1º Prémio: Registros para todos: Reg4ALL

Washington, United States
Sharon Terry
Ano em que foi fundado: 1986
Tipo de organização: Sem fins lucrativos / ONG/ Setor Civil
Orçamento: $1 million - $5 million
Website: http://www.geneticalliance.org/

- Medical Research
- Citizen participation
- Maternal health
- Mental health

Resumo do projeto

Pitch de Elevador (Explicação curta e direta)

Resumo conciso: Ajude-nos a lançar esta solução! Forneça uma explicação dentro de 3-4 frases curtas.

Reg4All: The registry for all people, all diseases, all health.
The world's first participant-controlled, cross-disease health data registry. Because the haystack is made of needles.
Giving participants control, accelerating research, allowing support and trials to flow to the people.

SOBRE O PROJETO

Problema: Este projeto busca solucionar qual problema?

People are looking for needles in the haystack, but the haystack is made of needles! We are missing the health research world's greatest assets: people and their health data, unified across all health and disease. People's (patients') health information must become easy to assemble, and must be done cross-disease and with the participants in control of what they share. Only then will we create the next breakthroughs in research.

Solução: Qual é a solução proposta? Por favor, seja específico!

The world's first ever participant-controlled, cross-disease registry for health and disease data.

Impact: How does it Work

Exemplo: Compartilhe um exemplo específico de como essa solução faz a diferença, inclua situações práticas.

We are helping fuel the movement toward individuals, families, and communities reclaiming control of their health. We invite them to control the registry that contains their health data. Respecting each participant's sharing/privacy desires, we help researchers engage with people and their data: to generate research hypotheses, discover research cohorts, enroll studies/trials, and achieve breakthroughs more quickly than before.

Impacto: Qual tem sido o impacto do seu trabalho até hoje? Descreva também o impacto esperado para o futuro do projeto.

- Thousands of users - Unlocking cooperation across ecosystem - First clinical trial ready preparing to use system - First data-based study ready to use system - Renewed hope from participant communities - Great entusiasm from the research community

Sustentabilidade

Plano de Sustentabilidade Financeira: Qual é o plano para garantir a sustentabilidade financeira do projeto?


Mercado ou Setor: Quais projetos ou organizações estão solucionando o mesmo problema que você e como essas propostas diferem da sua?

So many narrow or incomplete registries in the world. Some of those organizations may feel threatened by how Reg4All puts control in the hands of participants. With so many registries out there, we see some competition for the attention of consumers and researchers. But our marketing/attraction strategies will be quite different.
Equipe de fundação

My children were diagnosed with a genetic condition in 1994 and there was no treatment. We discovered there was no system for creating treatments. The aha came when I realized that while researchers were trying to find needles in haystacks, the haystack is made of needles - all citizens are able and willing if they are given the right tools - data sharing and access privacy preference tools.

Nome da Organização
Genetic Alliance

Sobre Você

Nome
Sharon

Sobrenome
Terry

URL do Twitter
https://twitter.com/geneticalliance

URL do Facebook
https://www.facebook.com/groups/15453400385/?fref=ts

As informações que você fornecer aqui serão usadas para preencher todas as partes do seu perfil deixadas em branco, como interesses, informação da organização e website. Nenhuma informação do contato será tornada pública. Por favor, desmarque aqui se você não deseja que isso aconteça..

INOVAÇÃO

Explique sobre o que trata a "inovação"; por exemplo, é uma idéia e/ou um modelo que você usa para concretizar uma idéia, ou talvez seria sua compreensão da população-alvo, etc?

It is time for individuals to reclaim their health, like they claim every other aspect of their lives. The time for paternalism is over. It is time for individuals, families and communities to drive research— to decide who will use their health information and why. To be drivers of research. Then incentives will align. Researchers strive for promotions and funding, industry strives for blockbusters and profit, and even advocacy organizations often strive to sustain their organization. Reg4All was created with the radical idea that patients and researchers should be able to join an online network that would link the two together in the spirit of sharing information for the greater good. Patients gain access to potentially life saving clinical trials, researchers gain access to a centralized database of participants, and data will be freely shared (respecting each participant's custom sharing/privacy settings, of course!) in BOTH directions.

This idea changes the way people view their health, pushes researchers to a 2-way relationship with patients, and transforms a broken system that does not serve enough of the population.

Descreva como o seu modelo de inovação é diferente de qualquer outra organização na sua área.

Disease advocacy organizations have attempted registries. But lacking committed researchers, often do not meet their data usage goals, and are hard to sustain financially. Commercial orgs also attempt registries, but find it difficult to sustain an environment of trust. And both advocacy and research communities too often take a single-disease approach.

Reg4All is cross-disease. It is participant centric, with trust as a founding principle. And it is designed for the widest proliferation, helping create and sustain new relationships between participants and researchers.

Que tipo de ambiente operacional e fatores da organização interna ajudarão o projeto a ser bem sucedido?

We operate on a 10+ year long foundation of openness, systems thinking, and respect of persons. We are a non-profit org that works like a lean startup. We surround ourselves with helpful voices. For example, we convened the ethics team for this project at its founding, making participant-centric governance a founding principle rather than just tacking on ethical oversight at the end.

We apply to health habits we’ve learned from the networked world. Less like traditional health research, more like facebook and twitter.

Como você garante que inova constantemente à luz de (potenciais) desafios externos, ou do seu plano de crescimento?

Embracing Eric Ries’ Lean Startup philosophies (Eric is a friend of one of our founders), we progress through product experiments. We see what works and we grow it. We see what doesn’t work, and we adapt. We weekly (and sometimes daily) learn from our metrics and our qualitative feedback.

Think, Make, Check. Repeat. Innovation is a way of life, not a project.

País da organização
US, DC, Washington

Modelo de Negócios

Desafio Sistêmico que você está tentando resolver [selecione apenas um]

Realinhar os incentivos no sistema público de saúde em mercados maduros, ou
Area da Saúde (mercado alvo) em que a necessidade está [selecione apenas um]
- Tratamento para doenças raras

Categorias ao longo do continuo da saúde que você está cobrindo [selecione todos que se aplicam]
- Prevenção, Diagnóstico, Intervenção, Acompanhamento, Tratamento de longa duração, Integração social.

Estágio que melhor se aplica à sua solução [selecione apenas um]
- Start-up e crescimento (piloto operando e em expansão)

Estratégias centrais do seu modelo de negócios
Abordagens para a mudança de comportamento no nível individual, Design centrado no paciente, Redesenho do sistema público de saúde para mais eficiência (em termos de processos, estrutura, etc), Papéis novos/redefinidos para prestação de serviços de saúde, Novas abordagens para a distribuição de produtos e serviços de saúde, Parcerias entre atores não convencionais (entre atores tradicionais e atores externos ao sistema de saúde), Novas estratégias de financiamento para a saúde.

Por favor, especifique:
Ferramentas mais relevantes que você está usando para implementar as estratégias descritas acima [selecione apenas duas]
- Tecnologia, Novas habilidades, Educação/treinamento, Financiamento comunitário.

Por favor, especifique:
Quem são seus clientes?
- Consumers
- Researchers/Pharma Cos
- Disease Advocacy Organizaions

Quais abordagens você usa para alcançar seus clientes?
- PR
- Links from partners
- Viral loops
- SEO
- SEM
- Events

Quais são suas atividades principais?
- Developing systems and user experiences
- Operating databases
- Exercising ethical governance
- Attracting consumers & researchers

Quais outros desafios – individuais, organizacionais ou de meio ambiente – você atualmente enfrenta ou poderiam impedir o futuro sucesso de seu negócio e como você pretende superá-los?

Genetic Alliance does not have very much experience running consumer-facing web products, and doing good branding and marketing. This is why we brought in an Entrepreneur-in-Residence who has deep expertise in these areas.

We also need more cash investment during the start-up phase on our way to reaching financial sustainability.

Descreva brevemente sua estratégia de crescimento futuro
CONSUMER SIDE: start with our core audience in rare disease. Use viral loops attract many more. Event marketing, SEO, SEM.
RESEARCHER SIDE: start with trials most desperate to enroll. Letters to researchers/medical centers. Event marketing. SEO, SEM.

Em quais dimensões de crescimento você atualmente está focando para sua inovação? [selecione todas que se aplicam]
Novo(s) grupo(s) de cliente(s), Nova(s) região(s), Novo(s) mercado(s)/país(es).

O que faz o seu negócio estar “pronto” para crescer?
We have proven with a pilot that our approach works. We are receiving high levels of interest from all quarters. We have a proven, collaborative team executing. We are using lean startup techniques and will execute micro- or macro-pivots as we grow.

Quais são seus objetivos-chave de crescimento?
2013: Tens of thousands of consumer participants. Tens of studies.
2015/2016: Millions of consumer participants. Thousands of studies.

9. País onde organização atua, possui seu projeto implementado
- DC, Washington

IMPACTO SOCIAL
Quais métodos de quantificação de impacto social você está usando (se alguma)?

We have created a whole second 'product' to watch, mine, and learn from online and usage metrics (including visitors to site, conversion rate to account users, # abandoned accounts, engagement on site per visit, source of visitors, success of marketing campaigns, successful research searches, etc.). We are in the process of building other metrics to measure more upstream impact such as clinical trials enrolled and at what speed, research questions formulated by individuals and communities and so on. Where possible, we are thoroughly metrics-oriented.

Suas solução poderia funcionar em outras local ou regiões? Se sim, onde?

It is designed from the ground up to be global in reach and in service. Health and disease know no national boundaries. We are in discussions for pilot projects in India and China. This solution is particularly pertinent to areas of the globe which are currently being exploited in clinical trials because they are in less regulated countries. This will also leap frog problems we have experienced in more developed countries with a sense of powerlessness and the belief that they are channels that will work to solve that engagement. In less developed countries, individuals have some advantage in that they are not already in rigid structures that have failed in the developed nations. However, they will need simpler access, for example through text based products.

Qual é a sua expectativa de impacto para os próximos 1 - 3 anos?

In the next 1-3 years we will see a greater number of individuals in clinical trials. We will see those trials enroll faster, and less trials close because of "low enrollment". We will see more diverse clinical trials - they will not just be the healthiest quartile of white men, they will include minorities and other underserved communities. We will also see more individuals and communities understand that they can reclaim their health. They can drive the clinical questions in trials that they believe will benefit them most.

Ultimately we will see faster drug and other therapy development, decreasing the 17 year, 90% failure rate for a one billion dollar price tag. Any improvement will save enormous amounts of money.

SUSTENTABILIDADE

Descreva sua estratégia financeira atual

We started with a grant from Sanofi. We added to that some in-house budget to get the pilot completed. In addition, development partners are donating some work.

Next, we simultaneously a) seek additional capital donations to fuel rapid growth ahead of sustaining revenue and b) begin to grow recurring revenue which will eventually sustain the whole project. Our strategy is to price access to data at price points vastly below current market rate. We are looking to iTunes and app store models - volume over high prices. At the present time, a pharmaceutical company might pay between $5,000 and $40,000 to accrue one individual into a clinical trial. We hope to make that price point less than $10 per person, or even better, a sustaining subscription model like Pandora or LinkedIn.

In addition, we are offering a Kickstarter type model for companies who seek individuals in specific disease areas.

Parceira da geração de receita na renda total da organização (em porcentagem)

80%

Vendas diretas a pacientes e outros beneficiários (em porcentagem)

60%

Das possíveis fontes dessas vendas, listadas abaixo, selecione todas que se aplicam à sua estratégia atual

Empresas Privadas, Outros beneficiários.

Taxes de licenciamento, por exemplo, para modelos de tecnologia/franquia (em porcentagem)

20%

Das possíveis fontes de oportunidades de licenciamento, listadas abaixo, selecione todas que se aplicam à sua estratégia atual

Fundações, ONG/OCS, Empresas Privadas, Governo nacional.

Contrato de serviço com organizações, por exemplo, governo, ONGs (em porcentagem)

20%

Explique sua estratégia de geração de receita mais detalhadamente

We earn money through:
- Sponsor ad placement
- Registry services for disease groups
- Subscription fees to researchers
Parcela da geração de receita na renda total da organização (em porcentagem)

20%

Estratégias de filantropia que você usa

Estratégia diversificada.

Explique sua abordagem filantrópica mais detalhadamente

Our philanthropic approach has three pathways:
1) We have received unrestricted grants from the family foundations of successful professionals in our field
2) We have applied for and received small grants from public foundations
3) We have competed for prizes in contests such as this and received them on occasion.

Fale mais sobre os itens selecionados; explique como você vai manter o financiamento.

- We will create focused success early on, then market opportunities based on those audience-specific success stories.
- We will grow our revenue channels through combination of great web based interfaces for low-touch revenue, and a small, talented sales/bizdev team for higher-touch opportunities.
- We will constantly watch for new or refined revenue opportunities to seize.

Anos em Operação

Em execução por mais de 5 anos

A organização recebeu algum prêmio ou reconhecimento público? Por favor, conte-nos mais detalhes

2007:
Sharon Terry won 1st Annual Patient Service Award from UNC Institute for Pharmacogenomics and Individualized Therapy

2009:
Sharon Terry is elected Ashoka Fellow for life.

Genetic Alliance received 2009 Research!America Award.

Genetic Alliance is named in 2009 Washingtonian’s Best Places to Work list.

2011:
Sharon Terry is elected to the Institute of Medicine’s Board.

Sharon Terry received 2011 Clinical Research Forum and Foundation’s Annual Award for Leadership in Public Advocacy.

2012:
Sharon Terry received 2012 FORCE Spirit of Empowerment award

2013:
Sharon Terry was recognized by FDA as one of 30 rare disease heroes

Source URL: https://www.changemakers.com/pt-br/healthbiz/entries/registries-all-reg4all#comment-0