



# 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.**

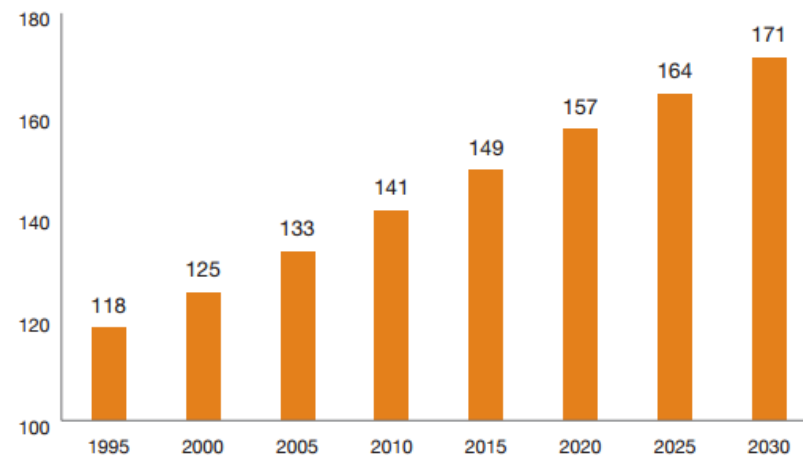
# Chronic and Invisible Illnesses

- **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

Number of People With Chronic Conditions (in millions)



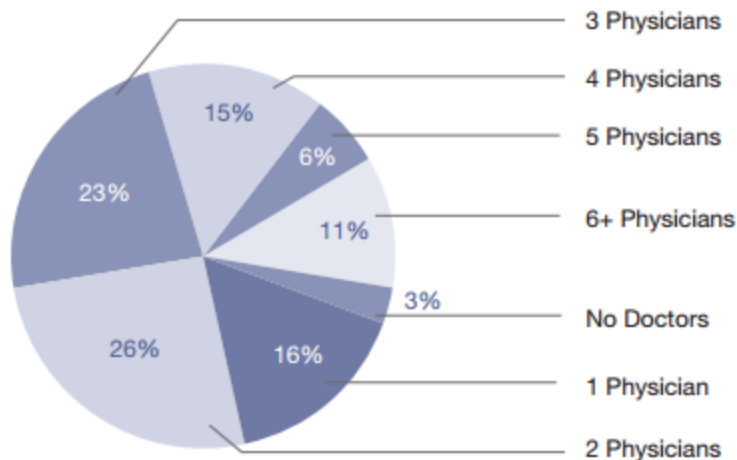
Source: Wu, Shin-Yi and Green, Anthony. *Projection of Chronic Illness Prevalence and Cost Inflation*. RAND Corporation, October 2000.

## Patient stories can create empathy

# Common experiences among the chronically or invisibly ill

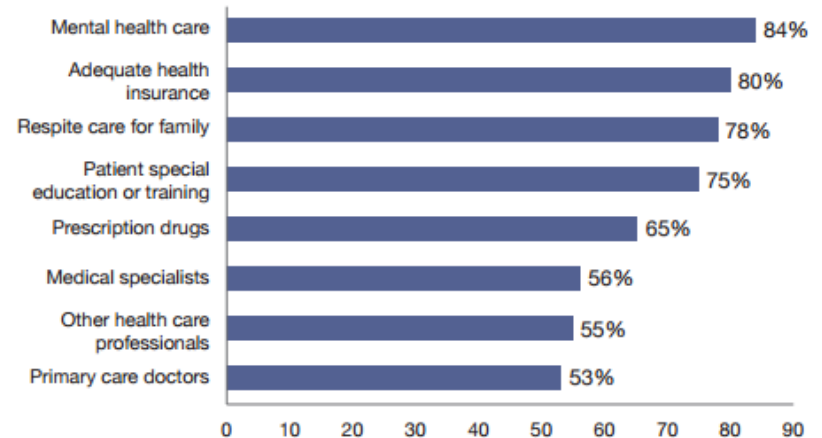
- Disbelief from family, friends and medical professionals
- Uncertainty from differing diagnoses
- Feeling like they are not getting needed care
- Guilt about how their illness affects others
- Stress from the financial pressures of medical care
- Fear of worsening illness

Number of Different Physicians Seen by People With Serious Chronic Conditions



Source: Gallup *Serious Chronic Illness Survey*, 2002.

Percentage of Physicians Who Believe Access Is Difficult or Very Difficult



Source: *National Public Engagement Campaign on Chronic Illness-Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

# What is causing these symptoms?

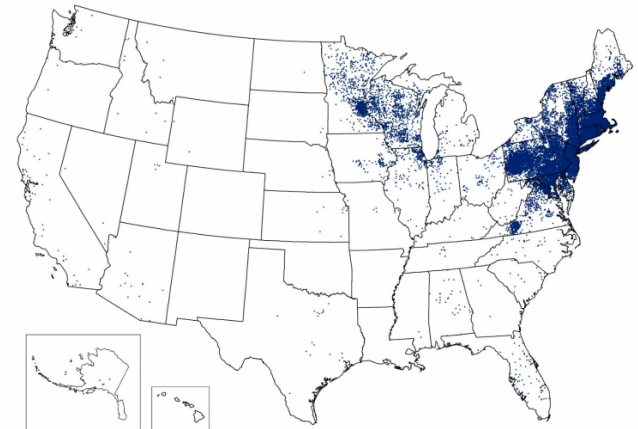
- Muscle and joint pain
- Insomnia
- Depressed mood and mood swings
- Confusion, difficulty thinking
- Difficulty concentrating
- Significant weight loss
- Headaches
- Impaired social and occupational function

# These are symptoms of:

- Lyme disease (and many other illnesses)
- Other tick-borne illnesses
- Myofascial disorders
- Mental illness
- Autoimmune disease
- ME/CFS (Chronic fatigue syndrome)
- Toxic exposure

## Reported Cases of Lyme Disease—United States, 2014

One dot is placed randomly within the county of residence for each confirmed case. Though Lyme disease cases have been reported in nearly every state, cases are reported based on the county of residence, not necessarily the county of infection.



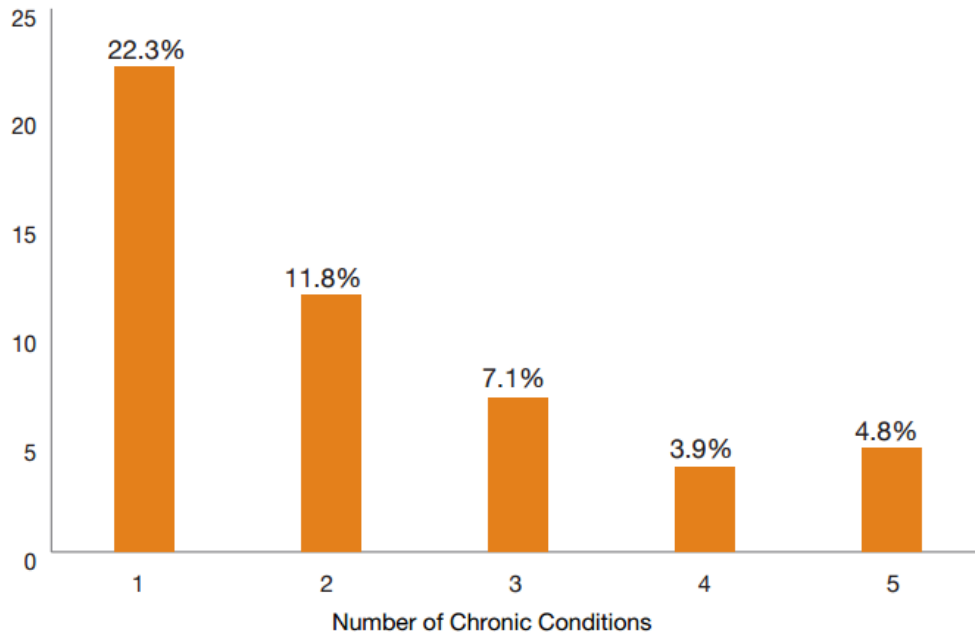
1 dot placed randomly within county of residence for each confirmed case

National Center for Emerging and Zoonotic Infectious Diseases  
Division of Vector-borne Diseases | Bacterial Diseases Branch



# Over 1 in 4 Americans have multiple chronic conditions

Percentage of All Americans



Source: Medical Expenditure Panel Survey, 2006

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



# CDC Chronic Disease Data Resources

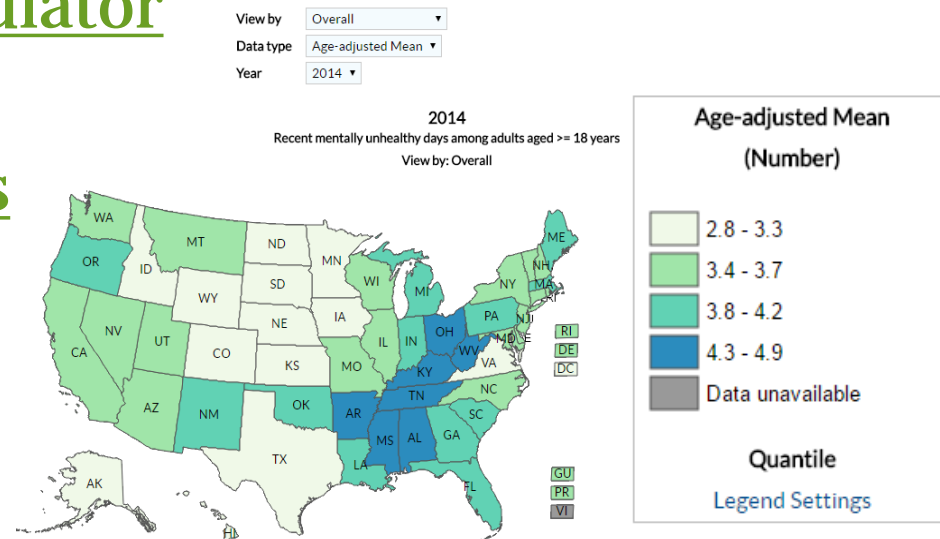
- [Chronic Disease and Health Promotion Open Data](#)
- [Chronic Disease Statistics and Tracking](#)
- [Chronic Disease Cost Calculator](#)
- [Chronic Disease Indicators](#)

## 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 >](#)





Data Resource	URL
Veteran Health Administration enrollees by county, FY2015	<a href="https://raw.githubusercontent.com/vacobrydsk/VAEnrolleesByCountyFY2015.json/master/VAEnrolleesByCountyFY2015.json">https://raw.githubusercontent.com/vacobrydsk/VAEnrolleesByCountyFY2015.json/master/VAEnrolleesByCountyFY2015.json</a>
Mild TBI Diagnosis and Management Strategies: Implications for Assessment & Treatment in Veterans	<a href="https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/TBIDiagnosisHCURReportFY14.json">https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/TBIDiagnosisHCURReportFY14.json</a>
Mild TBI Diagnosis and Management Strategies: VA's TBI Screening and Evaluation Program	<a href="https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/TBIScreeningFY12HSRD Seminar.json">https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/TBIScreeningFY12HSRD Seminar.json</a>
VA National Mental Health Statistics - 2015	<a href="https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/NEPEC_AnnualDataSheet_MH_FY15.json">https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/NEPEC_AnnualDataSheet_MH_FY15.json</a>
VA PTSD Veteran Patient Statistics - 2015	<a href="https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/NEPEC_Overview_PTSD_FY15.json">https://raw.githubusercontent.com/vacobrydsk/VHA-Files/master/NEPEC_Overview_PTSD_FY15.json</a>

Data Resource	URL
GLS Memorial Suicide Prevention: Youth Early Identification Referral and Follow-up, 2006-present	<a href="https://www.suicideprevention-datacenter.com/spdc/login/pud/pud_request.cfm">https://www.suicideprevention-datacenter.com/spdc/login/pud/pud_request.cfm</a>
Section Neurobiology and Treatment of Mood Disorders (SNMD)	<a href="https://catalog.data.gov/dataset/section-on-the-neurobiology-and-treatment-of-mood-disorders-snmd">https://catalog.data.gov/dataset/section-on-the-neurobiology-and-treatment-of-mood-disorders-snmd</a>
National Survey of Drug Use and Health Data Collection	<a href="http://www.samhsa.gov/data/population-data-nsduh/reports?tab=38">http://www.samhsa.gov/data/population-data-nsduh/reports?tab=38</a>
Availability and Usability of Behavioral Health Organization (BHO) Encounter Data, 2009	<a href="https://catalog.data.gov/dataset/availability-and-usability-of-bho-encounter-data-in-max-2009">https://catalog.data.gov/dataset/availability-and-usability-of-bho-encounter-data-in-max-2009</a>
CMS Impact of Chronic Conditions on the Cost of Cancer Care	<a href="https://catalog.data.gov/dataset/impact-of-chronic-conditions-on-the-cost-of-cancer-care-9dde4">https://catalog.data.gov/dataset/impact-of-chronic-conditions-on-the-cost-of-cancer-care-9dde4</a>
CMS Community Mental Health Clinic Cost Reports	<a href="https://catalog.data.gov/dataset/community-mental-health-clinic-cost-reports-a4813">https://catalog.data.gov/dataset/community-mental-health-clinic-cost-reports-a4813</a>
CDC U.S. Chronic Disease Indicators (CDI)	<a href="https://catalog.data.gov/dataset/u-s-chronic-disease-indicators-cdi-e50c9">https://catalog.data.gov/dataset/u-s-chronic-disease-indicators-cdi-e50c9</a>

• [Data.gov](https://data.gov)

# THE PRECISION MEDICINE INITIATIVE



Empower patients, researchers, and providers to work toward development of individualized care.



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 **time is right** because of:

Sequencing of the human genome

Improved technologies for biomedical analysis

New tools for using large datasets



# 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**
  - **<https://www.data.gov/event/data-transparency-2016-open-data-summit/>**

Thank you!

Texas **Suicide  
Prevention**



Office of Science and Technology Policy



U.S. Department  
of Veterans Affairs

**DATA**  
**TRANSPARENCY**  
**+OPEN DATA SUMMIT 2016**



# Sources and Resources

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# Sources and Resources

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- 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/>
- Precision Medicine factsheets: <https://www.whitehouse.gov/the-press-office/2016/03/07/fact-sheet-white-house-launches-opportunity-project-utilizing-open-data> & <https://www.whitehouse.gov/the-press-office/2016/02/25/fact-sheet-obama-administration-announces-key-actions-accelerate>
- Open Data resource: <https://www.data.gov/>
- Opportunity Project factsheet: <https://www.whitehouse.gov/the-press-office/2016/03/07/fact-sheet-white-house-launches-opportunity-project-utilizing-open-data>
- Gallup Chronic Disease Topic: [http://www.gallup.com/topic/chronic\\_disease.aspx](http://www.gallup.com/topic/chronic_disease.aspx)
- Texas Suicide Prevention Toolkit: [http://www.texasuicideprevention.org/wp-content/uploads/2015/09/2015\\_Toolkit\\_Online.pdf](http://www.texasuicideprevention.org/wp-content/uploads/2015/09/2015_Toolkit_Online.pdf)