

ENGAGEMENT AWARD FINAL SUMMARY REPORT

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## Matching Actions to Needs: What Matters Most to the Arthritis Community?

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## Project Methods and Key Findings

### Methods

The project had an advisory team comprised of AF staff, patients, and healthcare providers (HCPs) who provided guidance and oversight. The advisory team as well as broader AF leadership helped to identify people for the listening sessions, review/revise discussion guides, and review/revise the session summaries.

Listening sessions happened in different ways depending on the nature of the session. For example, the project team worked with clinical professional societies, clinics, and academic centers to recruit for HCP sessions, but patient sessions were recruited directly from the patient community through both local market and home (national) office staff. Each listening session was recorded (minus two, during which technical challenges arose). The sessions were transcribed and summarized.

For the final report, the 10 patient sessions and 10 healthcare provider sessions were summarized separately and the team will continue to analyze and compare and contrast the data to identify trends related to topics patients and HCPs find troubling and promising.

### Key Findings

#### Healthcare Provider Sessions

HCPs shared that challenges with paying for and accessing care are incredibly common. They include problems with insurance and health system restrictions and pressures, research funding limitations, reimbursement challenges, or rising patient costs for medications and other aspects of care. In clinic offices specifically, the administrative burden of issues like prior authorization or denied claims waste hundreds of hours. The family, financial, and other aspects of patients' lives are also significant in terms of

creating—or removing—barriers to quality care. Struggles with transportation, money, and childcare caused patients to have to miss appointments. The difficulty of coordinating care across various providers, pay for refills, and get referrals also contribute to delayed or omitted care.

The need for patient education is also a universal concern, whether it is increased awareness of research, better disease education, or stronger health literacy. Several HCPs identified the Arthritis Foundation as an important source of information and patient support, but many did not know exactly what the foundation does or how to best avail themselves or their patients of its information.

For those providing specialized services to arthritis patients like PT, OT, and surgery, there was concern that other clinicians did not fully understand how PT, OT, or surgery could be helpful or when in the course of someone's disease these services could be helpful. Several HCPs were frustrated by the lack of awareness and the resulting delay in or lack of referral, or in the case of surgeons, the premature referral when other nonsurgical tools would be more appropriate.

Similarly, there was a concern among specialized providers that arthritis was not a focus during their training and most of their experience with arthritis patients and providing arthritis treatment has been on the job. Many felt this was an area in need of major improvements.

All HCPs expressed difficulty with competing priorities where they practiced, wanting to spend a certain amount of time on what they felt was important, but being unable to because of other pressing demands on time. This was a particular problem in research settings where the desire to conduct research was at odds with other institutional needs, but it was also a problem in rheumatology and surgery settings where patients most needed things like pain management, care coordination, or mental/emotional health support, but those issues could not be addressed in the amount of time provided

for a given appointment. For pharmacists, this problem was made worse by their lack of “provider status” and the current expectation that patient-facing education and care coordination be done for free.

## **Patient Sessions**

### Physical Aspects of Disease

Some symptoms were common across all 10 sessions. Pain was consistently identified as the most difficult symptom. Some patients described it in detail, providing specific location and type of pain while others expressed the impact more in terms of how it changed their functional abilities and what “losses” they were experiencing as a result of their pain. Depending on diagnosis, fatigue was another significant issue—this was less of an issue in OA patients but a significant problem for both adult and juvenile patients with inflammatory diseases like rheumatoid arthritis or juvenile idiopathic arthritis (also called “inflammatory arthropathies”). Also specific to inflammatory arthropathies, swelling and redness were problematic; for young adults and children, this could be embarrassing because it makes them look “different” from their friends or classmates. In both OA and inflammatory arthropathies, structural damage to the joints was a major concern. The need for surgery came up in every listening session, with the most common interventions being hip and knee replacements, but ankle, wrist, neck, feet, finger, hand, TMJ, and other operations were also experienced by participants. The young adult and parent groups understandably had concerns unique to juvenile-onset disease, with eye involvement and concern about blindness being the most significant. Other JA-specific manifestations also surfaced like issues with TMJ, distal (the joint closest to the tip of the finger) finger joints, and some specific spine involvements. These groups also shared concerns about growth and not only the impact of the disease on growth, but the impact of treatments on growth.

Functional impacts from the disease were also common across all diagnoses, with only slight differences between age groups. Being forced to stop or change involvement in leisure and social activities, sports, and other similar things was difficult for many patients. This led to feelings of loss, sadness, and frustration. Similarly, many patients talked about how their disease had affected their career decisions—ending careers early, making different career choices, cutting back on travel—and this contributed to feelings of powerlessness and worry. For young adults and parents of children, concerns about functional ability affected short-term and long-term planning, from taking vacations to making college or career decisions. Interestingly, parents raised concerns about reproductive health, but young adults tended to not surface this concern. Common to both OA and inflammatory diseases, though for different reasons, lack of understanding of the condition contributed to additional frustration. In OA, it was the lack of awareness of how severe and impactful the pain can be; in inflammatory diseases, it was lack of understanding of what the diseases are and what they do.

Social and emotional aspects of disease surfaced across all sessions. The impact of pain, functional loss, and the unrelenting nature of the disease(s) resulted in feelings of loss and sadness and many patients or parents talked about depression and loneliness. Anxiety and worry were also common issues across groups, with fear of the unknown, dealing with access barriers, and even navigating scheduling of appointments and follow-ups contributing to patients and parents being overwhelmed. The extent of these problems was not limited to the patients themselves; parents described their own anxiety and concern and patients shared full-family effects. These social effects of disease also spanned all groups.

Parents talked about changing jobs in order to manage a child's condition; adult patients talked about missing time with grandkids or having to find an older group of friends who are more suited to their activity level. Parents were very concerned about their kids being "left out" at school and adult patients described similar sentiments, losing touch with people during periods of high disease activity.

With regard to experience of care, a few universal themes emerged from the groups about what makes the “best” clinician relationships and leads to the best care, including: clinicians who spend adequate time in clinic visits, be it a physician, nurse practitioner, or nurse, and are willing to openly communicate with the patient; the necessity of time extended beyond clinic visits to follow up and prompt return of phone calls, follow-through on process issues like insurance denials and pre-authorizations, and prompt attention on drug refills.

The two groups of Walk with Ease exercise class participants (primarily OA) surfaced a unique aspect of time not raised by any other group. They need clinicians who give them time to evaluate options, talk with family, and most importantly, pray, before making a choice. These two groups were conducted in Shreveport, Louisiana, and the participants were all African American, primarily native to Shreveport, with a deep and very open sense of faith. Also unique to the Shreveport groups was an overall appreciation and gratitude for their clinicians, versus other groups of adult patients who tended to have more dislike/negative experiences with clinicians than positive. For those followed by a rheumatologist, there was not a clear preference for rheumatologists over NPs or PAs, or a clear preference for NPs or PAs over rheumatologists; it generally depended on what a person had been exposed to and how solid the relationship was with whomever his or her clinician was.

There were also several surfaced challenges or barriers to receiving high-quality care. Cost consistently came up, across all groups, as a barrier to receiving high-quality care—or at least as a source of anxiety in the attempt to achieve high-quality care. As important as good communication was to facilitating good care, poor communication (e.g., judgmental or dismissive) were hallmarks of bad care. In almost every session, stories were shared about unkind remarks or unfortunate conversations that resulted in clinicians being “fired” by the patient or follow-up care being abandoned. Similarly, as important as adequate time and attention were to facilitating good care, feeling rushed

in clinic visits and experiencing missed follow-ups were a significant barrier to quality care. Related to this notion is the lack of coordination between providers, clinics, or health systems. Patients expressed not only frustration with how this affected their care, but with how much time and energy they had to spend serving as the single point of contact between all of the players in their medical team. In OA, the most problematic aspect of provider-patient communication was being “believed,” with many patients sharing anecdotes about how they were told to “get used to it” and that “everyone had arthritis.”

In juvenile arthritis, there was less discussion about providers in general and far less negative sentiment about providers—most energy was focused on the shortcomings of available treatments and lack of knowledge about long-term effects of therapies. The orthopedic surgery-focused group also raised issues with getting insurance approval for joint replacement or other surgical intervention, or with finding a surgeon willing to perform surgeries in young patients. Participants across all of the adult groups raised the issue of challenges with the initial information about diagnosis—that it was not made clear the disease was permanent, or in the case of OA, many people were not told they had OA, but rather that they had a “bad hip” or a “bad knee” that would be fixed with surgery.

Finally, in discussing involvement in research or clinical trials, there was wide variation in perspective. Across all groups, there was very limited involvement in research. Those who had been involved in research largely did so because they were “at the end” of their treatment options and felt there was nowhere else to go; even so, several shared they felt good about what they’d done because it contributed to the general knowledge of the community. However, there was a profoundly strong negative reaction to the concept of participating in research, particularly if there was a potential to be exposed to placebo. This sentiment was strongest among the juvenile onset disease groups. Interestingly, some patients in the OA groups did not have a strong reaction to placebo-controlled trials because there is nothing available to them now anyway. The other

enormous factor in willingness to participate is concern about losing stability—which may have taken years to acquire—in disease management. Many shared that they would never opt for research because they worked for years to find the medication combination that led them to some disease stability. When describing viable facilitators for participation in research, the answers were fairly similar across groups. Many felt that trusting and feeling confident in the care provided by a given clinician would make them more likely to participate in research—if that clinician were doing the research and made the invitation. Some participants were moved by the idea that involvement in research helps the broader community, but whether or not they’d ultimately be willing to participate boiled down to how stable they were on current therapy. In some conversations, the notion that involvement in research can help offset costs of therapy was slightly motivating. It didn’t necessarily move the dial from “no” to “yes,” but it could be a factor.

## **Project Impacts on Patients and Other Stakeholders**

The Arthritis Foundation will use the data from these sessions to inform its work, whether that involves funding research, creating education and resources for patients, or supporting advocacy efforts.

Specific to the patients, there were several domains of impact/outcomes. Within the realm of physical aspects of disease, the need for better treatments for OA stands out as a key theme (except for the subset of OA patients who felt that exercise and other self-efficacy was the best therapy). Among those with inflammatory arthropathies, the need for better understanding about how biologics work, for whom, for how long, and with what side effects was a clear need, particularly among young patients. Another research need emerged as the “why did this happen?” question and what could potentially be done to prevent onset of arthritis. For those already affected by disabling joint damage, many wanted a better understanding of joint replacement and repair surgeries, some guidance about when it is appropriate to take that step and which type of surgery or device is best.

Within social and emotional aspects of disease, it is clear that human-to-human support/community support is key to emotional health and healing. The challenge is making sure patients are aware of what resources exist so the task is to make clinicians better conduits and connect newly diagnosed patients to AF resources and community supports as soon as possible. Patients clearly want educational/informational resources, but they need help navigating—"I don't know what I don't know" came up. So the idea of curated, specific content that is manageable and accessible is key. In the OA space, it is clear that many patients feel dismissed or disbelieved and greater awareness is needed of the true and often devastating impacts of OA.

Several key areas also emerged from conversations about the experience of care. Cost and access barriers were surfaced throughout the groups and continued dedication to these issues on the advocacy side is certainly needed. The challenges with adequate time and appropriate communication in clinician interactions were equally prevalent but more difficult to address. Increased focus on training/resources for clinicians on patient-centered care and engaging in shared decision making could be the key. The AF's PRO program can be a useful tool for disease management and interaction with clinicians, but patients will need to fully understand the purpose of collection, the benefits of tracking, and the protection of the data shared. Clinicians will themselves need to be educated on PROs and how to better incorporate them into co-production of care plans and treatment goals.

Shifting to the concept of research, incentivizing participation in research continues to be incredibly difficult. Clearly any placebo-controlled trials or other research protocols that could result in a lack of effective treatment are nonstarters. Being recruited for research by a trusted clinician is helpful as is having a broader understanding of the value to the whole community, but if someone is (finally) stable on therapy, they are generally not willing to jeopardize that state. The people who tend to be most willing to be involved in research are those for whom no effective therapies exist (OA, and people with inflammatory arthropathies who've cycled through all available therapies).

Similar to the patients, there were several key domains of impact/outcome for the HCPs, namely, research considerations, advocacy considerations, patient education ideas, and general information to keep in mind for strategic planning and resource creation.

Research considerations include issues the Arthritis Foundation could explore as well as topics other key funders should consider. These included but were not limited to:

- Health system improvement with a focus on care coordination, and similar larger-context research projects
- The role of physical activity and nutrition on arthritis
- The impact of supplemental therapy on arthritis
- The effects of steroids on long-term health, especially in children, and the use of adult medications in children
- Mental health challenges in both pediatric and adult rheumatologic conditions
- Communication, whether patient/physician, physician/physician, full medical team communication, clinic to clinic, and health system to health system
- Research on physical therapy assessments prior to injections
- The impact of faulty movement patterns in athletes
- Intervention plans of activity as they relate to obesity and joint replacement
- Condition-based occupational choices, limiting factors or obstacles that are encountered, and impact on quality of life
- Measurement of OT care in-home vs. no care

- The cause of delays of necessary surgery—How bad does it have to get for them to go? What provokes them to go? (i.e., “I should have had hip surgery five years ago, and how does waiting too long affect quality of life?”)

Advocacy considerations were also numerous. Financial barriers are present in every HCP experience, whether from insurance and health system restrictions or the administrative burden of things like prior authorization and denied claims. While a drain on HCPs, these issues ultimately impact patients’ ability to access timely care and therapy. Pharmacist provider status was a significant barrier to pharmacists being able to play an expanded, patient-facing role. There were clear gaps in training for many types of clinicians, particularly specialized providers of care, who felt like arthritis-specific training was not available. Rheumatologists in particular have concerns about reimbursement policies, potential Medicare payment changes, and the impact low reimbursement can have on the already strapped rheumatology profession. Other concerns include the need for greater transparency in pharmaceutical pricing, rebates, claw-back provisions, and the role and function of pharmacy benefit managers.

Many key needs surfaced within the patient education focus. In many cases, the Arthritis Foundation has tools and resources that are specifically relevant to the identified needs. This indicates that the Arthritis Foundation has the opportunity to expand its efforts to reach more patients with targeted dissemination of education and resources, and to connect with more HCPs who can serve as conduits for information.

Finally, there were several findings that don’t fit within a particular category. There were widely expressed barriers to participation in research, and even those who had experience conducting research shared that they faced institutional barriers and pressures against conducting research. Furthermore, recruitment and retention remain significant hurdles to conducting research. Socioeconomic, geographic, and other patient characteristics came up in every conversation as drivers of health outcomes, with those most disadvantaged or under-resourced being most likely to receive the poorest quality care. There were not many ideas for combatting this widely shared issue, and this is important context for the team’s work. There was also a

widespread concern that arthritis was not a focus during clinical training and most practitioners had gained experience with arthritis patients and providing arthritis treatment on the job. Many felt this was an area in need of major improvements.

## **Project Accomplishments and Challenges**

### **Accomplishments**

The project team felt that all of its key objectives and goals were met, even if not in exactly the ways that were originally envisioned. In both patient and HCP engagement, the team was able to successfully gather all of the planned number and type of patients and HCPs, with a tremendously diverse spread across multiple HCP types and multiple patient types. Working closely with the local market staff and multiple HCP relationships, the team was extremely pleased with the turnout across all listening sessions. Similarly, the patient and HCP members of the advisory team played important roles, helping plan for the listening sessions and drafting or revising the discussion guides. The team members felt that they were able to get a far-reaching, diverse, and generally representative mixture of both groups. The project definitely created a neutral space for clinicians, patients, and caregivers to provide insight into their experiences in healthcare delivery and arthritis treatment, which was the envisioned “platform.” Multiple patients and HCPs said that they were grateful and excited to be involved, and followed up with requests to be involved in future sessions. All were eager to see the summarized information and to partner with the team as it moves forward on some of the key findings. The feedback has begun an honest conversation to identify where research and services are not meeting the needs of those most affected and what solutions could be employed to overcome challenges. The knowledge report has collected and synthesized the information gathered from the listening sessions and it outlines the issues and research questions or topics most critical to the arthritis community in an accessible format that can be utilized for further research purposes. The team will be using this report, sharing with multiple partners, and depending on the

findings to guide its strategic planning. The broader patient community will also have an opportunity to provide insights and commentary on the report and the team will partner with the patient community as it moves forward to execute on some of the clear calls to action.

## Challenges

The old saying “If you want to go fast, go alone, if you want to go far, go together” is always a useful guide in patient and stakeholder engagement! Working with a large group also requires a bit of additional time and planning, but the value of collaborating with a large and diverse team far outweighs the time and effort involved. Other minor challenges related to scheduling delays and making arrangements for the listening sessions. A few listening sessions were delayed or canceled, but the team was able to reschedule or shift course and identify new opportunities. As is always the case with technology, the team, of course, faced a few technological glitches with recording devices and/or clarity of recordings, but the team was able to draw from copious notes and team member recollections.

## Project Stakeholders/Collaborators

Throughout the project, the most notable impact has been on language and tone, as provided by patient and HCP feedback on various documents. The advisory team members and members of the patient leadership council have added some important and interesting lines of questions, most notably the concept of asking providers and patients the same question to see whether they view things similarly or differently. Two key examples were the inclusion of a question about adherence to medications (i.e., when I have not taken my medications as prescribed, here is why vs. why do you think your patients don't always take their medications as prescribed) and inclusion of a question about shared decision making (asking patients to “rank” where they fall on an SDM continuum vs. asking clinicians to rank their patients on an SDM continuum).

The patient and stakeholder advisory team members, AF staff, and community partners have been incredibly helpful in facilitating opportunities for sessions, particularly on the HCP front with sessions at American Occupational Therapy Association, American Physical Therapy Association, Childhood Arthritis, Rheumatology and Research Alliance, National Organization of Rheumatology Managers, Rheumatology Nurses Society, and Washington (state) Rheumatology Alliance. Additionally, the team had the pleasure and value of working with two orthopedic groups—OrthoCarolina and OrthoCincy, the University of Missouri-Kansas City School of Pharmacy, the National Recreation and Park Association, and the David Raines Community Center in Shreveport, Louisiana. Having the opportunity to work with these partners all around the country truly enriched the project and the team is very grateful to everyone who contributed to this project.

The most significant impacts are described above. Even through to the creation and revision of this final report, the advisory team members are contributing with feedback that helps to clarify the message, improve tone, and better communicate findings. The advisory team members and the broader patient community will also help in the coming months to determine the key action items to execute from the report findings.

## **Plans to Disseminate Findings from the Project**

The project team feels that this final report is just the first step of a long-term dissemination strategy. The team will share the report with many specific groups within the patient community as well as with the broader community, and with many specific HCP groups. It will be used to inform research funding strategy, and potentially influence the advocacy agenda, as well as outline needs for patient resources and education. The Arthritis Foundation's Patient Leadership Council, Senior Leadership Team, and other committees will be asked for ideas for use and dissemination of the work.

The two greatest dissemination challenges are handling the large amount of information collected and communicating fairly complicated topics in plain language. The team has such a

huge number of findings that it is difficult to narrow down and identify the most important messages, so the key will be to develop specific products for specific audiences. To manage the issue with plain-language communication, the team will rely on its many patient community members to co-create shorter, more targeted communication pieces as well as AF's marketing and communication experts, many of whom are well versed in health literacy and health communications.