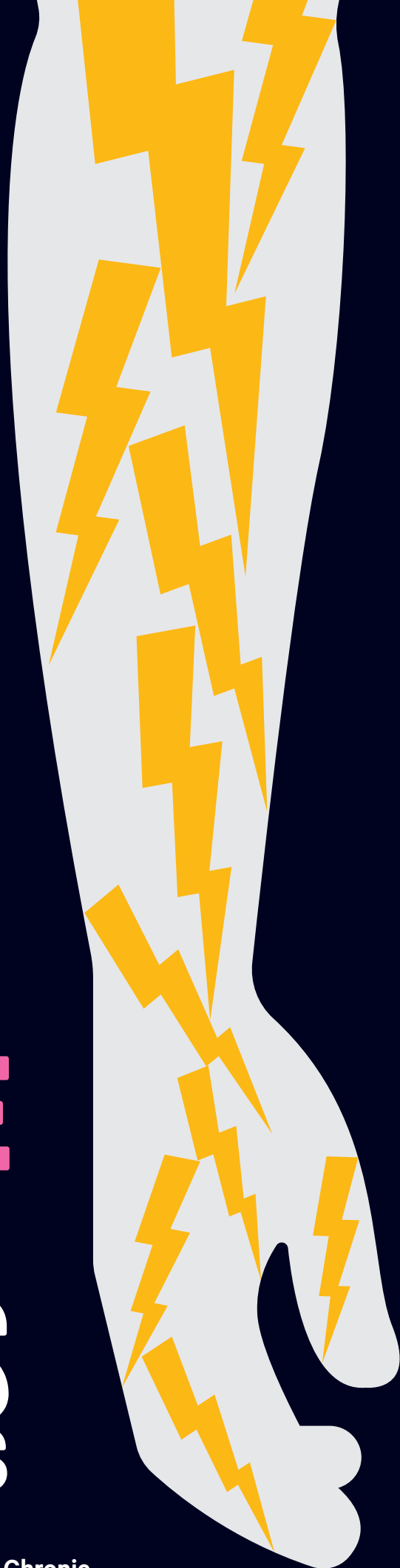


PAIN
PEOPLE
PLACE
VERSUS
ARTHRITIS



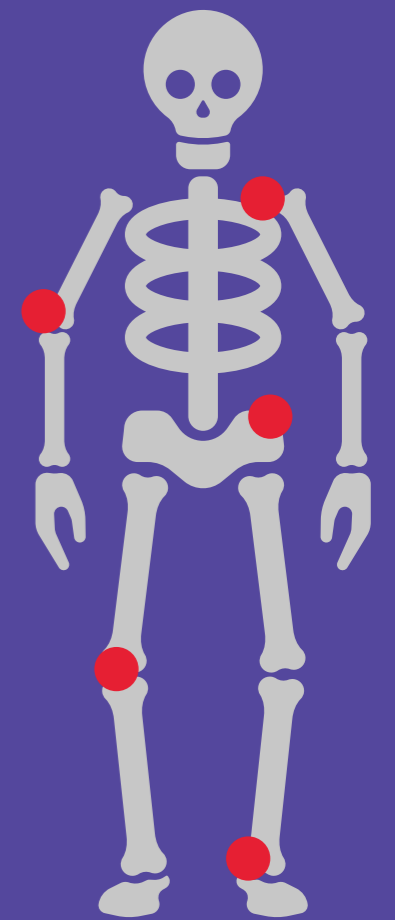
A Report on the Lived Experience of Chronic
Musculoskeletal (MSK) Pain in Grampian

THE PURPOSE

The purpose of this work was to design and deliver a record of lived experience of people living with chronic MSK pain in Scotland. Although the initial ambition was to focus on a range of localities across Scotland, with the work being carried out in April/ May 2020, the pandemic intervened and we were forced to revise the scale, reach and approach of this phase of the project.

This report provides a summary, based on one-to-one interviews, of the lived experience of 23 individuals living with MSK-related chronic pain in the NHS Grampian area. Participants come from a range of communities – rural and urban - and cohorts, e.g. people shielding during COVID-19 lockdown. The approach has provided a nuanced understanding of individual circumstances, of participant's communities, and a summary of the implications for services and policy development.

The work has captured voices that can be lost in other processes of patient involvement¹ and provides a basis for ongoing activity to ensure that issues specific to MSK pain are better understood and that diverse voices inform policy and service development.



¹ The report will help to inform the work of the National Advisory Committee on Chronic Pain (NACCP) and the Chronic Pain Reference Group (CPRG)

THE APPROACH

Six localities across Scotland² were identified along with staff from Versus Arthritis, who would support the project consultant(s)³ with local roll out.

The initial design of the project included survey work prior to recruiting participants for 1-1 interviews and focus groups. We would be working with local healthcare professionals and other key contacts to organise local publicity and events and would also produce an information pack to ensure that participants had access to resources and support following any engagement with the project.

Roll out of the project was planned for May/June but was put on hold in March when the pandemic emerged and lockdown was implemented. This was unfortunate but gave us an opportunity to incorporate an understanding of the pandemic/lockdown into the project when it restarted (whenever that would be).

In recalibrating the project, following an initial hiatus from March to June, we had time to reflect on the need for the

survey element and realised that relevant material had already been generated through the Versus Arthritis Insight Team and a range of surveys undertaken by our Policy & Public Affairs Team during the first phase of the pandemic.

We also had to reconsider our capacity to manage and deliver a programme of work across six localities, which would now be indirect and involve remote-only interactions with participants. Added to this was the fact that Versus Arthritis staff had to shift the emphasis of their own work to online support for people with arthritis, including volunteers; and, in doing so, learn new approaches and improvise solutions. Their capacity to support the Pain People and Places project was severely limited.

We decided to focus on one NHS board area, Grampian, as there was local staff capacity to support delivery and an existing relationship with the NHS Public Health team, which we hoped would be a focus for any project

outcomes. It also allowed us to test the approach and, given the uncertainties created by the pandemic, to progress virtually and yet in a very personal way. With the support of the local Versus Arthritis team, we concentrated on the 1-1 interviews and recruited 23 people to take part. The questions we asked were informed by existing Versus Arthritis survey work and tested before being finalised.

The interviews were conducted virtually using either Zoom, facetime or telephone. The interviewees, ages ranging from 20's to 70's, included working and retired people. Interviews were captured in an individual report which, although not verbatim, did include the broad range of issues covered by the interview. Once concluded the interviewers met and identified key themes.

This report captures people's experience of chronic MSK pain where they live. As importantly, it reflects the moment we are in – a global pandemic and it's local and personal impact.

2. Lanarksire, Glasgow, East Renfrewshire, Dundee, Western Isles and Grampian
3. The work was carried out by Birt Associates and led by Audrey Birt, supported by Hazel Mackenzie



SUMMARY INSIGHTS FROM THE QUESTION WE ASKED



Management of pain

There was a mismatch between the participant's narrative description of pain and how it was scaled on a 0-10 measure. Many people found it hard to scale as it's a fluctuating condition. This will be discussed later under the theme of pain.

Services/treatment

There was a stark difference for people in what services they received, which ranged from being given a link to a video on MSK conditions to a regular interaction with specialist care. For some there seemed to be a (learned) helplessness about how they approached seeking support. It was notable that very few had any support from third sector organisations.

Impact of lockdown on services/treatment

The consensus was that GP services and access to specialists were perceived to have 'disappeared' since lockdown.

Lockdown/exercise/deconditioning

When people were able to keep up with exercise this was not an issue as expected; however many described gaining weight and losing strength.

Shielding

Most people weren't shielding but those who were found it difficult and not necessarily helpful.

Key impact of pandemic/lockdown

Answers were very varied. Those who no longer travelled to work noticed some improvement in energy and pain, with some increase in time for self care. However, for many it was isolating. Working from home, sometimes with home schooling tasks, was described as very hard. Many described the loss of support and missing family as the biggest impact.

Lockdown upsides?

For some, **'having more time'** and the **'slower pace'** were seen as beneficial upsides of lockdown.

For others, the response was **"not a bl**dy thing!"**

Mental health

Most participants felt that lockdown had a negative impact on their mental health, often exacerbating the already existing impact of living with chronic pain.

Sleep loss, panic attacks, headaches, low mood were mentioned. People noticed their pain worsened if they were stressed or had a low mood, notably with sleep loss.

What matters most to you now?

This question was asked as a new lockdown tier system was being introduced, and the public was being encouraging to comply with standard protocols (social distancing, etc). Family was the consistent priority. Many had not seen relatives for a long time and didn't know when they would. For some it was staying positive and keeping a balance in their lives.

What could make the biggest difference to you now?

Answers were often around treatment -

"better pain relief"

"Don't want to wait for knee replacement till my 60's"

Some participants talked about wanting to get rid of anxiety. And, of course, getting rid of coronavirus featured regularly.

PAIN PEOPLE PLACE

Interviews were summarised in relation to the three themes. However, it's important to stress that, in analysing themes, we shouldn't lose sight of the much more fundamental emotional content of each interview, which is difficult to fully capture. The team carrying out the interviews talked about being impacted by the sadness and distress of many of those they spoke to, much of it related to the loss of contact, isolation and uncertainty.

“THE LEVEL OF EMOTION AND UNMET NEED WAS RAW”

PAIN

Not surprisingly the predominant themes emerged around pain. Most people found rating their pain very difficult⁴.

When the question was asked about how well the pain was managed, this was usually followed by a pause. Rarely was the answer, “well”. More often the question was answered with an apologetic, “not very well.” There was a level of shame attached to that⁵. Certainly, in the main, the person saw it as, to an extent, their failure, even when they went on to describe factors not necessarily in their control.

To illustrate her pain one woman, who had answered “not very well”, went on to say:

“I only sleep a few hours at night, it's from the pain in my hip. Every night I waken crying with pain and my husband says I moan in my sleep”. She rated this as 7-8. When she was asked about the impact of lockdown, she said her life had not changed - “my life is lockdown” and explained that her pain is so bad that there is no pleasure in going out.

This was echoed by a young participant whose pain control had declined with lockdown. She said that, at times, it felt that whatever she did, it only made things worse. And, like others, she felt trapped by it.

Medicating/coping/self-managing

The majority of participants used pain killers of some description. Although side effects could be troublesome and regular (cluster headaches, stomach problems, feeling dizzy or drowsy), people were still in search of the ‘holy grail’ of a perfect pain killer that worked and caused no side-effects. Most people, over time, settled for some kind of compromise between the side effects and the pain.

This ‘hope/compromise’ cycle has an impact on how people live their lives. The hope that medicine could be the solution is paramount even when experience suggests otherwise. And this is one of the key challenges of developing self-management solutions: shifting from the possibility of a magic bullet means letting go of an element of hope. Few people spoke of self-management, either as a concept or in using some of the practices. There was little evidence that most participants knew about organised pain self-management approaches.

However, one participant had looked at other supportive approaches and felt that “people need to know that they need to self manage”. She felt that she managed her pain well, practicing meditation and yoga. She joined a virtual group during lockdown but missed her yoga teacher although she did say that the lockdown had made her more self-sufficient and that her confidence had grown as a consequence.

Yoga, Tai-Chi and meditation were mentioned by a number of participants as helpful and there was a recognition that exercise was important. However, some people were stuck in trying to find a balance between exercise and accommodating any pain which accompanied physical activity. Avoiding the side-effects of painkillers – tiredness, loss of balance, dizziness – was also a concern. Formal classes were preferred to home-based/individual options as these offered reassurance and an opportunity to calibrate the balance of pain and gain.

Hydrotherapy

Several people spoke of the benefits of hydrotherapy, how it helped both mobility, strengthening of muscles to support painful joints and reducing pain. “You can get so tense

4. Observation from project consultant: “Perhaps this kind of rating is best in the here and now; like for post-operative pain. Ratings that use images rather than numbers might be easier to relate to. Or focusing on when, where and how pain is worst or triggered would be much more valuable”.

5. One of the reflections of the interviewers was that, in asking this question, “did participants hear an echo of the judgement they might experience in healthcare when trying to talk about managing pain?”

being in pain all the time, the only place I'm able to relax is in the hydrotherapy pool." One community had fundraised to build a hydrotherapy pool, which people attended up to twice a week. At £10 a session it meant it was out of some people's reach as a regular option. Others had access through the NHS but that tended to be limited to post-op or post-injury where the need is likely to be short term. Hydrotherapy as an option in supporting people to manage pain remains an important feature of the chronic pain landscape, especially at community level.

Joint replacement surgery

Access to joint replacement surgery was important as either an urgent need or as something which people hoped they would have recourse to when needed. Only a few participants complained about extended waiting times - about how long it takes from the decision to operate to the operation itself. The issue most raised was about criteria for surgery. Several people (in what was a small cohort), spoke of being told they would have to wait until their 60's for a joint replacement, even if that was, for some at least, twenty years away. One woman had an early form of osteoarthritis and was told by a doctor she was too young for surgery, despite it being a confirmed diagnosis from x-rays and scans.

Being rejected for surgery when your pain is getting worse, and your sleep is impacted affects every aspect of your wellbeing. It may worsen the situation, triggering long term issues with poor mental health, weight gain, chronic pain and loss of sleep. Using an arbitrary age, in this case, over 60, to judge clinical need seemed counterintuitive and represents a form of rationing.

“I FELT LIKE THE WORST MOTHER”

6. Arthritis as a long term condition was felt by many to be under-recognised and poorly understood – “maybe we need a campaign to let people know about arthritis”

Services

There is no doubt that formal healthcare plays an important role in how the people we talked to feel that they cope, and when that is lost they feel 'abandoned'. When lockdown started and services stopped or receded there was little recognition that 'patients', as part of the health-care team - 'partners in care' - also needed to know what was happening, and to have some kind of plan or shared understanding of how they would be supported to manage through the pandemic. For most, there was nothing. Even when they were shielding there was little communication. A person-centred approach was evident in some of the clinical and nursing relationships that people talked about, but little of this had any formal context, which left people vulnerable to external changes, especially in relation to services.

Recognition and understanding

Several participants talked about the lack of understanding of how difficult it is to live with chronic MSK pain.

“I live from one operation to another, with pain in recovery and the pain from the inflammatory process all the time”

People try to protect those closest to them, saying, **“I'm fine”**.

“Your pain affects your family too...I often feel he must be thinking, 'what a moan' and 'not another operation!'”

“I also feel bad when my arthritis⁶ stops me joining in with my grandchildren. So the pain affects everyone”

“I feel worthless”

“I felt like the worst mother”

PEOPLE

Services

Across participants, a sense emerged that a medical model persists in people's beliefs about what helps them to manage chronic pain. Many looked to their GP for help and support as, essentially, in their experience, there is no one else. Covid-19 has illustrated this in a very poignant way as many felt cut off from their GP. They could no longer make an appointment to see someone, instead being redirected to phone consultations. One person described the frustration of needing a face-to-face consultation, which took three calls and an email. 'Abandonment' was mentioned several times and it was suggested that someone checking in on them by phone, maybe even the receptionist, would have helped them realise that they hadn't been forgotten. Some mentioned not being believed in terms of their experience of pain or their condition.

"I just needed someone to put their hand on my shoulder and say I'm doing fine"

Specialist care was also criticised for just "dropping" people, including at times which might be critical, such as being started on a new medication. One person was supposed to have regular blood tests, because of potential damage to organs such as the kidney or liver, but had not been followed up for tests or even been contacted. People described being left fearful and alone.

"I was seeing the physio weekly until March and now nothing" (October was month of the interview).

Many had had regular follow up missed with no communication of the reasons or possible timelines for future appointments. Of course, the pandemic was recognised as the reason for this but there was hope that some things would be returning. Perhaps the biggest issue was lack of communication.

"We were told to remember the NHS was still there for us, but that wasn't my experience"

However, others remarked on how supportive their GP was and that they spoke to them on a regular basis (e.g. every six weeks).

For people living with long term conditions, care is at its best and most effective when it's relational. Whether it involves the GP, nurse, consultant or a care worker, care needs to be person-centred, discursive and collaborative. The experience of the people we talked to illustrated what happens when this is compromised or lost.

Informal networks and support

Informal support was key to everyone we talked to, family being mentioned as the biggest factor, although some people's families were physically/geographically remote and, therefore, not part of their practical support system. However, the greatest value of families was felt where they combined practical support – from help with shopping to elements of personal care – with emotional support – the hug of a grandchild was mentioned – and used this to gain the insights in order to play an advocacy role, i.e. to be part of the discussion around services and support.

Mental health

We asked people whether their mental health had been affected by lockdown. **"Oh God, yes!"** was the answer that captured the experience of many.

On occasion, those who were more rested because of lockdown, answered that their mental health had improved, as had their pain. But they were the exception; mostly, people felt more anxious, had sleep disturbance and some low mood issues .

When asked if lockdown had specifically affected their pain, all said yes, although, for those who had been able maintain some element of exercise, the negative impact was less.

The experience of pain is manifold - physical, neurological, emotional, social - and what emerged from the interviews illustrated this again and again. The loss of 'hugs' can be as instrumental in the experience of pain (and the capacity to manage it) as access to medication or services.



PLACE

Most of the people we talked to lived in rural or semi-rural areas, in areas of low population, sometimes widely distributed. The impact of living in these areas was particularly felt in relation to transport and travel, e.g. in the need for access to a car (and a driver as some were unable to drive) to travel to specialist appointments, exercise classes, etc. Travel itself can be exhausting and painful, so, for some, the use of phone calls and NHS Near Me had been especially helpful.

Access to walking in quiet areas was mentioned by several people, reflecting on 'closeness to nature' and that this could have a similar impact to the social connectedness more readily available in towns and cities. For some, lockdown had got them out into their wooded and hilly areas, reconnecting with the here and now, reducing stress and having an impact on wellbeing.

Access to a garden was also valued highly by many - for sitting, achieving their 'daily steps', or gardening itself. Many had their own gardens but not all; some had to access garden areas from high-rise flats and others from tenements, possibly a local park or allotment. Whatever the location and circumstance, access to the 'garden space' raised spirits, enabled connection and had a positive impact on their experience of pain.

Employment

Employment/workplace arose as an issue for those who were working throughout the pandemic and for some who were furloughed. The main issue was working from home, which was generally a mixed experience.

Not having to travel was a significant benefit for many who already found work travel painful and tiring. This was described as 'life changing' by several people. Some had asked to work from home before the pandemic, to help with pain and mobility, but had been refused. It wasn't lost on them that the societal pivot to home working exposed an unjustified lack of flexibility by employers. For some, the main impact was to leave them frustrated and angry. For others, feeling less tired and sore was enough of a gain to obviate any underlying sense of injustice. They were able to self care more, had time with family and most couldn't imagine going back to the previous arrangement.

However, some of those we talked to had young children at home and found the challenge of home schooling and working had a significant impact on the energy they had left to manage their pain. For others, it was felt most in their job shifting away from the face to face and relational, stripping it of the very thing that gave it value. And, of course, people missed their work colleagues and the friendship, support and emotional care they provided, all of which had contributed to their day-to-day management of pain. For some of those who had been furloughed, there was a realisation that their job, which was active and mobile, was an implicit part of how they self-managed.



LEARNING AND DEVELOPING

Pain People and Place: we started planning this project with only three 'P's' but soon added a fourth: Pandemic.

Although our initial purpose was focussed on listening to the lived experience of people with chronic MSK pain in their communities, the impact of the pandemic became explicit in what people told us.

Nevertheless, for all the circumstantial change – access to services and support, challenges of shielding, home working - the pandemic fundamentally exposed and amplified already existing factors in how people lived, day to day, with chronic pain: the importance of informal networks; the lack of support for and access to self-management; the need for physical activity (and the spaces to walk and exercise); the importance of the workplace and flexible approaches by employers; the need for ongoing communication with services. And, at root, the need to be seen and understood.

This report is an attempt to illuminate the landscape of chronic pain in Scotland. It isn't a policy report but should help inform our approach to policy, strategy and services. It reflects the lived experience of twenty three people in Grampian living with pain during a pandemic, parameters which denote both the strength of the content – particular people in particular communities talking in their terms during a critical period – and the need to build on this to bring other voices into the discussion.

However, we are also in a position to respond directly to what people told us, to help build capacity for self-management support in the Grampian area. Versus Arthritis staff are already working with project participants to develop a virtual support group, an outcome which reflects the development ethos which drives our work in Scotland.

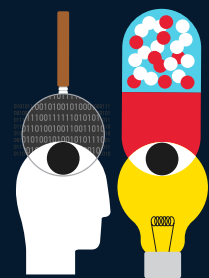
NEXT STEPS...

This is the first phase of an ongoing project and we are now scoping the next phase – looking at other geographical areas and issues around health inequalities.

The Grampian work will be fed into the work of the National Advisory Committee on Chronic Pain, the Chronic Pain Reference Group and the

development of the new Framework for Chronic Pain Service Delivery.

We will also look at the implications of what people have told us for our work on self-management, employability and physical activity.



Project consultants: Audrey Birt and Hazel Mackenzie (Birt Associates)
Project management: Alan McGinley, Angela Donaldson-Bruce
Project support and development: Phillip Neville, Joanne Moss
and thank you to all the participants for their time and their insights.