Reg4ALL

Registries for All Diseases

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Genetic Alliance
The Problem

From social networks to online banking, the Internet has made it easy to share and connect with the people we care about, and to keep track of the information that helps our lives run smoothly.

Why isn’t there a safe place to keep track of our health information online?

And why can’t we safely share it with the medical and research community - the people who can advance health for all of us?
Needles in Haystacks
The haystack is made of needles...
# Culture Shift

<table>
<thead>
<tr>
<th>Industrial Age</th>
<th>→</th>
<th>Information Age</th>
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<tbody>
<tr>
<td>Control means of production</td>
<td></td>
<td>Open means of production</td>
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<tr>
<td>Based on <strong>scarcity</strong></td>
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<td>Based on <strong>abundance</strong></td>
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<tr>
<td>Hierarchical / Command</td>
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<td><strong>Network</strong> / Collaboration</td>
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<td>Linear / Sequential</td>
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<td><strong>Organic</strong></td>
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<td>Win / Lose</td>
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<td>Win / Win</td>
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<tr>
<td>Materials</td>
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<td>Information</td>
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*but biomedical research and healthcare lag…*
We have the **tools** to address the problem of **fragmented systems**, and still we **lose opportunities** every day.

Data can accelerate **research and services**, help us to get **better patient outcomes**, and save **money**...
Getting Individuals onto the Information Highway

- Disease Specific Data Elements
- Common Data Elements
- Gamified Survey

Privacy Assured with PrivateAccess

Trust
Education
Engagement

Reg4ALL.org
Join Reg4ALL

13,000 disease pages
Hundreds of thousands of visitors
High SEO

Pharma and Biotech analyzing data to choose diseases
Liver cancer
To find out how your experience compares with others about this condition Click Here

Hepatocellular carcinoma is the major histologic type of malignant primary liver neoplasm. It is the fifth most common cancer and the third most common cause of death from cancer worldwide. The major risk factors for HCC are chronic hepatitis B virus (HBV) infection, chronic hepatitis C virus (HCV) infection, prolonged dietary aflatoxin exposure, alcoholic cirrhosis, and cirrhosis due to other causes. Hepatoblastomas comprise 1-2% of all malignant neoplasms of childhood, most often occurring in children under 3 years of age. Hepatoblastomas are thought to be derived from undifferentiated hepatocytes ([31: Taniguchi et al., 2002]).

Source: Online Mendelian Inheritance in Man
Liver cancer

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Reg4ALL
Information Highway

- Disease Specific Data Elements
- Common Data Elements
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Trust
Education
Engagement

Privacy Assured with PrivateAccess

Disease InfoSearch
Powered by Genetic Alliance

Reg4ALL.org
Set Privacy Settings for: Sharon

Donna's Recommendations

These suggestions give you more comfort and control relative to your confidential medical information. For a particular trial, give advance permission for researcher contact. For other studies, set your contact preferences to give you notice of researcher interest before you consent to contact.

Lower privacy concerns
Moderate privacy concerns
Greater privacy concerns

Advocacy & Support Groups

DIS-listed organizations serving your condition: Allow
Non-profit organizations serving your condition: Allow

Discover My Data: what's this?
Contact Me: what's this?
Use My Data: what's this?

Go Back  Customize  Next
### Privacy Settings

**YOU ARE CURRENTLY VIEWING PRIVACY SETTINGS FOR Sharon**

#### Advocacy & Support Groups
- DIS-listed organizations serving your condition: Allow
- Non-profit organizations serving your condition: Allow

#### Medical Researchers
- Researchers recommended by a DIS-listed organization serving your condition: Allow
- IRB-approved research addressing your condition: Allow
- All researchers: Allow

#### Data Analysis
- "Compare with others" feature: N/A
- "Show related content" feature: N/A
- Genetic Alliance Translational Research Network: Allow
- Oracle Health Sciences Network: Allow
- Newly-Released Data Analysis Platforms: Ask Me
Reg4All has simple and engaging surveys that ask general questions about your health and medical conditions.

Have fun finding out how you compare with others!

START HERE by answering a few simple questions

I deal with stress...

- 37% not well at all
- 63% extremely well

feedback on question (0)

I have been diagnosed with a...

- 38% chronic condition (i.e. develops and worsens over an extended period)
- 8% acute condition (i.e. severe and sudden onset)
- 8% both
- 44% neither

feedback on question (0)
Reg4ALL
Information Highway

Disease Specific Data Elements
Common Data Elements
Gamified Survey

Trust
Education
Engagement

Privacy Assured with PrivateAccess

Disease InfoSearch
Powered by Genetic Alliance

Reg4ALL.org
Common Data Elements

Measure the same thing
The same way
Across all diseases
Engagement
Education
Trust

Disease Specific Data Elements
Common Data Elements
Gamified Survey

Reg4ALL.org

Disease INFOSEARCH
Powered by Genetic Alliance
Disease Specific Elements

Detailed disease information

- Signs
- Symptoms
- Progression
- Adverse reactions
Architecture

Self-Reported Medical Information

Empower Patients to Authorize Data Access

Request Info. Transfers from Record Holders (Entitled under HITECH law)

Searchable Fully-Identified Protected Data Store

Authorized Document Exports

Authorized Data Searches in Oracle Health Sciences Network

Consent
Decline
Ask Later

EHR 1
EHR 2
EHR 3
EHR n

Researcher Query
Researcher Query
Researcher Query
Researcher Query
Add your piece to the puzzle.

Start Now!
Onward to the WE

N = They

N = Me

N = WE
“You never change things by fighting existing reality. To change something, build a new model that makes the existing model obsolete.”

Buckminster Fuller

Build the WE