



“Inspiring Hope” Ideathon

Together, let's raise greater awareness of clinical trials

A Call to Action: Raising Awareness of Clinical Research

What do you get when the top thought leaders in the clinical research arena issue a call to action?

Nearly 70 novel ideas to increase the awareness of clinical trials from a wide range of contributors culminating in an electrifying day of innovation, drawing more than 100 thought leaders and clinical research executives to Boston. Or in other words ... the Inspiring Hope Ideathon. This crowdsourcing event, which was co-hosted by INC Research, a global CRO committed to bringing innovation and value to customers, clinical research sites, and patients, and the nonprofit Center for Information and Study on Clinical Research Participation (CISCRP), was held September 27-28, 2016, at District Hall in Boston. New ideas from well-known as well as unfamiliar, yet trailblazing, entities were brought to the forefront to increase the visibility of clinical trials and the importance of participating in clinical research.

"We wanted to bring in new ideas from industries outside of the traditional mix of clinical research," says Clare Grace, PhD, VP, Site and Patient Access, at INC Research. "We received submissions from advocacy groups, entrepreneurs, and even from school children near and far, including Australia, Canada, Europe, and the United States."

Grace, along with Ken Getz, Founder and Board Chair of CISCRP, who has been a tireless advocate for increasing the visibility around clinical trials for nearly two decades, tapped into a rich network of like-minded and passionate individuals to be judges as well as mentors to the qualifying teams of ideators.

"I think raising public awareness and appreciation for clinical research is probably one of the rare instances in our professional lives where we have sort of a guiding principle that everybody can get behind because it is

just such a compelling concept," Getz says. "There is a selfless commitment that people are making to support the Ideathon; it's a great unifier."

The 13 teams that ultimately participated in the event, from the 14 finalists and nearly 70 ideas submitted, worked off line for weeks and then gathered Boston in September to bring their visions to life to solve one of the industry's most-pressing and critical challenges.

A recent study from CISCRP suggests that while there isn't a shortage of patients willing to participate in clinical research — an overwhelming majority (87%) of the public reports a willingness to participate if research made sense for them — there is the remaining challenge of creating awareness around the opportunities available to participate in clinical research studies.

Industry experts say there are several issues in play: lack of access, a dearth of education about the benefits of clinical research, scarcity of information about available trials, and the need to create a clear pathway to get patients into those trials.

According to Getz, the clinical research enterprise really needs to think about the challenge in a different light. "We have to think about it more as an implementation challenge that requires building all of the necessary pieces that can help raise awareness, ensure easier access, and establish a higher foundation of understanding, trust, and literacy," he says. "Ultimately, a lack of volunteers to evaluate potential therapies for safety and efficacy directly impacts the number and timeliness of new treatments available to meet patients' needs."

The Need for Clinical Study Volunteers

The numbers tell the story. Thousands of volunteers are needed to move a potential drug through the pipeline. Yet, almost three-quarters of the public has no idea

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Clare Grace, PhD, VP, Site and Patient Access, INC Research

“The excitement that this event generated, and the submissions that we received, signal a major step forward in addressing the perennial problem of poor clinical trial awareness and literacy. We were blown away by the quality [and quantity] of the entries.”



Ken Getz, Founder and Board Chair, CISCRP

what clinical research entails. Hence, according to the organizers, the need for initiatives such as the Ideathon.

- ▶ The average drug today must be tested by 3,700 volunteers before it is approved for use by the FDA. — Greater Gift Initiative
- ▶ 87% of the public reports a willingness to participate if research made sense for them. — CISCRP
- ▶ 74% say they have no real knowledge of the clinical research process. — CISCRP

Clinical trial awareness and participation are national concerns. According to the National Institutes for Health, clinical research should be seen as the social good that it is, and the first step in tackling this challenge is regularly getting the public to think about participating in clinical research. People need to understand how they can help advance the prevention, diagnosis, and treatment of disease.

According to the Tufts Center for the Study of Drug Development, two-thirds of investigative sites fail to meet patient enrollment requirements for a given trial.

The disconnect between the low participation rates and a high degree of willingness among the public to join studies suggests that the industry needs to better raise awareness about clinical research and how to access study opportunities.

Grassroots outreach and education efforts implemented by CISCRP and other organizations, along with campaigns run by individual site networks, have begun to raise public perceptions about the research enterprise.

But costs are too high for a single organization or site to support outreach efforts alone and there is a growing call for a more widespread, shared effort to increase general knowledge and public perceptions about clinical research. Riding the wave of open collaboration and clinical research crowdsourcing, INC Research and CISCRP organized the groundbreaking Inspiring Hope Ideathon to do just this.

The Ideathon had three goals:

1. Build a community of problem solvers
 2. Identify unique ideas that can make a difference to the broader community
 3. Provide a platform to develop an active community that will learn from each other and work toward a common goal to raise public awareness about clinical research and reasons to participate in clinical trials
- INC Research and CISCRP successfully used social media and a crowd-sourcing platform to attract new problem solvers. The results, according to Grace, were overwhelming.
- The crowd-sourcing competition inspired nearly 70 entries from around the world to help address the critical need to increase awareness of clinical trial participation among patients, healthcare professionals, and the general public.
- “We were extremely pleased by the incredible response, and I think this shows just how much pent-up interest and demand there is in finding creative and new ideas that address poor public awareness and literacy about the clinical research process,” Getz explains. “There were a tremendous number of really innovative ideas that are quite novel and disruptive. This is very exciting.”
- Ideathon leaders believe the ideas generated will help stakeholders from all facets of the healthcare industry recognize the “continuum between clinical research and healthcare.”
- According to Getz, the level of innovative ideas demonstrated at the Ideathon debunked commonly held views that everything possible has been tried to raise public awareness and increase the appreciation for clinical research, yet there has been no traction.
- “At CISCRP, we feel our work really has just begun and at the same time we’re looking to generate even more ideas,” Getz continues. “We want to find ways to leverage the really great concepts that came out of the Ideathon and find all of the different ways to help people partner and collaborate to make more of these ideas come to fruition. We’ve seen that there is potential for many of the ideas coming from the Ideathon, and now we have to focus our energy on how to best execute these great ideas and do it in a timely manner.”

From Ideation to Ideathon



In September 2016, more than 100 industry executives gathered in Boston for an in-person, crowd-solving event to bring the 13 finalist ideas, culled from nearly 70 entries, to life.

During the day-long event, ideators had the chance to collaborate and meet with their mentors to refine their solutions to present to the event's judges and other invited guests. The result was an eclectic range of thoughtful and innovative solutions to address one of the industry's most pressing issues.

Entries were reviewed by a panel of key thought-leader judges (see side panel for more information) representing a diverse community of stakeholders. From the dozens of entries, the judges selected 14 concepts to be presented during the live event. The judges evaluated the ideas based on innovation, feasibility of implementation, sustainability, and potential for impact in raising awareness of clinical trials, particularly among minority and vulnerable populations in a variety of diseases and medical conditions.

"Each judge was looking for something a little bit different or had their eyes on different types of ideas, but we all had a general framework that we were working from," says Getz, who also served as an Ideathon judge. "For example, how feasible is the idea to execute? What kind of impact do we think it would have? We were looking for those ideas that would have a broader reaching impact that could be scaled and that were sustainable."

The judges were challenged not just by the quality of the ideas, but the range of ideas — from those that were quite simple, but elegant, to those that pushed the envelope in terms of cloud-based or interactive Web 2.0 approaches.

Ideators were asked to address how their idea would address four problem statements involving clinical research's role in society:

1. Raise public awareness of the role that clinical research plays in our society.

The Ideathon Judges



Cerci Beltre

Director of Data Strategy and Business Development, Merge eClinical



Owen Garrick, MD

President & COO, Bridge Clinical Research



Kenneth Getz

Founder and Board Chair, CISCRP



Cassandra Harris

Manager, Health Education, MD Anderson Cancer Center



Jamie Macdonald

Vice Chairman, INC Research



Paulo Moreira

Vice President, Global Clinical Operations - External Innovation at EMD Serono, Inc.



Hugo Stephenson, MD

Principal Investigator, Executive Chairman, DrugDev



2. Build more momentum to increase personal, long-term and ongoing participation in clinical studies.
3. Stimulate more active engagement within the clinical research community, particularly with those who seek alternative healthcare options.
4. Create higher levels of recognition and appreciation for clinical trial volunteers.

Finalists also were encouraged to think about how their ideas could use data and new technology, re-purposing of current technology and crowd-solving solutions; create a positive impact, which will lead to more effective engagement with patients, healthcare professionals, and advocacy support groups as well as the general public; and determine if forms of digital and social media outreach also could be applied effectively.

“The submissions selected as finalists were the ideas that the judges believed held the most promise in the near term for spotlighting clinical trials awareness and supporting our goal to develop an engaged community that educates and advocates for clinical research,” Getz notes.

Innovation Through Collaboration

The shortlist of the top 14 ideas represent a broad spectrum of thinking ranging from an app that matches researchers with patients to a dramatization featuring a pop-up retail pharmacy to a concept that includes working with Google to include a “doodle” for various days of the year honoring female and minority populations who have participated in clinical trials. Other ideas included establishing a mobile unit that provides health screening, education, and access to clinical trials in rural and inner city areas.

Program judges say they will connect the Ideathon finalists to partners who will help them advance their project goals.

And the winner is....

From among the nearly 70 entries and 13 teams that ultimately participated in the day-long Ideathon, C2: The Clinical Study Change Agent Collective from the patient recruitment firm FCBVIO was selected as the winner of the

“It’s hard to implement ‘good ideas’ – I wanted to help give these ideas a chance by being part of the team thinking through all the issues.”

Edward S. Seguire, Jr., CEO, Clinical Ink

Inspiring Hope Ideathon. C2 was selected because judges believed the team’s idea to create a corporate social responsibility program had longevity, momentum, and begins at the start of the patient journey.

The team received a \$10,000 prize awarded by CISCRP and the opportunity to progress their idea into a viable solution to address awareness of clinical trial participation among patients, healthcare professionals, and the general public.

The team was led by Angela Radcliffe, Executive Vice President, FCBVIO, and Patrick Tobin, Executive Vice President, FCB Health, along with Meghan Kates, Tony Hursey, and Donna Fowle. Additionally, the team had input from Diane Montross of Shire and Lani Hashimoto of Novartis, as well as countless colleagues at FCB.

“The support and energy surrounding this premiere event has been outstanding,” Radcliffe says. “It’s wonderful to have a platform dedicated to driving big thinking around one of the core challenges of clinical trials and drug development. At the end of the day, we are all focused on increasing awareness of clinical trials to ultimately benefit patients and advance public health. We are excited about our concept and the potential of bringing it to life.”

According to Radcliffe, the genesis of the idea stemmed from her personal involvement with a patient registry after the tragic death of her brother due to long QT disease. Researchers determined that her family has gene related to an arrhythmia type disorder.

“We have a very large family, so the impact of being part of a study was really significant,” she says.

Subsequently, Radcliffe moved into the area of patient recruitment, and was really excited about the possibilities. However, she soon realized that it was a lot of the same brochures and tactics amidst a significant crisis.

“Because I had gone from none to one in terms of participation, I wanted others to understand the benefits that could be realized,” Radcliffe says. “But unfortunately



“The concepts developed during the Ideathon aren’t left in the room. These are valuable contributions presented to members of industry positioned to make them reality.”

Christine Pierre, President,
Society for Clinical Research Sites

most of us are not introduced to study participation until we are in a health crisis.”

Radcliffe believes the gap from having never participated in a clinical study to being part of a gateway trial — observational, registry, or healthy volunteer — needs to be closed. Additionally, participation leads to the demystification of the process and the realization of the benefits to one’s life. According to Radcliffe, good science can’t happen without proof, and we can’t expect good health without good science. But what if this proof is not accessible because of inadequate health literacy? The team questioned what would happen if the industry embraced clinical trial participation as another healthcare option — one that might impact not just health, but also the causes we care about?

Since the Ideathon, Radcliffe and her team have continued to evolve HealthProof and are diligently working on a beta program to be ready by the beginning of 2017 and look forward to piloting the program in the near future.

“Our mission is to transform care by making clinical research an essential part of the healthcare continuum, which in turn will improve outcomes and decrease cost of care overall,” Radcliffe says. “HealthProof is an innovative, customizable, corporate social responsibility framework for employers that leverages employee-driven advocacy and the momentum of the employee wellness movement.”

At its core, HealthProof is about delivering health literacy while teaching all to participate with purpose by understanding the impact of the choices they make for the causes they care about. The HealthProof framework offers education, activation tools, compelling campaigns, and a cause-driven community for all stakeholders. Inherently designed to create shared value, HealthProof provides benefits at the employee, employer, and social level and carries with it a significant ROI for employers.

According to Patrick Tobin, Executive Vice President, FCB Health, it’s imperative to educate people so they start to recognize that if they don’t participate in trials, and if there isn’t support and awareness for continued support of trials, then we are not going to have new medicines for emerging diseases and emerging health threats.



And the winner is ...

C2 : The Clinical Study Change Agent Collective
team and Ideathon judges



► C2 : The Clinical Study Change Agent Collective

The aim of this initiative is to amplify the participation message through novel voices and channels; harness the momentum of the wellness movement; advance health literacy to serve the greater good through advocacy; and empower employers to better serve their employees, their stakeholders, and their customers. By connecting the causes that people are passionate about with clinical trial participation, the goal is to create a corporate social responsibility program that improves health literacy and connects people through the cause they already are passionate about to clinical trial participation.

This program will allow companies everywhere to educate their employees, connecting clinical trial awareness and participation. The outcome is intended to normalize clinical trial participation as just one more option to serve the world and one more option in a company's personal healthcare arsenal.

Team Members:

- Angela Radcliffe, EVP, FCBVIO
- Tony Hursey, VP Operations, FCBVIO
- Donna Fowle, Account Services, FCBVIO
- Joseph Graiff, Director of Technology, VP – Digital Production, FCB Health

The Finalists ...

► Building Better Health

Through a concierge-type service, Building Better Health focuses on underserved patient populations, particularly U.S. military veterans who suffer from a litany of chronic conditions at a much higher prevalence than the general population of the United States. Reaching veterans requires a level of trust and approach with a unique understanding and level of compassion around the issues these individuals face. This project aims to collaborate with the relevant employers, associations, and drug sponsors to educate their at-risk workers/members about appropriate studies, and then support the patient volunteers throughout the study, increasing enrollment and retention.

“I was really happy to be part of, and a mentor at, the Inspiring Hope Ideathon as helping channel the power of collaboration toward enhancing the life of many is a crucial and rewarding activity.”

Frederic Marc, Lead Experience Designer, Medidata

Team Members:

- Zac Carr, Director, Strategy & Business Operations, Clincierge
- Liz Willock, Mid-West Regional Sales Leader, Clincierge
- Eric Nier, Regional Sales Leader, Clincierge
- Bob Fritzky, President, MedMatRx
- Ian Cook, Director, New Business and Operations, MedMatRx

► Clinical Trials Connect (CTC) White Coats

These ideators created an approach that humanizes the clinical trial process and connects clinical trials and their value not only medically but societally. Through video, “real people” are depicted to show the benefits of volunteering and how their contributions lead to medicines becoming readily available. The use of video was chosen as the primary storytelling medium because of its advantages as a conducive and concise way to tell a story over several formats. Through various formats — TV, social, and online media — messages can be delivered to a wide audience.

Team Members:

- Christine Zahren, Director, Clinical Trials Connect
- Fiona Cameron, Marketing Director, Acme Strategic

► Conduit Health Communications

Based on the concept that organ, tissue, and blood donation are critical to clinical trial success as well



“In order to genuinely improve the clinical research experience of our patients, it is crucial to explore new innovations as a collaboration across our industry.”

Dax De Leon, Clinical Patient Experience Manager, AbbVie

as patient participation, this program is intended to encourage people to learn about joining a clinical trial as a way to honor their loved one(s), equip them to easily and openly share their commitment and experience, and personally invite others to learn more. Through the execution of a standard communications campaign with a creative strategy and message, the result is an inspiring movement that allows people to share what they've done to benefit and honor others.

Team Members:

- ▶ Susan Sikora, President, Conduit Health Communications, LLC
- ▶ Jennifer Smoter, President, Amicus Communications & Brand Management, LLC
- ▶ DeAnna Dubose, Conduit Health Communications.
- ▶ Lissette Linares, Verge Scientific Communications

► Flex-e-Trial

Using state-of-the-art technology, Flex-e-Trial is a digital, interactive poster that generates interest among potential participants to find out about different trials, and sign up to ones of interest or share with friends. Each poster holds information for as many trials as the memory allows, and would be linked to an app. The posters can be rolled up and are easily portable, which enables institutions to take them to conferences, events etc. This would lead to a broader spread of awareness and an increase in areas with low patient recruitment. Users can search by disease and/or location, and on signing up would be added to a global database that could be used to notify them of future trials and also follow up with patients' post trial. This would lead to greater awareness of trials, particularly in areas of low patient recruitment.

The Ideathon Mentors



Karin Beckstrom

Innovation Lab Product Manager, ERT

Being a mentor in INC Research and CISCRP's Ideathon was an energizing experience. I helped channel passionate diverse thoughts into an actionable idea for raising clinical trial awareness.



Jennifer Byrne

CEO, PMG Research, Inc.

As an Ideathon Mentor, it was a fantastic opportunity to take a quick deep dive with a highly charged team's revolutionary idea to expand the value proposition of clinical trials.



Joan Chambers

COO, CenterWatch

It was an honor to be part of an event that will drive awareness, momentum and positive change for the clinical trials industry across professional and patient communities.



S. Robert Collins

Life Science Presales Manager, SAS Institute

The greatest benefits from the Ideathon are awareness and collaboration — directly and indirectly — even when people say, “I love Boston; why were you there?”



Lance Converse

Chief Innovation Officer, WCG Clinical

We must invest in new ideas that help consumers learn about the benefits of participating in clinical trials. Mentoring the Ideathon was one way WCG could help support this important cause.



Dax De Leon

Clinical Patient Experience Manager, AbbVie

In order to genuinely improve the clinical research experience of our patients, it is crucial to explore new innovations as a collaboration across our industry.



Beth Harper, BS, MBA

President, Clinical Performance Partners, Inc.

Serving as a mentor allowed me the opportunity to contribute my passion and expertise in a creative and meaningful way while also supporting the broader mission of CISCRP.



Jennifer Hayden

Patient and Investigator Engagement Manager, AbbVie

This was a unique opportunity to share new ways to approach patient education.



Kelly Johnston McKee

Advisor in the Clinical Innovation group, Eli Lilly and Company

By participating as a mentor, I was able to share my experiences with the team and help shape their great idea into a successful presentation.



Tom Krohn, RPh, MBA

Chief Development Officer, TrialReach

To me, it's personal. My life is one of empowering others. And nowhere is the need greater for change than in healthcare and research.



John Lewis

John Lewis, SVP, Policy & Public Affairs, Association of Clinical Research Organizations (ACRO)

Mentoring is important because no matter how good an idea it can always benefit from another informed, outside viewpoint. As an association, ACRO supports innovation.

**Frederic Marc***Lead Experience Designer, Medidata*

I was really happy to be part of, and a mentor at, the Inspiring Hope Ideathon as helping channel the power of collaboration toward enhancing the life of many is a crucial and rewarding activity.

**Sebrena Mervin-Blake***Director of Research Operations – Clinical Research Recruitment Center, Duke University Medical Center***Jim Murphy***CEO, Greenphire*

Clinical trials are central to the advancement of human health. By increasing awareness, participation and patient retention, progress can be accelerated.

**Melissa Nezos***Executive Director of Clinical Operations, NA, Chiltern International*

Being a part of change and innovation is exhilarating! It is also critical to bringing new therapies to patients and help to caregivers.

**Danielle Panetta***Advocate, Diabetes Patient & Research***Christine Pierre***President, Society for Clinical Research Sites*

The concepts developed during the Ideathon aren't left in the room. These are valuable contributions presented to members of industry positioned to make them reality.

**Edward S. Seguire, Jr.***CEO, Clinical Ink*

It's hard to implement "good ideas" – I wanted to help give these ideas a "chance" by being part of the team thinking through all the issues.

**Abbe Steel, MSc***CEO, HealthiVibe, LLC*

Mentoring gave me the opportunity to help cultivate innovative ideas to empower patients with the knowledge and resources to potentially improve their condition through research.

**Stella Stergiopoulos***Senior Project Manager, Tufts Center for the Study of Drug Development*

As an Ideathon Mentor, it was an amazing experience working with a team who was passionate in expanding clinical trial awareness with their innovative idea.

**Rick Ward***VP, Business Development, Greenphire*

Volunteering as a mentor for the Ideathon was a rewarding experience. While I hope that my insights and experience helped my team pressure test their concept and refine their presentation, observing the creative process and the passion dedicated to solving such critical challenges was a truly inspiring experience for me.



“We must invest in new ideas that help consumers learn about the benefits of participating in clinical trials. Mentoring the Ideathon was one way WCG could help support this important cause.”

Lance Converse, Chief Innovation Officer,
WCG Clinical

Team Members:

- ▶ Daniella Frisoli, SSU & Regulatory Specialist (SSU Academy), INC Research
- ▶ Julia McCann, SSU & Regulatory Specialist (SSU Academy), INC Research

► Google Doodles

Millions of people use Google every day. By showcasing clinical research through a medium that is so frequently utilized, more people will become aware of its importance.

The idea is to tap Google to include a “doodle” on its home page for various days of the year honoring a specific population to participate in clinical trials and or to improve treatment for a particular therapeutic area. Google would also include a link to various resources focused on clinical research opportunities for these specific patient populations. Clinical trial volunteers will feel recognized and appreciated when their specific therapeutic area and or population is exhibited on Google doodle. They'll feel good something they did is being honored and celebrated through something utilized by millions of daily visitors.

Team Members:

- ▶ Susannah Buzard, Associate Manager of Editorial Panels & Community Outreach, CISC RP
- ▶ Cynthia Korisky, Project Manager, Communicating Trial Results, CISC RP
- ▶ Matt Scanlon, Project Manager, Communicating Trial Results, CISC RP



“To me, it’s personal. My life is one of empowering others. And nowhere is the need greater for change than in healthcare and research.”

Tom Krohn, RPh, MBA,
Chief Development Officer, TrialReach

► HOPE.IN

The idea aims to raise public awareness by giving physical incentives for the general public through crowdsourcing. Through a crowdsourcing clinical trial enrollment reference platform combined with a trial medication/procedure compliance system, appointment scheduler, and online communication feature assisted with external crowd funding and social networking site cross-referencing and viral marketing, users receive an award by successfully referring and enrolling someone who is eligible for a particular clinical trial.

Once clinical participants are enrolled in a trial, the platform provides a compliance and communication channel between clinician/organization and patients/volunteers, such as a trial medication/procedure compliance system, appointment scheduler/calendar, and online communication feature. Further, by using short/brief, yet concise and simple online content, messages can be virally transmitted about what clinical trials can do and raise awareness to the general public.

Team Member:

- Ernest Suh, PharmD, Kaiser Permanente

► The Humanizers

This innovative idea is a series of video ads that will use humor to inform targeted demographics that wise people “in the know” participate in and recommend clinical trials to make a difference. Based on social media platforms, the success of the campaign would primarily be measured in views, shares and participation in clinical trials.

This series of TrueView in-stream skippable video ads

describe how clinical trials provide hope and lead to a better future for all. The benefit of using multiple ads with a common theme to target multiple demographics is the repetitive reinforcement to individuals and communities of the benefits of clinical trials, across age, race, and economic status.

Team Members:

- Rebecca Simpson, Marketing and Media Specialist, Jacksonville Center for Clinical Research
- Benjamin Donovan, Recruitment Specialist, Jacksonville Center for Clinical Research

► Langland

Medicines can’t exist without clinical trials. This idea dramatizes what a world without medicines would look like. It is an experiential interpretation of the true worth of clinical trials. It engages the general public in a way that they can really grasp, delivering a message with a visual immediacy rather than a theoretical one. It will be an original way to introduce the general public to clinical research and how volunteers play a vital role in drug development. The novelty of the event will create a huge amount of free coverage via PR and social media leverage. Shoppers entering a pop-up pharmacy with empty shelves would be greeted by “pharmacists” who explain that without clinical research studies we wouldn’t have approved medicines. The reaction of the shoppers would be captured on film and the edited footage seeded throughout social media. This media exposure would in turn encourage people to think more about the value of clinical trials, and their or a loved one’s likelihood of taking part in them.

Team Members:

- Kate Wheeler, Group Account Director, Langland
- Tora Shea, Account Supervisor, Langland
- Sarah Cannon, Senior Account Executive, Langland

► Patients Advancing Clinical Trials (PACT)

Patients deserve comprehensive, accessible information about treatment options. PACT is a patient engagement platform empowering patients to stop



cancer through clinical trial participation. This patient-centric platform is dedicated to providing personalized clinical trial information detailing relevant open trials, and trial updates to patients and caregivers. Patients learn about molecules being studied, in patient-friendly language. They could opt in to the PACT community, as an advocate or participant. The aim is to create a free online and POC resource for patient education on trial participation and options, empowering patients to engage in treatment decisions. (Note: PACT was unavailable to present on the day of the Ideathon.)

Team Members:

- ▶ Aurelie Macdonald, Managing Director, BioMark Consulting
- ▶ Michelle Lonchar, BioMark Consulting

▶ The S.T.A.R. Initiative E3 Team

The S.T.A.R. Initiative E3 Mobile Application will enable engagement, education, and enrollment (E3) through a mobile app that will match researchers and patients in comparative effectiveness research with the ultimate goal of enrollment into clinical trials. Initially, the initiative will deliver culturally specific educational and engagement resources to African-American women who have an interest in participating in clinical trials for breast cancer but lack resources and support. There will be a strong mentorship/educational component to support implementation and use of the mobile app so patients can become research ready to make the decision to enroll into clinical trials. While the initial focus will be African-American women into breast cancer clinical trials, the initiative is scalable to all patient populations.

Team Members:

- ▶ Regina Greer-Smith, Project Manager/Chief Engagement Officer, Healthcare Research Associates LLC
- ▶ Jerome Carter, Software Engineer/App Developer/Data Manager, Light of Day Media
- ▶ Beverly Rogers, Community Patient Consultant/Engagement Facilitation and Training, Momma's House,
- ▶ Funmi Apantaku Onayemi, Breast Cancer Research Consultant/Research Methodology, Training & Evaluation, University of Illinois

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Melissa Nezos, Executive Director of Clinical Operations, NA,
Chiltern International

▶ Virtual-osity: Fill the White Space

Fox Insight is an online longitudinal observational study aiming to collect the world's largest set of data from patients and caregivers on their daily lived Parkinson's experience. Following a traditional clinical study design, routine online questionnaires, substudies, and ancillary surveys can be connected to generate a truly holistic picture of participants' objective and subjective experiences. Through technology, geographic and time barriers are removed allowing easy study participation from across the globe. Not only does the program remove barriers to participation (geographic, transportation, cost, and time) but it allows for people to participate and use the information they submit to share with their providers. Active promotion of Fox Insight can help potential volunteers realize how easy it can be to participate in research, acting as a gateway to further education and engagement. In addition, the insights that individuals receive from the platform that they can share with their providers can help with determining how well medications are working and how the disease is progressing, as well as nutritional and physical therapy insights.

Team Members:

- ▶ Sara Berk, Associate Director, Research Partnerships, The Michael J. Fox Foundation for Parkinson's Research
- ▶ Kristin Demafeliz, Associate Director, Research Partnerships, The Michael J. Fox Foundation for Parkinson's Research
- ▶ Lauren McLaughlin, Associate Director, Research Partnerships, The Michael J. Fox Foundation for Parkinson's Research
- ▶ Lismelia Vargas, Research Partnerships Officer, The Michael J. Fox Foundation for Parkinson's Research



► WeHealth

WeHealth uses a validated crowdsourcing platform to raise awareness for clinical trials and recruit patients who meet eligibility criteria. Referral-based crowdsourcing was developed to find “needle in a haystack” targets such as fugitives and missing persons. WeHealth intends to apply this technology to the drug industry in order to more efficiently get clinical trial information to patients who can benefit. By tracking how shared messages propagate through social networks, the idea is to incentivize users when their sharing helps enroll clinical trial subjects. It is difficult for the average person to participate in clinical trial outreach, because they rarely know eligible patients for individual studies. By lowering the bar for who can get involved in clinical outreach and gamifying the recruitment process, the idea is to expand clinical trial awareness beyond the medical field.

Team Member:

- Will Raasch, CEO, WeHealth

► Wheel-n-Awareness

The idea is to bring greater awareness directly to the public in rural and inner city areas that are generally underserved by establishing a mobile unit that provides health screening, education, and access to clinical trials. Being mobile would allow researchers to go

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Jim Murphy, CEO, Greenphire

out to the community to introduce clinical research instead of the traditional modality where patients go to a clinic, site, or learn through a physician. The awareness and screening unit would have tools on board — videos, tablets, etc. — and staff who would appeal to the learning and communication styles of different people. Through education, while on board the mobile screening unit visitors will get an understanding of how to integrate clinical research as a care option. Additionally, by conducting routine visits to the community participants will be aware of upcoming visits and potentially refer family, friends, and neighbors for screenings.

Team Members:

- Deena Bernstein, VP Site Services Qcare, Quintiles
- Rod Walker, Associate Director, Site & Patient Networks — Operations Site Network Lead, Quintiles Precision Enrollment, Quintiles

Continue Inspiring Hope ...

The Inspiring Hope Ideathon team is interested in hearing more ideas regarding raising awareness around clinical trial participation.

“I really hope that more people will get behind this effort and recognize just how incredible we are as a community and that there are lots of really interesting solutions that we can collectively support,” says Ken Getz.

If you would like to submit an innovative idea or provide

feedback on the Ideathon, please email Rachel Minnick at rminnick@ciscrp.org.

To view a film capturing the highlights of the “Inspiring Hope Ideathon,” or for team videos, please go to: <http://whats-new.inspiring-hope-ideathon.com/videos>.

To learn more about the Ideathon, please go to: <https://www.ciscrp.org/events/inspiring-hope-ideathon/>



Reflections from the Patient Perspective

In an exclusive Q&A with Ideathon organizers, Jameisha Brown, Managing Chief Equipping Officer (CEO) of T3 Health & Wellness, PhD Student, Health Disparities Research Fellow, College Station, Texas Research, and most importantly a clinical trial volunteer and patient, provides her unique views on trial literacy and awareness, becoming an advocate, and ways to better engage with all sectors of the patient population.

Jameisha Brown

How important is clinical trials literacy and what is the potential real-world impact for patients if patient participation in clinical trials is improved?

BROWN. The provision of age-appropriate (child and adult) and understandable information and its comprehension are necessary for informed consent. Clinical trials literacy, mistrust of medical practitioners due to historical injustices, and being offered inferior medical treatments are a few concerns to address. Patients around the world are looking for novel prevention methods, treatments, and cures. One day one of those patients might be identified as your family member — your parent, spouse, or child. Innovation begs for new methods and ideas not processes as usual. Innovation must satisfy a specific need. Thus far, the mission to fulfill this void has been a bit misguided. The focus is too much on trial design and drug development but not enough on how to engage potential patients and volunteers. We need patient centricity.

As a “cancer thriver,” what is your past experience of clinical trials?

BROWN. My healthcare team described clinical trials as a hopeful opportunity that may get rid of my cancer using teddy bear demonstrations and drawings on a whiteboard, which helped me to understand my disease and treatment. I feel certain that relating the information to me in a manner I could understand at the basic level aided in my comfort with the uncertainty associated with clinical trial participation.

Can you describe your journey through cancer to advocacy?

BROWN. Most of us have at least one circumstance in life that totally transforms our perspective of the world. A wise, battle afflicted patient, who fought cancer for many years, related the words, “why not me?” That phrase opened my mind to a totally new clarity of life. Watching other patients’ courage and determination while being inconceivably sick inspired in me

“Most of us have at least one circumstance in life that totally transforms our perspective of the world.”

the ambition and strength I needed to get through not only sickness, but through life. After all, I had a tremendous team of doctors, nurses, family, and friends who believed I had the strength needed to conquer my illness. I first learned how to advocate for myself before I could for others. My battle with cancer was a springboard for my career. Through numerous healthcare encounters over the last 18 years I have observed the issues that patients and healthcare providers face. As an emerging scientist, I am hopeful that my research will contribute to the body of knowledge of potential solutions to health disparities.

How would you advise the clinical community to best engage with all sectors of the patient population?

BROWN. It is a truism that in clinical research that recruitment and retention efforts will be more effective when the methods are culturally appropriate for the populations to be included in the study. This should also be considered in study design. Cultural competency training can broaden the knowledge of the study providers and staff, increase cultural awareness, and an understanding of multicultural values and beliefs on the impact of the provision of care, and ability to communicate with diverse groups. Cultural competency is not just having staff who represents the race and ethnic backgrounds of the patient population. Cultural competence in healthcare describes the ability of systems to provide care to patients with diverse values, beliefs, and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs. Perhaps consent should leverage the power of technology; a short video or picture form may be a favorable opportunity for innovating the informed consent process for children and low-literacy populations.

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Giving Back — One to One



In recognition of the efforts and participation of the Inspiring Hope Ideathon's 14 finalists and winner — C2: "The Clinical Study Change Agent Collective," the Greater Gift Initiative (GGI), a non-profit organization dedicated to advancing global health and clinical trial participation, is donating 145 vaccines to children.

Greater Gift's mission is to advance global health and highlight the greater good of clinical trial participation by gifting a vaccine to a child in honor of every clinical trial volunteer. Currently, the GGI supports the Pentavalent Vaccine Campaign and by 2020, Pentavalent will have helped avert more than 5 million deaths.

Since 2010, the Greater Gift Initiative has donated more than 70,000 vaccines to children in developing countries as a way to give back and thank the volunteers who participate in clinical trials and contribute to the advancement of health worldwide.

Every year almost 2 million children die of vaccine preventable diseases. By honoring the approximately 2 million volunteers who participate in clinical trials every year, the GGI is helping make sure that no child is denied life-saving vaccines, which have done more than any other class of drugs to improve global health.

For more information about the Greater Gift Initiative, please visit <http://www.greatergiftinitiative.org>.