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HERN - Health Experience Research Network

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HERN

Lisa Acuff & Allison Cruise



What is HERN?

- HERN, or the “Health Experience Research Network” is a network using a specific **rigorous methodology** designed to support bringing **patient experiences** into changing healthcare
- Formed in the UK in 2001 as “DIPex International”
- US partnership started in 2014



How does the methodology work?

HERN's output is organized in **modules**:

- Modules are specific health topics, like “depression in young adults”
- Patients are recruited, in-person interviews are recorded (video, audio or written per request)
- Clips or transcript portions are **publicly** disseminated in organized format



Healthexperiencesusa.org (USA)

DEPRESSION IN YOUNG ADULTS

Overview

First Experiences with Depression

Depression & Other Conditions

Living with Depression

Getting Help

Helping Yourself

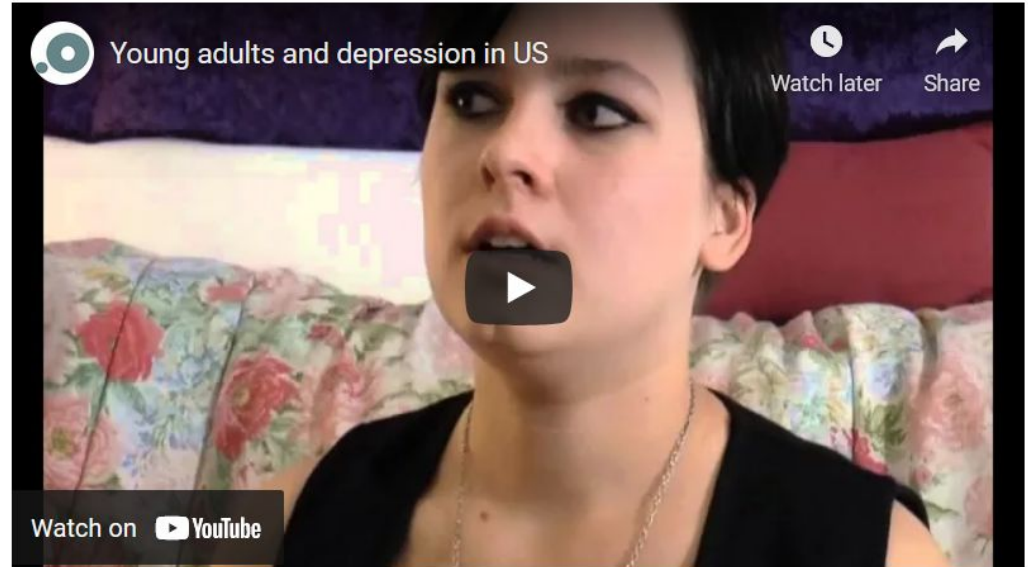
Messages to Others

People's Profiles

Resources and Information

Credits

OVERVIEW



Healthtalk.org (UK)

Long Covid In Adults

> Overview

> Long Covid experiences

What is Long Covid?

Symptoms of long Covid

Living with and managing long Covid symptoms

Impacts on other areas of life

Seeking help from health professionals

Sources of support and information

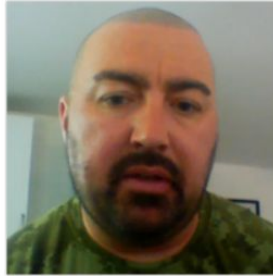
> People's Profiles

ALL

> Resources and Information

> Credits

Jamie



Brief Outline:

Jamie had cold or flu-like symptoms, but no cough, early in the pandemic (2020). He developed breathlessness and general malaise. His main challenges were getting a clear diagnosis for his illness and getting some people to take his symptoms seriously.

> More about me...

Jamie is an engineer in his mid-thirties. He lives with his wife and baby. Before Covid he was relatively fit and healthy.

He went to his local Covid hub in April 2020 feeling breathless. After testing his blood oxygen levels, he was advised that he probably had Covid and to rest. His wife developed similar symptoms but quickly recovered. Jamie's breathlessness lasted for a couple of months. He developed a 'horrible' general malaise, and had recurring throat ulcers, sore glands and some dizziness which he found scary and made him anxious. Later in 2020 he developed severe headaches. His whole body ached. It felt like a cross between flu and sunstroke.

How can libraries get involved?

- **“Community of practice”** - Knowledge and use of HERN resources
- **Involvement in module creation** - libraries as recruitment tools
- **Secondary use of data** - using, organizing and/or disseminating data already collected



How can libraries get involved?

- The HERN network is a collaborative, welcoming, multinational research partnership
- UNM is a strong and active HERN node!
- The HERN node meets regularly to share ideas, find partners and ask questions



Summary

- HERN is a **qualitative research methodology** that is dedicated to **openly sharing patient experiences**
- HERN methodology in the US is team-based
- Libraries have opportunities for involvement
- **Healthtalk.org & healthexperiencesusa.org** are where you can find modules to explore!



Thoughts to Consider

- Share the modules with others
- Consider use of the HERN methodology for your own research
- Join HERN to learn more!



