

Information Infrastructure for detecting and managing health effects of the oil spill:

Learning from the past, planning for the future

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Learning from the past:

Health events related to Katrina



Hurricane Katrina (Cat-5)
NOAA-18 AVHRR 1 km
August 28, 2005 @ 1950 UTC





VA Computerized Patient Record System experience after Katrina

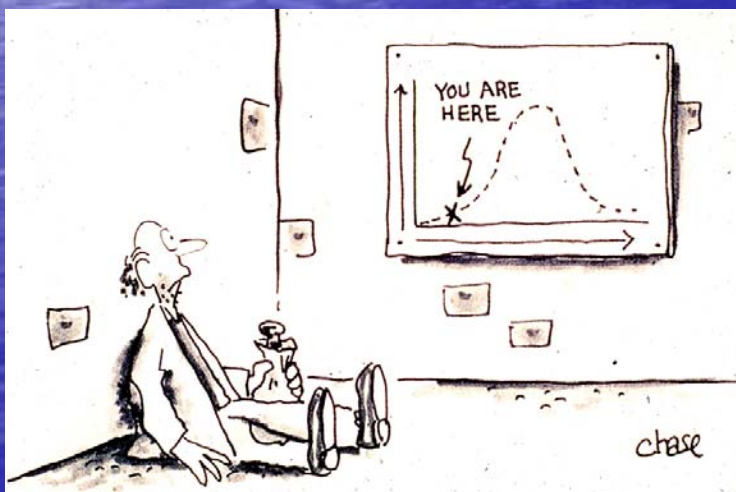
- 60,000 New Orleans veterans records transported via tape to Houston; reconstituted and running within three days
- Web interface created for all VA regions: 10,000 hits within a week
- *Evacuees dispersed to more than 200 healthcare sites in 48 states.*
- *The Electronic Health Record (EHR) was essential for continuity of care.*

Four Lessons Learned

1. Electronic health records are *the sine qua non* of effective care delivery and health effects monitoring for regional and national scale health events

Current state of EHR and decision support infrastructure

- Only 1.5% of US hospitals have full adoption of a comprehensive EHR*
- Only 17% of hospitals have computerized provider order entry (point for decision support alerts and reminders)*



*Jha AK, Blumenthal D, et al.
N Engl J Med. 2009 Apr
16;360(16):1628-38.

Four Lessons Learned

1. Electronic health records are *the sine qua non* of effective care delivery and health effects monitoring
2. Electronic health records are still the exception rather than the norm in the US

Help Katrina Evacuees with Health Care!

Help evacuees get a list of the Rx meds they were taking before the Hurricane hit!

It is easy! It is free! You can make a difference!

KatrinaHealth.org is a new, free, and secure online service. It provides Katrina evacuees, their authorized doctors and pharmacists with a list of the Rx Medications evacuees were taking before they were forced to leave their homes, lost their medications, and their medical records.



Supporters of KatrinaHealth*
American College of Physicians
American Medical Association
American Red Cross
Blue Cross and Blue Shield Association of America
National Association of Chain Drug Stores
National Community Pharmacists Association
U.S. Department of Health and Human Services
U.S. Department of Veterans Affairs

Participating Chain Pharmacies
Albertsons
CVS/Pharmacy
Kmart
Rite Aid
Target
Walgreens

KatrinaHealth.org

- Pooled pharmacy data from retail pharmacy chains, pharmacy benefits management companies
- Used by hundreds of providers and 27,000 retail pharmacies. 5000 provider database queries in first two months after the event
- Major impediments:
 - Availability not known by providers
 - Telecommunications disruptions
 - Identity management

Health Information Exchanges (HIEs)

- Not for profit, regionally based organizations that pool data from many contributing healthcare organizations and make it available to each one: sum greater than the parts; a boon to coordinated care
- Highly successful HIEs currently running in Massachusetts, Indiana, Tennessee

Four Lessons Learned

1. Electronic health records are *the sine qua non* of effective care delivery and health effects monitoring
2. Electronic health records are still the exception rather than the norm in the US
3. Effective analysis of health effects will require merging of data from a variety of sources:
 - Aggregation of clinical care events by thousands of practitioners and healthcare organizations
 - Prescriptions, Over the counter (OTC) med use patterns
 - Weather, ocean currents, environmental sensors
 - "On the ground" observations by persons 'at the scene'
 - Biomarkers of individual variation

Tools for agile data capture and analysis on focused health research topics

- Secure, web-based tools for distributed data management e.g., REDCap – Research Electronic Data Capture system of NIH-supported Clinical and Translational Science network



[Consortium Wiki](#) (Login Required)

Upcoming Events:

- Weekly All-Hands Consortium Meeting - Every Friday, 1-2PM Central
- REDCap Consortium Webinar - Tuesday, June 29, 2010, 2-4PM Central ([Register here](#))
- REDCap Day - Tuesday, August 17, 2010 - All day workshop @ Mayo Clinic ([Register here](#))

[Introduction](#) [Software](#) [Consortium Partners](#) [Become a Partner](#) [Video Resources](#) [Citing REDCap](#) [Library](#)

The REDCap Consortium is comprised of 118 active institutional partners from CTSA, GCRC, RCMI and other institutions, and it supports two secure, web-based applications (REDCap and REDCap Survey) designed exclusively to support data capture for research studies. The REDCap application is currently in production use or development build-status for more than 2350 studies with over 7670 end-users spanning numerous research focus areas across the consortium, and the recently released REDCap Survey application is now being adopted rapidly by consortium partners. To find out if your institution is already running REDCap services, you will find contact information on the [Consortium Partners](#) page.

Both REDCap and REDCap Survey provide: 1) a stream-lined process for rapidly building a database or online survey, respectively; 2) an intuitive interface for collecting data (with data validation); 3) automated export procedures for seamless data downloads to common statistical packages (SPSS, SAS, Stata, R); 4) advanced features, such as branching logic, file uploading, and calculated fields; and 5) a quick and easy software installation process. For more information on each software application, see the [Software](#) page.

The REDCap software application framework will soon be available in multiple spoken languages. Our primary challenge is finding qualified language translators (e.g. English/Spanish, English/French). The REDCap Consortium has experts currently working on several languages, and we anticipate rollout by Q3 2010. We are always looking to add and support new domestic and international partners in the REDCap consortium. Please see the [Become a Partner](#) page for additional information.

Map of REDCap Consortium Partners



Map Satellite Hybrid

POWERED BY Google

Terms of Use

Consortium Partners Multi-Center Partners

Advantages of REDCap and REDCap Survey

Availability - Software is available at no cost for REDCap Consortium Partners.

Secure and web-based - Input data or build an online survey from anywhere in the world over a secure web connection with authentication and data logging.

Fast and flexible - Conception to production-level database or survey in less than one day.

Multi-site access - REDCap databases/surveys can be used by researchers from multiple sites and institutions.

Autonomous utilization - Research groups have complete autonomy and control to add new users.

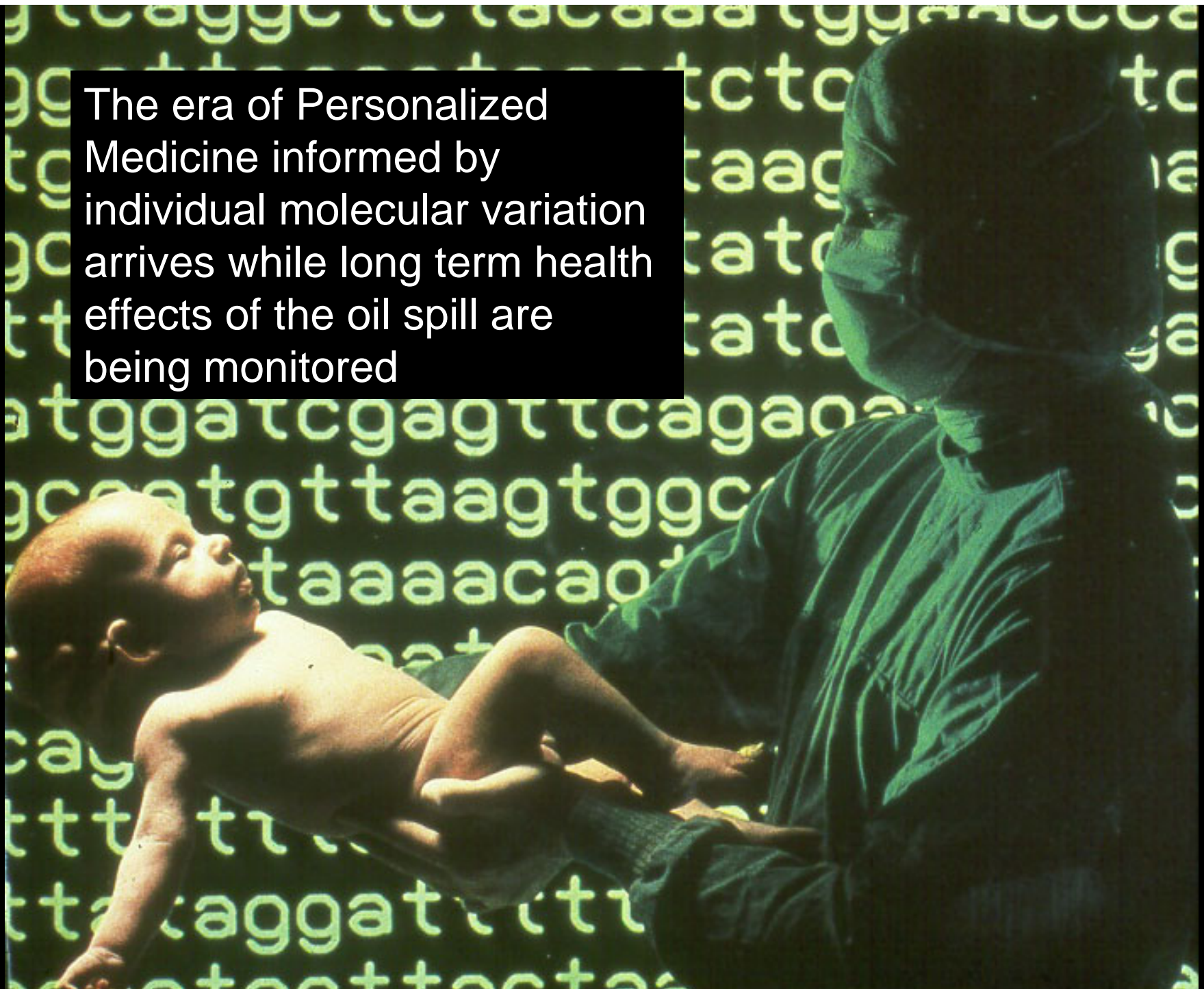
Export data to common data analysis packages - Exports raw data and syntax files for SAS, Stata, R, and SPSS.

Fully customizable - You are in total control of shaping your database or survey.

Advanced features - Mid-study modifications, auto-validation, branching logic, and calculated fields.

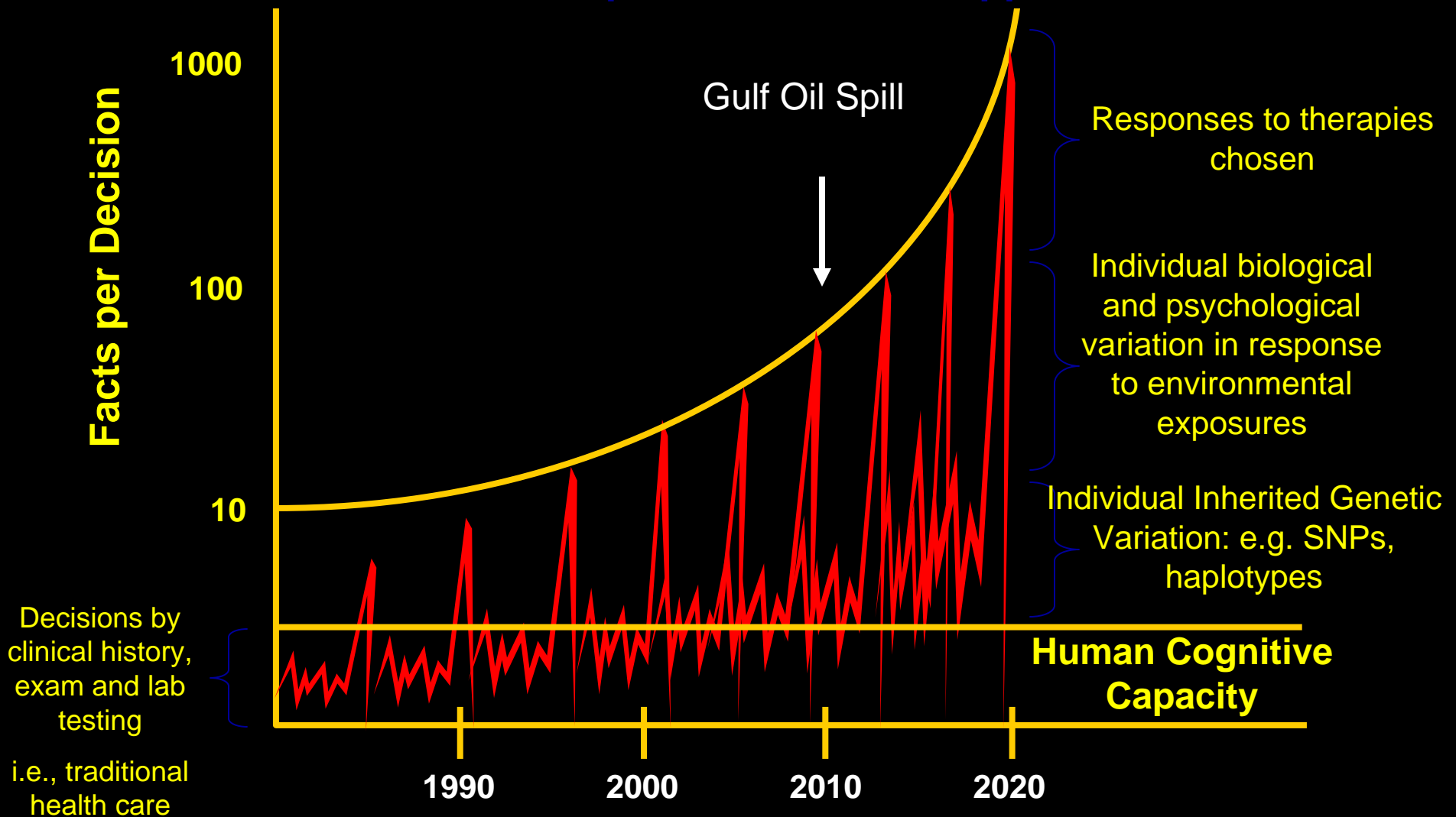
CTSA Clinical & Translational Science Awards
The Clinical and Translational Science Awards (CTSA) is a registered trademark of DHHS.

The era of Personalized Medicine informed by individual molecular variation arrives while long term health effects of the oil spill are being monitored



Helping Individuals and Professionals to do the right thing in the face of escalating complexity:

The Need for Person-Specific Decision Support Assistance



Four Lessons Learned

1. Electronic health records are *the sine qua non* of effective care delivery and health effects monitoring
2. Electronic health records are still the exception rather than the norm in the US
3. Effective analysis of health effects will require merging of data from a variety of sources
4. Individuals and healthcare practitioners will need evidence-based, person-specific decision support

Five Information Infrastructure Recommendations

1. Since the needed EHR infrastructure does not exist, immediately add resources to strengthen existing health monitoring and reporting mechanisms at local, state and federal levels

Five Information Infrastructure Recommendations

2. Accelerate adoption of interoperable electronic health records in healthcare practices in the region
 - Increase federal economic incentives already planned to make it attractive for healthcare organizations to move to EHRs
 - Make the Gulf region a model for successful implementation of advanced clinical systems
 - Create diagnostic codes for those EHRs that are specific to oil spill related exposures so that data can be easily pooled for analysis of trends

Five Information Infrastructure Recommendations

3. Create a Gulf Region Health Information Exchange (HIE) that merges the health data from practice based EHRs for effective monitoring of known and unknown health effects

Five Information Infrastructure Recommendations

4. Create an agile research data infrastructure for specific projects on health-related conditions (e.g., REDCap)

Five Information Infrastructure Recommendations

5. Make available authoritative evidence-based decision support via alerts and reminders delivered through the EHR infrastructure and through publicly accessible sources (print, broadcast media, websites, cell phone text messaging, social networking media such as Twitter, Facebook)