**Supplementary Table 2 – Clinical Symptoms Module Questions from the National ALS Registry Web Portal**

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| **Question** | **Description**  |
| 1 | Month 1st noticed weakness later diagnosed as ALS |
| 2 | Year 1st noticed weakness later diagnosed as ALS |
| 3 | Don't know when 1st experienced weakness |
| 4 | Part of body where 1st noticed weakness later diagnosed as ALS |
| 5 | Do/Did you experience cramps or muscle spasms? |
| 6 | Month 1st experienced cramps or muscle spasms |
| 7 | Year 1st experienced cramps or muscle spasms |
| 8 | Don't know when 1st experienced cramps or muscle spasms |
| 9 | Do/Did you experience scattered muscle twitching? |
| 10 | Month 1st experienced Scattered muscle twitching |
| 11 | Year 1st experienced Scattered muscle twitching |
| 12 | Don't know when 1st experienced scattered muscle twitching |
| 13 | Do/Did you experience difficulty swallowing? |
| 14 | Month 1st experienced Difficulty swallowing |
| 15 | Year 1st experienced Difficulty swallowing |
| 16 | Don't know when 1st experienced Difficulty swallowing |
| 17 | Do/Did you experience problems with speech? |
| 18 | Month 1st experienced Problems with speech |
| 19 | Year 1st experienced Problems with speech |
| 20 | Don't know when 1st experienced Problems with speech |
| 21 | Do/Did you experience difficulty controlling bowels or bladder? |
| 22 | Month 1st experienced Difficulty controlling bowels or bladder |
| 23 | Year 1st experienced Difficulty controlling bowels or bladder |
| 24 | Don't know when 1st experienced Difficulty controlling bowels or bladder |
| 25 | Have you taken riluzole (Rilutek®)? |
| 26 | Used power wheelchair or electric scooter |
| 27 | Month 1st Used power wheelchair or electric scooter |
| 28 | Year 1st Used power wheelchair or electric scooter |
| 29 | Don't know when 1st Used power wheelchair or electric scooter |
| 30 | Have you used noninvasive breathing equipment (Bi-Pap)? |
| 31 | Month 1st Used noninvasive breathing equipment (Bi-Pap) |
| 32 | Year 1st Used noninvasive breathing equipment (Bi-Pap) |
| 33 | Don't know when 1st Used noninvasive breathing equipment (Bi-Pap) |
| 34 | Have you had a tracheostomy? |
| 35 | Month 1st Had a tracheostomy |
| 36 | Year 1st Had a tracheostomy |
| 37 | Don't know when 1st Had a tracheostomy |
| 38 | Have you used an augmentative and alternative communication device? |
| 39 | Month 1st Used an augmentative and alternative communication device |
| 40 | Year 1st Used an augmentative and alternative communication device |
| 41 | Don't know when 1st Used an augmentative and alternative communication device |
| 42 | Have you ever enrolled in hospice program? |
| 43 | Month 1st Ever enrolled in hospice program |
| 44 | Year 1st Ever enrolled in hospice program |
| 45 | Don't know when 1st Ever enrolled in hospice program |
| 46 | Pneumonia that required treatment with medication |
| 47 | Have you experienced falls that caused injury significant enough that you were seen by a doctor? |
| 48 | Have you had a blood clot in arm, leg or lung requiring treatment with blood thinner? |
| 49 | Have you ever participated in any ALS research studies? |
| 50 | Are you potentially interested in participating in ALS research studies? |
| 51 | Have you ever attended an ALS multidisciplinary clinic? |
| 52 | Which hand do/did you write with? |
| 53 | Have advance directives established, such as living will? |
| 54 | Have you had genetic test for inherited traits that can cause ALS? |