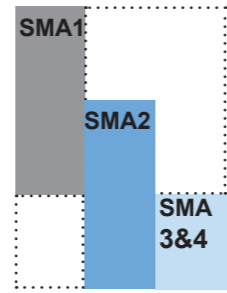
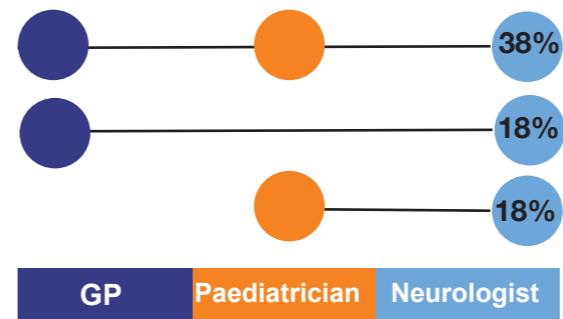


CURRENT EXPERIENCE

'Floppy' or weak baby
 Poor head strength & not being able to pull oneself up
 Poor leg strength or difficulty walking



28% of all participants were dismissed or not taken seriously before diagnosis



72% diagnosed through a blood test

88% knew nothing about SMA at diagnosis

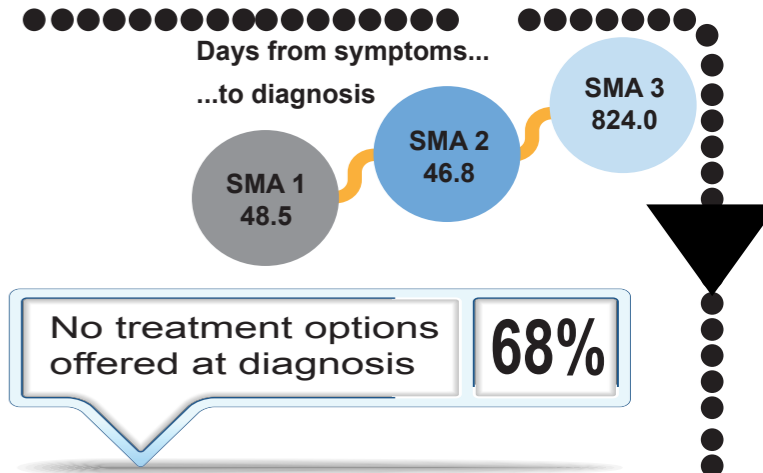
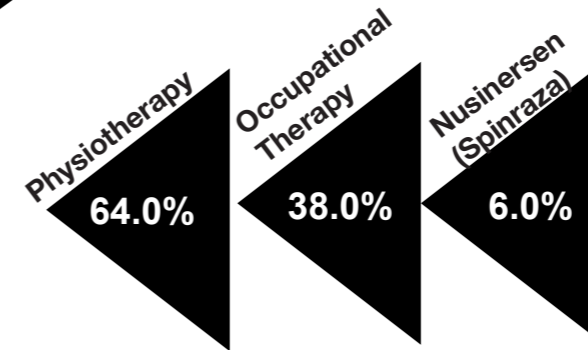
Most common symptoms observed before diagnosis

SMA 1 more likely to access information through health professionals



90% FELT RESPECTFULLY TREATED THROUGHOUT THEIR EXPERIENCE

SMA 2 more likely to access information through the internet



No treatment options offered at diagnosis **68%**

SMA 1 infants Poor quality of life FASTER PROGRESSION

SMA 2,3,4 Better quality of life SLOWER PROGRESSION

Quality of life

Communication & Information

Treatments experienced

Conversations about treatment

PATIENT EXPERIENCE EXPECTATIONS KNOWLEDGE

PEEK

www.cc-dr.org

SPINAL MUSCULAR ATROPHY



future expectations



Health Professional Communication

Keep up the good work, but perhaps a little more tailored communication for adolescents and adults

I don't think anyone can imagine how heartbreaking it is to know there is a potential treatment out there that could slow this thing down, but not be able to access it

I wouldn't want anyone to suffer from it, that's what I would like to see early newborn screening

We have the ability to be productive citizens but that can only happen when the health system works and sometimes, it just doesn't, I mean, especially if you need assistance or equipment but are held up by red tape

Involve us. At the very core of decisions, ask us and don't just sit in an office and make decisions for us without being connected with who you're making decisions about

messages to decision-makers

Treatment

Access to new treatments that slow progression and access to newborn screening/genetic testing

Care & Support

Support to maintain independence and a central point to access services

Information

Centralised, Australian-specific, practical and positive information



CCDR would like to thank each and every participant in this study
 We would also like to thank all of our study partners