Introduction

Fragmented systems of care often limit patient engagement, especially among underserved populations facing complex social and medical needs. Working together through the IHI/Pfizer Collective Action Collaborative, Primary Health Care (PHC) and the Iowa Community HUB (HUB) developed a patient journey map to better understand and improve the patient experience across all stages of care coordination, from initial wellness screenings to post-program follow up. This approach provides a structured visualization of patient emotions, barriers, and decision-making processes within the context of chronic disease prevention and health equity. The purpose of this initiative was to identify and optimize critical touchpoints where nurse care managers, community health workers, and navigators can reduce barriers, improve communication, and strengthen patient retention across the continuum of care. The journey map sought to capture how patients interpret screenings, manage fears, and navigate referrals to HUB-based social support programs.

Methodology

A qualitative, participatory design method was employed to co-create the journey map using data from participant interviews, navigator feedback, and care coordination observations. Each stage documented patient goals, emotions, questions, challenges, and provider opportunities to intervene through empathetic communication and motivational interviewing. Eight distinct stages were mapped:

Meeting with a Nurse Care Manager:
Patients come to the clinic with a mix of questions and concerns, seeking to understand how the care they receive will help them, how screenings relate to their health, and whether services are covered by insurance or will require out-of-pocket costs. Many worry about being judged or blamed for their health conditions, and their willingness to share information can vary day to day depending on pain, stress, or medications. Life circumstances such as unstable housing, limited transportation, and other social determinants often make health a lower priority, and some patients experience learned helplessness, feeling their actions have little impact on their health outcomes. Language barriers and limited health literacy further complicate communication, making it essential for clinic staff to approach each patient with empathy, patience, and clear guidance to ensure they feel supported and understood.

Determining Eligibility and Education
Patients seek support from the clinic to determine their eligibility for services, understand their health, and learn about available options for care or treatment. Patients often want clarity on the meaning of their results, whether their results are normal, and what steps they can take to reduce risk or improve their health. Many feel overwhelmed by the volume of information or anxious about trying new programs or treatment pathways, and barriers such as medical jargon, language differences, or unclear explanations can make it difficult to fully understand the significance of a diagnosis. Patients need their options explained clearly, with guidance, reassurance, and validation of their emotions and fears. They benefit from support in setting achievable health goals and learning about resources, such as the HUB, that can connect them with additional services and support systems to help navigate their care.

Referral to The HUB
Patients are referred to the Iowa HUB to connect with interventions and resources tailored to their health needs and to establish a supportive network, often with the goal of avoiding more severe, invasive, or risky treatments. They may have practical questions about the process, including whether someone will reach out to them or if they need to call, associated costs, whether they need to travel or if services can come to them, and whether they can use assistive devices. Patients' feelings range from excitement and curiosity about the resources and programs they may access, to hesitation, anxiety, or even apathy and disillusionment due to uncertainty about HUB services. Many face barriers such as transportation insecurity, mobility challenges, cost, limited technology literacy, or a lack of time and capacity to prioritize self-care. Providing validation of emotions and fears, slowing down to answer questions, clearly explaining what to expect, offering guidance, and reassuring patients are all essential to helping them feel supported and confident in engaging with the HUB.

HUB–Patient Connection and SDOH Screening
Patients engage with the HUB to identify challenges affecting their health, better understand their needs, and feel comfortable sharing sensitive information openly. They often have questions about the HUB's purpose, why they were referred, and how it relates to their provider, as well as whether someone will follow up if they don't hear back from connected resources. Many face multiple barriers—financial constraints, lack of transportation, limited local services, language or literacy differences, and difficulty using technology—that make prioritizing health needs challenging, along with balancing work, family, or caregiving responsibilities. Patients may feel hesitant or uncertain about whether the program will help, but they also begin to see a path to improvement with support. The HUB helps by making patients feel heard and safe, providing clear guidance and actionable steps, prioritizing the most urgent needs, connecting them to essential services, and setting expectations for follow-up to maintain engagement and improve health outcomes.

Shared Decision Making for Best Fit Program + Resources
Patients seek clear, understandable information about available programs, services, and resources and want to be actively involved in choosing options that align with their needs, values, and preferences. They often ask which programs are the best fit, what is expected of them, whether there are costs, time commitments, or eligibility requirements, and how participation will help them achieve their health or social goals. While many feel empowered and relieved to move from identifying problems to taking action, others feel unsure or anxious due to lack of prior experience or past negative interactions that make trusting programs difficult. Patients need guidance and decision support, clear explanations of options and outcomes, and programs that are feasible in terms of location, timing, and cost. Walking patients through the process, simplifying steps, and maintaining connection over time helps build trust, support engagement, and ensure they can fully access and benefit from services.

Program Enrollment
During program enrollment, patients want a smooth and straightforward process that helps them understand what participation requires, including appointments, paperwork, and eligibility criteria. They often have questions about what documents are needed, how long it will take to begin receiving services, who to contact for help, and whether the HUB will continue to support them throughout and after enrollment. While many feel hopeful and ready to take concrete steps toward change, others may feel overwhelmed by complex or repetitive requirements, especially when facing literacy, language, or time constraints. Providing step-by-step guidance, simplifying the enrollment process, and consistent connection helps ensure patients feel supported, engaged, and able to complete enrollment successfully.

Program Participation
During program participation, patients aim to follow through with activities and appointments, build confidence and skills to manage their needs more independently, and ultimately complete the program while experiencing meaningful improvements in health, stability, or quality of life. They may have questions about how to handle challenges such as transportation, time, or motivation, whether their plan can be adjusted as needs change, and what happens if appointments are missed. Patients often feel excited to make progress and supported by the group, while also experiencing stress as they balance participation with other life responsibilities or frustration if progress feels slow. Ongoing support from instructors and peers, regular check-ins, celebration of small and large successes, accessible environments, and clear communication help maintain engagement, reinforce that progress matters, encourage self-management, and reduce the risk of disengagement.

Post-Program Screening
After program completion, patients want to understand what supports and resources remain available and have a clear post-program plan to maintain the healthy habits they have built. They often have questions about what happens next, whether they can transition to additional programs if needs persist or change, and whether their healthcare provider will be informed of their completion. While many feel satisfied and proud of finishing the program, others feel nervous about losing support or fear "falling through the cracks" without structured guidance. Clear communication about achievements, next steps, ongoing resources, outcome measurement, warm handoffs to additional services, and closing the feedback loop with providers help maintain progress and ensure continued support.

Context:

Our patient is going to a Annual Wellness Appointment at Primary Health Care in Ames, IA. A Medicare Annual Wellness Visit (AWV) is a yearly, free preventive appointment to create or update a personalized, long-term health plan. It includes a Health Risk Assessment, review of medical/family history, routine measurements (height, weight, blood pressure), a list of current providers and medications, cognitive impairment screening, and a personalized, written prevention schedule.

① Meet with Nurse Care Manager

Goal of the person at this stage:
- Preventative care check in
- Access to condition management

Clinic Opportunities to Support:
- Reassure and validate emotions and fears
- Slowing down, spend the time to answer questions and educate on screenings and the implications of answers
- Rapport strengthening and building
- Motivational interviewing

③ Referral to The HUB

Goal of the person at this stage:
- Getting connected to an intervention to improve health and to resources tailored to their needs
- Getting connected to a support system

HUB Opportunities to Support:
- Validate emotions and fears
- Slowing down, spend the time to answer questions and educate on screenings and the implications of answers
- Explain what patients can expect and give guidance
- Offer reassurance

⑤ Shared Decision Making + Program Recources

Goal of the person at this stage:
- Gain clear information about the programs, services, and resources available
- Be involved in choosing interventions or supports that align with their needs, values, and preferences
- Have an actionable plan for accessing services and improving health/social outcomes

HUB Opportunities to Support:
- Create a space where patient feel heard, respected and safe sharing sensitive information
- Share actionable steps the patient can take while the HUB coordinates support
- Prioritize issues that are most urgent or impactful on health outcomes
- Provide immediate connections to essential services (food, housing, transportation, utilities)
- Set expectations for follow-up contacts to maintain engagement

⑦ Program Participation

Goal of the person at this stage:
- Follow through on activities and appointments
- Build confidence and skills to manage needs more independently
- Complete the program
- Experience real benefits that improve health, stability, or quality of life.

HUB Opportunities to Support:
- Provide regular check-ins to keep the patient motivated and engaged
- Celebrate successes (big and small) to build confidence and reinforce commitment.
- Coordinate communication between the patient and program staff to ensure smooth participation.
- Encourage self-management

② Determine Eligibility + Education

Goal of the person at this stage:
- Improving health
- Receive clarity on results
- Learning about supportive options

Clinic Opportunities to Support:
- Explain options clearly and give guidance
- Reassuring and validating emotions and fears
- Assist in creating an achievable health goal(s)
- Introduce HUB and resources patient can connect with

④ HUB - Patient Connection

Goal of the person at this stage:
- Identify challenges affecting their health
- Understand their needs better
- To feel comfortable sharing their needs openly

HUB Opportunities to Support:
- Create a space where patient feel heard, respected and safe sharing sensitive information
- Share actionable steps the patient can take while the HUB coordinates support
- Prioritize issues that are most urgent or impactful on health outcomes
- Provide immediate connections to essential services (food, housing, transportation, utilities)
- Set expectations for follow-up contacts to maintain engagement

⑥ Program Enrollment

Goal of the person at this stage:
- Complete enrollment smoothly and correctly
- Understand what participation requires (appointments, paperwork, eligibility).
- Learn how to best prepare for the program

HUB Opportunities to Support:
- Walk the person through the process
- Simplify the process
- Maintain connection with person to be sure they are engaging fully

⑧ Post-Program Screenng

Goal of the person at this stage:
- Understand what supports or resources are available after program completion
- Have a post program plan to maintain new healthy habits

HUB Opportunities to Support:
- Measure outcomes and identify ongoing needs.
- Connect them with another program that will further support their progress.
- Provide additional warm handoffs as needed
- Close feedback loop with provider reporting completion

Objective

By the end of this session, participants will be able to:
1. Describe how the PHC-HUB patient journey map identifies emotional, structural, and communication barriers across the continuum of care for patients facing social and health challenges.

2. Analyze how nurse care managers, community health workers, and navigators address social determinants of health (SDOH) to improve coordination and continuity between clinic and community systems.

3. Apply key learnings from the PHC–HUB patient journey mapping experience into practical strategies for building more engaging, trusted, and equitable care workflows.

SDOH

Social Determinants of Health (SDOH) are the social, economic, and environmental conditions in which people are born, live, work, and age, and they play a significant role in shaping health outcomes. Individuals who are marginalized or experience unmet SDOH such as; unstable housing, food insecurity, limited transportation, lack of insurance, language barriers, or discrimination often face compounded obstacles to accessing care. These barriers can make seeking healthcare difficult due to cost, time constraints, mistrust of healthcare systems, limited availability of culturally responsive services, and competing priorities for basic needs. As a result, health concerns may be delayed or go unaddressed, contributing to persistent health inequities.

Transportation · Financial Constraints · Insurance Access · Work Obligations · Language Barriers · Food Insecurity · Available Time · Housing · Dependent care for children or elderly adults

Results

Findings uncovered key emotional and cognitive themes: while patients often feel confused, anxious, and mistrustful during initial screenings, targeted follow-up, validation, and personalized support help them become more confident and engaged in their care. Common barriers include limited transportation, technology literacy, and uncertainty about program expectations. Implementing HUB interventions can lead to higher rates of engagement and follow-through, greater self-efficacy among participants, and improved linkage to community resources addressing food, housing, and medication access. Providers reported improved care coordination and increased confidence in making community referrals, with reassurance that patients will receive quality care beyond the walls of the clinic.

Analysis

The analysis section interprets the results and discusses their implications. It explains the meaning of the findings in relation to the research objectives and existing literature. The analysis may involve comparing the findings to previous research, identifying patterns and trends, or drawing inferences. This section should provide a critical evaluation of the results and their significance.

Conclusion

The PHC-HUB patient journey map offers a replicable framework for integrating community and clinical processes using a patient-centered design approach. By aligning goals, standardizing workflows, and enabling data sharing across clinic and community teams, it addresses emotional, cognitive, and logistical barriers throughout the care continuum. This integrated approach fosters trust, clarity, and accountability among patients, healthcare teams, and community partners. Beyond improving care coordination, it advances public health equity goals and supports the statewide incorporation of social care into preventive and chronic disease management models.

SCAN ME!

Key Sources & Acknowledgements
List the primary sources used during the research, such as academic articles, books, and websites.

PHC Logo/HUB Logo/IHI/Pfizer logo
Acknowledge the contributions of individuals or organizations who supported the research, such as supervisors, collaborators, and funding agencies.