people with chronic pain and arthritis who shared their first-hand experiences in helping us produce this guide.

We'd also like to thank Arabella McGuigan, Executive Producer including on shows for BBC3, ITV and Sky One, and others working in the TV and film industry, for their valuable input.

These insights have been used to produce something practical, which we hope will kick-start change across popular culture.

Publisher

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About Versus Arthritis

In 2017, Arthritis Research UK and Arthritis Care joined forces so that we could achieve more for people with arthritis. In September 2018, we became Versus Arthritis. Our main ambition is to develop breakthrough treatments, campaign relentlessly for arthritis to be seen as a priority and support people with arthritis whenever they need it.

Contact details

Versus Arthritis Media team: press@versusarthritis.org

Versus Arthritis helpline for people affected by the issues raised:

helpline@versusarthritis.org 0800 5200 520



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THE POWER OF TV AND FILM TO CHANGE PERCEPTIONS:

A foreword from Ellen Miller, Deputy CEO of Versus Arthritis

he statistics are staggering: in the UK, right now, more than 18 million people are living in chronic pain. About 10 million of them have arthritis and musculoskeletal conditions.

If getting your head round the numbers is difficult, imagining what it's like to live with chronic pain every single day is perhaps even harder. The excruciating discomfort of merely standing or sitting. The impossibility of enjoying more than a few hours of fitful sleep a night. The anxious and agonising wait for surgery. The relentless toll on your body and mind.

It can stop people being able to work, to socialise, to look after their family, or be intimate with a partner - with terrible consequences for their mental health.

But despite the devastation it causes to their lives and their loved ones, other people's pain is invisible. That's what makes it so easy to dismiss and overlook, so challenging to understand and empathise with, and, of course, so difficult to portray on our TV screens.

Our research reveals that out of 100 hours of the UK's most watched TV and films in 2019, just six minutes featured people in chronic pain. This lack of recognition and representation on our screens has real-life repercussions. It compounds the sense of

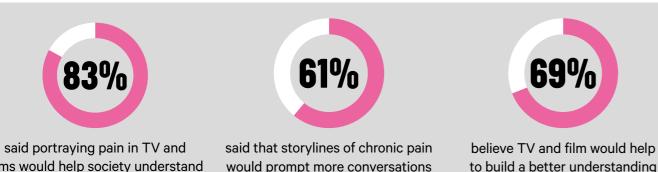
isolation and dismissal people with arthritis and related conditions frequently feel. It deters them from opening up to the people around them or seeking the help they need.

It is not overstating the case to say that, by telling their stories more often, and more accurately, the TV and film industry has the power to transform the lives of people living in chronic pain.

We asked 4,000 people with arthritis whether portraying pain in TV and films would help society understand their experiences better. An overwhelming majority – 83% – said it would. Many also said it would make a direct, positive difference to their lives, giving them:

• The chance to talk... Nearly two-thirds (61%) of the people we surveyed said that if the TV and film industry featured storylines of people in chronic pain it would prompt more conversations about what it is like to live with it.

 ...and to feel more understood. Over two thirds (69%) believe it would help to build a better understanding of the experience of living in pain, while almost half (48%) say it would make them feel more comfortable speaking about their pain with family and friends.



about what it is like to live with it

to build a better understanding of the experience of living in pain "I believe you come to a better understanding of almost anything if it's brought to life visually and you can see the details of how something affects a person or people fully."



As an industry, you have the power to shift perceptions about chronic pain. You can show millions the day-to-day reality of living with chronic pain. You can help people with arthritis to feel more able to speak up and ask for advice and support. You can help build a society that stops ignoring, silencing and forgetting people going through the agonising pain of arthritis.

And in doing so you'll still be able to grip your audiences - because pain is unpredictable, it profoundly affects people's emotions, behaviour and relationships, and it is a powerful reminder of human frailty and human strength.

That's why we have launched our campaign, The

films would help society understand their experiences better

"I think people rely on what they see on TV to inform themselves on certain conditions, and it's so important it's accurate"

Quotes from people with arthritis

Painful Truth, to make sure pain is portrayed more often, and more accurately, in TV and film. This guide, produced with input from industry experts and from thousands of people with arthritis, is part of that campaign.

I sincerely hope it will be used by you: the actors, playwrights, directors, scriptwriters, programme makers and commissioners for TV and films. It contains real-life stories designed to inspire dramatic, inspirational storylines that can help change perceptions about chronic pain forever.

Together, we can bring about change for everyone living with chronic pain - not just the millions affected by arthritis.

FOREWORD FROM JOANNA MONTGOMERY

s someone who has suffered from the pain of juvenile polyarticular rheumatoid arthritis (JPRA) for more than thirty-four years, I would love to see a TV show or film that accurately depicts what having chronic pain is like.

I was eight years old when I first remember waking up with stiffness in my thumb, fingers, neck, jaw, wrists and knees, but I didn't understand why. My parents thought it was growing pains, but by the age of 10 I was struggling to function. I found sleeping difficult, walking painful, and I was so confused and worried about what was happening. I was soon diagnosed with JPRA, and went from being a bubbly, confident girl to one who had to learn to cope with this horrible change. I became quiet and withdrawn, my confidence was completely shattered, and pain soon became the most familiar thing in my life. I felt lost, misunderstood and worried about what my future would look like.

I ended up missing school - sometimes for months on end - as I was so ill, fatigued and in pain. I was also getting treatments and intense therapies on and off which interrupted my education. My life became about just getting through each day instead of being carefree like other children. If there had been a young person or child on TV or in a film going through the same thing, I would have been able to relate and, in turn, would have felt understood.

When I left school at 18, I started training to become a nursery nurse. I thought that if I worked and acted the way 'normal' people did then my illness could stay hidden. To hide what I was going through, I would clench my jaw and wrap brown parcel tape around my joints underneath my clothes, so they felt supported. In front of others, I would hide my pain through the biggest smile and at times cry in the toilets so there was no risk of 'the truth' being uncovered. I did this for more than 30 years; I really was the master of disguise.

In 2018, the jaw pain I'd been experiencing throughout my life suddenly got very intense. In all honesty, and I don't write this lightly, I actually felt disappointed when I woke up in the morning, because I knew I'd be battling utterly unbearable pain all day; the pain was almost indescribable.

I waited a gruelling year for surgery to completely replace my jaw, and during this time I could no longer eat or sleep. In the months leading up to my operation, my jaw had collapsed due to the deterioration of my joints, so I had to have a series of steroid injections and surgical 'wash outs', which involves two needles being inserted into the jaw joint, one which pumps fluid into your jaw joint and one that removes fluid to get rid of the bone debris. It's a really uncomfortable procedure that makes you feel the most intense amount of pressure in your jaw - when I had it for the third time I was in floods of tears.

Everyone's story is different, but I would love to see a TV show or film with a character who shows what having chronic pain can be like. Someone who draws on the real struggle, fight and strength that is required to manage day-to-day.

This is an opportunity for the TV and film industry to influence people's understanding so that 'sympathy' can become 'empathy'.

FOREWORD FROM BEHAVIOUR AND MEDIA PSYCHOLOGIST, JO HEMMINGS

hronic pain is a much more widespread problem than people realise. In the UK alone it impacts nearly one in three, however too few people understand the daily grind of living with it. As someone who lives with chronic pain myself, I know all too well the toll it takes and the way in which it impacts the basic day-to-day things so many people take for granted.

We might not realise it, but TV and film play a powerful role in shaping our perceptions and scientific research has shown that the portrayal of certain conditions and disabilities in popular culture has a direct and profound correlation to our response and therefore our behaviour towards them – sometimes softening our attitudes, sometimes hardening them.

Think about the way it has helped to break down societal taboo around topics like mental health, cancer and domestic violence. Popular culture can and should play an important role in creating an environment where the millions of people living with chronic pain feel like they are seen and will be heard if they ask for help.

That's why I'm pleased to be supporting this campaign from Versus Arthritis and joining them in calling for TV and films to portray the experiences of the 18 million people living with chronic pain. Better depiction on screen will mean the millions of people with chronic pain are seen, heard and are able to ask for help.

WHAT IS ARTHRITIS AND WHO GETS IT?

he word arthritis is used to describe pain, swelling and stiffness in a joint or joints. Around 10 million people in the UK are thought to have arthritis, and it affects people of all ages – including children and teenagers.

Symptoms of arthritis can vary from week to week, and even from day to day, but many types, such as osteoarthritis and rheumatoid arthritis, are long-term conditions.

It's difficult to say what causes arthritis. There are several factors that can increase the risk of each type of arthritis – for example, it could be genetic.

The impact of arthritis

The pain of arthritis robs people of many of the things that make life worth living. Simple movements like walking, sitting and standing can be agony. A restful night's sleep is often impossible. It can force people to give up careers, shatter their dreams of raising a family, isolate them from friends, end intimate relationships, and devastate their mental health.

And yet, because chronic pain is invisible, it is easily ignored and dismissed, even by friends and family, and certainly by society at large. And this invisibility and subjectivity makes pain difficult to depict in TV and film.

That's where we come in

We're demanding that the pain and isolation of arthritis is no longer dismissed. We're constantly campaigning to challenge the misconceptions around arthritis, and to ensure it is recognised as a priority in the UK. We galvanise our communities into action against arthritis, and work to make sure people living with it seek the support they need. We're pushing to defy arthritis. We are Versus Arthritis.

Chronic pain

Long-term or 'chronic' pain is defined as pain that's lasted for more than 12 weeks or for longer than would be expected given the type of injury or level of damage.

Looking for help, advice or support for yourself or a loved one?

You don't need to face arthritis alone. Our advisors aim to bring all of the information and advice about arthritis into one place to provide support tailored to your needs.

Call us: 0800 5200 520 (Monday–Friday, 9am–8pm)

. Email us:

helpline@versusarthritis.org

Looking for help in depicting pain on screen? Email:

press@versusarthritis.org



Pain isn't just a physical sensation – it has emotional effects too. If you've had pain for months or years, it's not surprising that it can begin to affect your mood and self-confidence.









HOW TV AND FILMS PORTRAY CHRONIC PAIN

Versus Arthritis analysed every scene from the UK's most-watched TV shows and films in 2019. We found people's experiences of chronic pain were virtually invisible.



of the most watched TV and film in 2019 featured people in chronic pain, out of 100 hours. We also asked 4,000 people with arthritis about on-screen depictions of chronic pain:



say that they don't feel any character accurately represented their pain or condition. (over the past two years)

said that TV

don't portray

and films

pain well.

56%

34%

have never witnessed the portrayal of chronic pain in a TV show or film.

INVISIBLE STRUGGLE

Chronic pain is invisible, making it difficult to depict. But the lack of portrayals of chronic pain on our screens has real-world repercussions. From our research and speaking to people with chronic pain, we found that it leads to:

ISOLATION:



Despite pain being a common experience, one in four (26%) of the people we surveyed feel excluded by popular culture, while one in five (19%) say it makes them feel "invisible".

SILENT Struggle:



More than half (56%) of people with arthritis feel that the current portrayal of chronic pain contributes to society's lack of understanding about what it is like to live with. Half (52%) say the way TV and film portrays pain makes them speak up less about their pain with family and friends, while a third (33%) say it has made them less likely to get advice and support.

MENTAL Ill-Health:



One in three (37%) report feeling dismissed and isolated because of representations of pain in TV and film.



speak up less about their pain because of the way it is portrayed on TV and film. We understand that everyone experiences chronic pain differently and is at different stages with their condition, so what follows is not prescriptive. Rather, it is suggested guidance on how TV and films could tell the stories of people living with chronic pain, based on the experiences of those people themselves and input from the industry.

We believe TV shows and films should reflect real lived experiences across our society. That's why we are calling for the inclusion of storylines of chronic pain in TV and films. With your support, we want to break the stigma around pain that is leading so many to struggle in silence.

"I'm supporting this campaign as I think it's really important for people with chronic illnesses, particularly young people and those with invisible illnesses, to have representation in the media. By doing so, it will enable the public to have more understanding, and for those given a diagnosis to feel less lonely and more confident in discussing their disability." Jasmine, 17, who lives with juvenile idiopathic arthritis

"TV shows have the platform to educate people about arthritis conditions and how it is to live in constant pain, but they do not use their position well enough to do this." **Survey respondent**



Based on feedback from people living with arthritis and the industry itself, here are the seven most important steps:

Suggestions from people with arthritis

Here is just a taste of what the people who took part in our survey said:

"Show scenes where the pain is dismissed because that is a real and very hard part of living with a chronic condition.

"Don't make the condition someone's defining storyline - yes that might. be a large part of life, but there is also so much more to someone. than just their condition!"

"Don't always have the person" with chronic pain be miserable, show them as strong and determined to have a fulfilled life..."



Make sure a character's experience is authentic by researching symptoms, treatment options and specific conditions to find out how the condition you choose to portray can work with your other storylines (Note: Versus Arthritis and healthcare professionals can provide this kind of information)



Remember, chronic pain is unpredictable - show how the condition's symptoms can fluctuate



In performance, consider body language, gestures and facial expressions to make sure portrayals of chronic pain are accurate and realistic



Speak to people living with chronic pain about their day-to-day reality to weave in real-life experiences, and where possible, work with performers and writers who have their own direct experience of chronic pain



Include scenes that show someone managing/living well with their condition



Think carefully about the language you use and what it signals about the experience of living with chronic pain. For example, step back and double-check your script's wording is not accidentally reinforcing negative stereotypes





Don't make the condition someone's defining characteristic or sole storyline – a person is more than just their condition

> Thousands of people with arthritis asked us to share their experiences with the TV and film industry to ensure your storylines ring true.

Some of our supporters shared their first-hand experiences in the hope they will inspire your storylines and help kick-start change across the industry.



y arthritis is under control today, but after a long flare my pain signals are still rampant – this is called chronic primary pain.

I was diagnosed with juvenile idiopathic arthritis around the age of 12-13, although I first went to the doctor with symptoms around the age of 10. Because of my age, I was often told it was just growing pains, and nobody seemed to take things seriously. In my mid-20s, I started getting pain in my heels, blisters on my hands, rashes all over. This turned out to be psoriasis and psoriatic arthritis.

My arthritis has fluctuated a lot. In long periods of remission, which are close to a life without arthritis, I play a lot of sport and am as active as I can be – I make the most of it, basically. Then, in the bad periods, it's all ripped away from me. In a day, I can go from playing rugby for my local team, to not being able to walk. I've lost contact with entire groups of friends as a result.

I used to put walls up and not talk about my condition, probably because I felt quite shunned as a young person with arthritis. I was in hospital a lot, and even missed an entire year of school, but was always left in the dark about what was happening to me. It made me feel very isolated, so I kept it all to myself for a long time. But the truth is, the constant uncertainty around how I'm going to feel, and never knowing what else I might miss out on - it makes me feel depressed.

Being a father [has been] both brilliant and daunting. My flare-ups became a lot scarier, because I have to take care of my son no matter what level of pain I'm in. I've had nightmares of being so fatigued that I drop him.

Writing all my feelings down in my blog helped me so much, and it allows people to understand what I'm going through. In a similar way, I think greater portrayals of chronic pain on screen would really help people like me when trying to explain what it's like to friends and family. If done properly, it would be something we can hold up to people as an example, and would hopefully encourage more open conversations about pain.

Right now, the breadth and impact of chronic pain is not portrayed well in TV and film - that hopeless position where no one is coming to save you and nothing can take your pain away. Imagine breaking your leg, going to hospital, and being told there is nothing there to fix it. You put on a brave face all day, then later on all the emotion of the pain comes out as a huge mental health challenge. You're up at two in the morning, crying in the corner of the living room, unable to sleep.

Chronic pain is where mental health was ten years ago, and portraying it properly is going to take more than showing someone laying in bed screaming - yes, that's part of it but there are many more layers, like finance, relationships, and work.

hen I was first diagnosed, I had just started a new job and impacting me physically and mentally. wanted to show lots of interest. I was trying to be vibrant and Before lockdown I would have to plan hour keen while in pain. I also suffered really by hour what I was doing and be prepared badly with psoriasis for a long time when I in case things didn't go to plan. It was was in my early teens, so I'm used to having an emotional drain. Lots of cancelling a health problem. But you don't want to plans. My friends are understanding, but open up about this stuff when you're new to it was tough at the beginning. Constant a job. There's not enough trust at the start. uncertainty is the hardest thing to accept.

I spent so much time sat in bed in agony, not knowing what the hell was going on. It was scary and brought on a lot of anxiety. When I finally got my diagnosis it was very scary. I always thought someone telling me that I have arthritis was going to be the worst-case scenario.

I was overwhelmed with fear and panic for my future because I knew that I was too young to be diagnosed with this, and I was unsure if I could face the challenges ahead of me. I spent the first couple of months trying to ignore the fact that I had AS [axial spondyloarthritis]; it was a way of coping with the lifestyle change that I knew had to happen. It took time to accept this and, with support from those closest to me, I began to do my own research and learned a lot about the disease. As I accepted my condition, I became more



open with sharing how my pain was

"I would be so happy if there was better representation: as it would spread awareness of what we actually go through day in, day out... not just the physical pain but the mental and emotional aspect"

I would be so happy if there was better representation as it would spread awareness of what we actually go through day in, day out... not just the physical pain but the mental and emotional aspect, which is truly overwhelming for each of us. It takes so much strength to live with arthritis. I'd like more people to know and understand that.

KALIFA'S Story



zoned out when the rheumatologist told me I have rheumatoid arthritis. I was so confused, I thought arthritis was something that only affected older people, yet I was only 17. She didn't explain anything to me and just gave me a booklet on methotrexate and sulfasalazine.

I played a lot of netball when I started high school, but then I started to recognise swelling and pain in my knee when I was 14. It would always fall inwards or would lock, and I couldn't move it. Most people said it was probably growing pains. It got worse and I eventually had to give up netball at 16.

The best way to describe the pain for me is that when it's really bad it feels like there's a heavy golf ball lodged in my knee. This helps people because you can imagine what the inflammation looks like – it's a good visual aid.

My first year at university felt like the worst time to be living with arthritis. I couldn't drink much due to my medication, so people would always ask, 'Why aren't you drinking?' You just get tired of explaining and sometimes you get called boring. Socially it's hard, but it got easier as my flatmates quickly understood my situation. I haven't always had such an understanding response. A lot of people belittle the pain I am in or act like it isn't there.

Sometimes people think it's not that bad until they see the impact with their own eyes, like being unable to walk down steps; being bedridden with a flare up; or feeling the horrific side effects of your medication.

"I played a lot of netball when I started high school, but then I started to recognise swelling and pain in my knee when I was 14. It would always fall inwards or would lock."

For example, once I was on holiday with my boyfriend in Edinburgh and the cold weather meant we couldn't go out for dinner one night, because the pain was so overwhelming. I remember just crying on the bus at one point. That's when he realised how bad it was.

You don't see arthritis, and so people don't realise the emotional, physical and social impact it can have. had to give up my career as an investment banker, which I was working in for about a decade. The arthritis took over and I couldn't commit to the job any longer. This is one of the biggest losses.

My social life was also majorly affected because people just didn't understand. The fatigue can be crushing, and it's hard for people to realise just how crushing. I became jealous of people around me who were getting on with their lives, getting promotions, having babies. I can't have children because of my methotrexate prescription. So, I felt like my life was stopping or regressing. I felt bitter.

I developed many phobias: a fear of not getting enough sleep, of putting myself out there, of letting people down, of not being able to perform at work. If friends invited me to a party the following weekend, I couldn't commit because I didn't know whether I'd be well enough to go. How do you say that to a friend? This sort of thing was very hard for others to understand.

With friends of mine I've experienced, "Oh come on it can't be that bad!" But they and others don't know how to process what you tell them about chronic pain, they don't know how to respond to it. I think the big reason is because there's no fix to it, so people who don't live with it feel helpless, and that's uncomfortable.

"Looking back on it, I lost my 30s to arthritis. It's like a black hole in my life.

For about 10 years I suffered badly from depression. My world became very small for a while. One day I decided enough was enough. I made efforts to get over my phobias and the belief that I couldn't do things. Changing my mindset was absolutely crucial to turning things around. Looking back on it, I lost my 30s to arthritis. It's like a black hole in my life.

If our experience were to be projected on-screen, it would be bad if it was always the person who is conquering their pain or condition. Most people don't conquer. When you see cancer on-screen, it's always a person fighting, and if not then they're dying. I (we) don't want to see the plucky courageous person in chronic pain achieving everything they want to. Treat it realistically.

JASMINE'S Story

t's been difficult revising for my GCSEs and A Levels these last two years due to fatigue and pain after such a long day at school – it's so hard to stay on top of everything as well as catch up on missed work due to appointments. My flare up also came on quite suddenly during my exams, due to stress, so I had to start doing exams and work on a laptop and in a separate room, which was quite a big adjustment.

Getting individual teachers to properly understand has been a long process. Classroom set up isn't always great for me, high stools and labs can be difficult.

"People don't understand the change and think you're faking it or making it up."

It can be hard to explain how one week I'm well and the next I'm not. I did the school production where I was dancing and singing, but the next week I was really suffering. I chose to pay the consequences because I wanted to do the show for myself – I took more pain meds and oral steroids so I could do it, but after it was over, I was in a lot of pain. People don't understand the change and think you're faking it or making it up. I wish they knew that it still affects you, even if you look absolutely fine.

In response to our survey, some other people with arthritis suggested:

"[Show] what can happen to a perfectly capable person when they get pushed into the cycle of taking paracetamol, using ibuprofen, going to the pain clinics, physio ... begging to see a specialist after years of needing help or a diagnosis. Then waiting for treatment."

"Show the absolute terror when your back locks up and you can't reach your mobile to get some help, screaming in pain and suffering whilst terrified no one is coming. [Also] show how alone, isolated and desperate you feel. ... Sometimes you just want to end this pain and take back control of your life by choosing to end it. Also, how it affects even the smallest tasks... cleaning, mowing the lawn, taking a shower, changing the bed sheets, hanging out washing. People don't understand that a task that used to take five to ten minutes could take the whole day, with numerous sit downs."

Versus Arthritis can help scriptwriters, production houses or actors accurately represent chronic pain by providing:

Background info about arthritis, symptoms, treatment, and living with chronic pain

Key statistics, facts and figures on chronic pain and musculoskeletal conditions

Consultation and advice on characters and storylines to support realistic and accurate portrayals 4

Access to people living with arthritis, who can share their experiences

5

Signposting of relevant information or contact details of other organisations

Access to healthcare professionals and clinicians who can advise on portrayals and depictions

REFERENCES

About the research

As part of The Painful Truth campaign, Versus Arthritis has conducted three pieces of research:

1. Quantitative and qualitative analysis, conducted by Survation, of more than 100 hours of footage of the most watched TV and film of 2019 to assess how chronic pain is depicted. Fieldwork took place in July and August 2020, with analysis and report writing from the 14th - 21st August.

2. A nationally representative survey, conducted by Survation, of more than 1,025 UK adults (aged 18+) who have arthritis and experience pain, conducted between 9th and 14th September 2020.

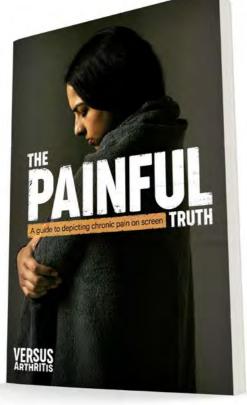
3. A survey of 4,000 people with arthritis conducted by Versus Arthritis via Survey Monkey, between 8th February to 9th March 2021.

Methodology: The Painful Truth study

Researchers analysed over 100 hours of footage from the most watched TV and film of 2019. Fieldwork took place between the 14th July and the 13th August 2020, with analysis and report writing from the 14th - 21st August.

Content included the top ten UK box office film releases and the top 10 most watched content on BBC iPlayer and Netflix among UK audiences (excluding soaps and nonfiction/documentaries).

They measured both the frequency and context of mentions and depictions of pain against a series of benchmark themes.



Full list of TV and film analysed:

UK Box Office Films (21 hours. 12 minutes)

- Avengers Endgame
- Lion King
- Toy Story 4
- Joker
- Star Wars: The Rise of Skywalker
- Frozen 2
- Captain Marvel
- Aladdin
- Spider-man: Far from Home
- Downton Abbey

BBC iPlayer (43 hours)

- Killing Eve, series 2
- Line of Duty, series 5
- Peaky Blinders, series 5
- Killing Eve, series 1
- Fleabag, series 2
- The Capture, series 1
- Silent Witness, series 22

Netflix (35 hours, 15 minutes)

- 6 Underground (film)
- Murder Mystery (film)
- The Witcher (series)
- The Irishman (film)
- After Life, series 1
- Stranger Things, series 3
- Sex Education, series 1

Nationally representative survey

Survation captured qualitative insights from online interviews with a nationally representative sample of 1,025 UK adults (aged 18+) who have arthritis and experience pain. Fieldwork was conducted between 9th and 14th September 2020.

Survey Monkey:

According to a survey of 4,034 self-selected respondents (3,990 of whom have arthritis or a musculoskeletal condition). conducted by Versus Arthritis via Survey Monkey between 8 February to 9 March 2021.

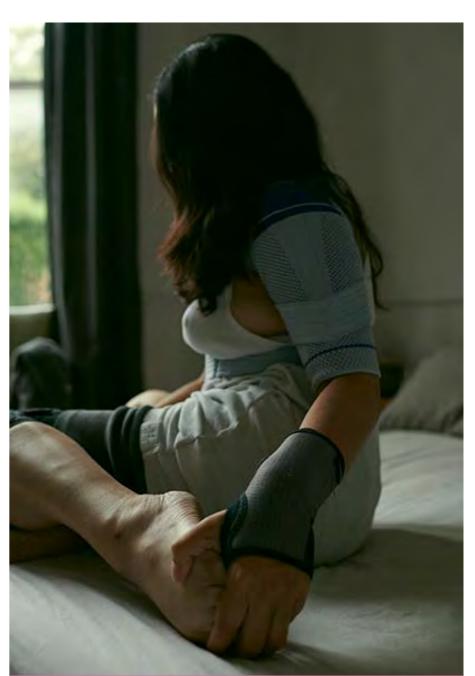
Not all respondents answered every question as they were given the choice to skip, but each question had at least 3960 respondents out of a total of 4,034 respondents. The respondents to each statistic are listed out below:

- Over half (56%) say that TV and films don't portray pain well (4,020 people answered)
- A third (34%) have never witnessed the portrayal of chronic pain in a TV show or film (4,020 people answered)
- 87% say that, over the past two years, they don't feel any character accurately represented their pain or condition (4,015 people answered)

4,013 people gave the following responses to the question 'If someone in the TV and film industry was writing a character with chronic pain or arthritis, what advice would you give them to portray the character accurately? (tick all that apply):

- Make sure a character's experience is authentic by researching symptoms, treatment options and day-to-day experiences (84%)
- · Consult with people living in chronic pain on language to be used (75%)
- Speak to people living with chronic pain to weave in real-life experiences (84%)

- and facial expressions to make sure portrayals of chronic pain are accurate and realistic (73%)
- Include scenes that show someone managing/living well with their condition (67%)
- Show how symptoms of the condition can fluctuate (81%)



- Consider body language, gestures Don't show scenes in which pain is dismissed (46%)
 - Ensure script wording does not reinforce negative stereotypes (58%)
 - Don't make the condition someone's defining characteristic or sole storyline - a person is more than just their condition (73%)

You can view our campaign video here. And for more inspiring stories please visit our website: versusarthritis.org/ThePainfulTruth

Thank you to the 4,034 people who took part in the survey, shaped this guidance and shared their experiences. With your help we can make societal change and enable people with arthritis to feel better represented, supported and heard.