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# UNMASKING PAIN

INSPIRING HOPE, CREATING WELLBEING

# Contents

2	<b>1. Introduction</b>
3	<b>2. Background</b>
<hr/>	
5	<b>3. Defining The Project</b>
5	A. Introduction
5	B. Aims
5	C. Approach
6	D. The Patnership
6	I. Partners in brief
7	II. Contributors in brief
8	E. Participants and Locations
8	F. Projects by Numbers
<hr/>	
9	<b>4. Activity Overview</b>
10	A. Phrases
10	B. The Process
10	I. The Lynchpin
11	II. Bridging the Gap
11	III. Distraction
11	IV. The Cultural Aspect - 6+ millions
12	V. Languages in the Landscape
<hr/>	
13	<b>5. Metaphors</b>
15	<b>6. Dissemination</b>
15	A. Project Presentations
15	B. Exhibition
15	C. Mini-Exhibition for GP surgeries
15	D. Presentations at other events
16	E. Creative Walks and Picnics
16	F. Online resources
16	G. Fuse Award
<hr/>	
17	<b>7. Evaluation</b>
17	<b>Outcome Summary</b>
19	<b>Quantitative Data</b>
19	A. Results in Behaviour Change
20	B. Changes in Pain and Emotiona Arousal and Physiological Measures
21	C. Summary
22	<b>Qualitative Data &amp; Interviews</b>
22	A. Focus Groups
23	B. Phenomenological Study
25	<b>Other Observational Data</b>
25	A. Professor Mark Johsnon
25	B. Rosie Cruickshank
27	C. Kali Chandrasegaram: an artist perspective
27	D. Film Production and Photography Team
29	<b>Themes of Change</b>
29	A. Change in Sense-making with "the Pain Experience"
29	B. Change in Emotionality
30	C. Change in Ability and Confidence to Communicate
30	D. Change in Sense of Self and Capability
30	E. Change Through Creative Arts Multifaceted Mediums
<hr/>	
31	<b>8. Summary and Learning</b>
31	A. Project summary
32	B. Summary of reflections for the future approaches
32	C. Conclusion
34	<b>9. Future Development</b>
35	<b>10. Appendices</b>
39	<b>11. Links/References</b>

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The Unmasking Pain report was conceived and directed by Balbir Singh in collaboration with Durham University, Leeds Beckett University, University of Leeds, Live Well With Pain in March 2024.

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**Designer:** Minh Nguyen

**Photography:** Malcolm Johnson, Julian Germain, Karol Wyszynski, Tim Smith, Paul Floyd Blake, Balbir Singh



## 1. Introduction

Unmasking Pain, funded by Arts Council England, is an innovative project exploring creative ways to depict life with persistent pain. During its two-year pilot phase (2021-23), this Fuse Award-winning initiative aimed to illuminate chronic pain through an artistic lens. The project, led by Balbir Singh Dance Company (BSDC) and various partners, conducted collaborative workshops and diverse creative activities. Participants discovered new ways to articulate and manage their pain, sparking important conversations about mental and physical health.

In its pilot phase, Unmasking Pain connected communities and transformed lives by offering alternative approaches to chronic pain, all without a medicalised perspective. The uniqueness lies in its foundation and execution within the creative arts, distinct from conventional health or care frameworks. Led by artists without a medical background, it provided a fresh and holistic outlook on pain. Participants described Unmasking Pain as an enjoyable experience, with dissolved hierarchy and human connection at its core.

Unmasking Pain is one part of BSDC's broader focus on creative health and environment in all its activities. The company aims for deep engagement at the intersection of arts and health, collaborating with various institutions and expanding its reach across different sectors. This framework aims to integrate arts into healthcare, offering innovative solutions to health challenges and promoting mentorship and education for future generations.



# 2. Background

Persistent pain is a huge worldwide health challenge. It is the primary reason people in the UK see their GP. It affects probably between one-third and one-half of the population of the UK, around 28 million adults. This is based on data from 2016 from the best available published studies, a figure likely to increase with an ageing population. The WHO recognised it as a priority disease in 2019. The main management approach for chronic pain itself is biomedical with the use of drugs or other interventions which have little curative effect ([link](#)). Medicines used for chronic pain like opioids and gabapentinoids provide some level of relief for less than 10% of the population, thus failing to remove the majority of pain experienced. They add a range of side effects in long term use that are harmful, especially with strong opioids. Investment into person centred approaches based on a biopsychosocial model have been limited despite the evidence that pain management programme approaches are helpful ([link](#)).

The rainbow model of health Fig 1. identifies the key factors that enable health functioning and shows the wider determinants of health, crucial to enable people with pain to regain and sustain their health.

The impact of chronic pain on health function (Fig 2.) is extensive and can range from mild, moderate or severe effects in how it affects people's physical, emotional and social capability. The severe impact of pain and disability is similar to that of a person suffering a stroke. Yet, people with pain and many of their clinicians struggle with its management. The current science of pain and how this can guide the ways to self-manage pain creatively are not well known or experimented with.

The recent 2021 National Institute of Health and Care Excellence guidelines to the management of chronic pain refer to the importance of self-management ([link](#)) and offer some direction for clinicians and links to online self-management help. The reality is the need to address the health and well-being of people with pain from different perspectives.

Health is a resource for living so we are able to:

- Undertake daily activities
- Join in social activities
- Do physical tasks
- Not feel bodily pain
- Feel peaceful and happy
- Feel full of life.

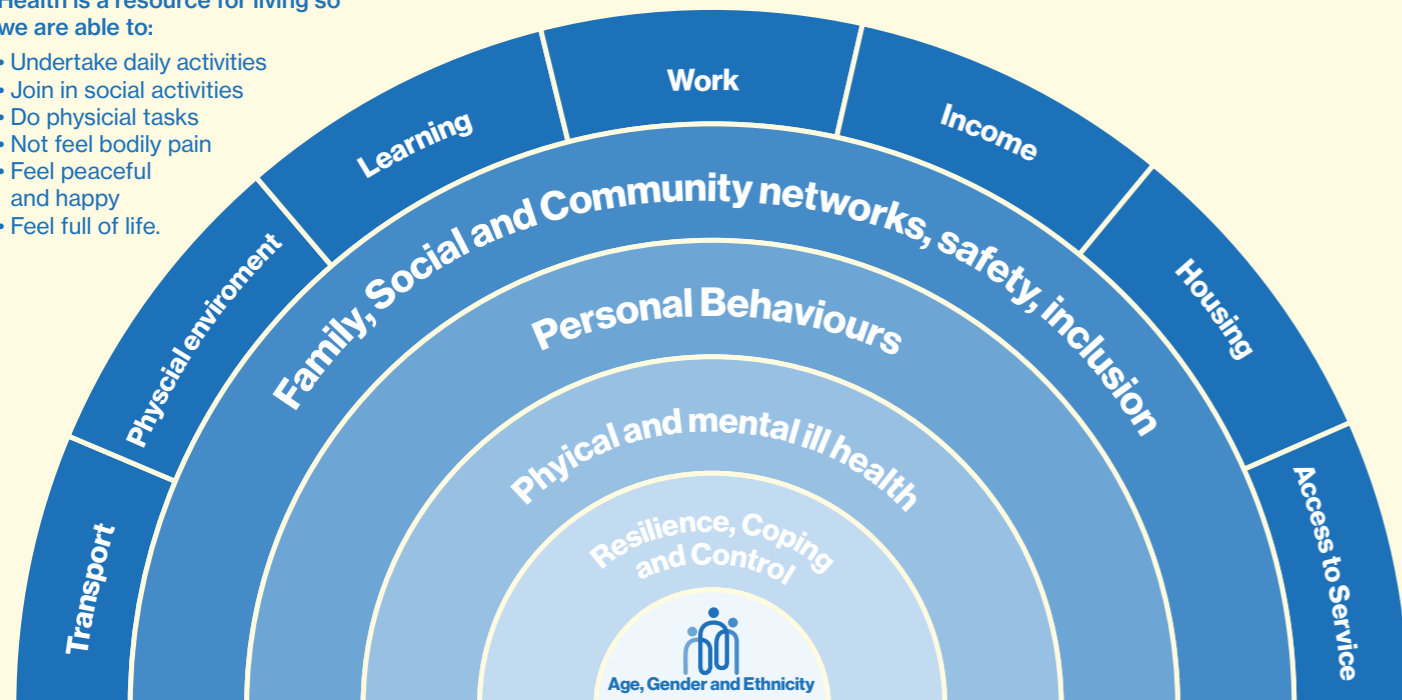
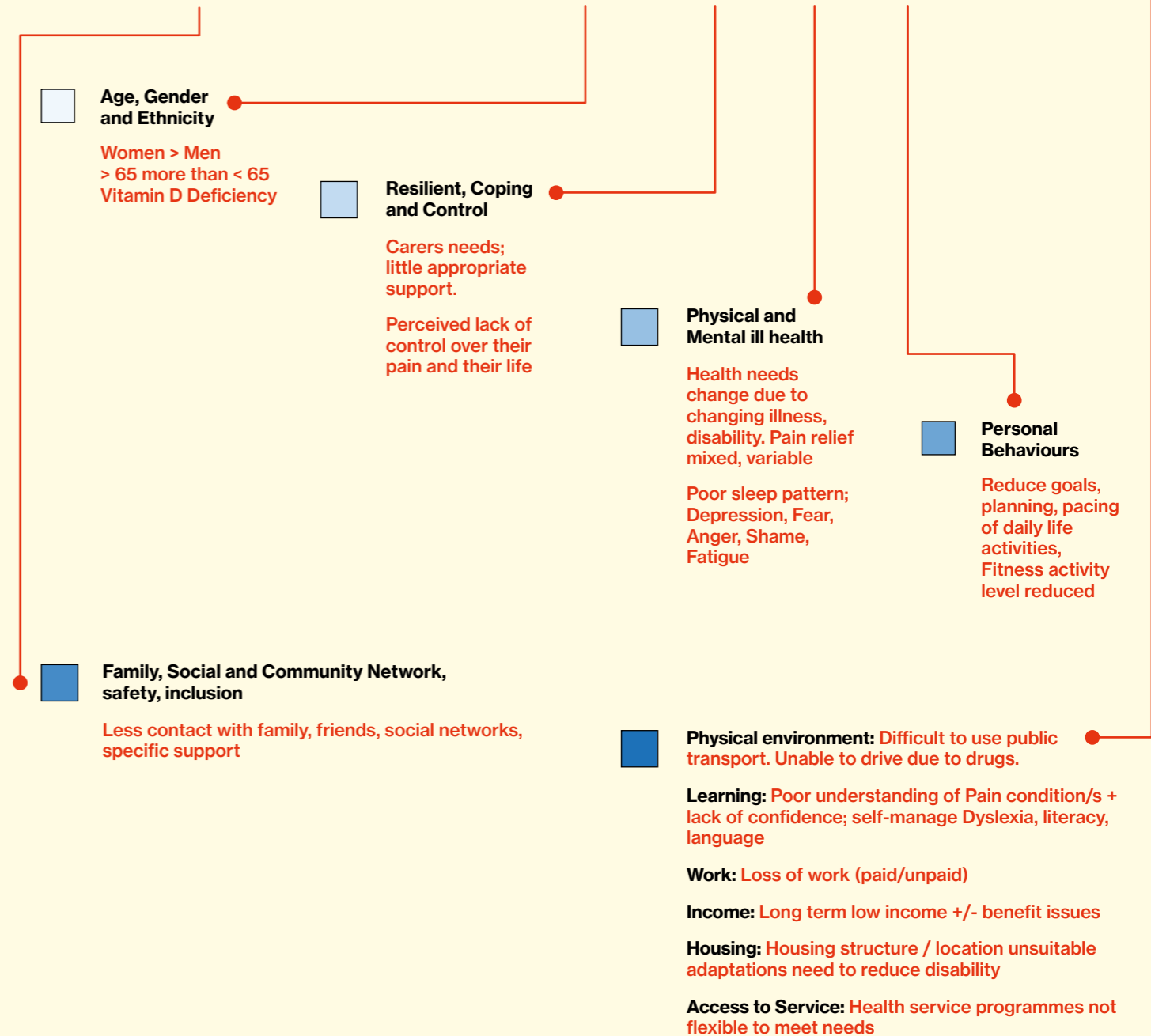
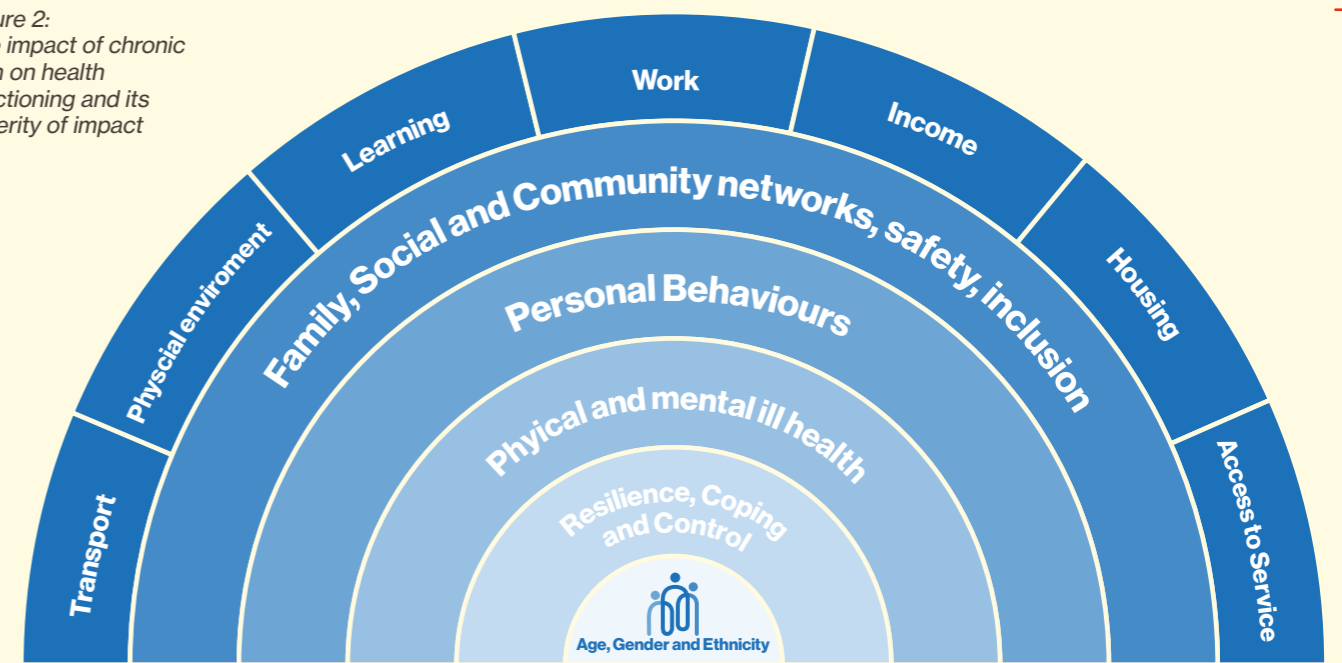


Figure 1. Socio Ecological rainbow model from Dahlgren and Whitehead

Figure 2: The impact of chronic pain on health functioning and its severity of impact



*“It was about ways of articulating, shaping and expressing pain, as well as dissolving it. Discovering tactics for distraction, cultivating new habits and growing creatively within ourselves, with others and in our relationship with the environment” - Balbir Singh*

## 3. Defining The Project

### A. Introduction

One of the biggest frustrations reported by pain livers is its invisibility. They want to tell their stories, but they are often faced with limited time of healthcare professionals and lack of understanding. They do not always have the vocabulary to express their stories. Unmasking Pain was initiated by BSDC, following conversations with Dr Frances Cole, a retired GP and renowned pioneer in the field of pain management, the founder of Live Well With Pain (LWWP). Balbir Singh, director of BSDC, then conceived Unmasking Pain to explore creative approaches to tell stories of life with persistent pain. Collaborators from the clinical and arts world came together to understand what difference might occur to

people and their health when engaged in a more socio-artistic creative approach. What transpired was a new partnership between BSDC, Leeds Beckett University and Durham University, LWWP and Space2. Additional expertise was brought by Dr Cole and Rosie Cruikshank, a pain physiotherapist at St Thomas' Hospital, London. All partners shared a commitment to understanding the impact of non-clinical interventions in pain management practice and challenging the established biopsychosocial model. The project's experimentation was supported by a range of creative arts within different supportive and stimulating contexts. The team evaluated outcomes both quantitatively and qualitatively.

### B. Aims

Key aims identified were:

- Co-create new vocabularies and ways of expressing pain
- Enable pain livers to unlock their creative potential and gain a sense of autonomy over their own stories where pain is not a defining feature them
- Support in-depth research that places equal value on clinicians and lived experience contributions
- Stimulate conversations and practice to transform pain self-management long term
- Explore evaluation including testing new technology that enables quantifiable measuring of the impact of arts participation of individuals taking part

### C. Approach

The project tackled diverse ways to explore pain with a non-judgemental and curious approach to engage those with pain in a rich mixture of creative arts. Balbir Singh believes that the arts are about story, emotion and expression - abstract, literal and places in-between. Dance is technical and expressional, movement is instinctive and purposeful, music stimulates the imagination. The classical Indian dance style Kathak was one of a few classical styles used on the project. It derives from Kathakars, storytellers who used dance, music, drama and poetry in the temples of North India. This style of performance coupled with Balbir's contemporary dance training underpins much of his

creative thinking. BSDC's outlook is global, creating work that celebrates the human condition and makes sense of who we are, our relationship with our bodies, minds and the world around us.

Balbir facilitated a team of experienced, multi-disciplinary artists including South Asian and Western contemporary dancers, musicians, visual artists, film makers, photographers and writers. The creative team met at the outset to explore themes and approaches and to embed a co-creative framework for Unmasking Pain. During these sessions it transpired that many of the artists, themselves, lived with persistent pain.



Balbir believed that the team could provide new ways for pain livers to look at their relationship with their body. New artistic forms of expression would reveal the stories to be told and the most appropriate vocabularies to tell them in. Dr Cole described these as "metaphors" as the project came into its own.

As the project developed, pain livers and artists discovered more about themselves through sharing stories and creating with others. Their health improved through a journey of "explorative joy". This experimentation was enabled by a range of creative arts within various supportive and stimulating contexts.

### D. The Partnership

The partnership was sparked through an introduction from media designer, David Andrassy, who had worked long term with both BSDC and LWWP. David could see the potential of the two organisations collaborating to further a holistic and creative approach to pain management. Following an initial conversation, Space2, an arts and social change organisation who regularly work with BSDC, came on board as producers. LWWP introduced further partners including Durham University's Pain Academy, with a track record of research and Leeds Beckett University's Centre for Pain Research.

### I. Partners in brief

**Balbir Singh Dance Company (BSDC)** is a leading intercultural company, pushing the boundaries of traditional dance and storytelling. Founded by choreographer

Balbir Singh, the company is renowned for its commitment to fostering cultural exchange and breaking down barriers, and explores the intersections of different cultures and sectors through its performances and projects.

**Live Well With Pain (LWWP)** is a cutting-edge organisation, developed by clinicians and pain-livers, for clinicians and those with lived experience to help clinicians support patients towards better self-management of their long term pain.

**Durham University's Wolfson Research Institute for Health and Wellbeing and Pain Academy (WRIHW)** is a major interdisciplinary unit within the university that fosters research on health and wellbeing. It seeks to improve the quality of people's lives by contributing to public policy, professional practice and development of new insights, products and tools.

**Leeds Beckett University Centre for Pain Research** led by Professor Mark Johnson PhD supported the project through their networks and connections across Yorkshire and the North East, including with the Flippin' Pain team and colleagues at Teesside University.

**Space2**, is an award winning arts and social change organisation, pioneering participatory practice, rooted in co-produced arts opportunities with local communities. Based in Leeds, they have 20 years' experience of delivering arts and health projects in some of the most disadvantaged communities in the country.

**More details about the partners can be found under the Appendices section (Appendix A)**

*“A richer understanding of the person to themselves and others and their relationship with their pain evolved through the process of listening and engaging. Beneficial change occurred as the artists and those with pain engaged in creative activities in numerous indoor and outdoor settings.” - Balbir Singh*

#### D. The Partnership

#### II. Contributors in brief

**Balbir Singh** - Artistic Director of renowned dance company, BSDC that offers a remarkable, ambitious and richly varied portfolio of work created through innovative artistic practice and choreographic methodology. He creates work that tells stories in inventive ways, foregrounding less heard voices.

**Kali Chandrasegaram** - is a multi-disciplined, experimental dancer and choreographer, working across many genres from Indian classical to contemporary. Kali believes in dance as a personal journey of the soul for self and communal awareness. Kali has lived with persistent pain for over two decades.

**Adam Strickson** - is an artist, writer and mask-maker. He is a teaching fellow at University of Leeds in the School of Performance, with a specialism in teaching intercultural performance.

**Chris Speyer** - is a visual artist based in Devon, with a background in theatre design, writing and ceramics who now creates small and large-scale sculptural work.

**Malcolm Johnson** - a photographer of live performances, opera and dance. He has worked with Opera North, stage@leeds and other theatre companies and organisations in Yorkshire and abroad.

**Villmore James** - was a founder, dancer, choreographer and teacher for many years with Phoenix Dance Company, touring extensively in the UK and abroad. Villmore now is a freelance dancer and choreographer who also experiences chronic pain.

**Devika Rao** - is a passionate and talented Indian Classical dance performer with a wealth of experience choreographing and dancing across the globe.

**Mansi Dabral** – is a London based Kathak dancer, trained for 13 years at Kathak Kendra, New Delhi, under eminent gurus. She was named Cultural Ambassador of India in 2005. To promote Kathak in the UK, she founded her academy.

**Dr Frances Cole** - is a retired GP and pain rehabilitation specialist. She developed the first UK primary and community care pain rehabilitation programme based on cognitive behavioural therapy principles in 1996. She is the

founder of LWWP and instrumental in the development of the 10-footsteps programme.

**Paul Chazot** - is Professor of Pharmacology in the Department of Biosciences at the University of Durham. He is the Director of the Durham WRIHW Pain Challenge Academy. His work involves ongoing successful research programmes in chronic pain, including the LWWP 10-Footsteps programme. Paul is a Fellow of the British Pharmacological Society.

**Mark Johnson** - is Professor of Pain and Analgesia and Director of the Centre for Pain Research in Leeds Beckett University's School of Health. Mark has been investigating the science of pain and its management since the mid 1980's. Mark and his colleagues, Kate Thompson and Ghazala Tabasam are looking at pain through innovative and holistic perspectives.

**Rosie Cruickshank** - is a pain management physiotherapist working on St Thomas' Input PMP programmes. Rosie assisted Frances Cole in UP project evaluation.

**Lottie Keyse** - MBIol student at Durham University, in the Biosciences Department, analysing the participant qualitative and quantitative outcomes from the Unmasking Pain project.

**Emma Tregidden and Dawn Fuller** - are founders and joint CEOs of Space2 now working as Emma and Dawn Collaborations. Both Professors in practice at the University of Cumbria. They have worked with Balbir Singh Dance Company for over a decade.

**Louise Trewern** – a pain liver all her life, Louise was until recently Vice Chair at The British Pain Society Patient Voice Committee. She is a Livers Expert Trainer for the LWWP 10-Footsteps programme. She is also a co-founder of the Footsteps Festival for people living with pain, their friends, family, and carers.

**Other artists and contributors included:** Anamaria Wills, Bisakha Sarker, Aniruddha Mukherjee, Bobak Champion, Elia Tomé, Ford Collier, Gareth Dakin, Jenn Wilson, Joe Harris, Jordan Mereil, Julian Germaine, Karol Wyszynski, Louise Grassby, Mark Baker, Madhura Godbole, Mussarat Rahman, Natasha Joseph, Nathan Towers-Islam, Oliver Dover, Paul Floyd Blake, Sam White, Sarah Partridge, Tim Smith.

**More details about the contributors can be found under the Appendices section (Appendix B)**

#### E. Participants and Locations

The project aimed to engage with pain liver in the North East and Yorkshire, targeting ethnically diverse areas and/or areas where there are currently high levels of prescribed opioid use, which often correspond to areas of high socio-economic disadvantage.

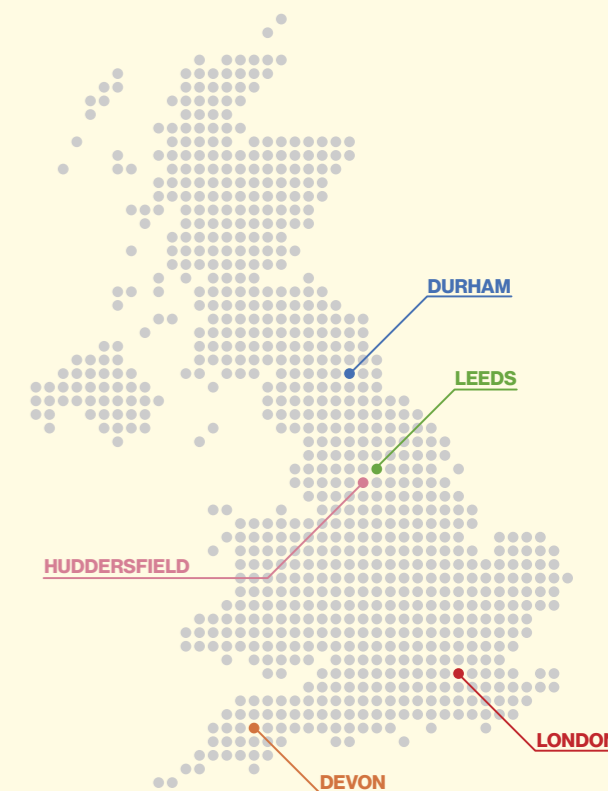
Participants all had experience of living with persistent pain. Most had chronic pain conditions and many have comorbidities, that is having other diseases or medical conditions present too.

Twelve participants formed the North East/Durham group and were drawn from local Parkinson's and Fibromyalgia support groups, some with limited mobility.

In Huddersfield, Adam Strickson, was already working with participants from 6 million+ Charitable Trust, offering creative arts projects 'with an extended family of refugees and local communities'. The group included mostly 40+ Syrian and Kurdish refugees, who had experience of injury in war and conditions like chronic arthritis and heart disease whose management had been hampered by the emotional trauma of being a displaced person.

Additional sessions in Leeds were held with participants of various Space2 projects, an organisation using arts and creativity to work with people living in inner East Leeds, some of the most disadvantaged neighbourhoods in the country. About a third of participants are living with a disability or long-term health condition. Those living with pain explain that loss of self-confidence is the first impact and fear becomes a constant of daily life.

Finally, Balbir Singh also partnered with long term pain liver, Louise Trewern and clay maker Chris Speyer in Devon. During the project development, as part of bid writing, Louise made some significant contributions to shaping the project. She had told her story many times and become a pro-active and expert self-manager of her pain. The southern partnership was aiming to explore how the creative process might aid the next step for pain liver, once they had told their story, a primary aim of the pilot project.



#### F. Projects by Numbers

##### Activity Summary

Number of artists/specialists and creatives	72
Number of artists paid days	222
Number of participants	84
Number of audiences - live	4,160
Number of audiences - online	14,782
Number of products and commissions	10
Number of performance and exhibition days	80
Number of sessions for education, training or participation	55
Number of artists and specialist days	465

##### Participants Sessions

Tasters	3 (CoLabs)
Devon	10 (CoLabs)
Durham	16 (CoLabs)
Huddersfield	6 (CoLabs) + 16 (Pop-up Shop Exhibition)
Leeds	4 (CoLabs)

# 4. Activity Overview

Unmasking Pain delivered a range of activities co-located in the North East/Durham and Yorkshire. The sessions that were delivered changed in response to engagement and uptake of workshops. The co-production approach meant that as participants gained confidence in their own creativity, they increasingly shaped the sessions. Film-makers and photographers documented the project.

A series of creative dissemination events were launched that included exhibitions, installations, performances, presentations, podcasts and lectures. Venues included shopping centres, GP surgeries and universities. The dissemination events intended to inform pain management specialists with an ambition to bring a creative interpretation of LWWP's Ten Footsteps resources to practitioners.

The pilot of Unmasking Pain delivered well beyond its anticipated outputs and exceeded expectations in terms of impact on participants, but also on artists and other contributors to the project. Unmasking Pain won the [Fuse Award for Innovative and Creative Communications](#) in 2023.



Figure 3. Summary of the Unmasking Pain Activity Diagramme

## A. Phases

The project unfolded in three phases:

**Phase 1. Engagement and recruitment including Taster Workshops** – Two taster workshops were conducted in Leeds and Durham, incorporating performances and informal discussions with the groups. These sessions marked the foundation of the relationship between the participants and the project team and set the tone for the ensuing activities.

**Phase 2. Delivery through a series of CoLab workshops** – Co-created and collaborative workshops were put together in each location to engage participants and partners in artistic activities. These fostered conversations that diverted the mind and unveiled new avenues for its self-management. In Durham, CoLabs were extended to 16 sessions over 8 days. In Leeds, CoLabs were carried out between Leeds Beckett and Space2, with the findings recorded. In Huddersfield, the project engaged with the 6million+ refugee and asylum seekers group. Additional activities took place in Devon in 10 sessions which flourished from the collaboration between Lousie Trewern, Chris Speyer and Balbir.

**Phase 3. Dissemination** – The project unfolded through a series of performances, presentations, and exhibitions in both Durham and Leeds, complemented by a digital collection and research papers, along with participation in creative health conferences. The initiative resulted in the creation of 10 new artworks, including performances, exhibitions, lecture presentations, and podcasts, which were shared over 80 days of performances and exhibitions.

Unmasking Pain exceeded its proposed outputs with a number of unanticipated events and activities, particularly involving the adaptation of the exhibition for different settings. From an opportunistic offer to take over a re-purposed shop in the Piazza Shopping Centre, Huddersfield, to a series of exhibitions in various GP surgeries from the Seacroft Primary Care Network, Leeds. Finally a digital collection including photo essays, podcasts, blogs, films and musical treatments was made available online and accessible with a QR code.

## B. The Process

### I. The lynchpin

Dancer and movement artist Kali Chandrasegaram has had chronic back pain since 2002. In exploratory sessions with BSDC, Kali was interviewed and able to respond with words, movement and rhythm to express his understanding of his long-term pain. Over time, this iterative process allowed the team to pinpoint the most effective questions and format, enabling the artist to explore pain through shape, music/sound, rhythm, colour, and its journey through the body. These sessions provided a safe space for vulnerability, anger or frustration, always concluding in a positive emotional state, 'a good place'. With this extensive preparation Kali became the lynchpin of the project, contributing significantly to its success.

When the different groups came together to participate in the CoLabs, these often started with a performance shared by Kali using dance, movement, shapes, music and props to express his own pain. This reduced pressure on participants to contribute immediately and established a shared lived experience between artists and participants, an essential pre-requisite to the co-produced approach of the workshops, bringing parity of status to everyone in the space.



## II. Bridging the Gap

Balbir viewed the process of Unmasking Pain as a triangular relationship consisting of:

- **His creative process, involving in-depth research, conceptual thinking, improvisation, building a team of intercultural artists willing to be taken out of their comfort zones by a strong vision, to become the bridge in realising the concept.**
- **Strategic thinking and partnership building, with a shared sense of ownership.**
- **Building trust with the participants involved as audience, collaborators and eventually opening up to being artists in their own right.**

At the heart of classical Indian dance and music is improvisation. That's not to say making it up as you go along, rather it means to work organically in a responsive way – to think quickly, intuitively, sense the energy of the space and enable the process to shift and grow safely in the moment. Thus, much of what was planned ahead would change during the CoLabs in response to the people in the room and how the process was unfolding.

Building trust with participants was in part made possible by the artists selected for the project, most of whom were deeply experienced in Balbir's collaborative and improvisatory practice. They brought their different personalities, life experiences and sensitivities to the work, connecting with participants and audiences in different ways. Ultimately, the aim was to dissolve the distance between artist and participant, reaching a point where the participants become artists and co-create the sessions. Testament to this approach was the North East group of participants with Parkinson's or Fibromyalgia, where retention of 12 participants was 100%, despite anticipating a one third drop-off rate.

## III. Distraction

An overarching theme of the process was the one of distraction. Engaging in various creative activities served as a purposeful distraction for participants, which allowed them to shift their focus away from pain and immerse themselves in the present. Over time, this extended creative mindset contributed to participants becoming less consumed and overwhelmed by pain in their everyday lives, offering a sustainable and positive impact on their overall well-being. The participants found valuable means of navigating their everyday experiences with greater resilience and greater distraction from persistent pain. Throughout the project, it was important to understand effective ways to create a framework for distraction and comfort. A simple greeting at the car park and a welcoming bouquet of colourful flowers before the sessions began would for instance set the tone for the day.

## IV. The Cultural Aspect - 6 million +

A key aspect of the project was the multicultural landscape in which artists, partners and participants from all cultural backgrounds could create safely. To reinforce this idea, Balbir Singh partnered with Adam Strickson, teacher of intercultural performance at the University of Leeds, and lead artist at the the 6 million+ Charitable Trust in Kirklees, West Yorkshire.

The Trust works with an extended family of refugees and local communities, expressing stories of the Holocaust, genocides and contemporary persecution. Adam Strickson introduced Syrian and Kurdish refugee participants to the project. They have experienced injury in war and conditions like chronic arthritis and heart disease whose management has been hampered by the trauma of being displaced. This added a new emotional dimension to Unmasking Pain. A significant



number of artists and regular volunteers at the Trust also have long-term physical pain but never address the problem. Working as part of Unmasking Pain allowed them to address these issues, and create conditions for everyone to be involved on an equal, collaborative basis.

Unmasking Pain brought the refugees, artists and volunteers to a deeper dialogue than is usually possible within the 6 million+ programme. Activities included watching Kali explore his pain in dance, creative writing in Arabic and English, working with clay, pastel drawing, group dancing and composing individual music pieces for participants. Everyone participated on an equal basis. Deepening friendships and sharing food were also important at each session. A fruitful online exchange of cultures between the white North East group and the 6 million+ participants enabled new pathways of vocabulary to express pain holistically.

*'We like to think of ourselves as an extended family and the artists and co-ordinators from Balbir Singh Dance Company easily and happily fitted into this' - Adam Strickson*

## V. Language in the Landscape

### Awakening Creative Senses

The concept of "Language in the Landscape" seeks to awaken our senses creatively, both in the external environment and within ourselves. Originating from collaboration with the Huddersfield group of the Unmasking Pain project, Balbir Singh encouraged participants to observe shapes of trees and branches, searching for letters of the alphabet. This exercise aimed to stimulate the creative senses of participants, urging them to perceive the world through a fresh lens. Aligning with the overarching ethos of BSDC, this approach reflects a fundamental curiosity about the human experience, inviting individuals to explore and engage with their surroundings in innovative ways. Unmasking Pain was conceptually steered by "Language in the Landscape" in its entirety.

### The Botanics : Reconnecting with Nature

Participants in the North East engaged in activities, numerous walks and collaborative sessions in the Botanical Gardens of the University. In that way, the project underscored the impact nature can have on our health and overall sense of well-being. Immersed in the serene beauty of the gardens, participants experienced in their own way the benefits of connecting with nature. The Botanical Gardens acted as a catalyst, to highlight the importance to reconnect with nature throughout the project.



# 5. Metaphors

As the project progressed and the collaboration across the “interface between science and arts” matured, Dr Cole described the emerging shared vocabularies and forms of expressions as metaphors. The use of metaphor became a strong, central theme of the project’s development, emphasised in the monthly partnership meetings that took place. Whilst current practice uses techniques such as a scale of one to ten to ask patients to assess their pain, the creative approach was enabling participants to express their pain better through metaphor including movement, colours, shapes and other artforms. Each session had a different creative focus, but linked through growing creative confidence, creativity and aesthetic awareness. These include:

## Clay-making

Adam Strickson is a talented artist and uses clay to sculpt, shape and model. In exploring how clay activity might support participants in shaping and making their pain tangible, Balbir brought Adam together with Villmore James. Through clay-making, Adam gained a sense of the process of sculpting pain and Villmore found a new way of telling his own pain story. This led to developing clay-based activity at Space2 with pain-liver Rob, at the Lawrence Batley Theatre, Huddersfield with the 6 million+ group and in Devon with Louise Trewern and Chris Speyer.

## Puppetry

As the project progressed and everyone knew each other better, artist Louise Grassby created puppets of each of the participants in Durham, which were gifted to them at a later session. Taking the CoLab to an outdoor space, the Botanics garden, everyone was asked to go for a walk with their puppet, see themselves outside of themselves and have a conversation with themselves, or with another person through their own puppets. *“The experience was profound and a highlight of the project.”- Balbir Singh.*

Responses were richly varied, with one participant going on to make puppets at home with her grandchildren, and others like Christine who kept the head of her puppet as a talisman on her keyring. She said *“every time I get my keys out and see it, I smile and for 30 seconds nothing else matters.”*

## Musical Treatments

Live music is a core ingredient of BSDC’s work and Balbir was keen to test the idea of non-medical treatments. Using tabla, a traditional North Indian percussion instrument, the team introduced the concept of rhythmic patterns, and cyclical motions. Participants linked these patterns to rhythms of the day, week, month, year and transposed these creative elements into other themes. Musical profiles for each person were built up including favourite music and moods or favourite places to listen to music. Balbir then collaborated with musicians Annirudha Mukherjee and Joe Harris to create what he called Musical Treatments. Through converting each participant’s name into a rhythmic pattern, the artists worked up personalised compositions, blending Indian classical music and western guitar harmony. The whole process for the 12 Musical Treatments (one for each participant to take home) was recorded and filmed.

## Knots

In a session centred around the theme of knots, participants creatively expressed bodily, mental, and pain-related knots using textiles and wigs. This artistic approach facilitated conversations between participants and the team, offering a visual language to share experiences and foster connections.

## Labyrinths

In one outdoor session the group created labyrinths. Indian Labyrinths, otherwise known as Chakra Vyuha, are a long established element of Hinduism. The project’s labyrinth was used as a metaphor to go into Kali’s mind. Unlike a maze, a labyrinth has a clear direction of travel, entrance and exit. This enabled a performance to be created that explored Kali’s mind as an artist living with chronic pain, allowing him to share his story metaphorically.

## Hopscotch

Activities based on the children’s playground game ‘Hopscotch’ were used to explore various themes, including the Ten Footsteps Programme. Artists demonstrated creative ways of moving through the Hopscotch boxes before inviting participants to join them through considerate and compassionate encouragement. Eventually, participants gained confidence to interact imaginatively with the boxes either on their own or with others, stimulating creative discussions about supporting people with pain.

Pictures from Unmasking Pain project activities (From left to right, top to bottom) including Clay-making, Puppetry, Musical Treatments, Knots, Labyrinths and Hopscotch.





# 6. Dissemination

The purpose of the project was not simply to work with pain-livers but also clinicians who specialise in pain management, to promote greater understanding of the lived experience of pain-livers. Ultimately, it is hoped that the project will enable clinicians to be better equipped to listen to the stories of pain-livers and feel confident in 'prescribing' non-clinical interventions and treatments.

The project developed a wide range of resources and hosted a number of different events to share learning, experiences, reflections and findings with wide, but targeted audiences. Central to the dissemination was an exhibition, developed in consultation with Leeds Primary Care Network, and adapted for each new venue or audience.

The list of all the public events and disseminations can be found under the Appendices section (Appendix C)

## A. Project Presentations

The initial project brief noted 3 presentations – one in Leeds, one in Durham and one at the Park Edge Practice in Seacroft to share findings with participants, stakeholders and other interested parties. In Durham a lecture/presentation was held at the University's School of Biological and Biomedical Sciences to an audience of participants and their families and academics. In Leeds it was tilted to student clinicians, local authority and local Primary Care Network. Balbir joined Professor Mark Johnson for a lecture at Leeds Beckett University to 150 undergraduates. This served as early exploration of how a new generation of clinicians can embed non-medical treatments into their practice early in their careers. This was considered an important next step for the project beyond the pilot phase.

## B. Exhibition

A significant amount of exhibition material was sourced over the duration of the project, with 1000 photographs alone being taken. The exhibition was designed with flexibility and care to enable its safe accommodation in every size of space, from GP practice reception areas and community health centres to purpose-built gallery spaces and lecture theatres. Exhibits included depictions of many of the metaphors, identified through the creative process. For example, a hopscotch board, a display of knots, puppets and masks depicting before and after states. The Unmasking Pain exhibition was accompanied by documentary photography, infographics and posters of shared learnings.

### Huddersfield Shops

In the Piazza, Huddersfield, BSDC was offered the use of repurposed shops to establish an installation about the project. This proved a useful site to test different ideas over a couple of months and to develop more exhibition material. It reached a public audience for workshops and performances leading to some unexpected conversations. Groups attending included adults with special needs, Devika Rao's academy students, local Brownies and visiting members of the public.

### Chapel FM

The exhibition/event took place at Chapel FM, an arts centre in East Leeds, where an "Aladdin's Cave" was set-up and key stakeholders and NHS staff from the Seacroft Primary Care Network met to discuss the potential of the project in the healthcare system.

## C. Mini-Exhibition for GP surgeries

The Unmasking Pain partnership worked closely with the Seacroft Primary Care Network and its team, to familiarise clinical and non-clinical staff with the project content and the potential for bespoke mini-exhibitions to visit the GP surgeries. In December 2022, a pop-up exhibition and demonstration were held for local GPs and social prescribers. In February 2023, a further session with a performance, exhibition and presentation was held at one of the local GP surgeries. A touring exhibition further visited 4 surgeries in East Leeds.

## D. Presentations at other events

Adam Strickson gave a talk on the project and its creative process as part of a day-long Sensory Storytelling Seminar held online and in person at the University of Leeds, reaching a wider arts-based academic and creative practitioner audience.

Professor Chazot presented findings at Our Wonderful Brain with Alzheimer's Research UK as part of a wider presentation of his research. Additionally, he delivered presentations at two ESRC IAA conferences in Durham as well as at the Society for Social Medicine & Population Health conference in Newcastle - [link 1](#), [link 2](#).

Unmasking Pain set up a stall at Preston Health Mela in an initiative organised by the National Forum for Health and Wellbeing in partnership with the University of Central Lancashire and the School of Medicine. Over 1000 students attended the event.

Notably, the project was celebrated in at the LWWP celebratory event in July 2023 at Durham. An article highlighting the project's significance was then published on UK Yorkshire Bylines, further amplifying its impact - [link 3](#).

*"This unique combination of Artists, Scientists, Health staff and Expert Pain Livers has come up with a winner, to give individuals their voice and new creative ways to self-manage their unique version of persistent pain. As scientists, we can provide both objective and subjective measurements of the effects of this approach on the physiological, physical and mental health status of the participants, to give a holistic validation of what we can already see of their "faces." - Professor Paul Chazot*

## E. Creative Walks with Picnics

These were held in Beaumont Park, Huddersfield and Dilston Physic Garden near Durham, an informal opportunity for participants and their families and friends to come together to learn about the full findings of the project and give feedback on the dissemination phase of the project.

A creative story walk, Taking Your Shoes for a Walk, was held in October 2022 at Durham's Botanic to a public audience.

## F. Online resources

Online resources include a 3-part podcast series, short films, digital photo essays and musical treatments.

The content recorded and created was extensive and told the stories of the participants in the context of Unmasking Pain. Below are listed some of the most important ones:

- A 15 min long documentary synthesising interviews from the participants and the project team can be found [here](#).
- A short video promoting the project can be found [here](#).
- An online gallery of photographs and posters documenting the project can be found [here](#).
- A series of mini soundscapes/musical treatments reflecting participants names can be found [here](#).

3 Podcast episodes with multiple people from the project:

- Durham: [Link](#)
- Huddersfield: [Link](#)
- Artist Kali Chandrasegaram: [Link](#)

By the end of March 2023, an online audience of 14,782 had been achieved.

## G. Fuse Award

In February 2023, BSDC won the Fuse Award for Innovative

and Creative Communications in partnership with Professor Paul Chazot and the WRIHW. Fuse, the Centre for Translational Research in Public Health, is a partnership of public health researchers across the five universities in North East England. The Centre works with policy makers, practice partners, the voluntary & community sector, and the public to improve health and wellbeing and tackle inequalities.

The award was celebrated in a Durham University event. It extended the profile of the project with coverage in national and regional media.



# 7. Evaluation - Outcome Summary

An interdisciplinary team of pain researchers, clinicians and non-clinician recorded with the artistic team the emerging multidimensional experience as well as the biopsychosocial change. It was drawn from three universities: Leeds Beckett University, University of Leeds and Durham University.

The extensive evaluation was multifaceted and used:

1. A range of objective quantitative methods, including physical activity of walking, sleep and physiological measures of blood pressure. It used novel AI machine-learned morphological and thermal imaging techniques as indicators of pain itself and physical and mental health.
2. Qualitative questionnaires from the participants with pain in focus groups at the end of the project sessions to gain sight into the process of change and what had changed individually. Also, interviews with artists with pain to explore the impact and evolving change for them through the project.
3. A descriptive phenomenological study led by Kate Thompson and Mark Johnson accompanied by their team at Leeds Beckett University.
4. Observational data from researchers of the experience recorded in written, visual, still and moving images of the process of change to identify the personal journey of changes.

The focus of quantitative evaluation was based on:

- Self-perceived change in the participants when thinking about their pain experience. Self-confidence to manage their life despite their pain and mental well-being and their use of daily medication using self-completion questionnaire tools
- The measure of emotional change with facial image changes using thermodynamic tools
- Changes in physical function, walking activity, sleep and daily blood pressure using Fitbit devices

The focus of qualitative change was based on the following observations:

- Participants and dance artists personal experiences of change in perception of self, others, their pain and the context
- Creative and artistic ways to self-manage pain observed by researchers

## Outcomes Summary

10 key outcomes were identified and evidenced:

1. Unmasking Pain encouraged participants to engage in creative activities
2. Participants felt more confident in managing pain without medication
3. Participants' perceptions of creativity underwent significant transformation
4. Reliance on pain medication decreased
5. Receptiveness to alternative creative ways to pain self-management increased
6. Participants' Confidence Scores increased
7. Participants' Pain Catastrophising Scores (PCS) decreased
8. Wellbeing index increased
9. Emotional Arousal Responses increased
10. Walking activity, general health and sleep quality increased; all physiological benefits of UP programme were maintained after completion for at least 3 months

The emerging themes of change and insights were many, wide and diverse reflecting the complexity of working with this flexible artistic engagement approach with the person with pain.

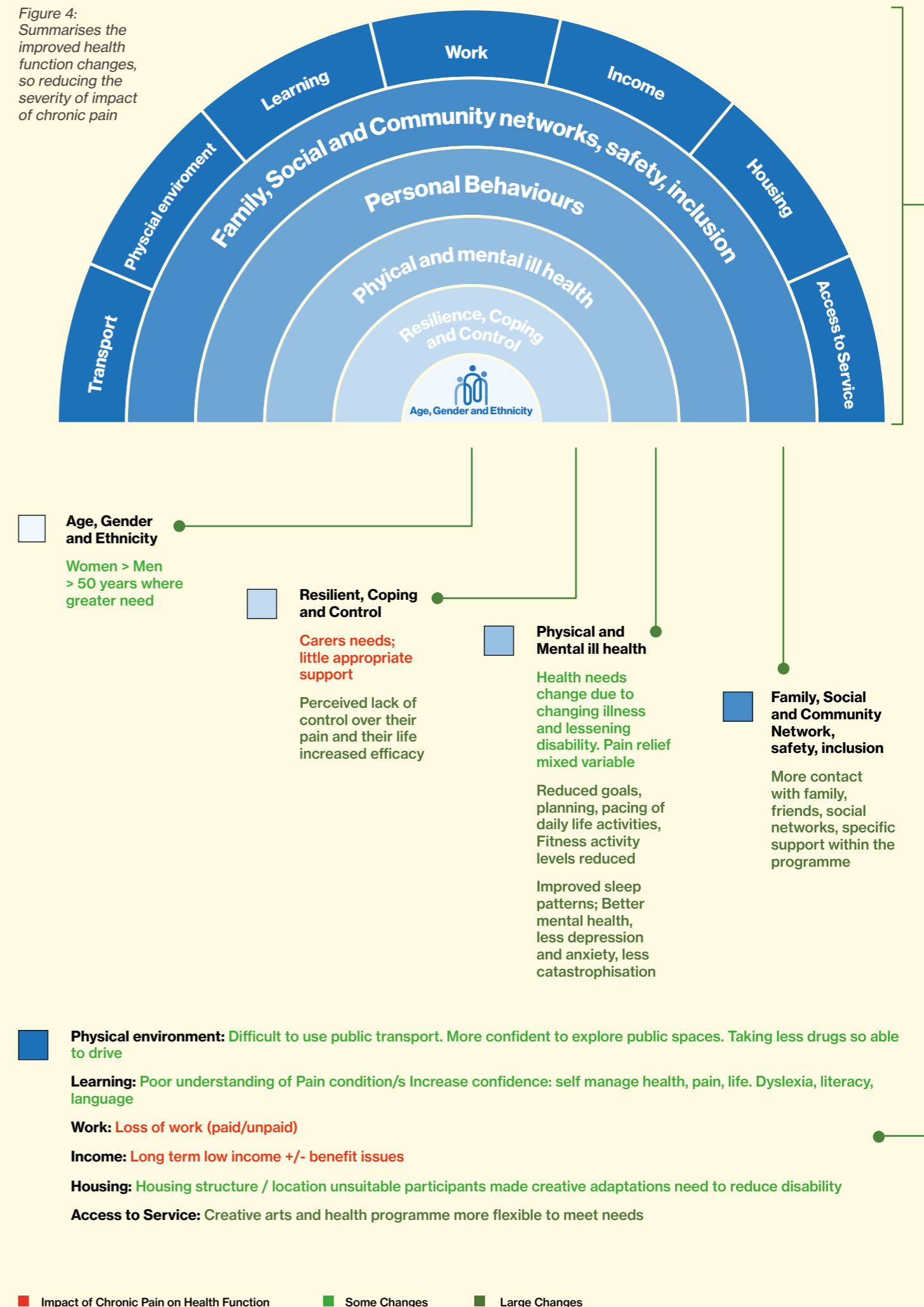
The project evaluation identified changes in health function physical, emotional and social function in these areas in green within the rainbow model of health (Figure 4). There emerged five key themes that suggest the process of change that improved overall health function areas (found on page 29).

The power of a non-clinical environment working with artists who address the person vs. the patient, offered an inclusive and safe place to experiment and create. The human engagement of the arts and artists had a powerful effect that created ownership and control of their pain and its impact on the individual.

The success of the project stemmed from the co-production between scientists, artists and expert pain-livers, all simultaneously sharing and learning from the experience, with a range of cultural ethnicity, backgrounds, gender and ages from County Durham and Yorkshire. Without exception participants, artists, pain rehabilitation specialists, scientists and project coordinators reported that involvement in the project affected how they think about pain.

*"The whole project, as well as each session, was a pilot, an experiment that has no set method" - Balbir Singh*

Figure 4: Summarises the improved health function changes, so reducing the severity of impact of chronic pain



# 7. Evaluation - Quantitative Data

The quantitative evaluation explored these outcomes of health function observing and recording changes in:

- Self-efficacy and use of pain self-management
- Reliance on pain relief medication
- Individual's perception of their pain experience using pain intensity and distress
- Mental wellbeing
- Emotional arousal responses to pain and daily life experience
- Physical and physiological functioning

The specific evaluation tools used:

- Mental health well-being used WHO-5 tool, pain self-efficacy (PSEQ 10) individual's pain management, pain catastrophising scale (PCS) to explore anxiogenic cognitive changes in perceptions of pain.
- Project questionnaires assess
  - Change in use of pain related medication.
  - Change pain self-perceived creativity.
- Focus group interviews to feedback the experience of participating Unmasking Pain and its range of creative art activities in relationship to the outcome areas above.
- Physiological changes and emotional arousal using thermal imaging cameras recording and "FitbitPro" device to measure 24/7 physical activity, heart rate, BP and sleep patterns.

## A. Results in Behaviour Change

The changes found were:

- 70% of participants' WHO Mental Wellbeing Index increased during the project indicating lessening of depressed and anxiogenic mood, improvement in mental wellbeing
- 100% of participants' Pain Catastrophising Scores (PCS) decreased during the project
- 80% of participants' Pain Self-Efficacy Confidence Scores increased during the project indicating improved confidence to cope with life despite the pain
- 50% of participants' creativity increased after the project compared to before involvement. Those whose creativity remained the same already viewed themselves as being 'always creative' before their participation in UP.
- 40% of participants' collaboration increased after the project compared to before their involvement. Once again, those whose collaboration remained the same already viewed themselves as being 'always collaborative' before their participation in UP.
- Reliance on pain medication decreased for 50% of participants, and stayed the same for the other 50%
- Receptiveness to alternatives of pain management, such as self-management behavioural change increased for 70% participants and stayed the same for the other 30%

Overall, all the measures used to track change in anxiogenic cognitions and self-efficacy exhibited significant change by the end of the project, which unfolded across a span of seven half-day sessions over the course of nine months. This could explain in part the positive change in receptiveness to self-management and the realisation of the role of creative arts in that aspect. This gain in self-efficacy was reinforced by feedback from the focus groups. The WHO-5 Mental Well-being scores indicated a significant change, accompanied by the reduction in depression and anxiety components which may have contributed to a change in receptiveness to self-management. This could be attributed to active physical engagement in the supportive and sensory environment, coupled with the attentiveness of the artists and the observed learning derived from Kali Chandrasegaram's creative dance expression of pain and life experiences.

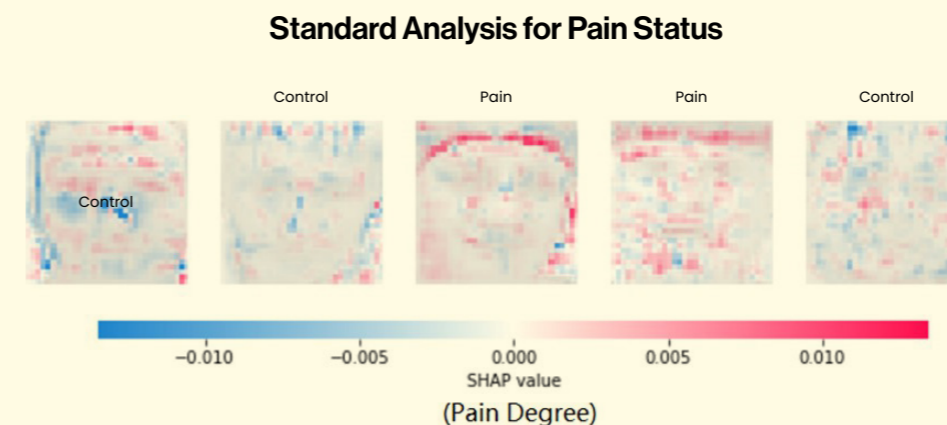


Figure 6. Facial imaging of emotional arousal status

## B. Changes in Pain and Emotional Arousal and Physiological Measures

The project used a new quantitative method to monitor physiological responses associated with pain, based on face morphological digital imaging in sitting and standing position (Figure 6). All of the participants experienced long-term pain in the lower half of their body. Images of the UP participants before and after the UP programme are currently under analysis.

which it can be detected. He evaluated the emotional arousal status of each of the participants during the course of the project.

Paul Chazot, professor at Durham University, used previously untried non-invasive methodology to classify human emotions through thermal images of the face. An emotion has a thermal signature and can be characterised by activity of the autonomic nervous system, which in turn provides a thermal imprint through

Before and after session images were taken at the second CoLab in Durham, using a thermal facial imaging system (FLIR C3-X Infra-Red Thermal Imaging Camera (n=12)) and consequently used as representative data. The key change analysed was the temperature at the tip of the nose for each individual before and after the creative session. 90% of the participants displayed a significant change in the nasal temperature (1.5-2.0 degrees C) indicating a change in emotional arousal state due to the experience within the session.

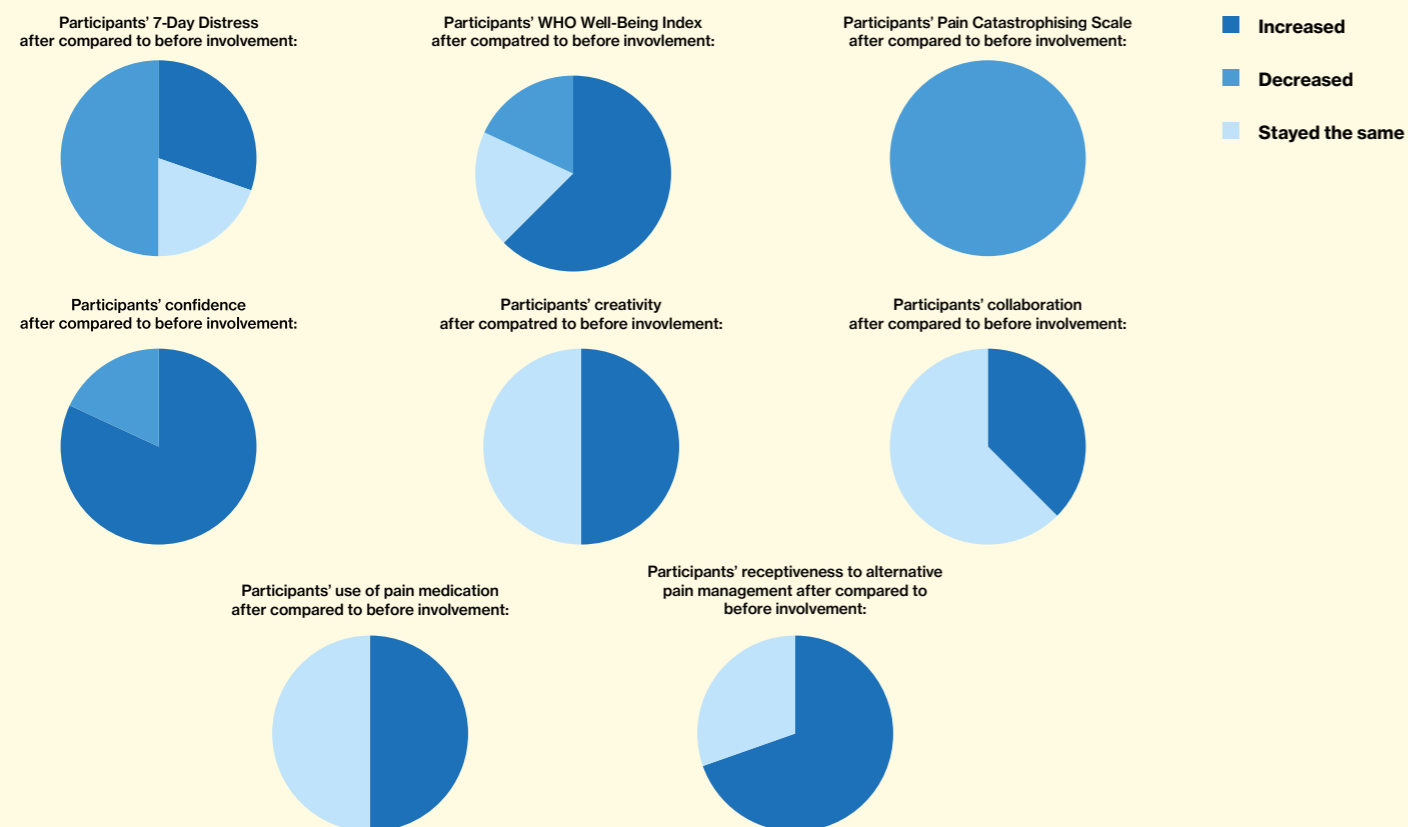


Figure 5. Questionnaire change pie charts for the 12 participants in Durham

## Change of Emotional Arousal Responses - Unmasking Pain Session 2

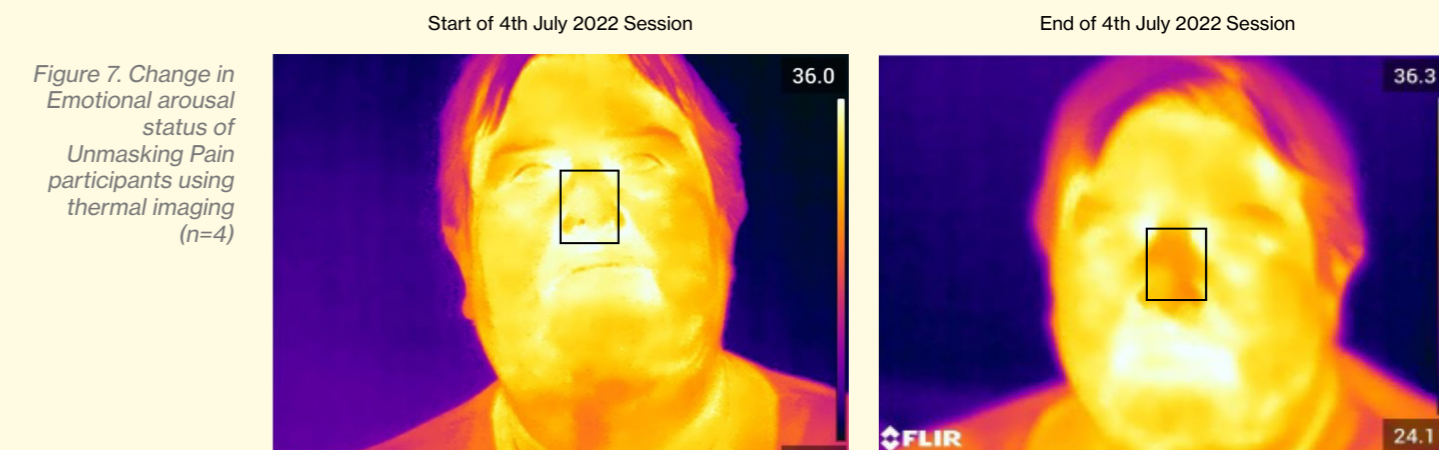


Figure 7. Change in Emotional arousal status of Unmasking Pain participants using thermal imaging (n=4)



Four participants agreed to wear a Fitbit Pro throughout the programme and for 3 months afterwards and access the effects of Unmasking Pain upon key physiological measures. We observed a number of positive effects of the programme, including decrease of mean resting heart rate (75 bpm to 70 bpm), increase in mean sleep time (+ 2 hours) and a doubling of total daily steps (movement activity), and importantly these effects were maintained for at least 3 months after the last Unmasking Pain session (n=4), indicating change in positive behaviour (Figure 8).

### C. Summary

The quantitative evaluation of the project served as an initial indicator of success for Unmasking Pain, revealing the physiological and positive impact the project had on participants. The data highlighted the tangible benefits in terms of improved health and wellbeing.

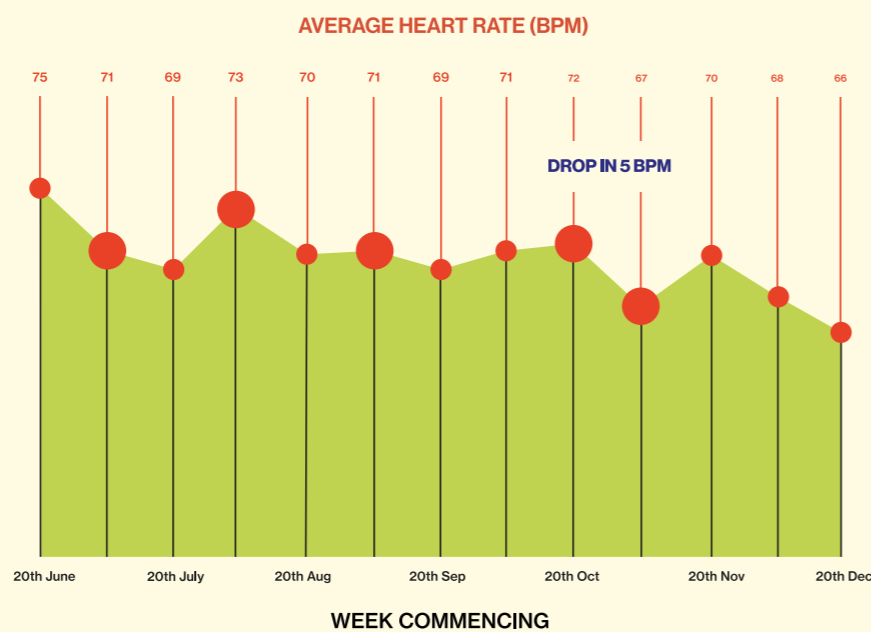
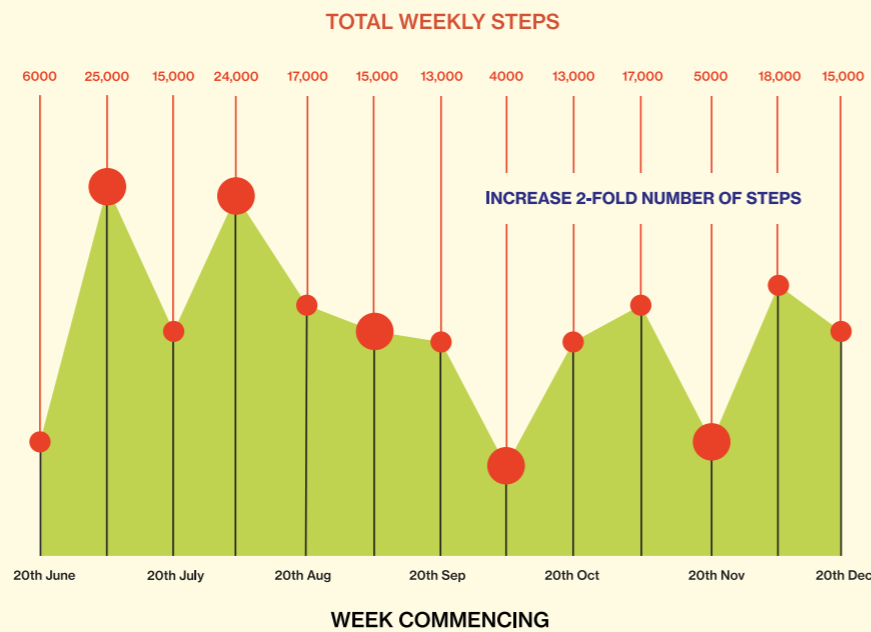


Figure 8: Fitbit results of physiological measures (n=4)

## 7. Evaluation - Qualitative Data & Interviews

On top of the hard data of the quantitative study, the Unmasking Pain team also set out to understand the impact of Unmasking Pain through a qualitative evaluation, collecting shared experiences in focus groups and individual interviews.

### A. Focus Group

A first set of conversations showed that all of the participants could list several new approaches they had taken up to help manage their pain better, and many were exploring arts mediums to find out more new ways for themselves. The feedback yielded several key findings, including a heightened understanding of the role and

involvement in art activities as a means to redirect a negative focus from pain and illness towards the discovery of their creative selves. Participants also highlighted the opportunity for shared experiences and connections with others, both those experiencing pain and the dance artists.

*"It made me remember that being creative was fun and helped me forget pain"*

*"I have found the creativity of making flower arrangements more important than taking painkillers"*

*"I realise I do not need to rely on pain medication now, I can use other methods to take my mind off the pain"*

*"The pain is always there but I feel more confident of carrying on without meds"*

*"Watching and listening to so many talented people"*

*"I've always been creative but never knew it"*

*"It has changed my entire perspective on creativity"*

The initial data, gathered through responses to a variety of questions, indicated positive changes in several aspects for participants in Unmaking Pain. These included shifts in creativity, collaborative engagement in creative activities with others, and an increased receptiveness to self-management approaches for pain, with 70% of the group demonstrating heightened openness to such strategies (Figure 9).

In summary, the findings suggest that all participants experienced a positive shift in confidence and awareness of their creativity and engagement with themselves and others. This empowered some participants to take more control in managing their pain, taking actions to improve physical and emotional health function and being more socially engaged despite the pain.

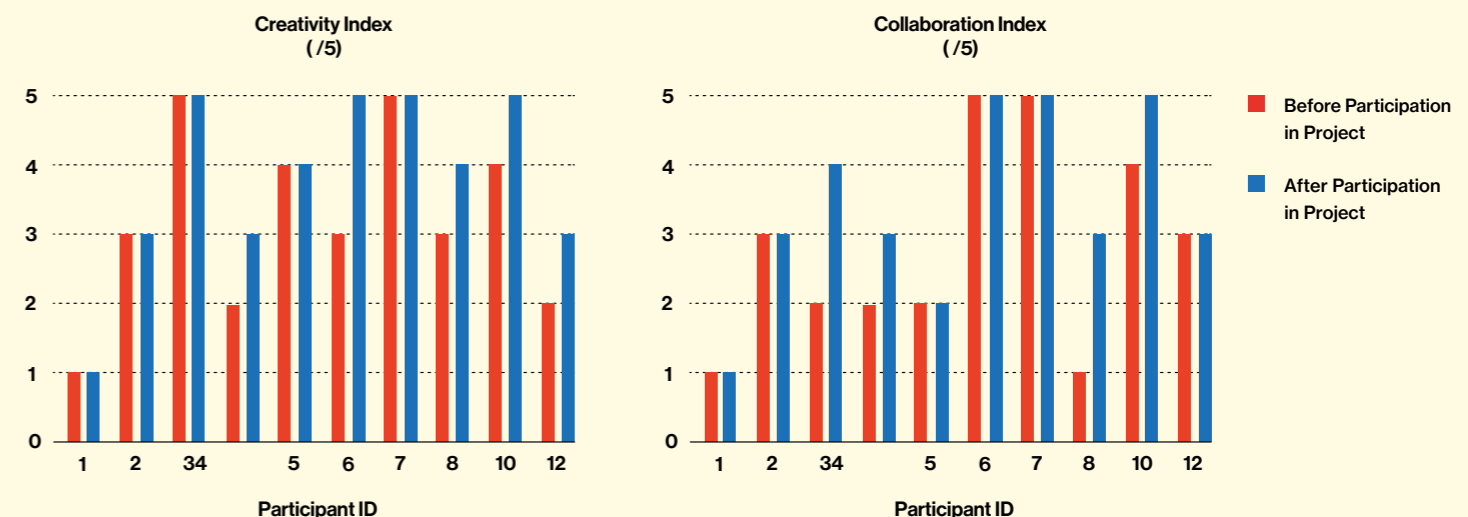


Figure 9: Change in self perceived creativity and self-perceived collaboration

## B. Phenomenological Study

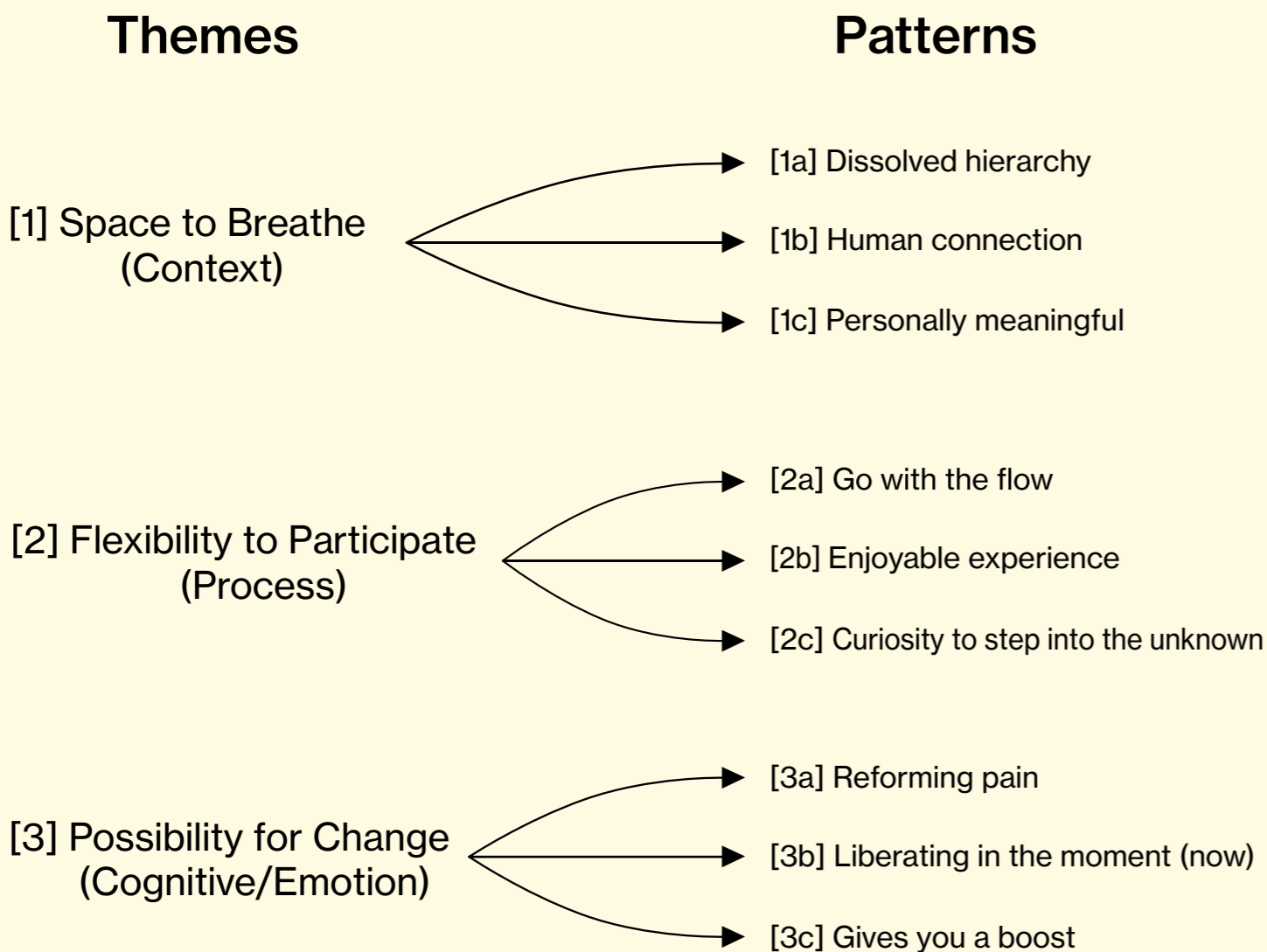
The qualitative evaluation was reinforced with a phenomenological research study led by Kate Thompson, Ghazala Tabasam, James Milligan, Angela Murphy and Mark Johnson from the Centre for Pain Research, School of Health, Leeds Beckett University.

They conducted nine in-depth semi-structured one-hour interviews with three artists, five workshop attendees and one pain rehabilitation specialist (7 female and 2 male participants). Data analysis revealed three overarching themes and nine sub-themes (patterns of data).

Each of the three overarching themes captures a different dimension of the experience of Unmasking Pain.

The theme Space to Breathe reflects the conditions, environment and setting that people experienced during Unmasking Pain. The theme Flexibility to Participate reflects the process that people experienced during Unmasking Pain. The theme Possibility for Change reflects the feelings and thoughts that people experienced during Unmasking Pain. Nine sub-themes derived from the three overarching themes are described here.

# The Experience of Unmasking Pain



## [1] Space to Breathe

### [1a] Dissolved hierarchy

Participants described people with pain (workshop attendees) and artists being on an equal footing because activities were co-produced, 'breaking down those barriers' previously experienced in healthcare settings. There were no set or rigid rules.

*"It became very much a two-way process. It was with the participants initially and then the bonding process moved out to the artist, what are they doing, why they're doing this, what we hope to achieve. And I think we were teaching them as much as they were teaching us"*

### [1b] Human connection

Participants described a person-centred experience where social bonds and sharing was valued.

*"The pain clinic was good, but it's very clinical. They don't give you the social side, so to speak. Where this was more - it didn't feel like they were teaching you things. It didn't feel rigid."*

### [1c] Personally meaningful

Participants described the tailor-made aspect of Unmasking Pain with attention to the person rather than the pain. This was demonstrated by the co-creation of personalised art, puppetry and musical treatments.

*"I can't believe someone has just serenaded me with a flute. It was just such joy. It's so lovely. And it was so different, to think of your pain in that way as well."*

## [2] Flexibility to Participate

### [2a] Go with the flow

Participants described how the level of participation was led by the workshop attendees who were free to explore activities without being forced or overly persuaded.

*"It was unscripted and it was how you felt in the moment. Yeah, and the flexibility to change direction too"*

### [2b] Enjoyable Experience

Participants described how artists purposefully circled around pain and placed enjoyable activities at the heart of the sessions.

*"We just didn't mention pain. We just did enjoyable activities. I'm very, you know, great to be involved with, a real privilege to be involved with them"*

### [2c] Curiosity to step into the unknown

Participants described how both artists and workshop attendees had to navigate new and unfamiliar territory, because the process was unscripted and iterative. Artists and workshop attendees had to 'step into the unknown'.

*"We did all sorts of different things, it was like going into the unknown every time you went into that room. I mean, sometimes you look and think, what's that woman doing with a fishing rod"*

## [3] Possibility for Change

### [3a] Reforming pain

Participants described how pain was given a new identity or form, for example by creatively giving pain shape, structure and appearance, and this was the first time they had expressed pain in this way.

*"It was amazing. It was absolutely amazing. I just sat there and looked at it [the claywork] and I honed it a bit and it was still really rough looking and it had knees and stuff like that and it was coming up out of the clay"*

### [3b] Liberating in the moment (now)

Participants described how workshop attendees were distracted from pain in the moment whilst enjoying the activities, and this was liberating.

*"To think that the form of a dance can distract you so much that you don't have that immense pain. It's just so liberating."*

### [3c] Gives you a boost (future)

Participants described changes in their longer-term outlook

*"It [the experience of Unmasking Pain] gave me a boost actually to carry on and hope for the future really."*

Unmasking Pain was described by all participants as an 'enjoyable experience', with 'dissolved hierarchy' and 'human connection' at its core. People living with pain described Unmasking Pain leaving them feeling liberated from pain in the moment opening up a future of new possibilities and perspectives. Some participants described a sense of freedom from the distracting and immersive nature of engaging with art and creativity. Others described how workshop activities provided a

safe environment to challenge their personal identity as a pain sufferer so that they could transition towards an identity that was much more than just pain, with transformative implications for the future. In conclusion, the study provided evidence that Unmasking Pain catalysed change in both mindset and behaviour towards a more positive future living with or without pain. More research is needed to ascertain whether sustained long-term benefit was achieved.

Figure 10: Phenomenological study data patterns

# 7. Evaluation - Other Observational Data

Each lead team member has contributed their summary from their discipline of their observations within the report. Clinician researchers and practitioners, Professor Mark Johnson, Ghazala Tabasam, Kate Thompson, and Rosie Cruickshank helped to gain a broad perspective of change occurring within the project process.

## A. Professor Mark Johnson

In a published journal article [“Pain through the perspective of art and creativity: insights from the Unmasking Pain project”](#) Professor Johnson and colleagues from the Unmasking Pain team discuss insights and perspectives emerging from the project. Johnson et al. explore how Unmasking Pain’s “new set of rules” contrasts with the experiences during clinical encounters. Johnson et al. point out the following emerging themes of the project; the distinct focus on the person vs the patient and the creation of a unique context through a multifaceted approach involving collaboration across Arts and Science. Johnson et al. particularly observe that:

- Unmasking Pain demonstrated how artists (non-clinical personnel) inherently focus on the person not the pain, something that clinicians may find difficult.
- Unmasking Pain demonstrated how environments in which art takes place (non-clinical places) affects the mindset of participants in a positive way.
- Unmasking Pain demonstrated how artists free up thinking and doing in people with pain and in pain rehabilitation specialists. This provides opportunities for pain-livers and pain rehabilitation specialists to engage in imaginative, creative, and playful activities. This may improve clinical encounters, improve pain management interventions, promote strategies for health and well-being through “explorative joy despite pain”.

Unmasking Pain catalysed conceptual thinking about existing models for pain. Johnson et al. explain how the biopsychosocial model of pain is still dominated by a biomedical paradigm and is fragmented in service delivery, and that Unmasking Pain supports a shift towards a model of pain that considers the experience of pain from the perspectives of the self, the body and the context.

Johnson et al. identified the power of a non-clinical environment working with artists who address the person vs. the patient offering an inclusive and safe place to experiment and create. The human engagement facilitated by the arts and artists yielded a profound impact, fostering a sense of ownership and control over individuals' experiences of pain. This ripple effect extended to the project's supporting staff, including artists, media professionals, and scientists,

prompting a significant shift away from a purely biomedical approach. The experience broadened perspectives, encouraging consideration of diverse avenues for research. Ultimately Johnson et al. concluded that art has the potential to shift people living with pain from “I can’t do it, I am not willing to do it” to “Perhaps I can, I’ll give it a go, I enjoyed it”.

*“It opened my eyes to different ways of looking at pain and different things that I can study about pain” - Participant*

## B. Rosie Cruickshank

Rosie Cruickshank, Pain Management Specialist Physiotherapist at St. Thomas’ Hospital, London who participated in the workshops, summarised the changes she viewed based on the Acceptance Commitment Therapy (ACT) model used within formal pain management programmes.

She emphasised that no single discipline alone is ideal for analysing the impact of the arts, a sentiment reflected in the Unmasking Pain project's collaborative approach spanning arts, health, medicine, and therapies.

In examining the creative arts therapies - Koch (2017) pointed out the challenge of defining active therapeutic factors, noting an “absence of theoretical models.” Both Koch and De-Witte et al (2021). have taken steps to identify specific and unique factors and domains in creative arts therapies. Rosie, working with the ACT model, expressed particular interest in understanding ACT processes during participants' interactions with the sessions and the creative processes. According to the Association for Contextual Behavioural Science, ACT is defined as follows: “In theoretical and process terms we can define ACT as a psychological intervention based on modern behavioural psychology, including Relational Frame Theory, that applies mindfulness and acceptance processes, and commitment and behaviour change processes, to the creation of psychological flexibility (Hayes, ND).”

Acknowledging that pain often leads to suffering, Acceptance Commitment Therapy (ACT) identifies two core psychological processes responsible for most psychological suffering: ‘cognitive fusion’ (getting stuck with thoughts) and experiential avoidance (struggling to avoid, suppress, or get rid of unwanted thoughts,

feelings, memories) (Harris 2009). ACT aims for ‘mindful, valued living’ (Harris 2009), rooted in mindfulness - ‘paying attention with flexibility, openness, and curiosity.’ The overall goal is psychological flexibility – the ability to be in the present moment with full awareness and openness to experience and to take action guided by values. ACT works through six core processes:

- Contacting the present moment
- Cognitive diffusion (separating from thoughts, memories)
- Acceptance (being open to making room for painful feelings, sensations, urges, and emotions)
- Self as context (the core ‘you’ that observes life’s changes)
- Values (what matters)
- Committed action (effective action)

To achieve healthy levels of psychological flexibility, individuals can utilise a combination of the six core processes of ACT. Rosie Cruickshank observed and recorded the following themes through the ACT processes to understand probable change in action.

- Arts facilitating flexibility of focus
- Arts facilitating connection to self (awareness and acceptance) and then connection to the body and moving
- Focus on the present moment
- Focus on self and what is valued
- Open to new experiences

She believes that the context of Unmasking Pain workshops contributed to the emerging changes within the person through:

- **Greater time given**, in an unhurried way and used differently and creatively.
- **Settings in non-health care locations**, often set in outdoor, nature based surroundings or indoor with multi-sensory creative offerings – which **changed the expectations** and valued the person’s experience (*“I didn’t know what to expect”, “Other than; I’ll give them my time to study me... I came with no expectations. I was surprised how good it was for me”*).

*“Expectations can significantly influence health outcomes and the observed sense was that people with pain were enabled to both make sense of their experiences with pain as well as shift their focus beyond it and explore new creative experiences with others. A more healing process. The creative process valued the person, with the artists listening and responding sensitively to the participants’ stories. The sense of valuing each individual within the group was made explicit through creating pieces based on them - for example puppets and musical recordings were created by the artists based on the uniqueness of each participant (which the participants used to have conversations with themselves in new ways).”- Rosie Cruickshank*



The list of all references in *Evaluation - Other Observational Data* can be found under the Links/References section.

### C. Kali Chandrasegaram: an Artist perspective

Kali has been a dancer and movement artist for over 25 years, taking a multi-disciplinary approach that encompasses many dance forms from classical Indian to contemporary and working in a variety of settings and sectors. He has lived with chronic pain since 2002 following a stint with a London dance company.

Throughout his training the message from his professional leaders and teachers was to enjoy the pain. He was encouraged to believe that experiencing pain was part and parcel of succeeding within the dance world. When Kali was asked by Balbir to become an artist on the Unmasking Pain project, he was intrigued by this potentially different approach to living with pain. As the preparation work progressed, Kali had his own revelatory moments and recognised that until now he had not wanted to know about the pain. He had been blocking it out as he had learnt during his dance training, but he now realised that he actually needed to acknowledge the pain and that it was not going to go away. As the project progressed the workshops became increasingly co-produced with artists and participants from the pain community, and the boundary between artist and participant blurred to 'us' with a sense of shared experience even if it was very different for each individual. For some, it may be physical but for others, as was the case with the group of refugees and asylum seekers in Huddersfield that Kali worked with, it was trauma-induced, living with the trauma of forced displacement. At the heart of the workshops was the use of a range of creative approaches and arts-based resources with an emphasis on 'good listening', so that everyone could tell their stories and know that that wouldn't be shut down, which can be a real issue with clinicians who are working within in challenging time constraints or simply do not understand chronic pain and how to support those living with it.

Kali's passion is dance and through Unmasking Pain, he learnt how to better articulate his own pain and how he is feeling through his artform and with words, on good and bad days. The project has given him time to open up and explore his feelings. Kali asserts that this is not something that we are often given time to do in day to day life. He started a daily conversation with his back as he increasingly accepted the pain and now gives his pain more attention and care. He has stopped bashing up his body during training, something he had done for many years and now takes time, pacing himself and refusing to rush. By arriving earlier, he allows himself time to talk to his back, "as a friend and make a deal with it".

He has now accepted his back pain as part of his identity and understands that this is part of a lifelong journey, as the pain has not gone in over 20 years. Balbir has asked Kali to choreograph a work in response to his pain and journey of acceptance to date. Whilst still a work in progress, he has created sections using a variety of props. Golden picture frames are

positioned and moved across his body to inform the audience member where his pain is and how it travels through his body. Balls of different colours, shapes and textures represent how the pain actually takes place and changes in his body.

Next, he wants the piece to convey the personal development he has experienced as part of the Unmasking Pain creative process, to encourage others living with pain to embrace a creative approach and pain management and arts communities to offer safe spaces where everyone can speak, be heard, be brave and let go of fearfulness.

Kali has also noticed that for the past two decades he had been hiding behind the beautiful make up and costumes used in Indian dance all the years and the pain was a hidden experience. He says that through this journey he has opened up and unmasked.

### D. Film Production and photography team

Visual media contributed importantly to the record of the project experiment. These contributions and materials are available and include the discoveries, understandings, interpretations and what occurred so as to illuminate and guide other such projects and experiments.

*"By visually depicting the process of participants gradually immersing themselves into art, I was able to understand the emotional journey they experience daily. That spectrum of emotions was unveiled as they worked through their pain and expressed their feelings with creative outlets.*

*Through the use of image and film, we were able to capture the transformative power of arts and creative expression, showing how it helped each participant to find a new sense of purpose and creative identity beyond their pain." - Elia Tomé*

Elia Tomé, creative producer who has chronic pain, shared his observations of the process within the project from his engagement in recording and compiling the project films.



# 7. Evaluation - Themes of Change

Five key emerging themes summarised below have been recurring in the evaluation process and seemed important to the people within the project both those with pain and those managing the project.

## A. Change in sense-making with “the pain experience”

This was a thinking shift from abstract thoughts to more concrete, tangible, understandable expressions about self, pain and engagement with the body, mind and the world/others. The project gave permission to explore within self, telling others and working with its medium, its arts and those artists with pain and other people. It enabled pain livers to express their personal experiences and stories of bodily senses, emotions, thoughts and journeys with or without words. So, a greater sense of acceptance of their pain and within them and that enabled the person’s unmasking of pain and revealing themselves. The labyrinth metaphor artistic dance activity used by Kali Lead Dance Artist is an example of this journey making and discovering the “current self” and the thinking of the journey.

## B. Change in emotionality

The emotions expressed or observed shifted from:

- Anger, frustration, shame, fear, worry; elements of these were defusing, lessening, reducing
- Lack of “joy”, pleasure, excitement, wonder

To:

- Pleasure, enjoyment, wonder, sense of relaxation, calmness; expressed and observed.
- Willingness to engage, curiosity

The mediums from clay to dance, puppetry and drumming facilitated this change for many participants. The colours, sounds and contexts likewise facilitated this change.



Figure 10: The shift in emotional state with Unmasking Pain

## C. Change in ability and confidence to communicate

Participants became more at ease with difficult emotions with greater awareness of mind. The dance activities of untying of the knots and the labyrinth, for example all offered insight into the emotional and physical impact of pain. The use of a range of other activities, such as puppetry, mask making, drawing allowed a way to communicate with the self and with others in a non-judgemental way. It allowed a real change in use of vocabulary, verbal and non-verbal through these different mediums. This seemed to enable the ability to observe oneself from outside and to disentangle the person from the “pain”. This included pain-livers, the artists and the project team itself.

*“The pain is always there, but I feel more confident about carrying on without it” - Participant*

## D. Change in sense of self and capability

Participants engaged in new relationships; people, places, creative arts, music, movement, writing. This revealed a beneficial change in their perception of self and capability.

*“Don’t see me for my condition, see me for me” - Participant*

Specific arts engagement seemed valued, e.g The Mask Making activity showed such aspects in change. The creativity fostered in one artistic activity seamlessly transferred to others, showcasing the depth of impact.

*“I have found the creativity of making flower arrangements more important than taking painkillers” - Participant*

So capacity changed in observations of participants and in the significant increase in self-efficacy. This seemed due to the combination of shared experience of dance artists with pain, puppetry, other art activities and other participants.

These observations reflected a notable increase in participants' self-efficacy. This positive change in capacity was attributed to the combined influence of shared experiences with dance artists who themselves had experiences with pain, as well as engaging in multiple art activities alongside fellow participants. The collective nature of these experiences contributed to the growth in participants' sense of capability and self-efficacy.

*“Seeing the artists dancing with pain. I’m thinking, well if they can, why can’t I?” - Participant*

## E. Change through creative arts multifaceted mediums

The project provided supportive, kind, safe, and flexible assistance, coupled with exposure to a diverse array of stimulating sensory experiences within a secure environment. In this framework, participants were able to develop their confidence and allow change to happen.

The exposure to Indian music, its range of instruments and rhythms, mythical stories of their gods and traditions offered a new stimulant to the participants mind. This nurtured a new sense of curiosity unburdened by preconceptions about the arts and intercultural experiences that might typically hinder engagement. Crucial was the non-critical support from those within the project, artists and support workers facilitating engagement with the creative process. The participants with pain moved from passive recipients to actively engaging both physically and mindfully in activities like knitting, music playing etc. Notably, one participant with dissociative disorder experienced focused attention on artistic activities, resulting in the absence of dissociative experiences within the workshops, marked by an array of new sensory, visual, and auditory encounters.

The activities were also a way of turning down or muting the volume of the pain by turning up the volume of creative engagement, social connections with others and collaboration.



# 8. Summary and Learning

## A. Project Summary

Participants in the project experienced a range of changes in their health and well-being from their participation in a rich artistic sensory experience supported by artists. They became more resilient and more confident to step outside the self-isolation of pain and participate in artistic creativity and engage in more practice in behavioural activities to enable their confident control of life despite the pain. They were more willing and receptive to consider and engage in their self-management of pain.

The changes observed and measured show how negative perception of pain can change and health and well-being can be positively improved. The world of arts and creative skills seem promising areas to explore further as the project shows the potential to change the pattern of chronic pain suffering. Artists with pain and participants with pain shared a unique insight into how creative arts can access their inner experience and offer possibilities to change, see change in others and muster their own resources to bring personal benefits to health. The project captured these personal health and hopeful changes with a range of mediums bringing visual and written evidence of its impact.

The Acceptance Commitment Model and the numerous quantitative and qualitative studies helped understand the changes in its widest sense and the reality that there is a need to shift perspectives to wider views. This indicates the need to review our approaches as both

neuroscience advances and an 'ecology of wholeness', people-centred model of health and pain (i.e. SOCIO-Psycho-bio model of persistent pain). The Dalgren and Whitehead model of health function shares the importance of the relationship between health and the multi-dimensional context of the individual and the changes occurred in many of these areas in the model with a non-BIO approach reflected in the light and dark green areas in Figure 3.

Pain is unpleasant and brings suffering and so is avoided as much as possible by all human beings. The project tackled diverse ways to explore pain with a non-judgemental and curious approach to engage those in pain with a rich mixture of creative arts. A richer understanding of the person to themselves and others and their relationship with their pain evolved through involving them in the process of listening and engaging. Beneficial change occurred as the artists and those with pain were engaged in creative activities in numerous indoor and outdoor settings and on an equal footing.

So the painful journey took a different direction, and the people emerged with a changed perspective. The pain became less invisible, they could see and understand it much better. They discovered themselves through stories and creativity with others. Their health improved through a journey of "explorative joy" with their own selves, their creativity and awakening through supported, compassionate creative arts engagement.



## B. Summary of reflections for the future approaches

Potential key themes to explore within an artistic, science with researcher approach

- 1. Expand the numbers of participation so to gain greater understanding on ways to engage with people with pain and the more specific benefits to health and healing to discover**
  - a. Role of the range of creative arts processes, from music activities to facial mask creation etc. to enable significant health function change
  - b. Sustain on-going self-creative engagement
  - c. Change in self-perception and relationship with pain so becoming a positive participator in your own life journey, self and others.
  - d. Blocks to above changes and why
- 2. Economic value of sustainable engagement with 28% of U.K population with pain with creative arts to confidently self-manage pain**
- 3. Valued ways of working to implement practically**
  - a. Style of open creative process by the artists and relationships with people with pain
  - b. Change in connectedness with others by those with pain
  - c. Safe spaces for creative engagement
- 4. Understanding of practical needs of those with pain in using these approaches**
- 5. Explore further the positive role of artistic approaches in diverse cultural groups to facilitate beneficial health and healing changes and connectedness with others.**

## C. Conclusion

Unmasking Pain possibly gave the first real-life opportunity of exploration and observation of the impact of creative arts on individuals' self-changing experience of their pain. It enabled them to participate in a waterfall of creativity and arts in safe, supported, non-medical space to embrace their creative potential and social interconnectedness.

It's worth of beneficial health-related outcomes deserves more exploration and effort given the impact of pain in an ageing and diverse population within the UK. It could prove economically viable and valuable across such a huge population of people disconnected and in significantly poor health.





## 9. Future Development

The Unmasking Pain partnership is committed to long-term development of the project working with lived experience communities and are seeking funding to deepen the research and impact in other geographical areas. New partners are likely to come on board as word of the project spreads and its practice may be applied to other areas of health and wellbeing. Researchers will continue to extract learning and findings from the raw data and experiential interviews to publish papers and further disseminate learning and reflections.

- Paul Chazot is currently in the process of preparing his paper for publication, presenting the findings from the quantitative study conducted throughout the project.
- LWWP's Ten Footsteps are being considered for creative interpretation and developed as Ten Creative Footsteps.
- Leeds Beckett University and BSDC will continue to explore how the project and its applications can be embedded in the curriculum of the next generation of clinicians currently studying at the University.
- Balbir Singh has been made an Honorary Fellow of Durham University's Wolfson Research Institute, bringing potential new opportunities for collaboration and sharing insight from the project.
- BSDC and Rosie Cruickshank are collaborating with [Breath Arts Research](#) to create a variety of performances at St Thomas' Hospital and deliver diverse evidence-based programmes across a range of art forms, meeting specific clinical and wellbeing needs on chronic pain.
- Balbir Singh and Mark Johnson will be presenting their work in a forthcoming two-day seminar on creative arts in research at the [Centre for Person-centred Care](#) of the University of Gothenburg in Sweden later in the year. The seminar will bring writers, artists and actors together in presentations, workshops and panel discussions. Associate Professor Birgit Heckemann, Specialist Pain Clinic at the Sahlgrenska University Hospital in Gothenburg, and Professor Axel Wolf, director of the Gothenburg Centre for Person-centred Care, will organise and coordinate the event.
- The digital collection will be fully curated and cohesively stored online, as a resource for arts organisations, pain lovers, pain management specialists, academics and others interested in this field of practice.

BSDC will continue to develop this creative practice with artists to bring increased resilience to artists and the sector, as artists deepen their relationship with the artform, better understand their bodies and movement and build confidence to embrace cross sector working, particularly with health.

The Unmasking Pain partnership wants to use the storytelling potential of the project to bring the message of arts and creativity as an effective treatment for self-management of pain into the mainstream. The partnership believes that it is imperative to counter the dominant narrative that exercise is the only non-clinical intervention available.

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Rosie Cruickshank	St Thomas and Guy's NHS Trust	rosie.cruickshank@gstt.nhs.uk

# 10. Appendices

## Appendix A – Partners in More Detail

**Balbir Singh Dance Company (BSDC)** is a prolific collaborator within the arts sector but also across sectors, a nationally leading, intercultural dance company, rooted in its Artistic Director, Balbir Singh's dual training in classical Kathak and western Contemporary Dance. BSDC uses multi-disciplinary approaches to creativity. "We have discovered the richest projects have been the ones where we all go on a journey together with a shared language of understanding, communication and activity. As the arts sector we are here to learn just as much from this project as the health sector and people with ongoing pain. For us the work is about the audience and having connection with them, allowing the work to resonate be it the artform, performing on stage, or used as a vehicle to connect with and allow people to tune into their health and wellbeing internally, collectively and outward-looking through dissemination." - Balbir Singh

**Live Well With Pain (LWWP)** is a cutting-edge organisation, developed by clinicians and pain-livers, for clinicians and those with lived experience to help clinicians support patients towards better self-management of their long term pain. It responds rapidly to immediate pressing frontline self-management needs of both people with pain, families and carers and their clinicians/non-clinicians. The medical model of care for chronic pain is redundant as pain scientists have shown a biopsychosocial approach is more effective to manage pain. Persistent pain cannot be 'fixed or cured' and needs person-centred management to help people live better lives with it. Live Well With Pain supports clinicians, especially general practitioners, to realise the need to change how they work with people with persistent pain and reduce reliance on medication only. Dr Frances Cole is one of the key driving forces behind Live Well With Pain, its Footsteps Festival and a pioneer within the sector. She is a previous Chair of the British Pain Society and set up the first Pain Management Programme Special Interest Group in Bradford in 1996. She is author of several books on pain self-management. Professor Paul Chazot holds a Chair in Pharmacology, and is Director of the Durham University WRIHW Pain Challenge Academy, Fellow of the British Pharmacological Society, and President of Durham Parkinsons UK branch. In collaboration with Dr Cole and Live well With Pain team, he has developed the GOTT and Pain Footsteps Festival, funded by multiple ESRC grants (SPF, IAA and DTP NINE).

**Durham University** Durham Wolfson Research Institute for Health and Wellbeing and Pain Academy is a major interdisciplinary unit within Durham University that fosters research on health and wellbeing. It seeks to

improve the quality of people's lives by contributing to public policy; professional practice and development of new insights, products and tools. The Pain Academy is a development of DWRIHW and is running Skills not Pills: community-based pain self-management – recognising that persistent pain is a huge health challenge. It is the biggest reason people in the UK see their GP. The World Health Organisation (WHO) recognised it as a priority disease in 2019. The National Institute for Health and Care Excellence has also recently accepted that current chronic pain medications have limited use, and in fact carry serious safety concerns and why reducing opioid prescriptions (for non-cancer pain) to zero by 2024 is a priority for Public Health England (PHE). It needs an understanding of the individual experience and person-centred management, to help people live better lives with it. The "Skills not pills" project is supported by their newly launched virtual platform: Footsteps Pain Festival (e-social prescribing) and future App and "Pain Pal" support network, developed and hosted by the Live Well With Pain team and Durham University. Their current programme is funded by ESRC (SPF), ESRC IAA, ARC, and ESRC (DTP NINE).

**Leeds Beckett University** Centre for Pain Research led by Professor Mark I Johnson PhD will support the project through their networks and connections across NE/Y, including with Flippin Pain team at Teesside University. They will engage undergraduates and local clinicians to participate in the Reflect CoLabs and wider project. Leads a vibrant team of investigators working in the Centre for Pain Research. They conduct a wide variety of programmes of research including: Factors influencing pain sensitivity response (e.g. gender, lifespan, ethnocultural, obesity); Factors influencing response to electrophysical interventions (TENS, acupuncture, laser therapy, kinesiology taping); Visual feedback, perceptual embodiment and pain; Epidemiology of injury and pain; Patient experience of pain; and Pain education. Mark's team conduct clinical trials (phase 1-3), laboratory studies on healthy humans using experimental models of pain, and evidence syntheses (e.g. meta-analyses including Cochrane reviews). The Centre for Pain Research at Leeds Beckett showcases their research at public engagement events including the Royal Society Summer Exhibition and Asia Techfest.

**Space2 (project managers)** Based in Leeds, Space2 has 20 years' experience of delivering arts and health projects in some of the most disadvantaged communities in the country. They hold a public health contract working in inner East Leeds to address health inequalities. They led one of the 37 Arts Council England

and National Association for Social Prescribing Thriving Communities projects working with a range of partners. In 2018 they worked with under-represented groups to co-create a touring exhibition to celebrate NHS, now part

## Appendix B - Contributors

**Balbir Singh** - Artistic Director of world-class dance company, Balbir Singh Dance Company that offers a remarkable, ambitious & richly varied portfolio of work created through innovative artistic practice and choreographic methodology. Balbir's approach is always intercultural and draws on diverse influences to create work that can be pure dance, cross-art-form or involve innovative cross-sector partnerships. He creates work that tells stories in inventive ways, foregrounding less heard voices.

**Kali Chandrasegaram** - is a multi-disciplined, experimental dancer and choreographer, working across many genres from Indian classical to contemporary. Kali believes in dance as a personal journey of the soul for self and communal awareness. Originally from Malaysia where diversity is ingrained, integrating differences is in his veins. He has been an artist in the UK Contemporary South Asian dance scene and worked for many of the genre's leading companies for over 22 years, teaching dance workshops in schools and for all ages and abilities. Worked in communities of different ethnic origins, in libraries of little towns, for older people in care homes, dance and disability, dance and dementia and dance for refugees. Kali has lived with persistent pain for over two decades.

**Adam Strickson** - Mask Maker Adam Strickson is a freelance artist, writer and mask-maker and teaching fellow at Leeds University in the School of Performance, with a specialism in teaching intercultural performance. Adam's recent creative practice includes working in communities with refugees and asylum-seekers making short films, puppets and masks with 6 million + His role in the project is to be part of the creative team, joining the CoLab process as a mask maker, teaching mask-making. Adam also wrote about the project as part of his academic work - [link](#).

**Chris Speyer** - Writer/Clay Sculptor Chris Speyer is a visual artist with a background in theatre design, writing and ceramics who now creates small and large-scale sculptural work. In 1997 he was elected a Fellow of the Craft Potters' Association, and in 2000 he became Co-Artistic Director of Monster Theatre Productions, a new children's theatre company in Newcastle upon

of the Thackray Museum of Medicine's Permanent Collection. Space2 also managed a number of cross-sector collaborations with BSDC including a national tour of Synchronised and associated outreach programmes.

Tyne. Chris has written 40 plays and musicals and two published novels. Chris worked with Balbir exploring the use of clay and with pain liver Louise Trewern to bring the project to Devon - [link](#).

**Malcolm Johnson** - a photographer of Live Performances with work included in book Photographing Opera at Opera North in Leeds, tracing the history and working practices of the company. He regularly photographs young opera performers at the National Opera Studio and has also worked with Theatre Companies such as Red Ladder and Slung Low, photographing rehearsals and performances in theatres and various locations. Malcolm has worked with BSDC on various dance projects capturing the rehearsal process as well as final performances for promotional material, social media and archiving - [link](#).

**Villmore James** - was a founder dancer, choreographer and teacher for many years with Phoenix Dance Company, touring extensively in the UK and abroad. He later joined Dundee Rep Dance Company as rehearsal director and then Co-Director. He has worked extensively as a freelance dancer, choreographer and dance consultant. Most recently choreographing with Alan Lyddiard on Performance Ensemble's 1001 Stories, working with people 55+. He has worked with BSDC developing its Celebrating Age strand. Villmore has had two strokes leaving him with chronic pain.

**Devika Rao** - is a passionate and talented Indian Classical Dance performer with a wealth of experience choreographing and dancing across the globe. She has also undertaken many teaching and workshop projects, giving children and adult's access to Indian arts through music and dance - [link](#).

**Mansi Dabral** - is a London based Kathak dancer, honed her craft for 13 years at Kathak Kendra, New Delhi, under eminent gurus. Awarded a National Scholarship, she became India's Cultural Ambassador in 2005, chosen by the ICCR. - [link](#).

**Louise Grassby** - is a freelance visual artist engaging in projects for dance and theatre organisations, including work at festivals, schools, museums and creative organisations on artistic projects. - [link](#).

# 10. Appendices

## Appendix B - Contributors

**Dr Frances Cole** - was a GP and pain rehabilitation specialist. She developed the first UK primary and community care pain rehabilitation programme based on cognitive behavioural therapy (CBT) principles in 1996. She developed a pain health needs assessment tool that won an NHS Modernisation award in 2005 and gained an NHS National Clinical Leaders Award in 2011. Frances is a past chair of the British Pain Society Pain Management Programme Special Interest Group. She is the founder of [Live Well With Pain](#) and instrumental in the development of The Ten Footsteps Programme, a step-by-step online guide to living well despite your persistent pain.

**Professor Paul Chazot FBPhS** - has developed multiple new clinical development programmes over the last 20 years, for chronic pain, for Alzheimer's Disease, Covid Brain fog and Post concussion syndrome.

Major Research Roles:

- Fellow of the British Pharmacological Society
- Founder and Director, Wolfson Research Institute for Health and Wellbeing Pain Challenge Academy
- Fellow, Durham Institute of Research, Development, and Invention
- Northern Health Science Alliance (NHSA) Repurposing Medicines Network Representative
- Biosciences research partner, spin-out company Nevrargenics ([www.nevrargenics.com](http://www.nevrargenics.com))
- TSC Committee member, REGAIN and iREHAB Long-Covid trials
- Past President, European Histamine Research Society (EHRS)
- Vice Chair, EU COST Action BM0806
- Chair, International Union of Pharmacological Societies Subcommittee
- Past President, Parkinson's UK Durham Branch
- Past Committee member, British Neuroscience Association

## Appendix C - Public Events: Performances/Lectures/Exhibitions/Walks

**Event:** Creative walk and picnic, as part of Sangam Festival  
**Date:** 12th August 2022  
**Venue:** Beaumont Park, Beaumont Park Road, Huddersfield HD4 7AY

**Event:** Performance and presentation to public and Durham participants  
**Date:** 22nd June 2022  
**Venue:** Dilston Physic Garden, Dilston, Corbridge NE45 5QZ

**Professor Mark Johnson** - is Professor of Pain and Analgesia and Director of the Centre for Pain Research in the School of Health. Mark has been investigating the science of pain and its management since the mid 1980's. Mark has published over 300 research articles and book chapters, and is considered a world expert on transcutaneous electrical nerve stimulation. Mark leads a vibrant team of investigators working in the Centre for Pain Research, conducting a wide variety of programmes of research.

**Rosie Cruickshank** - is a physiotherapist at St Thomas and Guys NHS, with a specialism in pain management and extensive experience of working with patients and researchers. She assisted Dr Frances Cole with the evaluation of the Unmasking Pain project.

**Emma Tregidden and Dawn Fuller** - Emma and Dawn were founders and Joint CEOs of Space2, based in Gipton, inner East Leeds. Space2 (founded in 2003) is an award winning arts and social change organisation, pioneering participatory practice, rooted in co-produced arts opportunities with local communities, to create authentic, relevant and representative work, maintaining high quality production values. Space2 works with diverse communities, particularly, those facing multiple socio-economic disadvantages and is based in one of the most deprived SOAs in the country, Gipton Leeds. Space2 uses arts and creativity to engage local people and/or those facing social isolation; mental health issues; health inequalities and lack of opportunity. Alongside this core mission activity, Dawn and Emma deliver consultancy to support like-minded arts and have worked with Balbir Singh Dance Company for over a decade.

**Event:** Contributor to Sensory Storytelling Seminar  
**Date:** 15th September 2022  
**Venue:** live and online at/from University of Leeds

**Event:** Creative story walk  
**Date:** October 28th 2022  
**Venue:** Durham University Botanic Gardens, South Rd, Durham DH1 3DF

**Event:** A pop-up exhibition /demonstration to local GPs  
**Date:** Thursday 15th December  
**Venue:** Chapel FM, Leeds

**Event:** A lecture/presentation for public, medics and academics  
**Date:** Thu, 26 January 2023, 14:30 – 16:00  
**Venue:** Calverley Building, City Campus, Portland Way Leeds Beckett University Leeds LS1 3HE

**Event:** An evolving installation in Huddersfield  
**Date:** various in December and February  
**Venue:** in various Temporary Contemporary pop-up units, The Piazza Centre, 23 Princess St, Huddersfield HD1 2RS

**Event:** Contributor to 'Our Wonderful Brain' with Alzheimer's Research UK  
**Date:** 11th February 2023  
**Venue:** Life Science Centre, Newcastle, NE1 4AD

**Event:** A performance/exhibition/presentation in a doctor's surgery in Leeds  
**Date:** Wednesday 22nd February Leeds (exhibition from 22.02)  
**Venue:** Park Edge Practice, Asket Drive, Leeds, LS14 1HX

**Event:** A lecture/presentation on Unmasking Pain  
**Date:** Wednesday 1st March  
**Venue:** Durham University, School of Biological and Biomedical Sciences, DH1 3DF

**Event:** Contributor to Preston Health Mela  
**Date:** 18th March 2023  
**Venue:** UCLan's Foster Building, Fylde Road, PR1 2HE

**Event:** Unmasking Pain exhibition material to students  
**Date:** 23rd March 2023  
**Venue:** Leeds Beckett University

**Event:** Mini Exhibition available for multiple doctor surgeries  
**Date:** From Wednesday 29th March - ongoing  
**Venue:** in various practices in Leeds addresses below:

- Park Edge Practice, Asket Drive, Leeds, LS14 1HX
- Windmill health Centre, 3a Whinmoor Way, Leeds LS14 5BD
- Oakwood Lane Medical Practice - 2 Amberton Terrace, Leeds, LS8 3BZ
- Foundry Lane Surgery, 95 Moresdale Ln, Seacroft, Leeds LS14 6GG

# 11. Links/References

## Background

- [N.I.C.E - Clinical Knowledge Summary - Chronic Pain - Reference](#)
- [N.I.C.E - Clinical Knowledge Summary - Chronic Pain - Background Information - How Common is it?](#)
- [N.I.C.E - Clinical Knowledge Summary - Chronic Pain - Management - Scenario: Management](#)
- [UKRI - The Dahlgren \(Whitehead rainbow\)](#)

## Activity Overview

- [Pioneering work from Paul Chazot and the WRIHW Pain Challenge Academy wins the Fuse Award for Innovative and Creative Communications](#)

## Dissemination

- [P90 Fuse award winning unmasking pain project: preliminary findings](#)
- [P89 Fuse award winning unmasking pain project: Insights from people with pain, artists, and pain specialists](#)
- [Living well with pain](#)
- [Unmasking Pain - The Documentary \(with subs\)](#)
- [Unmasking Pain - Trailer](#)
- [Unmasking Pain - Gallery](#)
- [Unmasking Pain - Musical Treatment](#)
- [Unmasking Pain Interviews Podcast - Durham](#)
- [Unmasking Pain Interviews Podcast - Huddersfield](#)
- [Unmasking Pain Interviews Podcast - Artist Kali Chandrasegaram](#)
- [UK Yorkshire Bylines article on LWWP event](#)

## Evaluation

- [Pain through the perspective of art and creativity: insights from the Unmasking Pain project](#)

## Future Development

- [Breathe Arts Health Research](#)
- [Centre for Person-centred Care](#)

## Appendices

- [Adam Strickson](#)
- [Chris Speyer](#)
- [Malcolm Johnson](#)
- [Devika Rao](#)
- [Mansi Dabral](#)
- [Louise Grassby](#)
- [Live Well With Pain](#)

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# UNMASKING PAIN

INSPIRING HOPE  
CREATING WELLBEING

[balbirsinghdance.co.uk](http://balbirsinghdance.co.uk)

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Balbir Singh Dance Company is an Arts Council England National Portfolio Organisation

**BalbirSingh**  
dancecompany



Supported using public funding by  
**ARTS COUNCIL  
ENGLAND**



**fuse**

The Centre for Translational  
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**LiveWell**  
with pain