



ACC Patient Community Survey Results (October 2010)

You have been heard!

With thanks to all of you who took the time to participate, this update summarizes the findings of our recent survey, as well as some of the ways in which we already are incorporating your feedback into our efforts on your behalf at ACCRF and ACCOI.

As you may recall, the survey focused on improving our organizations' understanding of the following:

- The priorities of the ACC community
- The communication preferences of the ACC community
- Interest in volunteering among members of the ACC community

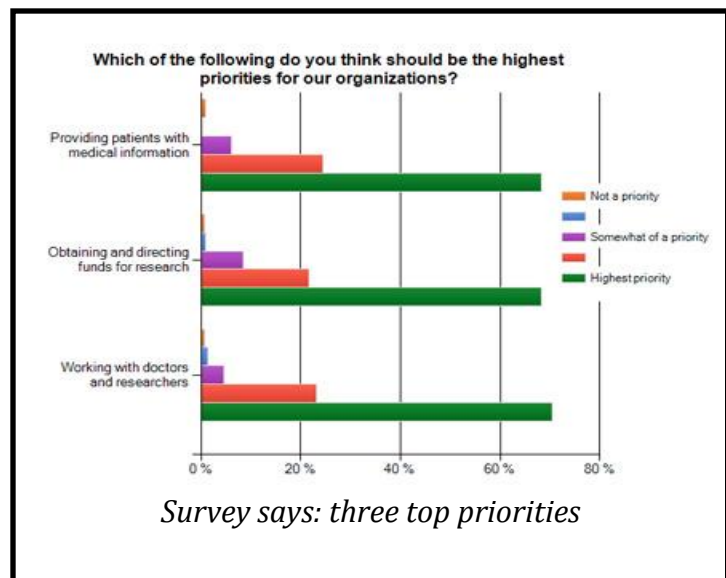
And your response was truly terrific, both in terms of quantity and quality. We had 380 replies from survivors, family members, friends and physicians. And while you replied as individuals from across the country and even around the world, the collective message you sent on behalf of the ACC community was crisp and clear.

Priorities

In terms of priorities, two big themes emerged:

1. Work with doctors and researchers, providing guidance and funding, with a focus on clinical trials
2. Work with survivors and their families, providing medical information and enabling personal connections

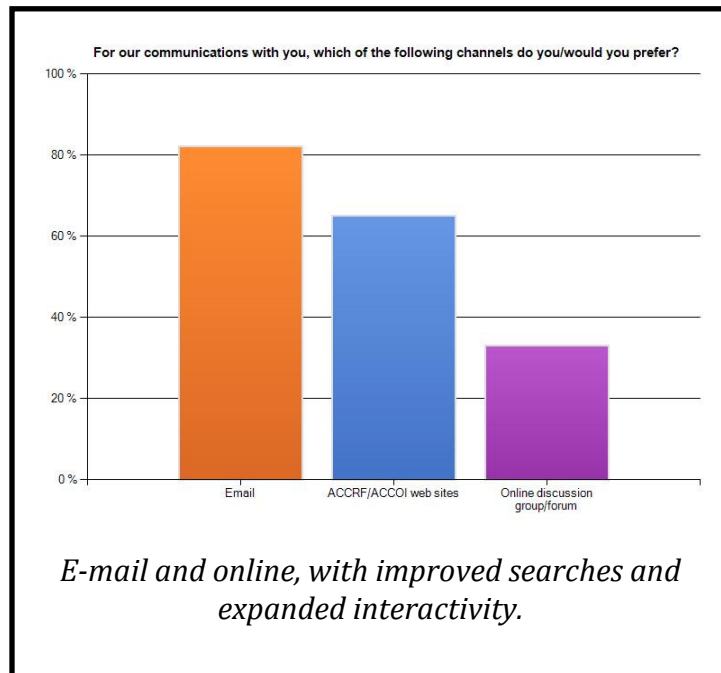
And we are doing just that, with ACCRF focusing its efforts on the former, while ACCOI is concentrating on the latter. Our two organizations want to make sure that the needs of the whole ACC patient community are being met, coordinating without duplicating each others' efforts.





Communication Preferences

With regards to communications preferences, email was the clear winner and our web sites the runner-up (www.accrf.org and www.accoi.org). At the same time, it also was clear that there is a strong interest in not only receiving information from us, but in sharing information with others, which bodes well for expanding the knowledge base and collective power of our community.



So with this in mind, both organizations are now looking to enhance our email updates and web sites, especially when it comes to improving searches and allowing interactivity. Meanwhile, ACCOI is investigating options for a site that would have some of the same functionality as Facebook, but be safe and private, and focused on ACC.

Volunteering

Last but not least, we were excited to see the enthusiasm of so many when it comes to volunteering, as we know all too well that none of us can beat this disease on our own.

Those of you who expressed an interest are likely to hear from us soon, especially when it comes to meeting the priorities you helped to identify --- fundraising to advance research and sharing information to help other survivors. Thank you and stay tuned!

If you did not sign up in the survey, it isn't too late! Please send us an email at info@accrf.org, letting us know your interests (fundraising and/or information sharing), and we'll be sure to add you to our lists.

Thank you again for your insight and ideas! And here's to continuing our efforts together to accelerate the cure, and support each other along the way.

Sincerely,

Jeff and Dan

Jeff Kaufman, Executive Director
Adenoid Cystic Carcinoma Research Foundation (ACCRF)

Dan Dube, President
Adenoid Cystic Carcinoma Organization International (ACCOI)