APRIL 2025

ADULTS' PERSPECTIVES REPORT

Spinal Muscular Atrophy uk
SUPPORTING • INFORMING • ADVOCATING

Scholar Rock

Biogen

SMA UK

Adults' Perspectives Report

April 2025

1.0 Background

Spinal Muscular Atrophy is a rare, neuromuscular condition. It causes progressive muscle wasting (atrophy) and weakness. It may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. How severely people are affected, and in what way, varies greatly.

Though understanding of the condition and its management and care has advanced over the years, there is no cure for SMA. Until late 2019 there were no NHS-approved disease modifying treatments (DMTs) specifically for SMA in the UK. There are now two NHS-funded drug treatments that may be prescribed for adults. They work best if started before there is any muscle weakness, or when this is minimal. However, they can stabilise the condition later in life making a positive difference[1]. For example, they may help with fatigue or preventing the loss of the ability to use a finger to control a powerchair or laptop.

Improvements in care, management and treatment have meant that many adults with SMA are living longer, healthier, independent lives.

'Now much more is known about SMA, I was aware that I might be able, for instance, to get equipment if I developed a chest infection, which has been my major concern in the last 15 years. Had I not got support from colleagues with SMA, and researched the options myself, I might never have engaged with clinicians at all. I am glad I did so! There are many things that people of my age with SMA begin to need that we would find difficult to get through the GP for instance, so specialist assistance becomes much more critical.'

Alice Maynard, Adult living with SMA type 2/3 67 years old, Milton Keynes

2.0 The International Standards of Care and the SMA Care UK project

November 2017 saw the publication of an update and revision to the 2007 Standards of Care (SoC) for spinal muscular atrophy (SMA)[2]. Written before the

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[1] Rouault F, Christie-Brown V, et al. Disease impact on general well-being and therapeutic expectations of European Type II and Type III spinal muscular atrophy patients. Neuromuscular Disord. 2017 May;27(5):428-438.

[2] Diagnosis and management of spinal muscular atrophy: Part 1: Recommendations for diagnosis, rehabilitation, orthopedic and nutritional care Diagnosis and management of spinal muscular atrophy: Part 2: Pulmonary and acute care; medications, supplements and immunizations; other organ systems; and ethics panel Eugenio Mercuri et al 2017

recent rapid development of the DMTs, these gave minimal guidelines for all countries. The authors acknowledged that they focused on the paediatric population and that more specific work was needed to address the SoC for adults.

Despite these guidelines, a recent publication[3] highlighted the relatively poor access to even the current SoC for many adults in the UK, especially when compared to paediatric care.

It was recognised that any updated SoC needed not only to address the changing needs of the paediatric population but also this lack of access to care for adults. They would also need to be appropriately developed to meet the changing needs of adults.

These SoC would also need to be forward looking and consider the needs of the current paediatric population heading towards adult years. This would include the growing cohort of children who, without newborn screening, have been diagnosed late with SMA Type 1. Though they have benefited from life-saving DMTs, many are living with a wide range of complex medical needs. They will be reliant on clinical and social care for the rest of their lives. With limited resources and a lack of appropriately trained clinicians, specialist adult SMA clinicians are concerned about the capacity to appropriately manage this new 'SMA phenotype'.

"As SMA is a genetic condition usually diagnosis in childhood we must make the most of the opportunity to work together closely as paediatric and adult neurologist to understand the needs of the new cohort of young people with type 1 SMA now happily surviving into adulthood to ensure adult services are ready and able to support them"

Dr Clare Galtrey Consultant neurologist, St George's, University Hospital, London.

The 3 – year SMA Care UK project was launched in 2024 to draw up new SOC for the UK. They will be developed by clinicians and the SMA community to begin to

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[3] Real-World Data on Access to Standards of Care for People with Spinal Muscular Atrophy in the UK Robert Muni-Lofra et al May 2022

address the concerns and care needs of everyone living with SMA from childhood to transition to adulthood.

2.1 Developing Standards of Care for adults

Ideally, any recommendations made through the SMA Care UK project will be evidence based. However, the vast majority of research and development in SMA care and management has been in the paediatric field. Given this, many of the clinical care recommendations for adults would, in the first instance, be based on the specialists in the different disciplines reviewing their experience and practice to agree a consensus.

In 2024, as the SMA Care UK Project began its work, SMA UK's Adult Advocacy Steering Group, made up of six adults living with SMA across the UK, highlighted how crucial it is that the voices of adults experiencing SMA care across the UK are heard throughout the process. From discovering their current experiences, to considering their future needs and determining the best management programmes. Adults living with SMA in the UK need a Standard of Care document that sets realistic expectations that will support them to find the best possible outcomes from treatment and care in a way that does not label them just as 'patients' and acknowledges them as citizens with rights and busy daily lives.

'The current standards of care is a medical model, which disables people. It is not reflective of the more forward-thinking social model of disability. We need a document that removes barriers and facilitates access to social care, essentially letting us live our lives.'

Kelly Gordan, adult living with SMA type 2, 35 yrs old, Stourbridge

3.0 SMA UK's Adult Perspective Workshops

Supported by industry partners, Scholar Rock and Biogen, SMA UK therefore brought together 28 adults living with SMA and seven specialist clinicians across two workshops in Manchester (January 2025) and London (February 2025).

The key questions were:

- **What are the past and current experiences of the workshop participants of the management of SMA and access to clinical care?**
- **What matters to adults today? What priorities do workshop participants have?**

- **What recommendations do participants have for the SMA Care UK Project and other stakeholders**?

3.1. Participant demographics

Home locations of workshop participants

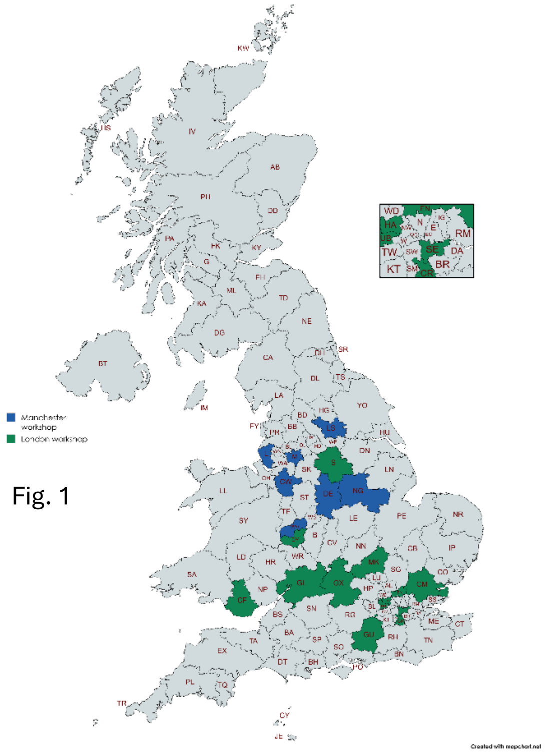

Fig. 1

- The workshops captured the perspectives of 28 adults living with SMA aged between 18 and 67, living across the midlands and the south of the UK. The map shows the areas in which they access their care and support.

- All participants were full time wheelchair users. 1 participant was able to stand and walk short distances.

	Number of participants			
	Type 1	Type 2	Type 2/3	Type 3
Manchester	1	7	-	6
London	-	6	1	7

Fig. 2

4.0 Past and Current Experience

Historically there has been a 'cliff-edge' between paediatric and adult services:

'Prior to the advent of treatment for Spinal Muscular Atrophy (SMA), many patients managed their symptoms in the community, sometimes with limited to no input from Neurology Services, especially transitioning from paediatric to adult services. Any clinic conversations we did have were often focused on managing decline and could be challenging. '

Phillip Kelly, Highly Specialist Neuromuscular Nurse & Care Advisor

With appointments largely consisting of difficult or one-way conversations, where the individual (seen as a patient) informed the clinician of their latest struggles, many people disengaged with specialist services. Workshop participants reported that the only appointments that were valuable to them were those that would support daily living, such as wheelchair services or social care assessments.

“I was born in the late 50s, before [the genetic cause of] SMA was identified. My sister also had SMA and had been subjected to unpleasant and intrusive interventions to try to fix her. Fortunately, in the five years before I was born the medical profession hadn't succeeded, so I was left largely untampered with. Apart from some pretty standard interventions when we went to special school, like the odd bout of physio, and a termly clinic (which seemed altogether pointless to us), I remained largely untampered with.

Alice Maynard, Adult living with SMA type 2/3 67 years old, Milton Keynes

4.1 Access to Paediatric versus Adult Clinical Care

Workshop participants experience of access reflected the findings of the May 2022 study on access:[4]

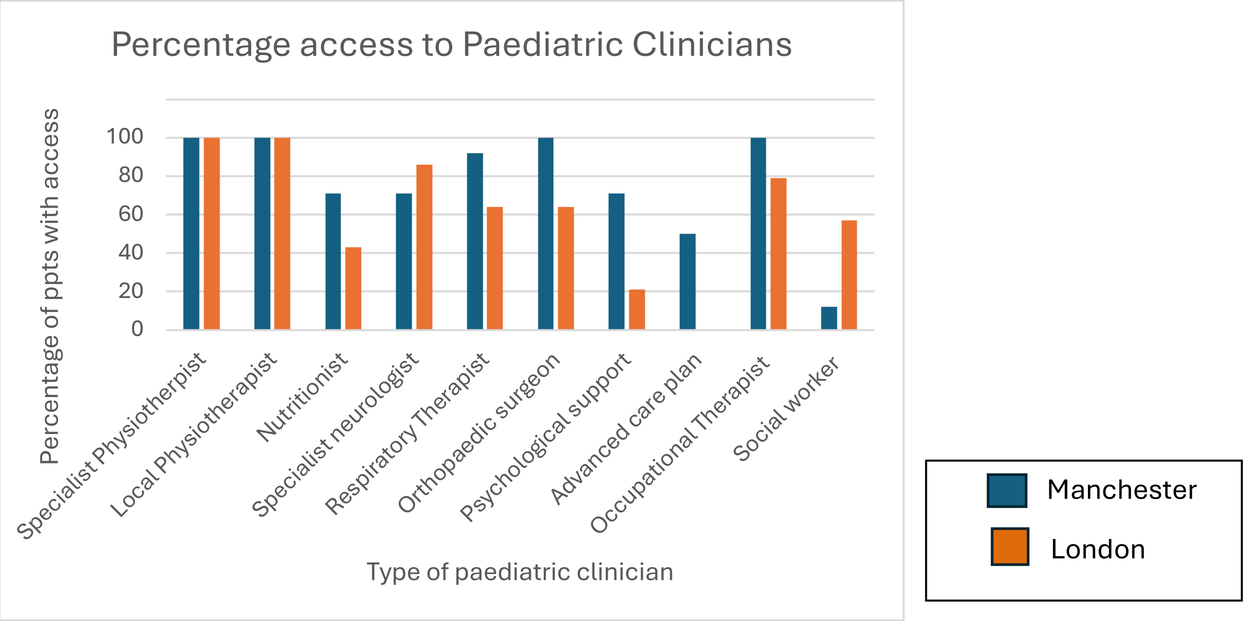

Fig. 3

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[4] Real-World Data on Access to Standards of Care for People With Spinal Muscular Atrophy in the UK Robert Muni-Lofra et al

Across geographical locations, they had had access to a variable multidisciplinary NHS paediatric team. Access to social workers and psychological support throughout childhood was more varied between the two workshop locations.

In contrast, workshop participants reported the following access as adults:

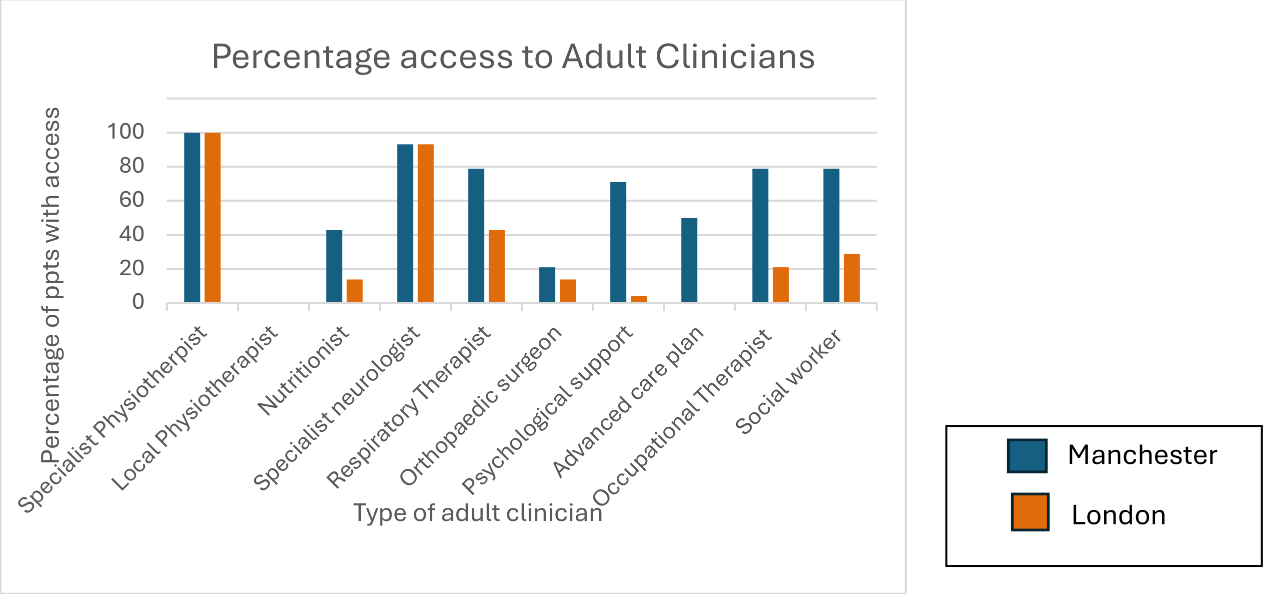

Fig. 4

It was noted that since treatments for SMA have become accessible for adults, specialist NHS neurologist and neuromuscular physiotherapist support has been secured for all adults living with SMA on disease modifying therapies. However, it was also commented that the 6 monthly specialist neuromuscular physiotherapy appointments only have the capacity to cover treatment outcome assessment tests that are required by the Managed Access Agreements (MAAs). Therefore, there is little or no formal advice on daily exercise or stretching routines.

Any access to regular, local physiotherapy disappeared once transitioned to adult services.

Access to orthopaedic surgeons had dropped dramatically, due to spinal surgeries being completed under paediatric services. Less than 20% of workshop participants retained any contact with orthopaedics for ongoing review through adulthood.

‘My last spinal review was in 2017, a year after my spinal fusion that I had at 13. At the age of 19, I noticed a change in the shape of my spine and contacted my hospital to request a review of this. At this time, I didn’t have any pain but thought it was important to get it checked as a pre-emptive measure. After spending a year and a half waiting for a review with a spinal surgeon, he felt he didn’t have

enough information to help me. I decided to find the surgeon who did my operation back in 2016. This took over a year of searching, and now at the age of 22, I experience constant pain in my spine and pelvis. After paying to see my surgeon privately, I am still waiting for further tests and the deterioration in my spine over the last two and a half years has been huge. It's frustrating because I feel that if I had had more consistent monitoring post-surgery, I would not be in this position now.'

Molly Everitt, adult living with SMA type 3, age 23, Devon

It was evident from this review of people's experiences that access to services differed depending on which NHS trust someone lived in. It was also clear that, though none of the workshop participants were receiving input from all the clinicians mentioned in the 2017 standards of care, some were accessing valuable support that is not mentioned in the document at all.

5.0 What matters to adults today?

5.1 Independent Living with appropriate health and social care

One of the key priorities shared by all the workshop delegates was the importance of independent living. There seemed to be little or no connection between health and social care, or guidance on how SMA clinicians could support access to appropriate care provision at home.

5.2 Clinical Priorities

In groups of 4 or 5, participants discussed the clinical support that would best meet their needs. Some had access to these services and were sharing the positive impact, others were discussing a wish list of services that would address current gaps in provision for them personally. Key discussion points were noted by each group. These notes were collated for analysis of themes and frequency.

Fig. 6 shows the common discussion areas between the groups across both workshops and the frequency with which those areas were discussed.

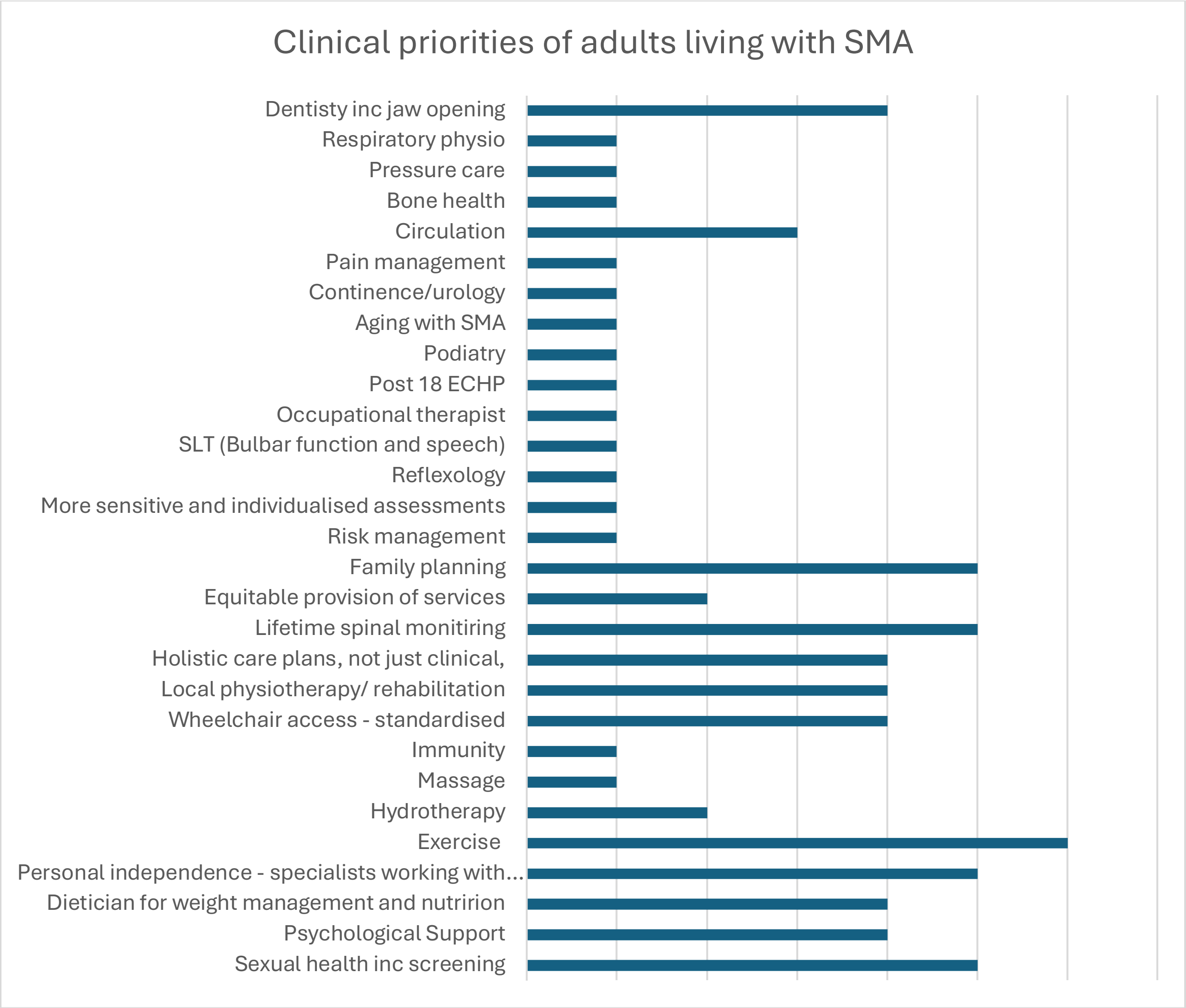

Fig. 6

Fig 6 clearly shows that there are several key priorities for adults living with SMA. Discussions revealed the following top priorities:

- Regular physiotherapy and exercise plans. Specialist neuromuscular physios should have the capacity within their clinic appointments to assess, practice and design individualised exercise and stretching plans to follow at home as part of an adult's daily routine. Where appropriate, this should start with a baseline assessment and set achievable targets that are reviewed at each clinic visit.
- Specialist dentistry
- Circulation
- Sexual health including family planning and screening
- Spinal monitoring. All workshop participants agreed that ongoing reviews of their spine would have been valuable to prevent or manage complexities that they have experienced post spinal surgery.

- Weight management and nutrition
- Psychological support
- Equitable access to equipment including wheelchairs
- Coordination between health and social care

5.3. Multidisciplinary Teams

Treatment has brought multi-systemic reported outcomes, including both stability and improvements in not just motor function but in fatigue, respiratory function, swallow, speech and appetite, to name a few. However, on an individual basis, improvement, progression, stabilisation or regression of symptoms is currently unpredictable. This suggests the clinical classification of SMA Type is no longer helpful. It was agreed that it is important that adults are monitored and that outcomes are sensitively measured. Specialist clinicians need a holistic and individualised approach to the management of the condition, involving a multidisciplinary team (MDT).

Those participants at the workshops who were most satisfied with their clinical care, reported access to a wider MDT. Reports were that this was particularly successful when:

- interventions are consistently reviewed since childhood.

-alterations to care and treatment are based on changing needs.

- there is efficient communication across the disciplines.

It was noted that MDT clinics have been established in specialist centres across the UK to monitor and assess the outcomes of new treatments. Whilst the treatment access is under a managed access agreement (MAA), these clinics are largely enabled by funding from Biogen for the delivery of Nusinersen. Additionally, the success of the clinics and the establishment of a well linked multidisciplinary team, seems to depend on the drive and motivation of the individual professional clinicians involved, and the capacity of the specialist centre. The future for these valued clinics is therefore uncertain.

The MDT clinic provision for SMA hardly existed before the introduction of DMT treatments for adult patients, except in the few centres where prior research was set up. Due to the standard clinic follow up time being limited to 15min, the clinic appointments were often only focused on any acute change in health or social circumstances.

The MAA for Nusinersen and Risdiplam required at least the selected sites to review their service provision and make adjustments to deliver the treatment efficiently, monitoring outcomes outlined by NHSE. This led to some provision being allowed in our clinics. For example, the service was allowed to have some flexibility to treat the 11 Nusinersen patients.

Since then, our service has evolved to treat 36 Nusinersen and 24 Risdiplam cases, still on the service agreement of those first 11 SMA patients on Nusinersen. This meant that, in order to ensure the timely delivery of treatment, small teams managing SMA patients worked round the clock, sacrificing annual leave etc as we felt the treatments were limb and lifesaving.

We delivered the service uninterrupted during COVID. This helped also to ensure that the outcome measures are collected longitudinally to help the approval process post MAA.

I must say that the contribution of the 'one of its kind' tariff approved by NHSE to support Nusinersen treatments helped obtain support from the Management team in obtaining extra physiotherapy time to help coordinate aspects of care in SMA.

We have moved on from the historic annual 15 min slot for an SMA follow up, to dedicating 60-90min per visit twice a year. However, this is not equitable across the UK. Some centres were only Risdiplam treatment centres and therefore did not receive the additional NHSE funding. Such centres have struggled to obtain appropriate support to increase MDT input. Nonetheless, the opportunity was created to benchmark the SMA service provision across the UK highlighting the disparities. With the MAA ending soon, there is a risk of regressing back to pre-MAA era of SMA care unless a standardised national framework is set up and commissioners' approval is obtained for implementation.

Channa Hewamadduma, Consultant Neurologist, Sheffield Teaching Hospitals NHS Foundation Trust.

5.4 Holistic coordinated care

These conversations highlighted the importance of not only a specialist MDT team, but also a holistic and individualised approach to care. This would involve close collaboration between specialist, local and social care teams. This echoes the promises made by the new Integrated Care Systems (ICS), created with the purpose of bringing together partner organisations to plan and deliver joined-up health and care services.

All of the workshop participants agreed that their local GPs did not have enough knowledge of SMA, it's multisystemic impact, the treatments or the individualised responses to treatments. Therefore, coordination of care and education for local clinicians has to be led by the specialist team. Close collaboration with local teams would not just facilitate education about SMA and how the condition impacts the person at an individual and holistic level. It would also allow referral requests, ideally through a care coordinator, similar to the system available to families of disabled children.

'*Care co-ordinators help to co-ordinate and navigate care across the health and care system, helping people make the right connections, with the right teams at the right time. They can support people to become more active in their own health and care and are skilled in assessing people's changing needs. Care co-ordinators are effective in bringing together multidisciplinary teams to support people's complex health and care needs.'* [5]

'She [care coordinator] makes life easier when it comes to appointments and advocating for our daughter and her needs. If there are times we feel we can't address an issue or we don't feel comfortable with guidance from a medical professional i.e. doctors, speech and language therapists, respiratory consultants, she has stood up for us every time and always backed us and our needs '

Charlie Brown, parent of child living with SMA

SMA UK have seen their support team playing an ever-increasing role in linking up health and social care teams across many and varied individualised situations.

'In 2024, 32 adults approached SMA UK's Community Support Team for help to address issues with their Care and Support packages.

Each person's situation was different, and due to their complexity, some issues were addressed more smoothly than others. Generally, throughout our support, we have found there to be very little understanding of SMA, and the impact on the person being recognised in individual support plans provided by the Local Authority or Integrated Care Boards. Raising awareness of SMA's impact for an individual with social workers and health assessors is crucial to enable a

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[5] NHS England » Care co-ordinators

comprehensive and holistic needs led assessment, that is a true reflection of the support a person requires.

Supporting the community across the whole of the UK we see the disparities that exist in both Local Authorities and with Integrated Care Board provision. A more cohesive approach, truly listening to understand those with lived experienced, could help support better outcomes for them, increase their independence, and fundamentally allow choice in daily living to be a real option for those living with SMA.'

SMA UK Community Support Team

Implementation of statutory support with care coordination would be a step towards recognition of the busy lives many people living with SMA live. They are not just patients.

Adults at the workshop discussed how both clinical and social support services seem to ignore the fact that they have lives to live, jobs to go to, families to manage and responsibilities to fulfil, just like other citizens.

Living with SMA isn't a full-time job; but chasing referrals, coordinating social care, wheelchair services, and fighting to be seen by the right professionals certainly feels like one. Now add running a business or working into the mix. The truth is that many third-party providers contracted in by the very system designed to support us, still don't grasp that disabled people work. They assume we're just sitting at home, available whenever they feel like showing up. The level of coordination required for these things is exponential and the truth is we have to do this ourselves!

Luis Castro E Canto, adult living with SMA type 2 aged 39, Essex

Many are not aware of the existence of care coordinators.

I did not know that some families of children with SMA have care co-ordinators/key workers. That would be so helpful in our situation. My son was diagnosed with SMA 3 in his early teens. He is now in his late 40s. At the time of diagnosis, knowledge of SMA was very little and there were no treatments.

As my son's SMA has progressed and he now uses a power wheelchair, he has had many hospital visits, both locally and also once or twice a year 40 miles away to our nearest Neurology centre. All these visits are via NHS Patient Transport - a nightmare when the actual appointment is short but the waiting time to be taken home can be four hours or more, sometimes in the depths of winter, with the vehicle making several long detours to pick up and drop off

other patients. My son does not drink for the whole day so that he does not need the loo, and it takes him a couple of days to recover from the exertion of the journey and the events of the day.

Being mostly homebound, home services are essential. With a lot of chasing, we get home visits from Community OTs (I think he must have had over a dozen or more of these over the years up to now - some very helpful and some not so), and the rare species called NHS Community Physiotherapists, who are not specialists in neuromuscular disorders. District Nurses have come and gone too. Over the last few years, he has also had Community Podiatrists visiting regularly to trim his toenails, but apparently the NHS have recently cut the funding for this, and he has been told to file his own nails every day or "get Mum to do it", or pay to get them trimmed. He has equipment supplied by the council Equipment Services, who turn up without warning at various times with equipment that is not always right, resulting in many emails and phone calls. I have to chase up NHS Wheelchair Services to supply and service his powerchair, necessitating his being on a waiting list for months and then more calls and admin to get things right.

I do all this liaising and co-ordinating by phone but mostly by email, necessitating time and energy - my son is almost 50 so you can guess how old I am!

We have also tried to get major home adaptations put in place (twice) via a DFG, but the admin and expense this generated meant it came to nothing.

Having said all this, we can contact his Neurologist with queries and they are quick to reply. They and his GP make referrals to community teams, which I usually have to chase up as the referrals seem to go into a black hole. The last referral was made as a "priority" in November 2024. After chasing, the OT came out in February 2025, but we are still waiting for the phantom NHS Physiotherapist to get in touch. Respiratory took their time too and forgot to send the sleep apnoea equipment - more chasing.

My son does help with the co-ordination of all his treatment when he can but, as severe fatigue and brain fog is a daily result of SMA, he finds this difficult, so he does what he can.

Therefore, a Co-ordinator/Keyworker for adults with SMA would be SO appreciated.

Mother and informal carer of adult living with SMA, Hampshire

5.5 Transition from Paediatric to Adult Care

All workshop participants agreed on the importance of a well-structured and positive transition process.

There were participants, across both workshops, who agreed that transition to adult services brought a significant reduction in the quality of multidisciplinary clinical care. Experiences of a lack of timely information, communication and collaboration had left some young adults feeling they were going into the unknown.

I felt ready to transition but had not received any information about the adult unit. My transition appointment was conducted online via Teams, but I only met the [neurology]Consultant.

When I went for my first appointment at the adult unit, I did not know anything about their clinic or the wider MDT.

Now I am established at the adult unit I know that I am receiving exceptional care and also did in paediatrics. However, I do feel that my transition could have been improved through simple changes, particularly stronger communication as I felt left in the dark as to whom was responsible for my care at the time.

Patrick Kelly, living with SMA type 1, 19 years old, Manchester

Those with positive transition experiences shared the positive impact of an MDT meeting early on in the transition process. Yet there is still work to be done to improve collaboration between clinical and social healthcare teams at the transition stage.

When we transitioned to adult care, things went fairly smoothly. We had a meeting with our health care team (including respiratory physios) to discuss our health care plan and prepared for the scenario that we end up in hospital. This has only happened once so far and went well.

We were fortunate enough to have our OT and physio be part of the young adults' team, meaning they are still supporting us in adulthood.

Social services was a little difficult. The care essentially stopped, and we had to be reassessed for things such as direct payments.

As children, we had a continuing care package, and when we turned 18, this was discontinued as we didn't meet the criteria.

It would be good if transitioning adults were to have a multi-agency meeting to assess all needs at once and prepare the service user and their families for the changing situation.

Sam and Alex, twins living with SMA type 2, 19 years old, Derby

5.6 Advanced Care plans

Only 7 participants (25%) had an advanced care plan. All of them lived in or around the Manchester area, all had retained access to this care plan into adulthood with regular amendments based on changing needs. All 7 shared the positive impact this process has on their health and social care experiences.

Many of the workshop attendees had never heard of an advanced care plan. They were not aware of its purpose as a document that outlines your wishes, beliefs, values, and preferences regarding your future medical care. It allows you to specify the types of medical treatment you want and appoint someone to make healthcare decisions on your behalf if you cannot do so yourself.

This is particularly important if you become unable to communicate your decisions. It is also vital in a rare disease like SMA where frontline emergency clinicians need to quickly understand the nuances of SMA and how emergency treatment differs from the usual protocol.

The process involves reflecting on your values, discussing your wishes with healthcare providers, and completing necessary forms. This planning empowers individuals to maintain control over their healthcare decisions and can also include personal and social care needs such as for a PA or a hoist whilst in hospital.

Workshop participants across the SMA spectrum had stories of being in local emergency care, treated by clinicians who did not understand SMA and its bespoke treatment pathways. All could see the value in having a care plan in place. From their perspective, this document should not be reserved for only those with the most medically complex cases. The process should be started with parents, reviewed throughout paediatric care and then revisited at transition, giving the adult ownership of the document. This would avoid difficult conversations at traumatic times of ill health.

5.6 A user-friendly Standards of Care document

All agreed that adults living with SMA need a Standards of Care document that they can use as an advocacy tool. The document needs:

- Visuals that are equally representative of the adult community

- Language that is in line with the social model of disability, recognising them as people, not patients.
- Standards based on clinical assessment and function, not on 'types'.
- An adult care summary document, separating their needs from those of the paediatric community.
- Recommendations of the clinical triggers that might initiate or adjust social care funding.
- Expectations set for the level of collaboration with local teams.

6. Summary of Recommendations

6.1 Advice for clinicians about how to support independent living

Unlike GP's at the primary care level, specialist clinicians, who know the adult living with SMA and their circumstances, will have a secure understanding of the specific ways that SMA impacts the individual in their care. This unique and expert perspective is invaluable for any social care assessment. As such, specialist clinicians, who work closely with adults (including consultant Neurologists, Clinical Nurse Specialists (CNS) and Neuromuscular physiotherapists) should be given the opportunity and the capacity to advocate for those they care for to have access to appropriate health and social care provision to enable them to live full lives as UK citizens.

6.2 Priority areas for consensus guidelines

Priorities for adults living with the SMA include:

- Specialist dentistry
- Circulation
- Sexual health including family planning and screening
- Lifetime spinal monitoring.
- Weight management and nutrition
- Psychological support
- Equitable access to equipment including wheelchairs
- Coordination between health and social care

Work to establish consensus guidelines for these topics needs to be initiated to ensure equity of care provision across the UK.

6.3 A Multidisciplinary approach to specialist care

All nominated specialist centres should have a team of specialists working together. They should have the capacity and the funding to offer a limited number of appointments through which they can meet the core needs of the individual.

This team should consist of the core specialist clinicians identified by the SMA Care project. They should carry out annual assessments using sensitive standardised and personalised outcome measures across a range of outcomes, not just focusing on mobility.

6.4 Holistic Coordinated Care

Support from a care coordinator would be hugely valuable to many. This should be a person who knows them, their condition and their needs. It could remove the daily burden of managing referrals and appointments.

There needs to be improved coordination between local and specialist services. For example, if an Individual needs podiatry or specialist dentistry, this could be a local appointment arranged via a referral from a specialist.

As a facilitator to collaboration between health and social care teams, a care coordinator could improve the efficiency and appropriateness of social care provision at home.

6.5 A collaborative transition period

This should be an extended period of time where there are opportunities for the young person to meet their new team and visit the new site. They should be well prepared for the changes in responsibilities, entitlements and processes that they might expect to experience in adult services.

6.6 Advanced Care Plans

These should be agreed for all. They should be individualised and holistic covering both health and social care needs. They should be started in childhood and annually reviewed. Ownership of this plan should be transferred to the individual at the transition phase.

7.0 Summary

A single user-friendly Standards of Care document

Adults and clinicians need a Standards of Care document that embraces all these recommendations. It needs to guide practice, and be available as an advocacy tool. Best practice should be driven by one standard of care that all centres are working towards. Not only would this reduce inequities seen across the UK, but it would also be a document that could be leaned upon when looking for funding to establish important MDT clinics.

The document needs:

- Language that is in line with the social model of disability, recognising them as people, not patients.
- Standards based on clinical assessment and function, not on ‘types’.
- Recommendations of the clinical triggers that might initiate or adjust social care funding.
- Expectations set for the level of collaboration with local teams.
- Visuals that are equally representative of the adult community.
- An adult care summary document, separating their needs from those of the paediatric community.