

National Advisory Committee for Chronic Pain

Minutes of meeting – 2 February 2021

Attendees

Chair: Dr John Harden, Deputy National Clinical Director, Scottish Government

- Dr Rachel Atherton, Scottish National Residential Pain Management Programme
- Liz Barrie (Patient Reference Group representative)
- Dr Greycy Bell, Medical Director, Dumfries and Galloway (Scottish Association of Medical Directors rep)
- Chris Bridgeford, Affa Sair (3rd sector rep)
- Arlene Byrne (Patient Reference Group representative -substitute)
- Paul Cameron, CMO Speciality Adviser for Chronic Pain, Clinical Lead NHS Fife Pain Management Service
- Prof Lesley Colvin, Professor at University of Dundee (Consultant Anaesthetist/ NHS Tayside)
- Sonia Cottom, Director, Pain Association Scotland (3rd sector rep)
- Angela Donaldson-Bruce, Versus Arthritis (3rd sector rep)
- Jenny Gow - (Patient Reference Group representative -substitute)
- June Greenhorn (Patient Reference Group representative – substitute)
- Marianne Hayward, Head of Health and Social Care, NHS Lanarkshire (Chief Officers' rep)
- Catherine Hughes (Patient Reference Group representative)
- Mary Loudon (Patient Reference Group representative - substitute)
- Jacqueline Mardon, NHS Centre for Integrative Care, NHS GGC
- Irene Oldfather, Programme Director, the Health and Social Care Alliance (3rd sector rep)
- Hussein Patwa (Patient Reference Group representative -substitute)
- Kathleen Powderly (Patient Reference Group representative)
- Fiona Robinson (Patient Reference Group representative)
- Ian Semmons (Patient Reference Group representative)
- Heather Wallace, Pain Concern (3rd sector rep)
- Aline Williams, Service Manager, NHS GGC Pain Service (Service Manager rep)

SG representatives

- Carolyn Chalmers, Improvement Adviser, Modernising Patient Pathway Programme (MPPP)
- James O'Malley, Scottish Government Policy Lead, Chronic Pain
- Emma Mair, MPPP Primary Care Clinical Lead
- Kieran Dinwoodie, MPPP GP Advisor
- Sharon Robertson - Secretariat, Clinical Priorities Unit

Item 1 - Introductions and apologies

JH invited everyone to provide a short introduction.

Apologies were received from Professor Blair Smith, Dr Patricia Roche and Louise Rogers. JH noted that an observer from the ALLIANCE was in attendance to support their work with Patient Reference Group, and the substitute members of the Patient Reference Group for Chronic Pain.

The group were advised that Scottish Government are continuing to work with Scottish Association for Mental Health about the offer to them to join the Committee and will provide an update in due course.

Recruitment will open shortly for a new national Clinical Lead for Chronic Pain and we would appreciate if the Committee could publicise this through their networks.

ACTION: Job Description and Role Profile for the Clinical Lead role to be circulated to Committee members with the papers.

Item 2 - Chair's welcome and review of ways of working

JH provided a brief background on his role in Scottish Government, including his appointment as Deputy National Clinical Director and Chair of the NACCP in October 2020.

JH asked if everyone had read the Terms of Reference and Role Profile and invited comments or concerns – there were none.

JH reminded everyone that it was important for the group to be inclusive and that it would be looking for consensus. While the Committee is not responsible for the actions of members beyond the work of the Committee, as members we are now speaking with one voice and it is expected that attendees will uphold the values and the work of the Committee. All members are expected to engage in good faith, support each other and build connections and networks.

Members were asked to respect confidentiality until Minutes are made public and therefore meetings are not to be recorded

The group's overall aim is to improve outcomes for people with chronic pain and to support services to remobilise during and after the pandemic and to deliver Government's commitment on a new Framework for Chronic Pain Service Delivery by the autumn.

Due to the current pandemic and short time-frame ahead of the pre-election period this will be challenging, so we will be asking members to engage with the work of the Committee between meetings.

JH emphasised that the Committee itself will not take decisions but will make recommendations over which Ministers have the final word. It is important that everyone's views are heard and respected.

Item 3 - Brief update on current status of pain services

Brief updates were provided Scottish Government, 3rd Sector and the Patient Reference Group on the current challenges facing pain services and the work of the Committee (see **Annex A** for these updates).

JOM provided short update on wider state of services in NHS Boards as they manage the current wave of the pandemic.

SC provided an update from the third sector organisations on how their work has been impacted.

FR provided a view from the patient perspective.

Item 4 - Brief update on pain service improvement work

CC provided a short update on some of the work that's underway with regards the Modernising Patient Pathway Programme Primary Care projects, and the InHealthcare remote pathway for chronic pain (see **Annex B** for this presentation).

Item 5 - Discussion on proposals for new Framework for Chronic Pain Service Delivery

JH explained the purpose of the draft Driver Diagram that had been shared with the group and asked for feedback and any additions or clarification.

LB felt the shared aim was correct and harmful variation should be reduced. The group must look at why waiting times for current services are not prioritised, and how there can be improved access to treatment and shorter waiting times.

CB agreed waiting and return patient times should be considered. Affa Sair are producing a pain management program that will include patients helping patients (e.g. self-management and complementary therapy). He also highlighted the importance of educating junior doctors on chronic pain and ensuring learning from people with lived experience.

HW said there is a need for continuing support after people have attended NHS pain management services. There are a significant number of people who have to be re-referred back into services, and consideration for this should be captured in the secondary drivers. She also called for the role of the third sector to be highlighted more prominently in the draft work plan given their important role working with health professionals and communities. LC agreed with points raised about the importance of the third-sector which had to be highlighted, including the sector's own unique expertise in supporting people with chronic pain. ADB, CB and SC agreed with these comments in the meeting chat-bar.

CC noted that waiting times were just one important measure of service quality and that a measurement and performance framework would need to be developed to underpin the work plan outlined in the driver diagram.

AW had discussed the paper with service leads and while supportive of a 'Once for Scotland' approach, felt that it should be noted that this was a very ambitious aim, given the diversity in services across Scotland and ongoing workforce challenges faced by some Boards.

KP agreed with the aim but stressed that waiting times must be reduced as a priority given the impact on patients. She indicated that while the aim was aspirational, it is important to focus on the reality on the ground and the current state of services.

JH highlighted that the Government are aware of the issues services and patients are facing, but that it was important that services are supported to be fit for purpose in the future rather than returning to the same situation that existed pre-COVID.

KD said that as GP their role is a busy one currently, and involves a range of work from chronic pain appointments to covering vaccination sessions with colleagues impacted by this workload. He highlighted his practice is carrying out a test of change project involving a multidisciplinary team with increased patient access to an occupational therapist and recent support from a mental health nurse. He indicated the majority of people with chronic pain don't require access to highly specialised treatments (e.g. level three, hospital-based care) but rather needed early access to appropriate support and care in their community. AW and FR agreed with this comment in the meeting chat-bar.

MH agreed it was important to ensure there was support in the community to address the current waiting times for specialist services. She also highlighted that other services are currently dealing with very long waiting times, and that staff are also keen to ensure improvement and redesign of services.

LB said in her opinion services haven't improved in recent years and that it was important to ensure there was a care pathway in place to ensure the patient can see the right person at the right time. JG agreed with these comments in the meeting chat-bar. She highlighted the importance of looking at changes in staffing and service provision, for example changes to nurse-led chronic pain services in NHS Lanarkshire.

HP said there should be a focus on mental health access given the impact of waiting times on quality of life, for example ensuring early intervention via digital services. HP said these should be part of chronic pain consultations and considered good practice. CB agreed with these comments in the meeting chat-bar. HP also highlighted the opportunity presented to re-design services in a way that is inclusive as possible, including for disabled people. He also recommended that there could be better utilisation of NHS Inform to share information and resources for people with chronic pain.

JM said that she felt the shared aim should reflect elements of preventative care in order to ensure there is earlier intervention and support. She also felt the secondary drivers should put a greater emphasis on the importance of non-pharmacological approaches to support chronic pain. LB said this should not be at the expense of drug treatments which are needed, and JH explained that prevention is part of the wider solution for chronic pain and may not be appropriate in every individual case.

There were a number of related comments in the meeting chat-bar on opioid prescribing and associated issues which highlighted the importance of a person-centred approach and patient choice.

KD agreed with a prevention-led approach and highlighted that assessment of GP case-load reveals that chronic pain patients make up a significant portion of their work, equal to or more than other long-term conditions. He emphasised the importance of advocacy as part of the solution, including taking a public-health approach to both recognise chronic pain as a long-term condition and address existing misconceptions about the condition and how it can be managed.

GB said it was important the Framework encompassed a person-centred biopsychosocial approach, and this should be reflected in the aim. She also suggested the current draft might be focused too much on NHS services and should take into account the other elements which contribute to chronic pain and its impact.

ML said there may be links between chronic pain and increased mortality and more work is needed to understand if this is the case. She also agreed that self-management is important, but in many cases is related to musculoskeletal pain which can be treated. She said it was important that the Framework improved support for all types of pain.

JH advised that all comments (both written and verbal) will be fed into further iterations of the draft Driver Diagram and shared with the Committee before going to the Minister. KH asked why there was no patient representative on the Remobilisation and Restart group how this can be influenced by the Committee. JH advised he is a member of the Remobilisation Group and can therefore ensure there is feedback from the NACCP.

Next steps and summary of agreed actions

JH stressed that it is vital that Committee members engage with the work of the Committee given the tight timescales we are working towards, and there will be significant work between meeting and he greatly appreciated the time and support of the Committee.

JH also thanked Professor Blair Smith for his service as National Clinical Lead for chronic pain over the last number of years.

ACTIONS

- SG colleagues to circulate all written updates and presentations with the meeting minutes.
- SG to update the draft Driver Diagram following the input of the Committee and circulate for further comment ahead of a submission to the Minister.

Dates of next meetings

Wednesday 21st April

Monday 14th June

Monday 9th August

SG Secretariat - Update on NHS Scotland and pain services

NHS Scotland

- The NHS remains under severe pressure. There has been a rapid rise in the number of COVID-19 hospitalisations in the past few weeks, fuelled by the new variant strain.
- National performance continues to be extremely challenged due to Covid related staff absences and an increased Covid prevalence leading to long delays and reduced capacity.
- The increased COVID-19 presentations are combining with usual seasonal pressures on capacity, such as increased trauma presentations due to weather conditions.

Pain Services

- **NORTH OF SCOTLAND:** Boards are currently facing challenges in providing essential care across all services, including cancer treatment. However additional capacity has opened in the Private Sector to support urgent and cancer surgery. All boards in the NOS are providing essential services which will include pain services where they can, in line with workforce challenges.
- **WEST OF SCOTLAND:** Boards are only able to provide essential services currently and that is expected to extend at least for a further few weeks into February. However additional capacity has opened in the Private Sector to support urgent and cancer surgery. The general picture is that, where possible, almost all services are having to support the increased Covid demand in wards and ICU with nursing staff. However, pain services continue to be provided for essential care, the only area that has been flagged as being reduced currently is for lignocaine injections but expected to resume once the Covid demand reduces.
- **EAST/SOUTH OF SCOTLAND:** Some of the group work that had been planned is understandably delayed, with the hope to resume this once a safe environment returns. Pain staff are now returning to their substantive posts following their work to provide Covid-related care, but this is subject to change at short notice as Covid demand fluctuates. Changes and redesign continues, for example at NHS Lothian a new location has now been identified for their pain service

Sonia Cottom - Feedback for NACCP – 2nd February 2021

Firstly, I wanted to thank the committee for allowing us in the 3rd sector the opportunity to report on some of our findings and experiences over the last few months. Thank you to Angela from Versus Arthritis for her feedback on the great work achieved over the last 12 months. Due to time limitations, I have not included specific individual charity outputs and outcomes, but maybe something to consider for the future going forward is written key updates to be provided prior to each of these meetings from organisations and Boards, it was something which seemed to work well when we had the respective Service Improvement Groups.

It is during this COVID-19 crisis that we have seen an increased demand for many of our services within the 3rd sector which very quickly some of us round the table here had to move to on-line delivery - now chronic pain sufferers have been faced with the additional challenges not only of cancelled surgery, suspension of pain clinic appointments, but of increased social isolation which naturally compounds their daily issues of heightened stress, anxiety along with the impact on mental health and quality of life.

Looking at the principles and priorities of the remobilisation framework, the role of the 3rd sector is clearly an important one as it creates the opportunity for Boards and IJB's to integrate the contribution and utilisation of the 3rd sector into the prioritisation of maintaining capacity for Covid-19. Working in collaboration with many of the Boards, they have clearly recognised the importance of digital support and are willing to embrace a more blended model of service delivery as an integral pathway. Within such remobilisation plans, we appreciate that there is a need to alleviate the backlog of referrals for pain services and after all these years, this is certainly more than ever the perfect opportunity to get self-management integrated better into Primary Care. What both ourselves and VA found was that many of those who would usually be considered most distant from the digital world, are really enthusiastic to engage when they have the appropriate support, which is tailored to their needs.

On the point of future planning and referrals, it is welcomed across third sector organisations that our increased work and quickly adapted services have been recognised. However, cognisance must be taken that in order to continue to provide this increased level of support for Health and Social Care Partnerships and adapt to varying needs, sustainable funding is needed for this. Some of the following examples are experiences from the 3rd sector within this group have experienced over the last few months and seeks to highlight what the future focus needs to be on.

1. NHS Boards should not be put in the position of funding the 3rd sector through endowment funding. Many are providing vital collaborative services, making a clear, positive effect on outcomes. It is clearly written in many agreed principles of endowment funding that such grants should not be used for substituting core provision – of which the Scottish Government has committed to in the new framework for chronic pain service delivery – and furthermore, this is not a sustainable method of funding for long-term planning. This brings me back to the importance of having the right membership around the table with key decision makers responsible for budgets.

2. It also follows on from the above that by supporting co-production methodology, funding needs to be made available to 3rd sector in order to effectively plan, deliver services and report on outcomes. Many trust funders will now not fund anything they consider to be a core statutory provision within NHS services. So you can see how 3rd sector could potentially be disadvantaged from funding especially if engaging collaboratively with Boards.
3. If the value of self-management and reducing people's long-term reliance on specialist services and treatments which demonstrate low clinical efficacy, then patients need help to be better engaged with the concept of self-management. An example of this over the past few months has been the number of patient referrals received direct from Primary Care and then when we go to contact the patient, they have no idea either who we are or that they were being referred and sometimes from the conversation, it has been an inappropriate referral whereby they are actually requiring a higher level of care and support, e.g. PTSD. Whilst we appreciate that time is maybe limited to explain self-management and we also recognise that many people might not take everything in during a GP appointment, this is maybe an example of the type of action needed within the framework around pathways, language and a more holistic modelling approach.
4. In terms of Data as a Primary Driver, it would be welcomed for agreed key measured outcomes (not necessarily outputs) to be recognised for the effectiveness of 3rd sector provision. In being introduced and dealing with new healthcare professionals enquiring about our service, we are regularly being met with the question around the "evidence-base" for our work. Whilst we report on three recognised evaluation tools, the credibility for self-management would be greatly enhanced if we had the data to understand for example, the reduction in secondary care referrals when self-management is introduced at the time of presenting in primary care, the reduction/effect on prescribing, increase in quality of life.....as well as the key powerful anecdotal comments being recognised. Moving the focus from simple wait times and incorporating "key difference" data can surely provide a much better picture of the **difference** being made (or not) and the ability to identify more clearly where the gaps are in service provision. Having statistics to show that there is a 18 week waiting list for 400 for a first appointment does not help in identifying if all those people really need to be there and asking the question what is happening to people in the meantime whilst they wait?

I appreciate that this is maybe quite a lot of things for consideration here but I hope it helps to provide some insight into some of our current and future challenges and opportunities and hopefully helps towards modelling the framework going forward.

Patient Reference Group - Emergency Treatment During Covid Response

The emergency treatment issues were there before Covid, however Covid has nationally highlighted the issue.

Our treatments in clinics have all but stopped, even some of the restarted appointments for injections and infusions have yet again been cancelled or delayed.

The only routes open to complex patients is to travel to clinics in Liverpool, Doncaster and London to seek private pain injections and infusions. I have been travelling to Doncaster since last May and I am travelling again tomorrow. Like many of us seeking private treatment, we are desperate and can just about afford it but there are thousands of patients who cannot afford it or subject themselves to the pain caused by the journey.

The other route is to go for an acute pain admission. We are taken into hospital for a minimum of 3 to 5 days (depending on where you are in the country) and placed on an IV of morphine and may be sedated. To subject ourselves to days in hospital at increased risk of catching Covid instead of a 2 hour visit to obtain an injection or infusion is barbaric.

I am going to give you a couple of examples which we recently became aware of.

A young woman who received 4 injections per year for pain was reduced to only 1 per year as that is all the health board could provide, this was pre covid. She was prescribed Methadone and Oramorph instead. She had a huge flare of pain on Friday night and her parent called NHS24 to ask a doctor for guidance on dosages of the meds as her pain was excruciating. She was told that the only route open to her daughter was to go to hospital for IV Morphine, the young women did not want to go on her own but as she is of age was told her mum could not go with her, due to the patients poor mental health and previous bad experience of acute pain admission, she could not go. No doctor phoned her back and she was instead referred to her GP on Monday morning. Her GP yesterday could not help her as they did not have the expertise to help.

This young patient is still in excruciating pain. Her mother is currently working 2 jobs to try and afford private injections for her.

A lady who has been damaged with vaginal mesh received 4 nerve blocks per year and coped really well. Her health board has now stopped all injections and infusions and has no plans to reinstate them. This lady is now on Fentanyl patches and oxycodone alongside other pain meds, these meds do not allow her to live her life, they are no substitute.

My own pain, I have bilateral hydronephrosis. I can get up to 50 spasms per day. I can only liken it to the cramp you get in the middle of the night in your calf, the spasm is horrific and you still feel the ache of it the next day. Imagine that in your kidneys 50 times a day, morphine and gabapentinoids don't kill the pain. The only thing that truly works to take away the pain is 6 weekly infusions of Lignocaine. Despite what the current Public Health Minister states, we are not choosing to travel for private care, we have been left with no choice.

Acute pain admissions may seem like the answer but they are nothing more than a sticking plaster on a large gaping wound, what do we do when we are discharged from hospital? We need a better solution than an acute pain admission. The problem is that every patient is at risk of an emergency admission or doped up to the eyeballs with opiates and gabapentinoids. Opiates and Gabapentinoids are not the answer but faced with a patient who is in extreme pain, what else is there when clinics are closed?

We are told that anaesthetists are needed for Covid patients, but a lot of these clinics are only held once a week or are a nurse led clinic.

Joe Fitzpatrick promised last year that Chronic Pain patients should not be left for 7 or 8 months again without treatment and Dr Harden you agreed, but we are still left without treatment. We need urgent remobilisation of clinics, injections and infusions for patients.



Modernising Patient Pathways Programme NACCP Update

Carolyn Chalmers
Improvement Advisor
2nd February 2021



MPPP NACCP Update 02/02/21

MPPP work programme supported by:

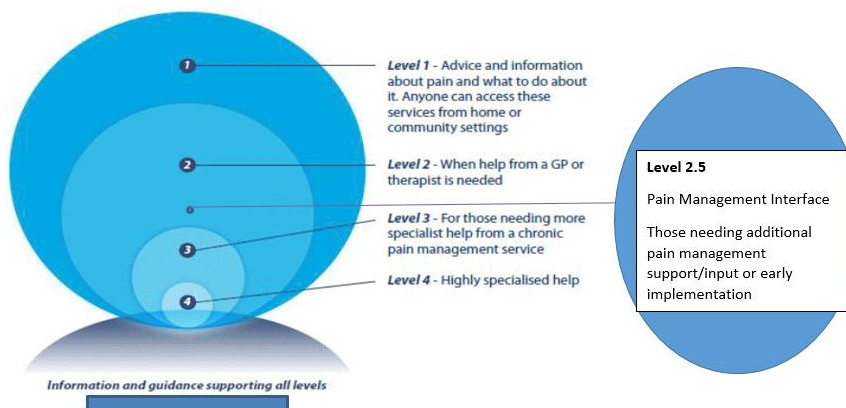
Primary Care Clinical Lead – Emma Mair, Specialist Pain Physiotherapist, NHS Ayrshire and Arran
Kieran Dinwoodie – GP Advisor, GP NHS Lanarkshire
Carolyn Chalmers - Improvement Advisor
MPPP Clinical Network and Pain Team Scotland

Current focus of work:

Primary/Secondary care interface and pain management expertise in Primary Care
Supporting effective prescribing
Remote Healthcare Pathways

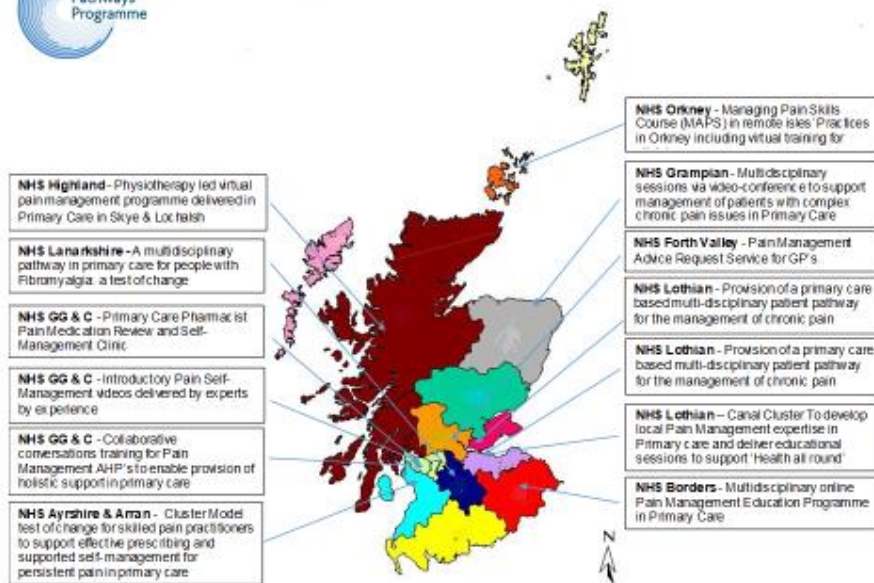
Chronic Pain Scotland Service Model

Most people get back to normal after pain that might come on after an injury or operation or for no apparent reason. Sometimes the pain carries on for longer than 12 weeks despite medication or treatment – this is called chronic or persistent pain.





Pain Management Projects 2020/21



Remote Healthcare Pathway for Pain Management

- Inaugural meeting of Clinical Advisory Group held on 20th January to explore the potential for Pain Management
 - To provide information about the Inhealthcare platform and how it is currently being used in Scotland
 - To share the Chronic Pain Core Minimum Dataset as a possible starting point
 - To garner views and invite expressions of interest in developing further
- Next meeting to be scheduled week beginning 8th March