

# BRINGING THE PATIENT PERSPECTIVE TO CANCER RESEARCH

*Focus Group Summary Report*



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## *Focus Group Summary Report*

*This report summarizes a focus group discussion convened by the Research Advocacy Network (RAN) and facilitated by Carol White, principal of CBWhite Market Research & Strategy, on May 30, 2013, in Chicago, Illinois. In addition to RAN co-founders Mary Lou Smith and Elda Railey, nine patient representatives participated in the discussion: Greg Bielawski, Cynthia Chauhan, Arlene Dahm, Karen Durham, Charles Florsheim, Pat Gavin, Mike Katz, Craig Lustig and Ginny Mason. Wayland Eppard also submitted written comments but was unable to attend the meeting.*

## **Purpose**

Although advocates may play many different roles, this discussion focused on gaining a deeper understanding of how advocates bring the patient perspective to cancer research. Therefore, they are most often referred to as “patient representatives” in this summary. There are numerous strategies for successfully developing a relationship with basic and translational researchers to achieve positive outcomes for cancer patients. The goal was 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.

## **I. Defining the roles, goals and responsibilities of patient representatives**

Most importantly, patient representatives put a face on a life-threatening disease in situations where research is discussed, designed and implemented. This may be in situations where there are basic or translational researchers who commonly have little or no contact with the people their work is designed to help. The term researcher is used broadly, recognizing that in some cases, advocates may be representing the patient when working with researchers who are also treating physicians and see patients regularly.

The opportunity to interact with patient representatives enables basic and translational researchers to:

- Actually talk to people who have taken and been helped by a drug they were involved in developing. When one participant told a researcher he was a Stage IV survivor, the researcher said, “I’ve never seen Stage IV except under a microscope or at a funeral home.”
- Move from the abstract and theoretical to reality.
- Validate the work they are doing in their labs. “Researchers ask: Should I keep doing this, does anyone care, have I contributed?”

The opportunity to interact with researchers enables patient representatives 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. For example, help researchers understand the impact on the patient when multiple chemo treatments are proposed, or the patient concerns about privacy, safety risk and pain when a biopsy is required to participate in a trial.
- Say what researchers are reluctant or unable to say, such as “This is unacceptable for many patients. Depending on the patient, these concerns can be devastating.”
- 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.
- Bring a sense of urgency to the research process. IRBs have a habit of tabling projects for administrative reasons. Patient representatives can try to discourage that. They also remind researchers: “I have a disease that might take me out or make me face consequences that could be difficult. I need help now, or yesterday.” I try to teach research advocates with whom I work not to personalize this way but to be a voice for all patients. I believe this kind of personalization can actually be a barrier to the relationship.
- Ask questions and push back, especially in the case of a complicated schema that would be difficult to communicate to patients.
- Keep research relevant. Some researchers become so immersed in their science they forget about being clinically meaningful. For example, the biomarker they’ve been studying for 20 years needs to have some meaning to patients. “It’s not just about advancing knowledge. It’s about advancing treatment of disease.”
- Act as the conscience of the group, redirecting the science onto the patient. “Will this trial fly in the community? Why will a local oncologist recommend it, and why would I ask a patient want to participate?”

To be taken seriously and to be effective, patient representatives have a responsibility to prepare before they sit at the research table – and to 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.”

Since patient representatives are frequently included on grants primarily because the funder requires it, it is particularly important to make knowledgeable contributions. “You have to prove you’ve earned your place at the table.”

## II. Defining and measuring success

Patient representatives define success in numerous ways, both small and large.

- 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 gets changed because of patient representative input.
- When a 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.

A few participants described some of their personal successes as a patient representative:

- 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.

### 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. "Advocacy is like watching grass grow." However, the longer you're involved, the more potential impact you can have.
- Seek to collaborate. "Researchers are good people. They just don't always understand the impact of their work on individual patients."
- Disagree respectfully.
- Be disruptive. Activism can be effective in some policy issues, such as accessibility to trials or allocation of research funding.
- Be tenacious and persistent.
- Identify researchers who are very good at encouraging and integrating patient representative input and use them as role models.
- Use only experienced representatives for basic science research. Basic science and translational research can be especially challenging and difficult for patient representatives to make relevant contributions to the conversation.
- Be informed and assertive. DOD and ACS grants, for example, include specific goals. Patient representatives need to be willing to ask how proposed research meets those goals. Also, it's important to be prepared enough to hit the ground running.
- Be willing to ask for help, and take advantage of available resources such as organization staff members. "It's important to reach out to whoever is asking you to do work to say, 'I don't understand. How can you help me understand?'"
- Recognize that some situations are simply no-win.

#### IV. Strategies and situations that interfere with achieving success

- Although being disruptive can generate positive benefits, it's a double-edge sword. When patient representatives are disruptive, researchers may lose respect. "It's important not to be viewed negatively."
- Negative behavior or uninformed/unprepared patient representatives. "One patient advocate can kill it for everyone else."
- 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. "Bring different perspectives, not necessarily different priorities."
- Style without substance. Building a knowledge base is critical.
- Generation gap. Patient representatives tend to be older, and the younger generation takes a different view and a different approach. For example, thanks to social media, they communicate very differently. This can be both a problem (concern about possible damage to progress/procedures current patient representatives have worked hard to develop) and an opportunity (social media may make it easier to solicit input from a large numbers of patients).
- Failure to set expectations. Researchers need to tell patient representatives what they need from them, and, on the flip side, patient representatives need to educate researchers about what they can do.
- Can be frustrating and difficult to have impact when patient representatives are used to simply "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.) may have difficulty separating their clinical role from their advocacy efforts and try to dominate and alter the discussion at the expense of other patient representatives.

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."

#### V. Looking at the big picture: progress and challenges

The roots of patient representation in cancer research go back to activism in the AIDS community. Today, the expectation and norm is that patient representatives should be present in all research forums. The seasoning and 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.”

Although significant progress has been made, numerous challenges remain – and new challenges continue to emerge. These include:

- Knowledge deficit. Growing need for patient representatives knowledgeable about biomarkers, genomics, targeted therapies and other new research approaches.
- High turnover among patient representatives. An active “farm system” needs to be created to replace older, retiring representatives. Making advocate term limits consistent with scientist term limits on government committees, as many committees now permit re-election of/extension of terms for scientists but not advocates.
- 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. “People don’t know you can put an ‘s’ on advocate.”
- 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.

## VI. Recruiting and supporting new patient representatives

Although it is difficult to define the profile of an ideal patient representative, current representatives share a responsibility to recruit good advocates and mentor them. It also may be important to expand recruiting efforts beyond survivors to caregivers or family members in cases such as brain tumors, pancreatic cancer or pediatric cancers. Veteran patient representatives also should make the effort to talk to researchers to smooth the way for new representatives.

Discussion participants disagreed on the question of whether or not there is a difference in the effectiveness of paid versus volunteer patient representatives. Some believed volunteers could not be held as accountable as employees, others felt expectations should be similar. Some thought paid staff lacked the passion of volunteers, others pointed out that passionate volunteers sometimes moved into paid positions.

Suggested recruitment and support strategies:

- Create pathways to representation, especially for young people. For example, one participant encouraged a college student survivor to submit a poster at a conference.
- Recruit from a wide variety of sources. The first generation of patient representatives evolved from support groups. Younger people tend to rely more on virtual support groups, so social networking offers recruiting possibilities. Camps for young people with cancer are another source.
- Integrate information into the treatment process about the opportunity to serve as a patient representative. At community hospitals, cancer centers or wherever patient are treated, introduce the concept of getting involved in patient representation in the same way a social worker talks to patients about community resources.
- 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. Younger survivors may be willing to commit the time for a few years but then want to move on with their lives.
- Encourage community-building. Patient representation can be isolating work. Creating a community of mentors would also be valuable.

Advice for new patient representatives includes:

- 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 some conversations early on 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.

## VII. Vision of patient representation in the future

The participants envisioned the role of patient representatives evolving in the future. They even grappled with what the best name for the role might be: patient representation, research advocacy, something else entirely?

The role in the future will likely expand beyond the research table, thanks to social media and other technology. Patient representatives could be part of online panels, or do web-based surveys, or even get involved in international advocacy. There is strength in numbers, so the more patients they connect with, the more they can strengthen their voice in the research process.

If advocates could be seen as a member of the research team, rather than just involved in the design of the trial, they might be able to move the development process along more quickly.

## VIII. Getting there from here

Future success depends on creating a cadre of advocate leaders who can help define what research advocacy is and what it is not, and who can educate researchers about the role of patient representatives. Some participants feel there is competition between advocate organizations, or at the least a silo effect, and that a 'space' (virtual or physical) for patient representatives to connect would be useful. "Having a conference for research advocates across the board with some learning modules and networking time would be very beneficial."

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Consolidation, financial pressure and “attitudinal issues” have led to reductions in research advocates in some organizations. However, participants believe that in the face of more limited resources and a more complicated research environment, there should be more – not fewer – patient representatives. Achieving this goal may require seeking validation from the bottom up, not the top down. Rather than investing time in encouraging policymakers to make patient advocacy a priority, it may make more sense to promote change by turning to patients – most of whom are unfamiliar with research advocacy – and explaining its value to them. “If we tell patients we’re threatened, we give them something to rally around.”

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