

# 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.**



# Patient Reported Outcome Measures (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.