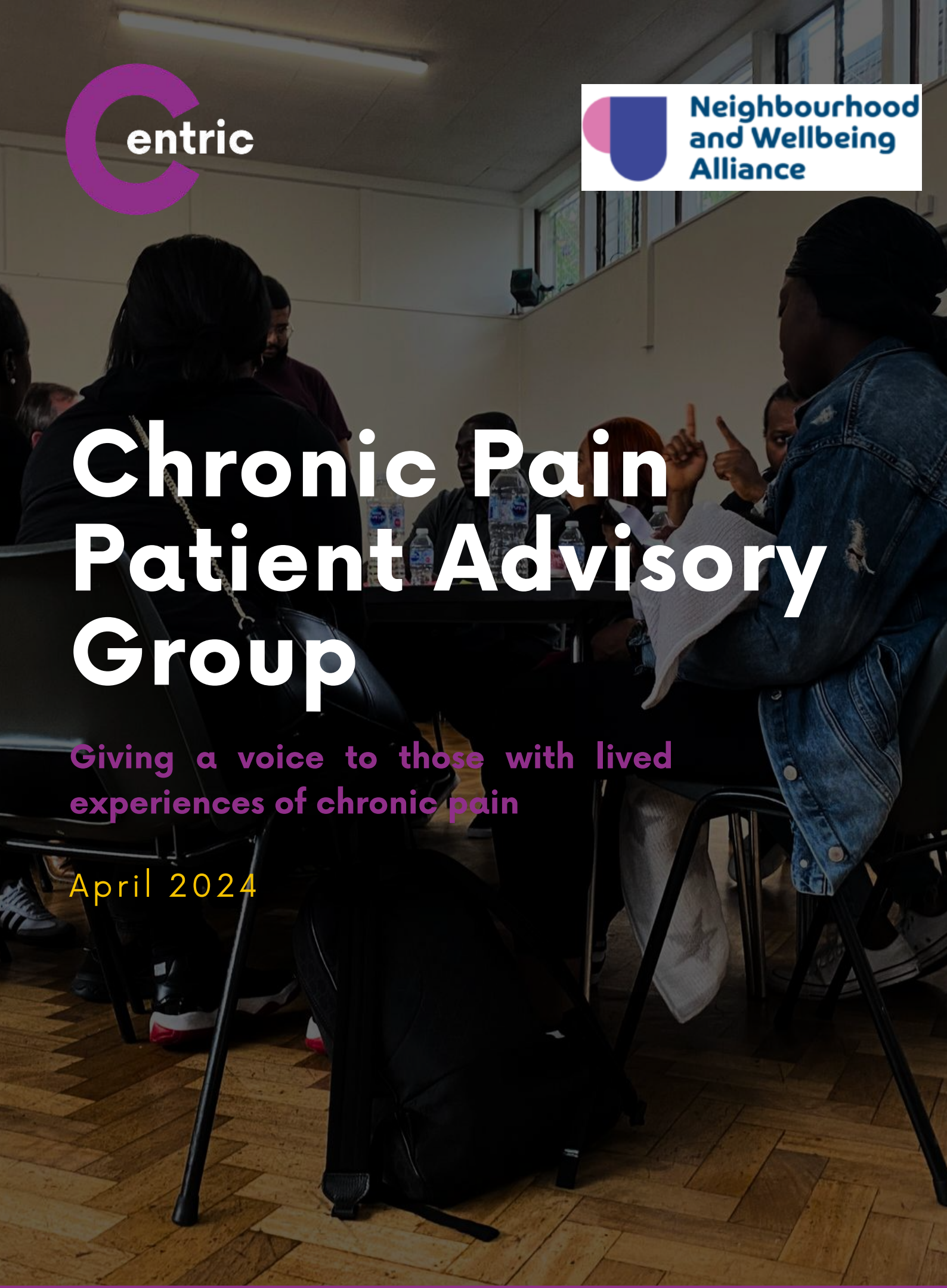


Centric

Neighbourhood and Wellbeing Alliance

Chronic Pain Patient Advisory Group

Giving a voice to those with lived experiences of chronic pain

April 2024

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Executive Summary

Between one-third and one-half of the UK population, which is nearly 28 million adults, are affected by chronic pain, according to the most reliable published studies. This figure is likely to increase further in line with an ageing population. [1]

Centric collaborated with the Neighbourhood and Wellbeing Alliance to enhance the relationship between Lambeth residents with chronic pain and the Chronic Pain Workstream. Dr Dianne Aitken, who leads the community of healthcare professionals, has been seeking input from service users and providers to develop innovative approaches to improve services. By adopting a Service User approach, the Patient Advisory Group set out to better understand the perspectives, concerns and needs of those living with chronic pain issues.

During our project, we utilised a qualitative research methodology by embedding focus groups alongside a case study approach.

Chronic pain is often an invisible condition, which in turn presents patients with a variety of additional challenges, such as seeking medical assistance. The Patient Advisory Group (PAG) has explored negative encounters with healthcare services, the lack of empathy and support, and the brief length of appointments with a lack of follow-up, which can often leave patients feeling disappointed and dissatisfied with their experience.

The introduction of digital self-management tools like the Leva and MyCharts apps has improved patients' communication and access to healthcare. Chronic pain negatively affects mental health and well-being, influencing patients' responses and engagement, especially when they are experiencing pain.

The Patient Advisory Group sessions also provided a key opportunity to share thoughts and experiences with a view to working on creating a resource pack which could support and benefit others who experience chronic pain.

It is clear from our findings that significant changes are needed to improve the quality of life of chronic pain patients in Lambeth. Our recommendations include the involvement of healthcare professionals specialising in pain management for a continuation of the PAG, prioritising patient-centred care initiatives, including cultural competence training for healthcare providers, co-design accessible resource packs for chronic pain patients and investing in digital literacy programs for community members to reduce reliance on digital tools. Offer comprehensive resources on pain medications, improve engagement through social media outreach, and establish online support groups moderated by professionals. Additionally, it guarantees free access to exercise programs suitable for chronic pain sufferers, both in-person and online, with flexible eligibility criteria to cater to diverse preferences.

We hope to enhance the current awareness of chronic pain issues in order to empower community collaboration with aligned organisations whose collective goals and efforts can further improve equality, diversity and inclusion essential to an improved quality of life experience for all.

Introduction

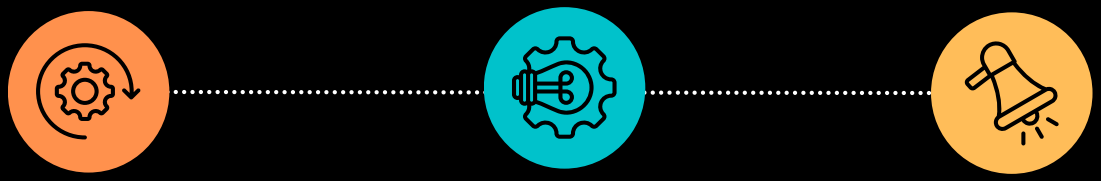
Centric is collaborating with the Neighbourhood and Wellbeing Alliance to improve relationships between Lambeth residents with chronic pain and the Chronic Pain workstream.

The Chronic Pain Workstream is a community of healthcare professionals in Lambeth who meet to discuss chronic pain issues. They share their work, ideas, and research to enhance services for those experiencing problems. Dr. Dianne Aitken leads the sessions and seeks input from service users and primary and secondary care providers. The group aims to create opportunities to understand service users' perspectives, interests, and concerns. They collaborate to develop innovative approaches and provide feedback on the progress and advancements of the workstream.

By adopting a Service User approach, we offer residents a platform to share their experiences and contribute to service decisions, ensuring that their voices are heard and their perspectives valued. Creating a safe space with others provides support as it becomes a place to gain knowledge to improve current services.

This project emerged from research into broader **Medical Scepticism** [2] and our **Chronic Pain** [3] project, in which patients spoke of needing greater insight from health care services and sentiment of feeling heard and listened to.

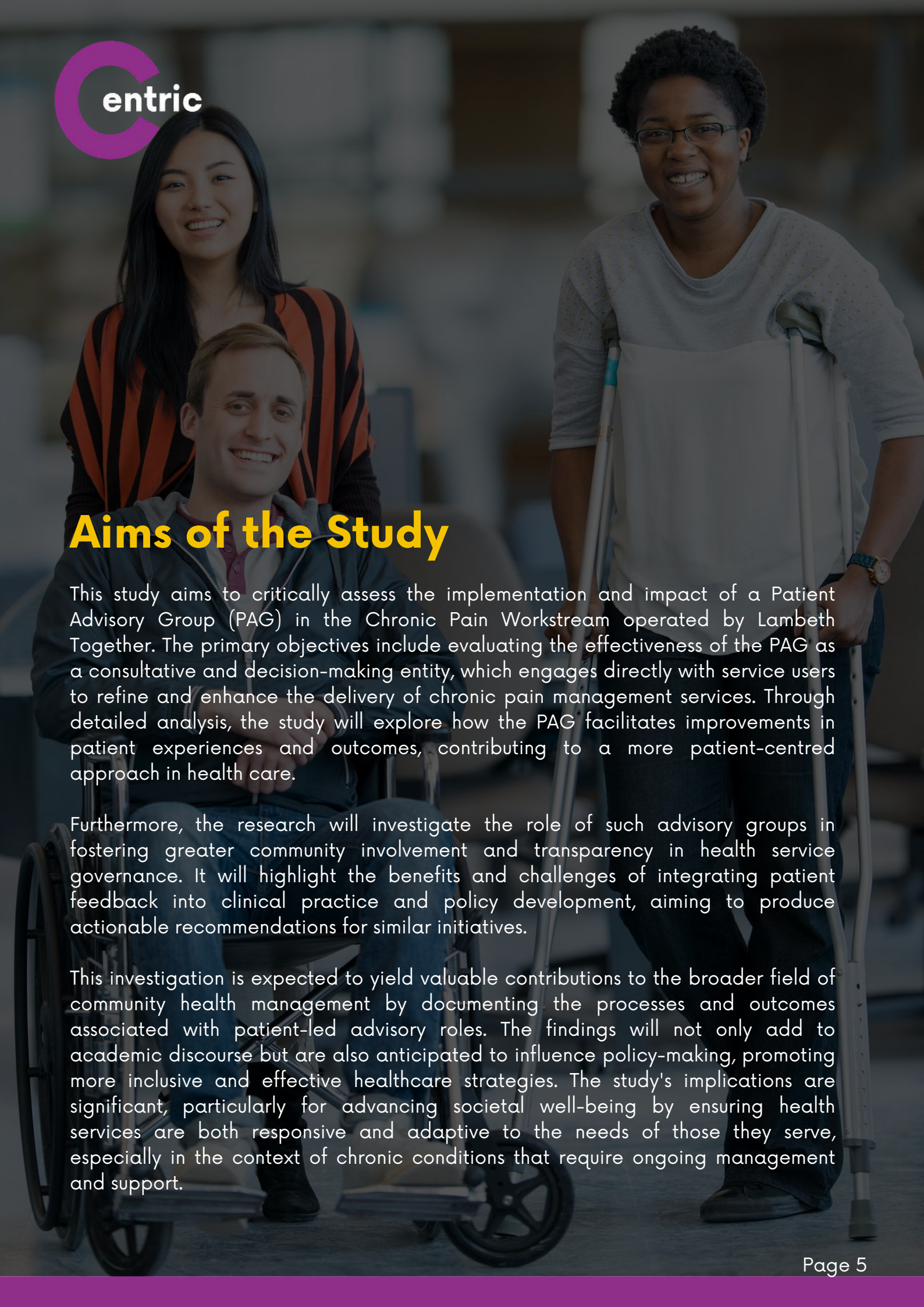
We assembled a group of 8 residents living with chronic pain to share their experiences, insights into existing services, and ideas for potential solutions. Their input was integrated into the chronic pain workstream sessions, ensuring their voices were heard and their perspectives considered.



Medical Scepticism
2021

Chronic Pain Project
February 2022 - May 2022

Patient Advisory Group
November 2022 - April 2024



Aims of the Study

This study aims to critically assess the implementation and impact of a Patient Advisory Group (PAG) in the Chronic Pain Workstream operated by Lambeth Together. The primary objectives include evaluating the effectiveness of the PAG as a consultative and decision-making entity, which engages directly with service users to refine and enhance the delivery of chronic pain management services. Through detailed analysis, the study will explore how the PAG facilitates improvements in patient experiences and outcomes, contributing to a more patient-centred approach in health care.

Furthermore, the research will investigate the role of such advisory groups in fostering greater community involvement and transparency in health service governance. It will highlight the benefits and challenges of integrating patient feedback into clinical practice and policy development, aiming to produce actionable recommendations for similar initiatives.

This investigation is expected to yield valuable contributions to the broader field of community health management by documenting the processes and outcomes associated with patient-led advisory roles. The findings will not only add to academic discourse but are also anticipated to influence policy-making, promoting more inclusive and effective healthcare strategies. The study's implications are significant, particularly for advancing societal well-being by ensuring health services are both responsive and adaptive to the needs of those they serve, especially in the context of chronic conditions that require ongoing management and support.

Ethical Considerations

The ethical framework of this study was meticulously designed to ensure respect, fairness and care for participants, particularly given the vulnerabilities associated with chronic pain and the diverse backgrounds of the participants. The following points outline the key ethical considerations adhered to throughout the project:

- **Informed Consent:** All participants provided informed consent before participating in the project. This process involved clear communication about the purpose of the study, the nature of participation required, potential risks, and the benefits. Participants were assured of their right to withdraw from the study at any time without any consequences to their care.
- **Confidentiality and Privacy:** Measures were implemented to protect the privacy and confidentiality of participants' information. Data collected during the project was anonymised and securely stored to prevent unauthorised access. Any sharing of information outside the immediate research team was done only with the consent of the participants.
- **Cultural Sensitivity:** Given the focus on a mix of demographics within the group, the project took special care to approach the research topics with cultural sensitivity and awareness. The team was mindful of cultural nuances in communication and health perceptions, which guided the design of recruitment materials and the conduct of the sessions.
- **Equitable Treatment:** Efforts were made to ensure that all participants were treated equitably and respectfully, regardless of their ethnic background or gender. This was particularly important in group discussions and activities, where the facilitators promoted an inclusive environment where each participant felt valued and heard.
- **Handling of Sensitive Topics:** Given the potential for discussions around chronic pain to evoke emotional distress, facilitators were prepared to handle sensitive topics with empathy and professionalism. Participants were provided with support and resources for additional help if they experienced discomfort or emotional distress during or after the sessions.
- **Beneficence and Nonmaleficence:** The research team was committed to maximising the potential benefits of the project while minimising harm to the participants. This involved continuous monitoring of the participants' well-being throughout the project and adjusting methodologies as needed to ensure participant comfort and safety.
- **Representation and Voice:** The project was designed to empower participants by giving them a voice in a research area that directly affects their lives. This was particularly significant given the historical underrepresentation of minority groups in health research. The study's outcomes aimed to reflect the genuine experiences and needs of the participants, contributing to more effective and culturally appropriate health service improvements.

By adhering to these ethical considerations, the project aimed to uphold the highest standards of research integrity and respect for participants, ensuring that the study's findings could be utilised to effect positive change in chronic pain management practices within diverse communities.

Research Sample

The Patient Advisory Group (PAG) sample was comprised of participants who were actively dealing with chronic pain, defined as experiencing ongoing pain for six months or more. The participants were initially referred by their General Practitioners (GPs) and community organisations during a previous project and subsequently responded to an invitation for self-referral to this specific project, which focused on feeding back to the Chronic Pain Workstream.

The recruitment strategy intentionally targeted mixed demographics, including Black, Asian and ethnic minority groups within the Lambeth community, to ensure the study addressed the unique experiences and needs of these populations in managing chronic pain.

The project started with eight participants. Although three participants dropped out due to various challenges associated with their conditions, they were replaced to maintain the group size, thus ending the project also with eight participants. This approach ensured continuity and consistency in the feedback and interactions within the PAG.

Efforts were made to balance the gender representation within the group, and the final composition included members from Black African, White British, Black African, Caribbean, Asian and Black European backgrounds. This diverse grouping was instrumental in enriching the discussions and insights generated by the PAG, providing a broad spectrum of perspectives on the experiences of chronic pain management in a community setting. The diversity within the group not only facilitated a richer dialogue but also aimed to reflect the wider demographic characteristics of Lambeth's diverse community.



The Project Team



Elaine Brown
Senior Community Researcher



Raquel Caires Januario
Project Manager



Muhammed Rauf
Project Director

Our Methodology

In Lambeth, pain is the second-most-common long-term condition amongst residents, affecting 13% of the population. [4]

Centric partnered with Neighbourhood and Wellbeing Delivery Alliance at Lambeth Together to create a Patient Advisory Group to engage Lambeth residents who experience chronic pain to better include their voices in decisions that Neighbourhood and Wellbeing Delivery Alliance make for those with such conditions.

Data Collection Methods

Focus Group (Online)

The PAG project conducted two introductory and six quarterly focus group sessions to provide effectively spaced opportunities for connecting participants during the project timeline. Due to the sensitive nature of the project aims, notes were taken only after each session.

Case Studies

We embedded two case studies from the group of eight. Each case study explored the participants' experiences, current needs, and areas for improvement in their overall experience. This qualitative approach allowed us to gather more in-depth insights into the chronic pain experience within an established and empathetic safe setting.

Data Analysis Techniques

Thematic Analysis was used to analyse our Qualitative Research Methodology data, which is embedding by a focus group and case study approach. Focus groups are a form of group interview that capitalises on the communication between research participants in order to generate data. [5] A case study is expected to capture the complexity of a single case, which should be a functioning unit, be investigated in its natural context with a multitude of methods, and be contemporary. [6] Thematic Analysis (TA) is an accessible, flexible, and increasingly popular method of qualitative data analysis. Learning to do it provides the qualitative researcher with a foundation in the basic skills needed to engage with other approaches to qualitative data analysis. In this chapter, we first outline the basics of what TA is and explain why it is so useful. [7]

Justification of Methodological Choices

The methodological choices of utilising online focus groups, conducting case studies, and employing qualitative analysis techniques were deliberate and informed by the overarching goal of inclusivity, depth, and sensitivity in engaging Lambeth residents experiencing chronic pain. These approaches facilitated the collection of rich, nuanced data and empowered participants to actively contribute to the decision-making processes of the Neighbourhood and Wellbeing Delivery Alliance at Lambeth Together.

Timeline

From Vision to Success

Neighbourhood and Wellbeing Alliance

Recruitment
November 2022

Reached out to networks such as a chronic pain research project and our Lambeth contacts. We created a registration form to ensure we keep to the criteria.

1

Intro Sessions
December 2022

Facilitated introduction session to allow group to get to know each other and elect a Chair.

2

6 Quarterly Sessions
January 2023 - April 2024

Facilitated sessions to keep the conversation going on chronic pain, look into primary and secondary care services.

3

Feedback into the Workstream
January 2023 - April 2024

Quarterly meetings between our PAG sessions with a member from the PAG, we presented feedback.

4

Mentoring
January 2023 - April 2024

Mentoring was provided throughout the project.This included one to one session with the Chair to support them in their role leading the group.

5

WhatsApp Communication
December 2022 - April 2024

Created a WhatsApp group to ensure we kept the group engaged between meetings, reminding them of expectations and sharing information relevant to health topics .

6

Presentation at Study Day
September 2023

The PM and Chair presented the project overview at the Primary Care Pain Study Day at King's College Hospital.

7

Case Study
March 2024

2 case studies were conducted with PAG members exploring their experience and learnings in the group.

8

Anyosis and Reporting
November 2022 - April 2024

Throughout the project, analysis was conducted with the conjunction of report writing

9

Limitations

This section outlines the key limitations encountered in this study involving the Patient Advisory Group (PAG) for chronic pain management. Recognising these constraints is crucial for understanding the scope of the findings and their implications. The limitations range from participant engagement issues and representativeness of the advisory group to technological barriers and methodological challenges. Each of these factors could potentially influence the outcomes and effectiveness of the recommendations provided, thus impacting the overall validity and applicability of the study's conclusions.

- **Participant Engagement and Retention:** Consistent participation from all members of the PAG might be challenging, given the personal health burdens and varying levels of commitment. This could affect the reliability and continuity of feedback and insights provided.

- **Representativeness of PAG:** While efforts are made to ensure that the PAG is representative, the group might still not capture the full diversity of experiences and needs of all chronic pain sufferers in Lambeth. This limitation could affect the generalisability of the findings and recommendations.

- **Impact of Negative Past Experiences:** The previously negative experiences of PAG members with healthcare professionals, as highlighted in the insights, might bias their feedback and interactions, potentially skewing the perspectives shared towards more negative aspects and overshadowing positive developments.

- **Technological Barriers:** Members of the PAG may have difficulties using digital tools like the Leva app and the MyCharts app. This technological divide could limit the accessibility of certain proposed interventions and feedback mechanisms, particularly for older or less tech-savvy participants.

- **Time Constraints and Project Scope:** The project is constrained by a specific timeframe of 12 months, which was then extended to 17 months. This may not be sufficient to observe the long-term effects of interventions or changes in healthcare service delivery. This could limit the ability to measure the true impact of the PAG's feedback on chronic pain management practices.

- **Resource Limitations:** Limited resources made it challenging to arrange in-person meetings and provide extra support where necessary, especially given the rising costs, which impacted each member of the team.

Challenges & Successes

Our Challenges

- Some members dropped out early in the project due to their chronic pain issues, which they found too difficult to manage while committing to the planned participation. Additionally, these members often struggled with other issues, including mental health.

- Obtaining dates in advance for the Chronic Pain Workstream sessions, due to short notice, meant PAG's members were not always available.

- Chronic pain, alongside unexpected personal matters, caused the 1st Chair to leave the post.

- The presentations do not offer sufficient discussion or question time regarding issues related to the topic or experience.

Our Successes

- A group of community members dedicated to long-term self-improvement came together to discuss their struggles in safe and supportive sessions that aided their mental health and the process of pain.

- WhatsApp group support has created its own support network for each other, that is still ongoing

- PAG input into the Chronic Pain workstream has lead to change in Lambeth health services example: a new Chronic Pain register for all Lambeth GPs

Unintended Outcomes

Lambeth Primary Care Pain Study Day Event - PAG presentation
We were invited to present the findings from the Patient Advisory Group (PAG) at the Lambeth Primary Care Pain Study Day Event held at King's College Hospital. During the event, our Centric Project Manager, Raquel, and PAG Chair, Keith, presented the findings to medical professionals such as GPs, consultants, physiotherapists, and pharmacists.

The audience was pleased with our powerful insights and input, and many had questions and wanted to understand more. Throughout the event, as more presentations took place, the PAG's inputs kept relating back to what was found within the group. This has gained recognition, and till this day, it is talked about in chronic pain workstream sessions. [8]

"The number of doctors and pharmacists who were in the packed room was phenomenal. Some really interesting research, too, on the predominance of chronic pain sufferers occupying a large portion of surgery facilities. It was an honour to be part of this event." - **Keith (PAG Chair)**



Lambeth Primary Care Pain Study Day Event

PAG Attended the Cost of Living and Multiple Long-Term Conditions Introduction Event
We also extended our invitations to the PAG (Patient Advisory Group) to attend upcoming Centric events that may be relevant to them. This included our recent event introducing our COL & MLTCs projects, which was open to the community and stakeholders. It was designed to create a bridge between both parties and involve them in the project outputs, such as co-design sessions to develop cost-of-living incentives and other research initiatives.

Some members of the PAG who attended the event got involved in the conversation and engaged with others facing similar situations. They had the opportunity to engage with both the community and stakeholders. Lambeth and Southwark councils, Elifinty, and Hyde Housing Association were present at the event, signposting and providing advice.



COL and MLTC Introduction Event

Unintended Outcomes

/continued.

Impact on Lambeth Together Initiative

The Patient Advice Group played a significant role in influencing one of Lambeth Together's initiatives, resulting in the establishment of a Chronic Pain Register in Lambeth. This register is now operational across all Lambeth GP surgeries and stands as the sole chronic pain register currently in action throughout the UK.





NIHR Knowledge Exchange Event



Chronic Pain Patient Advisory Group

PAG Sessions

Introduction to PAG Sessions

As part of the Patient Advisory Group of residents in Lambeth with chronic pain, we conducted focus group-style sessions to explore chronic pain and gather feedback from residents. These sessions were held online via Zoom every three months, with a total of eight sessions scheduled.

Our community research team, comprised of Lambeth residents, took charge of and guided each session, fostering discussions about the immense effects of pain on their daily lives. They also shared insights and feedback regarding healthcare services, such as the Leva app. We also created a WhatsApp group to aid communication between sessions and provide additional support.

Following each session, our team analysed the data collected and identified key themes to guide the upcoming sessions. We also attended Chronic Pain workstream sessions to help shape services and ensure that the voices of Lambeth residents with chronic pain were heard.





Chronic Pain Patient Advisory Group

PAG Sessions Insights



Insight 1

Engagement with Healthcare Professionals

Engagement with Healthcare Professionals

The Patient Advisory Group (PAG) have voiced numerous instances of negative interactions during their interactions with healthcare services. They express a sense of neglect and lack of empathy, reporting that their concerns are frequently overlooked or misunderstood, particularly patients dealing with invisible conditions that cause chronic pain. Sadly, many feel dismissed when seeking assistance. The brevity of appointments and the absence of follow-up exacerbates the situation, profoundly affecting their well-being, considering the persistent nature of their chronic pain.

"They didn't listen; there is nothing there for people"

"There is an expectation that you'll be fine!"

Lack of empathy from staff was also recognised in our work with Kings Collage Hospital (KCH), with similar themes highlighted.

Many patients have recounted negative encounters with healthcare services, leaving them feeling disillusioned and unsupported. Consequently, some individuals have developed a reluctance to seek out medical assistance, while others persist in their pursuit to be heard, refusing to relent until they receive the necessary support.

A prevalent concern among these patients revolves around the adequacy of pain management treatment. While pain control medications are readily available, there is a pervasive sentiment that there is insufficient support regarding medication cessation, side effect monitoring and identifying optimal pain management avenues. Patients actively seek alternative pain management strategies, cognisant of the potential long-term repercussions of relying solely on medication. However, they often find themselves at a loss, unsure of where to begin or whom to approach for guidance, but they do appreciate what the NHS provides and understand the restrictions, such as budgets, that impact the quality of care given.





Insight 2

Communication

Communication

Healthcare Communication

The significance of clear communication within healthcare systems, spanning from healthcare professionals to patients and between primary and secondary care, is evidently lacking in current services. The Patient Advisory Group (PAG) encountered challenges in obtaining answers to their queries at the GP level, observing similar struggles faced by GPs in connecting with secondary care. Notably, delays in the transmission of hospital letters from consultants to GPs were observed, with letters often arriving belatedly or not at all. This resulted in prolonged waits, sometimes spanning months, both for patients to receive a copy of the letter and for GPs to be informed.
Furthermore, the PAG highlighted the necessity for patients to maintain their own administrative records to ensure they possess copies of all relevant letters, reflecting the overarching difficulty in communication within the healthcare system.

Leva App Review

The Patient Advisory Group (PAG) was assigned the task of evaluating the Leva app through the getUBetter platform. [9] Designed as a digital self-management tool, the Leva app offers support for common musculoskeletal injuries and conditions such as back pain, neck pain, knee pain and pelvic floor health. It features a library of videos providing valuable information, support and advice on various conditions.

During one of our PAG sessions, guest speakers introduced us to the PAG app. However, encountering challenges, only a few members of the group successfully accessed it, while some couldn't locate it within the getUBetter interface. Even among those who gained entry, locating the specific Leva sessions proved cumbersome. Nonetheless, several PAG members found the app's video content to be beneficial and expressed intentions to continue utilising it in the future.

Concerns were raised concerning the accessibility of the GetUBetter platform, particularly for older individuals who might not be as proficient with technology. The discussion highlighted the existing gap, acknowledging that despite the bulk of technology in modern society, certain demographics—such as the elderly or those with learning disabilities—may face challenges in accessing digital tools due to a lack of familiarity or limited access to smartphones or computers.

Despite the concerns raised, half of the Patient Advisory Group expressed a desire to continue utilising the Leva app. This highlights the potential value perceived by some members, indicating that with improvements in accessibility and usability, the app could still serve as a valuable resource. For instance, it would be beneficial to make guidance on managing pain easier to access and utilise, such as by providing convenient access to video content that offers support.

Communication

/continued.

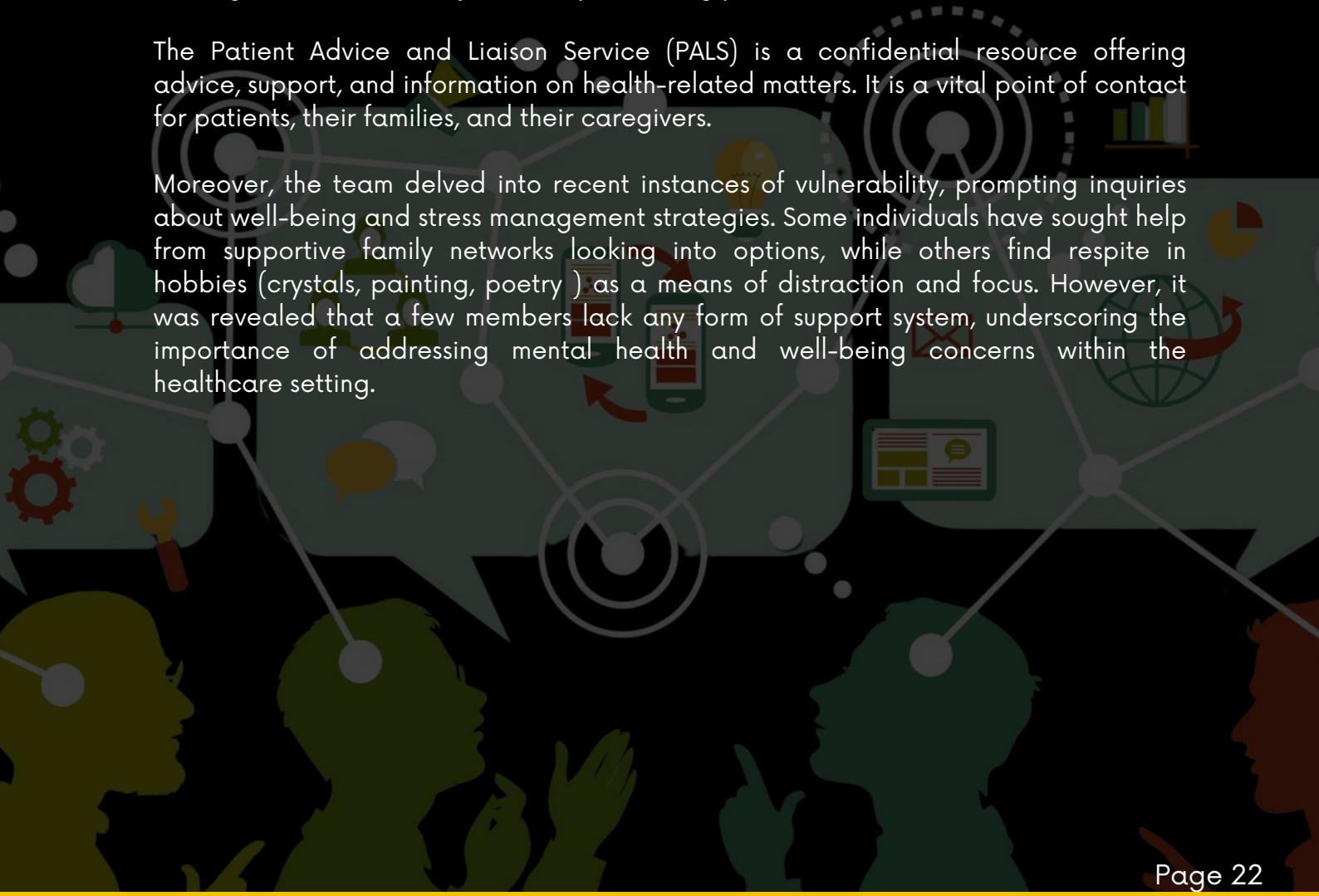
The dearth of effective communication erodes patient trust in healthcare services, compelling them to revisit GP surgeries to address issues they believed were previously resolved through communication. However, there is a glimmer of hope as patients have recently noted a positive change with the introduction of the MyCharts app, now available at St. Thomas' Hospital and others. [10] It was noted that this tool has significantly sped up the receipt of letters, results, and appointments, signifying a positive step towards addressing the longstanding communication challenges within healthcare.

The Patient Advice and Liaison Service (PALS)

During discussions, it became transparent that individuals who attempted to voice their grievances by contacting the Patient Advice and Liaison Service (PALS) [11] often encountered dismissal or received no response. It was noted that PALS occasionally failed to adequately acknowledge the patient's perspective, leading to frustration among some members of the Patient Advisory Group (PAG). One PAG member expressed profound frustration, describing the system as "broken," particularly when addressing pain that can exacerbate emotional distress. As a result of these discussions within the PAG, two individuals took matters into their own hands, independently seeking answers to their questions by accessing private health care instead

The Patient Advice and Liaison Service (PALS) is a confidential resource offering advice, support, and information on health-related matters. It is a vital point of contact for patients, their families, and their caregivers.

Moreover, the team delved into recent instances of vulnerability, prompting inquiries about well-being and stress management strategies. Some individuals have sought help from supportive family networks looking into options, while others find respite in hobbies (crystals, painting, poetry) as a means of distraction and focus. However, it was revealed that a few members lack any form of support system, underscoring the importance of addressing mental health and well-being concerns within the healthcare setting.





Insight 3

Mental Health & Resilience

Mental Health & Resilience

During our sessions, we came to appreciate that chronic pain has a significant impact on mental health and overall well-being. Some individuals find it difficult to communicate with healthcare professionals when their pain levels are high and their emotional tolerance is low. This can lead to misconceptions from healthcare professionals towards patients and vice versa.

Patients understand the importance of engaging in activities that promote physical and mental well-being. However, due to the high cost of living, they have to prioritise food and housing expenses over activities that could benefit their health. This financial burden can impact their feelings towards future appointments with healthcare professionals, as they may feel uncertain or sceptical about how the appointment will go, especially if they have had past negative experiences with healthcare professionals.

Low emotional tolerance can also affect how someone processes pain and may impact the amount of time it takes for them to come to terms with their illness or find ways to cope. Being diagnosed with a condition that causes chronic pain can result in a grieving process that impacts mental health as individuals come to terms with the realisation that their mobility and independence may be impacted, as well as long-term pain.

To help them cope with this, we created a SWOT analysis to show them their strengths, weaknesses, opportunities and threats. Our aim was to support the team in processing their pain and to help them understand that the quality of life may be different due to their pain, but there are still ways to have a good quality of life. We worked with them over the course of the project sessions and questions in the WhatsApp group.

During our conversation, the team acknowledged that there are a few weaknesses and threats that affect them on a daily basis. They also recognised that they may not be able to complete a certain sport like they used to, but they believe there might be another way to get involved and still enjoy it. "Maybe I need to set aside my ego and try for enjoyment rather than participation."



CHRONIC PAIN PAG SWOT ANALYSIS

Centric

Neighbourhood and Wellbeing Alliance

Strengths

What helps you manage your chronic pain to prevent it from impacting your chronic pain?

- Learning to live with it and act accordingly!
- Receiving answers for queries I have about my health. Having a firm understanding of what I have and what I need to do to safeguard my future
- Hobbies ex: roller-blader, crafting 'Meditate instead of painkillers'
- Having the correct support from my medical team and especially family and friends.
- Warm-up exercises to help ease pain
- Accepting it and making it a normal part of my life. Being able to say, 'this is me,, and that's ok'.

Weaknesses

What areas are you struggling with regarding your chronic pain?

- As per my recent physio appointment, I felt my concerns weren't heard. Having a condition that is longstanding does mean that I now have the ability to identify changes that might cause a serious flare. From my recent experience, this was not regarded, and my flare-up was normalised. I do get the feeling that the NHS works on cure rather than prevention.
- It can be a struggle to balance my work life and my social life. Often, I have to choose either, not both, and that naturally means my social life takes a hit. To counterbalance this, I surround myself with those who understand my fatigue and pain..
- It can affect your ability to function at home and work. You may find it difficult to participate in social activities and hobbies, which could lead to decreased self-esteem. It is also common for people with chronic pain to sleep a lot.
- The pain is there whenever I put on a coat or jacket or otherwise try to use my left arm adventurously. I am learning to live with it.

Opportunities

What current opportunities could help you cope, and what do you wish was made available?

- Stopped me from doing sports.

  Maybe I need to set aside my ego and try for my enjoyment rather than participation

  Finding accessible sports that suit those with chronic pain.
- Losing weight

  I don't want to do it on my own, I'm not motivated - Find someone who would want to go exercise with me - talk with local people, like parents, to try to organise a mum's gym.

  Finding accessible sports that suit those with chronic pain.
- Skating, but I can't because I use and need a crutch, I want to feel free.

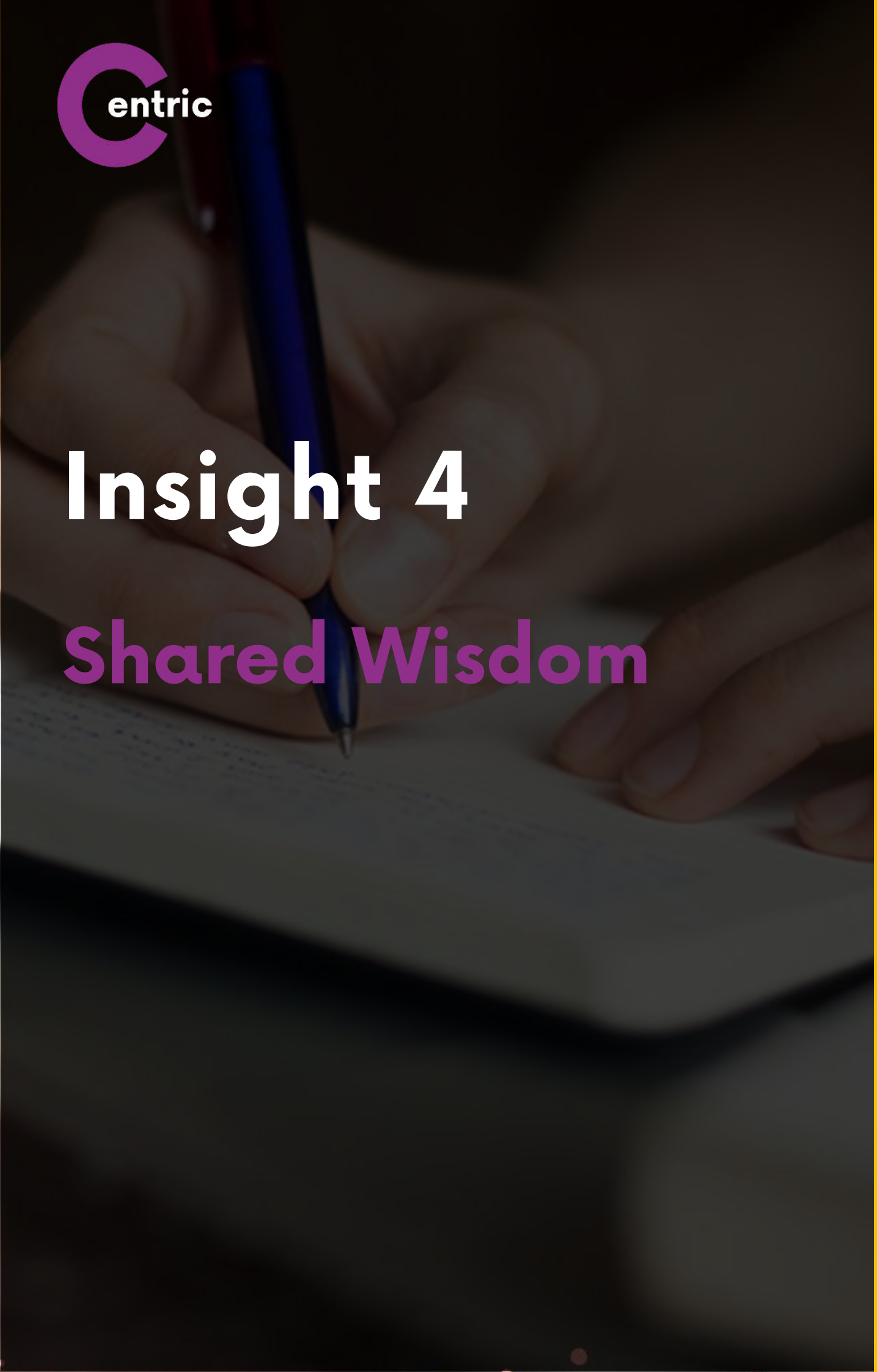
  Finding an alternate that could be done.

  Finding accessible sports that suit those with chronic pain.

Threats

What are some factors outside of your control that affect your pain management?

- Random flare-ups
- Lack of funding - can't get to certain activities to improve help due to cost - for example, swimming or hobbies.
- Infections
- Lack of support from family & friends, for example, with household chores
- Traumatic events



Insight 4

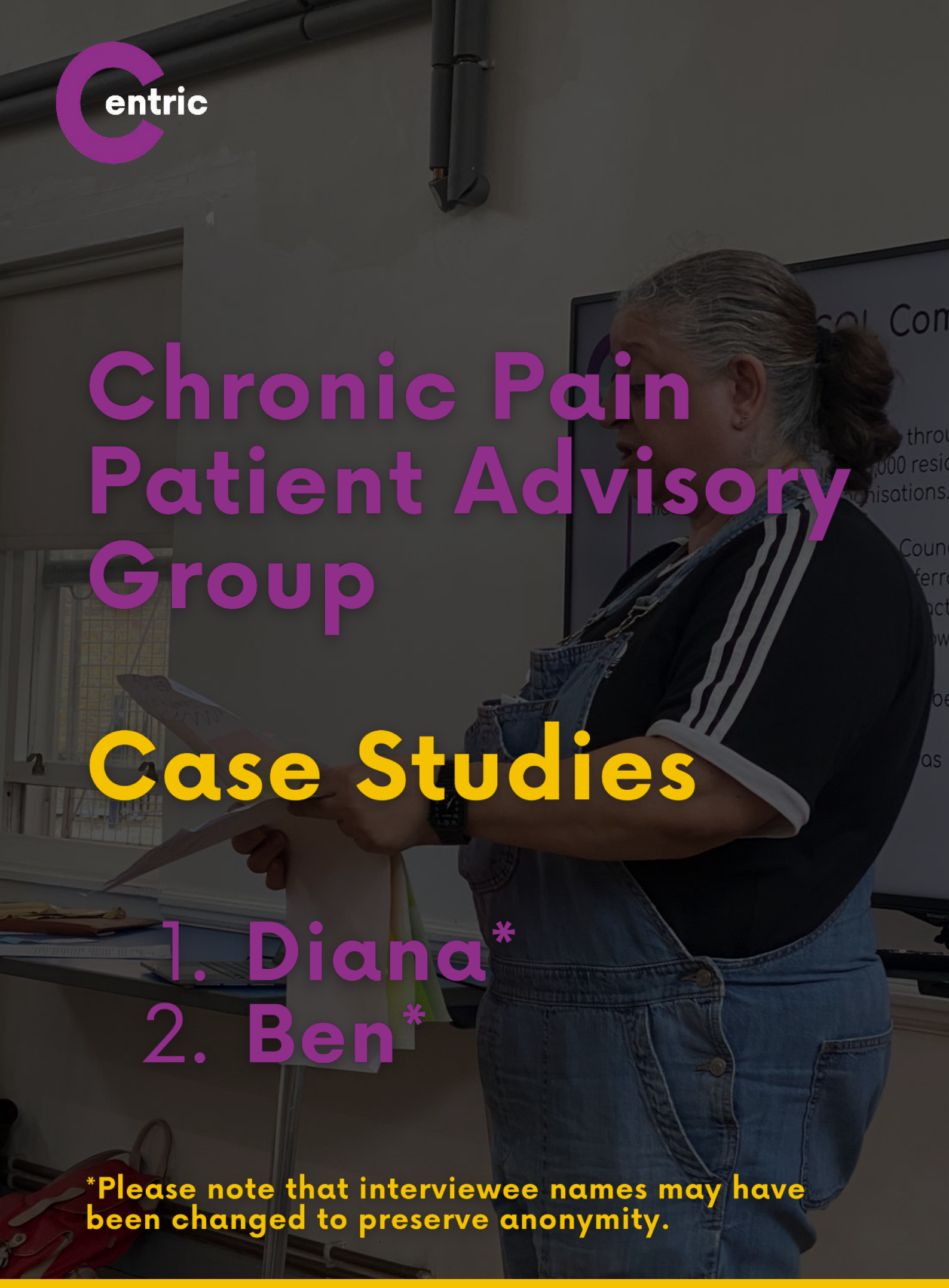
Shared Wisdom

Shared Wisdom

Throughout our sessions, the Patient Advisory Group (PAG) has demonstrated profound collective wisdom by actively listening to each other's experiences. This has cultivated an engaged and empowered group dynamic, where members feel supported and understood.

Together, they have crafted a resource pack specifically tailored to individuals grappling with chronic pain. Through meticulous examination, we delved into the multitude of challenges and barriers faced by chronic pain patients. Leveraging this deep understanding, we have compiled a comprehensive list of resources aimed at providing assistance and support.

Ways to cope with long waiting times	Additional information about medications and alternative options	Understand the support and pathways available for weaning off pain medications
Create online support groups for specific conditions in Lambeth with a skilled admin for monthly/ bi-monthly assistance and specialist input	How to manage activities to improve quality of life without worsening the condition	Map of accessible places for chronic pain sufferers with minimal barriers



Chronic Pain Patient Advisory Group

Case Studies

1. Diana*
2. Ben*

*Please note that interviewee names may have been changed to preserve anonymity.

Diana

Summary

Diana's chronic pain journey started in the 1990s when she was diagnosed with Lupus. Although she didn't particularly find the pain clinic helpful, the supplementary treatments of acupuncture, physio and hydrotherapy did help her pain management. She has a strong conviction and belief in God. This would seem to allow her to 'smile through her pain' and keep her strong.

At first Diana was uncertain about joining the Patient Advisory Group, being sceptical of what she might gain from participating. However, she has found it helpful to understand other people's experiences of chronic pain, especially those who share similar health concerns. She felt that supporting each other with suggestions or just listening has helped her develop a deeper understanding and, with her mental well-being. Diane expressed the importance of just giving it a go, as we could all learn from each other by having a safe space to talk in similar situations.

On whether she'd recommend the group to others, Diana says:

"I would say just to get involved. Let's go because, like me, they could learn a little but they could learn a lot. They could also give others in the group the benefit of their experience."

Background

- Female
- 55-64 years
- Black African / Black British African
- Christian
- Multiple long-term conditions
- Physical disability and/or condition
- Service-user/Patient
- Born and raised in the West Midlands.
- Broadcast journalist by profession then administrator signed due to Lupus.
- Multiple surgeries on hips, knee and shoulder
- Faith is important

Diana

/In Depth.

Chronic Pain Journey

Diana's Multiple Long Term Conditions are significantly impacting her daily life and have left her with limited options for chronic pain remedies. This has also created additional challenges in her interpersonal capabilities.

"My experience of pain is, it has been direct and very painful. I've endured it now for over 40 years with a smile on my face."

"I've got pain in many kinds of different areas of my body. My faith has seen me through or is seeing, I should say, and the smile - comes from the joy within my heart, the joy of the Lord. The Bible says the joy of the Lord is my strength."

"I had acupuncture for 5 weeks and physio for 6. . . I've tried Bitter Leaf for when my blood sugars go high. It was the Moringa seed [that] actually helped too. There was always a bit of exercise involved. But one thing I found, especially when it came to walking, they would say - oh, you must walk, you must walk. So I went to hydrotherapy." [Diana felt little thought was given to the tiring effects of walking there And back.]

PAG Impact

Diana's initial apprehension delayed her joining the PAG project, however she eventually got involved and gained supportive knowledge from sharing her experiences with fellow pain sufferers.

"I don't join a group unless I know there's going to be some sort of benefit. I was also thinking that maybe there's something here for me. Somebody might be able to help me with this horrible pain that I'm in. Somebody might have some suggestions..."

"I've come to realise that there are people who are in pain. I listen to their stories, I read what's happening with them. Every now and again, I read what pops up because you never can tell if somebody might offer something like a suggestion that might help another person. I think that as much as I can give information, I can listen, I can also add to what somebody else might have offered."

"It's helped me to understand that there are other people who are in worse situations [than] me or in a situation which is similar to me. It was the mental health side of things too. Sometimes we don't realise what information we've got tucked away until we start using it; until we find ourselves in a situation whereby we need to talk about certain things, and then a lot of stuff just comes flowing through."

Chronic Pain Medical Input

Healthcare professionals need to listen more empathetically in order to evaluate chronic pain patients more holistically and therefore effectively.

"So where they're not cognisant with chronic pain, I feel that they need to listen more attentively to their patients. It's not that they don't listen. And it's not that they don't really know anything about it. They know, but they don't know as much as the patient knows."

Ben

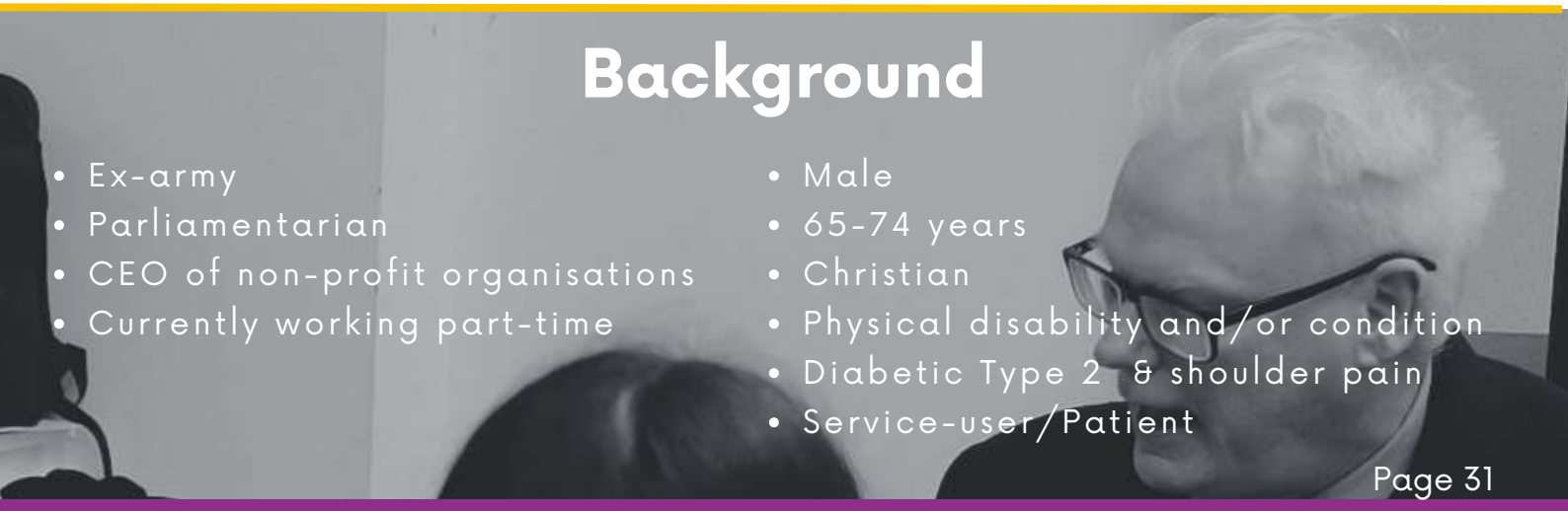
Summary

Ben fell from a ladder about seven years ago which has resulted in constant pain in his left shoulder, which limits certain everyday activities. This shoulder pain makes it difficult for him to perform simple tasks such as putting on a jacket or threading loops on his belt. He has sought support from his GP and tried physiotherapy, but unfortunately, he felt that it didn't help much.

The group provided a safe space for people to talk about their pain when they cannot discuss it with their families. The PAG's WhatsApp group also acts as a good support network and facilitates communication among the group members. This has helped Ben maintain a positive outlook by continuing to listen and broaden his awareness at a suitable pace for him.

Ben had an overall positive experience being a part of the Patient Advisory Group. He said that being in the group helped him gain knowledge and motivated his understanding through interacting with fellow chronic pain sufferers. As a result, he has now tried to follow up on his chronic pain issues further with his GP.

In his own words, Ben describes his feelings about what he learnt from the group: *"What I learned from it was that a collective sense of solidarity is a great comfort to many people, and I think that shows up in our WhatsApp group and the meetings; I think people do derive a great deal of comfort just from sharing with others who do understand where they're coming from. They're not alone, and that's a great help. I think it's an extraordinarily worthwhile project. I really do. I highly commend it."*



Background

- Ex-army
- Parliamentarian
- CEO of non-profit organisations
- Currently working part-time
- Male
- 65-74 years
- Christian
- Physical disability and/or condition
- Diabetic Type 2 & shoulder pain
- Service-user/Patient

Chronic Pain Journey

Following suggestions for routine but unsuccessful therapies, Ben had resigned himself to suffering in silence with his chronic pain and impaired mobility before getting involved with the PAG project.

"I'm reminded of my pain every time I try to put on a jacket because I can only lift my arm so far, and if I try to put on a belt, for example, and thread it through the loops on my trousers, I mean, I can only get my hand back so far without it actually then triggering a very great pain in my shoulder. Every time I put on a coat or a jacket or anything like that, I feel that twinge. The physio gave me some of these elastic bands that you tie one end on a door and then move your arm backwards and forwards and things like that, which I thought would help it, but it didn't."

"I think I recall when [the PAG] said, well, why haven't you done more to go and sort yourself out as it were? So I think that that's been very good too, to make one think - what more can one do personally about things? I went back"

PAG Impact

Ben's perception and understanding of the value of chronic pain management has developed significantly as a result of his involvement with the PAG project - whose aims and supportive benefits he has discovered are immensely relatable.

"I found it interesting because I realised that there were people in really very serious, chronic, constant pain and some people really quite disabled, as a result, and . . looking at the way they manage things and opening my eyes to that, was really very interesting." "I mean, you've only got to see somebody just posting something on the WhatsApp group saying they're not particularly well that day, and others just pitch in and say, well, you know, have faith, etc. So, I think that's good. It's a great mutual support mechanism."

"It's opened my eyes to what some people have to live with, and that wasn't immediately apparent, and in a way, why would it be? And so, it's brought me into contact with people. It's increased my understanding of the human condition that people are going through. But I doubt that I would have ever gotten to that knowledge without being part of the PAG"

Mental Health and Well-being

Ben's realisation of the isolating impact of chronic pain taught him the value of shared and supportive understanding with fellow PAG members. This awareness has helped him to avoid the intense loneliness which had previously limited his ability to cope with his condition. His active contribution to comfort fellow sufferers has reinforced his personal appreciation for the support received from the group.

"I know people living with severe pain can feel very isolated, and even though they may be getting professional help, that doesn't help them in the darker moments of the day or night when they're going through a lot of pain . .There's a lot of loneliness out there of people who don't feel that well; nobody really understands them, and that's something that PAG totally overcomes because they're suddenly in with a group of other people who do only understand only too well what they're going through."

"I think that probably there's a great deal of comfort, not necessarily physically but certainly mentally, to people to know that they've got a group they can talk to and people understand them, you don't always get that I'm afraid from professionals. . . I think there is a therapeutic benefit to be had if you feel you're making a positive contribution. . . I'd like to think I'm doing that. that some of the exchanges have been of help to other people, and if you feel you're being useful in making a contribution, that derives a great deal of personal benefits."

Discussion

This section explores the complexities and outcomes associated with the implementation of the Patient Advisory Group (PAG) for chronic pain management in Lambeth, focusing on the tangible successes and challenges experienced throughout the project.

Challenges: The project encountered significant barriers, such as the dropout of members due to the debilitating nature of chronic pain and accompanying mental health issues. These dropouts highlight the intrinsic challenges of maintaining consistent participation in health advocacy initiatives where participants themselves are affected by severe health conditions. Additionally, logistical issues, such as obtaining advance dates for the Chronic Pain Workstream sessions, impeded consistent participation, reflecting the need for more flexible planning in future initiatives. The unexpected resignation of the first Chair due to personal and health reasons further exemplified the volatility that can impact leadership in community health settings.

Successes: Despite these hurdles, the project achieved notable successes. The establishment of a dedicated community group provided critical support, aiding members' mental health and fostering a robust support network through platforms like WhatsApp, where members shared coping strategies and encouragement. This peer support mechanism became a cornerstone of the project, enhancing participant resilience and engagement.

Incorporating PAG Insights: Insights from the PAG directly influenced local health services, leading to significant enhancements such as the creation of a Chronic Pain register for all Lambeth GPs. These contributions underscore the practical value of patient-led advisories in real-world healthcare settings.

Notably, during the Lambeth Primary Care Pain Study Day Event, the PAG's findings were presented, receiving high praise and sparking detailed discussions among healthcare professionals about the prevalence and management of chronic pain. This interaction not only provided validation for the PAG's work but also ensured that their firsthand experiences were integral in shaping healthcare practices and policies.

The engagement at the Cost of Living and Multiple Long Term Conditions introduction event further illustrated how PAG members could influence broader community and healthcare discussions, ensuring that patient voices are at the forefront of healthcare planning and execution.

Reflections: The experiences detailed by the PAG members during the project—from the challenges of navigating healthcare interactions to the emotional and physical toll of chronic pain—highlight the critical need for healthcare systems to be more responsive and adaptable to the needs of chronic pain sufferers. These insights are invaluable for informing future strategies, suggesting a shift towards more patient-centred care practices and the importance of incorporating direct patient feedback into healthcare service design and delivery.

In conclusion, while the project faced logistical and participatory challenges, the successes and insights gained underscore the transformative potential of patient advisory groups in enhancing health service responsiveness and effectiveness. Future initiatives should build on these learnings, prioritising flexibility, support and direct patient involvement to foster more inclusive and effective healthcare environments.

Conclusion

Patients with chronic pain often struggle to find enough support and care from healthcare professionals. Regardless of their best efforts, patients with chronic pain often struggle to find sufficient support and care from healthcare professionals. In addition to the challenge of their pain, this can create additional negative feelings of being neglected, misunderstood, and dismissed. The short appointments, lack of follow-up, and inadequate pain management treatment and alternatives exacerbate what is already debilitating condition, further undermining the patients' sense of well-being.

Those who seek alternative methods to manage their pain often face the dilemma of identifying whom they need to approach or where to start seeking support. Patients face significant uncertainties due to their chronic pain. Therefore, it is crucial to recognise and address appropriate solutions to provide patients with the necessary support and guidance for improved care and quality of life.

The PAG's collaborative wisdom has been important in creating a tailored resource pack that addresses the multitude of challenges and barriers that chronic pain patients face, providing peer support to learn from each other's experiences. They continue to correspond on the established Whatsapp group and motivate each other to overcome the physical and mental barriers they face. They have felt a sense of accomplishment through assisting in the development of the Leva app through the GetUBetter platform and highlighting the value of digital self-management tools for musculoskeletal injuries and conditions. This has allowed for improved communication, which was a constant theme throughout the project. However, their being able to communicate with each other seemed to alleviate their concerns and improve their mental well-being.

Peer support and close working with the Lambeth Together Chronic Pain workstream were two important aspects of this project's success for both the well-being of the PAG group and for service development in Lambeth. The Study Day in KCH, among feedback in the workstream meetings and directly from clinicians and other healthcare professionals, showed that the project had a positive impact on everyone involved. The project and ways of working between Centric, Lambeth Together, and the PAG represent a closely-knit relationship through which health inequalities can be addressed, providing a platform for authentic voices, lived experience and knowledge-sharing that serves the betterment of mental and physical well-being of patients, and those who are delivering services to support them in overcoming challenges they may face.

The value of the PAG in Lambeth has been made clear through our interactions at each stage of the project. PAG members are keen to continue supporting each other and Lambeth Together in improving primary and secondary care services, and despite the project's conclusion, will continue to meet, advise and support one another while working with Centric in projects such as Cost of Living & M LTC's funded by Impact on Urban Health. They are ready and eager to engage in more research and have become a cohort that could be described as an active research community.



Chronic Pain Advisory Group

Recommendations

Recommendations

1. **Continuation of the Patient Advisory Group**
Continuation with the involvement of healthcare professionals specialising in pain management. This addition will provide valuable expertise to address questions and offer informed advice, further enhancing the effectiveness of the group's initiatives and support network. Included both in-person sessions and online platforms to accommodate diverse preferences and facilitate broader participation.

2. **Enhance Patient-centred Care**
Working alongside LNWDA and stakeholders to prioritise initiatives that enhance patient-centred care, specifically for chronic pain management. This includes training for healthcare providers on cultural competence and sensitivity to better understand and address the unique needs of diverse populations such as how language is used when working with patients. e.g ''we would like to work with you." rather than "we want to use you".

3. **Comprehensive Resource Pack**
A pack encompassing chronic pain patients in Lambeth to disseminate their shared wisdom. Ensure this resource pack is available during GP appointments and via online platforms to empower patients in managing their chronic pain effectively.

5. **Support Digital Literacy and Access**
There should be an investment in digital literacy programs for community members. Additionally, ensuring that digital platforms used for health management are accessible and user-friendly for all, especially the elderly and those with disabilities.

7. **Resources on Medications and Alternatives**
Better quality information regarding pain medications and alternative treatments. Address concerns regarding medication weaning, particularly for pregnant and breastfeeding mothers and other concerns that may be raised about pharmaceutical options.

8. **Improve Engagement Methods**
Utilising social media outreach and collaborating with the NHS. Additionally, online support groups moderated by skilled facilitators and professionals should be established to provide consistent support sessions. Increase the frequency and depth of meetings to facilitate comprehensive discussions on pain management strategies and address patient needs effectively.

9. **Complimentary Exercise Programmes**
Sessions are suitable for patients experiencing chronic pain, including hydrotherapy, swimming, yoga, and pilates, with flexible eligibility standards. Provide a range of options, including both in-person and online formats, to accommodate diverse preferences and requirements.

Research Recommendations

1. **Longitudinal Studies on Chronic Pain Management**
Conduct longitudinal studies to track the long-term effectiveness of patient-centered care models and community advisory groups like the PAG in managing chronic pain. This could help identify sustained outcomes and improvements over time.

2. **Comparative Studies Across Different Communities**
Implement comparative studies that examine the effectiveness of chronic pain management strategies across different ethnic and socioeconomic groups. This could help identify specific needs and effective interventions tailored to diverse populations.

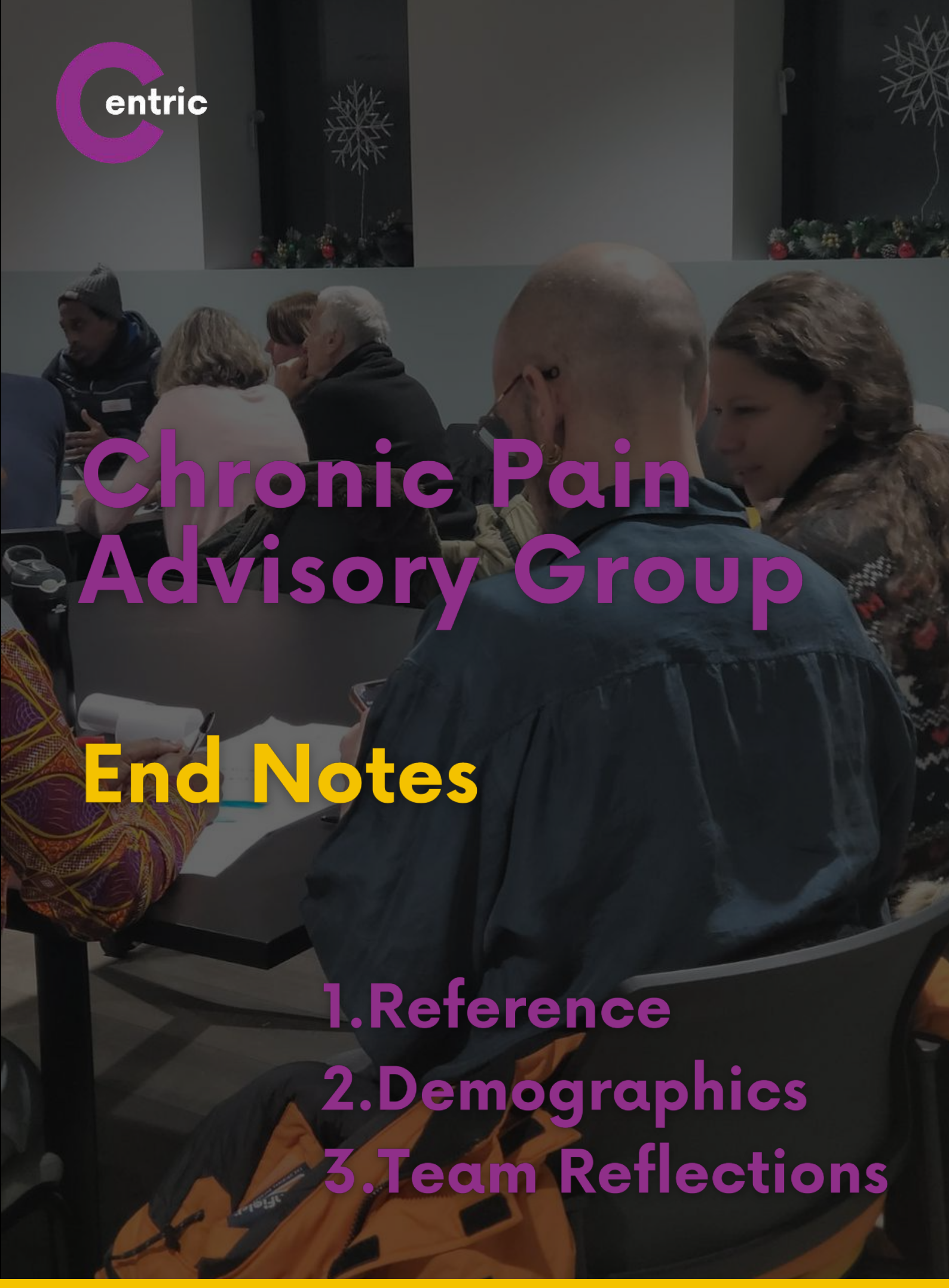
3. **Impact of Cultural Competence Training**
Research the impact of cultural competence training for healthcare providers on patient outcomes. This includes measuring changes in patient satisfaction, adherence to treatment plans, and overall health outcomes post-training.

4. **Technology and Chronic Pain Management**
Investigate the role of technology in enhancing chronic pain management, particularly the effectiveness of digital health tools and telemedicine in improving access to care for underserved populations. This could also explore barriers to technology use, such as digital literacy.

5. **Patient Engagement and Health Outcomes**
Study the correlation between the level of patient engagement in advisory groups and health outcomes to quantify the benefits of involving patients directly in health service planning and decision-making.

6. **Barriers to Effective Pain Management**
Further research to identify and understand the systemic, logistical and personal barriers that prevent effective pain management, especially in minority communities. This includes studying the effects of stigma, healthcare provider biases, and economic factors.

7. **Mental Health and Chronic Pain**
Deepen research into the intersection of chronic pain and mental health, particularly looking at how chronic pain contributes to or exacerbates mental health issues within minority communities.



Chronic Pain Advisory Group

End Notes

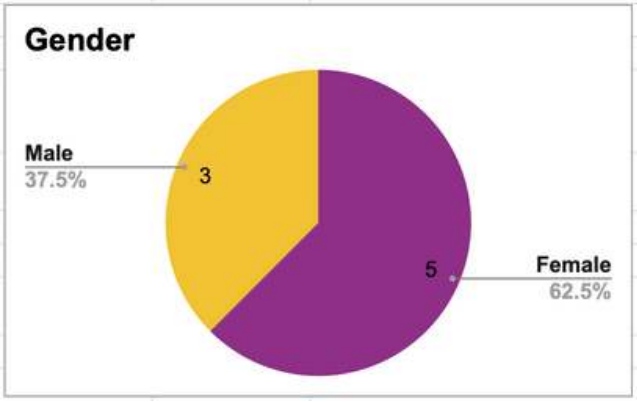
1. Reference
2. Demographics
3. Team Reflections

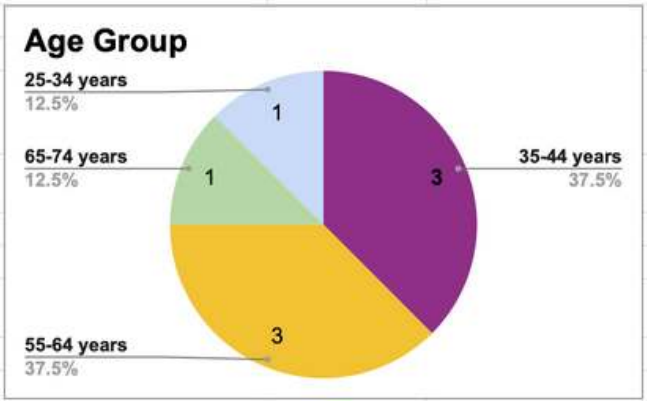
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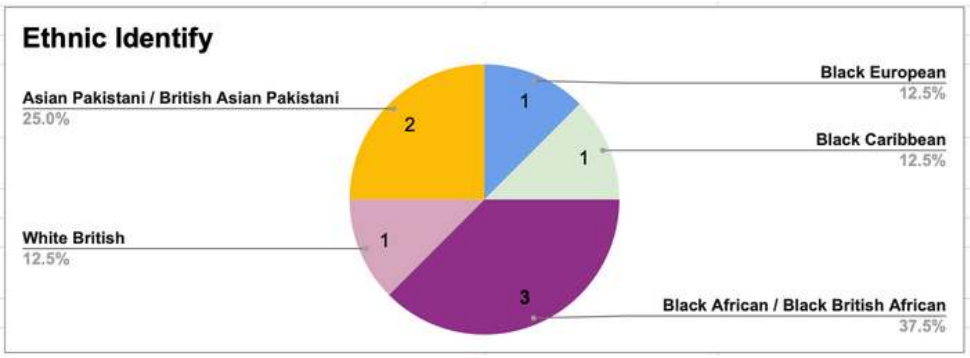
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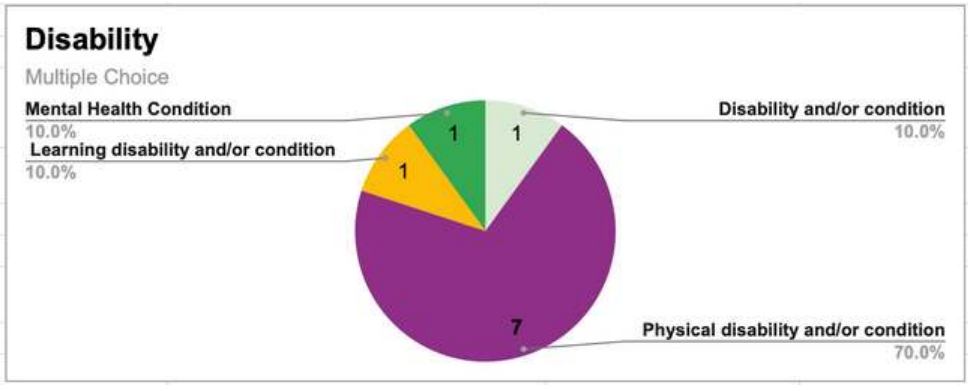
Participant Demographics

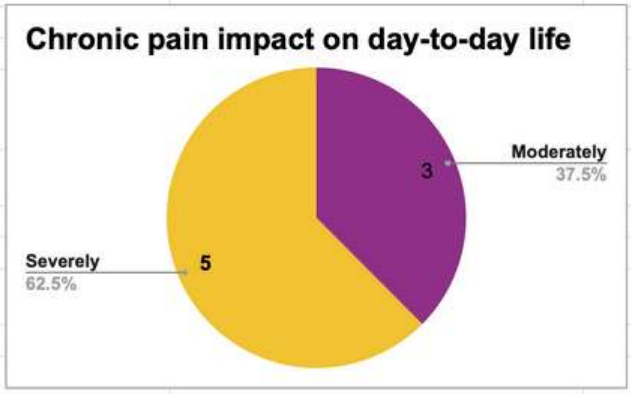
For this project, we recruited across different ethnicities with a focus on the inclusion of those from underserved communities.











Team Reflections

"Being part of this project has been a mind-blowing experience. I've seen a group of strangers become a support system for one another. It's a holistic way for individuals with similar situations to be there for each other, provide feedback to the chronic pain workstream, express their thoughts and feelings, and talk about day-to-day challenges.

They have built a way of thinking about life and how precious it really is. Not being able to do the things that non-disabled people can do has limited them, but it has also kept them wanting more in their lives. It's been a way for them to keep thriving. Through their suffering, they have learned how to be resilient and how to keep pushing through for those they love most.

Each member of this patient advisory group has brought something essential to the table, including their lived experiences that have impacted the initiatives of the Neighbourhood and Wellbeing Alliance in different ways. They have brought difficult experiences to light and emphasised the importance of being seen and heard as someone with chronic pain. They know there are challenges, but they appreciate every single little thing that the NHS does provide and can provide. They can also see and feel when things go wrong and how much it impacts their mental health, emotional tolerance, and overall experience. Pain can impact everyone in different ways. It can take away parts of you and restrict your daily living.

Being part of this patient advisory group has been an inspiring moment for me. It has given me a better understanding of others and a sense of not being alone. I myself suffer from chronic pain, and I understand how it can change your life in so many different ways. Being part of this project has pushed me to advocate even more for people's voices to be heard. Every voice is validated, and every experience needs to be heard. Institutions need to listen to those who haven't been heard, those who have had the lived experience, and those who still speak their story. Change takes time, and it's important to manage the community's expectations while ensuring it understands that change is needed in the current system.

Raquel Caires Januario, Project Manger

Team Reflections

/continued.

My role in this project was supporting the Project Manager in developing and coordinating this fledgling group and laying out our work plan - recruitment. The intention is to look into their experiences as individuals who live with chronic, physically limiting, painful conditions yet are frequently also in employment. In November 2022, I knew nothing of this. I do now and have had the slightest experience of 'pain'. I also attended quarterly meetings with the Lambeth Together Project Manager and the regional-wide team meetings. With such a diverse group, six weekly meetings were like new starts in sessions one and two, and there needed to be more time to remember/gel. Had it been possible, monthly would have allowed for greater attendance, bonding, subject questioning and benefit.

Our early meetings encouraged lively debaters and reticent individuals to come forward; all were encouraged to think about becoming 'Chair' and report group matters back to Lambeth Together. We perhaps didn't recognise that even a seemingly strong character 'up for the challenge' had frailties and was overwhelmed by the task. In the first few months, we saw others withdraw, and those who stayed draw together under a new Chair and, with increasing confidence, speak about their situation and turn on their zoom video - occasionally. I learned that members wanted to inform clinicians of their situations and hope for better. They, all different, could relate, share, support and empathise with each other, however large or small their condition. I learned how Pain can limit life, reduce opportunities and pride, keep things at a surface level, and cause such struggles and yet each was doing the best with what they had. Each has to find coping skills, keep others from knowing, carry their documents to appointments and be their own advocates, smiling despite exhaustion and frustrations.

Our PAG members were pleased the project was given an extension, and there was a definite uplift in mood and relationships in those last two sessions. Knowledge and understanding that They - with others - have brought substantial changes to how things come together, are managed in the broader services did please all of them. Our final session in March '24 showed a heartfelt appreciation for each other and an expressed need to meet in person. While that has yet to happen, it will; they want it to be so.

Elaine Brown, Community Researcher

Acknowledgements

We extend our heartfelt appreciation to all the participants whose unwavering dedication and willingness to share their experiences significantly enriched our project. Their honesty, openness, and commitment were invaluable in shaping our understanding and guiding our research efforts.

We would like to express our sincere gratitude to the Lambeth Together Neighbourhood and Wellbeing Alliance and Dr. Dianne Aitken for granting us the opportunity to be part of this remarkable journey. Their support and collaboration have allowed us to embark on an adventure aimed at bridging the gap between individuals living with chronic pain and healthcare services.

Additionally, we wish to acknowledge and express our gratitude to our esteemed colleagues who provided invaluable support and resources throughout the project duration. Their provision of high-quality resources, insightful feedback, and technical assistance played a pivotal role in the successful execution of our research endeavors. Their unwavering support and expertise were instrumental in overcoming challenges and achieving our project objectives.

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Thank You For Your Attention!