



# UK SMA

## PATIENT REGISTRY



**Are you registered?**  
[www.sma-registry.org.uk](http://www.sma-registry.org.uk)

A secure, online database of genetic and clinical information of individuals affected by SMA living in the UK & Ireland.



Contact us: [smaregistry@newcastle.ac.uk](mailto:smaregistry@newcastle.ac.uk) or 0191 241 8640



## PROMs

(Patient Reported Outcome Measures)

Have you reported your PROMs?

-  Share experiences of activities of daily life and quality of life.
-  Collected through questionnaires via UK SMA Patient Registry website.
-  PROMs & medical data should be reported close to clinic visits.
-  Provide your perspective about SMA and related interventions and treatments.
-  Provide essential information to NICE and NHS England.