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Arthritis Care Model: Human-Centered Design Recommendations Report

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Contents

Context & Approach	3
Key Takeaways from Human-Centered Design Sessions	4
– Key Takeaway #1: A care plan must reflect a patient’s lived experience, desired outcomes, and evolving needs.	
– Key Takeaway #2: Intentionally integrating the right care team members (including social service agencies and other community-based organizations) helps address patient-driven needs, but there are significant barriers.	
– Key Takeaway #3: Care team members (both internal to a health system and external partners) need to be able to communicate back and forth.	
– Key Takeaway #4: Resources for clinicians and patients should be aggregated, vetted, and disseminated.	
– Key Takeaway #5: A thoughtful, effective screening tool (and creativity in how/when it’s administered) could help increase the number of individuals that receive early interventions.	
Recommendations	6
– Recommendation #1: Create a central repository for arthritis resources and programs.	
– Recommendation #2: Develop a decision aid to use when counseling and referring patients.	
– Recommendation #3: Develop an accreditation process for organizations offering AAEBIs and other evidence-based interventions.	
– Recommendation #4: Design a model that integrates care team members that meet patient needs.	
– Recommendation #5: The resulting framework needs to be flexible for different capabilities, models, and health system situations.	
– Recommendation #6: Considerations for a pilot program include demographic considerations, flexibility in reimbursement arrangements, and a strong relationship between a health system, payers, and community resources.	
– Recommendation #7: Seek input from different perspectives, including patients, to ensure that the model can implemented in the real world and improve patient outcomes.	
– Recommendation #8: Select/develop a screening tool for arthritis patient quality of life	
Moving Forward	9

Context & Approach

In 2022, under the direction of and partnership with the Centers for Disease Control and Prevention (CDC) Healthy Aging Branch/Division of Population Health and the National Association of Chronic Disease Directors (NACDD), Leavitt Partners conducted an environmental scan and key interviews to understand the landscape of integrating physical activity into the screening, counseling, and referral pathways for people with arthritis. This research surfaced a number of barriers and potential high-impact areas to explore that could better integrate physical activity, where clinically integrated, and ultimately improve function and quality of life for patients. One key barrier identified during this process was the limitations of addressing arthritis-specific issues due to time constraints of primary care provider. During these visits, primary care physicians (PCPs) have little time to screen for physical activity, let alone counsel patients on how to properly integrate more physical activity and then refer to an arthritis appropriate evidenced-based intervention (AAEBI).

Between January and March 2023, a panel of experts was convened in order to creatively address this barrier by integrating more care team members (both clinical and non-clinical). This Advisory Panel included experts from diverse backgrounds that could contribute their experience, subject matter expertise, and perspectives, including patients, patient advocacy, clinical professional organizations, primary care, clinical specialties, physical therapy, public health, community health workers, community-based organizations, and payers.

Leavitt Partners, in collaboration with CDC and NACDD, facilitated three human-centered design sessions that explored ways to increase self-management behaviors—including physical activity and lifestyle change—for people with arthritis. The overall goal of these sessions was to inspire a more expansive, flexible vision for how care teams can better collaborate with adults with or at risk of osteoarthritis in shared decision making to increase self-management behaviors, including physical activity and lifestyle change, ultimately improving function and quality of life. A human-centered design approach was chosen in order to embrace collaboration, creativity, and empathy and to leverage unique, varied perspectives. When asked to reflect on their experience in these sessions, a majority of Advisory Panel members reported that these sessions provided opportunities for collaboration and that these sessions encouraged them to think in new ways. Many panelists mentioned that they valued the opportunity to hear from diverse voices across various professionals and to look at the issue through a variety of viewpoints.

The sessions were designed to accomplish the following:

1. Set the focus, align expectations, ensure the Advisory Panel members have a shared understanding of the problem and environment, create empathy for the individuals of focus, and begin to brainstorm potential stakeholder involvement.
2. Brainstorm potential stakeholder involvement, identify the tools that each care team member has that might influence behavior change, review and add to the journey maps, and begin to surface opportunity areas to further explore.
3. Discuss the feasibility and impact of key ideas surfaced by the Advisory Panel in order to increase self-management behaviors.

A summary of each session provides more robust details and recommendations specific to each session ([Session 1](#), [Session 2](#), [Session 3](#)). This report outlines key takeaways across the three human-centered design sessions and posits some recommendations based on the ideas surfaced during all sessions.

Key Takeaways from Human-Centered Design Sessions

The three human-centered design sessions resulted in robust discussion on many aspects of the screening, counseling, and referral process. Details on each can be found in separate meeting summaries (linked above); below we highlight several of the key discussions from all sessions.

Key Takeaway #1: A care plan must reflect a patient's lived experience, desired outcomes, and evolving needs.

Advisory Panelists repeatedly emphasized that a care plan must reflect a patient's experience and desired outcomes, and it must also be dynamic so that it can reflect evolving needs and circumstances.

When co-designing a care plan with a patient, the care team should limit their assumptions about a patient and seek first to understand the patient's priorities and desired outcomes. Based on a solid understanding of a patient's unique lived experience and goals, clinicians should develop a care plan (and a care team) to meet those goals.

In addition to being patient-driven, care plans should also not be static, but rather build upon themselves and pivot when something isn't working for a patient. Creating unique, flexible care plans that align with a patient's goals (and their perception of how they would attain those goals) could promote long-term adherence and improved quality of life.

This kind of personalization can be difficult to achieve in a short visit once a year, and integration of different care team members to truly explore components of a care plan and then help drive follow-through can help improve patient outcomes.

Key Takeaway #2: Intentionally integrating the right care team members (including social service agencies and other community-based organizations) helps address patient-driven needs, but there are significant barriers.

An individual with arthritis has several co-related needs that often are best addressed through many pathways. They have clinical needs (to help diagnose and provide clinical direction) and social needs (to help provide support, overcome barriers, and provide follow-through). There is no one clinician that can provide this support. One individual, for example, could benefit from a primary care visit, follow-up with a specialist, visits with a physical therapist, physical activity opportunities through community-based organizations (CBOs), transportation support, behavioral counseling, patient navigators help patients connect with the right resources, and community health workers to ensure the pathway resonates with the individual and cultural context. Often, these needs can be met by leveraging team members within the health system; not necessarily creating a new role, but maximizing individuals already embedded in the system. There is an opportunity to integrate community resources and social services into the care pathway to meet these diverse needs. Depending on existing resources, assets, and needs, these organizations and agencies can fill clinical gaps to support people with arthritis. This integration could also decrease provider burden and allow providers to best utilize their time with patients.

However, integrating these services is notoriously difficult due to barriers including the costliness in modifying EHRs to reflect a patient's journey outside of a specific facility and the instability that community organizations often suffer from (e.g., inadequate funding, staff, support, etc.). Integrating care team members and organizations into the care pathway cannot happen without adequate reimbursement pathways for social service agencies and CBOs to meaningfully and sustainably participate in the care team. Often, services that could provide the needed support for people with arthritis do not have a clear reimbursement path, leaving non-traditional care team members relying on short-term

Human-Centered Design Recommendations Report

grants to provide services (in the case of CBOs), insufficient reimbursement for lifestyle change, and difficulty in getting reimbursement altogether.

Key Takeaway #3: Care team members (both internal to a health system and external partners) need to be able to communicate back and forth.

In order to take advantage of opportunities to screen, counsel, and refer patients to physical activity programs, there needs to be a way to communicate between all relevant parties. An increased ability for different clinical and non-clinical entities to communicate back and forth would compound the impact of efforts to increase physical activity and other self-management behaviors.

In order for clinical and non-clinical organizations to coordinate patient needs, they need to be able to share information. A clinician, for example, might refer a patient to a CBO, but they might not know if the patient was contacted, if they joined the program, or what the results are. Improving this communication would increase the abilities of different care team members to provide better care, as well as build trust between the different organizations. A PCP, for example, might be more inclined to refer a patient to a program that has facilitated patient outcomes in the past.

However, this ability to communicate between all partners has been a long-standing challenge to adopting innovative, patient-driven solutions. While platforms like UniteUs can be integrated in an EHR to help providers connect to CBOs and provide bi-directional communication, there are challenges that make this process difficult. An increasing number of CBOs are collaborating as local, regional, or statewide networks to work with health systems to co-design a platform to remove burdens inherent in the referral process.

Key Takeaway #4: Resources for clinicians and patients should be aggregated, vetted, and disseminated.

Providing educational resources—both for providers (to understand the benefits of physical activity) and for patients (to access educational content)—could increase physical activity and other self-management behaviors. Advisory Panelists shared considerations throughout the sessions that apply to developing (and sharing) resources:

1. Consideration should be given to how to increase uptake of such a centralized repository. Just because it exists doesn't mean clinicians will know about it or feel comfortable using it.
2. A central repository from a trusted source with up-to-date information on AAEBIs available in the community would likely increase uptake of these resources and ultimately increase physical activity.
3. Educational resources should be tied to specific diagnoses and patient needs. Accessing the wrong information could potentially increase pain, and it needs to be ensured that patients access the right information based on their health status.
4. Health literacy should be an important consideration as material for patients are developed so that the messaging resonates with the target population.
5. Patients could benefit from additional education and information before their visit based on any concerns mentioned during scheduling.
6. Electronic Health Records (EHRs) hold potential as an important tool for referrals to resources and would also address physician barriers related to lack of time and understanding of referral opportunities. Ideally, making educational tools freely available through as many EHR vendors as possible would help address inequities in accessing material and increase counselling opportunities.
7. EHRs are notoriously difficult to modify; building an app with shared resources available for anyone to download could help bypass limitations of EHRs.

Human-Centered Design Recommendations Report

Key Takeaway #5: A thoughtful, effective screening tool (and creativity in how/when it's administered) could help increase the number of individuals that receive early interventions.

Advisory Panelists had a robust conversation about the role of screening tools in identifying individuals for counseling and referral to self-management behaviors, including physical activity. (Components of a screening tool were discussed throughout the sessions, but was specifically explored in [Session 2](#).)

Although the focus of these sessions was specifically about screening for physical activity, the lack of a quality, arthritis-specific screening tool could complicate the issue. While routinely screening for physical activity can benefit arthritis outcomes, there was sentiment around the need for tools that can be used to identify people with arthritis and track clinical progress. For example, Exercise as a Vital Sign (EVS) is an effective screening tool for physical activity levels, but not for early-stage arthritis, especially inflammatory arthritis diseases. One member suggested the possibility of adding questions to the Patient-Reported Outcomes Measurement Information System (PROMIS) to screen for both physical activity and arthritis simultaneously. Another member suggested using EQ-5D, a 3 – 5 question tool in 5 domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression or combine these questions with Physical Activity Vital Sign (PAVS) to get a broader picture of the patient's arthritis situation rather than focusing solely on physical activity levels. To ease clinician burden, one member suggested taking advantage of already built-in or required screening tools as much as possible, such as Patient Health Questionnaire-2 (PHQ2)/Patient Health Questionnaire-9 (PHQ9), General Anxiety Disorder-7 (GAD7), and Screening, Brief Intervention and Referral to Treatment (SBIRT). Regardless, these screenings should be succinct and prompt further assessment as necessary.

Recommendations

Based on the robust discussions across the three human-centered design sessions, the following recommendations are presented for the Advisory Panel to consider during the model design phase.

Recommendation #1: Create a central repository for arthritis resources and programs.

Advisory Panelists discussed the need to make provider and patient educational material and program information widely available and accessible, including finding ways to integrate the material into the clinical workflow. While one option could include EHR-driven solutions, there are cost-related barriers that could impact scalability.

Instead, we recommend beginning by building out a central repository of arthritis-specific materials for patients and providers to access. This would allow resources to be sourced, evaluated, endorsed, and distributed. The Advisory Panel could begin by reviewing existing resources and opportunities to expand or improve access to them. We anticipate the need to develop or update material to ensure accessibility, appropriate reading levels and language, and cultural considerations.

The Advisory Panel should also consider identifying all the available arthritis programs and interventions, including organizations that provide these services, their locations, and how to contact them to refer patients and individuals. Consideration should also be given to developing the central repository in a way that guides patients to the right resources and programs that match their health status and needs to ensure patients avoid resources that might exacerbate their condition.

Whatever evidence-based arthritis care model is developed, there will likely be opportunities to embed a central repository into the clinical workflow, making counseling patients on the benefits of physical activity and referring them to appropriate resources and programs more streamlined and easier on the provider.

Human-Centered Design Recommendations Report

Recommendation #2: Develop a decision aid to use when counseling and referring patients.

Much of the human-centered design sessions discussed how to successfully center the needs of the patient and appropriately refer them to the right program or intervention. In order to accomplish these goals, the Advisory Panel identified the need for a decision aid tool to help route patients to the appropriate evidence-based program. Such a tool could increase the care team's understanding of available programs and supports, make it easier to counsel patients, and increase referral opportunities.

To build a decision aid, the Advisory Panel could begin by identifying and cataloging the available arthritis resources, interventions, and programs. Elements to catalogue include:

- a description of the program
- program content
- target population
- type and intensity of activities
- format of the program classes (in-person, online, etc.)
- patient baseline activity level
- program length

See the American Physical Therapy Association's (APTA) [decision aid](#) used by physical therapists for an example to build on.

The first step in the decision tree could begin by identifying whether to refer a patient to physical therapy, physical activity, behavioral or cognitive support, or a combination. Consider whether separate decision trees would be appropriate for various clinicians (e.g., PCP, rheumatologist, orthopedic, etc.) and whether a navigator should assess the patient along with the clinician to determine necessary services. For a full picture of the right intervention to refer an individual to, inclusion of patient complexity and patient activation should also be considered, such as health and wellbeing, social determinants of health, health literacy, etc.

Recommendation #3: Develop an accreditation process for organizations offering AAEBIs and other evidence-based interventions.

Providers will want assurances that interventions and organizations to whom they are referring their patients are effective. Ensuring that an intervention is evidenced-based and backed by research can help a clinician feel confident in that intervention. Likewise, knowing that an organization offering that intervention is accredited—or following specific standards/criteria—can increase confidence in recommending a program.

Crucial to developing accreditation—both of interventions and of organizations—is the need for an organizing body to take ownership, get buy-in and input from diverse stakeholders, document decisions and rationale, and provide technical assistance.

By looking at other models with an accreditation process, like the National Diabetes Prevention Program (National DPP) lifestyle change program, an accreditation model that incorporates elements in which providers will have increased trust in the referrals they make could begin to be constructed. In developing the accreditation process, consideration should be given to providing sufficient resources to organizations to successfully complete accreditation. Lessons could be pulled from existing CDC-recognized organizations that participate in the National DPP lifestyle change program. Specifically, lessons around how much effort was needed to become CDC-recognized, what some of the biggest challenges were, how becoming CDC-recognized changed their relationship with providers and health systems, etc.

Human-Centered Design Recommendations Report

Recommendation #4: Design a model that integrates care team members that meet patient needs.

The Advisory Panel should consider ways to integrate traditional care team members (such as physical therapists, specialists, mental health professionals) as well as care team members that are on the cusp of traditional care models designed to connect patients with resources and programs (such as patient navigators, health coaches, community health workers). In some cases, these care team members might be internal to the PCP's clinical network, and in other cases, external community resources might be leveraged. In both cases, the ability to communicate information back and forth is crucial.

As the care model is evaluated, consider tracking data showing how these non-traditional care team members are supporting referrals and patient outcomes as a result of program participation. This evaluation and data validation will help confirm the value of non-traditional care team members and provide evidence that could be used to support scaling of the model to other locations.

Recommendation #5: The resulting framework needs to be flexible for different capabilities, models, and health system situations.

Across the human-centered design sessions, Advisory Panelists emphasized that a framework for increasing the screening, counseling, and referral for self-management behaviors should be able to scale to the realities of different health systems. For example, while an extremely effective approach would incorporate a fully-staffed care team—with physical therapists, community health workers, patient navigators, specialists—different facilities may not have those partnerships in place. A care model or framework should provide guidance for meeting patient needs, with the flexibility to adapt to different situations.

Recommendation #6: Considerations for a pilot program include demographic considerations, flexibility in reimbursement arrangements, and a strong relationship between a health system, payers, and community resources.

Advisory Panelists flagged items that should be considered when identifying a pilot site, including:

- a. **Equity considerations:** A model needs to incorporate considerations to address health equity, including disparities in access, rural vs. urban, socioeconomic challenges, and other disparities in care. Consideration of geographic, demographic, and commitment to equity should influence which health system is identified.
- b. **Reimbursement for community organizations:** When developing such an approach, careful consideration should be given to how CBOs and other non-clinical partners will be reimbursed. If a new care model successfully increases referral opportunities, CBOs and other non-clinical partners will require sufficient resources to support lifestyle health improvement and social needs for people with arthritis. In addition, all care team members should be permitted to practice at the top of their licensure or skillset while also receiving appropriate payment for the services provided to ensure it is economically viable.
- c. **Flexible reimbursement opportunities:** A challenge identified throughout the sessions was the inability of traditional fee-for-service (FFS) payment models to incentivize access to more expansive care team members, including non-clinical partners and qualified healthcare professionals (QHP) such as exercise physiologists. Alternative payment models (APMs) such as condition-specific bundles, accountable care organizations, etc. could help provide flexibility outside of the FFS system. Consideration could be given to payers or hospitals that currently participate in value-based payment models as a starting point for piloting a new payment model. However, scaling a program tested in a flexible environment could prove challenging, as many health systems continue to rely on a traditional FFS approach. During the pilot phase,

Human-Centered Design Recommendations Report

consideration should be given to evaluating the successes and potential challenges of the value-based model and preparing to share the results during the scaling phase.

- d. **Strong payer/provider relationships:** Often, alternative approaches to providing care relies on a strong relationship between a payer and provider, so that they can adequately share the risk for the patient population and have an equal incentive for patient outcomes. Therefore, a strong relationship with a payer and provider would likely provide an optimal environment for piloting an innovative approach to increasing self-management behaviors, including physical activity and lifestyle change.

Recommendation #7: Seek input from different perspectives, including patients, to ensure that the model can be implemented in the real world and improve patient outcomes.

The Advisory Panel explicitly and intentionally sought representation from different perspectives, including patients, patient advocacy, clinical professional organizations, primary care, clinical specialties, physical therapy, public health, community health workers, community-based organizations, and payers. Not only should these perspectives continue to be sought out by continuing to engage Advisory Panel members throughout the care model process, but additional feedback should be sought out to ensure that the model can be applied in practice. Patients, specifically, should be consulted to ensure that a model meets their needs. While a process needs to be clinically feasible, it also needs to be patient-centered and designed to help engage patients with arthritis through a shared-decision making process (not just move them through a series of steps).

Recommendation #8: Select/develop a screening tool for arthritis patient quality of life

Because a screening is the first step in connecting patients with physical activity, consideration should be given to what screening tool is used in the model. Some considerations flagged by the Advisory Panelists include:

- Be comprehensible and culturally relevant to patients.
- Address/trigger more in-depth questionnaires.
- Should lead to conversations around goals and accessible resources.
- Take advantage of already built-in or required screening tools.
- Consider how and when these tools are administered.
- Be succinct as possible.
- Take advantage of different mediums, including a phone call, text, or patient portal.

Moving Forward

In the next phase of the work, we will take the recommendations from the human-centered design sessions to co-create an arthritis care model with the design team that includes screening of persons with arthritis for quality of life, brief advice and counseling, and referral to lifestyle management programs. This model will be tested in a health system pilot and will be spread based on a successful evaluation of the pilot.