CLINICAL TRIALS **TRANSFORMATION** INITIATIVE

Tool 2. Assessment of Patient Group Internal Aspects: Focus

Assessment of Patient Group Internal Aspects	YES	NO	NA	Notes
Vision/Areas of Focus: Are the patient group's vision, mission, goals, and areas of focus clearly stated and reasonable?				
Do these statement seem to reflect sound judgment regarding the disease space and state of the science?				
Is commitment to these statements demonstrated in the patient group's activities and performance?				
Do these statements seem reasonable relative to the patient group's current or projected budget?				
Operations: Are the patient group's operational programs well structured, performing well, and demonstrating measurable impact?				
If the patient group awards grants, are awards made via a credible application and peer review process and do the awards reflect the vision, mission, goals and area of focus?				
Does the patient group have and make good use of solid scientific/medical professional staff and/or advisors?				
Does the patient group have an effective fundraising and budgeting process adequate to its vision, mission, goals and areas of focus?				
Does the patient group receive good ratings from charity monitors such as the Better Business Bureau and Charity Navigator?				
Does the patient group's collaborative model include partnering options for sponsors outside of grant-based options?				
Budget and Fundraising: Do the patient group's budget and fundraising programs seem adequate to its needs or show signs of being able to become so?				
Has the patient group been able to marshal the resources required to establish important assets for development (e.g., patient registry, natural history database, clinical network)?				
Does the patient group devote a healthy percentage of its budget to its operational program vs. its overhead (e.g., administrative and fundraising costs)?				

Assessment of Patient Group Internal Aspects	YES	NO	NA	Notes
Does the patient group's budgets over the last 5 years demonstrate a fundraising capacity that is steady or growing and diverse in sources?				
Communications: Does the patient group have the communications systems needed to facilitate development across the full continuum?				
Does the patient group have sufficient internet and social media presence?				
Does the patient group issue a variety of publications to various audiences?				
Does the patient group use these communications effectively to educate, motivate and engage its patient community, medical, scientific, industry and government partners?				
Does the patient group use these communications effectively across all the phases of clinical development in which it is engaged?				

To learn more about CTTI's Patient Groups & Clinical Trials work, please visit https://ctti-clinicaltrials.org/our-work/patient-engagement/patients-groups-clinical-trials/