

**SUPPORT OUTSIDE OF
THE CLINICAL WORLD**

**JOINING SERVICES
TOGETHER**

**INVOLVING PEOPLE WITH
ARTHRITIS TO SHAPE
HEALTHCARE**

**TACKLING WAITING LISTS
AND SUPPORTING PEOPLE
WHILST THEY WAIT**

MAKING CHANGE HAPPEN

Sharing stories to improve services in musculoskeletal care

**VERSUS
ARTHRITIS**

MAKING CHANGE HAPPEN

SHARING STORIES TO IMPROVE SERVICES IN MUSCULOSKELETAL CARE

Versus Arthritis exists to enable people living with arthritis and other musculoskeletal (MSK) conditions to get the best possible information, treatment and support they need at the right time for them. There are an estimated 20.3 million people in the UK with an MSK condition¹. People living with these conditions tell us that they value and rely heavily on input from healthcare professionals, but only just over half are satisfied with the support that they receive². Conversely, healthcare professionals report lack of time, some lack specialist skills, and many feel helpless when supporting people with MSK conditions³.

The Covid-19 pandemic has brought unprecedented challenges for health and social care across the UK. Working in changing environments with mounting pressures, fewer resources, and ever lengthening waiting lists, lots of local health systems are considering how to change the way they work to meet the needs of people with arthritis now and in the future. Delivering impactful improvement takes time, relationships, and resources. The size of the task that lies ahead can feel complex and daunting, but at local level, attempts at improving are happening every day.

Formal case studies can be powerful at igniting change, but all too often they only share what went well, giving imbalanced and sometimes unrealistic experiences

for others to act upon. Based on the feedback we have received, Versus Arthritis is for the first time adopting an informal storytelling approach to describe attempts at improving care. These stories are from different parts of the MSK pathway, from a range of professionals across the UK. They vary in their levels of evidence, scope, scale, and methodology. We have tested this approach with decision makers as well as people with arthritis, who unanimously agreed that informal, non-technical, 'warts and all' stories, add the most value to their existing thinking.

Versus Arthritis advocates the implementation of evidence-based interventions and treatments, and firmly supports the involvement of people with lived experience in the designing of local services. However, we acknowledge that this sits alongside high quality exploratory and innovative front-line work led by brilliant people up and down the country. These efforts and experiences are worth sharing, so others can decide if there might be potential for making similar changes in their own area.

We have loosely grouped these stories into themes to help you navigate this catalogue, and we hope to add to it over time.

To submit your own story, or share your views, email
Healthservicesimprovement@versusarthritis.org

¹ Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2019 (GBD 2019) Results. Institute for Health Metrics and Evaluation (IHME), Seattle, 2020.

² Unmet Needs Study, online panel of 2246 people with arthritis – Revealing Reality December 2020

³ Healthcare professional Insight – Kantar Public – 2016

ENDORSEMENTS

“All the stories are shorter and less formal to other case studies, making it easier to feel like one can apply these changes at work. At their best, they highlight the important role relationships can have on the success of projects.” Larry Koyama, Head of First Contact Practitioner Implementation at the Chartered Society for Physiotherapy and Versus Arthritis Clinical Champion

“I really like the storytelling, reflective approach of what worked and what didn't, including some top tips.” Emma Mair, Pain Management Physiotherapist, NHS Ayrshire & Arran

“There is a good spread of how people with lived experience can take part in a range of different projects and use their voice to shape things for the better.” James Warren, Versus Arthritis Volunteer

“Personal stories are easier to relate to and visualise.” Carolyn Chalmers, National Improvement Advisor, Modernising Patient Pathways Programme, NHS Scotland National Centre for Sustainable Delivery

“I will use these case studies in our MSK transformation work. I will use them with multi-disciplinary groups and our MSK Service User and Carer Group to get their views about whether we should do some of these things locally.” Elizabeth Williams, Transformation Manager for Planned Care, NHS Bristol, North Somerset & South Gloucestershire CCG

“Real human experience resonates with acknowledging the challenges. If it all appears rosy it probably isn't true and won't feel credible.” Jane Ferreira, Head of MSK Together, Mid Nottinghamshire ICP.

“I like the ones that are evidence based, likely to deliver impact and be replicable.” Ruth Sephton, Consultant Musculoskeletal Physiotherapist, St. Helens and Versus Arthritis MSK Champion

“Cascading information like this increases the opportunity for it to be 'taken up' by somebody and repeated which can only lead to better care for people like me.” Debra Dulake, Versus Arthritis Volunteer.

“These stories are inspiring but also outline the challenges which clearly can be real barriers to change.” Gwyneth Richards, Advanced Physiotherapy Practitioner, Hywel Dda University Health Board, Ceredigion

“I will share these with colleagues when looking at service design or change. They provide readers with a solution to an issue, or a path to resolving it, helping staff feel that they can overcome obstacles.” Mark Etherton, RightCare Lead Manager, East Riding of Yorkshire CC

“ARMA welcomes these stories which will be a resource for everyone working to improve services. They are real and allow people to learn from others facing the same challenges.” Sue Brown, CEO, ARMA

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- The Complex Pain Team in Camden
- Multi-disciplinary Team working North Tees & Hartlepool.
- Volunteer led, group pain management courses in Clough GP surgery

How might we involve people with lived experience to shape local healthcare?

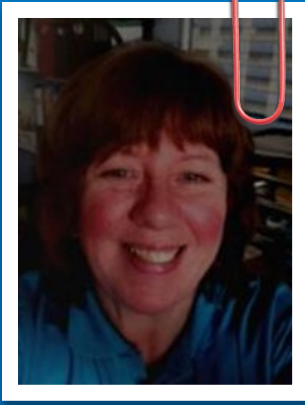
- Community of Practice in physiotherapy across Staffordshire
- Power shift at pain clinics in Bristol

How might we tackle waiting lists, and support people whilst they wait?

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Stories of change

SUPPORT OUTSIDE OF THE CLINICAL WORLD



Fiona Collins

Specialist Rheumatology
Physiotherapist

Fiona.Collins3@ggc.scot.nhs.uk

Stories of change

MOVING FORWARD WITH FIBROMYALGIA IN GREATER GLASGOW AND CLYDE

This pilot service developed a Tai Chi group and education as a treatment for fibromyalgia.



What we did

Our initial programme started 15 years ago and was hospital-based. We offered hydrotherapy classes and education sessions. We couldn't meet the demand for hydrotherapy as so many patients were being referred, so we changed to low-level group-based exercise classes. We've evolved it onto Tai Chi sessions, where people can sit or stand. In addition, there is group pain management and education. We teach stretches and talk about pacing. This combination seems to be the most successful. We try and offer a stepping-stone into community activities. We did not accept direct GP referrals because demand is so high. We got funding from a single health and social care partnership to run a pilot scheme in local leisure centres. This covered a part-time assistant practitioner, some admin and leadership support to change the outpatient services.

Our motivation

Treating fibromyalgia is challenging, and in some areas, there is no patient pathway. People seeking help sometimes report they are not believed by professionals. Some areas are remote, and people struggle to access healthcare. We used a hydrotherapy pool for chronic pain, but the need was so great, I knew we had to investigate different models for pain management.

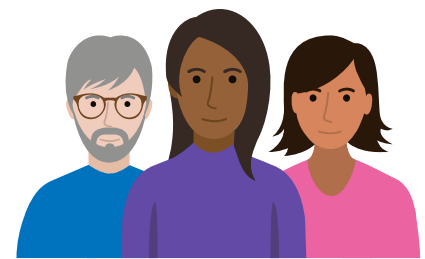


The difference we are making

Evaluation showed patients like the groups. Every so often I will get a letter or a card from a patient that says this has completely changed their life. Completion rates are always going to be variable. Those living with more severe symptoms did not do as well as those with moderate symptoms.

What's next?

A year from now, I would like to have organised a pilot project where we can support expert patients who are interested in becoming role models for others to take the programme forwards.





Making change happen

I feel so sorry that these people don't get the help they need. I've heard so many times from various professionals through my career 'Oh, we don't do fibromyalgia' and you wonder what is going to happen for them then? Pain is pain. These people have really difficult symptoms to cope with. We've come to the conclusion that we shouldn't call it fibromyalgia in our area. Maybe just pain or chronic fatigue. The stigma is still there.

Early intervention is crucial, so we must find more ways to support people as early on their journey as possible. Timing is also key. If people get help when they are at their most ready, they can make great progress and have a life changing experience from the help they receive. 'Living Life to the Full' is a helpful Cognitive Behavioural Therapy resource, and we also give out the Versus Arthritis leaflets to people.

More needs to be set up outside of the NHS, so patients are helped in places they can keep on attending. This helps them feel that their best coping strategies lie in their community.

Getting better from fibromyalgia is like a game of Snakes and Ladders. If we can get you off the bottom line, then that's progress. But life will continue to be full of ups and downs. We can't undo ten years of pain in a few sessions in a clinic. Accepting little bits of progress is what we should focus on. Being able to say 'What do we want to be able to achieve here?' would be a good way to look at it, rather than setting goals that will fail both patients and professionals. Staff want to get job satisfaction and you don't always get that with fibromyalgia. That needs to be acknowledged too.

Most people with fibromyalgia are unfortunately still not able to access this service. So much more needs to be done to help people living with this condition.

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"If life was just one big hydrotherapy pool that would be great, but it isn't."

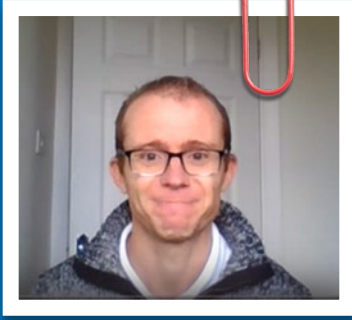
Top tips

- Support services are best set up in the community rather than in healthcare settings.
- Find ways to work on the negativity from some professions and help reduce the stigma by re-framing what is possible for people living with fibromyalgia.
- Sharing peer-to-peer experiences does help.

"I found speaking to others on the course helped, as I didn't feel it was just me complaining. I was not alone in how it affected people." Participant



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David Easton

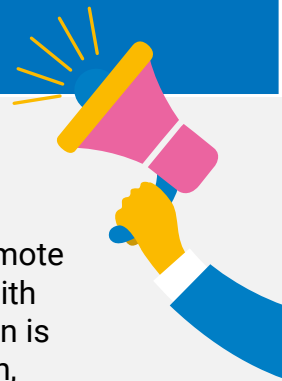
Physiotherapist and
Clinical Champion

David.Easton@wales.nhs.uk

Stories of change

SPREADING ESCAPE-PAIN ACROSS WEST WALES

Scaling an evidence-based, group education, self-management and exercise programme for people aged 45+ with knee and/or hip pain.



What we did

In April 2019 I became a clinical champion and had time away from my day job to promote and embed ESCAPE-pain into health boards across Wales. I worked in collaboration with clinicians and system leaders, as well as the leisure sector, to ensure that ESCAPE-pain is offered as a routine core treatment option in Cardigan, Cardiff and Vale, Aneurin Bevan, Betsi Cadwaladr and Hywel Dda. People with knee or hip pain are offered a six-week, 12-session group education and exercise class with a trained facilitator to help them manage their symptoms.

Our motivation

People with arthritis often receive conflicting messages about how to manage their pain.

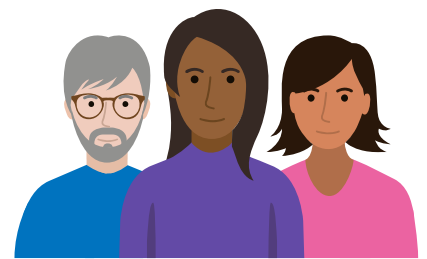
Healthcare professionals are under time pressure and do not have anywhere they can send people for structured education, exercise and peer support combined.

The difference we are making

ESCAPE-pain is an evidence-based programme with a return on investment of £5.26 for every £1 spent. Participants report improvements in pain, function, psychological wellbeing, and less reliance on medication. Those results played out in Wales. Group models are so important for people. We saw belief systems entirely changed.

What's next?

We've created an All-Wales ESCAPE-pain Team Network. I am hoping this will be part of the recovery plan from Covid-19 because we are not going to meet waiting-time targets.





Making change happen

I completed change management training that helped me think everything through. I created allies, but it was a slow start. I worked with the leisure sector and negotiated free use of the facilities. Finding the right location for classes and building up referrals from colleagues took time. My passion and drive for helping people living with pain kept me going. It was frustrating, but I got confidence knowing that other people had been here before me scaling ESCAPE-pain, and change had stuck. As long as I implemented the model that carries the evidence base, I knew the impact would be incredible.

I did everything I could, that I didn't need permission to do, before I approached the decision makers. Then, I went into those key meetings like a bull in a china shop. I should have tuned into everything else first, asking how my change was in line with what the senior leaders wanted to focus on at the time. There was initially resistance from the system to change. I used the data and evaluation as well as local need to help me make the case. I've had to be honest that we won't see the financial impact on the wider system for another three or four years. The ability to keep being able to push back and demonstrate the evidence helped. But, it was all set up and ready with patients on a waiting list. That's how we got a 'yes' to one programme. Groups started and patients became our strongest advocates, telling their friends to ask for referrals too. I had a support worker to help things run smoothly. Gradually, more sites started up.

It would be really clever to take patients to those senior leadership meetings. We sometimes are so desperate to make services better for patients, but we forget to bring them with us. Rather than it being difficult, we just don't do it. I think it would be warmly received.

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“Solutions will bring other challenges, and that’s ok. It’s a normal part of the change process to have barriers and continuing difficulties.”

Top tips

- Work with the willing. Look for allies, and if you don't find them, keep looking, and invite them back later.
- Workforces are dynamic, so make sure that people who are driving the change can make it stick.
- Repeating the same messages multiple times does help people change their thinking over time.

Want to know more?

www.escape-pain.org

hello@escape-pain.org

[Ken's story](#)

[Celebration video - patient and partner experiences](#)

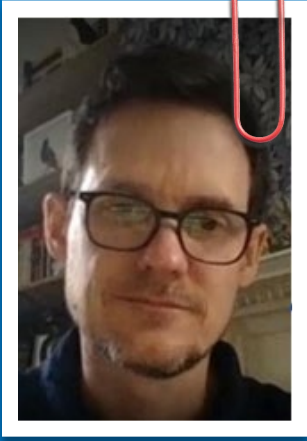
[The story of scale up report](#)



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Dr. Chris Jewitt

GP in Gateshead,
& Prescribing Lead for
Newcastle Gateshead Clinical
Commissioning Group (CCG)
chris.jewitt@nhs.net

Stories of change

REDUCING OPIOID PRESCRIPTIONS IN GATESHEAD

Incentivising change and working together to tackle excessive pain medicine prescriptions in the north east of England.



What we did

There's plenty of evidence now that shows chronic pain does not respond well to opioids. To tackle high levels of prescriptions in the north east of England, our Clinical Commissioning Group (CCG) supports local GP surgeries to reduce the number of prescriptions by providing data, support, and visiting local GP practices. Together, we share information, best practice, success stories and innovative ideas. We've also been financially incentivising change. It keeps these important issues on the agenda, by giving a reward for doing this work.

Our motivation

The National Institute for Health and Care Excellence (NICE) guidelines on the treatment of chronic pain in England recommends that pain medicines such as gabapentin, other opioids and paracetamol should not be prescribed because they may not work, could be harmful and/or cause addiction. Many people living with pain take these drugs long term.

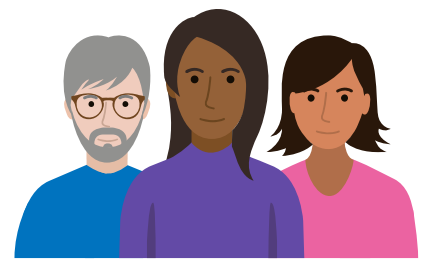


The difference we are making

Data shows that opioid prescriptions in the north east are down almost 25% and at our GP practice it's about 27% over the last two or three years. That's the big headline figure. There have been reductions in the prescribing of gabapentinoids by 17% as well, but we're tackling both issues head on.

What's next?

We've always intended to do more work on involving patients and I think we've done that on a bit of an ad hoc basis. It's very difficult to coordinate it on limited resource.





Making change happen

Historically these drugs get prescribed short-term, but then inadvertently that continues longer term. People often end up getting their doses increased because they get used to a particular dose, so it becomes less effective and then the easiest thing and the knee-jerk reaction is to increase the dose, but then ultimately that becomes ineffective and just makes the matter worse. There are also ongoing social challenges associated with the diversion of opioids to other people in our area. Drugs prescribed by a doctor sometimes get sold on by patients to people who are addicted to them.

The driver for reducing these drugs is not about cost. They are not expensive. It's purely about health benefits for people. One of the main issues is that they create dependency and so these drugs can lead to patients feeling that the drug is giving them some benefit, but it isn't helping their pain. It might just be helping them in some other ways which we would recognise as harmful, but the patient may not. People are also more likely to be prescribed other drugs and end up in hospital. 10% of hospital admissions are due to medication-related problems, so this work has wider benefits on the healthcare economy and system.

Reducing the number of pain medicines offered to people living with pain is often time consuming and difficult. It's getting harder as time goes by because it's easy to get quick wins with patients who are willing, but then you end up with more challenging consultations. It has been very hard in lockdown having conversations about reducing doses over the phone. In addition, people continue to get these drugs from other parts of the healthcare system, which makes it very hard for GPs.




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“People living with pain who have been given these medicines for a long time, are suddenly being told to just cope with the pain better. It's a really hard message.”

Top tips

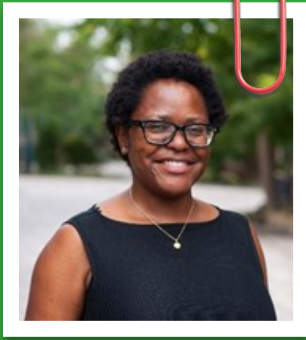
- Providing data, support and encouragement is helpful.
- Clinicians and prescribers should do a thorough medicine review regularly.
- Look for ways to reduce doses, plan reviews to avoid repeat prescriptions, and have these discussions whenever possible.
- A practice-wide policy is helpful and avoids patients receiving conflicting advice from different clinicians.
- People living with chronic pain often find Tai Chi, Pilates, gardening, gentle walking, wildlife groups or just someone to talk to helpful.



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Stories of change

JOINING SERVICES TOGETHER



Jackie Walumbe

Advanced practitioner physiotherapist in pain at University College London Hospitals & doctoral researcher
jackie.walumbe@nhs.net

Stories of change

SUPPORTING PEOPLE EXPERIENCING CHRONIC PAIN IN A&E AND HOSPITALS TO GET THE HELP THEY NEED FROM COMMUNITY SERVICES IN CAMDEN

A roaming, innovative multi-disciplinary team (MDT) working with patients across hospitals, community services and primary care.



What we did

A two-year pilot took a relational approach to change, meaning we focussed on establishing working relationships with people in different organisations and with patients, carers and family members. A new MDT was created with pain consultants, nurse specialists, specialist pain physios, pain psychologists and admin support. First, we collected a range of data, as well as patient and staff experience. We targeted people attending hospital (and being admitted) with complex pain and took time to better understand the issues contributing to their symptoms. We worked across the health sector to provide the 'right care at the right time'. We offered bespoke education and case-based support. We worked with patients who had repeated and chaotic inpatient stays or emergency attendances and tried to set up more local and long-term support in the community.

Our motivation

Healthcare professionals feeling unable to help people with pain who were hospital inpatients. Organisational benchmarking showed outcomes and efficiencies needed to be improved. Survey results showed a groundswell of patients telling staff things needed to be done differently.



The difference we are making

People became active managers of their long-term health conditions. They reduced medication, became more active and avoided unproductive use of resources. Total cost of the pain service to commissioners is £541,585 with estimated savings generated in the region of £550-700,000. Staff reported feeling less distressed.

What's next?

I hope in two or three years, we might be able to move to wherever there is need. I would like to do it all again in the next borough, the next area, the next town.





Making change happen

We started by talking to people in hospital with pain, who would say things like ***"I go to my GP. I'm on medication already. I've been to the pain clinic. I've seen a rheumatologist. I don't need an operation and I've seen the physiotherapists and an osteopath. I'm just going round and round."***

As this was a new service, it was about winning hearts and minds. The team had a specific remit to support a range of healthcare organisations in improving pain management. We attended a series of study days for hospital staff. We went to GP events. We did home visits with other practitioners. Network meetings were a huge part of it. I'd go down and sit in A&E for the day, just to talk to anyone I could. We left a lot of cards. We also trained nurses as our champions, so they helped spread the word.

The model I thought was going to work has not worked at all. I thought we'd be teaching patients to take personal responsibility. However, what I found worked for me was quite different. It's not an education package and off you go, but you keep dipping back in and checking in with people. Case management is something we don't do very much of. Maybe we should do it more because that's made a huge difference.

There's a pull for certainty when things are messy and complicated, but we made a commitment not to become too rigid as a service. This can only work if we have the flexibility to work with patients and other services in an iterative way. Big plans haven't been good for us. Instead, we tried things for a couple of weeks, then asked "How's it going? That's not working." Changed it. We collected data, measured, and told everyone about it.

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"There's an ongoing struggle here, because we should have a nice little outcomes box we can tick, but we want to maintain our ethos of roaming across services. If we can't cross the silos and the boundaries, then I'm not sure that we would be very effective."

Top tips

- Collect and use data, collect patient stories, and bring people with lived experience on board so they help you define the problem.
- Understand your decision makers, local drivers, policy and metrics that underpin the priorities.
- Use continuous improvement tools and implement in a cyclical and iterative way.
- Talk to everyone and anyone, taking a relational approach to change.
- Stay versatile and flexible.

Want to know more?

[Patient Voices video](#)



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Lynsey Hetherington

Integrated Musculoskeletal
Service Lead at
North Tees and Hartlepool
Foundation Trust
lynsey.hetherington@nhs.net

Stories of change

INTEGRATING SERVICES TO PROVIDE BETTER CARE FOR PATIENTS IN NORTH TEES AND HARTLEPOOL

Building relationships across services including rheumatology, nurses, physiotherapists and other MSK clinicians, service leads, and patients has led to more joined up and timely care.



What we did

The integrated MSK service at the Foundation Trust has linked up to work more closely with pain management and rheumatology services. We went through a collective coaching process to tackle some of the complex challenges across our systems. Together, we have created a new pathway that went live in October 2020. There is now a single point of access, where the MSK leads triage everyone who comes through the service. Other changes include:

1. Steroid injections moved to physiotherapists to add to rheumatology capacity.
2. MSK services signpost people to wider support such as ESCAPE-pain.
3. Redirected people experiencing fibromyalgia and hypermobility to MSK services.
4. A 'ghost' referral system has been set up so people can digest information and activate support a time that is right for them, rather than being sent an appointment automatically.

Our motivation

Waiting times were long. Services weren't provided at the right place or the right time for patients. Not all patients found review appointments helpful or necessary. Rheumatology capacity was not well utilised for a wholly rheumatology caseload.

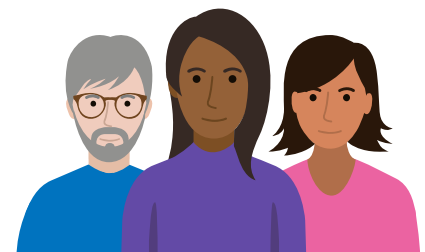


The difference we are making

We only have a small amount of evidence. We have reduced the number of referrals into rheumatology by 18-20%. Those patients will have a better range of options in the MSK service.

What's next?

We are working hard on a virtual hub, to make sure patients are getting the best possible information at the earliest possible time.





Making change happen

The stakeholders from Integrated Care System for this work included rheumatology, nurses, MSK clinicians, service leads and patients. We got together and outlined what challenges we faced. Then we split into smaller groups to come up with some quick wins. We decided to create a new pathway. In order to support this, the Trust decided to support a coaching approach for service leads and clinicians. We used a company called 'Think On' to coach us. Our facilitator guided us, kept us on track and held us accountable to the changes we agreed on. This process removed the learnt mental history about old dynamics and ways of working across teams and opened our minds to new ways of doing things together. It allowed us to be exploratory and look for solutions. From that, we decided to develop a single point of access for every patient who was referred into our services collectively. We agreed on the components for keeping patients safe and set up lots of safety nets accordingly.

I have had to embed all the new ways of working into processes, like IT. It was like mind gymnastics! It has been extra challenging because IT and admin have been caught up with covid recovery. We struggled to test the electronic referral service, which we've had to review. We triage all new referrals once or twice a day, flagging appropriate referrals to rheumatology.

We probably made a mistake at the start by not inviting GP's into the coaching. We are still questioning whether we should have had patients involved for that part too. Having included patients in the initial stakeholder discussions, we are working to become more experienced and confident with patient involvement as a Trust.

Linking patients to different pathways to the Community Pain Management Clinics is really important and we continue to work to improve this.

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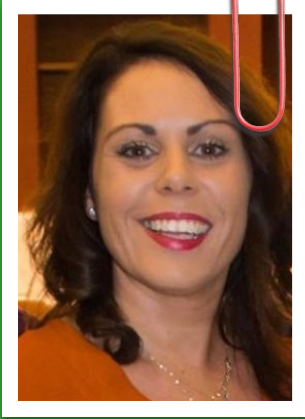
"Even if we didn't all agree with the final decision about what would change across the services, because we'd been part of the process together, it has been easier for everyone to support it."

Top tips

- Having the time to step back and look at what you are doing together is invaluable. Coaching did this for us, and helped us think about what needs to change, and why. A high-quality facilitator really helped.
- Taking a gamble to release clinicians and service leads for two consecutive days was a risk, but it paid off.
- Connections with people are crucial. One miscommunication can put those barriers back up. The harder we've worked on our relationships, the lower the barriers across teams have got.
- Involve GPs and patients from the start.



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Gemma Mallon

Senior Social Worker,
Dundrum and Clough
GP Surgery

gemma.mallon@setrust.hscni.net

Stories of change

IMPLEMENTING VOLUNTEER LED GROUP PAIN MANAGEMENT COURSES AT CLOUGH GP SURGERY

Creating a new offer for people who were experiencing pain was given full clinical support and buy in from the outset across the multidisciplinary team (MDT).



What we did

Two years ago, a multidisciplinary team (MDT) was set up at Clough GP Surgery. This meant patients could see a GP, physiotherapist, advanced nurse practitioner, social worker or pharmacist within their own GP surgery. Versus Arthritis already ran pain management courses in other places led by volunteers, so it was mutually beneficial to take this idea forward, with full clinical support and buy in across the MDT. A social worker and social work assistant invited 65 patients from the surgery to join two separate programmes as a trial. Letters and leaflets were sent out, with an optional open evening before the course for people to help decide if it was for them. Two six week pain management courses were then successfully delivered by Versus Arthritis Volunteers, both at capacity of 15-17 people.

Our motivation

10% of patients in one surgery were living with pain such as back pain, fibromyalgia and arthritis and not getting support. Nothing was available in the community to help people with persistent pain. People said they needed help managing their pain. There was a policy drive to reduce inappropriate pain medications in the area.

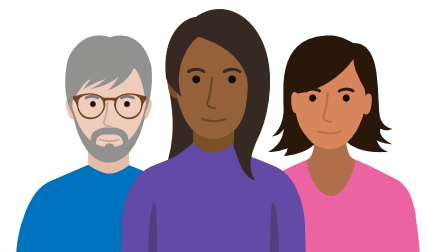


The difference we are making

Reduced patient attendance at the surgery. Reduced prescriptions and medications. Patients reported reduced isolation. Good attendance at physical activity groups. Post-course support was offered, including local support groups, walking groups and four Tai Chi programmes. These have been specifically set up for people to continue to self-manage through community activities.

What's next?

I am hoping to get it back up and running as soon as we can after covid.





Making change happen

It was such a bonus setting this up as an MDT, because all the services are in the same surgery. If we weren't connected like that, I don't think it ever would have happened. We wouldn't even have known what the drivers were that we could use to get conversations started unless we were set up this way.

Once we had done our mapping and come up with a plan, it was all about communication. We knew it would start small. It was really just phone calls to get things set up. We connected with Versus Arthritis and agreed how things could work. We agreed to each take on some of the costs like recruitment, resources, volunteer expenses, venue and refreshments. We need to use the voluntary sector more, because they have expertise of their own outside of the clinical world. For us, it was Versus Arthritis, but every area will have things they can tap into. Every GP surgery will have a list of people living with pain. Peer led trainer volunteers have brilliant rapport because they have lived experience too; it makes a big difference.

I have told colleagues about this work, and others have started looking into similar things. I couldn't believe the amount of energy and speed with which it has all happened. We're restricted by things like volunteer capacity and the list is still very long. I am hoping for 3-4 programmes each year with new support groups for people after the programme is finished.

Now GPs are recommending it, that endorsement makes a huge difference in terms of uptake. On one occasion we had a 86 year old who went into see the GP, who walked her down the corridor and into the pain management programme, which she completed. Once you have the patients and the buy-in from clinicians, positive things happen.

“Usually there is no one proactively scrolling through all these patient records to look for solutions. We did some mapping and came up with a plan.”

Top tips

- Information and evidence need to be out there. Try a newsletter for everyone to share what is coming up with the drivers for change and local plans.
- Get into the practice-based learning time for clinicians and get in front of them to talk.
- Show medical professionals exactly what they'd be sending patients to.
- Everyone needs to believe it will make a difference. Get everyone you can on board.

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INVOLVING PEOPLE WITH ARTHRITIS TO SHAPE HEALTHCARE



Kay Stevenson

Consultant, physiotherapist
& Honorary Professor of
Clinical Care and Leadership
kay.stevenson@mpft.nhs.uk

Stories of change

DEVELOPING A COMMUNITY OF PRACTICE IN PHYSIOTHERAPY ACROSS STAFFORDSHIRE

Translating evidence into services by building local partnerships and sharing power.

What we did

The National Institute of Health Research has brought all the available research from physiotherapy together into one document. Members of the Impact Accelerator Unit and Keele University convened a Community of Practice, made up of academics, clinicians, commissioners, service managers and people with lived experience. The group decided which interventions from the research document to implement locally. They did so by asking: Is this a clinical priority? Is this a commissioning priority? Is this a patient priority? Is it supported by NICE? Is there return on investment data?

Following that, these interventions were selected for implementation: STarT Back / iBeST / I-SWAP / ESCAPE-pain / IMPaCT Back



Our motivation

There is variation and inconsistency in MSK services across the region. This compelled us to find a way to even out those differences, using evidence to guide us.

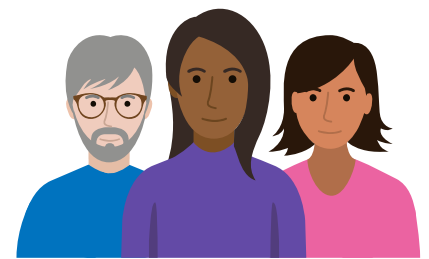
The difference we are making

STarT Back uptake increased. Created relationships between people with arthritis, clinicians & commissioners. Moved to virtual meetings due to COVID. Moved to evidence-based virtual exercise classes. Appointed first ever paid Physical Health Peer Support Worker. Wrote an Easy-Read version of the NIHR themed review.

What's next?

A volunteer has been recruited as the first ever patient in a paid role. Mike is going to be sitting with us in our meetings, holding us to account.

"The thing that has encouraged me is that the concept of the role and the response to it across many services has been so positive." Mike Brooks





Making change happen

Everybody is trying to do their very best for patients with muscle and joint problems. Some people are basing what they do on their years and years of clinical experience. Others are doing their very best based on the evidence, but that can create inconsistency. That doesn't happen in just MSK. Some services have never been exposed to the latest thinking or the latest evidence or research on what is the best thing to do for people with muscle and joint problems. In Staffordshire, that's what we're trying to even out. If you like, it is trying to make the offer as good as it can be, evidence-based and consistent for everyone.

For us in Moving Forward, the first step was deciding it was going to be a shared endeavour. Some services don't have a patient who sits with them to hold the mirror up and reflect back what they're actually doing. For the first time we had academics in the room, alongside patients who have lived experience of health conditions and use services, as well as commissioners who designed the services. We developed a Community of Practice to fulfil this function, and collectively decided how services should change. What were the most important things we needed to focus on across Staffordshire? When I looked around that room, I realised that a group like that had never come together before. We used some tools to help people understand the research, and then to prioritise it. It sounds fancy, but it was a table, that's all it was. Yes, no. Yes, no, to all the questions. So, at the end of the first meeting, we had a list of what we all thought should change. We looked at each other and thought, "yeah, that feels about right." We had translated the research document into a conversation, and a plan.

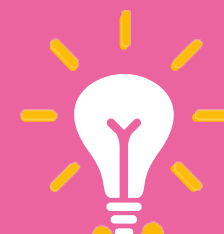
"We all look around at each other and wondered why we had never got together like this before."

Top tips

- Engage patients in the conversation about what good care looks like.
- Make friends with people outside your immediate sphere of influence.
- Contact those who have done it before because they can share their experiences
- Work with the willing.

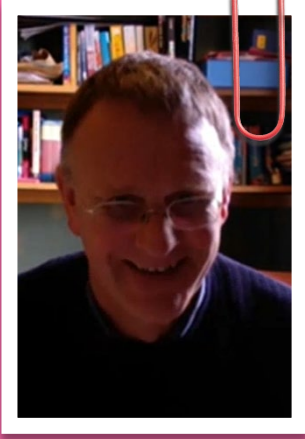
Want to know more?

[Moving-Forward.pdf \(nihr.ac.uk\)](#)
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Nick Ambler

Clinical psychologist and pain specialist at Southmead Hospital, Bristol

Nicholas.Ambler@nbt.nhs.uk

Stories of change

A POWER SHIFT AT PAIN CLINICS IN BRISTOL

We figured out a protocol for changing the ending of group clinics, so there would be long-lasting peer support without clinical input.



What we did

We realised that that the 'professionals know best' model wasn't working too well for many people. About ten years ago, we began training volunteers who had been participants at previous clinics, to co-deliver the training. This helped, but people needed longer term support and social groups to help them maintain their progress. One group helped us change our protocol, so a social network is now built by every group. This means group support carries on beyond the clinical input in a way that suits people's needs.

Our motivation

When people come to our pain service, they have been living with pain for an average of 8 or 9 years. They have struggled in their relationships with healthcare professionals who are unable to cure the core problem. Living with pain can be incredibly isolating. In healthcare, we don't address the social dimension of recovery. Not well enough anyway. People attending pain clinics often don't get good long-term outcomes.

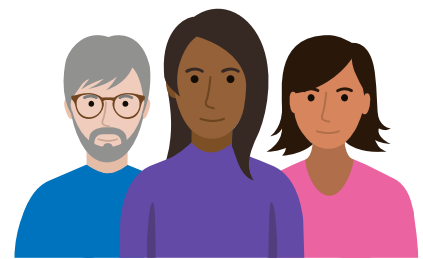


The difference we are making

Introducing patient tutors portrayed empowerment. Over 30 have since trained and worked alongside the professional staff. The idea of whole groups maintaining their own meetings flowed from this. Qualitative findings suggest patients have fewer setbacks. We have seen how groups gather around to support individuals when they need it. When additional professional support is required, individuals are much clearer about what specific help they need because they already have that social support around them. That reduces demand on our services.

What's next?

We have already partnered with a team in Southampton and another in Glasgow to help spread this approach. We'd also like to be able to gather more evidence about its impact both for individuals with chronic pain and for the healthcare system that supports them.





Making change happen

Ten years ago, we were running therapy courses for the effects of chronic pain in which the health professionals led everything. Two types of courses matched different levels of need and we ran in varying locations. We believed it was an accessible, flexible, effective set-up. We appreciated that course participants learned as much from each other as they did from the professionals and we nurtured this. We began a new model where people who had completed the programme trained as co-tutors, to act as a role model for how much can be achieved in the treatment programme. But we still underestimated their eventual impact.

When a course ended, many felt that they could get a great deal more from further support. There was a particular event at the end of one course when the participants directly challenged me. ***"This is not fair. You're gonna drop us, but we still need help. We've all found this useful. What are you going to do about this?"*** I put it back to them, that they figured out how best to move this forward and I agreed to support them. They found a venue and started meeting regularly, and there wasn't much more to it than that. I met with them 6 months later and they were really well organised. They had continued to follow the treatment method for tackling their areas of difficulty. They drew confidence from being able to solve problems and make progress without professional input. They learned from each other. They made it sociable, more pleasurable than attending a treatment course and they supported each other when anyone had a difficult spell.

I asked for help to figure out how we could encourage others to do what they had done. Eventually, I mean several years later, we had a protocol that changes the end of our groups. A volunteer visits to describe how to set up. There's a video and information. The therapists withdraw without closing the group. Since then, numerous groups have kept going. We give guidance but most groups organise themselves in a way that suits them. This is jaw-dropping because we are not used to seeing these kinds of long-term successes. I've noticed that our NHS follow-up meetings were not being led by me anymore. I'm a guest whose role is to try to catch up with what they've been doing. If this catches on it could make a huge difference for people living with pain.

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"People living with pain can build their own unique social dimension for recovery and recuperation from something that's incapacitating. If you look at it on paper it looks small and subtle, but it's radically different."

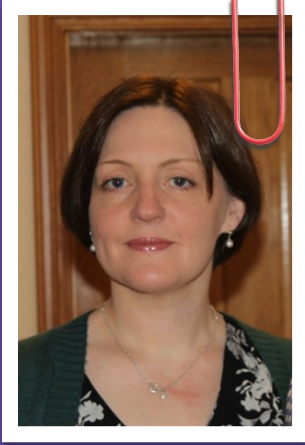
Top tips

- You'll be amazed by the impact of involving patients in your service delivery. It's the single biggest potential revolution in the care of long-term conditions.
- You have to figure out the local way which you can do it and be realistic, so what you start doesn't just fizzle out.
- Don't be frightened to give it a go, you're not going to lose anything from trying.



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TACKLING WAITING LISTS AND SUPPORTING PEOPLE WITH ARTHRITIS



Claire Benson

Rheumatologist

Claire.Benson@belfasttrust.hscni.net

Stories of change

TRIALLING A MEGA-CLINIC TO CONNECT WITH PEOPLE WAITING FOR NON-URGENT RHEUMATOLOGY APPOINTMENTS IN BELFAST

More than 5,000 people are waiting for appointments on the rheumatology Belfast Trust lists, and some have been waiting since 2014.



What we did

Our first ever *mega-clinic* was trialled in early 2020 to get patients a diagnosis and point them in the right direction. 200 patients were reviewed and validated by medical and admin staff to make sure they still wanted to be seen. Subsequently, 97 patients were invited in one Saturday morning. Bloods and x-rays were done in advance with results available to support decision making. 66 attended and 30 of these were seen by Versus Arthritis staff and offered local group support or self-management courses (12 took it up).

Our motivation

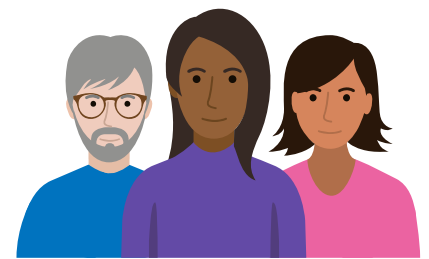
Many of the people on our waiting lists are living with pain and haven't got a diagnosis, so that's distressing for them. Staff capacity is limited, and urgent cases are always prioritised, which means we just don't see new patients who aren't urgent.

The difference we are making

Overall, 91% of the patients were discharged from the service waiting list, with 85% saying the service was excellent. No one who wanted help was left without it. We've had no re-referrals back into the service from that patient cohort. All the medical staff who took part in the first one want to come back, and others want to join.

What's next?

The physiotherapists, occupational therapists and other services would like to have been invited. We plan to have them at the next evening clinic, once it is safe to do so. These clinics have to be trialled in parallel with other things.





Making change happen

Versus Arthritis sometimes offer information hubs (stands) in Northern Ireland, in tandem with rheumatology clinics. The sessions enable volunteers to engage with people where they signpost, give out information and refer to self-management courses. A Hub was put on for the mega-clinic. There was also a consultation room which meant people could be spoken to individually and privately. At one point there was a queue for it. It was really beneficial to have this kind of presence.

We were surprised at how positively patients reacted to the clinic. We were a bit anxious about the response we would get. We assumed people might feel a little aggrieved that they waited so long. But they got a diagnosis which provided some closure. Many discovered there was no medical pathway for them, so they would have to rely upon themselves and try self-management. People were more open and positive than we expected. When you see the patient feedback, it encourages you to go on.

We offered services to 200 patients over a weekend. That's still a drop in the ocean compared to 5,000 on the list. Staffing and space will continue to be an issue. We probably can't do too many Saturday mornings. But, we had to start somewhere, and we have to start small and build up the evidence. Perhaps we can influence the commissioners to fund our service to support this huge number of patients moving forward. We probably have to look at different models. We can't just discharge 4,000 people back to general practice without ever having seen them when they have sat on the waiting list for that length of time.

We could have improved on our patient engagement. We don't engage with patients directly on our development. We sought their views on the clinic, and we did an evaluation and captured satisfaction, but we could develop it more.

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"We ran a high-volume clinic for our longest waiting list waiters, to facilitate diagnosis and discharge. It's a week's worth of work in half a day."

Top tips

- Find a way of providing patients with a resource or a network that gives them some way of supporting themselves whilst they wait for clinical input.
- It can be really beneficial to give nurse specialists, or other professionals the chance to do something they wouldn't ordinarily do. They really enjoyed doing it, and their skillset shone through.
- Versus Arthritis' role was important because they provided onward support, information, education and signposting to other resources. That's what made it different from just an ordinary outpatient clinic.

"All staff were very considerate and took time to listen and explain. I was very relaxed for this appointment." Mega-clinic patient



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Sam Haworth-Booth

Senior Physiotherapy
Manager,
Aneurin Bevan University
Health Board
sam.haworthbooth@wales.nhs.uk

Stories of change

GROUP EDUCATION SESSIONS GIVING OPTIONS, ADVICE, KNOWLEDGE (OAK) FOR PEOPLE WITH OSTEOARTHRITIS OF THE KNEE ACROSS GWENT

OAK has given patients confidence to make decisions that are appropriate for them to manage the condition they live with now and in the future.



What we did

We wrote, delivered, and tested a 90-minute group education session for people with knee pain who might consider surgery. Providing an OAK session meant that patients were given high-quality education and advice by a physiotherapist in their local community. Clinical and self-referral were accepted. We encouraged self-referral and attendance by a family support member. Group discussion benefitted all of those in a session whether they have the condition themselves or supported someone who did. The group benefitted from the group. During COVID we delivered the sessions remotely. The service is available to anyone in Gwent, which includes five local authority areas.

Our motivation

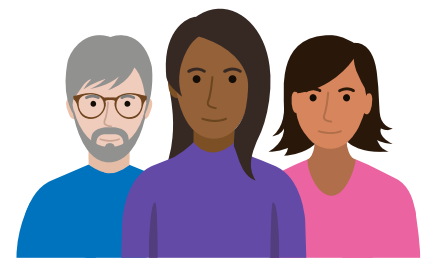
A Welsh Audit Office report showed low satisfaction levels for people who had knee surgery. Primary care colleagues lack time to spend educating people one-to-one so patients could consider which might be best for them. Pre-operative patients were not fully aware of the risks and benefits associated with the surgery prior to referral to see an orthopaedic surgeon.

The difference we are making

249 people attended the pilot. Understanding of OA and available management options were improved. Exercise (52%), weight loss (27%) and physiotherapy (21%) were cited by patients as ways they would manage their condition. People enjoyed the session. A survey at 12 months revealed the above methods were still being used.

What's next?

Once classroom sessions are safe again post COVID, we will continue to offer remote sessions as an option as it gives people an alternative way of attending. The Health Board has also piloted and rolled out OAK sessions for people with back pain.





Making change happen

From an initial idea between primary care and physiotherapy colleagues, the idea of OAK was discussed with clinicians (including surgeons) and shared with patients for their views. The programme was then written by a physiotherapist and nurse with experience in adult education, including a lesson plan, and ensuring we had the correct resources (props and films). Films took a while to source and make. It is worth investing the time to get this right. We tested the first session with a group of people living with osteoarthritis of the knee and asked for their feedback. We evolved it, and then piloted the programme in three areas for approximately six months. It is now delivered by a team of physiotherapists and administered by the Person-Centred Care Team.

Promotion is challenging. Word of mouth is powerful. Information sent to colleagues did not always get to the correct person or emails might be missed. We developed bilingual posters which we sent out to GP practices, libraries, leisure centres and pharmacies, and also promoted it on the Health Board Twitter and Facebook accounts. Digital literacy was not initially an issue when the sessions were classroom based, but it is now an issue as we are doing sessions remotely. Clinicians were driven by the need to have high-quality conversations, whilst respectfully managing patient expectations and frustrations within a group environment. In addition to communication, training focused on motivational interviewing, we realised that shared decision-making training would be an essential asset. This has now been completed and embedded into the OAK and physiotherapy service. We tried to book community-based venues, which took a while to find. Cost, accessibility, parking and public transport had to be considered. We piloted evening sessions as this had been requested but we found that few people attended. We will have to monitor this in the future.

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“People need to have a better understanding of the options to help manage their condition, much earlier in their pathway.”




Top tips

- Work with community facilities, such as libraries, who might provide publicly trusted spaces at no cost.
- Support clinicians who might have reservations about delivering advice in new ways, framing it as part of broader, relevant principles such as ‘right conversations’ and Shared Decision Making.
- Take the time to evolve the content based on feedback and input from clinicians and patients alike.

Want to know more?

<https://abuhb.nhs.wales/hospitals/a-z-hospital-services/physiotherapy/oak/>



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Peter Reid

Advanced Physiotherapy
Practitioner
NHS Forth Valley
peter.reid@nhs.scot

Stories of change

A NEW APPROACH TO SUPPORTING PEOPLE WITH ARTHRITIS IN NHS FORTH VALLEY THROUGH BETTER INFORMATION, ADVICE AND EXERCISE.

We changed the way we support people living with lower limb arthritis, by giving them the information and support they require to help manage their condition more effectively.



What we did

We took forward a 'Best in Class' approach by making the best and most effective use of available services, funding, staffing, equipment and communications.

The initial component was for me to be embedded in GP practices as a First Contact Practitioner. I would generally see people over the age of 40 with knee or hip pain. This 'one stop shop' meant I could diagnose, order investigations, spend time with people and talk through their condition and the options available.

Next, we looked at community-based exercise solutions. We began offering simple circuit-based group exercise classes, charging £2.40 per session. This grew to three venues with 30 people a week attending each one.

Our motivation

Longer waiting times for orthopaedics and physiotherapy resulting in low patient satisfaction and some referrals to these services could have been managed differently. Referrals to orthopaedics were high, but conversion to surgery was low. Scottish Government initiative to improve primary care.



The difference we are making

The project at nine months showed a 36% reduction in referral rates for orthopaedics and an 18% reduction in physiotherapy referrals from the areas the project was operating in. Measuring patient outcomes was more difficult because the survey responses from a service user questionnaire were low, but 25% of those who responded reported a significant improvement.

What's next?

After the project finished, I left the secondment, and other First Contact Practitioners came into post soon after, to support the ongoing work to educate and support people with arthritis and reduce the need to refer them to other services, where possible.





Making change happen

NHS Forth Valley had developed a Primary Care Improvement Plan. As part of this, we looked at long waiting lists for orthopaedics and asked 'Why is this happening? Why are they so high? What's going on?' The data showed that people who were seeing orthopaedics were regularly being referred back to physiotherapy services or being discharged. People were waiting for long periods to get information they could have been given much earlier. There was a stakeholder event with local patients and patient representatives to discuss how we could do things differently. Everyone agreed the way forward was to focus on primary care. Funding was available from a number of sources to deliver a 'Best in Class' programme, the majority of which was spent on staffing, as well as some equipment and information resources.

I was therefore seconded into a GP surgery as an Advanced Practice Physiotherapist. Then needed a community-based exercise solution which we delivered at GP practices which grew over time. This made a real difference. I would go and visit participants after six weeks and see people skipping around the place, who a few weeks before were limping with two sticks. There were some really good news stories. For example, we had reports of small social groups forming where participants would socialise together, talk about how they're coping and provide mutual support. A larger GP surgery which hadn't taken part in the wider project became our biggest promoter of the exercise classes. We used the exercise groups to advertise separate education sessions offered once a month, where I would do a presentation in a community venue. Around 10-15 people would come each time and people really appreciated learning about their condition and how to manage it.

Although it sounds like hard work to set up exercise classes with multiple local authorities, it is effective and helps to save time and money. It can be hard to measure impact in the wider system, but the patients who participated in the programme can tell you what they have got from it.

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"Mostly, people don't want to bother their doctors, they don't want to go to hospitals, they just want to know how to manage by themselves."




Top tips

- Focus on changing approaches within GP practices and put in place alternatives to hospital referrals. People need information before a referral or prescriptions.
- Allow people to come the exercise sessions free for a month before they start paying £2.40 a session as this helps people see if it's for them.
- Ask the patient at their very first appointment "What do you want to happen? What do you think you need and how can we work together to achieve it?"
- Listen to patients and find out how they want to be supported.

Want to know more?

<https://nhsforthvalley.com/health-services/az-of-services/physiotherapy/musculoskeletal-physiotherapy/>



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