Patient and Healthcare Provider Roles in Clinical Trials

WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

PARTICIPANT/ PATIENT	CLINICAL TRIAL PROCESS	HEALTHCARE PROVIDER
Learn about the clinical trial process Ask your healthcare team about clinical trial opportunities Look on clinical trial sites for opportunities (clinicaltrials.gov)	**ACCESS TO CLINICAL TRIALS**	Educate/provide resources to participants about clinical trials in general Share information about potential clinical trial opportunities
Become well informed about details of a study	**RECRUITMENT**	Be well informed of the study plan and objectives Answer questions about the study protocol
Participate in the screening process, including any tests and evaluations, and participate in discussions with members of the research team	**CLINICAL TRIAL PROTOCOL**	Identify potential participants based on eligibility criteria Review medical history, perform tests, and evaluations as part of the screening process Participate in discussions with potential participants
Review all information related to the clinical trial including how the trial will work, the location and frequency for study visits, the overall time commitment, potential risks, and benefits of participation Make a list of questions and be sure that all questions are answered Discuss the opportunity to participate in a clinical trial with a loved one or trusted advisor	**INFORMED CONSENT PROCESS**	Provide comprehensive information about the clinical trial in the appropriate format, level, and language of the participant Ensure the participant understands all aspects of the clinical trial process Devote sufficient time for encouraging and answering questions Establish a contact person for follow-up questions Use a Shared Decision Making tool to guide the discussions between participant and health care team if possible
Attend all study visits Undergo tests and assessments per protocol Communicate with research team about potential side effects or concerns Ask questions	**STUDY VISITS**	Conduct all study assessments/measurements to evaluate safety and efficacy as per study protocol Provide opportunities for participants to report potential side effects, share concerns, and ask questions
Learn about the results of the study, and how this may impact future studies or hemophilia care	**STUDY RESULTS**	Summarize the study results in a preferred format and language for participants Provide participants with a summary of the study results
Participate in long-term follow-up and/ or a patient registry as applicable	**LONG-TERM MONITORING**	Reinforce the importance of long-term follow-up and/ or participation in a patient registry as applicable