


BRINGING THE PATIENT
PERSPECTIVE TO CANCER
RESEARCH

FOCUS GROUP SUMMARY REPORT

Research Advocacy Network

Advancing Patient-Focused Research



This work is licensed under a Creative Commons -
Attribution-Non-Commercial-ShareAlike License (US/v3.0)
<http://creativecommons.org/licenses/by-nc-sa/3.0/>

Non-commercial uses are thus permitted without further permission from the
copyright owner but should be attributed to Research Advocacy Network.
Permissions beyond the scope of this license are administered by the copyright
owner, Research Advocacy Network.

Research Advocacy Network

Advancing Patient-Focused Research

BACKGROUND

- Convened by the Research Advocacy Network (RAN) and facilitated by Carol White, principal of CBWhite Market Research & Strategy
 - May 30, 2013, in Chicago, Illinois
- Participants:
 - Mary Lou Smith and Elda Railey
 - Greg Bielawski
 - Cynthia Chauhan
 - Arlene Dahm
 - Karen Durham
 - Charles Florsheim
 - Pat Gavin
 - Mike Katz
 - Craig Lustig
 - Ginny Mason
 - Wayland Eppard (written comments)
- Funding acknowledgement:
 - 2013 educational grant to Research Advocacy Network from Genentech BioOncology

Research Advocacy Network

Advancing Patient-Focused Research

PURPOSE AND GOAL

- **Purpose:**
 - To gain a deeper understanding of how advocates bring the patient perspective to cancer research. *Note: Advocates referred to as “patient representatives” in summary.*
- **Goal:**
 - To gather information on the “who, what, where, when and how” that could be used as the basis for a future document that would provide insights on how to most effectively help new advocates establish more dynamic, productive relationships with researchers and help more seasoned advocates expand their activities.

4 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

I. DEFINING THE ROLES, GOALS AND RESPONSIBILITIES OF PATIENT REPRESENTATIVES

- Patient representatives put a face on a life-threatening disease in situations where research is discussed, designed and implemented
- Basic and Translational Research
 - Move from the abstract and theoretical to reality.
 - Validate the work they are doing in their labs.
- Opportunity to give researchers feedback on proposed trials from the point of view of how meaningful, useful and safe suggested actions will be for the patient.
- Say what researchers are reluctant or unable to say.
- Identify potential “red flags,” such as research questions beginning with “wouldn’t it be interesting if...” that may intrigue scientists but offer little benefit – or cause extreme discomfort – to patients.

5 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

I. DEFINING THE ROLES, GOALS AND RESPONSIBILITIES OF PATIENT REPRESENTATIVES (CONTINUED)

- Bring a sense of urgency to the research process.
- Ask questions and push back, especially in the case of a complicated schema that would be difficult to communicate to patients.
- Keep research relevant.
- Act as the conscience of the group, redirecting the science onto the patient.
- Patient representatives have a responsibility to prepare before they sit at the research table
- Actively participate in discussions. “Speak, but speak with knowledge. You’ve got to do your homework. Don’t look like a deer in the headlights.”
- Make knowledgeable contributions. “You have to prove you’ve earned your place at the table.”

6 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

II. DEFINING AND MEASURING SUCCESS

- What is success:
 - When researchers listen, and when they take time to engage in conversation with patient representatives.
 - When researchers argue among themselves, then turn to a patient representative and ask, "What do you think?"
 - When a policy or protocol gets changed because of patient representative input.
 - When consent documents are changed to make them more patient-friendly.
 - The ability to keep the focus on outcomes and speed up a sometimes unwieldy process.
 - For example, help prevent reviewers from delaying a trial for a drug with the potential to extend some patients' lives for several months pursuing non-material tweaks/improvements like sentence structure or beefing up the scientific rationale. "If you're in the room changing things, speeding things up, you're changing outcomes."
 - When researchers consider patient representatives so much a part of the team that they ask them to give a presentation or write an article.
 - Seeing that more research is being done, as has happened with pancreatic and breast cancers.

7 This work is licensed under a Creative Commons - Attribution-Non-Commercial-ShareAlike License (US v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocacy Defined: Research & Practice

II. DEFINING AND MEASURING SUCCESS

- Examples of success:
 - Creating a network of influence by engaging other patients as research advocates.
 - Reducing central IRB turnaround time from 90 to 30 days.
 - Changing the standard of care for myeloma.
 - Removing unnecessary bone marrow biopsies from clinical trial schemas
 - Helping clinical researchers understand they have to explain procedures to patients in language patients can understand.
 - Seeing a kidney cancer cell for the first time in a researcher's lab. "I was excited and he was, too." The scientist, a bench researcher, now goes out to talk with patients about his research.

8 This work is licensed under a Creative Commons - Attribution-Non-Commercial-ShareAlike License (US v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocacy Defined: Research & Practice

III. STRATEGIES/BEST PRACTICES THAT CONTRIBUTE TO SUCCESS

- Patience and a long-range perspective. Recognize that earning the respect of researchers is an ongoing process that takes time and that results won't be immediate.
- Seek to collaborate.
- Disagree respectfully.
- Be disruptive.
- Be tenacious and persistent.
- Identify researchers who are very good at encouraging and integrating patient representative input and use them as role models.
- Use experienced representatives for representation in basic and translational science research.
- Be informed and assertive.
- Be prepared enough to hit the ground running.
- Be willing to ask for help, and take advantage of available resources
- Recognize that some situations are simply no-win.

9 This work is licensed under a Creative Commons - Attribution-Non-Commercial-ShareAlike License (US v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocacy Defined: Research & Practice

IV. STRATEGIES AND SITUATIONS THAT INTERFERE WITH ACHIEVING SUCCESS

- Disruptive behavior can generate positive benefits or may cause researchers to lose respect.
- Negative behavior or uninformed/unprepared patient representatives.
- Unwillingness to collaborate and grow, or be open to other perspectives.
- Failure to give credit to other patient representatives, or to take the time to make them equal partners if they have less expertise or experience.
- Lack of advocates because there are few survivors for that particular type of cancer.
- Competing agendas between different patient representatives.
- Style without substance. Building a knowledge base is critical.
- Generation gap.
- Failure to set expectations.
- Using patient representatives to “check the box” for inclusion of advocates/patient representatives on program and funding requirements.
- Patient representatives who are also physicians or health care provider team members (nurses, etc.) that cannot separate their clinical role from their advocacy efforts.

10 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patient Impact & Progress

SHARING STRATEGIES

- Patient representatives who are unwilling to share their strategies can also be barriers to having a positive impact on a wider scale.
- Reasons they may choose not to share include:
 - They have a personal agenda vs. being focused on the patient community. They seek to make themselves more important, not to advance research.
 - That's their personality.
 - They see themselves as “professional advocates.”

11 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patient Impact & Progress

V. LOOKING AT THE BIG PICTURE: PROGRESS AND CHALLENGES

- Roots of patient representation in cancer research go back to activism in the AIDS community.
- Expectation now for patient representatives to be present in all research forums.
- The development of advocates is improving their impact.
- Evidence of success includes:
 - In research grants, such as DOD and NCI, defining the impact of research on cancer has been institutionalized as part of scoring.
 - Patient-reported outcomes, vs. only clinician-reported outcomes, now have clinical relevance.
 - In clinical trials, the word “participant” has replaced “subject.”
 - Words matter. Now working on getting researchers to say “The protocol failed the patient” vs. “The patient failed the protocol.”

12 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patient Impact & Progress

PROGRESS.... BUT CHALLENGES REMAIN

Challenges:

- Knowledge deficit.
- High turnover among patient representatives
- Lack of transparency, in both research forums and advocacy organizations.
- Researchers' belief that if they include a single patient representative, they have fulfilled their obligation.
- Recruiting a wider diversity of patient representatives – age, gender, race, type of cancer. Looking at ways to include patients with comorbidities and/or multiple cancers.
- A lack of understanding about the value of research advocacy still exists among research leadership.

13 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patient Impact Research

VI. RECRUITING AND SUPPORTING NEW PATIENT REPRESENTATIVES

Ideal profile

- Difficult to define the profile of an ideal patient representative,
- Need mentoring
- Broad approach to recruiting

Paid vs. Volunteer

- Difference in effectiveness?
- Difference in passion?

Suggested recruitment and support strategies:

- Create pathways to representation, especially for young people.
- Recruit from a wide variety of sources.
- Integrate information into the treatment process about the opportunity to serve as a patient representative.
- Model patient representative behavior by placing advocates in waiting rooms of hospitals.
- Set the bar high, and people will step up.
- Be flexible on expectations.
- Encourage community-building. Patient representation can be isolating work.
- Create a community of mentors .

14 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patient Impact Research

ADVICE FOR NEW PATIENT REPRESENTATIVES

- Understand it can be a lonely job, with hours spent at the computer trying to research information or provide input. Only other patient representatives truly understand what you do.
- Be patient because the learning curve is steep and progress can be slow. (Again, the process can be compared to watching grass grow.)
- Many researcher's work does not include significant social interactions so they may seem less approachable to patient representatives. Therefore, patient representatives may need to learn to network with people "who aren't warm and cuddly" and develop strategies to "approach folks who aren't that approachable."
- Using newness or inexperience can be helpful as a way to ask researchers to explain what they do.
- Get advice from more experienced advocates on which researchers are good to connect with and who to avoid.
- Having conversations with researchers who are good communicators can provide confidence for more difficult encounters.
- Don't get discouraged or take criticism or setbacks personally. Don't give up.

15 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patient Impact Research

VII. VISION OF PATIENT REPRESENTATION IN THE FUTURE

- What should it be called? Patient representation, research advocacy, something else entirely?
- Role likely to expand beyond the research table, thanks to social media and other technology for remote (on-line) participation in panels.
- Role should be viewed as member of the research team.

16 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patients' Interest in Research

VIII. GETTING THERE FROM HERE

- Need a cadre of advocate leaders
 - Define what research advocacy is and what it is not,
 - Educate researchers about the role of patient representatives.
- Acknowledge and help resolve competition between advocate organizations by sharing and networking.
- Consolidations, financial pressure and "attitudinal issues" have led to reductions in research advocates in some organizations.
- In the face of more limited resources and a more complicated research environment, there should be **more** – not fewer – patient representatives.

17 This work is licensed under a Creative Commons -Attribution-Non-Commercial-ShareAlike License (US/v3.0) <http://creativecommons.org/licenses/by-nc-sa/3.0/>

Research Advocacy Network
Advocating Patients' Interest in Research
