

## Appendix B: Managed Access Patient Agreement Form

To be signed by patient and/or parent or guardian AND clinician

I understand the conditions of the Managed Access Agreement (including the conditions under which access to risdiplam will stop being provided as part of this agreement) and agree to give my treating clinician permission to enter collected data as specified in the Managed Access Agreement into the SMA Reach registry. I also agree to co-operate with my treating centre to ensure that I/my child receives the standard of care as indicated by the status of my/my child's condition. You may withdraw your consent for your participation, or the participation of your child in the Managed Access Agreement at any time without prejudice. Withdrawal of participation in the Managed Access Agreement will effectively stop access to Evrysdi treatment. A patient may inform their physician of their decision to withdraw consent at any time.

**Name of Patient:** \_\_\_\_\_

**Signature of Patient (if over 16):** \_\_\_\_\_

**Date:** \_\_\_\_\_

### **If patient is under 16 without informed assent**

I understand the conditions of the Managed Access Agreement including the conditions under which access to risdiplam will stop being provided as part of this agreement) and agree to give the treating clinician permission to enter collected data as specified in the Managed Access Agreement into the SMA Reach registry. I also agree to co-operate with my treating centre to ensure that I/my child receives the standard of care as indicated by the status of my/my child's condition. You may withdraw your consent for your participation, or the participation of your child in the Managed Access Agreement at any time without prejudice. Withdrawal of participation in the Managed Access Agreement will effectively stop access to Evrysdi treatment. A patient may inform their physician of their decision to withdraw consent at any time.

**Name of Parent or Guardian (if patient under 16):** \_\_\_\_\_

**Signature of Parent or Guardian (if patient under 16):** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Name of treating clinician:** \_\_\_\_\_

**Signature of treating clinician:** \_\_\_\_\_

**Date:** \_\_\_\_\_