Health Communication core

COMMUNICATION STRATEGIES FOR RESEARCHERS
Recruit, retain, educate, disseminate, and collaborate

DF/HCC Clinical Investigator Education Series

February 1, 2018

HealthCommCore.org

Presentation goals

Role of strategic communication in research

Strategic process

Solutions to research challenges, tips
- –Recruitment
- –Retention
- –Intervention
- –Dissemination
- –Collaboration

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Communication = "sharing or imparting information."
The HCC creative team doesn't analyze genome datasets or identify tumor subtypes.
But we help researchers get there.

In this presentation we will share:
- Examples of our work with researchers to address their communication challenges
- Tips based on our experience that we hope you will find useful
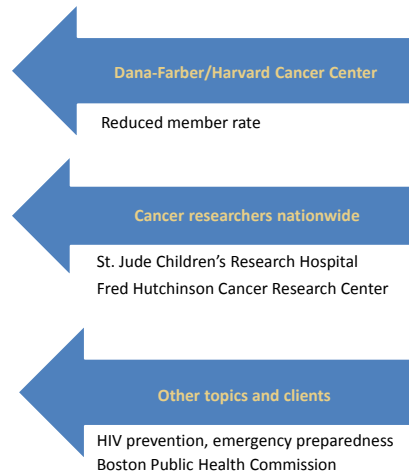
Who we are…Health Communication Core

Vish Viswanath, PhD, faculty director
Catherine Coleman, assistant director
Adam Gerberick, graphic designer
Shana McGough, writer/editor
Dave Rothfarb, web developer/programmer

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We are a small collaborative team. HCC was founded at DFCI in 1999 by Karen Emmons, PhD, a researcher who is now the Dean of Academic Affairs at Harvard School of Public Health.

Our focus is on how to get information about health to diverse audiences in order to improve health outcomes.

Who we work with…

Dana-Farber/Harvard Cancer Center

Reduced member rate

Cancer researchers nationwide

St. Jude Children's Research Hospital
Fred Hutchinson Cancer Research Center

Other topics and clients

HIV prevention, emergency preparedness
Boston Public Health Commission

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We work on large and small projects, locally and nationally, for
- Researchers
- Clinicians
- Public health leaders
- Administrators

What we do…

Communication services
- Identity (naming and logos)
- Content
- Design
- Websites and hosting
- Programming
- Social media
- Outdoor/transit media

Specialized expertise
- Research, clinical care, public health
- Cultural competency

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HCC provides a full spectrum of communication services, customized to meet the needs of each project.

Our rates are much less those of external agencies providing similar services.

The value-added we offer is our specialized expertise. We work within the same environment as our clients, and we share their commitment to improving health outcomes.

Start with strategy

Goal: What do we need to achieve?

Audience: Who do we need in order to achieve it?

Call to action: What do we need them to do?

Messaging: What might motivate/discourage them from doing this?

Outreach: What are their communication preferences? How and where can we reach them?

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Here is how we do what we do. It all starts with strategy.

A client may come to us saying, "I need a logo" or "I need Twitter." We help them take a step back, and help them identify what will get them to their goal. We ask:
- What do you need to achieve? Define it, specifically and concretely. What will success look like?
- Who do you need in order to achieve it?
- What do you need those people to do in order to achieve your goals?
- What might motivate or discourage them from doing this?
- What are their communication preferences? How and where can we reach them?

RECRUITMENT

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Each solution is unique to each challenge.

The process for getting there is the same, but the solution—whether it's social media or subway ads, is never the same.

Here are to solutions to research recruitment challenges.

GI Oncology Biobanking

Goal: Recruit healthy controls

Audience: Information overload, misconceptions about "gastrointestinal cancer"

Messaging: Sharing journey, contributing to research, ease and convenience of participation

Outreach: Waiting and infusion rooms, patient education events

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The GI Oncology Biobanking at DFCI needed help recruiting health controls—specifically, spouses and friends of GI oncology patients--people who were not genetically related to the patient, but were likely to share similar behaviors and environments.

Systemic challenges included a new, more complex process for recruiting and consenting healthy controls.

Potential volunteers also faced barriers to participation:
- Information overload at the time of a new diagnosis
- Feeling emotionally overwhelmed as they support their loved ones through treatment decisions
- Misconceptions that stomach cancer is the only kind of GI cancer

We developed messages to address these barriers and tap into their motivations:
- Sharing their loved ones' cancer journey
- Contributing to research
- Helping at a time when they felt helpless
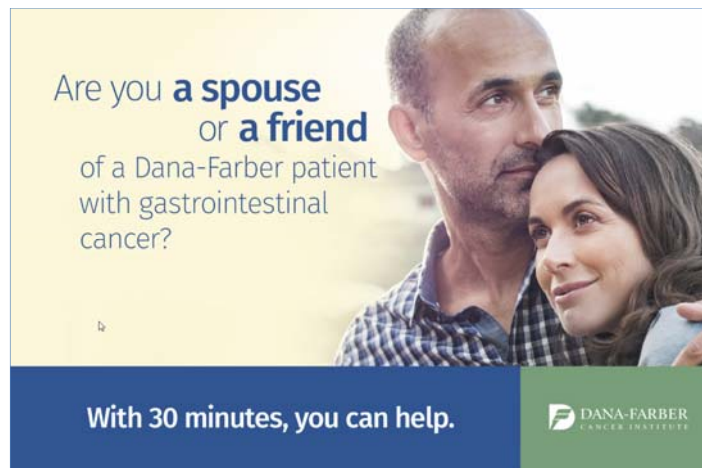
We determined that the best way to reach potential participants was during down time, for example in waiting rooms or infusion rooms, after they had settled into the treatment routine.

We developed an an info card that provides all the information they need, without requiring a research coordinator to explain the study. The card conveys, at a glance:
- Who, specifically, is needed
- You and your loved one are sharing a journey
- This is a quick and easy way to help other people
- This is something positive that can come out of a time that feels negative

Side two provides minimal but critical information:
- List of cancers that are considered "gastrointestinal cancer"
- Eligibility criteria
- Participation requirements
- Call to action: Contact us

MGH Depression Clinical and Research Program

Goal: Increase recruitment for multiple studies

Audience: Feeling hopeless, lack of motivation, unaware of one's depression, stigma, lack of awareness about treatment options

Messaging: Altruism, sense of hope, access to novel treatments, MGH reputation

Outreach: Stand-alone website
  –60% US adults seek health info online

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The Depression Clinical and Research Program at Massachusetts General Hospital came to HCC with a more complex recruitment challenge.
- DCRP recruits for an average of 10-20 studies at the same time
- The program's studies sometimes compete with each other for the same pool of potential participants

Information about open studies was only available through the main MGH website:
- Not where the general public would think to look
- Institutional look and feel
- Overwhelming amount of information
- Long list of studies, unformatted and uncategorized

People with depression present unique recruitment challenges:
- Feeling hopeless
- Lacking motivation
- Being unaware of one's depression
- Fearing stigma
- Lacking awareness of innovative treatment options

60% of US adults seek health information online. The solution was a recruitment website that was separate from, but linked to, the MGH site.

The study recruitment site looks personal and welcoming. The key messages conveyed on the home page are:
- MGH's institutional gravitas
- A sense of hope
- Appeal to altruism
- Affirmation that options are available

The home page allows people to easily find the information they need, with one-click access to:
- Background information about depression
- Information about open studies
- Easy ways to contact the program
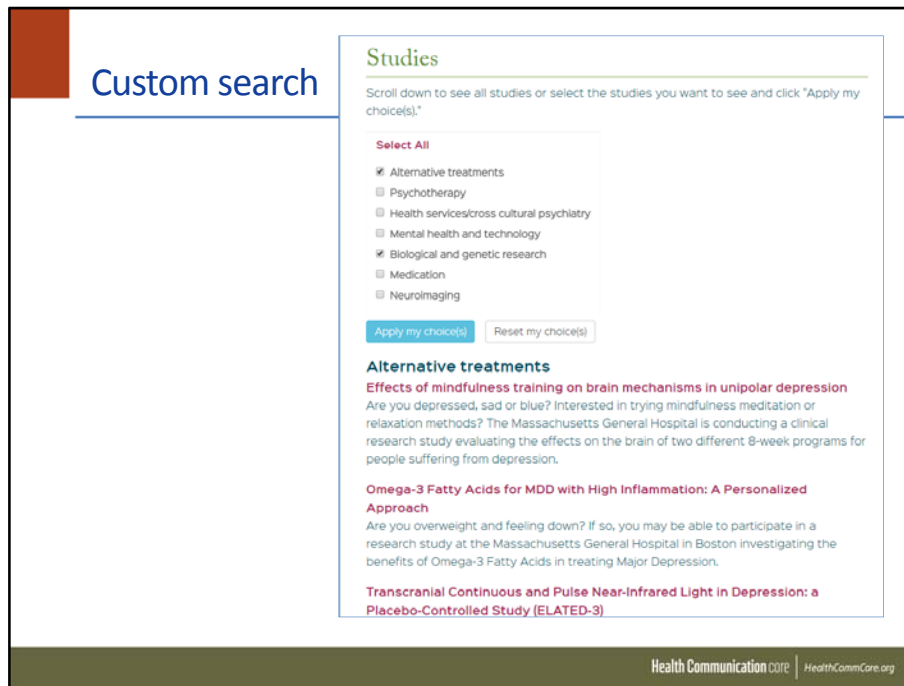
On the "Our studies" page, visitors are presented with a simple list of the kinds of treatments that are available. They are able to select the type of studies they are interested in, resulting in a customized list based on their personal preferences.

We monitor the website traffic statistics for sites we develop. This site:
- Gets 600-1000 visits/month
- The "Our studies" page receives the most visits, after the home page.
- One study, which was featured on WBUR's Commonhealth and Facebook, received 6,500 visits In one month.

Site analytics, which are free, can also tell us:
- What kind of devices visitors use to access the web
- What city they are from
- How many pages they visit
- How long they are on the site

Recruitment tips

Altruism a common motivator
- –Communicate how will participation help others

Passion of the PI/research team

Convenience and ease of participation
- –Value participants' time and competing priorities

Outreach
- –Identify where/how to reach potential participants
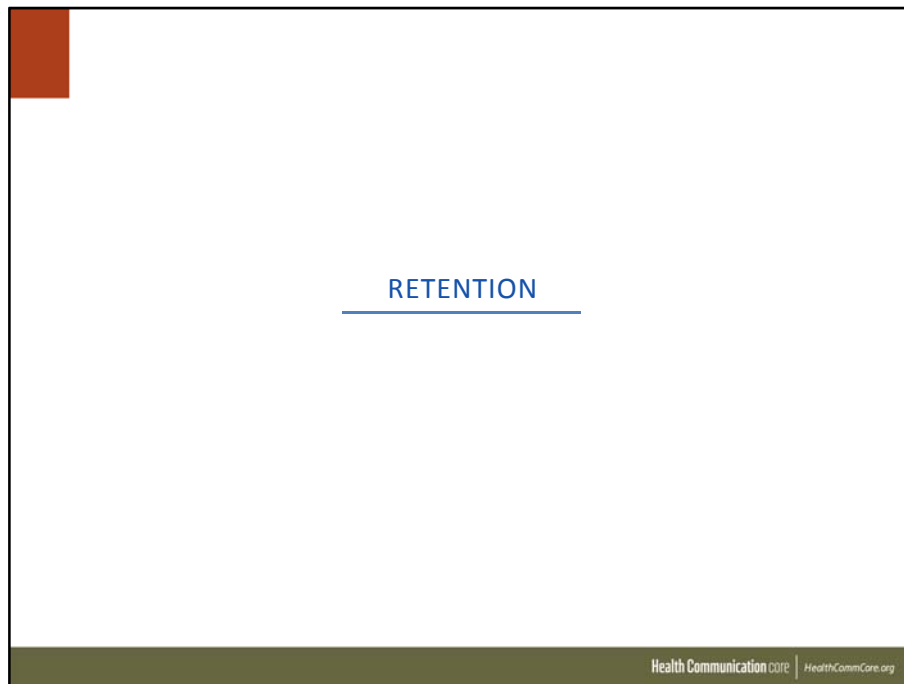
RETENTION

After accrual comes loss to follow up.

Many studies, whether they require a few months or a lifetime commitment, face this challenge. Studies often focus on recruitment and don't think about retention until enrollment starts dropping off.

Think about retention from the start. Include it in your grant budget and in your study's communication strategy.

Childhood Cancer Survivor Study

Goal: Increase participant engagement

Audience: Busy, not aware of how their data was making a difference

Messaging: Helping others, contributions to scientific advances, convenience

Outreach: Diverse preferences

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CCSS is in its third decade of tracking the long-term effects of cancer and therapy among a cohort of 25,000 survivors.
- It is known as the Long-Term Follow-Up Study to its participants.
- The backbone of the study is the data they collect from participants every few years through follow-up surveys.

The CCSS research team at St. Jude Children's Research Hospital in Memphis, TN engaged HCC to help increase participant engagement and maximize survey response rates. As part of the communication strategy development process, we interviewed participants from across the US. They told us:
- I feel honored to be in this study, to be able to help other people.
- I always intend to complete my survey but sometimes it ends up at the bottom of a pile of paper.
- It's a challenge to find time to complete the survey.
- I didn't realize I could complete it online.
- I'm not really sure how by data is being used, and what the study is accomplishing.

Newsletter

We developed a dynamic, updated visual approach for all study-related materials:
- Newsletters
- Website
- Surveys (print, online, mobile)
- Sub-study recruitment materials (postcards, app icons)

The front page of this issue includes:
- A note from the PI saying "thank you"
- Information about how to protect their health
- An update about an innovative sub-study about skin cancer

Newsletters also include:
- Visuals of cohort's demographics, to help build a sense of community and demonstrate the significance of the study
- Highlights of recent media attention
- Study achievements
- Participant profiles
- Summaries of recent research results
- "We're glad you asked" FAQs
- Reminders to update contact information

The newsletter is now distributed as a self-mailer, so the eye-catching graphics are immediately apparent (not hidden in an envelope).

Recontact card

People *move.*
Email addresses *change.*
Cell phones *replace* landlines.

But we can't replace you!

Please take a minute to confirm your contact information.

St. Jude Children's Research Hospital
LTFU
Long-Term Follow-Up Study

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A glossy, oversized postcard encouraged participants to update their contact information in advance of the upcoming survey release. Content on the front and back:
- Affirmed the value of their participation
- Detailed the multiple options for providing updates
- Highlighted the benefits of participation
- Thanked participants for their commitment and contributions

Survey "heads up" card

A few weeks ahead of a survey mailout, participants receive a "head ups" postcard letting them know that the survey is shorter than in previous years.

The card also announces that a mobile version is now available, and reminds them of the print, online, and telephone options for completion.

HCC also designed an elegant, square "thank you" card that is mailed after completion of the survey.

Retention tips

Keep in touch
- –Regular contact calendar
- –Keep communications fresh

Say "thank you"
- –At each contact point

Demonstrate value of participation
- –Updates on study's progress/achievements

Give back
- –Relevant, useful health information, support resources

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Don't just get in touch with participants when you need something from them. Be sure to "give back" to them, and say thank you frequently.
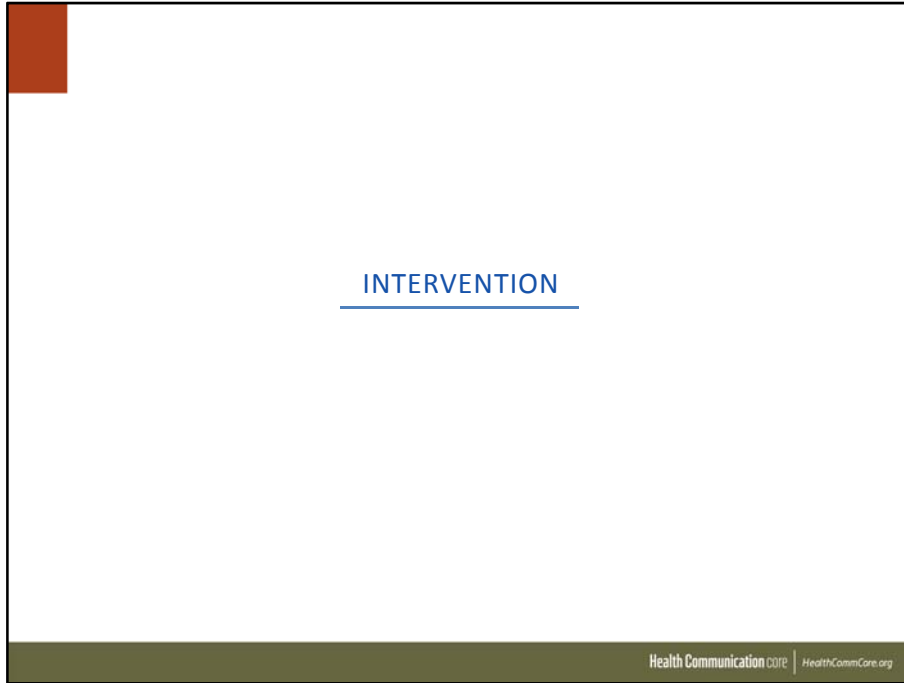
INTERVENTION

HCC helps researchers intervene with information that can influence behavior and improve outcomes.

UP (Understanding PrEP) decision aid

Goal: Clinical tool promoting shared decision making about pre-exposure HIV prophylaxis

Audience: Primary care physicians, high-risk men

Messaging: Positive, trustworthy, culturally competent

Programming: Individual risk assessment, values clarification, "next step," summary, no data storage

Outreach: Physician offices, internet searches

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HIV pre-exposure prophylaxis (PrEP), which consists of taking one pill a day, is more than 90% effective in preventing transmission of HIV among men having sex with men (MSM) who are at high risk.

PrEP can be prescribed by primary care physicians, but many PCPs:
- Are not aware of PrEP
- Are not comfortable discussing sexual behavior
- Have misconceptions about PrEP (e.g., toxicity, effects on other risky behaviors)

MSM also had misconceptions about PrEP and faced barriers of:
- Not being out to their providers
- Fear of being judged

HCC developed a name for the decision aid (UP: Understanding PrEP) that communicates its goal in a positive way.

Interactive clinical decision aid
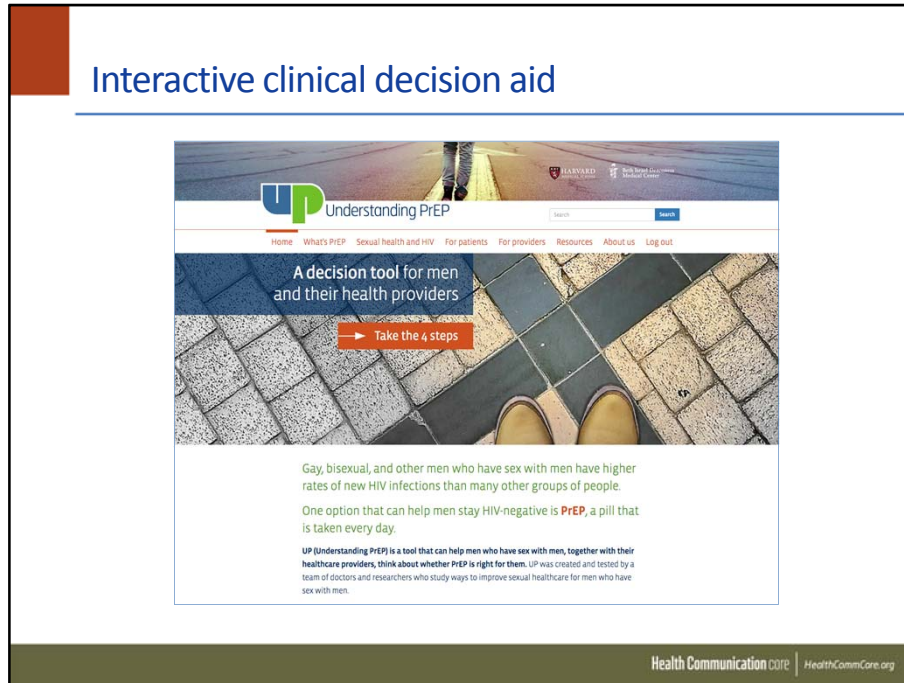
The goal of the UP decision aid is to promote discussion among providers and patients.

The most prominent feature on the home page is its red action button: Take the four steps.

The site's menu also provides access to:
- Background info about PrEP
- Patient info about how to talk to your provider
- A provider section with suggestions about how to discuss PrEP and prescribing guidance

Risk assessment, values clarification

After answering a few questions about their sexual history and STD history, users of the decision aid view a graphic display of how many men who answered like them would and would not become infected with HIV if they were using PrEP.

Step 3 helps them focus on what's most important or worrisome to them—from fear of becoming infected, to concern about having to take a pill every day.

Step 4 asks them to identify their next step—talk to friends, think about it, or start PrEP.

Preliminary testing results

Testing with PREP-inexperienced MSM and primary care providers in real and simulated clinical visits @ Fenway and BIDMC

—Providers: 99% found it helpful and would recommend it to other providers

—Patients: 97% found it helpful, 85% likely to recommend to friend

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The UP decision aid is currently being tested in clinical settings, and preliminary results are positive.

Intervention tips

Cultural competence
–Are literacy level, graphics, and messages targeted to participants?

Clear, concise
–Simple, direct information

Concrete
–Action oriented

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Cultural competence takes into consideration the unique characteristics of the people you want to reach—age, gender, sexual orientation, race/ethnicity, culture, geographic location, literacy level, etc.

Everyone--including other researchers—appreciates concise, well organized, easily scannable content.

Provide a specific call to action so the audience is clear on what to do and how to do it.

DISSEMINATION

The goal of publishing research results is to get them into the hands of people who can use them—either to inform further research, or to translate them into practice.

Include a dissemination plan in your grant application and communication strategy.
- Identify and respond to the funder's dissemination requirements are
- Utilize the preferred channels and formats of the audiences you are sharing results with

The Center for Work, Health, and Wellbeing website is a channel for disseminating results of the Center's research on total worker health.

The home page targets its diverse audience of researchers and practitioners with appropriate resources so they can quickly access what they want:
- Published research
- Implementation tools
- Learning events

The Center recently released new Guidelines for Implementing an Integrated Approach. The Executive Summary and full Guidelines can be downloaded from this page.

In order to collect dissemination data, HCC created a pop-up that collects minimal data from people who want to download the entire Guidelines. This allows the Center to:
- Track the number of downloads
- Identify people's organizational affiliations
- Collect contact information for potential qualitative follow-up

Dissemination tips

Include dissemination in research plan

Target dissemination to needs of different audiences (other researchers, policymakers, primary care physicians)

Don't leave dissemination to the end of the funding cycle, when you've run out of time and money. Include dissemination in the communication strategy to ensure that what you're developing is right for the available dissemination channels (press releases, social media, briefs, etc.)

COLLABORATION

Center for Cancer Genome Discovery

Goal: Promote collaboration

Audience: Researchers

Messaging: Collaborate with us, here's what we offer

Outreach: Conferences, online

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CCGD's mission is to promote access to the new cancer genome analysis technologies it develops, and to collaborate with basic, translational, and clinical investigators to discover genomic alterations in human cancer.

An at-a-glance outreach card was developed to increase awareness of collaboration opportunities and encourage potential collaborators to contact the Center. The card is distributed at conferences and other events.

Proposal management website

To facilitate the collaboration process, HCC developed a proposal management website. The site merged and replaced two outdated sites.

The site manages the entire proposal review lifecycle. New users can register, admins can assign members to review committees, and the status of reviewers' decisions are easily viewed.

The site allows fast searching/sort of data.

Let's talk!

Questions?
Free consultation
Grant application budgets

Email: catherine_coleman@dfci.harvard.edu

We welcome inquiries about our services and are happy to explore with you how we can help.