

TSC CLINIC STANDARDS TABLE

	Core standard #	Core criteria description	Gold standard #	Gold criteria description
Clinical care	1	Director with medical board certification in their country of clinical practice in a specialty related to one or more aspect of TSC. Co-director may be named to assist with oversight of the clinical mgmt of the clinic. Co-director is a MD, PA, or NP with certification in their respective profession.	1	In addition to meeting core standard, TSC Clinic provides care in 6 or more specialties such as: cardiology, dentistry, developmental medicine, endocrinology, epileptology, gastroenterology, genetics, genetic counseling, neuro-oncology/oncology, neuropsychology, neurosurgery, ophthalmology, psychology/psychiatry, social worker, surgical oncology, urological surgery, interventional radiology
	2	Director/co-director will serve on the TS Alliance Professional Advisory Board (PAB) for a renewable 3-year term	2	Provide care for adults and children, care includes comprehensive outpatient consultation, inpatient evaluation as needed, and follow-up recommendations
	3	At minimum provide care in 3 core specialties (derm, nephrology (or urology), neurology). If children's only, cardiology recommended; and pulmonology recommended if adult women seen.	3	Upon invitation, a healthcare provider affiliated with the TSC clinic (in addition to the Director and if applicable the Co-Director) will agree to serve a three-year renewable term on the PAB.
	4	Should provide comprehensive initial evaluation on new patients, and on an as needed basis, provide recommendations for follow-up care.	4	The TSC Clinic administers the TAND Checklist annually or as needed.
	5	All healthcare providers associated with the TSC Clinic are expected to be listed on the TSC Clinic Update Form with their email address for TS Alliance contact purposes only.	5	The TSC Clinic utilizes telemedicine technology to provide consultation to children and/or adults with TSC.
	6	All healthcare providers associated with the TSC Clinic are expected to keep the Clinic Director or Clinic Coordinator updated about a child or adult with TSC who was referred to them.	6	One or more key healthcare providers complete at least one CME course related to TSC every two years.
	7	The Clinic Director shall identify his/her core healthcare providers and should meet at least annually to review new treatments, research, and clinical trials for individuals with TSC.		
	8	Staff should include someone to assist with coordination of services and/or clinical care. Time commitment is based on clinic's needs.		

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Educational resource	9	Clinic should serve as an educational resource to educate the lay public, healthcare providers, educators, and individuals with TSC and their families about TSC; Clinic should work closely with the TS Alliance to disseminate information and to promote awareness of TSC.	7	In addition to meeting core standard, Clinic should hold at least one virtual or face-to-face TSC meeting annually to update the participating healthcare providers, local and/or regional healthcare providers and/or individuals with TSC and their families.
			8	The TSC Clinic shares a TSC-related publication or other resource materials authored by one of their healthcare providers with the TS Alliance and other TSC Clinics.
Partnership	10	Clinic should develop a mutual partnership with local community alliance (where one exists); volunteers will provide resource materials, and clinic will refer to community alliance	9	In addition to meeting core standard, the clinic director or colleague (co-director, specialty healthcare provider, nurse coordinator) accepts an invitation to serve on a TS Alliance committee such as an ad hoc, advisory). A greater than 50% attendance is expected.
	11	When TS Alliance extends an invitation to the Clinic director, co-director, or other TSC Clinic healthcare provider, the group should collectively participate (as a speaker or attendee) in at least 3 TS Alliance sponsored clinical or research events per year such as webcasts, "meet-the-expert" gatherings, research conference.	10	The TSC Clinic participates in the on-site TSC Clinic Ambassador Program.
			11	The TSC Clinic Director and/or Co-Director attends the TSC Clinic Directors Meeting.
Clinical trials & basic science research in TSC	Gold standard applies		12	One or more TSC Clinic healthcare provider conducts investigator-initiated TSC Clinic trials.
			13	One or more TSC Clinic healthcare provider participates in a TS Alliance or industry-sponsored TSC clinical trial.
			14	One or more TSC Clinic healthcare provider conducts basic science research in TSC.
<p>Guidelines description</p> <p>A TSC Clinic is expected to 1) submit a TSC Clinic Update Report annually to maintain or upgrade their designation in good standing, 2) submit a TSC Clinic Change Request Form whenever there is a change in the Director, Co-Director, Administrative, or Nurse Coordinator position, 3) participate in the "TSC Clinic Patient and Family Experience of Care Survey " Program, 4) have their key healthcare providers complete one CME course related to TSC every two years.</p> <p>Clinic designation categories</p> <p>1) Provisional TSC Clinic meets seven core standards and will have one year to achieve full status (i.e. meets the eleven core standards)</p> <p>2) TSC Clinic meets the eleven core standards</p> <p>3) TSC Center of Excellence meets the eleven core standards and at least 9 of 14 gold standards (4 in clinical, 2 educational, 2 partnership, 1 research)</p>				