

# Linking and Amplifying User-Centered Networks through Connected Health (LAUNCH)

*Solving the Last Mile Problem in Cancer Care*



Bradford W. Hesse, PhD  
David K. Ahern, PhD

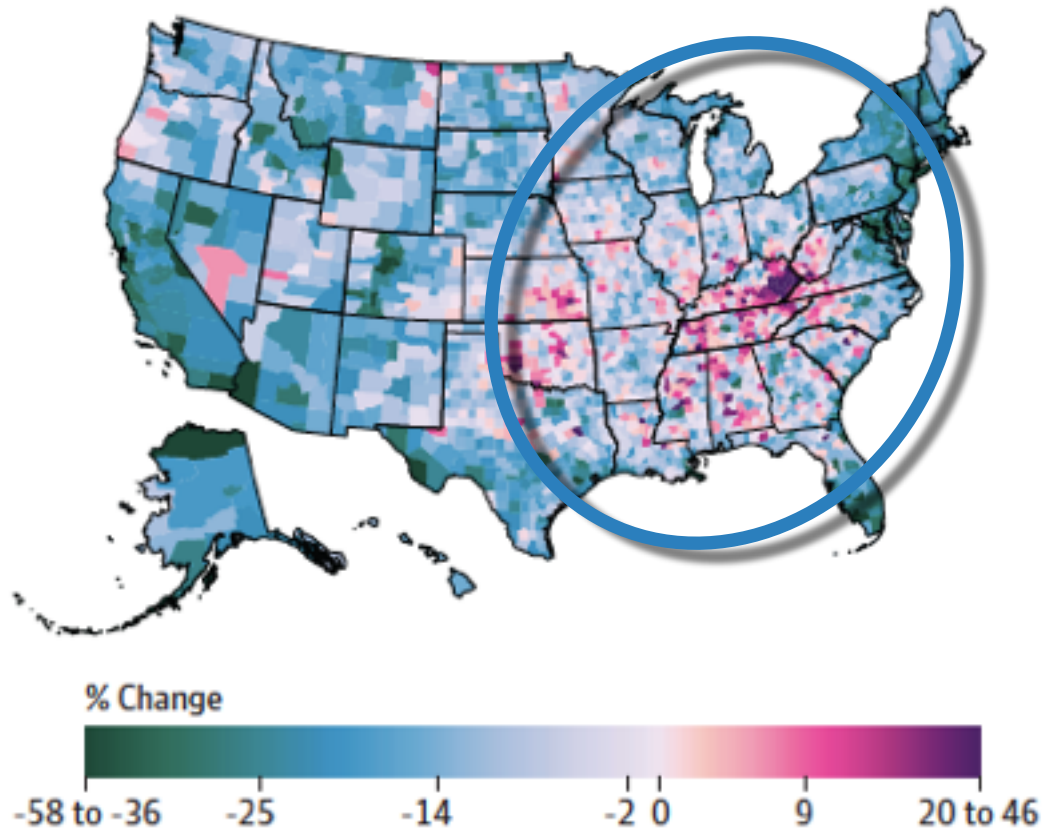


# Background

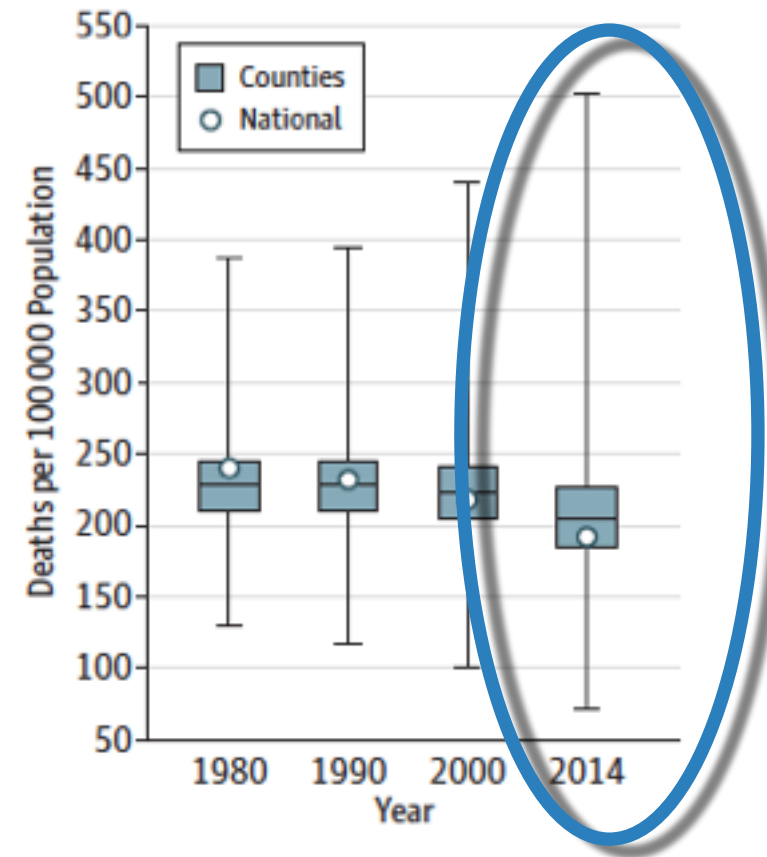
Bradford W. Hesse, National Cancer Institute

# Reversals in Progress: Percent Change & Age-Adjusted Mortality – All Neoplasms 1980 - 2014

**B** Percent change in age-standardized mortality rate from neoplasms between 1980 and 2014, both sexes



**C** Age-standardized mortality rate from neoplasms over time



Source: Mokdad AH, et al. Trends and Patterns of Disparities in Cancer Mortality Among US Counties, 1980-2014. *JAMA*. 2017;317(4):388-406. doi:10.1001/jama.2016.20324



# The Tyranny of Distance: Industrial model of bringing *patients to care* is insufficient.



In almost all the studies analyzed, patients who lived far from hospitals and had to travel more than 50 miles had a more advanced stage at diagnosis, lower adherence to encoded treatments, a worse prognosis, and a worse QoL.



**Source:** Ambroggi, M., Biasini, C., Del Giovane, C., Fornari, F., & Cavanna, L. (2015). Distance as a Barrier to Cancer Diagnosis and Treatment: Review of the Literature. *Oncologist*, 20(12), 1378-1385. doi:10.1634/theoncologist.2015-0110.

# The Last Mile Problem: Bringing evidence-based medicine *equitably* to all populations.

22%  
Reduction in  
Cancer  
Deaths

## Los Angeles Times

July 10, 2018

**More Than 20% Of Cancer Deaths Could Be Prevented If Each American Received High-Quality Care, Study Suggests.**

The [Los Angeles Times](#) (7/10, Kaplan) reports a [study](#) published in CA: A Cancer Journal for Clinicians suggests "it is possible to eliminate more than one in five cancer deaths in the U.S. even if researchers never invent another test or treatment" if every American could "take full advantage of the best medical care the country has to offer. If they were to do so, the country's cancer mortality rate would fall by 22%, according to researchers from the American Cancer Society." The piece says, "It may sound like a pipe dream, but there's evidence that it's already happening thanks to the Patient Protection and Affordable Care Act," adding that a study in the Journal of the National Cancer Institute found that the ACA contributed to "a shift in cancer diagnoses, with more cancers being found while still at an early stage."

Source: Siegel, R. L., Jemal, A., Wender, R. C., Gansler, T., Ma, J., & Brawley, O.W. (2018). An assessment of progress in cancer control. *CA Cancer J Clin*, 68(5), 329-339. doi:10.3322/caac.21460

# Connected Health: Move *evidence to individuals* equitably and at scale.



**Don Berwick**  
Institute for Healthcare  
Improvement

“There is now a worldwide collection of efforts, which is showing how much we can leverage knowledge through [health information technology] so that literally the **best knowledge** in the world can **reach everyone** in the world, at low cost and at no delay.”

-July 9, 2015 to President's Cancer  
Panel



# President's Cancer Panel: Improving Cancer-Related Outcomes with Connected Health





# Recommendations



**Enable  
Interoperability**



**Enable Individuals  
to Manage and  
Participate in  
Their Care**



**Support the  
Oncology  
Workforce**



**Ensure Adequate  
Internet Access**



**Facilitate Data  
Sharing and  
Integration**



**Conduct High-  
Priority Research  
to Advance  
Connected Health**





# Recommendations



Support the  
Oncology  
Workforce

Action Item 3.1: Incentives for workforce support.

**Action Item 3.2: Employ human centered design.**

Action Item 3.3: Interfaces for oncology workforce.



Enable Individuals  
to Manage and  
Participate in  
Their Care

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◀ Research

## Health Design



# Recommendations

**Action Item 4.1: Bolster public access.**

**Action Item 4.2: Ensure provider access.**



“Connect2HealthFCC is exploring the intersection of broadband, advanced technology and health and further charting the broadband future of health care – serving as an umbrella for all FCC health-oriented activities to help enable a healthier America.”

# The LAUNCH Project

David K Ahern, Special Advisor to the FCC

# Crossing the Digital Divide: FCC joins NCI & Amgen in creating an accelerative demonstration project in the spirit of moonshot.



## FCC and NCI team up to expand broadband access to cancer care in rural Kentucky

December 26, 2017

by John Fischer, Staff Reporter

The Federal Communications Commission (FCC) and the National Cancer Institute (NCI) are teaming up to enhance cancer care in rural communities by providing greater access to broadband technology.



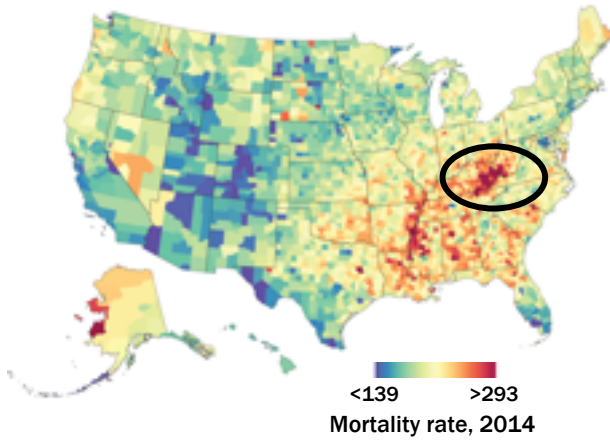
*NCI and the FCC are teaming up to increase access to broadband connectivity for cancer care in rural areas*

## Amgen Enters Groundbreaking Collaboration To Improve Symptom Management During Cancer Treatment

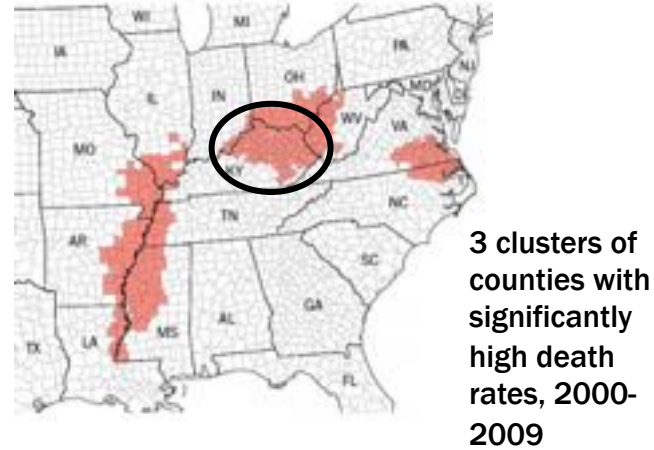
**Public-Private Partnership Aims to Connect Underserved Cancer Patients to Enhanced Symptom Management Support Through the Use of Connected Technologies**

THOUSAND OAKS, Calif., May 23, 2018 /PRNewswire/ -- Amgen (NASDAQ:AMGN) today announced a groundbreaking collaboration with the National Cancer Institute (NCI), the Federal Communications Commission (FCC) Connect2Health Task Force, the University of Kentucky (UK) Markey Cancer Center and the University of California, San Diego (UCSD) Design Lab to support the improvement of cancer outcomes. The L.A.U.N.C.H. (Linking & Amplifying User-Centered Networks through Connected Health) program will use human-centered design methodologies to identify the needs of patients, caregivers and healthcare providers. The program will use these insights to develop and deliver a connected solution for patients to be able to better manage their cancer symptoms. While the project will initially be focused on underserved populations in rural, Appalachian Kentucky, the goal is for it to serve as a model for future symptom management projects across the nation.

All Cancer Mortality



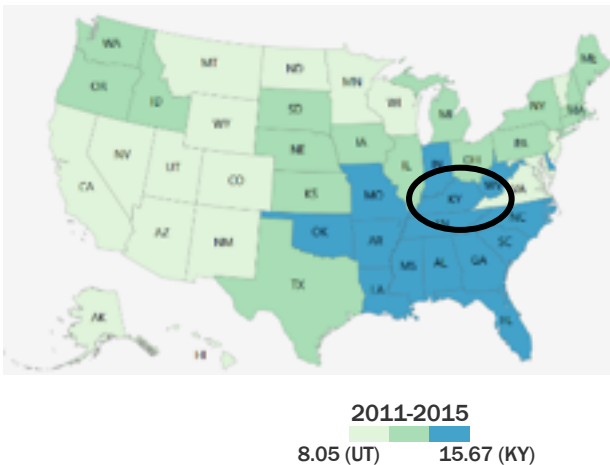
Colorectal Cancer Mortality



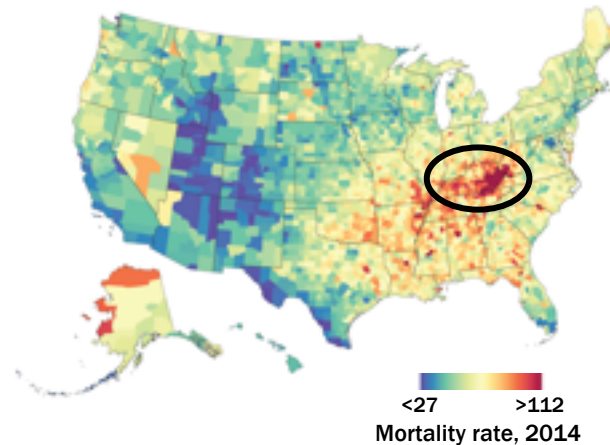
# Why Eastern Kentucky?

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HPV-Related Cancer Incidence



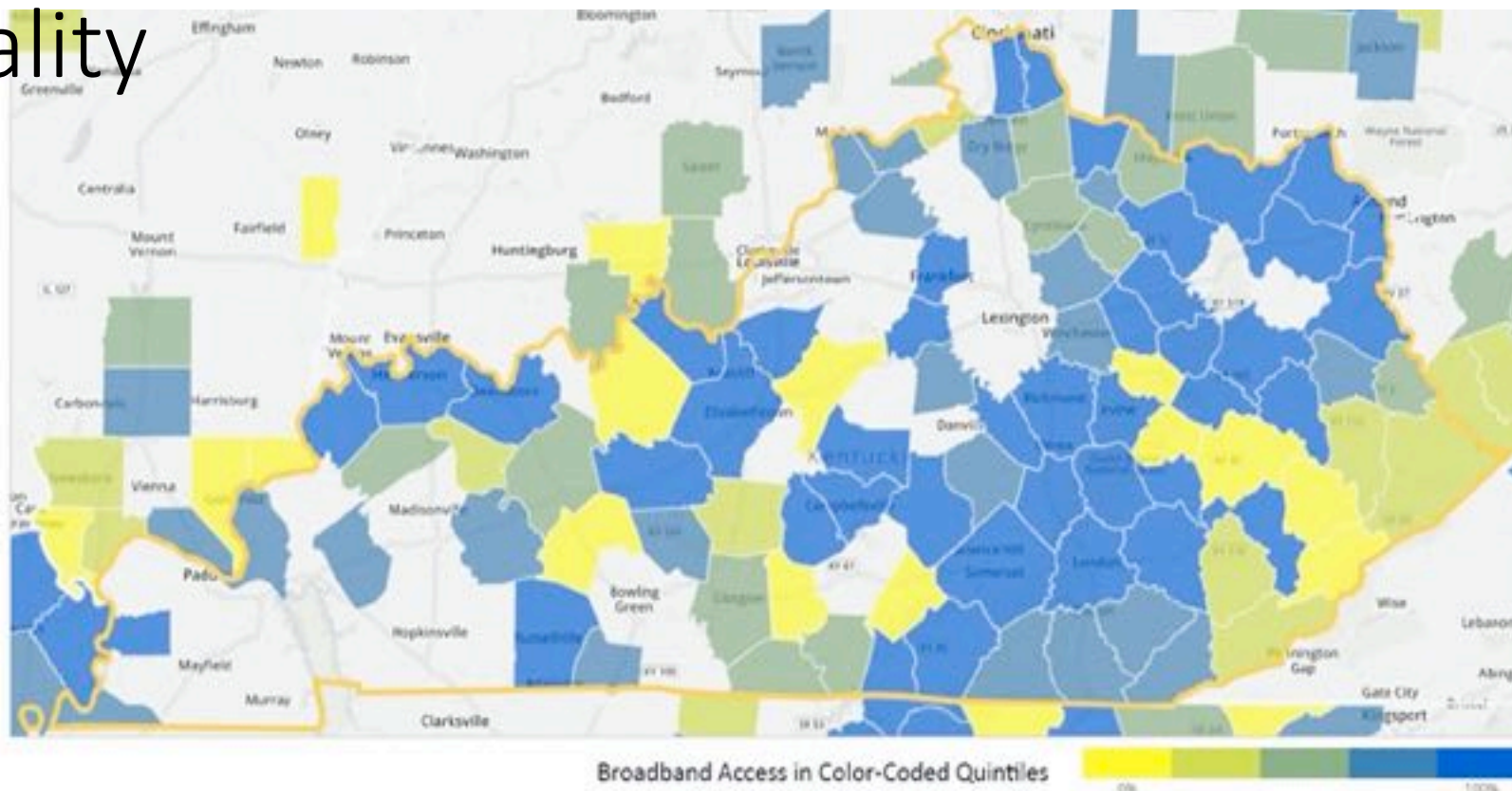
Lung Cancer Mortality



Source: JAMA (2017); Cancer Epidemiol Biomarkers Prev (2015), CDC



# Dual Burden: Low Internet Access, High Mortality



**Broadband Access and Lung Cancer in Kentucky.** This county-level map of Kentucky visualizes fixed broadband access in those counties where the lung cancer incidence is *greater* than the Kentucky average (i.e., more than 89.6 cases per 100,000 persons). It then identifies connectivity gaps—the lighter the color, the lower the percentage of households with broadband access, as shown in the legend which divides access into five color-coded quintiles. The large cluster of counties in the Eastern Kentucky region is the broad target area for the L.A.U.N.C.H. initiative – where we see some of the highest lung cancer incidence and low broadband access (i.e., in the 0-20% or 20-40% ranges).

# Community Innovation & Co-Creation is at Heart of Demonstration Project



Don Norman, PhD



Eliah Aronoff-Spencer, MD PhD



Lisa Nugent, Executive Director for Customer Experience, Amgen

COMMUNITY-BASED, HUMAN-CENTERED DESIGN (2.0)

DON NORMAN<sup>1</sup>

Executive Summary

I propose a radical change in design from experts designing for people to people designing for themselves. In the traditional top-down approach, experts study, design, and implement solutions for the people of the world. Instead, I propose that we leverage the creativity within the communities of the world to solve their own problems: This is bottom-up design, taking full advantage of the fact that it is the people in communities who best understand their problems and the impediments and affordances that impede and support change. Experts become facilitators, by mentoring and, providing tools, toolkits, workshops, and support.

The principles of human-centered design have proven to be effective and productive. However, its approach is generally used in situations where professionals determine the needs of the target populations and then develop products and procedures to address the needs. This is Top-Down design. This works well for mass produced items.

These methods are effective, but they fail to consider the local needs, cultures, and history of individual people and communities. We believe that the people best equipped to address these issues are the people who live there.

In this brief note, I quickly review the four principles of human-centered design, the difficulties faced by the traditional top-down approach, and the proposed bottom-up, community-based approach. There are already multiple examples of the power of bottom up design. We propose to build on this work, bringing together the many different communities so they can all share and learn from one another, yielding a powerful set of tools that can be freely adopted and used by people around the world.

THE FOUR PRINCIPLES OF HUMAN-CENTERED DESIGN

1. Understand and Address the Core Problems. Solve the fundamental, underlying issues, not the symptoms.

2. People-Centered. People-centered as opposed to technology-centered, ensuring that the outcome is appropriate for the history, culture, and environment

3. Use a Systems Approach. All major, important issues are actually part of a complex sociotechnical system.

4. Rapid Iterations of Prototyping and Testing. Start with non-working simulations, moving to partial solutions and finally to full, continually refining

- 1 Learn

Formative research exploring rural health disparities, information technology gaps, barriers and innovations in cancer symptom management
- 2 Listen

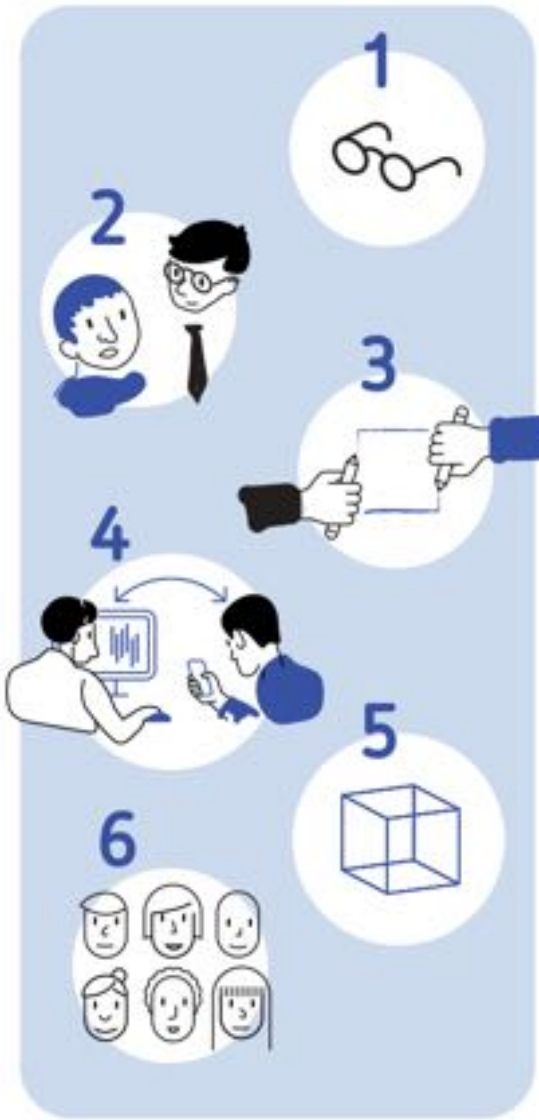
Engage patients, support networks and providers to understand needs, attitudes and context in underserved communities
- 3 Co-Create

Work with patients, caregivers, healthcare providers, and communities to co-design interventions to support better symptom management
- 4 Pilot

Conduct agile pilots integrating technology and human interventions to develop flexible toolkits for symptom management
- 5 Improve

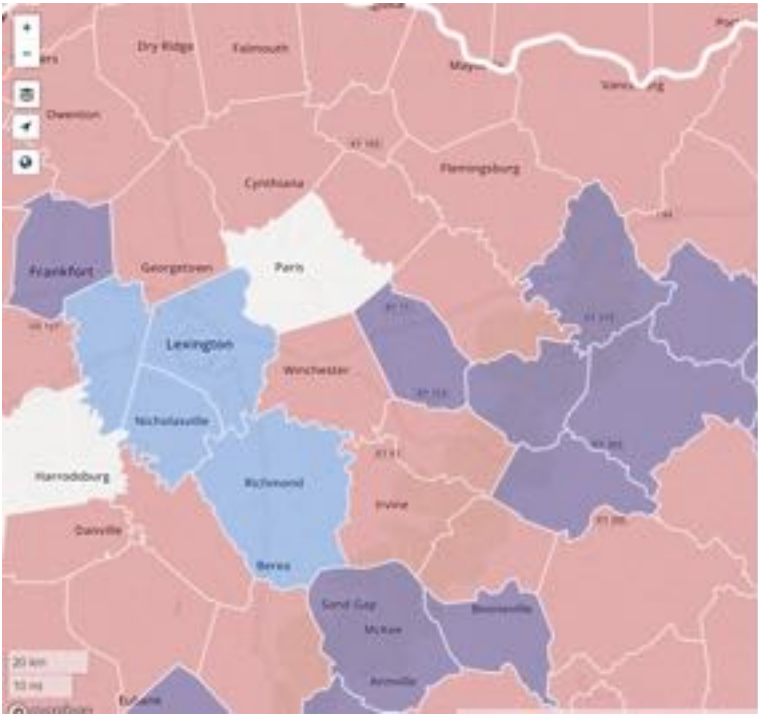
Evolve using feedback from pilots, field research, and co-creation sessions; iterate, test and improve interventions
- 6 Scale

Deliver toolkits and ultimately a scalable platform for community led development of health interventions nationally (LAUNCH-PAD)





*Data Analysis: E.g., Double Burden Counties  
[Low Broadband, Poor Health Outcomes]*



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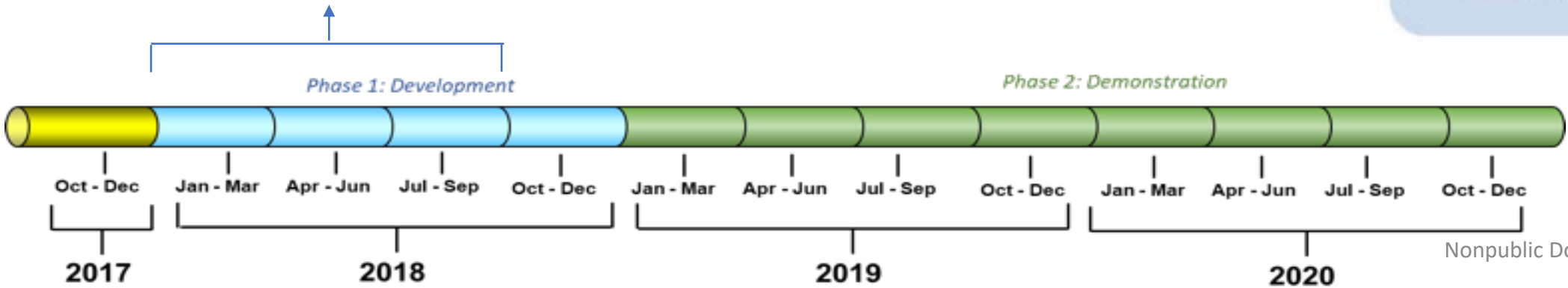
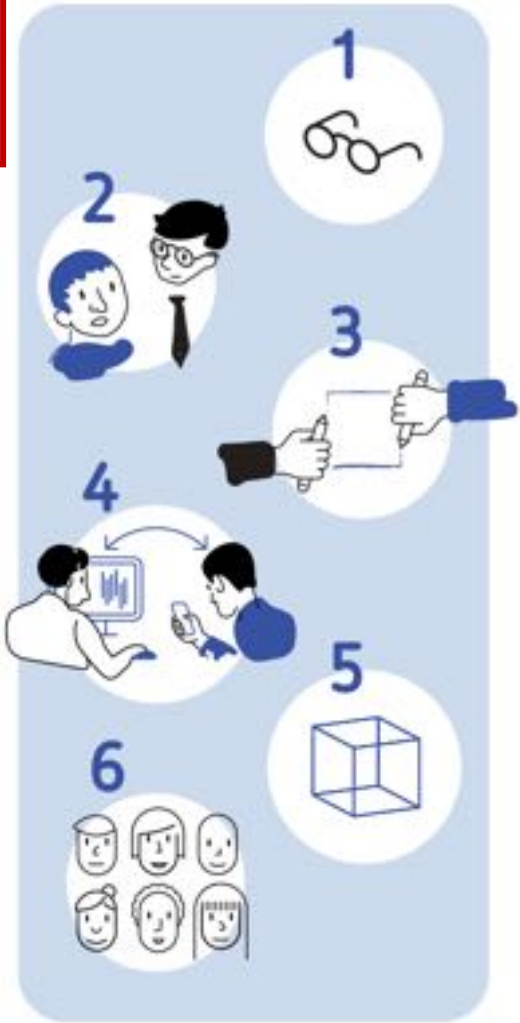
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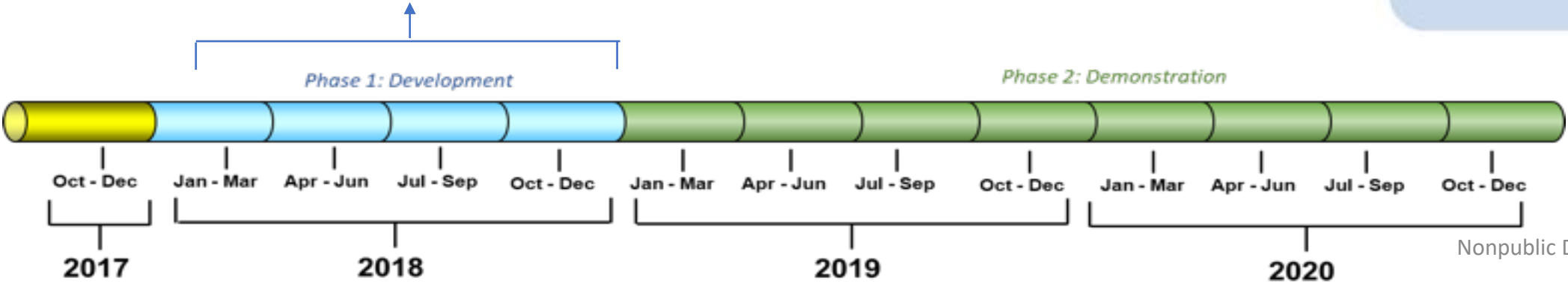
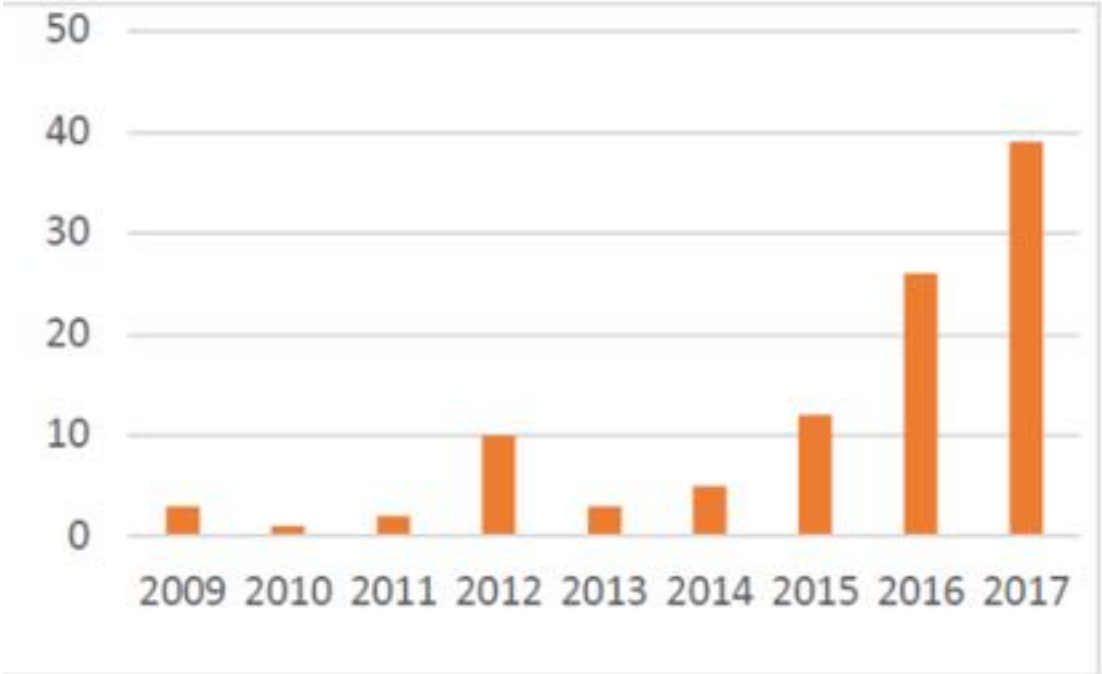
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Lit Review: Symptom Management, Distress Screening, Patient Engagement

Articles addressing symptom management



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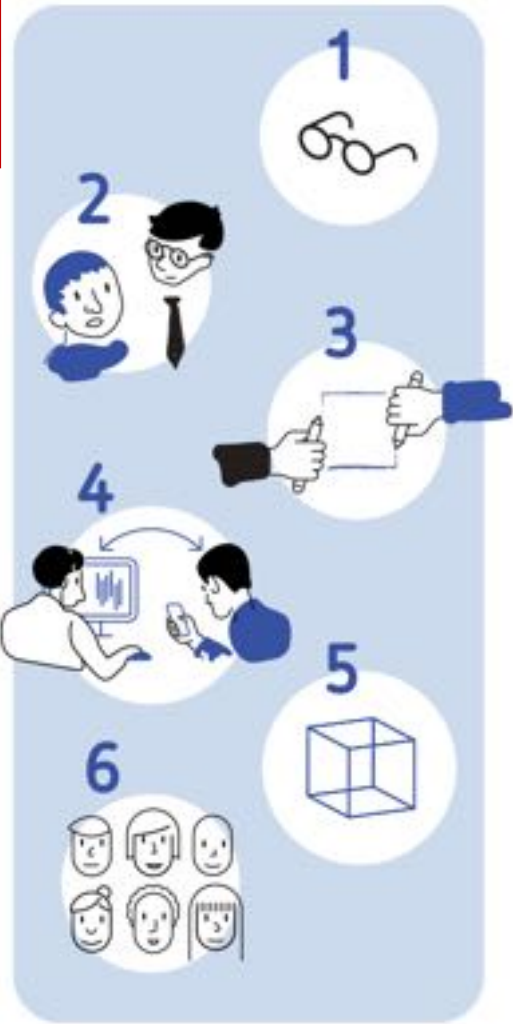
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Formative Observations: Contextual  
Inquiries, field observations, interviews



Cognitive Anthropologist:  
Melanie McComsey

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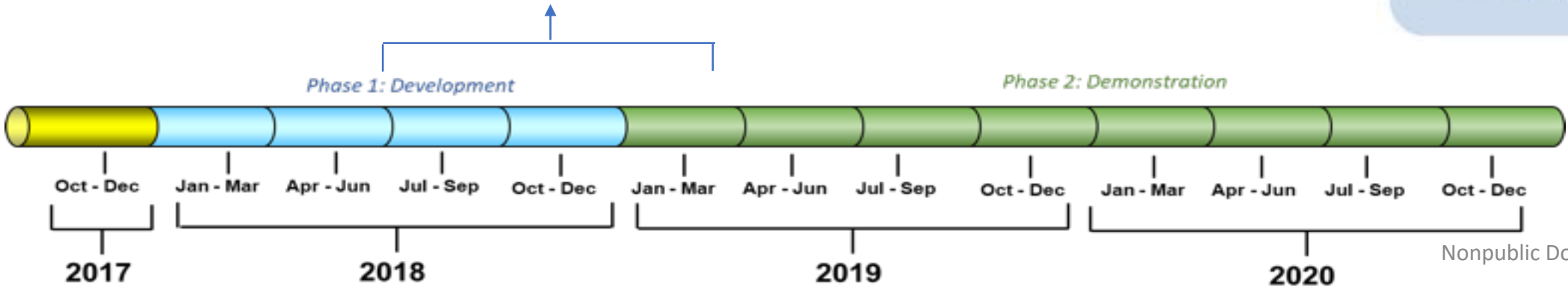
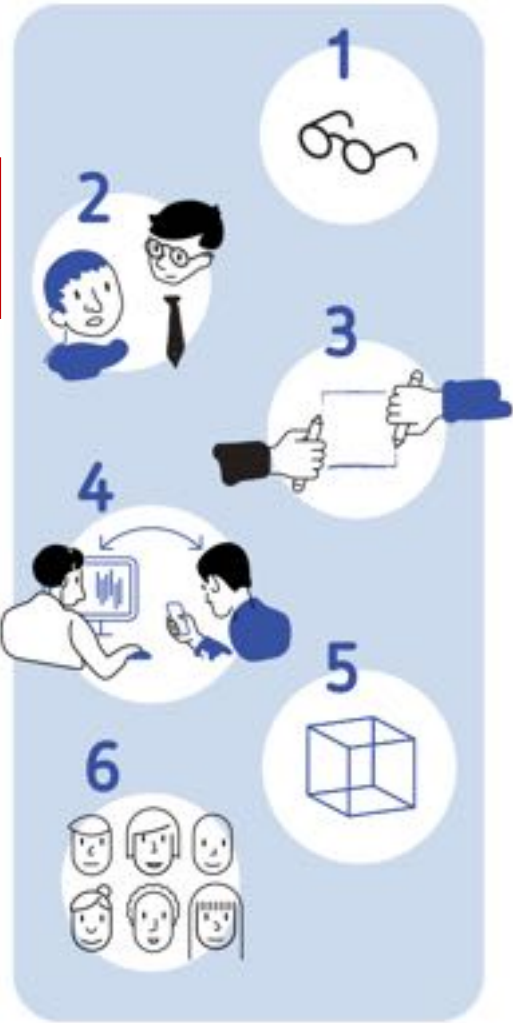
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# Ethnographic Insights

## • Community Insights

- Resistance to projects by “outsiders”
  - Recognition that development is needed
  - Tension between tradition and progress
- Strong community orientation, self-sufficiency
- Solutions should empower communities to solve local problems

## • Health Care Insights

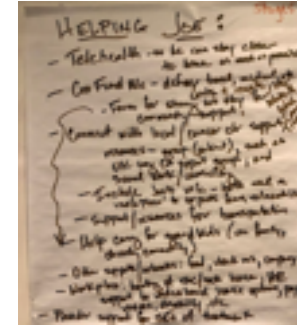
- Community-level resources complement traditional facilities; e.g.,
  - Kentucky Homeplace, deploying community health workers
  - American Cancer Society’s Health Advisors
  - Local health departments, serving as hubs for connecting people to resources
- Access to specialty care, mental health care, & transport are challenges

## • Connectivity Insights

- Wide variability in broadband access
  - Some telecommunications cooperatives providing fiber to home
  - Broadband seen primarily as economic issue
  - Cost and local politics obstacles to expansion
- Patients worried about privacy, scammers, decreased face time



*Local Autonomy Valued for Progress*



*Kentucky Homeplace*



*ACS Health Advisors*



*Shaping Our Appalachian Region (SOAR)*



*People's Rural Telephone Cooperative (PRTC)*



## Co-Creation Exercises: Field-based “design labs,” clinical/engineering partnerships



HELP IMPROVE THE LIVES OF UK MARKEY CANCER PATIENTS!

# L.A.U.N.C.H.

LINKING & AMPLIFYING USER-CENTERED NETWORKS THROUGH CONNECTED HEALTH

## INNOVATION

## STUDIO

SATURDAY,  
FEBRUARY 9th  
2019

Drs. Tim Mullet and Robin Vanderpool will be hosting an innovation studio to brainstorm new and better ways to understand and manage symptoms during cancer treatment and survivorship. We invite anyone who has/had cancer, been part of a family experiencing cancer, or those who provide care for patients to come and co-design solutions with us. No artistic, technological, or design experience is necessary. Just bring yourself, your ideas, and your enthusiasm to change the lives of cancer patients in Kentucky.



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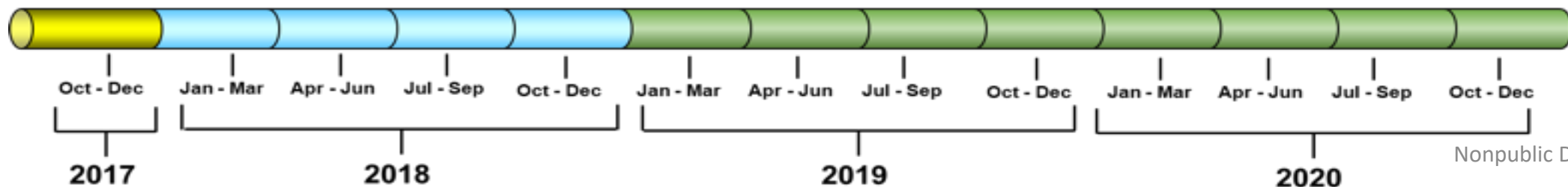
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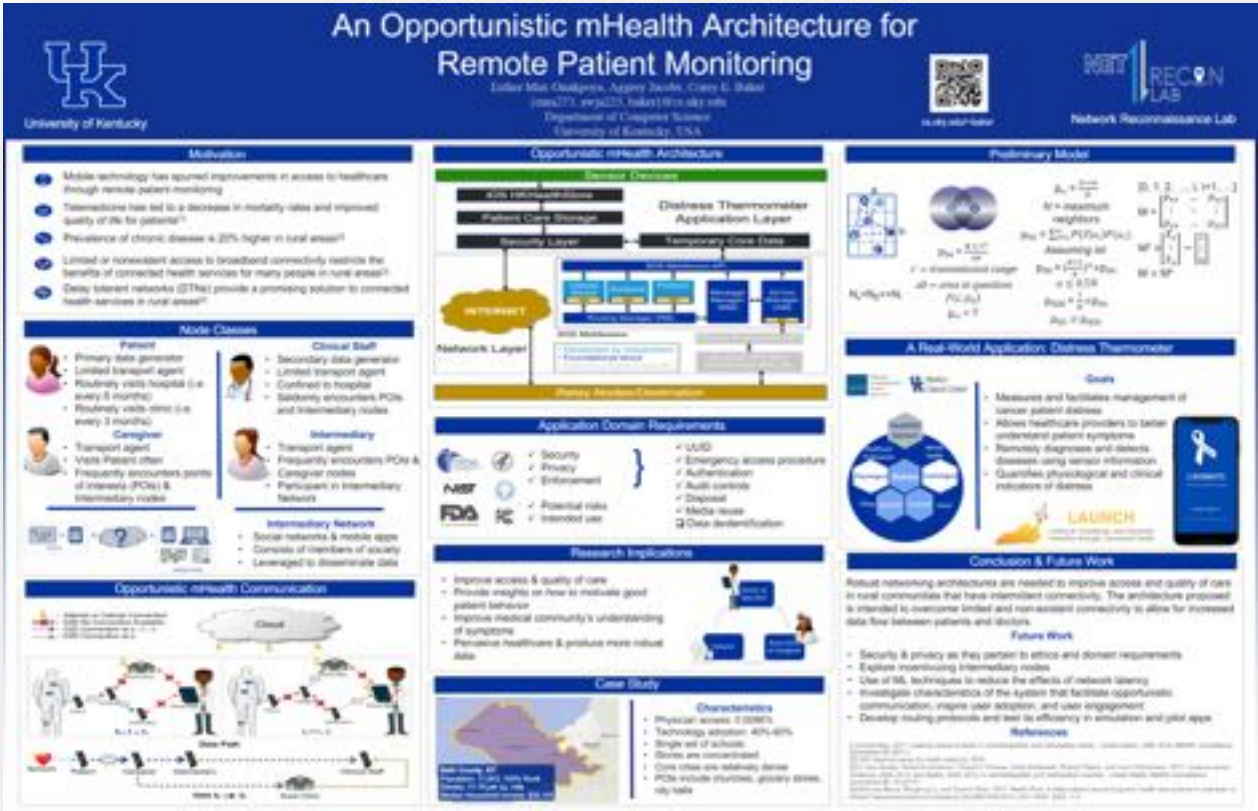
Phase 1: Development

Phase 2: Demonstration

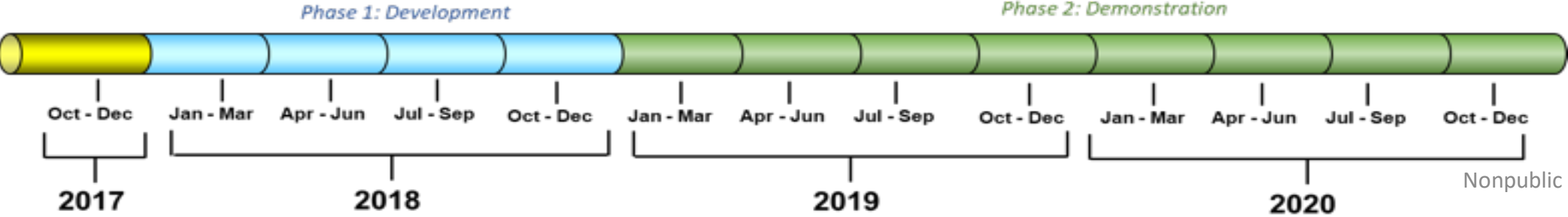




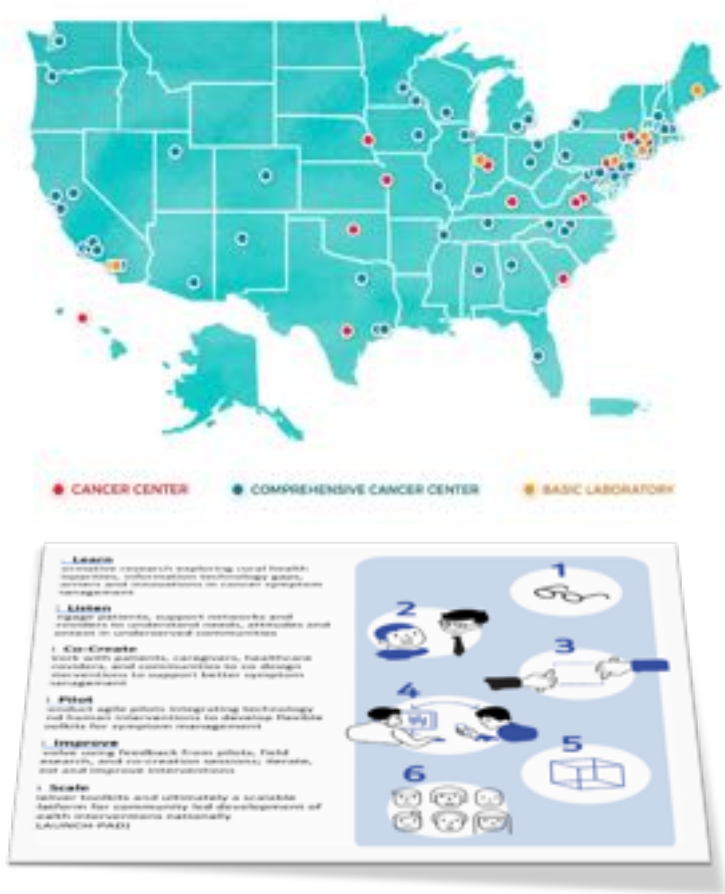
Pilot - Improve: Target meaningful system metrics, iterate on sociotechnical interventions



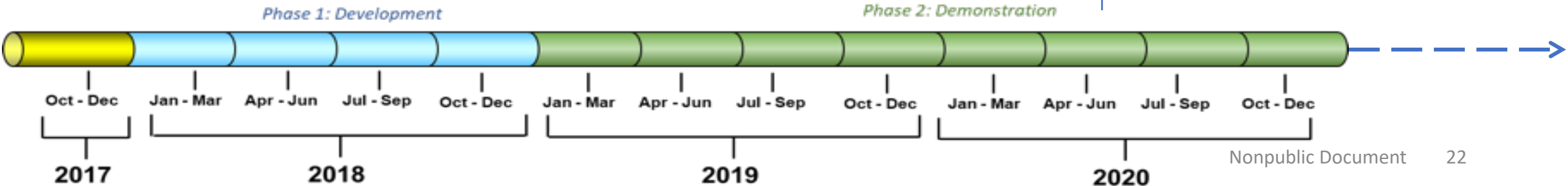
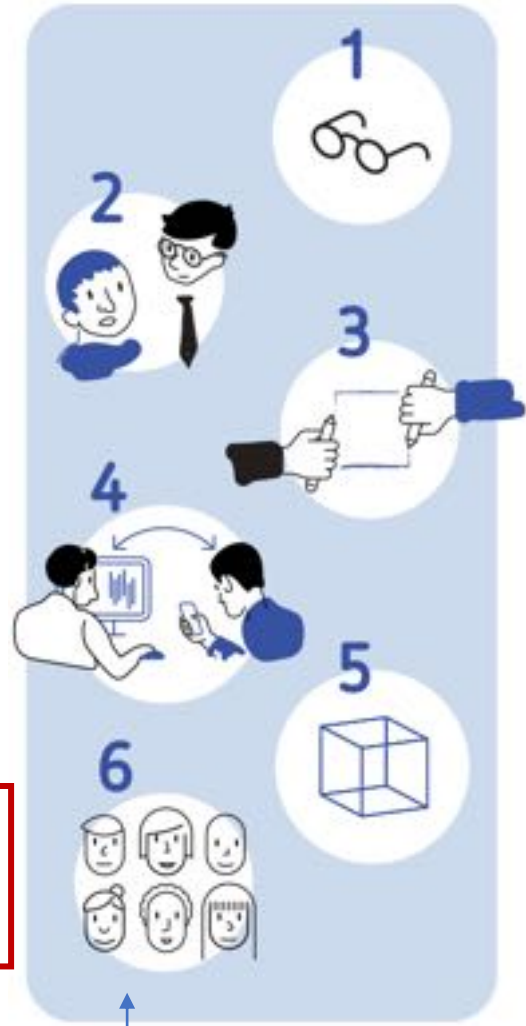
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Platform for Agile Development: Blueprint for launching similar implementation laboratories at scale



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# Next Steps:

1. Work together in creating a **successful demonstration project** in Kentucky [with documented impact]
2. Strengthen the FCC-NCI “**Blueprint**” as a framework for scaling to other cancer centers, areas of country
3. **Align funding/action** across sectors to achieve national impact together over time.



Platform for Agile  
Development:  
**LAUNCH PAD**

Connecting Action,  
Stimulating the  
Ecosystem

