Marketing and Clinical Trials

How do we work together?

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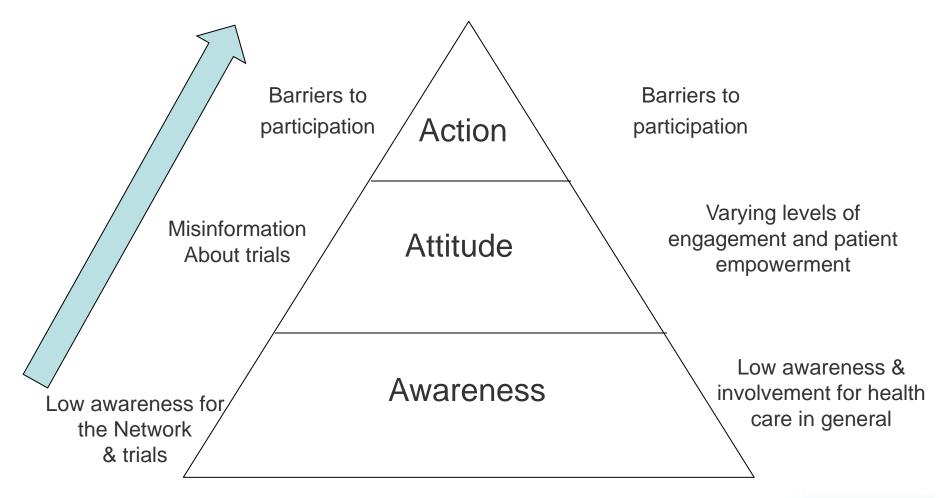


The Challenge

- How do we let our communities know about the availability of clinical trials while still:
 - Maintaining patient confidentiality
 - Following human subjects research best practices, and
 - Following IRB regulations



The Consumer Behavior Model





Key Sensitivities

- Misconception that "placebo" means no treatment
- Belief that standard of care is better than clinical trial
- Fear of being a "guinea pig" (free rider effect)
- Concern that insurance company will not pay for treatment
- Concern about potential side effects/fear that quality of life may be reduced

Source: Harris Interactive (2000). Mills et al (2006)

Exacerbated by media coverage of conflict of interest issues in the pharmaceutical industry (one unethical act taints the entire process), history, cultural and ethnic factors.

ONE CANCER SETWING

What can you do

- Raise awareness of the Network
 - Use the logo on your web site and materials
 - Link to: http://unclineberger.org/unc-cancer-network-clinical-trials
 - Publicize network activities in employee communication, physician communication
 - Use the network identity every time you communicate
- Educate patient audience about clinical trials: http://www.cancer.gov/clinicaltrials/learningabout
- Educate provider audience about clinical trials opportunities and how to talk to patients: http://www.cancer.gov/clinicaltrials/learningabout/outreach-education-advocacy

Partner with local advocacy groups

- Support groups
- Leukemia and Lymphoma society chapters
- ACS chapters
- BCAN
- There are many disease-specific advocacy organizations and they often want to hear from our physicians about new treatment opportunities!



Talking about Trials

- Keep messages simple
- Avoid jargon, use lay language in marketing (this can be an IRB challenge)
- Always define the trial's phase and objectives
- Reiterate message that all patients receive standard of care



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Helpful Tips

- If your organization has a newsletter, magazine or other publication, a "soft" article about clinical trials is a good way to begin communications.
- Opening a new study is a great excuse to communicate.
- Data is useful but research shows that personal stories are more persuasive – this also allows you to use one patient as a trial spokesperson, minimizing potential HIPAA concerns.
- Enhance personal stories with photos/video if possible.
- Use the NCI resources, they are complete, targeted and helpful (they have videos and have no objection to outside organizations linking or reposting).

A Word About Social Media













- Unless the trial is:
 - Behavioral
 - Measuring the impact of social media

USING SOCIAL MEDIA IS A BAD IDEA

- Not considered secure
- Loss of control of message



Questions?

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Human Subjects Rules

- No incentives beyond cost of participation
- In public relations, do not provide call to action/information about how to participate unless asked by the reporter
- In general, seek IRB approval of any communication with a call to action:
 - All paid advertising (ad copy, layout)
 - Don't assume that IRB approval of one medium (PR) means it is approved for other media (e.g. ads, social media, videos)
 - Be particularly careful about "trigger language": seeking, recruiting, enrolling, for more information call or email XXX.
 - Keep language consistent across all channels (don't use different wording in a video than what you used in a press release)



HIPAA

- Address misconception that clinical trial participation = unlimited disclosure of PHI
- Always obtain a signed release ahead of time
- If a participating patient agrees to work with you on communications or marketing outreach, ensure that they understand:
 - Their diagnosis and name will be disclosed
 - They can control the level of detail they disclose
 - What you are asking them to say (it goes without saying that this is the truth)
- Sample patient questions:
 - When were you diagnosed?
 - How did you learn about this trial?
 - What would you tell others who were considering participation?