

Fifth Group Meeting: Minutes

All-Party Parliamentary Group on Axial Spondyloarthritis November 2020

Introduction

This document contains the minutes from the fifth meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting – *Axial SpA and Hydrotherapy: Exploring Provision and Improving Access* – took place virtually, on Wednesday 4th November 2020.

Welcome and introductions

1. Greetings from the Chairs

APPG Vice-Chair Tom Randall (Conservative MP for Gedling) welcomed attendees to the fifth meeting of the APPG on Axial SpA and provided a brief overview of the meeting's agenda and objectives, which were focused around exploring the role of hydrotherapy in the management of axial SpA (AS) and the state of play in service provision across the country.

Apologies were received from APPG Co-Chair Lord Campbell-Savours, who was unable to join the meeting due to conflicting Parliamentary business.

Presentations

2. Presentation from Peter Kellythorn (NASS Member)

Peter Kellythorn (NASS member) delivered the meeting's first presentation, providing attendees with a short overview of his experiences of accessing hydrotherapy care and the impact it has had on his management of axial SpA (AS). Peter first accessed hydrotherapy care whilst on a two-week residential course at the Royal National Hospital for Rheumatic Diseases in Bath. Hydrotherapy was available every day whilst on the course and Peter described the benefits arising from this as "superb", leading to significant improvements in his condition, flexibility, and reducing levels of pain. After the Bath residential course finished, Peter was able to make use of hydrotherapy services at his local hospital in Bedford, taking up a course of 6 sessions that was available for NHS patients over a time span of 2 years, after which he was required to access hydrotherapy as a private patient.

Peter explained how each hydrotherapy session led to a reduced need for medication, enhanced balance and contributed to improved sleep. With hydrotherapy sessions typically lasting longer than a standard appointment, Peter described how they gave him more time to discuss his condition with his physiotherapist and supported a more general improved sense of wellbeing. Peter described the respite from the pain of axial SpA (AS) as a long-term condition as vital, and something that wasn't really achievable through other forms of therapy.

Unfortunately, Peter explained how his local hydrotherapy pool in Bedford was affected by a decision to close, which effectively took all of these benefits away. An inability to manage his pain through hydrotherapy meant that Peter needed to increase his medication, and he found that flare-ups lasted for longer and recovery time from these increased. Peter also began suffering from increased anxiety, leading to depression, something for which Peter is now taking additional medication for. Peter explained how no advanced notice that the pool would be closing was given to him, and that he only found out when turning up for an appointment. Peter, and many other patients who relied on the pool, were offered no viable alternative.

Peter described broader flaws in the decision-making process to close the pool. The local health and scrutiny committee were not informed about pool closure and a consultation process only started after pressure from local stakeholders. Not all stakeholders were included in the consultation process, and there is a sense that the eventual decision to close the pool may have resulted in waiting times for land-based therapies increasing due to extra demand arising from the lack of hydrotherapy access. Combined, the removal of hydrotherapy care for Peter has led a significantly negative impact on his condition and exacerbated many of the challenges already faced by someone living with a long-term condition such as axial SpA (AS).

3. Presentation from Dr Carol McCrum (Consultant Physiotherapist, NICE Fellow)

Dr Carol McCrum discussed her involvement in the development of the NICE guideline for Spondyloarthritis and how the Guideline Development Group (GDG) considered the role and evidence of hydrotherapy as a component for the guidelines.

The NICE GDG explored the question of the effectiveness of hydrotherapy compared with standard care for managing spondyloarthritis, against a range of different potential positive outcomes. Dr McCrum explained how the review found 1,623 potentially relevant articles, of which 5 Randomised Control Trials (RCTs) and 7 observational studies were identified as presenting strong enough evidence that could be factored into the guideline development process. Despite this, the research was largely seen as of lower-quality evidence, which wasn't able to adequately demonstrate significant improvements in the outcomes of patients who were engaged in various forms of hydrotherapy care.

Dr McCrum noted that there did appear to be evidence supporting interventions that had hydrotherapy as a component of their care, particularly in terms of demonstrating overall improvements in quality of life, however there were many broader challenges with the way in which the research was carried out. Most of the studies were also quite old, which meant they weren't able to incorporate effective measurement scores such as BASDAI (the Bath Ankylosing Spondylitis Disease Activity Index). The studies also didn't effectively capture whether their various interventions supported maintaining function and reducing disease progression, which could have strengthened their findings had they been included. There was a lack of studies carried out in NHS settings and a general absence of robust economic evidence.

Dr McCrum explained that as NICE is unable to make recommendations for areas that aren't well-evidenced or where there is a lack of compelling cost-effectiveness data, this ultimately limited the scope for how hydrotherapy was positioned within the guidelines. The guidelines therefore were only able to set out the recommendation: 'consider hydrotherapy as adjunctive therapy to maintain pain and function.' Two research recommendations however were included within the guidelines, as a means to try and address the evidence gaps that had been identified.

The main research recommendation was to capture the *short and long-term effectiveness and cost-effectiveness of improving patient reported outcomes in spondyloarthritis*. This would help to address the gap in well-conducted RCTs that included long-term follow-up that would help to capture the benefits of hydrotherapy. The hope is that this research would also help to capture which type of hydrotherapy intervention is helpful, and the type of exercises that should be undertaken within pools. The second recommendation that was identified was *exploring the role of hydrotherapy in managing flares in people with spondyloarthritis*. There is currently no real evidence in this area, but Dr McCrum highlighted that it could be represent a key benefit of hydrotherapy which needed explaining. There was a final research recommendation around the benefits of carrying out hydrotherapy in a warm or standard-temperature pool.

Dr McCrum concluded by reiterating the real need for the generation of robust new evidence for hydrotherapy, including evidence that could help to demonstrate its impact from the perspective of Patient Reported Outcome Measures (PROMs). This would help to quantify what is a meaningful benefit in hydrotherapy, who's more likely to benefit, and how best to support those with extra-articular challenges.

4. Presentation from Claire Jeffries (Physiotherapy Clinical Specialist, Solent NHS Trust)

Claire Jeffries provided attendees with an overview of the findings of two pieces of research that had been carried out in recent years, to help build a clearer national picture of hydrotherapy service provision across England.

Claire first explored research that she had carried out in 2018 on behalf of NASS and in partnership with Melanie Martin (MCSP Advanced Physiotherapy Practitioner/ Topol Digital Fellow) that looked to map the availability of hydrotherapy services across the country. Two surveys were carried out, helping to capture the perspective of physiotherapists and patients. 250 NASS members responded to the patient survey with feedback indicating that all axial SpA (AS) symptoms improved through the delivery of hydrotherapy care, in particular the management of stiffness, mobility and an individual's mood. Survey responses also revealed some of the main barriers that patients experienced in terms of accessing non-NHS pools for hydrotherapy,

including the water being too cold, as well as the pools being overly-crowded, and not feeling comfortable in a public setting due to the nature of their condition.

100 physiotherapists responded to the professional survey, with 46% of service provider respondents stating that they were aware of barriers to providing local hydrotherapy services to axial SpA patients. The most common identified barrier was not being able to meet service demand, and the impact of staff vacancies. Lack of needed investment was also highlighted as a key challenge. At the time of the 2018 survey, 1 in 5 pools were under threat of closure, 32% were previously under threat of closure, and 12% of respondents reported that a local service had unfortunately been closed in the last decade.

Claire Jeffries then provided an overview of the results from a new 2020 Freedom of Information (FOI) request, carried out by NASS on behalf of the APPG, with the ambition of improving understanding of the impact that COVID-19 was having on hydrotherapy services in England. The FOI was sent to all Trusts in England and achieved a 69% response rate (90 responses received). In their responses, 89% of Trusts reported having access to a local hydrotherapy pool. The most common reasons for not having access to a local hydrotherapy pool were a lack of funding and investment. 90% of these pools were open prior to COVID-19, but the FOI responses revealed that 21% of Trusts were unsure whether local pools would reopen after COVID-19 pressures had abated, with almost half of Trusts saying that local pools were due to reopen but were unable to give indications of when this would be. Worryingly, respondents indicated that 3% of pools are not due to reopen after COVID-19

The most common reasons identified by respondents for not having clear plans in place for reopening pools was a lack of changing room capacity due to social distancing requirements, cleaning needs, a lack of general access to the pool as the site was currently being used for other means (e.g. storage), and physiotherapy staff being still redeployed. Pools that did plan to reopen but didn't have a date for doing so were impacted by similar factors, including 12 services highlighting that their local pool was currently being used for other functions. The majority of services (94%) that did plan to reopen indicated that their capacity would likely be reduced when compared to 'normal' levels due to the impact of COVID-19, with the average hydrotherapy capacity estimated to be 37% of pre-COVID level (some services estimated having as low as 12% of normal capacity).

Moving forwards, Claire Jeffries highlighted how the results emphasised the need for a joint voice across axial SpA and other patient populations that also rely on hydrotherapy care to make the case for protecting and widening the delivery of hydrotherapy services. Stakeholders should look to make the case for investment in local hydrotherapy pool facilitates so they can run effectively and argue for hydrotherapy to be prioritised within any hospital redevelopment, for both axial SpA patients and for those with other conditions.

5. Presentation from Natalie Beswetherick (Director of Practice and Development Directorate, Chartered Society of Physiotherapy)

Natalie Beswetherick delivered the final presentation of the meeting, providing a brief overview of the role and membership of the Chartered Society of Physiotherapy (CSP). Natalie explained that hydrotherapy represents part of the CSP's scope of practice and that the CSP has a dedicated professional network of aquatic therapy specialists. This network worked with Public Health England and local government stakeholders to support safe reopening of hydrotherapy pools through the COVID-19 pandemic where possible.

Natalie emphasised the benefits that effective hydrotherapy care delivery could bring to those living with axial SpA as well as a range of other long-term conditions. She explained how hydrotherapy access unfortunately remains a postcode lottery for many people across the UK, with current services that do exist more likely to be due to a moment of history rather than coordinated and assessed patient need. These hydrotherapy pools have unfortunately been in the firing line when local Trusts have been looking to make cost-savings, as decision-makers can often perceive these services to be expensive to run and inefficient.

The CSP has identified several key learnings from its recent activity to support hydrotherapy provision. The first of these is to encourage working in close collaboration with key stakeholder help understand and articulate patient need. These stakeholder organisations should include patient groups (such as NASS), clinical experts, including from the Aquatic Therapy Association of Chartered Physiotherapists (ATACP), local

staff and individual patients. Natalie also suggested that engagement with local MPs can be helpful in building advocacy for these services, particularly when this is backed-up by the patient voice.

Natalie also reiterated the importance of having robust evidence in place to challenge potential hydrotherapy pool closures and the importance of comprehensive equality impact assessments being carried out in any local decision-making process. Often these assessments haven't been carried out, and where they have, they can be superficial, with little underpinning evidence of the method of assessing the impact of a closure. Moving forwards, Natalie issued a call to action for clear hydrotherapy commissioning guidance to be developed that would support services to meet the needs of local populations across the country.

6. Formal APPG Business

Before the session moved onto Questions & Answers from attendees, APPG Co-Chair Derek Thomas MP carried out formal business for the group.

This included the nomination of Tom Randall MP to the position of APPG Co-Chair, with Derek stepping down from his current role. Derek explained how Tom's personal experience of living with axial SpA (AS) meant that he was particularly well-placed to lead the group moving forwards, although Derek would still provide support where he could. Tom Randall thanked Derek for the nomination and for all the work that he has put into the group, confirming that he would be delighted to take up the position of Co-Chair, alongside Lord Campbell-Savours. Tom explained how this was a cause that was close to his heart, and that a recent axial SpA (AS) Parliamentary Adjournment Debate that he had helped to secure had provided a real springboard for further action, and a cause for optimism. Tom added that he hoped to support efforts to secure the best treatment and care for people with axial SpA (AS) in the years to come.

7. Question and Answer Session

Dr Dale Webb, NASS CEO, chaired the Question and Answer session. Before opening the floor to attendees, Dr Webb thanked Derek Thomas for all the support that he has provided to the APPG and those affected by axial SpA (AS) since helping to form the group in 2019. A summary of questions and answers has been included below:

The disconnect between current hydrotherapy evidence and the 'lived experience'

- Roger Stevens (Chair of NASS Portsmouth) explained how first attending hydrotherapy sessions in 1996 has helped to "change his life". Despite describing himself as an initial 'sceptic' of the service, Roger explained how accessing this care has improved every facet of his condition, leading to significantly better wellbeing and helping him to effectively self-manage. Roger explained that not having access to hydrotherapy during lockdown has been "awful". Peter Kellythorn agreed with these sentiments, describing how exercising in the warmer water of a hydrotherapy pool was particularly positive whilst in flare, helping him through what can be especially difficult times.
- Attendees agreed that there was a general disconnect between the individual experiences and benefits associated with hydrotherapy and the lack of robust evidence that currently exists. It was felt that this was a key challenge to address moving forwards.

Mitigating the impact of COVID

- Attendees discussed opportunities for exercise during COVID-19 in the absence of hydrotherapy, and the how the impact of lockdown could be mitigated. Roger Stevens described weekly Zoom sessions that he could participate in and which were being delivered by local physiotherapists. He explained that whilst the physical benefits of these weren't quite the same as hydrotherapy, being involved in group sessions had helped to improve his mental wellbeing, not least because he was back in touch with other patients experiencing similar challenges.

Best practice and demonstrating efficiency

- Rachel Lewes (NASS Bristol Physiotherapist) described how she looks to embed hydrotherapy best-practice in her local area. She explained the challenges around securing sufficient access to hydrotherapy sessions for patients, and that she has looked to extend the number of sessions local patients are able to access, through articulating how good hydrotherapy care helps to keep patients

out of other, more expensive parts of the healthcare system. She added that hydrotherapy sessions also provide opportunities for important wider holistic care, including the ability to share lifestyle advice and support wider cardiovascular improvements, helping to improve an individual's overall quality of life.

- Jacqueline Pattman (Chair of the Aquatic Therapy Association of Chartered Physiotherapists) considered the challenges involved in making an effective business case for local hydrotherapy services. She explained that in clinical practice there's little time to deliver research, which was potentially a factor in the lack of existing evidence. Jacqueline described how she set up two hydrotherapy groups in the late 1980s and early 1990s which are both still running, and could help to potentially demonstrate the longer-term physiological benefits associated with hydrotherapy care. She has also supported the introduction of 'MYMOP' outcome scores and 'Jam' scores that she hoped would help to start building stronger patient outcome data.
 - Moving forwards, Jacqueline explained that she saw a role for organisations like NASS to work with professional associations to develop a unified voice to champion hydrotherapy. She also suggested that there were opportunities to work with other organisations like Swim England and GoodBoost, as this wasn't necessarily an area that the NHS could support through its own means

Building local links and developing a business case

- Claire Jeffries acknowledged the difficulties of advocating for hydrotherapy when there is a potential lack of strong local support in place. Claire explained that she is lucky to have very supportive local commissioners, and that she has helped to strengthen how hydrotherapy is perceived through raising its profile and highlighting its benefits where possible. Claire felt that taking forward activity to help build a template business case would be hugely beneficial and suggested that this could be something that having APPG support for would help to improve the way it was received by local decision-makers.

The importance of adequate assessment

- Natalie Beswetherick explored the challenges around pool closure decision-making processes. She highlighted several examples of areas that hadn't carried out appropriate impact assessments, which meant that relevant patient groups had been excluded from the process. Coordinating action to challenge these situations was key and could help to transform local decision-making.
- Dr Helena Marzo-Ortega raised concerns around the overall health of hydrotherapy care across the country. Drawing on her local geography, she mentioned that there is currently insufficient access to hydrotherapy for patients across the Leeds region. She agreed that in the absence of really strong evidence at present, articulating the patient voice was an essential means of protecting hydrotherapy, not just in axial SpA (AS) but for many conditions with similar disease manifestations.

Cost-effectiveness of hydrotherapy

- In response from an attendee question around whether any Quality-Adjusted-Life-Year (QALY) data existed in hydrotherapy, Dr Carol McCrum highlighted how NICE had explored cost-effectiveness of hydrotherapy whilst developing the spondyloarthritis guidelines. Whilst there wasn't specific QALY data identified, Dr McCrum explained it was recognised that there wasn't considered to be any significant financial impact for delivering hydrotherapy for those with axial SpA (AS).
- Dr McCrum emphasised the importance of generating new data that would help to robustly demonstrate the benefits of hydrotherapy. She added that developing a clear hydrotherapy research strategy would help to support NICE making a change to how hydrotherapy is included within its spondyloarthritis guideline. Natalie Beswetherick suggested there could be potential to deliver a retrospective study exploring how losing access to hydrotherapy during COVID-19 may have led to increased medication needs and condition deterioration for individuals, and that this could provide a platform for further research. Dr Marzo-Ortega highlighted the importance of incorporating mental health benefits as part of any research plan.

Engaging with local politicians

- Tom Randall MP considered potential ways of challenging hydrotherapy closure decisions. He suggested that engaging with local MPs and asking them to contact local commissioners and providers to scrutinise decisions was key. He was also encouraged by the case for highlighting how the delivery of effective hydrotherapy care can prevent more expensive 'downstream' costs from occurring, and that this could be a powerful lever for decision-makers.

8. Meeting Close

Dr Webb and Tom Randall thanked attendees for contributing to this afternoon's meeting, which had highlighted a number of promising opportunities that could be taken forward to strengthen hydrotherapy, including the importance of developing a new hydrotherapy research agenda. Tom Randall reiterated his enthusiasm for supporting this workstream and the broader efforts of the APPG, and closed the meeting by encouraging everyone to stay safe in the weeks ahead.

Further Information

For any further information about this meeting or the APPG on Axial SpA, please contact appgsa@mandfhealth.com