



**PALLIATIVE CARE
RESEARCH COOPERATIVE**



Recruitment Innovation Initiative



Participant and Provider Recruitment Measures

Objectives



- Identify barriers/challenges to research recruitment in a palliative population – and strategies to overcome them!
- Identify referral sources
- Identify strategies to collaborate with internal and external recruitment sources
- Identify “champions”
- Understand benefits to the patient
- Understand benefits of conducting research in the home setting
- Develop Key Messages

Challenges to Recruitment in Palliative Care



- Finding eligible patients – “needle in a haystack”
- May be burdensome to very ill patients
 - Rapid disease progression in this population
 - High number of co-morbidities
 - High symptom burden
 - Poor prognosis
 - High degree of psychosocial stress
 - Concomitant med changes
 - Poor performance or functional score
- Staff, family “protective” of patient

Challenge: Finding Eligible Patients



- Multiple settings and providers
- Varied diagnoses
- Must meet special criteria:
 - prognosis
 - stage
 - function
- Inclusion/Exclusion criteria sometimes missing from records

Referral Sources



Brainstorm:

“Do we have the population in our database?”

AND

“Who is seeing this patient population?”

Prioritize and Focus your options!

Who is your target population?



- Acute or chronically ill patients
- Caregivers
- Connect primary source with target population

Consider Screening Primary Sources



- Internal Database of patients
- Community Partners
- Internal and External Providers
- Facilities
- Hospices

Other Referral Sources



- Council on Aging
- Eldercare or daycare centers
- Palliative care – inpatient and outpatient
- Tumor board
- Support groups (cancer, dementia, etc)
- Breast cancer centers
- Home Health Agencies
- Hospice
- Specialty groups (pulmonary, cardiology, nephrology)

Screening Strategies



- Daily census review in EMR
- Database search
- Admission screening questions
- Emails to Internal and External providers
- Attend Interdisciplinary Group or departmental meetings

Chart Screening Tips - General



- Set a schedule
- Identify the resources
 - EMR
 - Paper Charts
- Identify the process for notifying the providers
 - Ensure all involved know the process
- Identify a timeframe for follow-up
 - Create a Watch-List
 - Provide study materials

Chart Screening – Other Providers



- Confidentiality Agreement/Business Agreement
 - Defines who, what, where, and how
- HIPAA Compliance
 - No direct contact with patients
 - Providers or staff approach patients to gain interest and authorization for contact
- Schedule chart reviews & stick to It

Chart Screening – Other Providers



- Identify “go to” person in each office for follow-up on potentials
 - Helps relationship building if this is the same person each time (external site)
- Provide IRB approved study brochure
- Identify a location to keep information in their office
 - small binder with “watch list”

Challenges: Burden + Protectiveness



Palliative care patients may experience greater research burden due to:

- Symptoms
- Competing demands
- Psychosocial distress

Family caregivers and clinicians will be very protective!



Recruitment Strategies

There are two key ingredients:

Education
and
Communication!

Recruitment Strategies - Patient



- Print (Newspaper) ads
- Brochures
 - Generic and Study Specific
- Television and Radio ads
- Social Media/Internet
 - Company Website, Facebook, Blogs, Craig's List
 - Company profile
 - List types of studies available
 - Advertise studies (IRB approval)

Brochures



- Great recruitment tool
- Study specific brochures provide simple detail for the patient and family.
- Generic brochures provide simple detail about being a volunteer in a research study.

Recruitment Strategies



- Site Specific Strategies
 - Your own database – *daily* chart review
 - Study info in admission or new patient packets
 - Monthly in-services with providers
 - Website
 - Attend Department and Team Meetings
 - Weekly e-mails highlighting study
 - Monthly brainstorming sessions with study team

Recruitment Strategies: Incentives



- Be Creative
 - Recruit Subinvestigators from community offices
 - Identify procedures they will conduct related to study and identify appropriate payment for their time.
 - Create friendly competition between departments
 - (Example) The department who recruits the lowest number provides breakfast for the highest enroller
 - Say Thank You
 - Small gift cards/coffee cards as thank you's to non-research staff who assist with recruitment.

Recruitment Strategies - Clinician



- Doctor to Doctor letters
- Brochures
 - Generic and Study Specific
- Lunch-n-Learns
- Chart reviews with community offices
 - confidentiality agreement
- Monthly Presentations
- Key Messaging

Identify and Develop Champions



- Educate on Benefits
 - Potential for better control of symptoms
 - Research arm adds support
 - Home visits lessen burden
 - Gives meaning to patients
 - Adds to evidence basis in our field
- Develop Key Champions within your organization and with community partners – RNs/NPs/PAs/MDs

This will be the KEY to referrals and ultimately your overall success!

Identify Champions - Community Partners



- When planning for a study think about where the best recruitment sources are for patients:
 - Oncologists
 - Pain Specialists
 - Internal Medicine
 - Skilled nursing facilities
 - Assisted/Independent Living Facilities
 - Hospices
 - Palliative Care
 - Home Health agencies

Community Partners



- Identify other office staff as champions –nurses, NPs, PAs
- Put brochures in doctors waiting rooms
- Find out support groups and have CRN educate on applicable studies
- Develop key relationships with staff personnel so they don't see research team as an intrusion but a help to their pts

Community Partners - Education



- Arm providers with study brochures
- Educate non-physician and physician providers on study drug
- Create provider brochure with inclusion/exclusion criteria
- Ask staff “ In thinking over your patients, is there anyone who might suffer from...?”
- Discuss the trial offers meds at no cost and the potential benefits

Creating Partnerships



- PI Involvement crucial
 - 1: 7 – 10 successful partnerships come from outreach
- Picking strategic subinvestigators
 - Study specific
 - Time commitment
 - Consider specialty

Considerations Post Enrollment



- Difficulty contacting patients or caregivers
- High number of reported AE/SAE
- Noncompliance secondary to physical/mental deterioration
- Diary and or questionnaires too cumbersome
- Collaboration needed with primary physician or specialist regarding med changes, hospitalizations, etc.

Garnishing Provider/Staff Buy In



Why should my patient participate?

Develop Key messaging around:

- Benefit
- Support/safety
- Meaningful work
- Legacy
- Attempts to reduce burden

Understanding Barriers – Staff Buy-In



- Staff Buy-In
 - Perceived burden to patients
 - Wary of side effects
 - See “research” as experimental
 - Lack of understanding benefits
 - Additional time required for staff
 - Concerned about additional workload, “full plate”
 - May be inflexible to change
 - Often think they know “best” treatments

Overcoming Barriers – Staff Buy-In



- Education and participation are Key!
 - Orient new staff to the research process
 - Communicate openly and honestly with providers and staff
 - Include staff members in patient visits
 - Share the Informed Consent Form with staff
 - Encourage and respond quickly to questions and concerns
 - Celebrate patient success stories with those involved and their peers

Recruitment Strategies- Patients



- Important, Important, Important!!!
 - Be Available
 - Honest
 - Respect
 - Dignity
 - Compassion
 - Establish Boundaries
 - Don't Deviate from Protocol

Understanding Barriers - Patient and Family Perception



- “Guinea pig” mindset
- Disease progression and symptom burden
- Wary of side effects
- May feel overwhelmed, “I don’t want anymore to have to do.”
- Family fears and concerns
- Caregiver burden

Patient Recruitment Strategy



Develop Key messaging:

- Benefits of study
- Risks – with attention to safety and close monitoring
- Patient and family centered approach
- Revolve around patient’s schedule
- Assuring patients – collaborative medical care
- Family participation welcome
- Voluntary participation
- Withdraw at any time
- Care will not be compromised
- Keep primary physician informed

Ease Patient Burden through...



- Home research visits:
 - Convenient for patients
 - Can be home bound and on their own turf
 - Schedules revolve around patients
 - Drug therapies brought directly to patient
 - EKGs, labs done at home
 - Can set up technical equipment (log pads, etc.)
 - Saves valuable time/effort vs. clinic visit
 - Family often involved

Recruitment Aids- Patients



- Tools for Success
 - Create a Checklist of Supplies and check off those needed at the visit
 - Ask the patient who they plan to have present for the visit
 - Extra copies of the Informed Consent Form
 - Plan time for the Investigator / Subinvestigator to talk with the patient or caregivers about any concerns - Pts should never feel pressured or rushed!

Benefits of Clinical Research



- Offer new treatments to symptoms that are inadequately controlled
- Focus on therapies improving overall QOL and functional status
- No cost for study medications
- Research team adds another dimension of care for patients
- Sense of leaving a legacy
- Meaningful task to patients
- Can reduce Caregiver burden by controlling symptoms more effectively

Key Messaging



- Overcome barriers to recruitment and enrollment in clinical studies
- Develop a uniform, consistent message across sites
- Messaging framed in a positive, engaging format, at an 8th grade educational level

IT WORKS!

Key Messaging



- ✓ SAFETY
- ✓ COMFORT
- ✓ CONVENIENCE
- ✓ REASSURANCE
- ✓ TRUST
- ✓ RESPECT

Key Messaging



- Use dedicated recruitment personnel
- Role play using key messages
- Focus on language used
 - not a subject put a 'participant'
 - not a trial but a 'study'
- Point out benefits of contributing to knowledge base and personal legacy

Key Messaging



- Assure the patient that...
 - a decision to participate is voluntary and they can withdraw at any time.
 - their physician will be kept informed about their participation in the study
 - while the study is important, their care and safety are top priority
- Key Message should reflect the Informed Consent process.

Key Messaging



- It is of the utmost importance that the Investigator and study staff know the protocol in detail.
- This ensures quality, compliance, and aids in successful recruitment.

Key Messaging can help!

Flexibility is Key!



- Be flexible! Staff should be flexible with everyone involved in the research process.
 - Patient and Family
 - Inform the patient and family that they are the priority and every effort can be made to arrange visits to fit their schedule and situation.
 - Providers
 - Assure providers about the research process and the flexibility afforded to patients and families.

Summary



- One good referring office or provider can identify several patients
- Successful enrollment breeds increase in referrals, especially when research is seen as beneficial
- Time spent educating both patients and providers is well worth the effort as it will contribute to:
 - Enrollment
 - Compliance
 - Quality
 - Growth
 - Evidence based medicine