The Intersection of Chronic and Invisible Illnesses and Mental Health: Federal Initiatives Driving Change

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What are chronic or invisible illnesses?

- Invisible illnesses have little to no overt indicators
- A chronic illness is a long-term condition that will not immediately cause someone’s death
- Many chronic illnesses are also invisible illnesses, but not all are.
Chronic and Invisible Illnesses

- Mental illness
  - Depression
  - PTSD
  - Anxiety disorders
- Digestive disorders
- Myofascial disorders
- Migraines
- Acquired infections
  - Lyme disease
  - HIV
  - Parasitic infections

- Cancer
- Autoimmune diseases
  - Lupus
  - Rheumatoid arthritis
  - Type 1 diabetes
  - Multiple sclerosis
- Back/spinal cord injury
- Heart disease/defects
- Thyroid disorders
- Huntington’s disease
Data can help frame chronic/invisible illness

- Almost half of Americans have a chronic illness
  - 60% between ages 18-64
  - 90% of seniors
- Physical illness or pain are major factors in up to 70% of suicides
  - 50% of these suicides are under 35 years old
  - Depression rates are 15-20% higher in the chronically ill

Patient stories can create empathy
Common experiences among the chronically or invisibly ill

- Disbelief from family, friends and medical professionals
- Uncertainty from differing diagnoses
- Feeling like they are not getting needed care
- Guilt about how their illness affects others
- Stress from the financial pressures of medical care
- Fear of worsening illness

Source: Gallup Serious Chronic Illness Survey, 2002.
What is causing these symptoms?

- Muscle and joint pain
- Insomnia
- Depressed mood and mood swings
- Confusion, difficulty thinking
- Difficulty concentrating
- Significant weight loss
- Headaches
- Impaired social and occupational function
These are symptoms of:

- Lyme disease (and many other illnesses)
- Other tick-born illnesses
- Myofascial disorders
- Mental illness
- Autoimmune disease
- ME/CFS (Chronic fatigue syndrome)
- Toxic exposure
Over 1 in 4 Americans have multiple chronic conditions

- >50% of Lyme patients have other infections
- 1/5 – 1/4 of Lyme patients have a diagnosable mental illness.

Source: Medical Expenditure Panel Survey, 2006
CDC Chronic Disease Data Resources

- Chronic Disease and Health Promotion Open Data
- Chronic Disease Statistics and Tracking
- Chronic Disease Cost Calculator
- Chronic Disease Indicators

**Use the Data Portal**

Need to work with CDI data directly?

Go to the Chronic Disease indicators Data Portal to create your own filtered CDI dataset, customize visualizations, download CDI data, and more.

[Chronic Disease Indicators Data Portal >](#)
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Empower patients, researchers, and providers to work toward development of individualized care.

The time is right because of:

- Sequencing of the human genome
- Improved technologies for biomedical analysis
- New tools for using large datasets

Research based on the cohort data will:
- Lay scientific foundation for precision medicine
- Help identify new ways to treat and prevent disease
- Test whether mobile devices, such as phones and tablets, can encourage healthy behaviors
The Opportunity Project
Let's build something amazing together.

- Puts data and digital tools in the hands of families, communities, and local leaders
- Use curated data related to opportunity from across federal and local governments
  - Build digital tools that improve people's lives
- Access the resources and services that a family, individual, or community needs to thrive
• Open Innovation for Mental Health, Invisible Illness, and Suicide Prevention

• Leverage federal data resources and foster federal collaboration and creativity
  ▫ Data analysis and scientific support
  ▫ Develop tools and resources for suicide prevention
  ▫ Plan and execute events to raise awareness for open data and mental health
Health Data Events: Hackathons

• Mental Health Hackathon – Dec 12, 2015
• Yale’s Hack the Brain – February 5-6, 2016
• DC Open Data Hackathon – March 4-5, 2016
• Bayes Hack – April 23-24
• MIT Grand Hack – April 29 – May 1
• 2016 Health Datapalooza – May 8-11
• National Civic Day of Hacking – June 6
• Lyme Innovation Hackathon – June 17-19
Come join us for these events!

• VASPI - Veterans Affairs Suicide Prevention Innovations
  ▫ September 9-10 (World Suicide Prevention Day)
  ▫ Washington D.C. VA Medical Center
  ▫ To register, text “VASPI” to 59937
  ▫ Donate data!
    • Text “VAdata” to 59937 to help build our demo dataset

• White House Open Data Summit
  ▫ September 28
  ▫ Washington D.C. Convention Center
  ▫ Celebrating 8 years of progress in open data
Thank you!
Sources and Resources

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- CDC chronic disease and health promotion open data: https://chronicdata.cdc.gov/
- CDC chronic disease statistics and tracking: https://www.cdc.gov/chronicdisease/stats/
- CDC chronic disease cost calculator: https://www.cdc.gov/chronicdisease/calculator/index.html
- CDC chronic disease indicators: http://www.cdc.gov/cdi/
- Open Data resource: https://www.data.gov/