

Survey Examining Patient and Family Perspectives of Spinal Bracing for SMA in the U.K.

Performed by SMA U.K.

Analysed by Dr William Quelch



Sheffield Children's
NHS Foundation Trust

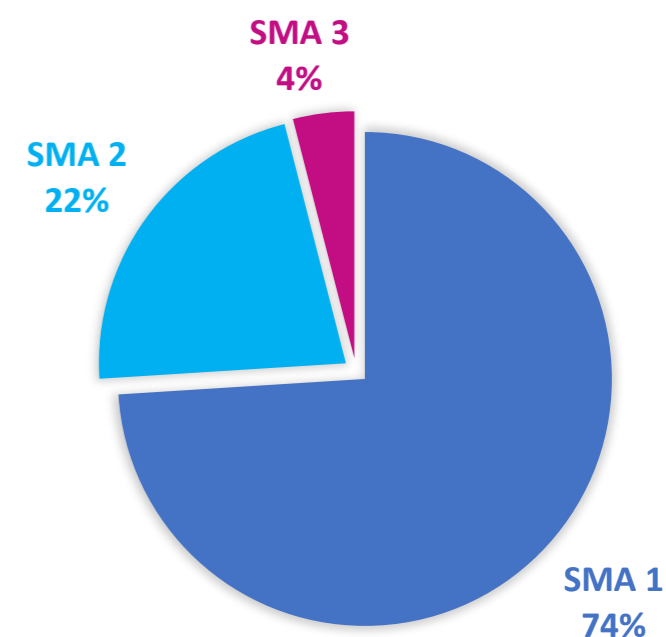


Demographics

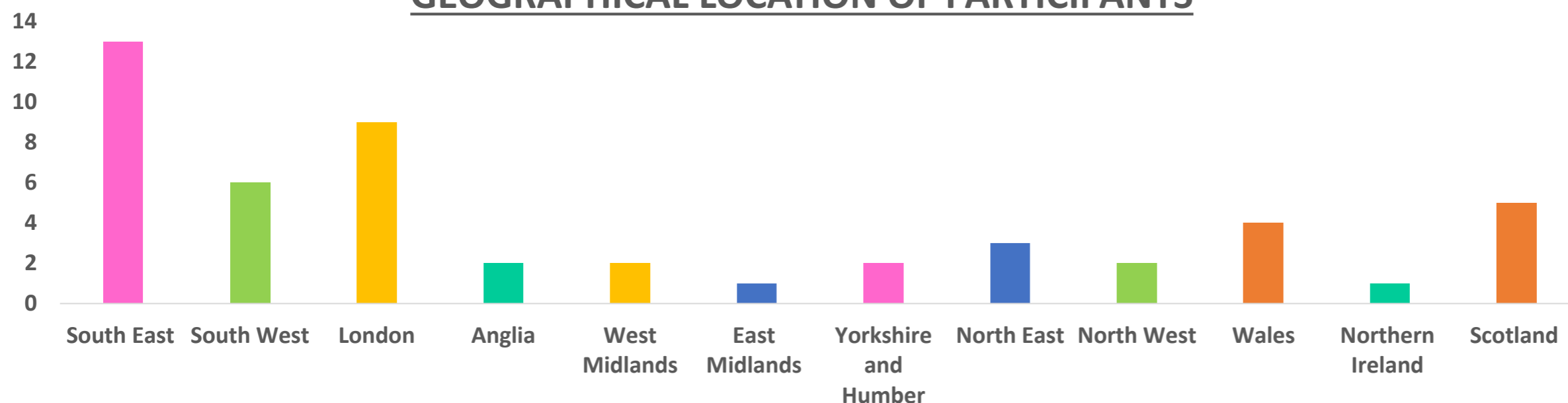


- 52 respondents to survey
 - 50 participants with viable data
 - Predominantly patients with SMA Type 1
 - Majority of participants from the south of England

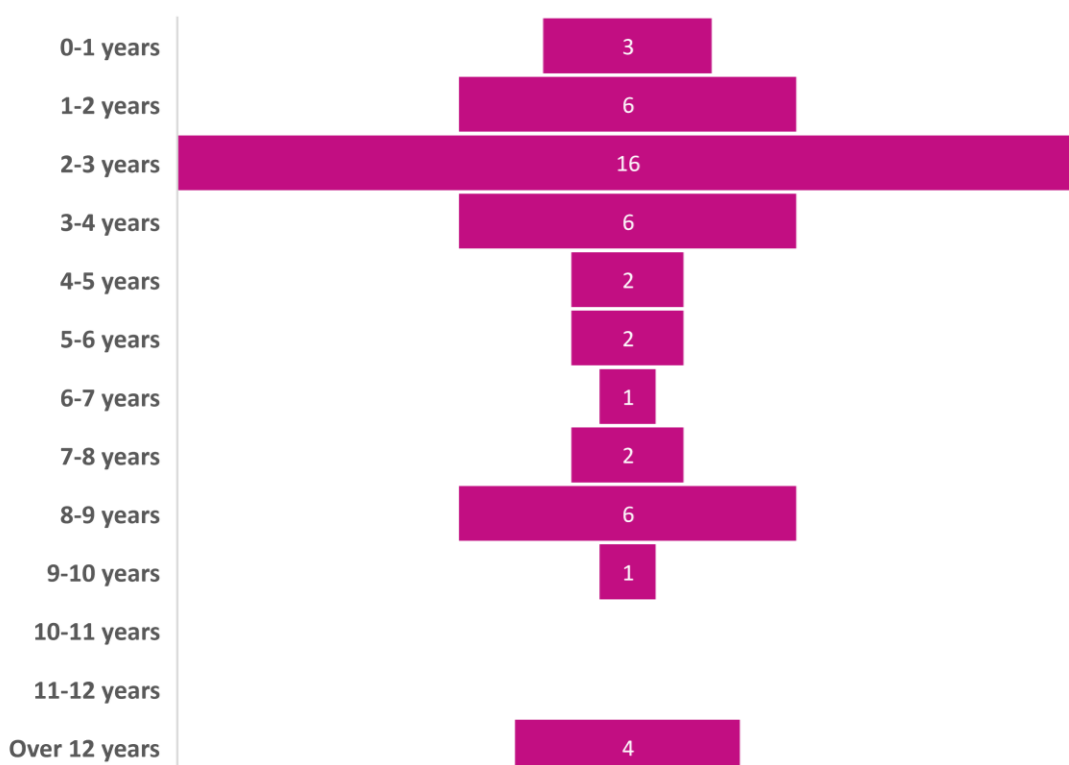
SMA TYPE



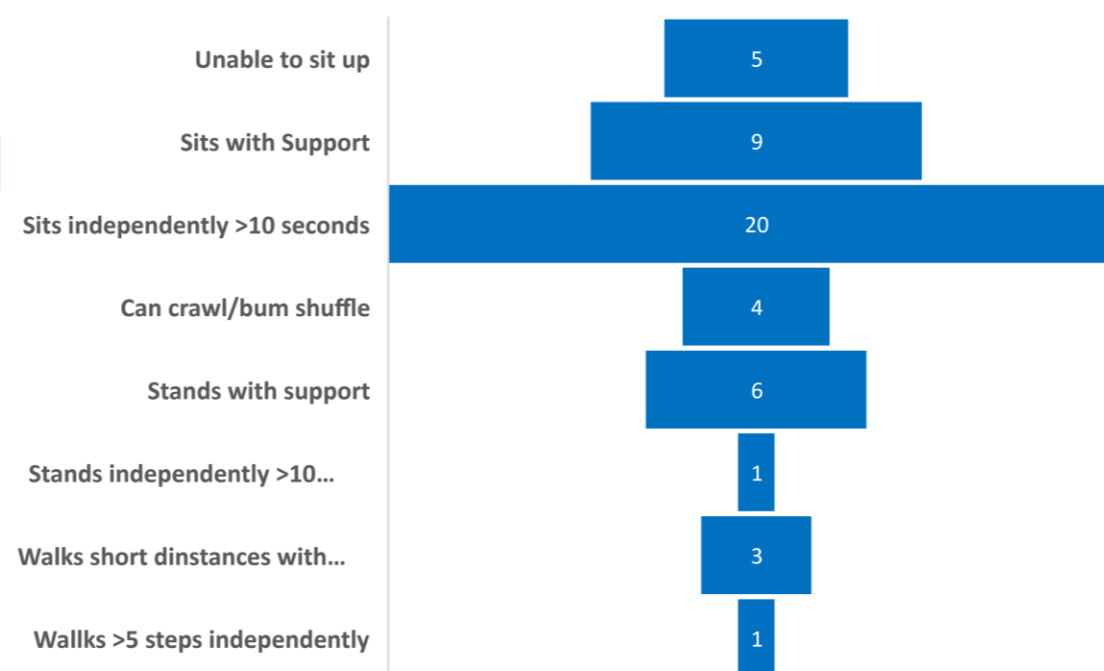
GEOGRAPHICAL LOCATION OF PARTICIPANTS



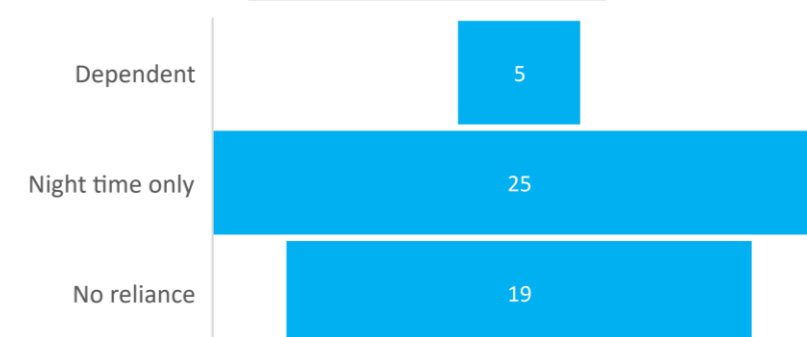
AGE OF PARTICIPANTS IN SURVEY



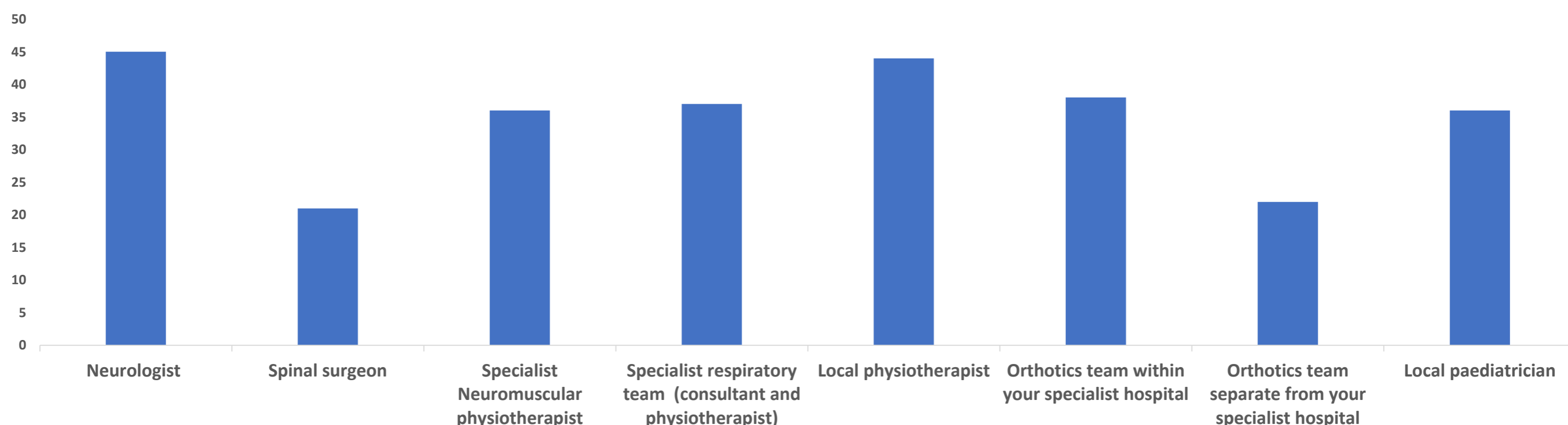
MOTOR MILESTONES



NON-INVASIVE VENTILATION REQUIREMENTS



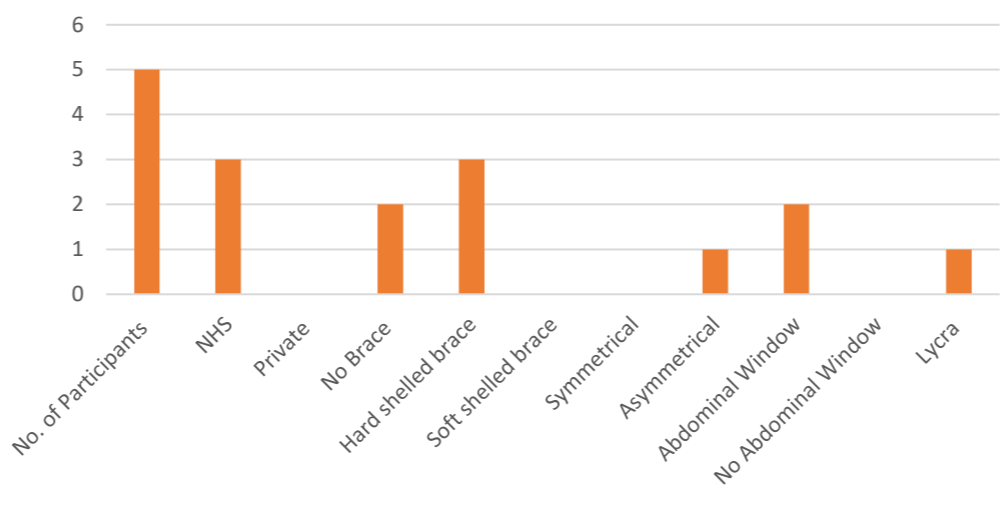
PROFESSIONALS INVOLVED IN SPINAL CARE



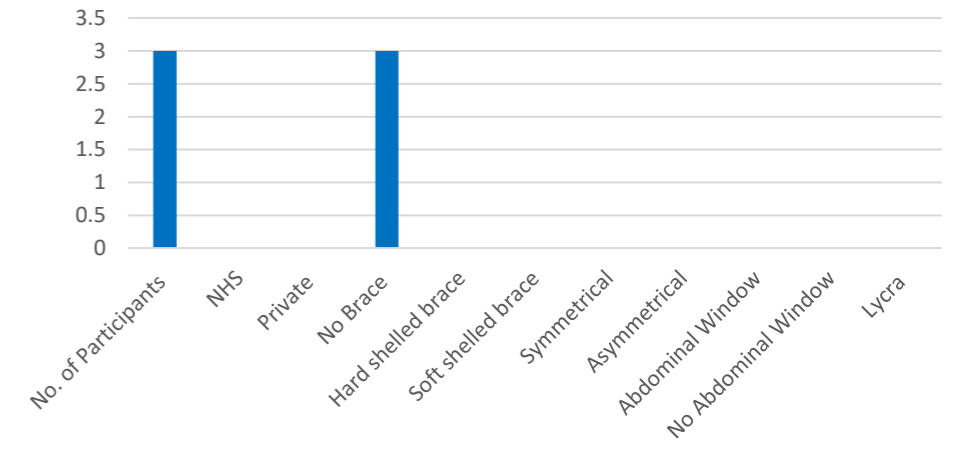
Bracing methods provided across the U.K.



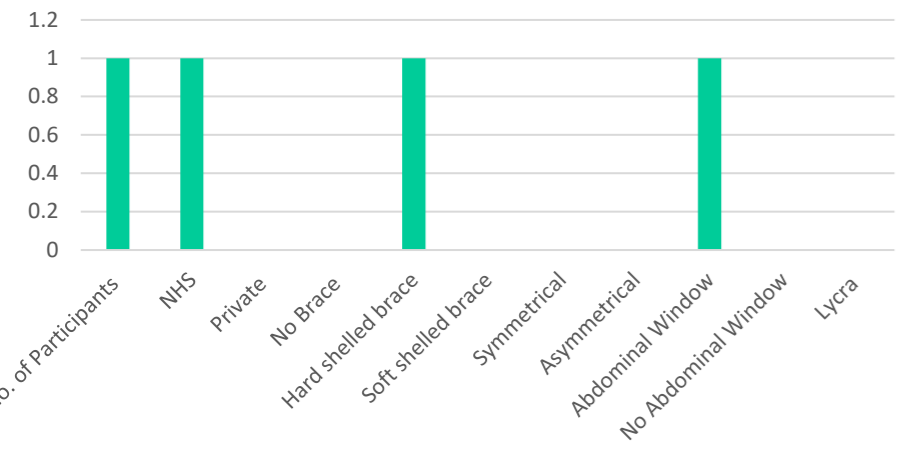
Scotland (n=5)



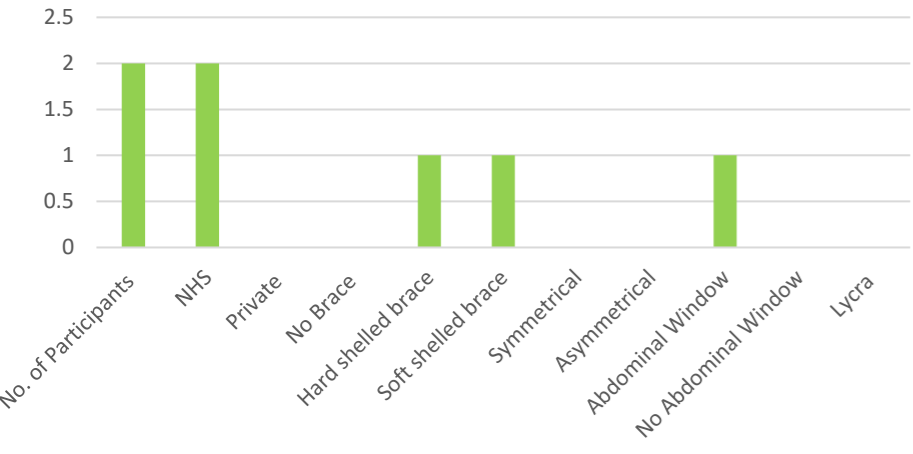
North East (n=3)



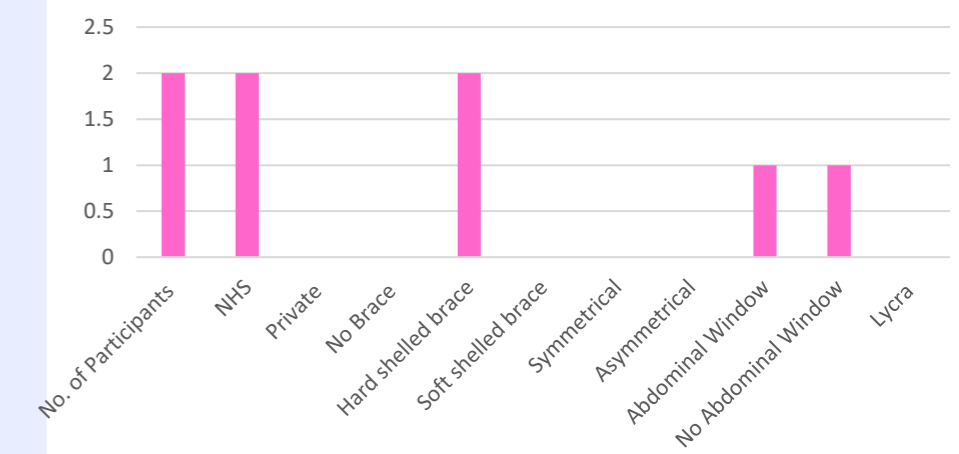
Northern Ireland (n=1)



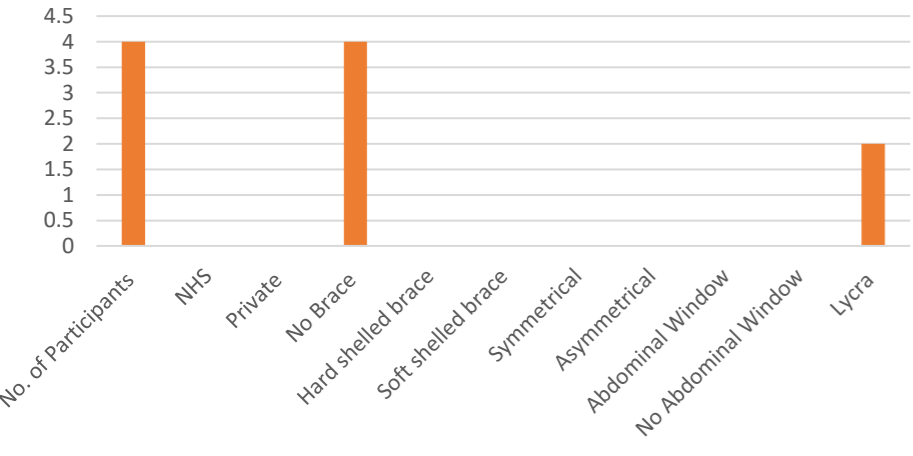
North West (n=2)



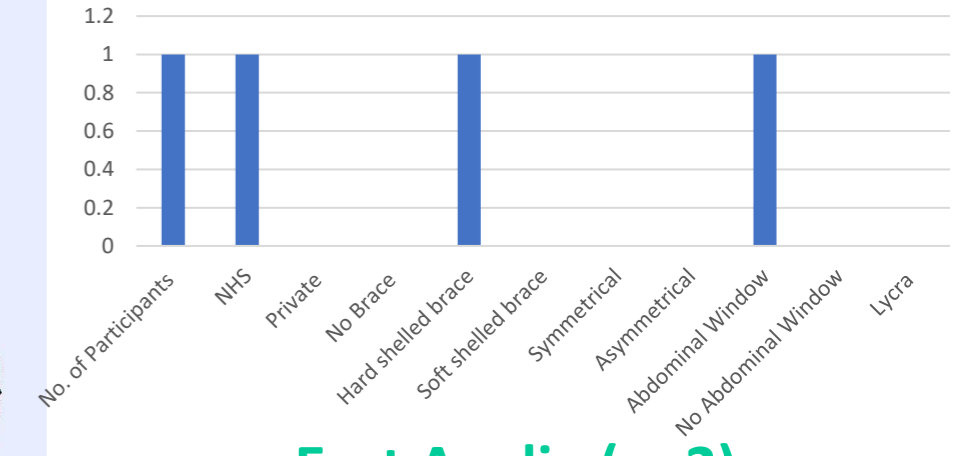
Yorkshire and Humber (n=2)



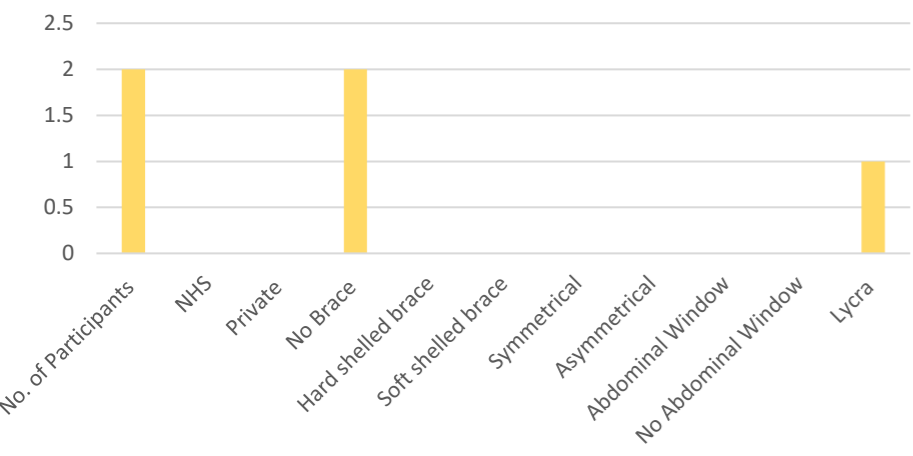
Wales (n=4)



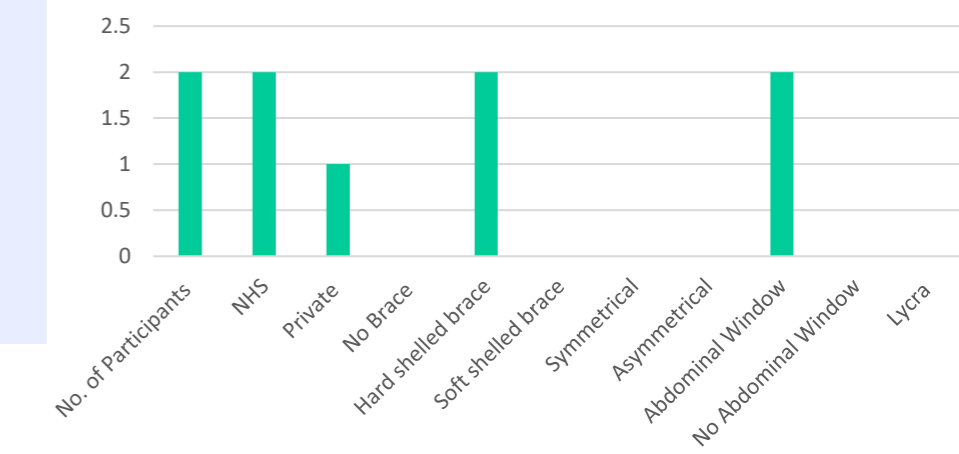
East Midlands (n=1)



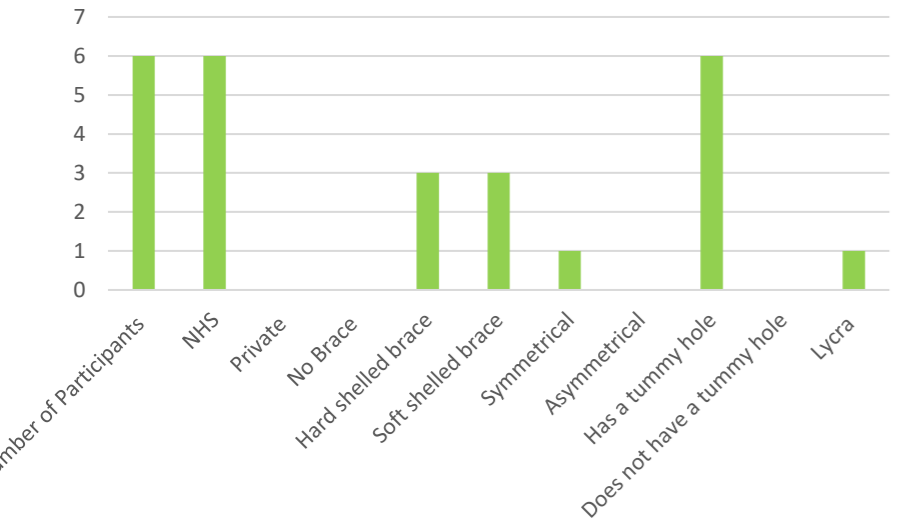
West Midlands (n=2)



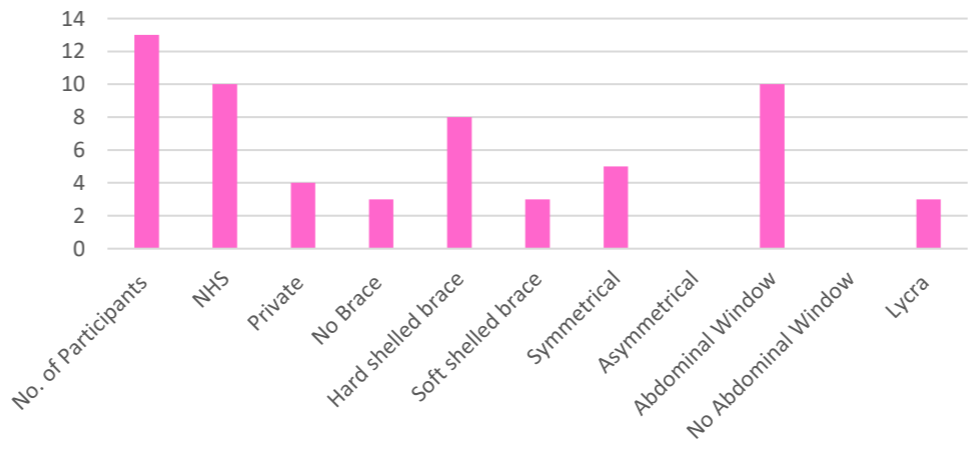
East Anglia (n=2)



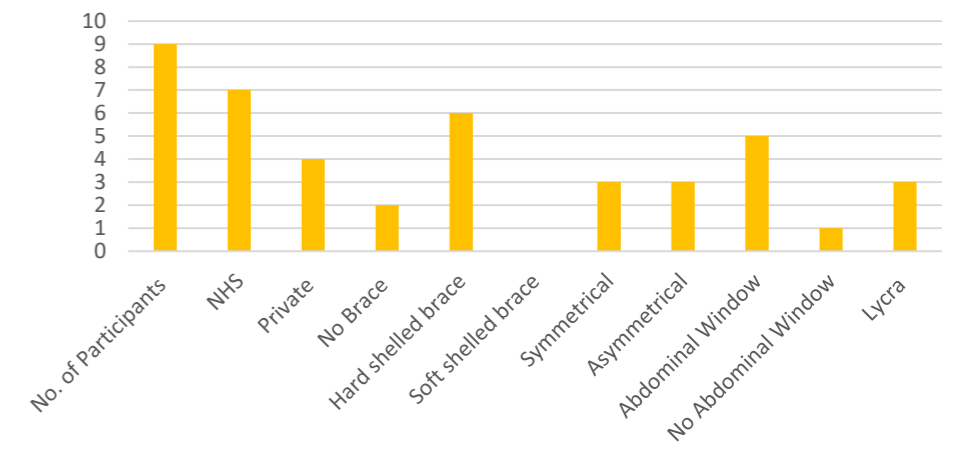
South West (n=6)



South East (n=13)



London (n=9)

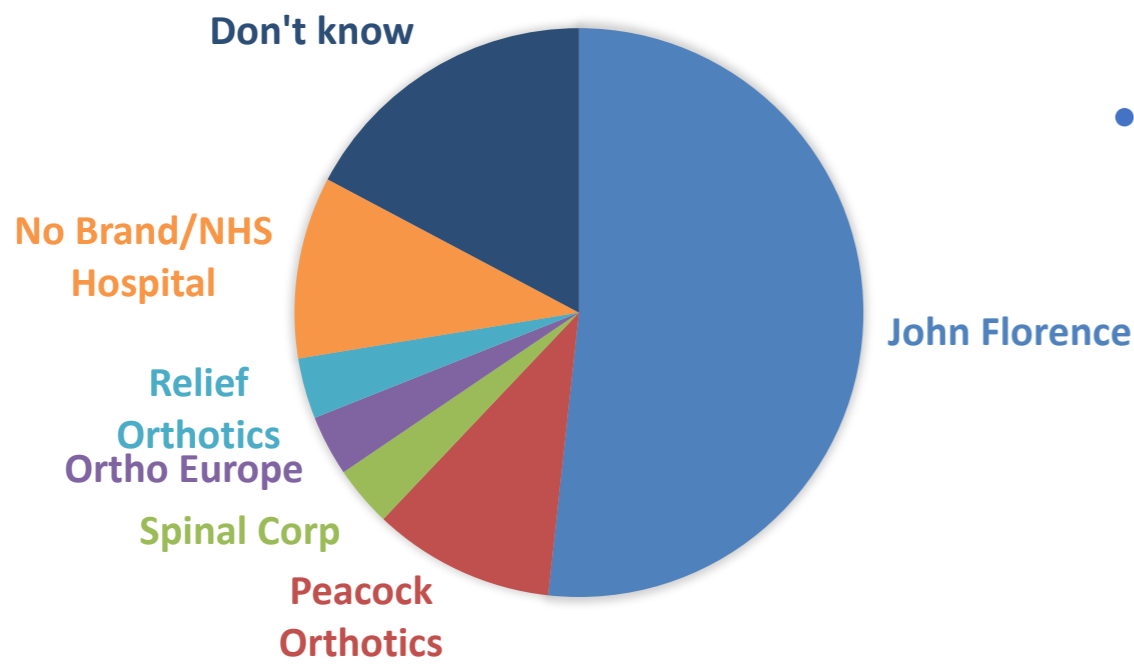




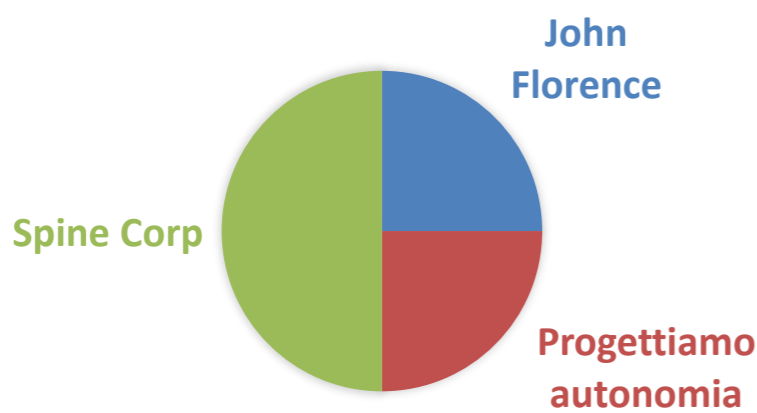
Spinal Bracing in the NHS

- Large variety in manufacturers of spinal braces and in advice for duration of wear
- NHS braces perceived as only somewhat effective and only moderately well tolerated
- Lycra preferred to rigid bracing in some areas of the U.K.

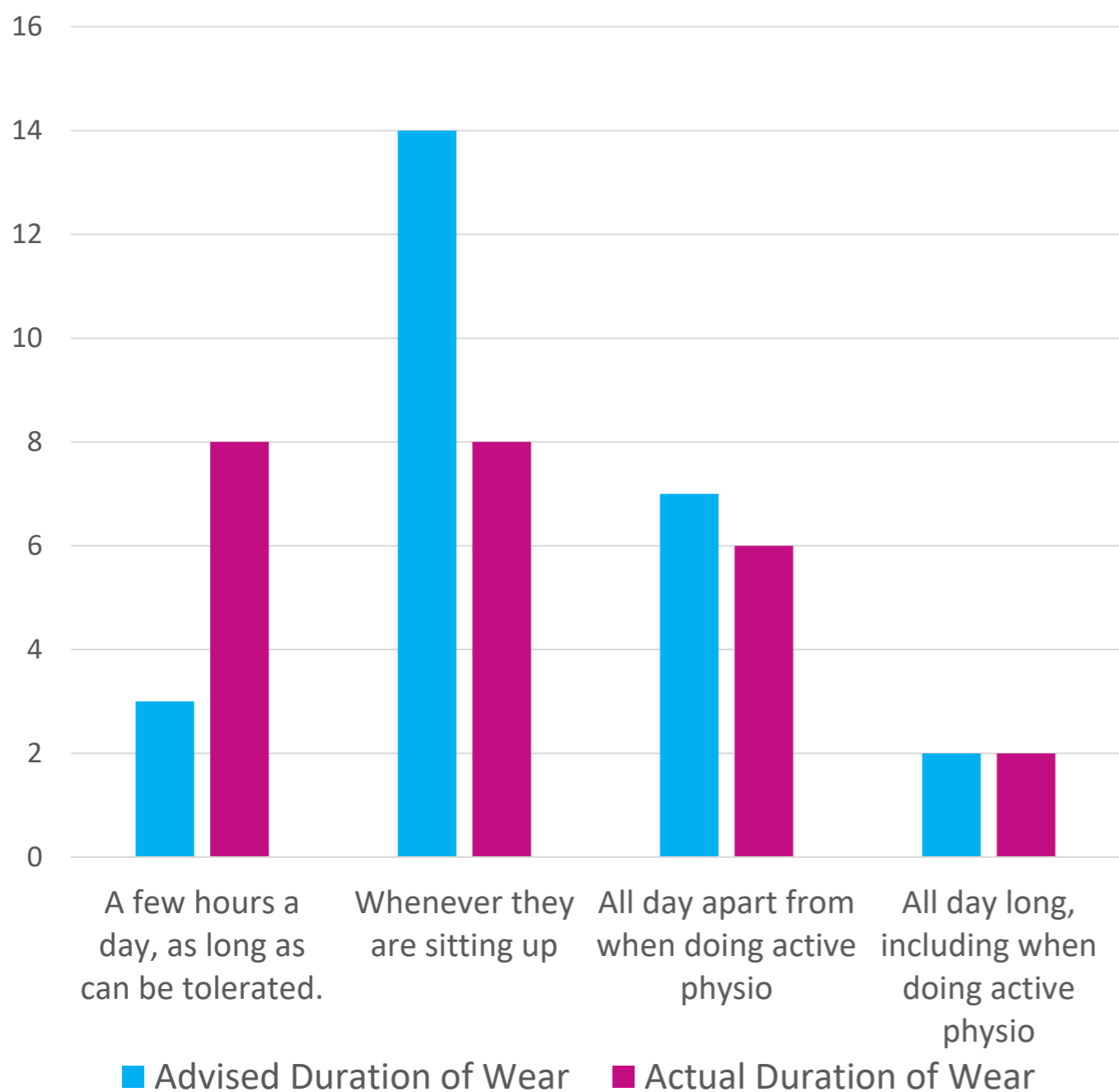
SUPPLIERS OF NHS BRACES



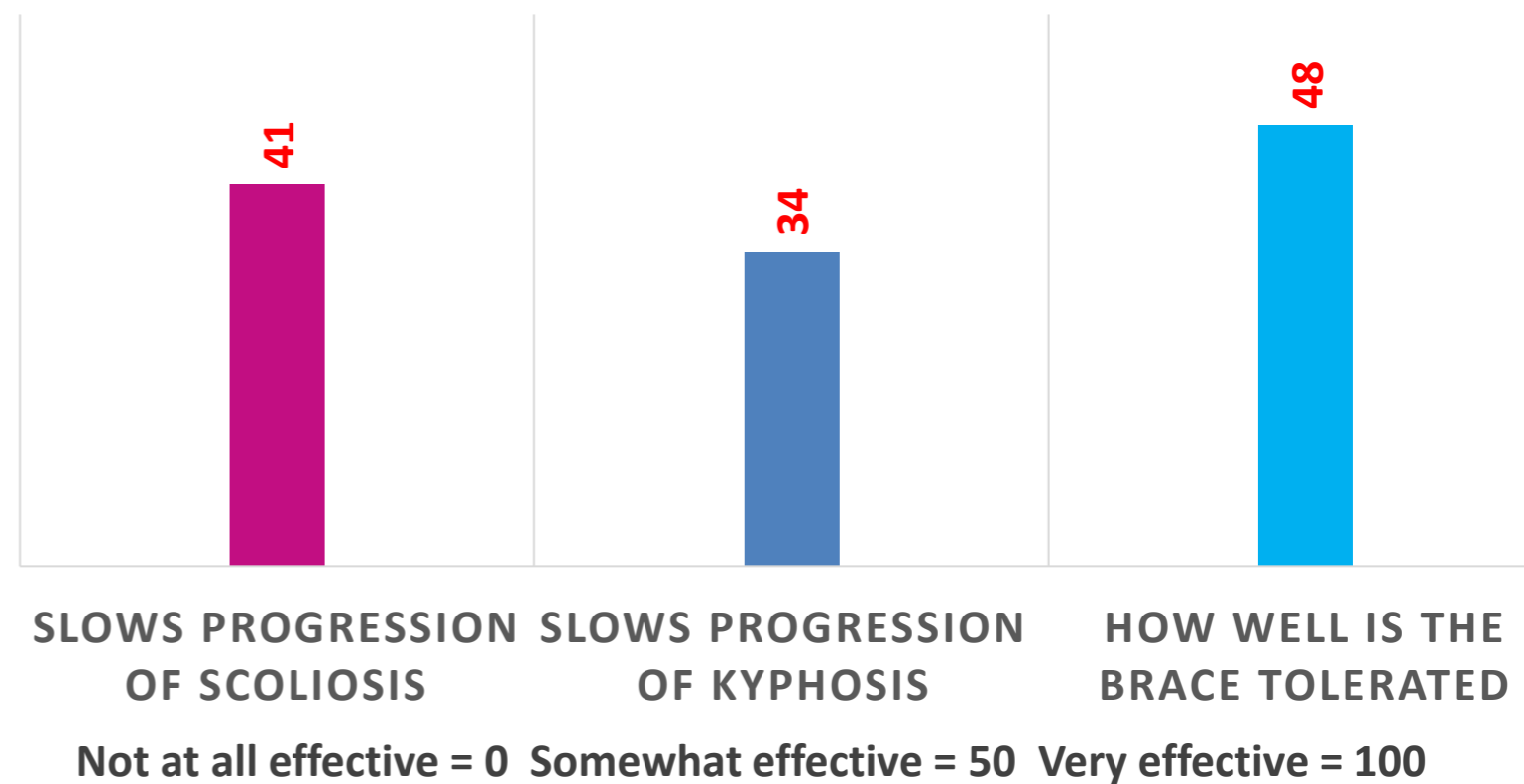
SUPPLIERS OF PRIVATELY FUNDED BRACES



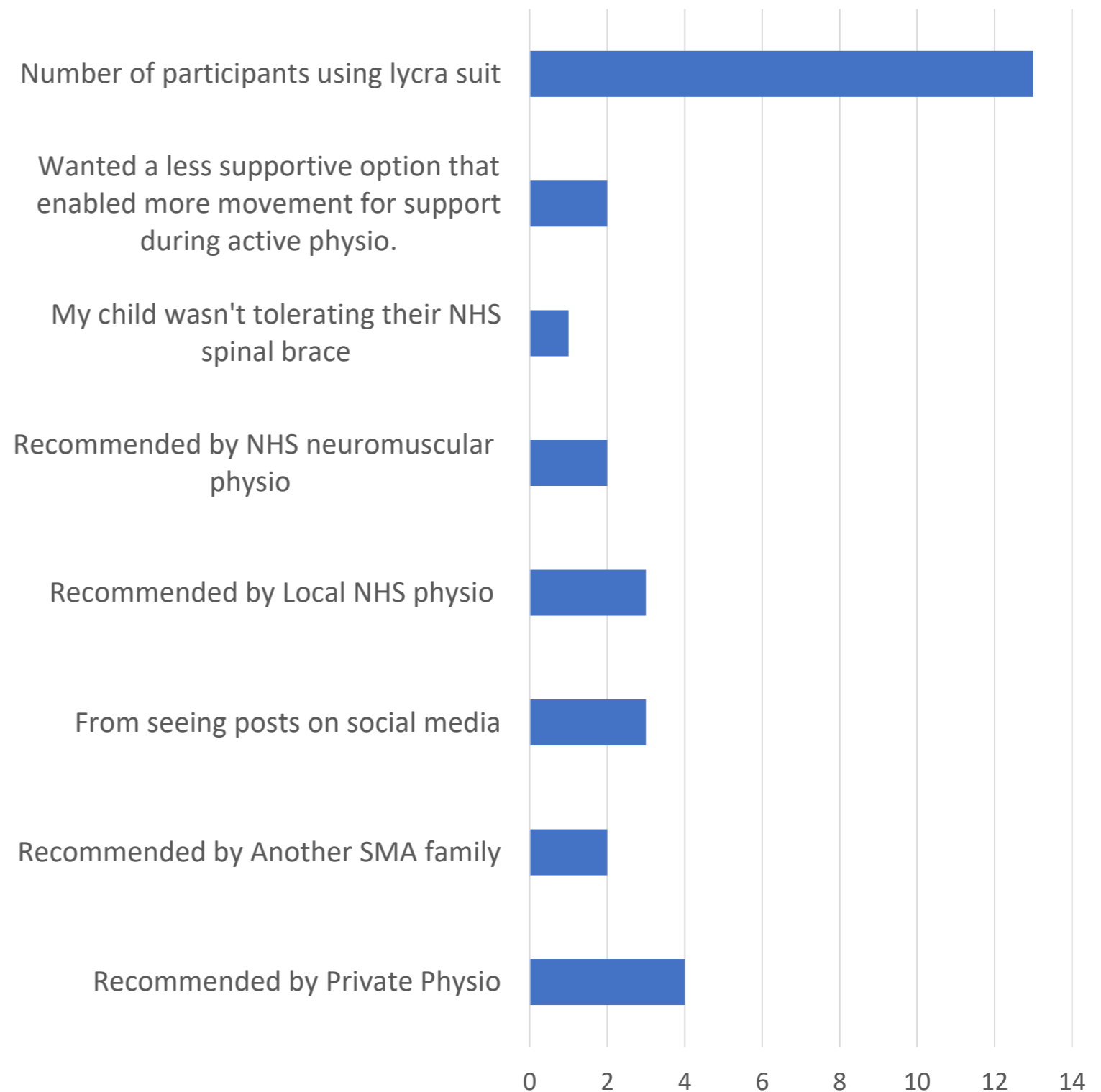
TIME SPENT WEARING BRACE



PERFORMANCE OF NHS SPINAL BRACE



USE OF LYCRA SUITS IN SMA



Service Users Experience and Opinions of Spinal Bracing Service in the U.K.



"For us the bracing worked well to help sit and for us as parents to do something"

"I think that in our situation hip displacement had exacerbated the curvature"

"My child doesn't like the brace, when he wears it, he doesn't move or play"

"No x ray was done to identify how the brace needs to help his spine"

"The team are great but my son changes shape quite quickly and then the brace doesn't fit properly"

"Once transitioned to adults no one monitors now it is up to us to go and be cast every two years and obtain funding from our ccg"

"Spinal management was not something my child was offered. I had to push for an X-ray and a spinal brace"

"Physios who work with the children on a weekly basis must be involved in the process"

What is your perspective of your child's NHS spinal brace or the standard of care you received?

"We are grateful to have the brace but just wish there was more knowledge surrounding bracing SMA kids and slowing down scoliosis....we have had to push for and ask for a lot ourselves"

"We are very pleased with our child's privately purchased brace. He has a kyphosis and this brace help him a lot to correct his posture when sitting"

"There is no competition in the market so there is no environment for change. This is the main problem - the NHS are just outsourcing to a 3rd party who have no incentive to try harder, try new techniques, or advance their ways of doing things"

The brace our son currently has... is a corrective brace. It is over correcting his curve purposely to encourage his spine to go in the opposite direction it currently is...For that reason it is obviously less comfortable for our son to wear, but that's because it is doing its job.

"The braces are too tight. They are impossible to wear"

"The brace has supported him well in his seating position in his wheelchair"

"so many appts it gets overwhelming"

Comments on the effectiveness of your child's NHS brace

"Not effective at all, he is having his 3rd brace and sadly all of them are done privately"

"We had a few TLSOs made through the NHS and always had issues with them fitting"

"Flimsy and doesn't seem supportive or fit very well"

"It is not about looks. I do not want her to have to have spinal surgery at a young age. I do not want her to have breathing and swallowing problems...Her spine has been terribly mismanaged"

"The whole process was not great; it felt very disrupted"

"I think the spinal surgeon, the physiotherapist and orthotist should be in the same room when the child is scanned/fitted for the brace"

"I can't believe that these professionals don't come together to discuss what should be done for the child"

"The process was clear; the design was made taking into consideration the x-ray, correction was applied and a review after fitting was done to ensure the effectiveness of the brace"

Why did you decide to purchase an orthotic spinal brace privately and how effective was this?