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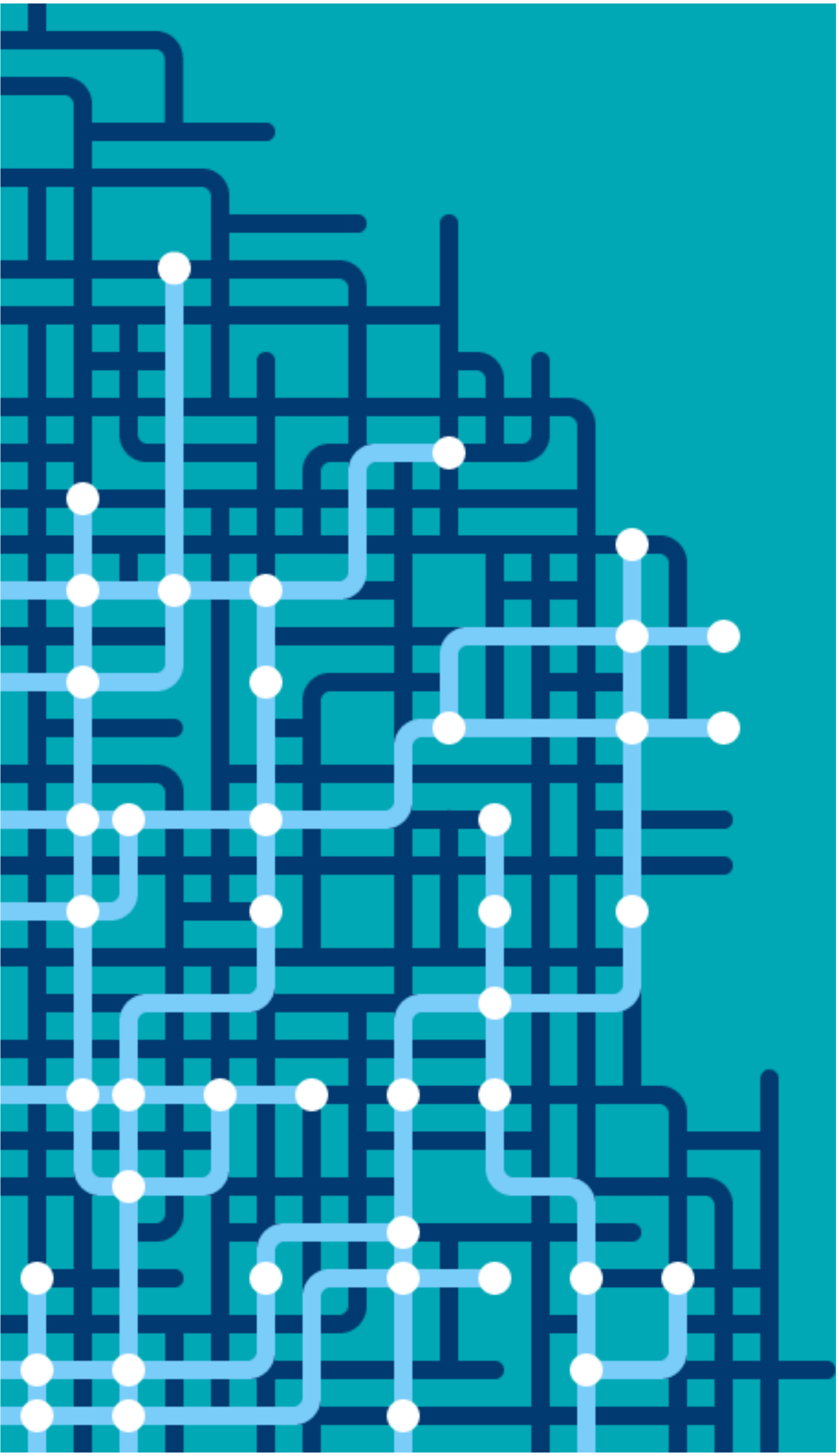

Ideal Model of Care

2023 Arthritis Foundation Ideal Model of Care Report

Executive Summary

The health care system in its current form continues to fail patients with chronic diseases like arthritis, and there is a great need for truly patient-centered care that prioritizes the whole patient, from diagnosis through long-term maintenance. To address this, the Arthritis Foundation has embarked upon a multi-year initiative, called Ideal Model of Care, to help patients realize an ideal health care experience without challenges they currently face, from expensive out-of-pocket costs to insurance barriers to poor care coordination.

We collected extensive data through formal surveys, patient listening sessions and expert interviews across the health care ecosystem. These highlighted common themes that will form the basis of our initiative.

1. **Meaningful Patient Engagement.** The patient community and patient-reported outcomes have a vital role in driving this initiative. Funding is needed for research and programs that will empower people with complex chronic conditions to interact effectively with the health care system. Patients should be comfortable advocating for themselves with their providers, insurance plans and other health care stakeholders. Opportunities include patient representation on insurance plan committees and other coverage decision-making bodies, effective tools for shared-decision making, robust development and utilization of patient-reported outcomes measures and patient-centered strategies to assess the value of treatments.
2. **Value-based care.** Gold standard models involve a care team providing wrap-around, holistic care for the patient. This includes social workers, mental health specialists, physical therapists, and others. Shifting the focus from short episodes of care toward total lifetime care and costs of care for patients living with arthritis entails two key elements: **Care coordination**, including access to care coordinators, or "navigators," supports moving from fee-for-service toward value-based care, including interoperability of electronic medical records across health care systems and caregivers. A **right-sized care team** includes access to the providers needed to manage arthritis, appropriate incentives in a value-based care design, insurance coverage for complementary therapies, and more.
3. **Technology as a solution.** Digital tools tailored to specific patient conditions could help improve health care, from symptom management and insurance coverage to telehealth. Improving digital infrastructure and system interoperability are key to achieving better health outcomes.
4. **Accessibility and affordability.** Access to health care should be viewed across the lifetime care needs of patients — without disruptions resulting from unaffordable **out-of-pocket costs and barriers to accessing care.** This may include lowering caps on out-of-pocket costs for therapies and services, ensuring access to copay assistance, guaranteeing access to plans with flat copays instead of coinsurance, and reforming step therapy and prior authorization.
5. **Overcoming health disparities** must be a factor in all health care reforms, including policies to address social determinants of health, socioeconomic disparities, geography, clinical trial diversity, improved data collection, and cultural competency in provider settings.

These themes and opportunities for action will be prioritized across the Arthritis Foundation. They will form the basis for our advocacy work in the years to come, beginning with the 2023 federal and state legislative sessions and policy arenas. We will work with legislators, policymakers, health systems, health care providers and other decision-makers to develop these themes and recommendations into true value-based, patient-centered care actions.

Introduction

The U.S. health care system often falls short of delivering true patient-centered care. Traditionally, it emphasizes fee-for-service or volume-based care, and a lack of integration exists across providers, systems and sectors. Patient conditions and treatments have increased in complexity, yet the health care system has not evolved to meet these new demands. For myriad reasons, stakeholders are not incentivized to prioritize the long-term, comprehensive health of the patient. For example, providers may treat only one condition; payers operate in one- or two-year budget windows; and employers consider a person's employment span rather than the patient's life span. As a result, patients with chronic conditions end up following health care rather than their health care following them.

A 2022 report shows that 44% of Americans give a failing grade to the U.S. health care system.[1] Meanwhile, health care costs continue to rise, so people are paying more without perceiving a commensurate added benefit. Among Organization for Economic Cooperation and Development (OECD) countries, the U.S. spends the most on health care per capita – more than $8,700 – yet has the lowest life expectancy at 77.3 years.[2] We often hear talk about the U.S. health care system being broken, and it seems most people agree there must be a better way — but what is that better way, and how can it be scaled to reach all patients?

The answers are complex and there is no single "fix." However, the Arthritis Foundation has embarked on an ambitious goal to analyze the health care challenges impeding people with chronic diseases like arthritis and formulate solutions to help them realize their Ideal Model of Care. To make true progress on improving health care delivery while lowering costs, we believe every question and every answer must keep the patient at the center.

I. THE ARTHRITIS PATIENT'S EXPERIENCE

Arthritis is an umbrella term referring to over 100 diseases of the musculoskeletal system. Most forms of arthritis fall into one of two categories: degenerative or autoimmune arthritis. This is not just an "elderly disease." Two-thirds of people with arthritis are under the age of 65, and nearly 300,000 children in the U.S. are living with doctor-diagnosed arthritis. The U.S. Centers for Disease Control and Prevention (CDC) reports arthritis affects almost 60 million adults in the United States, or about one in four adults, though new estimates claim this is closer to one in three. Arthritis is the leading cause of disability in the U.S., and it is predicted that nearly 78.5 million adults will have arthritis by 2040. Pain, swelling and stiffness are the most common symptoms arthritis patients initially experience, and early symptoms may be easily dismissed. But arthritis is a progressive disease, so a timely diagnosis can impact patient outcomes for years to come.

If a patient does not receive a diagnosis and treatment plan within the first weeks or months of symptom onset, long-term complications can arise, including permanent joint damage, organ damage, and a diminished likelihood of achieving remission. Research has shown that patients who receive early aggressive treatment after symptom onset have improvements in pain within 12 weeks and are more likely to have less joint damage than those who don't. However, receiving an arthritis diagnosis is not always straightforward. People generally visit their primary care

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[1] West Health-Gallup. "West Health-Gallup 2022 Healthcare in America Report." 2022. https://www.gallup.com/analytics/401972/healthcare-in-america-2022.aspx?utm_source=newsletter&utm_medium=email&utm_campaign=newsletter_axiosvitals&stream=top

[2] Trilliant Health. "2022 Trends Shaping the Health Economy." October 2022. https://www.trillianthealth.com/insights/reports/2022-health-economy-trends

physician first, and they may see multiple providers and go through a barrage of tests, including blood work, X-rays, physical exams and MRIs before receiving a diagnosis. With some forms of arthritis, such as rheumatoid arthritis, a person typically experiences symptoms for at least six weeks before receiving a formal diagnosis. Estimates vary, but it takes approximately six to 11 months after symptoms begin to receive a diagnosis and begin treatment.

In addition, comorbidities, especially heart disease, diabetes and obesity, are common among those with rheumatic diseases, and each presents unique challenges and disease-specific barriers. Adults who have arthritis and any of these comorbidities are less likely to be physically active, which puts them at greater risk for complications from chronic conditions, according to the CDC.[3]

Treatment of autoimmune forms of arthritis often begins with conventional synthetic disease-modifying antirheumatic drugs (DMARDs), such as methotrexate, and escalate to include biologic therapies. While biologics lead to a higher quality of life and improved outcomes for many patients, many others try multiple biologic drugs without success.[4] A retrospective study conducted from April 2015 to January 2019 found the overall prevalence of failure to biologics was 58%, with 77% failing to respond to the initial treatment and 23% for whom the drug lost effectiveness over time.[5] It is common for a therapy to work well for a while and then lose its effectiveness, forcing the patient to try new treatments again. An Arthritis Foundation study from 2016 found that patients typically tried two or three biologic therapies before finding one that worked well. Unfortunately, some people with autoimmune forms of arthritis do not positively respond to any therapy. Biomarker testing in RA is a promising frontier in identifying the biologic class to which the patient might best respond. This could be a game-changer in getting the right therapy early and preventing worsening disease.

Osteoarthritis (OA), by far the most prevalent form of arthritis, does not have a disease-modifying drug. Managing OA, therefore, typically requires a multimodal approach of therapeutic options, including nonsteroidal anti-inflammatory drugs (NSAIDs), and nontherapeutic options, such as self-management programs. The Arthritis Foundation and American College of Rheumatology jointly released clinical treatment guidelines for OA in 2019, with strong recommendations for exercise, weight loss, self-management programs and NSAIDS.[6] Further, increasing research is showing the importance of exercise in managing arthritis, especially OA, and there are a number of Arthritis-Appropriate Evidence-Based Interventions (AAEBIs) specifically designed for people with arthritis, such as Walk With Ease, Tai Chi for Arthritis, and Chronic Disease Self-Management Programs.[7] Because there is no disease-modifying drug for OA, many people with this disease experience destruction in the affected joint and eventually need a joint replacement.

Surgery is a common, though expensive, treatment for people with musculoskeletal conditions, but it doesn't always result in the best outcome for the patient. For example, a person with arthritis may see multiple specialists in multiple health systems. They could receive every type of imaging and injection to relieve their pain and improve function before they see a physician who recommends a knee or hip replacement. That patient may proceed to have surgery with a bundled payment system, and it is successful. However, the patient is still miserable because the treatment focused

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[3] Centers for Disease Control and Prevention. "Arthritis Data and Statistics: Comorbidities." August 4, 2022. https://www.cdc.gov/arthritis/data_statistics/comorbidities.htm

[4] Novella-Navarro, M., Plasencia, C., Tornero, C. et al. "Clinical predictors of multiple failure to biological therapy in patients with rheumatoid arthritis." Arthritis Research & Therapy. Volume 22. Article 284. December 9, 2020. https://doi.org/10.1186/s13075-020-02354-1

[5] Fatani, Arwa; Bugshan, Nada; AlSayyad, Hanan, et al. "Causes of the Failure of Biological Therapy at a Tertiary Center: A Cross-Sectional Retrospective Study." Cureus. September 13, 2021. doi: 10.7759/cureus.18253

[6] Kolasinski, Sharon L; Neogi, Tuhina, et al. "2019 American College of Rheumatology/Arthritis Foundation Guideline for the Management of Osteoarthritis of the Hand, Hip, and Knee." Arthritis & Rheumatology, vol. 72, no. 2, 2020. https://www.rheumatology.org/Portals/0/Files/Osteoarthritis-Guideline-Early-View-2019.pdf.

[7] Osteoarthritis Action Alliance. "Arthritis-Appropriate, Evidence-Based Interventions (AAEBI)." May 1, 2023. https://oaaction.unc.edu/aaebi/.

solely on the joint and not on their bio-psycho-social needs, which would have addressed the appropriateness of the procedure for that patient, not simply efficiency and surgical quality measures.

Putting this all together, timely diagnosis and appropriate treatment are crucial for overall health outcome and prevention of severe disease. We believe that if all sectors of health care prioritized the long-term health of the patient, outcomes would improve, costs would drop and patients would receive higher-value care.

II. THE PROBLEM WITH U.S. HEALTH CARE

Rising costs, increased barriers to care, a lack of transparency, disparate business models with misaligned incentives, and system fragmentation combine to create a health care system that often works against people with chronic diseases like arthritis.

Costs of Health Care

Health care spending surpassed $4 trillion in 2020, and a 2022 report shows that by 2030 it may reach 19.6% of GDP.[8] As these costs — borne by employers, insurance providers, patients and taxpayers —continue to rise, barriers to affordability and coverage for patients are also rising. The CDC estimates that direct and indirect costs of arthritis are more than $300 billion annually. A 2017 *Health Affairs* article showed that over 25% of workers with arthritis who had disability leave took it and over 10% of those who didn't have disability leave took it anyway.[9] The CDC estimates that five chronic conditions – several of which are common comorbidities of arthritis – cost U.S. employers over $36 billion a year in lost productivity.[10]

Rising costs of health care are an increasing burden on employers who offer health insurance, often forcing them to cut costs or limit benefits. Annual premiums for employer-sponsored family health coverage reached $22,221 this year, up 4% from 2021, with workers on average paying $5,969 toward the cost of their coverage. Out-of-pocket maximums are on the rise as well: 27% of covered workers plans have an out-of-pocket maximum of $6,000 or more.[11] High-Deductible Health Plans (HDHPs) are increasingly common in the employer market and deductibles in these plans have gone up more than $500 on average since 2010 to $2,424 for individual coverage and $4,705 for family coverage in 2021.[12] The number of people enrolled in HDHPs has also risen in recent years; 28% of covered workers in 2021 are in HDHPs. Coupled with rising premiums and copays, the median spending on health care was 11.6% of household income in 2021. As a result, the U.S. has reached $140 billion in medical debt and 17.8% of people who *have* insurance experienced medical debt in 2020.[13] In other words, health care is increasingly unaffordable — and unattainable — for many

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[8] Poisal, John A.; Sisko, Andrea M, et al. Health Affairs. "National Health Expenditure Projections, 2021–30: Growth to Moderate As COVID-19 Impacts Wane." Vol. 41, No. 4. March 28, 2022.

[9] Health Affairs. "Workforce Health and Productivity." February 1, 2017. Vol. 36. Issue 2. 200-201. https://www.healthaffairs.org/doi/epdf/10.1377/hlthaff.2016.1580.

[10] Centers for Disease Control and Prevention. "Chronic Disease Fact Sheet: Workplace Health Promotion." June 9, 2022. https://www.cdc.gov/chronicdisease/resources/publications/factsheets/workplace-health.htm.

[11] Kaiser Family Foundation. "2021 Employer Health Benefits Survey." November 10, 2021. https://www.kff.org/health-costs/report/2021-employer-health-benefits-survey/#:~:text=Annual%20premiums%20for%20employer%2Dsponsored,is%20%241%2C669%20for%20single%20coverage.

[12] Trilliant Health. "2022 Trends Shaping the Health Economy." October 2022. https://www.trillianthealth.com/insights/reports/2022-health-economy-trends.

[13] Trilliant Health. "2022 Trends Shaping the Health Economy." October 2022. https://www.trillianthealth.com/insights/reports/2022-health-economy-trends.

Americans.

Prescription drug costs — specialty drugs in particular — have escalated at a particularly high rate. Spending on anti-inflammatory drugs, like those used to treat autoimmune forms of arthritis, tops all other therapeutic areas, accounting for 35% of specialty pharmacy spending.[14] As with premiums and deductibles, payers, pharmacy benefit managers (PBMs), and health care purchasers have responded by implementing ways to curtail drug utilization and/or spending, such as requiring patients to pay co-insurance for specialty drugs or requiring step therapy or prior authorization. These policies have a perverse impact on people with chronic diseases who rely on consistent treatment to manage their disease. A 2021 AMA survey showed that 34% of physicians reported prior authorization had caused a serious adverse event in patients.[15] A 2022 Office of the Inspector General report showed that 13% of prior authorization requests were denied by Medicare Advantage plans — even though they met Medicare coverage rules.[16] Avalere data shows a 163% growth in step therapy from 2014 to 2020 for rheumatoid arthritis single-source brand drugs, which are "FDA-approved brand medicines produced by only one manufacturer – or single source – on the market."[17] A 2016 Arthritis Foundation study showed that over 50% of respondents were required to try two or more drugs before they could receive the drug prescribed by their provider; of those, step therapy was stopped 39% of the time because the drug was ineffective and 20% of the time because the patient's condition worsened.

A common approach to curb specialty drug spending is to institute co-insurance for specialty tier drugs. This is prevalent across commercial, Medicare and Exchange markets. State and Federal Health Exchange plans typically require co-insurance for specialty tier drugs, with many plans currently offering 35% co-insurance and up to 50% for many bronze plans. Biologic medications to treat arthritis range from an average retail price of approximately $5,000 to over $8,000 per month, which means a patient could be required to pay more than $4,000 out of pocket for one prescription. Even assuming a lower, 20% co-insurance, a patient would pay over $1,000.

How does this impact the patient? Out-of-reach costs lead to treatment delays or patients abandoning their treatment, which leads to worsening of disease and higher costs to the health system in the long run. About 3.5 million adults 65 and older and 1.8 million Medicare beneficiaries under 65 had difficulty affording their medications in 2019, according to data released by the National Health Interview Survey.[18] In a 2021 Arthritis Foundation survey, 39% of respondents had difficulty affording their out-of-pocket costs and 54% had suffered financial hardship as a result.

Health Disparities

Although anyone can develop arthritis, some populations are disproportionately affected, including African American/Black, Hispanic/Latin American, Asian American, low-income, and individuals living in rural areas. Additionally, osteoarthritis and rheumatoid arthritis disproportionately affect women. These patients often experience delayed care,

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[14] Trilliant Health. "2022 Trends Shaping the Health Economy." October 2022. https://www.trillianthealth.com/insights/reports/2022-health-economy-trends

[15] American Medical Association "2022 AMA Prior Authorization (PA) Physician Survey." 2023. https://www.ama-assn.org/system/files/prior-authorization-survey.pdf.

[16] U.S. Department of Health and Human Services. "Some Medicare Advantage Organization Denials of Prior Authorization Requests Raise Concerns about Beneficiary Access to Medically Necessary Care." April 27, 2022. https://www.cdc.gov/nchs/nhis/index.htm.

[17] Avalere Health. "Utilization Management Trends in the Commercial Market, 2014–2020." November 29, 2022. https://avalere.com/insights/utilization-management-trends-in-the-commercial-market-2014-2020.

[18] "2019 National Health Interview Survey (NHIS) Public Use Summary Report." September 2020. https://www.cdc.gov/nchs/nhis/index.htm.

skepticism by providers (for example, regarding pain thresholds in Black women), and increased activity limitations.[19] Language and health illiteracy are common barriers for some, as is the ability to work and participate in daily living, issues compounded by systemic barriers to care. These populations also disproportionately have other chronic conditions that can further exacerbate arthritis symptoms, including diabetes, heart disease and anxiety.
Geographic disparities impact experience of care as well. Timely access to providers is essential for managing a chronic disease, but fewer rheumatologists are available in rural states than in metropolitan areas. Six states have no pediatric rheumatologist at all and five states have only one. Telemedicine can sometimes bridge this gap but only if patients have internet access and can afford the technology — which many in these populations cannot. In fact, a recent National Health Interview Survey found that telemedicine use was higher in urban areas (40.3%) than in rural areas (27.5%).[20]

System Fragmentation

A fragmented health system exacerbates barriers to care, especially for people with chronic diseases. Some argue that third-party payers in the fee-for-service structure drives overutilization by both patients and providers, thus driving up costs. For example, payers set reimbursement prices for physicians and services and if those fees are inadequate then physicians may increase volume or service activities to compensate. This discourages physicians from collaborating across specialties to deliver the best care for the patient's lifetime continuum. A fee-for-service model incentivizes volume regardless of the level of care provided or health outcomes. This directly contradicts what people with chronic conditions need, which is access to holistic, well-coordinated care that includes support for medication management, health literacy and coaching, transitional care, and a core care team of clinical and allied health professionals.
Data silos add another major barrier. Many entities collect patient data – whether clinical, demographic, or claims-based – but that data across systems is not integrated to create a holistic picture of the patient's progress, outcomes and needs. Electronic Health Records are not fully interoperable across providers and systems, sometimes even within the same system. Further, there is no consensus standard for data inputs and electronic exchange of information among all members of the patient's care team. The pharmacist or provider may not have full information about the patient's benefits or other key information; and the employer providing those benefits may not have full understanding of the costs and health needs of the patient. The proprietary nature of data, paired with the lack of incentives to aggregate it to manage patient care, perpetuate the problem.

Value-based care arrangements and bundled models hold promise for providing higher quality care at lower costs, but financial and business considerations often interfere with delivering truly patient-centered care through these initiatives. Provider practices may not be willing or able to accept the financial risk; the parties involved in a value-based contract may not agree on metrics or financial terms; and small or solo practices may not have the resources to participate.

Transparency and Patient Engagement

Many patients feel they have little agency or control in the health care system, largely due to lack of transparency into the decisions, processes, and data points that could help them navigate it. Patients generally cannot access the true prices of treatments and services and they are not part of the process in setting formulary and coverage policies.

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[19] How It Hurts Report. Arthritis Foundation. May 2021. https://www.arthritis.org/liveyes/insights/how-it-hurts#:~:text=Extreme%20Pain%20in%20Real%20Life,people%20with%20arthritis%20often%20face.

[20] Lucas, Jacqueline W, and Maria A Villarroel. National Center for Health Statistics "Telemedicine Use among Adults: United States, 2021." October 2022. https://www.cdc.gov/nchs/data/databriefs/db445.pdf.

Undergirding this is the fact that “value-based care” often is not based on patient preferences or measures. Rarely do measurements for assessing the value of health care include outcomes that are important to patients, truly placing the patient at the center of care. Some health experts argue that value is created over the lifetime continuum of a patient’s medical condition, not on episodic care. We believe this is especially true for patients living with chronic conditions, including the 100+ types of arthritis. If they are not reaching their health goals, what value is added for them?
Quality measures are used to determine whether a health care model has met its quality and value-of-care objectives, so it may be the most crucial place for patient engagement. For care to be patient-centered, it must measure what matters to patients, considering their health goals, challenges and preferences. Patient Reported Outcomes (PRO) measures are often incorporated into assessments of quality, though this is not standardized, and many PROs measures are outdated or inadequate. The National Committee for Quality Assurance (NCQA) convened a workshop in 2018 to identify gaps in outcomes measurement in rheumatoid arthritis and identified three key challenges: underutilization of disease activity assessment tools and RA-specific measures; technology barriers in measuring and reporting outcomes; and implementation of alternative payment models to support patient-centered care.[21] There have been efforts for several years to harmonize and standardize outcomes measures for arthritis, including PROs, but there is not yet a standard that incorporates the range of outcomes and quality-of-life measures that matter to patients.

The Patient-Provider Experience

The experience of care goes hand in hand with patient engagement. Positive health outcomes and quality of care are dependent on a meaningful experience with health care providers, including shared decision-making for treatment plans, feeling heard and having trust.

Health literacy is an important factor in patient engagement and a meaningful provider experience, and the burden is often on the patient to acquire health literacy on their own. Without health literacy, patients may miss doctor appointments, not complete registration forms, misread medication labels, not adhere to their treatment, and have trouble remembering or understanding complicated health information. Clear communication with patients in ways they understand can help ease their worry, improve their ability to make informed joint health decisions and better manage their condition.

Whether providers are in-network and available also has a major impact on the patient’s experience and care. An increasing workforce shortage in rheumatology leaves fewer physicians available to treat a growing number of patients, and an increased administrative burden for practices results in less time providers have to spend with patients.

In sum, rising health care costs are creating pressure to curb utilization, which negatively impacts chronic disease patients who need consistent, affordable care to manage their disease. The fee-for-service model and traditional incentive structures are not conducive for delivering value-based, whole-person, longitudinal care, and they perpetuate silos and data fragmentation. A squeezed workforce makes it more difficult for patients to get timely treatment. The profit-generating nature of the health care system and focus on each stakeholder’s bottom line prevents the prioritization of patient preferences and goals, which is what is truly needed to improve health outcomes.

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[21] National Committee for Quality Assurance. “Rheumatoid Arthritis: Transforming Care Delivery to a Value-Based Model.” October 29, 2019. https://www.ncqa.org/white-papers/rheumatoid-arthritis-transforming-care-delivery-to-a-value-based-model/.

Why Change Is Needed Now

Over 157 million Americans live with a chronic disease, including more than 58 million who have arthritis with a projected increase of 20 million-plus in the coming decades. The direct and indirect costs will correspondingly rise. While we have already discussed anti-inflammatory drugs topping specialty pharmacy spending, other arthritis-related interventions lead health spending in other ways. Nearly one million hip and knee replacements are performed in the U.S. every year, and that number is expected to rise to 3.5 million by 2030.[22] Reimbursement among commercial payers for in-patient hip or knee replacement surgery in 2021 averaged over $39,000 and reimbursement for outpatient surgery averaged $12,000.[23] Layered with indirect costs of lost productivity and absenteeism, the health care system is costing billions of dollars every year – and employers are losing billions of dollars every year. A 2017 *Health Affairs* report showed that employers are losing $1.8 billion in lost productivity from disability claims alone.[24] Billions of dollars could be saved and patients and providers would benefit if health care were reformed to deliver value-based care in a truly patient-centered way.

In short, prevalence of chronic disease is rising and so are the costs associated with treating these diseases. The trajectory of out-of-pocket costs is unsustainable and health care purchasers need new ways to lower costs.

III. METHODS

To better serve the arthritis community, the Arthritis Foundation launched a multi-year initiative to identify an ideal model of care for arthritis patients. The goal is to further define priorities and streamline access to meaningful, coordinated, patient-centered care. Phase I included collecting patient data and interviewing experts to 1) identify the major health care challenges across a patient's health care experience; 2) better understand current challenges and opportunities in patient-centered care; and 3) identify gaps that patient advocacy organizations like the Arthritis Foundation could fill.

This report includes information gleaned from a patient survey, patient focus groups, health care provider focus groups and interviews with subject matter experts across the health care ecosystem. Arthritis Foundation staff also attended in-person value-based care programs and conferences to gather information and observe real-world evidence of innovative health-delivery and payment models. This report shows the findings on which the Foundation's priorities and opportunities in establishing arthritis care goals are based.

Methodology

We launched our "expert road show" in August 2021. We identified subject matter experts in value-based health care and/or health systems to interview, including individuals and organizations in academia, government, health care providers, manufacturers, hospital and provider office administrators, insurance payers, pharmacists, data experts,

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[22] The Center. "Knee Replacement Surgery by the Numbers." November 11, 2022, https://www.thecenteroregon.com/medical-blog/knee-replacement-surgery-by-the-numbers/.
numbers/#:~:text=Almost%20one%20million%20hip%20and,common%20orthopedic%20procedures%20performed%20today.

[23] Kaiser Family Foundation. "2021 Employer Health Benefits Survey." November 10, 2021. https://www.kff.org/health-costs/report/2021-employer-health-benefits-survey/#:~:text=Annual%20premiums%20for%20employer%2Dsponsored,is%20%241%2C669%20for%20single%20coverage.

[24] Health Affairs. "Workforce Health and Productivity." February 1, 2017. Vol. 36. Issue 2. 200-201.
https://www.healthaffairs.org/doi/epdf/10.1377/hlthaff.2016.1580.

employers and community leaders. We conducted more than 30 one-on-one interviews of 30 to 60 minutes between August 2021 and August 2022. In addition, we established a task force comprised of nine of the interviewees from various backgrounds and experiences to advise the Arthritis Foundation on the feasibility and technical components of developing an ideal model of care.

Next, to further understand the value-based care space we researched existing value-based care models generally and specifically for arthritis. Our Advocacy & Access team, working in collaboration with the INSIGHTS team, reviewed existing INSIGHTS and Foundation survey data to understand the major disrupters in our patients' health care. We also performed a literature review on health care access and value-based care models. In addition to many print materials shared through the expert interviews and stakeholder focus groups, we searched PubMed and Google Scholar for documents and manuscripts from peer-reviewed, academic journals and publicly available papers resulting in more than 50 source documents collected between August 2021 and October 2022. We gained additional relevant information cited in webinars, podcasts and news reports.

In August 2021 we disseminated a survey to the Arthritis Foundation Patient Voice Panel, LiveYes! INSIGHTS participants, and Advocates, yielding 3,421 respondents. The survey asked questions in three domains: insurance and access barriers, care coordination and health literacy. In March 2022, we met with five focus groups of 20 patients and patient advocates each to gain deeper insight into common challenges and recommendations to improve the patient and caregiver experience of care. Patients were prompted to rate their experience with health care, describe the care providers they regularly see specifically for their arthritis care, describe common challenges in care coordination, whether they feel their experience with arthritis care is unique or common and whether they know others who experience the same access barriers, explain what works best or most seamlessly and what their ideal care team might look like.

Once we curated all the patient data and expert interview findings, we crafted a series of surveys that were sent to our Patient Leadership Council (PLC), National Advocacy Committee (NAC), state advocacy chairs, and Foundation Advocacy Ambassadors. The first-round survey, which yielded 14 responses, included a high-level ranking of 10 policy access categories. The second-round survey, yielding 22 responses, requested that patients rank policy priorities of importance.

We then organized the data points into categories and analyzed the results using the public health framework known as the Five *A*s of Access to Care: 1) Affordability – the ability to pay for health needs and costs, 2) Availability – the ability to be seen quickly when needed and to have health insurance coverage, 3) Accessibility – having providers locally available and easy to get to, 4) Accommodation – receiving convenient and coordinated care, and 5) Acceptability – having a level of comfort between health care providers and patients and with the health system, regardless of socio-economic characteristics. This framework was developed and proposed by researchers Roy Penchansky and J. William Thomas in an article published in 1981 regarding the definition of "access" in health policy and research services. It is the most cited framework for identifying health care needs, services and the ability to place the patient at the center of all care models. We felt it would be an important basis for the "5 *A*s of Arthritis Access to Care" used to analyze the data and propose solutions for our Ideal Model of Care.

Finally, we grouped the findings according to the different phases of the care continuum: time to diagnosis, time to treatment, continuity of treatment, and overarching lifetime considerations of the patient. This is where the challenges and potential solutions lie.

IV. FINDINGS

All the findings from Phase I pointed to five major goals for a patient-centered ideal model of care:

1. Meaningful patient engagement
2. Value-based care
3. Technology as a solution
4. Accessibility and affordability
5. Overcoming health disparities

The findings illustrate access to care barriers along each state of a patient's journey: arriving at a diagnosis, finding the right treatment, maintaining continuity of care, and finally, considering the patient's lifetime continuum, overall well-being and wellness. As such, the following presentation of findings will be categorized according to these phases of the disease journey, with the findings relevant to our core themes embedded within each phase of the disease journey from arriving at a diagnosis to finding the right treatment.

Arriving at a Diagnosis

Diagnosis is the first and often most pivotal barrier for arthritis patients. Many respondents noted that they wished they had sought a diagnosis and treatment for their arthritis sooner because they didn't know how severe their condition was. Diagnosis delays can be due to unrecognized symptoms, lack of provider access and misdiagnosis. The average time to diagnosis for axial spondylarthritis, for example, is six to eight years. One patient indicated it can be difficult to get into the system in the first place. Workforce shortages are a major problem; a rheumatology office manager noted there is a six-month wait in his practice, so patients are not able to get timely care. This also impacts treatment adherence, because the practice doesn't have the time or bandwidth to make sure the patient comes to follow-up appointments. More well-trained nurses and allied health professionals in rheumatology are also needed.

An expert interviewee noted that the increasing rate of health care consolidation also impacts patient access to providers. Multiple patients reported inaccuracies in provider networks or that providers were no longer in-network when their insurance plan changes.

Finding the Right Treatment

Most respondents reported positive interactions and conversations with their doctor; they feel their provider answers their questions, explains things in an easily understandable way and that their health care choices are respected. In focus groups, many individuals shared that their relationship with providers "can make or break" their experience with the health care system.

Patients indicated the importance of taking a friend, family member or caregiver to appointments. These individuals can provide additional context, take notes and share insights that patients may be unable or unwilling to share.

Our patient survey and focus groups found that bedside manner and how much time providers spend answering questions matter greatly to their experience of care. Nurses and other support staff may have more time to answer the patient's or family's questions and have a better understanding of the mental, financial and other impacts of arthritis on the family.

The five goals for a patient-centered ideal model of care are key to improving diagnostic and treatment decisions.

1. Meaningful Patient Engagement

This is a broad category with two primary elements: facilitating patient empowerment in their own health care, and meaningfully incorporating patient perspectives in health coverage decisions. Key areas include:

- A focus on health literacy by health plans, providers and patient advocacy organizations
- Meaningful opportunities for patient representation on insurance plan committees and other coverage decision-making bodies
- Tools for effective patient-provider communications and patient self-advocacy
- Robust development and utilization of patient-reported outcomes measures and patient-centered value assessments for treatments
- Improved shared decision-making in determining treatment plans

2. Value-Based Care

Considering the patient's overall well-being and wellness across their lifetime

Several interviews highlighted aspects of patient care, including prevention and wellness, which transcend a particular time in the patient journey. Several experts reported an increasing emphasis on wellness by employers who recognize their role in employee well-being and its impact on productivity and health costs. Lifestyle interventions are a key part of symptom management for arthritis; abundant data shows the impact of obesity on joint health, the importance of exercise in maintaining joint function, and the effect of mental health on everything from worker productivity to readiness for surgery and overall clinical outcomes.

Another interviewee noted that we spend too much time on symptom management and not enough on prevention and identification of the root causes of disease.

Early access to the right providers and treatment

Getting early access to the right treatment means having a care plan that addresses all the patient's care needs. For example, experts noted that mental health professionals should be introduced early in treatment, especially for kids with arthritis. And survey results and expert panels agreed that early access and adherence to physical therapy is critical for managing arthritis and often improves health outcomes.

Most people living with arthritis regularly see two or three health care providers specifically for arthritis. As discussed earlier, respondents indicated having from three to 14 providers for their overall health care. Some families reported their child with juvenile arthritis had more than 25 doctors. Most commonly, providers for arthritis patients include rheumatology and primary care physicians as well as an ophthalmologist, orthopedist, orthopedic surgeon, physical therapist, occupational therapist, and integrative care providers like acupuncturist, chiropractor and medical massage therapist. Other providers mentioned that an arthritis patient may need include a neurologist, cardiologist, sports medicine specialist, dermatologist and dentist.

An ideal model of care is a value-based model that encompasses and accounts for multiple providers delivering patient-centered care for the totality of the patient's needs.

The pharmacist could play a stronger role in medication and symptom management for patients who require medication, but reimbursement issues and other barriers often prevent the pharmacist from being able to perform these functions. Patients without therapeutic options – including those with OA, those who have tried and failed the available pharmacologic options and those who have not found an ideal treatment – might find that their physical therapist is best suited to manage their care.

Care coordination

Our expert interviews found that some of the biggest obstacles involve system fragmentation: silos, lack of interoperability and continued reliance on fee-for-service.

Common challenges patients face in coordinating their own care include:

- Feeling as if they're acting as their own professional care administrator/coordinator/navigator.
- Telehealth, which can make appointments easier to access for patients, also may contribute to miscommunication or preconceived assumptions by the patient and/or provider. Compared to in-person interactions, it can be challenging, with nonverbal communication barriers such as gestures or facial expressions indicating pain, understanding or approval.
- The fact that doctors and other care providers do not know or talk to one another, sometimes even in the same health system.
- Electronic medical records systems are not interoperable across systems, complicating communication among providers. It can take months for medical records to be released, which delays a patient's ability to see their new provider.
- Poor transition from pediatric to adult care due to a variety of factors, from care coordination of seeing a pediatric to adult physician to health insurance changes and difficulty transferring medical histories and records.

Patient survey and focus groups found that:

- 42% of respondents feel their arthritis care is not well-coordinated; of those, 60% say the lack of coordination has negatively impacted their health.
- Patients reported their desire for a dedicated coordinator to manage appointments, medication refill requests, answer insurance questions.
- Care coordination must be meaningful; in some cases, the care coordinator simply summarizes the treatment notes. Meaningful coordination includes "quarterbacking" treatments and instructions from all the providers.

Patient-Reported Outcomes (PROs)

Several experts in value-based care emphasized the importance of developing and incorporating better patient preference and outcomes measures. We must measure what matters to patients, they noted; data interoperability does not matter if you are measuring the wrong data points. Patient needs and preferences change over time, so PROs collection and evaluation should be an iterative process. One expert noted that PROs need to be updated in a more patient-centered way. Of note, PROs for osteoarthritis (OA) are harder to measure because there is no disease-modifying drug to treat it. And while there are measures for joint replacements, that represents only one episode of care across a chronic disease journey.

3. Technology as a Solution

Through our expert interviews, a common theme was that arthritis patients need more digital tools tailored to their condition in ways that manage their care holistically. Digital tools can assist patients with symptom tracking, health coverage tracking, updates on important information as well as device-tracking options.
Our data found that:

- More than half of survey respondents required additional medications for pain, depression, anxiety or other symptoms and/or developed new or worse joint damage when their arthritis was not well controlled.
- The transition from pediatric to adult care is not always well executed; the patient can be abruptly cut off by pediatric providers when they reach age 18, though others may be seen until age 21, 26 or other.
- Technology will be an increasingly important tool in health care and digital tools that are tailored to patient conditions and needs are needed, including real translation to health care providers of evolving symptoms and a holistic look at all issues, including mental health.
- Integrated patient data is of the utmost importance; integrated data warehouses may provide a mechanism to break silos and gain a more holistic look at patient costs and outcomes. Further, standards for patient access to pricing and benefit information are necessary to improve data transparency.
- Symptom management through digital tools and remote therapeutic monitoring shows promise for improving health outcomes.

4. Affordability and Accessibility

When considering accessibility and affordability, we considered the expectations and characteristics of patients and the health system at-large. Here, affordability refers to whether a patient – or the health system at-large – is able and willing to pay for health services, though other non-financial considerations are also significant. Accessibility directly refers to geographic or physical preferences or constraints that determine the patient’s ability to receive care assuming they can afford it.

- 37% of respondents reported trouble affording their out-of-pocket costs this past year, including high prescription drug copays and co-insurance and difficulty with insurance-mandated protocols to find an effective treatment. Of those respondents, 54% say they have incurred debt or suffered financial hardship as a result.
- Difficulty affording out-of-pocket medical expenses had an impact on care: 45% of all surveyed said they delayed refilling a prescription, 41% said their health care worsened and 41% switched medications as a result.
- Patients often pay for their own ancillary supports, such as specialized exercise equipment, orthotic walking shoes or gym memberships.

Further information from our interviews found that:

- Office managers want specific information available to share with patients about out-of-pocket costs for their treatment options.
- A benefits consultant and pharmacist said affordability of treatment is the single largest barrier to patient care.
- Employers are increasing their emphasis on wellness and providing coverage, services and resources to address employee well-being, which has a tangible benefit for health, productivity and health costs.
- Employers often do not have the data or transparency into their employee health costs and coverage processes to know whether the plans they are purchasing will truly maximize health care quality and lower costs. The inability of employers to have comprehensive, integrated data makes it difficult to know how affordability issues may be impacting their employees; plus, employees are often afraid to talk about their care challenges with employers, which widens the disconnect.

5. Health Disparities

Considering a patient's social determinants of health is critical to identifying effective treatments that are responsive to the patient's environment. Our patient survey and focus groups found that:

- Access to a support network and sufficient income for housing and living expenses were most cited as the top barriers to reaching health goals.
- Geographic accessibility greatly impacts a person's experience with their health care, not only by proximity to specialists and resources available, but also travel time for infusions. It may also affect internet access, which is necessary for many resources and telehealth access.
- Geographic disparities impact more than distance; it also correlates to economic and social factors. Pain and functional limitations of an arthritis patient in a higher socio-economic status community are reported to be less severe than in patients living in poverty or restricted access areas. Furthermore, the lack of adequate nutritious, affordable high-quality food and safe neighborhoods prevent individuals from eating healthfully and exercising, which is a barrier to overall wellness and to weight loss in overweight arthritis patients — the added pressure on their feet, ankles, knees and hips lead to worse outcomes.
- Those who have had a diagnosis for long enough and who gain more resources and knowledge often have an easier time managing care.

In addition, considering the bio-psycho-social model — not simply the biomedical model — is critical.

- More focus on social determinants of health and health equity have led to increased investments in grants, clinical trial diversity and other areas. But vast opportunities for additional support continue, especially when considering the patient's lifetime continuum with the health care system as opposed to a single episode of care.
- The relationship between social determinants of health and health outcomes requires a holistic view. For example, managing patient behaviors can impact overall health outcomes, much as insurance can affect whether patients must go through prior authorization for injections or receive a knee brace with ease. The key is to intervene early with physical therapy and mental health support.
- Access to interventions can be problematic depending on one's insurance. For example, people on Medicaid often have more difficulty getting certain types of arthritis interventions.

V. DISCUSSION AND OPPORTUNITIES FOR ACTION

The insights we heard from patients and health experts were surprisingly similar. There were no categories that included insights from only patients or only health experts. For example, patients indicated a desire to better track their health care digitally, and health experts frequently noted digital tracking tools as an important component of improving health outcomes in a patient-centered way. Our core areas of focus were determined by the cross-cutting themes we heard, including digital tools as a means of improving health care processes and health outcomes; transparency of data and information to and about the patient; and health equity.

Our findings pointed to two main tenets that must be in established for health care to be truly patient-centered:

1. Health care should follow the patient rather than the patient following health care.
2. The system should be designed to manage patient risk, not financial risk; we should be focusing on health, not health care (i.e., outcomes vs the expense of treatments).

Some solutions may require federal or state legislation, particularly for legal barriers that may prevent aspects of value-based contracting or providing telehealth across state lines. Other solutions can be achieved through rulemaking, such as standards for electronic exchange of data. Yet many solutions could be implemented directly by health system stakeholders, such as incorporating patient goals and patient-reported outcomes into care plans.

The following section offers further discussion, examples and opportunities for action across our five main areas of focus.

Meaningful Patient Engagement

The relationship between the patient and provider is central to the patient's experience and health outcomes, so it's important to start with that. The provider consistently ranks as the most trusted source for clinical and treatment information for the patient; building trust and ensuring that the patient feels empowered to ask questions and be part of the process should be foundational in the patient journey.

- **Recommendation**: Providers should present options, provide information on risks and benefits to the patient, assist them in understanding the options, and establish health care goals led by the patient. They should also make patients feel comfortable sharing their questions, goals, concerns and any barriers to achieving their goals.

Payers and pharmacy benefit managers (PBMs) are key to determining the manner and timeliness with which a patient accesses their treatment. Formularies determine everything from drug tiers and step therapy to prior authorization protocols and more. Pharmacy and therapeutics (P&T) committees, which often determine which treatments are covered and how, do not typically include patient representatives. Patient representation would provide real-world perspective of why a patient might transition between medications, the health impacts that those transitions can create, reasons why a self-injectable versus an infused medication may be necessary or vice-versa, how cost-sharing impacts medication adherence and much more.

- **Recommendation:** Payers and PBMs should include patient representatives on P&T and other treatment review committees.

Patient reported outcomes (PROs) are central to patient engagement and ensuring that treatment decisions are made with the patient's experience in mind. While there are PRO measures in rheumatology and orthopedics, they are not comprehensive and patients may not have had a voice in their design. PROs designed and implemented with patient input can ensure that the value of treatments and clinical decisions are being assessed with measures that matter to patients, making them truly patient-centered.

- **Recommendation:** Any stakeholder engaged in quality measures and PROs should develop processes to ensure patient representation in the design and implementation of their measures and survey instruments.

Value-Based Care

Reimbursement and Incentives

Multiple health care providers and patients we spoke with discussed the disconnect between incentives and targeted outcomes in care bundles. They noted that even if a value-based care approach improves health outcomes, the financial incentives for Medicare bundles often make them untenable to participate in long-term due to many reasons, including low reimbursement rates. Specifically, those developing care bundles must differentiate between government and commercial plans when considering their patient health insurance market share; they must acknowledge the differences between chronic and acute care needs; and they must coordinate across specialties and health disparities. Challenges with effective value models include figuring out how to operationalize them with all stakeholders in alignment; reluctance to try new tactics rather than relying on "tried and true" models; having the ability to scale or have non-academic centers participate; improving integration across providers; and addressing longitudinal factors, such as lifetime costs and health outcomes for a chronic disease and defining where the model begins and ends.

Our research and expert interviews found that:

- Care coordination must be a quality measure or built into the business model so there is incentive to coordinate care.
- Having a care coordinator monitoring the patient's health care needs holistically and managing all aspects can better ensure optimal continuity of care.
- A pharmacist noted that pharmacists have the infrastructure and education to serve as care coordinators, provide medication management education and address medication adherence.
- Rheumatology practices that employ nurses to manage care coordination see much higher patient satisfaction and outcomes.
- Access to physical therapy services is critical for post-surgery patients and other arthritis patients with joint pain. While adherence after a formal PT program can be difficult, technology and telehealth make it easier for patients to access on their own and keep up with exercise regimens.

While fee-for-service payment models yield volume-driven and fragmented care, comprehensive-care payments may lead to value-driven coordinated care. Arthritis bundles must redesign the delivery model. In a 2020 *Health Affairs* article, a 10-year meta-analysis of 20 studies "showed that **bundled payment** maintains or improves quality while lowering costs for lower extremity joint replacement."[25] Further, "the available studies did not show evidence of

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[25] Agarwal, Rajender, et al. "The Impact of Bundled Payment on Health Care Spending, Utilization, And Quality: A Systematic Review." Health Affairs. Vol. 39, No. 1. January 2020. https://doi.org/10.1377/hlthaff.2019.00784.

potential unintended consequences from bundled payments" and "no association between bundled payment participation and changes in quality of care…"[26] Other research concluded that patient-reported outcomes had no meaningful difference in "function, health, or pain after hip or knee arthroplasty" for individuals who received care from hospitals participating in bundled payment programs.[27] Existing models organize care by specialty and discrete services (imaging, primary care, hospital care, pain management, behavioral health, orthopedic surgery, etc.). Many patients need help accessing shared resources, including nutrition, mental health, pain management, medication management and other risk modifiers. Under a bundled model, a core team, including a physician, physical therapist, care coordinator and ancillary service providers, such as physician assistants and nurse practitioners, work together in complementary roles.

- **Recommendation:** Value-based care models focusing on the patient should integrate a core care team to lower costs and improve patient outcomes by reducing health risks including wellness promotion and generating system-wide savings.

New technologies, treatments, services and procedures historically have led to people living longer. And growing older often brings an increasing prevalence of chronic conditions and more complex care needs. These trends demand changes in payment and health care delivery.

- **Recommendation:** The U.S. health care system should continue to migrate away from fee-for-service payments toward value-based care models that deliver holistic, whole-person care, and consider new opportunities for Accountable Care Organizations, Alternative Payment Models, and other non-fee-for-service plans with
  - Clinically integrated networks,
  - Patient-centered value assessment and quality measures, and
  - CMS Innovation Center bundled payment and shared savings models for patients living with arthritis.

Incentives are needed to prevent costly, time-consuming, sometimes unnecessary treatments with minimal benefits for the patient or health ecosystem, and instead to reward higher quality care and patient outcomes. Initially, value-based care trends are beginning to see some success in reducing unnecessary medical costs, improve care quality and provider relationships and even generate savings to the system. This should be viewed from the lens of a chronic disease patient who requires a lifetime of consistent care from multiple providers. Use of an Alternative Payment Model by one specialist may yield some improved outcomes, but if it exists in a silo, it does not benefit the patient holistically. This is a challenge all stakeholders involved in chronic disease care should prioritize in thinking about the future of value-based care.

Right-Sized Care Team

Access to the right providers at the right time can include:

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[26] Lewin Group. CMS Bundled Payments for Care Improvement initiative models 2–4: year 5 evaluation & monitoring annual report [Internet]. Baltimore (MD): Centers for Medicare and Medicaid Services; 2018 Oct [cited 2019 Oct 28]. Available from: https://downloads.cms.gov/files/cmmi/bpci-models2-4-yr5evalrpt.pdf Google Scholar

[27] Finch DJ, Pellegrini VD Jr, Franklin PD, Magder LS, Pelt CE, Martin BI; PEPPER Investigators. The Effects of Bundled Payment Programs for Hip and Knee Arthroplasty on Patient-Reported Outcomes. J Arthroplasty. 2020 Apr;35(4):918-925.e7. doi: 10.1016/j.arth.2019.11.028. Epub 2019 Nov 26. PMID: 32001083; PMCID: PMC8218221.

- Improved provider accessibility within insurance networks
- Insurance coverage for complementary therapies
- Access to providers and specialists via telehealth, particularly across state lines
- Coverage and access to mental health providers
- Coverage for dental services
- Increased authority for pharmacists to provide medication management and other services

Rheumatologists often act as the primary care provider for patients with arthritis. However, current popular reimbursement models are primary care-focused and do not typically accommodate situations where patients see their team of specialists regularly instead of a primary care physician.

Some current initiatives are considering how to empower pharmacists to do more medication management. The GTMRx Institute found that a “sustained team-based approach reduces clinician burnout,” and pharmacists can develop stronger relationships with patients because they see and interact with them more frequently. They can also refer patients in local settings for testing, connect their lab reports to the physician and align on screening so patients do not have to wait until they are in an acute state and need urgent medical attention.[28] This group encourages physicians, clinical pharmacists and other team members to “share a complete commitment to medication optimization by providing tools, data, practice standards and implementation resources to advance their ability to optimize medication use.”[29]

- **Recommendation**: Incentives for models supporting **a right-sized, integrated care team** must appropriately reimburse and address the risks providers face by being part of one of these models. These incentives must be designed to ensure the right members of a care team can deliver appropriate components of care. For example, pharmacists may be best suited to manage medication adherence, but they are not reimbursed for this time, leaving the burden to the already time-strapped physician to effectively manage every patient’s medication adherence.

Care Coordination

People with chronic and/or comorbid conditions need good care coordination and providers need tools to manage patients’ needs, including technology, phone access for patients, telehealth options and care managers. Having the ability to easily and directly connect with their providers should reduce patients’ avoidable hospital admissions or readmissions and ideally reduce the number of days they require inpatient care. Those with complex health needs often have multiple chronic or serious medical conditions. Their care may be further complicated by functional limitations or unmet social needs, resulting in their need for care from multiple providers and community support systems.

Successful care coordination can provide new and improved care supports for people with chronic conditions. It can also lead to stronger relationships between patients and providers and between hospitals and providers and acute/post-acute care integration. Challenges to care coordination include the need to develop financial and care integration in managed care, to incentivize federal and state dollars dedicated to piloting new models of care, to improve health literacy and reduce patient confusion, and to improve integration of services, financing, care team and treatment.

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[28] GTMRx Institute. “About Us.” 2019. https://gtmr.org/about/

[29] GTMRx Institute. “About Us.” 2019. https://gtmr.org/about/

- **Recommendation:** A strategy is needed to accelerate the adoption of value-based care models, to design opportunities for scaling up value-based care and to replicate them nationwide relatively quickly to provide broader supports and alignment of initiatives.

Additionally, improving care coordination requires strategies to:

- Ensure patients have access to care coordinators or navigators to help them understand their coverage options and navigate coverage barriers as they occur.
- Continue the shift toward value-based care, including CMMI demonstration projects, health system pilot projects, and opportunities from smaller or rural practices to learn and adopt best practices.
- Continue to develop and put in place standards for the electronic exchange of medical records across the health care system.
- Provide caregiver support.

Below is a more detailed discussion of care coordination examples and needs.

While Medicare does offer care coordination in a fee-for-service model, such as Chronic Care Management (CCM) or Transitional Care Management (TCM), patients still require person-centered, centralized management of patient care and coordination. In 2015, Medicare began to pay separately under the Medicare Physician Fee Schedule for CCM services to Medicare patients who have multiple chronic conditions. New billing codes have been established to pay providers, and patients gained the ability to reach a care team member when necessary.

Interoperability and accessibility of electronic health data are crucial to care coordination. The lack of communication and crossover among most electronic medical records systems impairs coordination, inhibits the ability to gather and track real-world data and prevents the patient from fully participating in their own care. Importantly, CMS has taken steps to require further standards for patient-facing APIs, provider-to-provider APIs and payer-to-payer APIs. With these standards, CMS addresses several major roadblocks: patients don't always know the status of prior authorizations or even what treatments require prior authorization; providers can't always access patients' health records from other providers; and payers can't aways access patient data from the patient's previous payer, causing disruptions in care when a new payer's prior authorization or other treatment protocols conflict with the patient's current treatment. These standards are a significant step toward more streamlined, better coordinated care.

There are other examples of states and academic institutions working towards better care coordination. In the **State of Maryland,** payment rates are regulated statewide, and hospitals are responsible for per-capita spending on patients based on their residential zip code. Hospitals organize and fund care-management staff to coordinate care, such as developing a care plan, overseeing patients' self-management of medications, coordinating with home- and community-based clinical service providers, and managing referrals, follow-ups, and the systematic assessment of the patient's medical, functional and psychosocial needs.

The Musculoskeletal Institute at the University of Texas at Austin, Dell Medical School, is embracing bundled payments for value-based care and/or integrated clinical and provider workflows. UT Austin has designed and implemented an innovative value-based care model using Integrated Practice Units (IPUs). This model is designed to maximize patient health outcomes by integrating a multidisciplinary care team (including, for example, surgeons, chiropractors and social workers) specializing in specific conditions (such as osteoarthritis, back pain and rheumatology).[30] Health and care services are structured around the individual patient's needs, bringing providers together daily to assess the patient's goals and increase value. This model thus far has succeeded in delivering less expensive and more efficient care, yielding improved overall health outcomes. Further, psychological and social determinants of health receive close attention, which leads to more appropriate diagnosis and treatment/management of conditions at lower costs to patients and the health system. Providers communicate effectively with patients by gaining trust, showing empathy, personalizing care and helping them form healthy habits beyond diagnosis. Connector teams or integrated practice units also can link the population with community health interventions with medical care treatments.

Having a care coordinator in place to keep all the pieces together and monitor the patient's health care needs overall helps ensure continuity of care. Ideally, every patient would have a care navigator. Frequently, the **roles of the pharmacist** and **of the physical therapist** were brought up in our research findings. This may be an area of potential opportunity for health care team members like pharmacists and physical therapists to play enhanced collaborative roles to further benefit patients.

- **Recommendation:** A quality measure or reimbursable code should be in place to ensure that the care coordinator is appropriately incentivized and resourced.

Technology as a Solution

- **Recommendation:** Collection and extraction of data must be coordinated along with resources to interpret and analyze the data. Some companies have collection processes, but they don't have the right resources to pull and analyze it to facilitate an appropriate medical intervention. And some companies have resources but no coordination in accessing data in a way that could drive a different outcome or intervention.

EHR interoperability and data integration are critical. Respondents felt that having a central tracking location for records and communication of the care plan among providers would have the biggest impact on improving their care coordination. Patients in systems with interoperable records found that the best and most seamless aspects of their care included electronic records and communication with providers.

- **Recommendation:** More emphasis is needed on data standards and processes to manage transitions of care, as this is where many data exchange problems happen. Payer formularies or policies often change when transitions happen and/or the patient never fills the prescription, and there's not a central hub to keep that patient from falling through the cracks.
- **Recommendation:** An Intelligent Health Record would incorporate all patient data and could be accessed any time on any system.

Finally, telehealth has and will continue to play a role in access for patients. Whether due to geographic or time barriers, telehealth options provide patients a quick and efficient opportunity to check in with providers and ask questions. It also is a comfortable and flexible option for both patients and providers, and although telehealth isn't appropriate for some arthritis-related appointments, it increases access opportunities.

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[30] The University of Texas at Austin Dell Medical School. Department of Surgery and Perioperative Care. "Immersion Program in Value-Based Health Care." 2022. https://dellmed.utexas.edu/units/department-of-surgery-and-perioperative-care/immersion-program-in-value-based-health-care-musculoskeletal-institute.

Accessibility and Affordability

Getting the right treatment plan only works if the patient can afford their treatment and access it easily, but out-of-pocket costs and utilization management are two significant barriers for many patients.

Out-of-pocket costs

There are many policy solutions to lower costs for patients. Together or individually, the following can make a big difference for treatment access and adherence:

- Lower caps on out-of-pocket costs for treatments and services.
- Ensure access to copay assistance.
- Ensure access to plans with flat copays as opposed to co-insurance.
- Allow pre-deductible coverage for drugs used to manage chronic conditions.

- **Recommendation:** Use tools like Real-Time Benefit Tools (RTBT), which can help patients understand their cost-sharing obligations and make more informed decisions about treatment.
- **Recommendation:** Get patients on the right treatment early to save costs to the system in the long run and use biomarkers that can help identify the treatment that will work best for the patient.

Utilization Management Barriers

Barriers associated with utilization management often persist even after the patient gets on the right treatment, including repeated prior authorization requirements for the same therapy; mid-year formulary changes; insurance plan changes that also change provider networks or step therapy protocols; and the introduction of new treatments for which prior authorization or step therapy is required.

Our patient survey and findings found that along with out-of-pocket costs, the two most common barriers to care include “insurance does not cover” and “step therapy.” Providers note that prior authorization and step therapy are increasingly burdensome, and practices are having to devote more staff and resources just to manage these processes.

- **Recommendation:** Enact state and federal laws and regulations to establish commonsense guardrails for appropriate step therapy use.

Health plans should take steps to implement these solutions on their own. In the absence of that, state and federal legislators should:

- Reform step therapy, placing guardrails on the timeliness, utilization and review of step therapy results.
- Reform prior authorization, placing guardrails on the timeliness and frequency of requirements.
- Prohibit mid-year plan formulary changes.
- Streamline the appeals processes to ensure patients understand and can execute an appeal.
- Ensure access to real-time benefits tools.

Health Disparities

While addressing health disparities should be embedded throughout all aspects of health care, they should be a specific focus in these four recommendations:

a) Addressing social determinants of health in a number of ways, such as using Medicaid authority to provide transportation and housing support and improving health plans' data collection for better resource allocation.
b) Addressing geographic disparities through increased telehealth access, loan repayment for providers who practice in underserved areas and other workforce policy solutions.
c) Increasing clinical trial diversity and representation, which is currently being addressed through state and federal legislative efforts and should also be undertaken directly by manufacturers.
d) Improving cultural competency in provider settings.

To expand further, we offer the following:

a) While value-based care approaches are helpful in improving patient access, they have the potential to worsen disparities as we are seeing such plans disproportionately rolled out in higher socioeconomic locations.

   - **Recommendation**: Prioritize how to implement value-based programs in rural or underserved areas and how to scale best practices, like the use of telehealth and digital tools, in practices and systems that don't have adequate resources and services to roll out full-scale programs.
   - **Recommendation:** Address Social Determinants of Health with "boots on the ground" at the local level, which could be a good role for community pharmacies to play.
   - **Recommendations:** Make shared decision-making driven by the patient a standard in provider offices. Patients often don't feel heard, which leads to mistrust and trouble getting the right treatment plan for the patient's goals. It can also contribute to misdiagnoses, delays in diagnosis and delays in treatment.

     - Establish an industry standard that the arthritis patient is not allowed to "deteriorate." Any coverage or care processes that would lead to worsening of disease is unacceptable.
     - Allocate resources to educating and empowering patients to advocate for themselves and incorporate this thinking into all care-delivery improvements.

b) Several sources recommended improving access to **high quality data,** improving data collection and reporting as keys to reducing health inequalities. Health plans are uniquely positioned to support in this area, especially at the population level, though they are not necessarily motivated by long-term goals. For example, a physician may see a patient for 50 years, but the patient may have five or more health insurance providers with different policies during that time.

   Disparities often manifest in the heterogeneity of insurance and payment access, complicated by state variations in insurance requirements. Confusion around legality and outdated or inconsistent data standards limit progress. Emphasizing the importance of data collection and showing how this information can reduce disparities may positively shift mindsets and elevate trust. Reporting information should remain voluntary and ensure patients' privacy and protections.

Accessing **health equity** information can be difficult due to mistrust in marginalized communities. For example, patients living in rural areas must travel long distances to reach their providers, and providers often don't relate to their patient's lifestyle or home situation either geographically or culturally. Having a provider who understands and can appropriately engage is critical.

- **Recommendation:** Better data collection and evaluation and more targeted resources are critical to overcoming disparities. Pain experiences and outcomes differ greatly by zip code, even in the same region. Health plans and other relevant stakeholders should collect data regarding demographics, social determinants of health and other key information that could be used to tailor resources to specific underserved, vulnerable populations.

c) Women of color historically have worse quality of care, worse outcomes, higher disease incidence, inefficient pain management and shorter life expectancies. They also report less trust in their care providers compared to white women. Members of LGBTQ+ communities report avoiding health care altogether due to anticipated discrimination, which may manifest in delayed medical care and distrust or dissatisfaction with the health system when they do engage. They also report higher trust and satisfaction with telehealth than with past in-person visits, so digital tools may be key to support these communities.[31]

- **Recommendation:** Digital health tools and telehealth are two strategies to help overcome infrastructure barriers, especially for rural, underserved communities. They present opportunities to fill a lot of gaps, such as scaling to small practices with fewer resources and enabling continuous patient monitoring.

d) Medicaid plays a key role in advancing racial health equity by offering access to health coverage for many people of color and children through CHIP, ensuring access to care and providing financial protections. States have proposed new approaches to CMS through Section 1115 waivers, including changes to managed care arrangements, provider benefits and increasing access to care.[32] While access to care and social determinants of health remain critical components of improving arthritis care, zip codes can be used to identify resource needs and track outcomes trends.

- **Recommendation**: Within their authority, state Medicaid departments should prioritize resource allocation to identify and address social determinants of health.

VI. CONCLUSION

Creating a truly ideal model of care for patients living with arthritis requires a systemwide shift to patient-centered, holistic and integrated care across a patient's lifetime continuum. Patient measures must capture information important not only to clinicians but also to the patients. The patient's preferences and goals should be discussed, leading to a stronger relationship between the patient and provider and ideally resulting in improved health outcomes. These all drive toward the need for renewed incentivization, financial restructuring of the health system and securing the resources necessary to care for people with chronic, often complex conditions. Creating such changes could employ

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[31] Rockhealth. Startup innovation for underserved groups: 2021 digital health consumer adoption insights. 2022. https://rockhealth.com/insights/startup-innovation-for-underserved-groups-2021-digital-health-consumer-adoption-insights/.

[32] Agarwal, Rajender, et al. "The Impact of Bundled Payment on Health Care Spending, Utilization, And Quality: A Systematic Review." Health Affairs. Vol. 39, No. 1. January 2020. https://doi.org/10.1377/hlthaff.2019.00784.

technology to conform to patient needs, improve digital infrastructure to capture broader and better categories of data and integrate health systems.

The Arthritis Foundation is doing its part to make progress in these domains. More details on our programs and initiatives, found in the next section, include everything from scientific research to diversity, equity and inclusion and health literacy. Based on this report we will be aggressively ramping up our efforts to help patients achieve their Ideal Model of Care. This will include:

- Engaging our patient volunteers directly with these principles to develop their own Ideal Model of Care goals.
- Engaging with state and federal policymakers to remove barriers to achieving our proposed solutions.
- Engaging with health care providers and health care systems to facilitate patient engagement, shared decision-making and patient-centered care delivery.
- Engaging with health plans and health care purchasers to engage patients in coverage decisions and prioritize the holistic, lifetime care needs of patients.
- Engaging all stakeholders to address health disparities and to utilize technology to facilitate better integration and coordination of care and health outcomes.

Appendix

Arthritis Foundation Resources

- Rx for Access: Your Coverage, Your Care Toolkit
    - This powerful resource helps patients better understand health coverage options and prepare for open enrollment; choose the right coverage for arthritis care needs and minimize claim denials; manage the denial process with step-by-step instructions; and reduce costs and find financial assistance programs.
    - Rx for Access is a free, comprehensive resource. Navigating the marketplace, formularies and other aspects of coverage can be incredibly challenging, and patients with chronic diseases often face additional barriers and challenges. Resources such as Rx for Access help to improve health literacy.
- **Arthritis Foundation Connect Groups**
    - Live Yes! Connect Groups are in-person and virtual groups that bring together parents/guardians of children or adults living with various types of arthritis and rheumatic diseases. They are focused on both fun social activities and informative events and activities, and they offer a place of understanding and encouragement for people living with arthritis and their loved ones. Fostering relationships allows patients and caregivers to feel less alone and creates a safe space to discuss personal challenges and successes and to share advice regarding care, treatment, navigating insurance plans and more.
- **Funding research**
    - Arthritis Foundation Science & Research
    - The Arthritis Foundation places a high priority on both clinical and translational scientific research in osteoarthritis, juvenile arthritis and rheumatoid arthritis in addition to supporting workforce development

  programs, including several Clinical Fellowships and DEI Inclusion Programs for U.S. rheumatologists in training. Additionally, the Advocacy & Access department advocates for and supports legislation that would benefit research and scientific development.

- **Funding workforce**
  - JA Victory: Congress OKs Funding to Repay Student Loans of Specialty Doctors
  - Ensuring there is an adequate number of health care practitioners and providers in a given area is key to lowering barriers to care and improving health equity by reducing disparities. This can also improve overall health outcomes and cut costs by eliminating the need to travel long distances to see a provider. There is currently a shortage of pediatric subspeciality providers in the United States — an issue felt by the juvenile arthritis community. The Pediatric Subspeciality Loan Repayment Program addresses this disparity by offering loan repayment to pediatric subspecialists practicing in underserved communities.

- **DEI initiatives**
  - Arthritis Foundation Statement on Diversity, Equity & Inclusion
  - The Arthritis Foundation is committed to Diversity, Equity and Inclusion (DEI) to support the training of a diverse generation of rheumatologists and to improve health outcomes for all patients with rheumatic diseases, especially those living with arthritis. To that end, we are advancing and funding research that improves health outcomes across different racial and ethnic groups as well as socioeconomic status. In an initiative we began in 2021 and 2022 to increase diversity in rheumatology, we issued an RFP for two programs. The first program provides seed funding for programs aimed at supporting research and improving health outcomes among different racial and ethnic groups and socioeconomic backgrounds. The second program seeks to increase diversity in the field of rheumatology by providing a stipend to medical students and residents in rheumatology. In an effort to reach a broad audience of patients, providers and community members, we hosted the inaugural 2022 DEI Science Summit in October of 2022. Stakeholders in a variety of groups and professions came together to discuss ways to encourage outreach and retention of under-represented minority individuals in rheumatology training programs. The findings from the summit will inform 2023 DEI planning grants.

- **INSIGHTS and Patient-Focused Drug Development (PFDD) meetings**
  - OA Voice of the Patient. OA VOP Report. March 8, 2017.
  - Externally Led Juvenile Idiopathic Arthritis Patient-Focused Drug Development Meeting Report. V 1.3. October 7, 2019.
  - Live Yes! INSIGHTS studies were aimed at individuals 18 and older living with arthritis and parents of children aged 5 to 17 living with juvenile arthritis. It was one of the largest Patient Reported Outcome (PRO) studies in the United States and captured results from over 40,000 participants. The aggregated data provides a picture of life with arthritis. It is used by the Arthritis Foundation and shared with our research and innovation partners to conduct research that increases understanding of arthritis.