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8 – 12 JULY 2023 | SYDNEY, AUSTRALIA

Co-Design Research in Consumer Health Informatics

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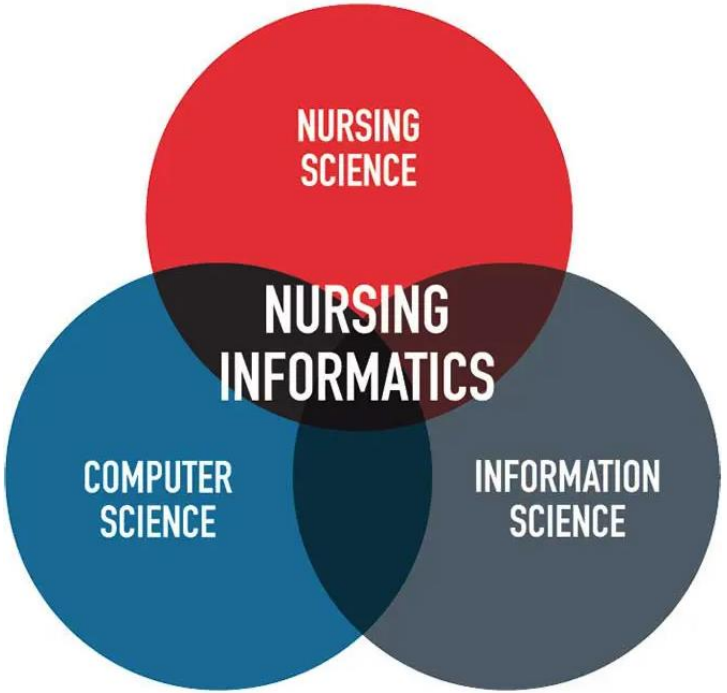
Assistant Professor,

University of Minnesota School of Nursing

AIDH IMIA

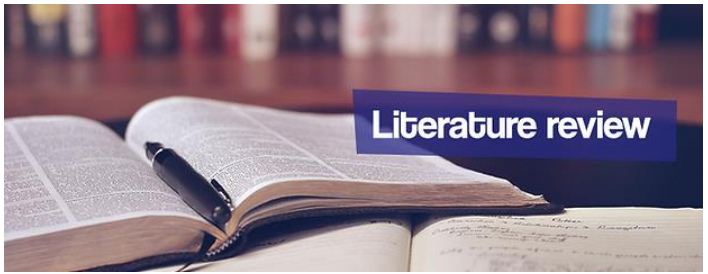
Introduction

- Assistant Professor of Nursing
- Medical-Surgical Nurse
- Public Health Nurse
- Consumer



Research Interests

- Health Equity & Health Promotion
- Informatics
  - Clinical Decision Support
  - Digital Health
    - Mobile Health
  - Consumer Health Informatics (CHI)
- Research Methods
  - Implementation Science
  - Qualititative & Quantitative
  - Library Science



CHI-WG Subcommittee Initiatives

- Consumer Health Informatics Working Group (CHI-WG)
- MeSH Group
  - Consumer health informatics
  - Wearable devices
- Co-Design Nerds
  - Co-design of smartphone apps to self-manage diabetes

Difficulties Discovering CHI-related Literature

LACK OF

STANDARDIZATION

Increasing Visibility of CHI & Co-Design Literature

The art of DISCOVERABILITY

- Document Consumer Engagement
- Submit CHI & Co-Design Author Keywords
- Good Metadata (MeSH Terms)

THINK OUTSIDE THE BOX

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@kimkater

Co-Design Research and the ACTIVATE Digital Health Platform

Katherine Kim, PhD, MPH, MBA

Principal, Consumer Health Informatics, MITRE Corporation and Adjunct Associate Professor, University of California Davis

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Need for Participatory Frameworks Throughout the Consumer Health Informatics Continuum

Understand Needs	Design right	Implement well	Evaluate
Conceptual Model and Framework	Landscape assessment	Study Design	Feasibility
Contextual Inquiry	Stakeholder co-design	Fidelity	Outcomes
Interviews	Rapid prototyping	Technology	Participant-driven outcomes
Observations	Iterative test and refine	Usefulness	User experience
Cultural probes		Usability	Utilization
		Facilitators and barriers	Technology acceptance and use
			Value

Participatory Approaches

Frameworks

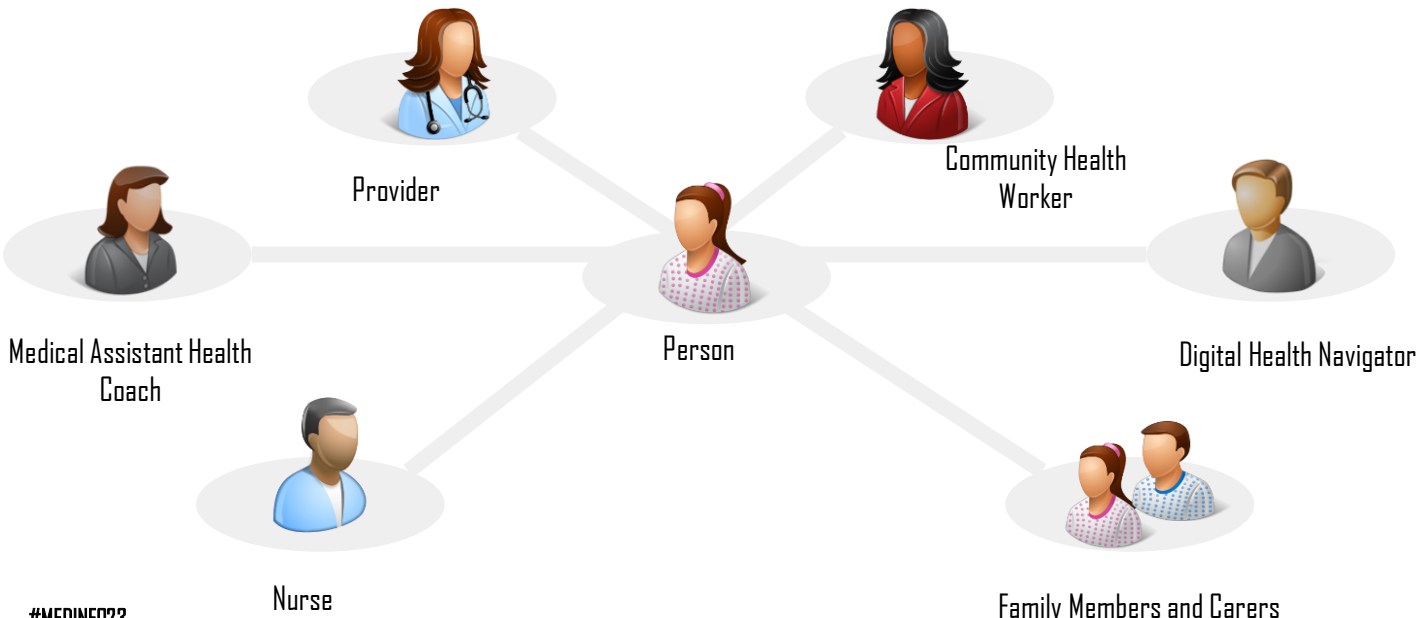
1. Community Based Participatory Research – Community drives research priority and contributes in order to act in interest of community
2. Citizen Science – professional and community members engage as equals in production of scientific knowledge and action in interest of community
3. Participatory Design & Production – a democratic process of engaging stakeholders in identifying problems and designing solutions
4. Contextual Design/Human Centered Design- designing for life, not tasks

Participatory Approaches

Methods

- Rapid Prototyping – creativity through rapid-cycle, hands-on builds for solution design
- Contextual Inquiry – qualitative methods to elicit understanding of life and situations
- Design Thinking – a methodology for creative problem solving
- User Centered Design - methods to focus on solutions that work for people
- Numerous data collection and analysis methods: observation, interview, cultural probes, diaries, visual ethnography, workflow analysis, etc.

Embedded co-design approach to maximize usefulness, usability, outcomes with over 20 community co-designers



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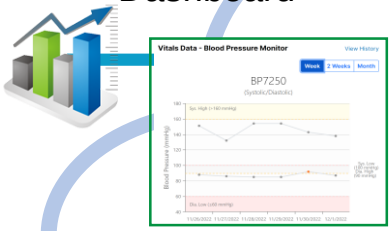
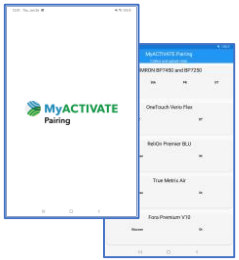
ACTIVATE

ACTIVATE Participant Dashboard



MyACTIVATE Pairing App

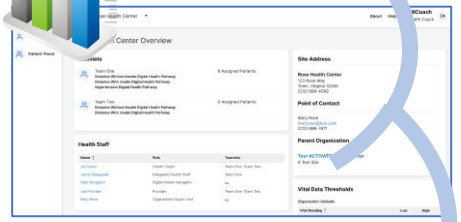


ACTIVATE Server

Batch

HL7v2

ACTIVATE Program Manager



Participants

PATIENTS

Tablet or Smartphone

Virtual Visit System

Electronic Health Record System

Healthcare

TEAMLETS

@TheInstituteDH

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Improvement in Clinical Outcomes

- 3.5 point reduction in hemoglobin A1c
- 20 point reduction in systolic blood pressure
- 5 point reduction in diastolic blood pressure

- For more information see our panel Session 28

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@LilianaLaranjo

Co-designing a conversational AI intervention to support patients with atrial fibrillation

Liliana Laranjo

Senior Research Fellow

Westmead Applied Research Centre,

University of Sydney

CHAT-AF

CHAT-AF
Supporting Patients with Atrial Fibrillation

JMIR RESEARCH PROTOCOLS Laranjo et al

Protocol

Coordinating Health Care With Artificial Intelligence–Supported Technology for Patients With Atrial Fibrillation: Protocol for a Randomized Controlled Trial

AUTOMATED PHONE CALLS

EMAIL

TEXT

EDUCATION WEBSITE

CHAT-AF

Central monitoring unit oversees the program. **If issues are identified, a phone call with a trained health counsellor is triggered** to clarify issues and then connect them to their doctor.

Max has AF

Max is enrolled in the 'AF-Support Program'

@24-48 hrs
Max receives his first automated phone call and is reminded to **book a GP** appointment and asked if he needs help finding/getting to a GP.

@14 days
Max is asked about his **symptoms, medication confidence** and if he has attended his **GP appointment**.

@1 month
Max is asked about his **medication adherence**.

@2 months
Max is given information on **lowering alcohol intake** and the importance of regular **BP monitoring**.

@3 months
Max is told how AF patients have an increased risk of **stroke**.

@4 months
Max is given information on **sleep apnoea** and **weight management**.

@5 months
Max is asked about his **symptoms, medication adherence** and is given information about **AF procedures**.

Co-design partners

- Patients and health consumer representatives
  - **Patients**: experts in their individual lived experience; specific needs, preferences, solution ideas
  - **Health consumer/patient representative/advocate**: representing more than individual experience; speaking on behalf of other patients/consumers
- Primary and secondary care healthcare professionals (eg GPs/family physicians, cardiologists)
- Health informatics and behaviour change experts
- Health technology company

Co-design process (patients and clinicians)

1. Needs assessment
2. Script and educational content development
3. Prototype testing (think-aloud testing of phone calls)
4. Prototype refinement (e.g., simplifying language)
5. Intervention testing: 6-month trial + semi-structured interviews
6. Intervention refinement

Co-design process

Witteman HO et al. An **11-item measure of user-and human-centered design for personal health tools** (UCD-11): development and validation. JMIR. **2021**;23(3):e15032.

UCD-11

A VALIDATED MEASURE OF USER- AND HUMAN-CENTERED DESIGN FOR PERSONAL HEALTH TOOLS

1. Were potential end users (e.g., patients, caregivers, family and friends, surrogates) involved in any steps to help understand users (e.g., who they are, in what context might they use the tool) and their needs?
2. Were potential end users involved in any steps of designing, developing, and/or refining a prototype?
3. Were potential end users involved in any steps intended to evaluate prototypes or a final version of the tool?
4. Were potential end users asked their opinions of the tool in any way?
5. Were potential end users observed using the tool in any way?
6. Did the development process have 3 or more iterative cycles?
7. Were changes between iterative cycles explicitly reported in any way?
8. Were health professionals asked their opinion of the tool at any point?
9. Were health professionals consulted at any point before a first prototype was developed?
10. Were health professionals consulted between initial and final prototypes?
11. Was an expert panel involved?

Scoring: 1 point for each yes. Possible scores range from 0 to 11

Witteman et al. Development and Validation of UCD-11: An 11-Item Measure of User- and Human-Centered Design for Personal Health Tools, JMIR.org. doi: 10.2196/15032

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Co-design of Health Informatics Solutions with Patients and Community in Appalachian Kentucky

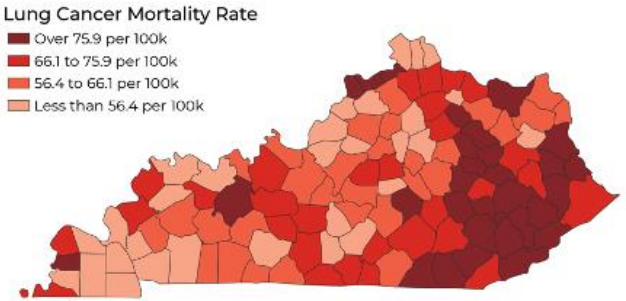
Ming-Yuan Chih, PhD, ACHIP, FAMIA

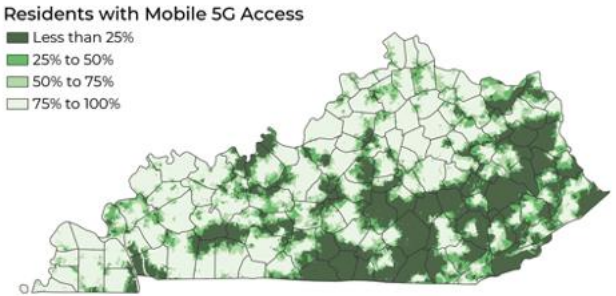
Associate Professor

University of Kentucky

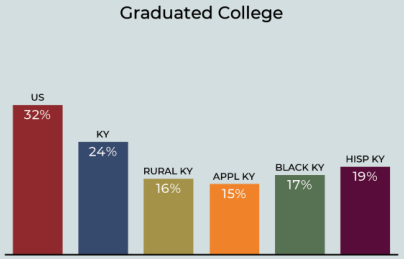
AIDH IMIA

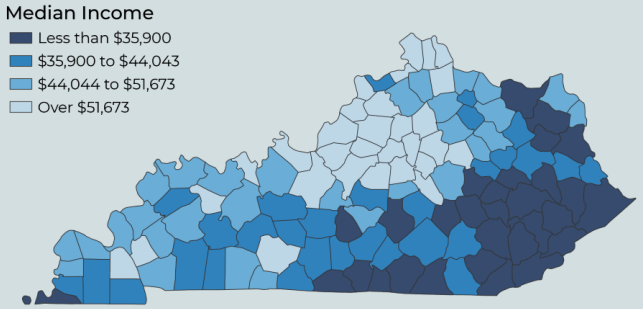
Kentucky - Triple Burden

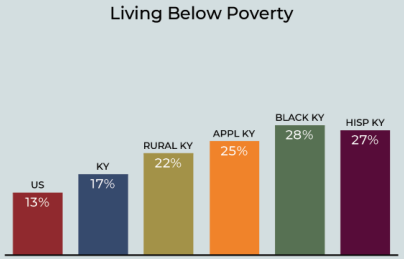


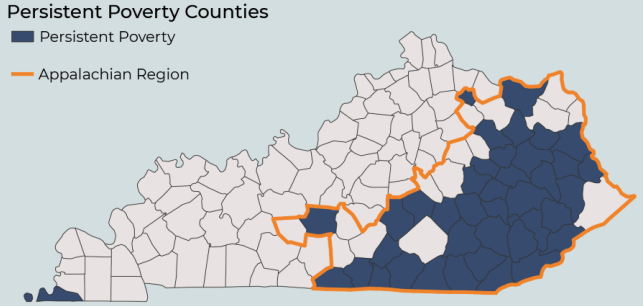


Social Determinants of Health — Society







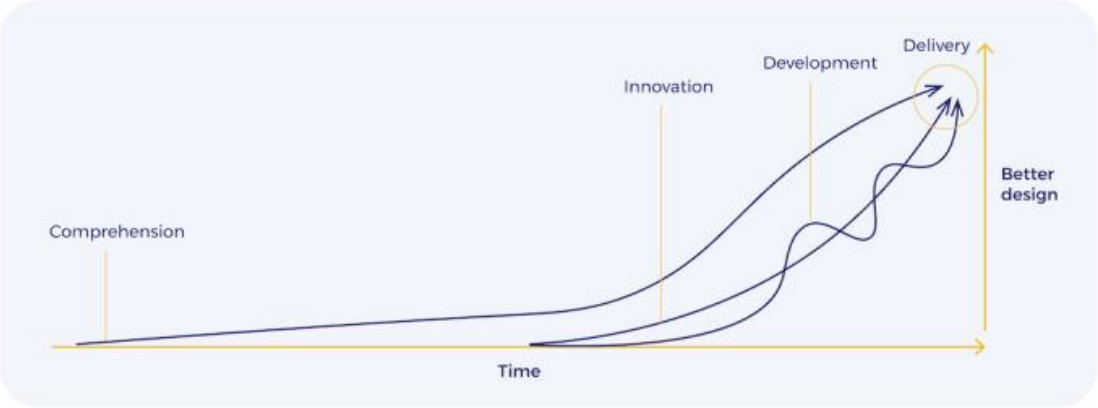


ACS, 5-Year, 2015-2019 · USDA ERS, 2015

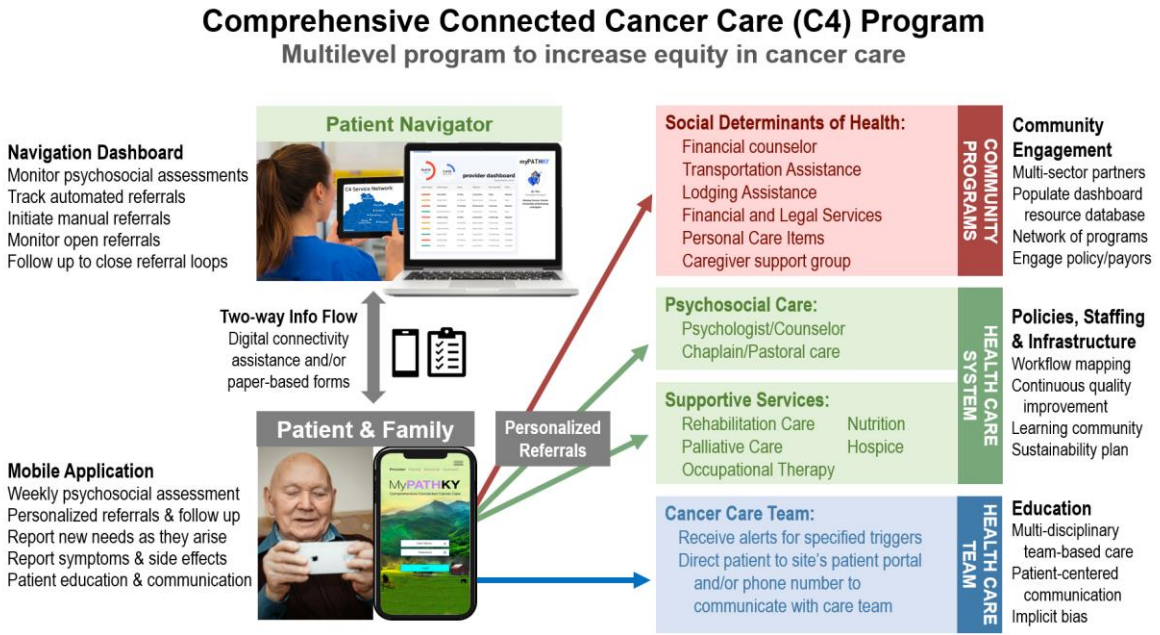
2021 Kentucky Cancer Needs Assessment

LAUNCH

Designers worked with patients, family caregivers, oncologists, surgeons, nurses, social workers, technologists, insurance, broadband, and pharma to co-design new mHealth intervention systems together.



Comprehensive Connected Cancer Care (C4)



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- Federal Communications Commission. FCC-NCI Broadband Cancer Collaboration. Accessed June 19, 2023. https://www.fcc.gov/health/cancer.
- National Program Office. Alliance for Equity in Cancer Care: An Initiative funded by Merck Foundation. Accessed June 19, 2023. https://www.equityincancercare.org.
- Aronoff-Spencer, E. et al. Designing a Framework for Remote Cancer Care Through Community Co-design: Participatory Development Study. J Med Internet Res 24, e29492 (2022).

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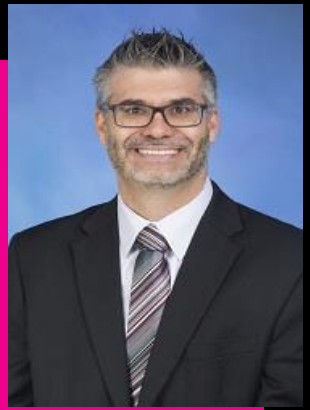

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Key Finding from: Co-designing Health Informatics Solutions with Patient and Community Members: A Collaborative Workshop. AMIA 2022 Symposium

Scott Sittig, PhD, MHI, RHIA

Associate Professor

University of Louisiana at Lafayette

Key Findings

- Co-design of consumer health informatics solutions is a mindset that includes patients as equal partners in the design and research process.

- Inclusion of participatory methods is essential to understanding the needs of the patient/consumer.

Key Findings

- Designers are not the typical users, so the patient/consumer needs to come first.

- We should continually give the patients/consumers priority and always incorporate their needs/preferences into the working context of the design.

Key Research Areas Among Workshop Participants

- Patient and Provider Tools
- Community Engagement
- Health Equity
- Mental Health
- Remote Patient Monitoring

Panelist Questions

- What adaptations to co-design are needed to account for cultural differences among countries, regions, and/or populations?
- What additional resources are needed to account for cultural differences among countries, regions, and/or populations?
- What are potential benefits of co-design approaches in consumer health informatics and in what cases is co-design not useful?

Thank you