

flu near you
do you have it in you?

WELCOME!

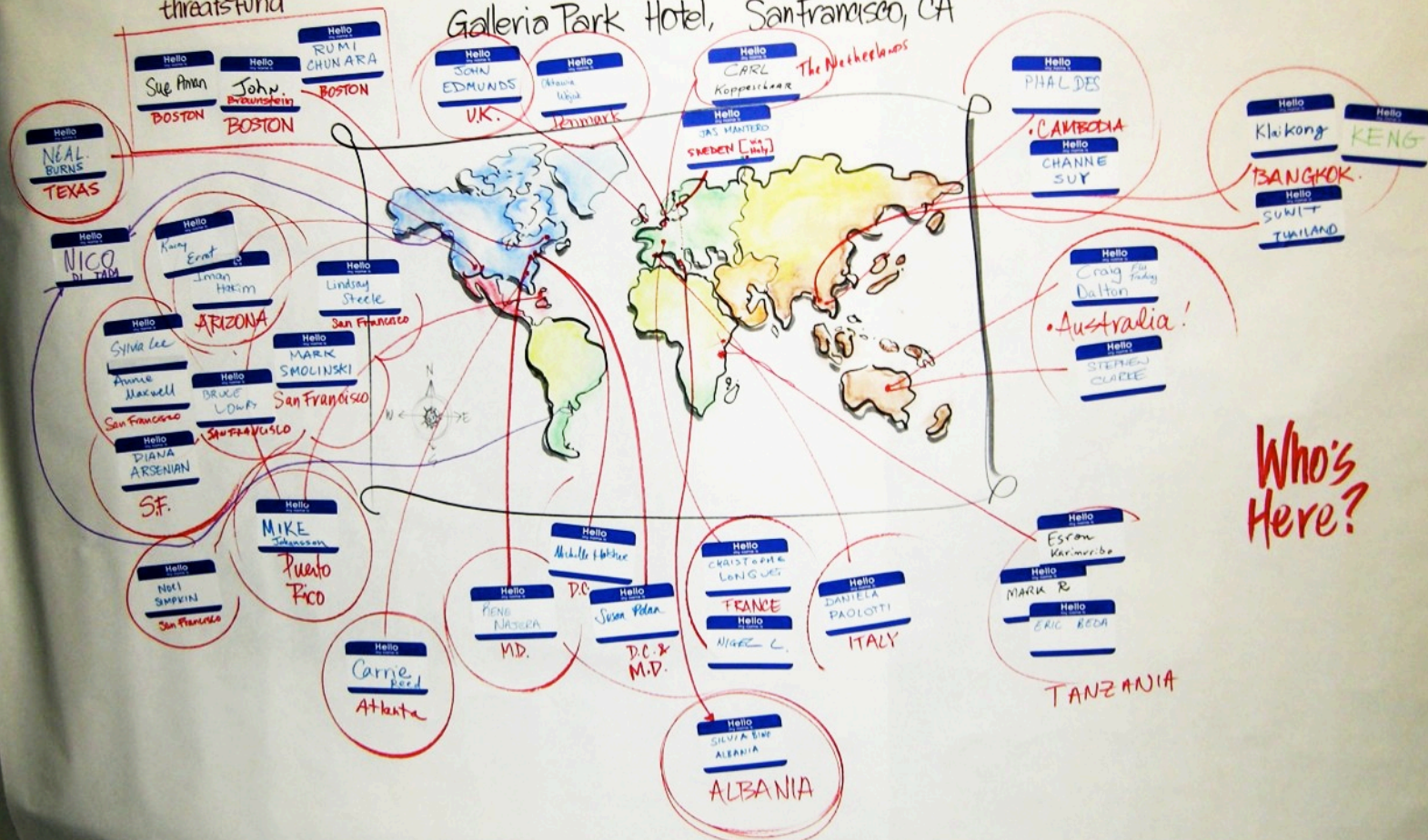
HealthMap
Global Health, Local Knowledge

FLU NEAR YOU WORKSHOP

July 25-27, 2012

Galleria Park Hotel, San Francisco, CA

skoll global
threats fund



They came from near and far

WELCOME!

to the

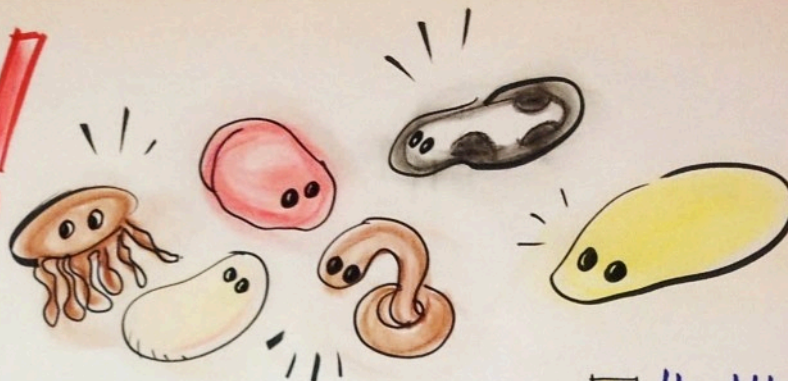
INTERNATIONAL WORKSHOP ON SELF-REPORT SURVEILLANCE



Mark Smolinski

Our Goal:

To advance
Self-Reported, Participatory
Surveillance for Influenza
and other diseases.



Health Map

- John Brownstein
- Susan Aman
- Oktawia Wójcik
- Rumi Chunara

SKOLL Global Threats Fund.

- Mark Smolinski
- Annie Maxwell
- Larry Brilliant
- Bruce Lowry
- Sylvia Lee

- Lindsay Steele
- Veronica Garcia
- Noel Simpkin

HOST TEAMS



APHA

- Susan Polan
- Michelle Holshue

We welcomed all with opened arms

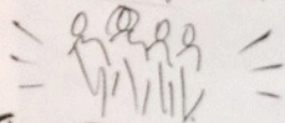
ROLES



• Mark

• Diana

• The Host Team



• The Participants

★ GOAL

• OUR GOAL IS TO ADVANCE SELF-REPORTED, PARTICIPATORY SURVEILLANCE FOR INFLUENZA and OTHER DISEASES.

flu near you
do you know in you?
WORKSHOP



OBJECTIVES

• EXPLORE OPPORTUNITIES TO IMPROVE DATA COLLECTION AND VISUALIZATION PLATFORMS.

• EXPLORE HOW REGIONAL SYSTEMS CAN OPERATE AS AN INTEGRATED GLOBAL RESOURCE.

• EXPLORE BROADER APPLICATIONS FOR PANDEMIC THREAT DETECTION BEYOND INFLUENZA.



RULES



• OPEN, SHARING ENVIRONMENT!

Experience

• COLLABORATION

• ALL IDEAS are Valid

• CO-CREATION

We had a purpose.

INTERNATIONAL WORKSHOP ON SELF-REPORT SURVEILLANCE

WEDNESDAY JULY 25



■ L · U · N · C · H

- 1:00 ● WELCOME & INTRODUCTIONS
 - OBJECTIVES, AGENDA, ROLES, RULES
 - PARTICIPANT INTROS + OUTCOMES. 30 min
 - GROUP Report Out! --- 25 min.
- 2:00 ● OBSTACLES, CONCERNS & CHALLENGES - group discussions. (30 min)
- GROUP REPORT OUT (4 min/per group)
- 3:00 ■ COFFEE BREAK
- 3:30 ● SURVEILLANCE Systems Presentations
 - FLU NEAR YOU
 - FLUTRACKING
 - INFLUENZA NET
- 5:30 ● WRAP UP - RECAP DAY 1.
- 6:30 ■ RECEPTION! **BRINDISI** Cucina di Mare!
- 7:00 ■ DINNER @

THURSDAY JULY 26

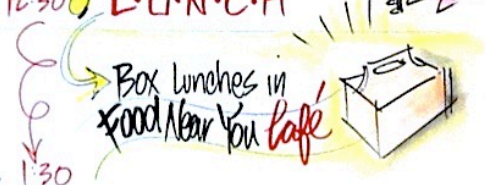
- 8:00 ● BREAKFAST
- 9:00 ● WELCOME & REFLECTIONS ON DAY 1.
- 9:15 ● DESIGNING the PERFECT SYSTEM
 - BREAKOUT INTO 3 GROUPS AND ILLUSTRATE THE PERFECT SURVEILLANCE SYSTEM.
- 10:15 (BREAK)
- 11:00 ● PRESENTATIONS & SYNTHESIS
- 12:00 L · U · N · C · H

- 1:00 ● TECHNO GEEKS & DISEASE DETECTIVES BREAK OUTS
 - DISCUSS "THE PERFECT SYSTEM"

- 2:30 BREAK
- CONT. WORKING IN BREAK OUTS.
- 4:00 ● WORKGROUPS PRESENT! 15 min each
FEEDBACK → on sticky notes
- 4:30 → END OF DAY 2
- 5:00 ● MEET @ Hotel Lobby
Buses leave for Dinner!!
- 9:45 ● Buses depart Academy of Science
→ back to Hotel by 10:00

FRIDAY JULY 27

- 8:00 ● BREAKFAST
- 9:00 ● RECOLLECTION of PAST 2 DAYS HIGHLIGHTS.
- 9:30 ● MOVING FORWARD
 - FOCUS ON "LAUNCH"
 - 5 Break Out Groups - vote w/your feet!
 - Develop Next Steps.
- 10:30 ● BREAK
- 10:45 ● NEXT STEPS Presentations
- 11:30 ● OUR COMMITMENT wall.
- 12:15 ● WORKSHOP EVALUATION
- 12:30 ● L · U · N · C · H



We devised a plan to spend 48 hours together.

VALIDATE!
The results we get!



PARTICIPANTS' OUTCOMES

1. This project needs to be taken seriously.

2. Surveillance standardization

3. Discuss/Assess the right tools for the job.



4. Different groups can have their own systems → an ecosystem of groups.
→ Develop their own tools/reports.

5. Have a good incentive model for PPL to participate in disease surveillance.

6. What do we do with info. collected by disease surveillance system? How do we use it?

7. How to balance bet. certainty of results vs. early release timing of results? Balance between complicated reporting & simple consistent reporting?

D. Arisman

8. Utility of tool for EID tracking

9. How to incorporate CLOUD data w/ govt. data?

10. How to have surveillance in resource constrained settings?

11. Interest in exploring Beyond Flu!

↳ What's out there?
What's working/not?

12. Social Media - what are others doing?

13. Mobile phones → specifically in remote areas around the world.

14. What is the Best System? Platforms?

15. How do you get people involved? Informed?

16. How do you get different communities to access the Internet?
System? Report to it? Share the info?

17. OUTREACH + RECRUITMENT
18. DATA Visualization → appealing for Public Use?
19. Validation of Results + Integration w/ existing tools.
20. DATA Analysis

Analyze + Compare Data.

21. Understand the Perfect System from an end user's perspective.
What do they need to BE MORE INVOLVED?

22. EMPOWERMENT of the People. Go Beyond self reporting to Self mgmt.
From ID to Non-Communicable.
From developed world to developing world.

23. Improve Participation + Keeping People once they start.

24. Explore new ways to collect DATA.

25. Link Academia and Communities of Practice/surveillance.

5.

We elicited desired outcomes toward our 3 objectives

What difference does it make?

Representativeness?
How important is it to understand the population we are working with?

Reaching People.

OBSTACLES, CONCERNS, and CHALLENGES

Accessibility

Technology challenges

Diff. languages

Literacy

Privacy of Data.

Govt. Support.

Without their support, the projects can't go forward.

Doctors

Advertise the System

Govt.

How official does the system appear to people?



Economic Impact of False Alarms!

Language/Cultural Sensitivity.

Having representative Data is the answer.

SIZE of the Survey can be a problem.

We want a system where Communities can report as a group.

User Experience

Visualization



Metrics

Is this working?

Does it add value?

Who is this Data for?
Who's the audience?

Difficult to identify full signals.

People gaming the system
children or teachers can participate.

Simple

It should be a "relaxed" system.

Data Validation

Is data useful? Interesting?

How to make use of multiple data streams?

Why would you use the tool?

Age group?

What can I get if I use the data?

A way to measure the severity of symptoms.

Alerts
Active information

Is this a SURVEILLANCE tool?
or are we entering the "research domain"?

D. Arsenian


We allowed for one hour of potential negative energy...

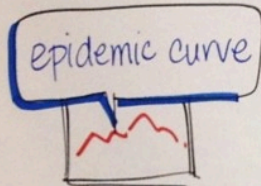
-
- Diagnostics**
- Lack of control how people interpret the data.
 - It's a Project for everyone.
 - How do you get the info out to the most vulnerable?
 - Govt. systems may lag behind... How do you interpret early signals.
 - Problem → Self-Diagnosis Is it accurate?
 - Tools
 - Developing Countries
 - Developed Countries
 - All communities can use it!
 - Medical/Legal aspects of how far do you go providing diagnostic help.
 - Metrics • Usefulness of the System
 - To get Valid data, you need to ask More Data.
 - Testing • Validating
 - Data.
 - How many questions do you ask?
 - Politics
 - Funding
 - Support, Acceptance from leaders.
 - Who owns the Project?
 - Policy
 - Participation
 - Technology - language barrier.
 - ↳ Access, privacy, security
 - The Sharing of Data
 - Amongst Countries?
 - Add GIS data (Weather, Climate).
 - Travel Advice... For the Public
 - ↳ Create something different...
 - Integrated Data.
 - Translating these systems into other emerging diseases.
 - Diseases → can be geographically specific. We need to share the info.

...no one ever said our mission would be easy.

We shared learnings, experiences, and perceptions
about the utility of weekly self-reported
surveillance for symptoms of the flu
with developers of three systems:

Flu Near You in the U.S.
Flutracking in Australia
Influenzanet in Europe

flu near you 
do you have it in you?



● Health Map - Mining the Web collecting data.



● Relying on individuals to report to us.
Giving Back

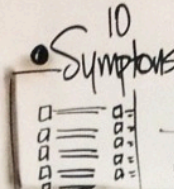


● Outbreaks Near Me
● People are willing to adopt the technology.

● iPhone Submissions vs CDC sentinel surveillance.

A worthwhile effort!

D. Arsenian.

● 10 Symptoms


● email
● gender
● date of birth

Feedback.

● It tells your other friends that you're in the System!

Expansion to Spanish!!

● Measure % of People who are sick and go to the doctor.

● Registration

● Puerto Rico. Dengue Map. We can capture other diseases. Flu, leptospirosis.

● facebook integration



● Minimum Questions get more Participation!

● Feedback

CDC
Expanding the System.

● 7,000 people in the system
● 5,000 → are confirmed



● Real time User Dashboard.



Household Members.

DATA

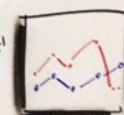
What is **USEFUL** and what is just **INTERESTING**?

● there are limitations...

● What do we do w/ the Data?


● FNY Epidemiology
● Case Definitions

● GFT
● CDC ILI
● FNY



● Graphs.

● Are showing massive numbers of "Pins" meaningful?

Flu near you 
do you have it in you?
Flu activity in your Area.

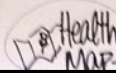
● Maps.



● Links.

● Epidemic Curve.

● Get Vaccinated!



LABCORP

● Viral Confirmation

Denominators.

● Flu Near You APP



● Mobile Phone

● Surveys.

● Flu Map.

● Push Alert.

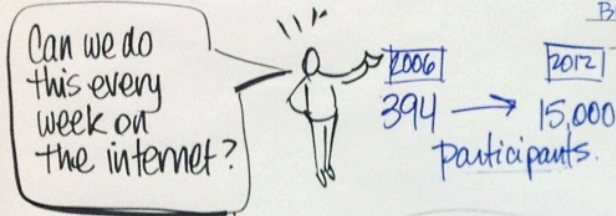
● Monitor your Personal Progress.

● Simple & Straight forward.

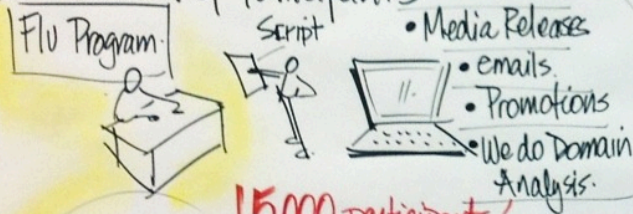
INTEGRATED DATA

• AUSTRALIA.

• FLUTRACKING: Australia Online Surveillance-like Illness.



• Recruitment of Participants:



15,000 participants!

- People sent out emails to friends to participate.

May 1, 2012
- Launch -

• Median Weekly participation 93%-96%

2008-2011

Why?

It takes a few seconds.

Great to achieve something quickly on Monday morning!

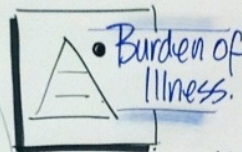
D. Arsenian.

Challenges:

- Younger People w/ higher rates of ILI but lower rates of vaccination.
- Does high socioecon. status of our participants threaten Bias info?
- Is it FLU near you?

We don't do OFF-Season!

Hunter New England NSW HEALTH.



Doctor Visits.



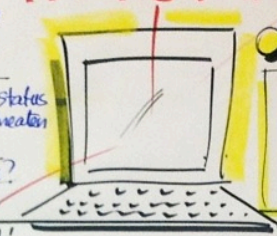
Lab Notifications

Field Vaccine Efficacy.

Some Insights.

- Recognised early that 2009 pandemic was mild in most.
- Detect bias of the "health care system"
- Rapid changes in vaccine uptake detected
- Developed burden of disease pyramid

PARTICIPATION



Weekly Survey

Fever? ☐ Yes ☐ No ☐ Don't know
Cough? ☐ Yes ☐ No ☐ Don't know

SUBMIT

- IF YOU SAY "YES" to both QUESTIONS, then you get more QUESTIONS.

Diagnosis



Doctors Visit

Lab Tests.

Number of Surveys completed...
875,874

Number of Participants that completed at least one survey since 2006: 17,658

Influenzanet

- We started in 2003 Netherlands Belgium

The Great Influenza Survey

- Cold
- Flu



We showed Percentages.

Recruitment: Media

Epiwork

Produces Forecasts

- All graphs collect real time info.



It was set up in a matter of weeks.

Single Intake questionnaire:

- Postal code
- Age
- Smoker
- Transportation
- Vaccine
- Allergy

From west to East and from South to North (3 months)

When will we have the FLU?



→ All European countries using ONE system

- Sore throat?
- Cough?
- Fever?
- Muscle Pain?
- Symptoms.
- at least 38 degrees.
- Ignore symptoms Participants already had on Registration.
- Participate @ least 3 Times.

PARTICIPATION

It's hard to get participants, but once they are in... they stay. We are represented in many countries.

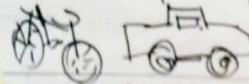
Contact patterns

Mobile apps
Facebook
Twitter.

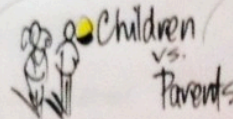
Disease Radar

- Pneumonia survey in the Netherlands.
- Infectious disease(s) radar:

- Is there a difference in the use of transportation?



- Pets/animals?



www.influenzanet.eu

→ look at the graphs!
→ download the data!

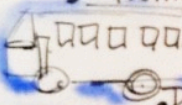
BEHAVIOUR

GP Systems

- Not consistent bet. countries
- How many people visit a Doctor?

Seasonal FW

- Young Children
- Brothers + Sisters
- Mother
- Father



Public Transportation

Should I go to work if I'm sick?

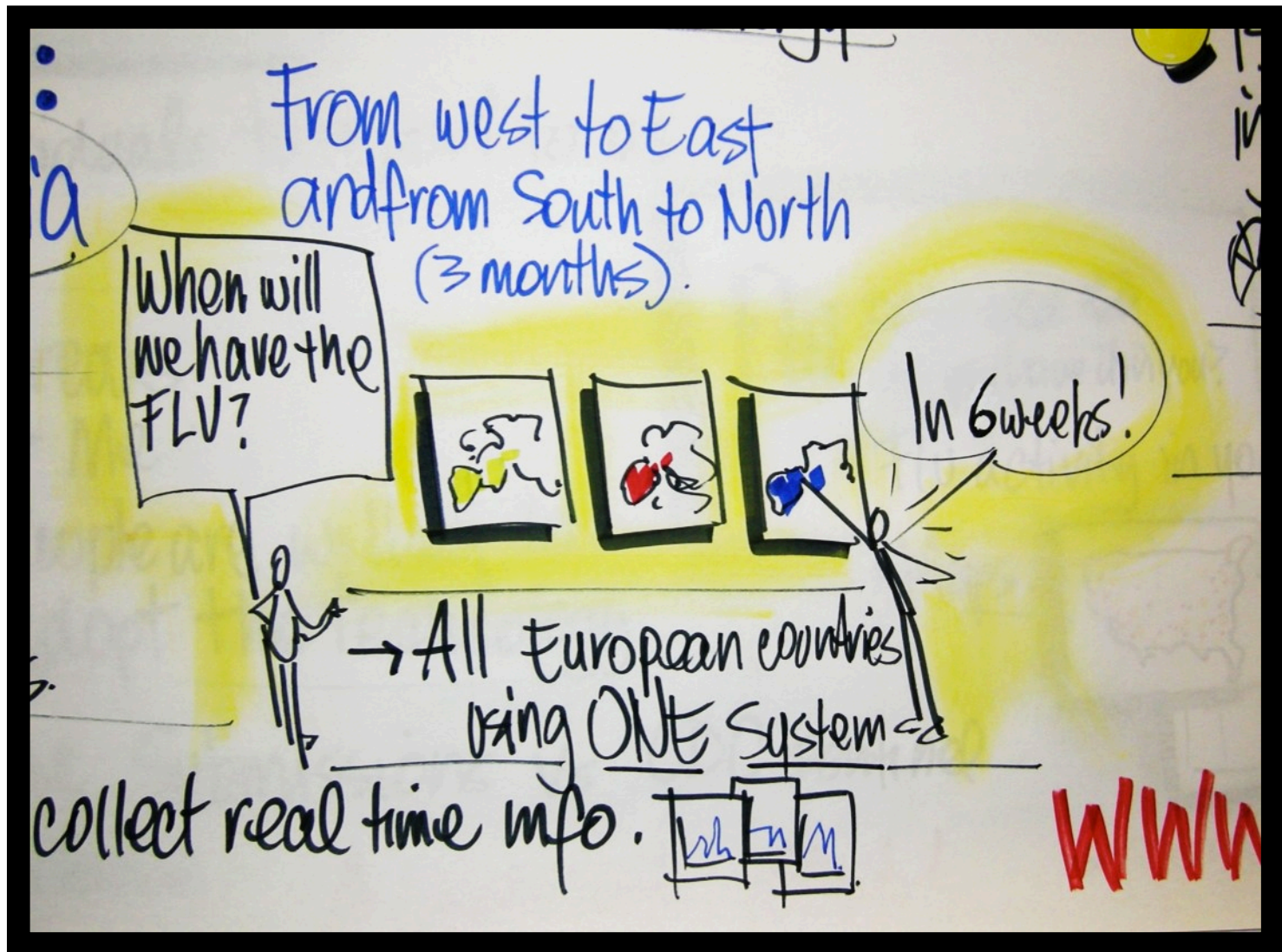
Data on Tropical Influenza remains scarce... no data.

Rainy Season

Do Earth's Seasons create a belt...??

"highways" in a global circulation pattern may have been observed.

Women - More Flu symptoms.



Detail from Influenzanet

I'm witnessing
the Birth of a New
SCIENCE!



eBay



Skoll
Foundation

Skoll
Global threats.

Social
Entrepreneurs
get funded!

We work on
Global THREATS.

Middle
East
conflict

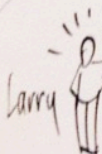
• Water

• Climate change

• Pandemics

• Nuclear
Weapons

We look for things that
can go across all these threats.



We want the TOOLS (all the tools)
that will stop the threat of disease.
We should stop OUTBREAKS.

From becoming
PANDEMICS.

there's something growing here...

A.
Consortium of
Grass roots
enterprises.



Giving back

Clues, Ideas, recommendations, anything
that will reduce incidents.

... it's not just about gathering data & information

* Stakeholder Mapping

↳ Have you done it?

* Outreach?

* Feedback?

D. Aronson

//

a special visitor...

WELCOME! DAY 2.

July 26, 2012.



● I want to
REPORT From
where I was!!

● Relevance of the
System.

● How do people
report when they
TRAVEL

● Where did
You get sick?

● **EMPLOYMENT**
What kind of Health Care do you do?

● Background Survey.

● Weekly Survey

● Contacts Survey

↳ Conversations
↳ One-to-One contact
↳ Who did you speak with?

● **REFLECTIONS**
of Day 1...

● FLW related
to Pigs/Swine.

↳ Participants reporting
on their own animals.

Early
Signals.

Choice: to
unsubscribe.

★ **More
Representation**

★ **Share
Best Practices!**

★ **Recruiting**

● How do you
exclude people
from the system.

● Who participates?
Diff. levels of education.

● Create a
"Manual"

↳ Best
Practices.

● Newsletters.

↳ to people who
respond to the
Survey.

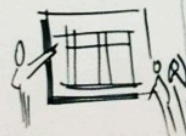
★ **Education**

Reaching
People who
don't have access.

★ **Publish the data!**

● Reporting through
the **COMMUNITY**.

↳ Get representation from the very young.
Technical barriers.



I have no
access to
the Internet.

● To you have
Contact w/children, sick patients??

**We need to make children
aware about this...**
"Mad cow" ~ angry words!

We split into three groups to see if each could come up with the 'perfect' system...

TITLE: REAL-HEALTH

CUSTOMIZABLE + STANDARDS

* An ECO SYSTEM
of Interacting
Tools

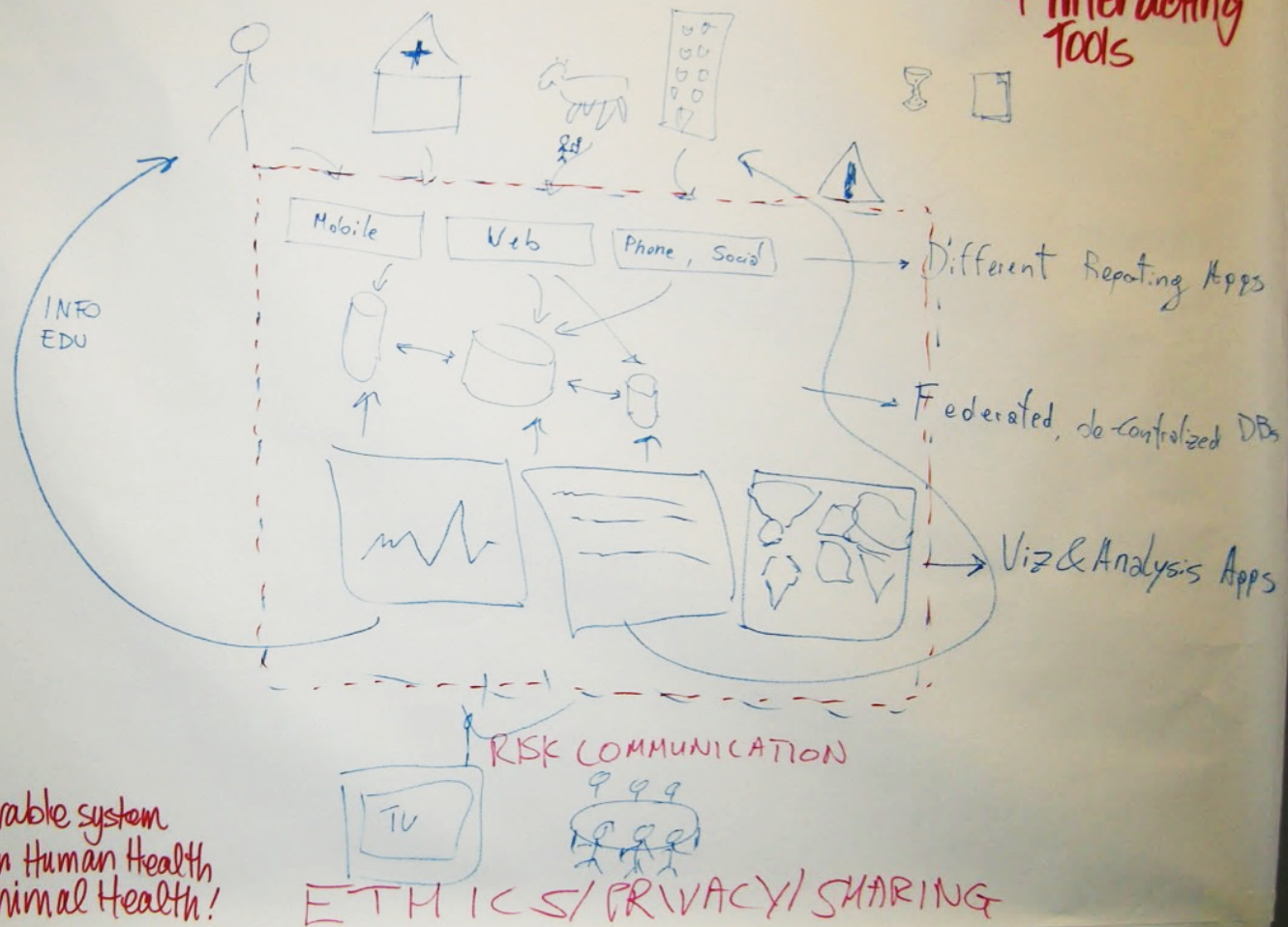
• INPUT

• STORAGE

• ANALYSIS

• OUTPUTS

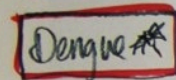
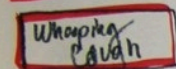
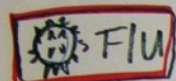
* the
→ interoperable system
between Human Health
and Animal Health!



TITLE:

U-NAME IT!

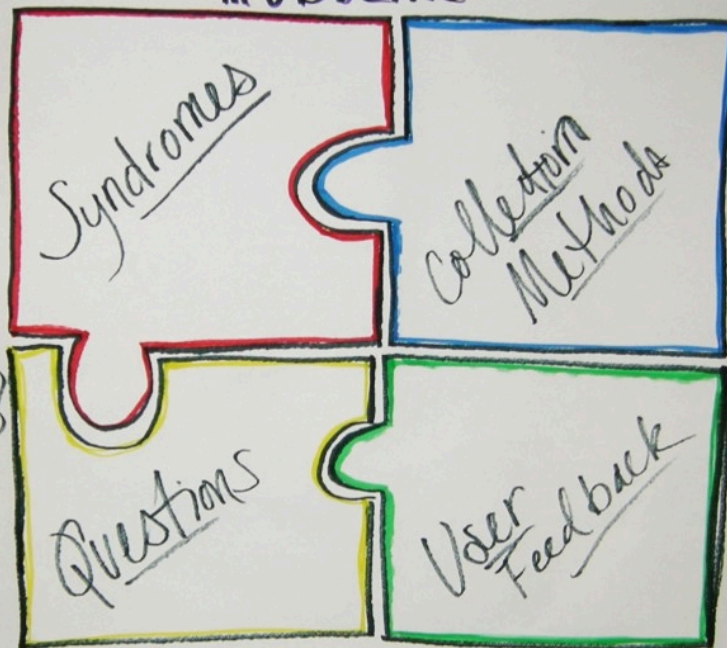
CUSTOMIZABLE. OPEN SOURCE. MODULAR



Q's (Weekly)
Simple
Fever?
Cough?
Vomiting?
Complex

makes it quick & easy!

Where does it hurt?



Demographics

Basic	Optional
• Age	• Travel
• Gender	• Lifestyle (Occupation)
• Location	• Exposures (children animals)
• Vacc status	

Self-report

Group Report

Event Reporting

Input



Health Report

points/rewards

Self-care tips based on symptoms
(NOT DIAGNOSES)

Prevention

Get OFFICIAL Messages Out

*Anonymity

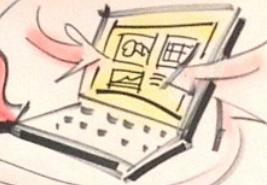
*Periodically → weekly?

*Is it a tool for Authorities to use for Action??

TITLE: GLOBAL HEALTH SURVEILLANCE FOR the People, By the People!



The Perfect System



• Nobody suggested this should only be about FLU...

• Nobody OWNS the Data.

Value in Data.

* Is it self Sustainable?

* Who's Responsible for the Aggregated data?

• One Health & Event Reporting.



• Ensuring one Regulated Body
• Unified dissemination

• Distributed + Customizable

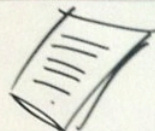
• Standards

• Open Source

1 CUSTOMIZABLE

• Real-time

1 TRANSPARENCY
w/ the End User.



• Multi Purpose

Clearly communicated to the User (the purpose of what it's used for)

1 Maintain TRUST

• Actively linked to Health Authorities.
(local, International... etc.)

• Health Authorities may want to use the System to Report back!

• Connected to a Validation System ??

You have to have an option.

→ An official challenge for Validation.
Customizable.

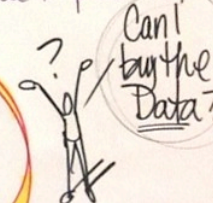
• Open Architecture.

Can we use your User Base?

Question

• Who are the Customers of the System?

SHOULDN'T BE FOR COMMERCIAL PURPOSE.



3:30pm

OSECAPRIEHRVAENIA • REPORT-OUTS

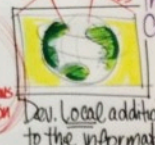
TECHNO GEEKS

- It's Open Source
- Vocabulary
 - the system decides how much people Report.
- People choose how much of their data is shared w/ others.
 - They own it and decide how much it's shared.
- Mobile Tools
- Web based Report
- Design Your Own Service
- The Architecture can provide APIs
 - Everyone can create a new application and plug in the data to the eco-system.
- Storage of Data (Store or share)
- Visualizations, maps
- Tools - a component
- It's up to the Org. that creates the Reporting tool
 - Feedback
 - what they give back.
- Tool for Policy Makers



DISEASE DETECTIVES

- What's the Focus?
 - Pandemic Detection or "normal" Surveillance?
 - could be useful as a Pandemic Tool!
 - Testing + Validation
- Speed
 - look @ demographic data
 - Timely data
 - Get the data early
- Standards
 - Important to have Core standardization
 - Symptoms
 - Syn drome
 - Denominator definition
 - Case definitions
 - Dev. Local additions to the information
- What's the Benefit for the People?
 - Applicable + Universal
 - Core Standards
 - @ what Point can these systems trigger action
- Order of Development
 - Future → Move to more diseases
 - Long term → Chronic disease
 - One Health
 - Report on the health of your Animals
 - social epidemics
 - Obligations for follow-up
 - Find better ways to capture more children (a children's version of the system)
 - Uncertainty/error
 - Adjust for the biases
 - Feedback



POLICY WONKS

- Legal
 - Data Sourcing
 - Int. Data Sharing
- Rules/Structures
- Sustainability
 - Prove it as a useful disease detection.
- Requirements
 - Open Source
 - Transparency
 - Benefits
- Political
 - Interacting w/ groups who might think you are stepping on their toes.
- ETHICS - How do you use the data you collect?
- Commercialization
 - Core Data is available for the Public.
- PRIVACY - People understand what they need to do → TRANSPARENCY
- Regulation
 - Government
 - Academia
 - Private Sector
 - Citizens
 - Research
 - Legal
 - Funding
 - How to make decisions
 - Protocol
 - Code of Conduct
- Governance: who owns this?
 - "Coalition of the willing"
 - We need more EXPERIENCE on the ground. THERE'S MUCH COMPLEXITY.

The 'perfect' system was tweaked by the participants

Welcome Day 3

We need an active strand coming from a Resource Poor Setting

We should start doing this in THAILAND

Governance Issue.

We need to Talk to each other.

We need to hear from the "New Kids on the Block"

3 systems! coming together
 this is the first meeting.
 It can be the beginning of a community.

WHO can act on any source of information

Partnerships Relationships.

Collaborative Consumption

PROOF VALIDATION
 Reflections of Day 2.

Adding Diagnostics To Validate the Results

CROWD SOURCING

*We need to proof that it works.

*It gives much more than just data.

Surveillance



World conferences, meetings, ...

Expertise

Ideas

Discussions

What would be the Right Structure to keep the Conversation going → to action?

It needs to be:

- Nimble
- Transparent
- Small

- Maryland-MRITS
- Mexico
- Canada → BC → Montreal
- Salvador (Bengha)

SOCIAL MEDIA

A source of information

Open Source

Measuring illness

Customizable

Animal data

Climate



People data

Geography

Show people in Public Health what the system can do.

Existing Systems.

What's the Best Mechanism to work w/ a group of people?

Health Care

PUBLIC HEALTH

Give advice on what kind of testing they should have.

Threat: We distribute the information too quickly before it gets integrated.

The Commitment Wall...

**OUR GOAL IS TO
ADVANCE
SELF-REPORTED,
PARTICIPATORY SURVEILLANCE
FOR INFLUENZA
AND OTHER
DISEASES.**



flu near you

Name: MARK SMOLINSKI

Organization:

SSTP



skoll global
threats fund

