EMPOWERING PROVIDERS TO EMPOWER PATIENTS (EPEP)

Resource Guide | Best Practices for Talking About Clinical Trials With Myeloma Patients

Patient Empowerment Network

UNDERSTANDING THE CRITICAL ROLE OF CLINICAL TRIAL NURSES

- Clinical trial nurses play many vital roles in the care of their patients, including that of caregiver, communicator, educator, and advocate.
- They are the healthcare professionals with the most interpersonal contact with the patient.
- They serve as a conduit for dissemination and coordination of information between patients and the healthcare team.
- They must be understanding and empathetic to the unique needs, challenges, and viewpoints of patients throughout the disease continuum, from diagnosis through survivorship.

[Source]

HCP-RECOMMENDED STRATEGIES TO EFFECTIVELY COMMUNICATE ABOUT CLINICAL TRIALS

- **Use a structured approach.** Communicate with potential trial participants in a structured manner. Consider the Four Habits Model: invest in the beginning, elicit the patient's perspective, demonstrate empathy, and invest in the end.
- **Address common barriers.** Barriers to effective communication include language differences, low health literacy, cultural beliefs, and mistrust. Strategies to overcome these barriers may include plain language, teach-back method, cultural competence, and transparency.
- **Provide clear and accurate information.** Explain the trial accurately: the purpose, procedures, risks, benefits, alternatives, and rights of the participants. Consider visual aids to improve comprehension.
- **Assess patient understanding and readiness.** Assess a patient's readiness and understanding to give informed consent to a trial with communication techniques such as open-ended questions, reflective listening, and motivational interviewing.

[Sources: 1, 2, 3, 4]

DISCUSSING CLINICAL TRIALS WITH PATIENTS

1. **Explain the Purpose of Clinical Trials.** Discuss how clinical trials are research studies with patients.
2. **Discuss the Benefits and Risks.** Educate patients about the possible risks of the therapy being studied. Also discuss the potential benefits, such as access to new treatments before they are widely available.
3. **Provide Alternatives.** Consider what other options for treatment are available. This helps the patient make an informed decision about whether to participate in the trial.
4. **Discuss Informed Consent.** Help patients understand the informed consent process, and comprehend how the research treatment differs from the standard-of-care treatment.
5. **Address Concerns.** Help patients overcome the commonly reported fears of randomization, of receiving a placebo, and of potential adverse effects.
6. **Discuss the Practical Aspects.** Patients may need to speak with the research team and their insurance to learn whether treatment will be covered. Be able to refer patients to support resources.

[Source | Source]

TIP "Research nurses can play an extremely pivotal role in ensuring that we're not only at point-of-consent educating, but way before that, getting involved in pre-screening activities in order to ensure that we're looking at a diverse population." - RuthAnn Gordon, MSN, RN, FNP-BC, OCN

TIP "How can we harness all of our resources to provide the best care to a patient? Clinical trials are one of them. Clinical trials will offer support so that the patient can have access to a pharmacist, a social worker, a dedicated nurse, a dedicated line to call if they're having a symptom." - Beth Faiman PhD, MSN, APN-BC, BMTCN, AOCN, FAAN, FAPO

TIP "I tell all of my nurses, nurse practitioners, even physicians, just ask a patient. Don't think that because they live an hour away, they're not going to want to participate in a well-designed clinical trial without even asking them."
Beth Faiman PhD, MSN, APN-BC, BMTCN, AOCN, FAAN, FAPO

TIP "I think one of the most important things about when to talk to the patient is every time, anytime, right? And introducing that upfront I think is really important so that we don't leave clinical trials sort of as a last thought and the patient have that feeling." RuthAnn Gordon, MSN, RN, FNP-BC, OCN

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