**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