**Additional file 5: Table S5.** Survey questionnaires for HCPs with limited experience with TSCa

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| **Questions** | **Choices presented** | |
| 1) Which of these tests do you regularly perform to diagnose TSC? | * MRI of the brain * CT of the lungs, liver and kidneys * Ultrasound scan of the kidneys | * Echocardiogram * Ultrasound eye exam * Skin exam * Genetic testing * Other (please specify) |
| 2) In your experience, what are the barriers to effective assessment of neurocognitive difficulties in a TSC patient? | * Lack of routine checks for neurocognitive symptoms known to be associated with TSC * Lack of neurophysiological tests * Limited experience with comprehensive assessment of cognitive development or behavior * Limited experience with diagnostic criteria for psychiatric disorders * Other (please specify) | |
| 3) How often do you assess cognitive and behavioral issues in TSC? | * Never * Rarely * Sometimes * Only if the patient/caregiver or HCP requests it * Once a year | |
| 4) How difficult is it for you to refer a patient to psychiatry? | * Easy * Somewhat difficult * Difficult | * Very difficult * Not required |
| 5) In your experience, what barriers are there to effective collaboration between non-psychiatric HCPs and psychiatrists in terms of TSC treatment, if any? | (Select all that are appropriate)   * Lack of time/resources in psychiatry * Reluctance among psychiatrists to take on TSC patients due to the multifaceted nature of the disease/lack of disease understanding * Reluctance among HCPs to refer TSC patients for psychiatric assessment/treatment * Other (please specify) | |
| 6) How confident are you in knowing when to refer a patient to a psychiatrist? | * Not confident * Somewhat confident | * Confident * Very confident |
| 7) How often did you refer a patient to a psychiatrist? | * Never * Rarely * Sometimes | * Regularly * Always |
| 8) How confident are you in discussing psychiatric assessment and treatment requirements with a patient or patient family/caregiver? | * Not confident * Somewhat confident * Confident * Very confident | |
| 9) In your experience, how often do you think that patients/patient’s families feel stigmatized when referred to psychiatric services? | * Never * Rarely * Sometimes | * Often * Always * I don’t know |
| 10) In your experience, do you think standard psychiatric therapy works for TSC patients? | * Never * Rarely * Sometimes | * Often * Always * I don’t know |

* CT, computed tomography; HCP, healthcare provider; MRI, magnetic resonance imaging; TSC, tuberous sclerosis complex. aHCPs with limited experience with TSC refer mainly to primary care physicians