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How an Innovative Healthcare Partnership Facilitated Earlier Identification of Patients at Risk for Axial Spondyloarthritis (axSpA)

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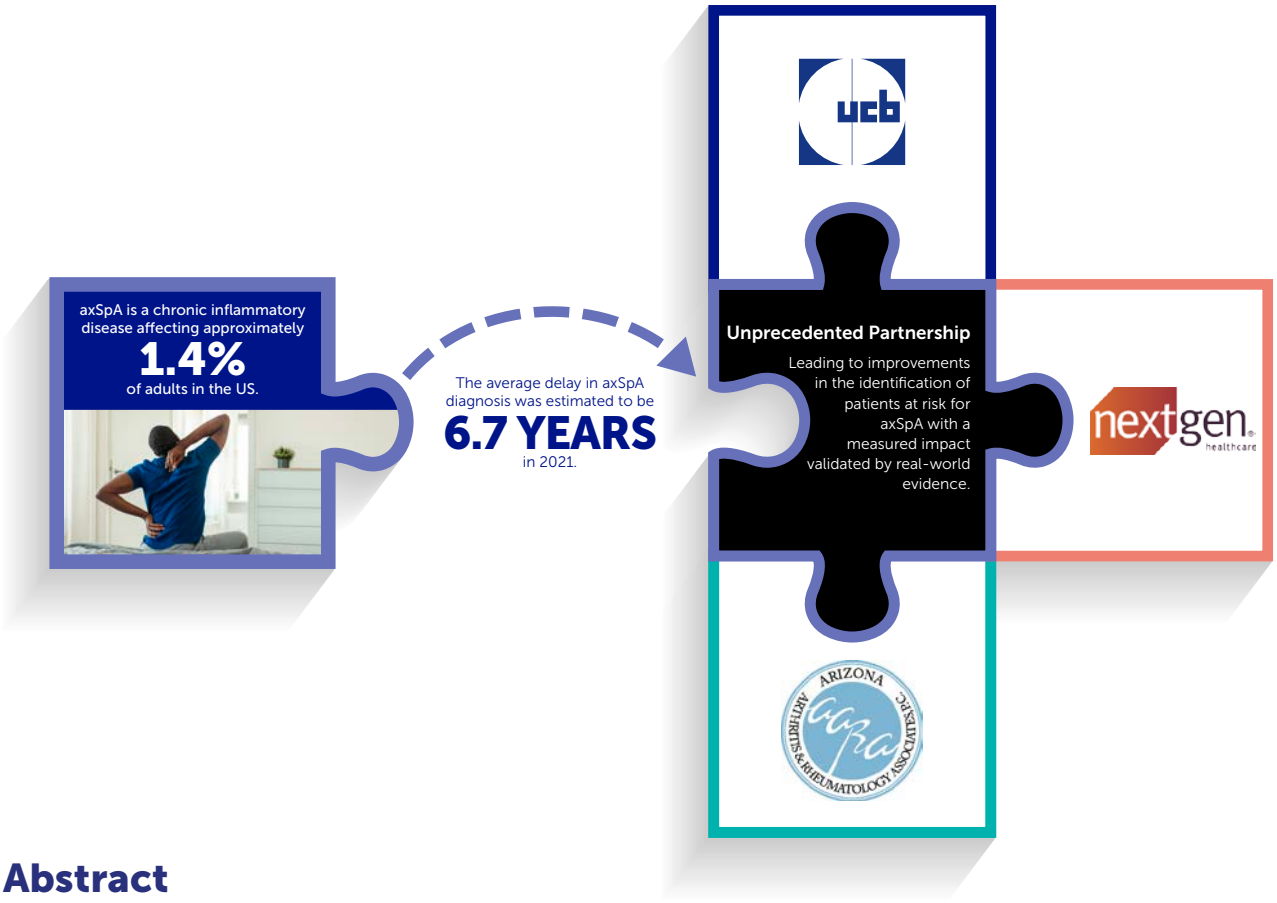


Abstract

Purpose: Axial spondyloarthritis (axSpA) affects 1.4% of US adults, with chronic inflammatory back pain (IBP) before age 45 as the primary symptom. Delayed diagnosis and underrecognition lead to poor outcomes, while healthcare workforce shortages limit providers' ability to meet the needs of the increasing number of patients with back pain. This real-world study assesses the impact of integrating an automated inflammatory back pain (IBP) screening tool and query system into the electronic health record (EHR) to facilitate the earlier identification of axSpA in new and established patients in a community rheumatology practice.

Methodology: A validated IBP screening tool was incorporated into the EHR patient intake form through an innovative partnership between NextGen Healthcare, UCB Ecosystem Partners, and Arizona Arthritis and Rheumatology Associates (AARA), a large rheumatology practice with 12 clinics in the Southwest US. The EHR automatically generated customized alerts, which were sent to the treating rheumatologist for review. Additional tailored EHR queries were used to identify potentially overlooked patients. New patients were those with their first or second visit during the two-year study period (October 2021 to October 2023), while established patients were those with their third or later visit before January 1, 2023.

Results: Of 19,875 new patients screened, 1,457 (7.3%) had a positive IBP screening, with 180 (12.4%) later diagnosed with axSpA. In a separate analysis of 94,606 established patients, 223 (0.2%) had a positive IBP screening, and of those, 61 (27.4%) were ultimately diagnosed with axSpA. Overall, 14.3% of positive IBP screening forms were associated with an axSpA diagnosis.

Conclusion: Integrating an automated IBP screening tool and query system into the EHR in community practices, including rheumatology, can facilitate earlier and more efficient identification of patients with axSpA. This approach may close gaps in care by identifying previously missed patients while also improving long-term outcomes through earlier diagnosis and treatment initiation.

Overview of the axSpA Family of Diseases

axSpA is a group of chronic inflammatory rheumatic diseases primarily affecting the sacroiliac joints and spine.[1] The collective term, axSpA, includes both ankylosing spondylitis (AS) and non-radiographic axSpA (nr-axSpA), which are distinguished by the presence or absence of definitive structural damage on radiographs, respectively (**Figure 1**).[1,2] Despite this radiographic distinction, the two conditions exhibit similar disease activity and reduced quality of life.[3]

axSpA affects approximately 1.4% of adults in the US.[4,5] However, its true prevalence remains unknown because of significant diagnostic delays, disease underrecognition, and data analysis challenges.[5]

The individual clinical burden of axSpA is significant due to symptoms that include chronic low back pain (LBP), fatigue, sleep disturbance, depression, and sexual dysfunction, among others.[6] Furthermore, a delay in axSpA diagnosis and treatment is associated with an increased burden on the healthcare system due to more significant disease activity, poorer treatment response, and a higher prevalence of depression. Without an accurate axSpA diagnosis, patients may not receive appropriate treatment and may, therefore, experience more severe symptoms and less favorable long-term outcomes like irreversible loss of spinal mobility.[1,7] In contrast, early diagnosis and treatment of axSpA are associated with improved symptoms, physical function, and quality of life, as well as reduced inflammation measured using magnetic resonance imaging.[7,8] Together, this suggests that earlier intervention during the window of opportunity may lead to improved long-term patient outcomes and underscores the need for patients with axSpA to be identified and treated as early as possible.[9]

Factors Contributing to the axSpA Gap in Care

The average delay in axSpA diagnosis was estimated to be 6.7 years in 2021[10] and has been reported to be as long as 13 years.[2] Several factors contribute to this care gap, burdening patients, clinicians, and the community.[11]

One significant challenge in diagnosing axSpA is that one of its key symptoms, chronic LBP, is prevalent in the general population. Chronic LBP can be classified as either inflammatory back pain (IBP) or mechanical back pain (MBP), depending on the underlying origin, and differentiating between the two etiologies remains a challenge (**Figure 2**).[1,5,12]

Importantly, studies have estimated that IBP is present in up to 80% of patients with axSpA.[13-15] However, axSpA accounts for only about 5% of all chronic LBP cases.[1] Characteristics of IBP in patients who later receive an axSpA diagnosis include insidious onset, appearance before age 40, and persistence for at least 3 months.[5,16] In axSpA, IBP typically improves with exercise and upon waking but does not improve with rest.[5] Without proper identification of IBP, patients with axSpA may remain "hidden" in the larger population of individuals with chronic LBP, thereby perpetuating diagnostic delays.

Another factor contributing to the axSpA care gap is the presence of extra-musculoskeletal manifestations, such as uveitis, peripheral arthritis, dactylitis, psoriasis, inflammatory bowel disease, and enthesitis, which complicate care coordination.[1] These varied signs and symptoms often lead patients to visit multiple specialists and receive several misdiagnoses before an accurate axSpA diagnosis.

A third contributing factor is the lack of standardized screening paradigms for axSpA. For instance, while imaging can be a useful screening tool, its use is cost-prohibitive in many countries.[14] HLA-B27 levels have been used as a

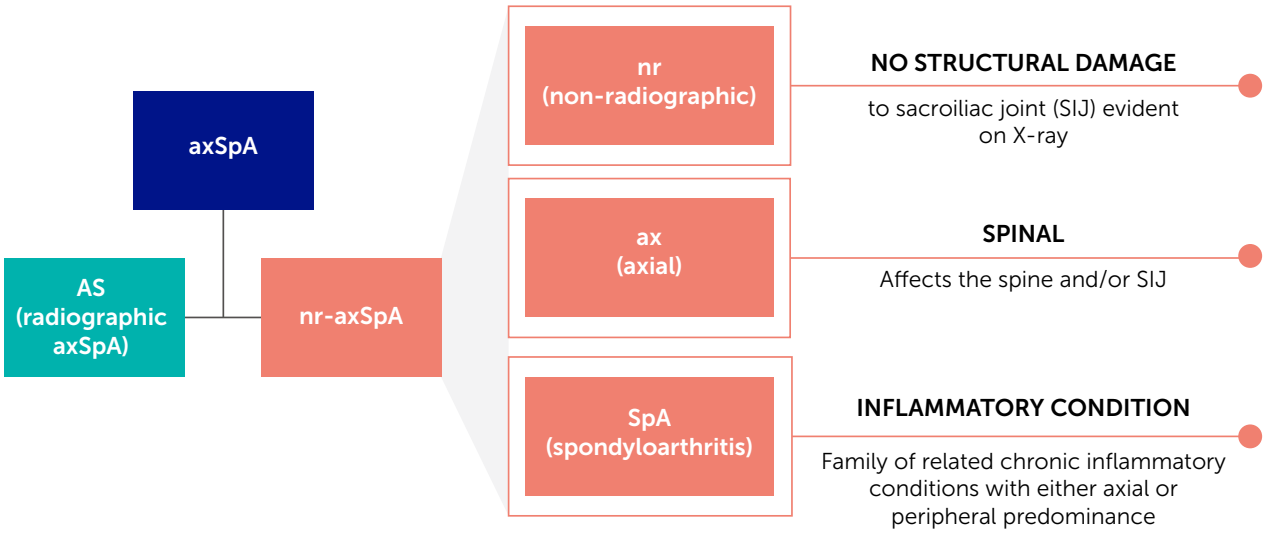


Figure 1. Overview of the axSpA Family of Rheumatic Diseases.

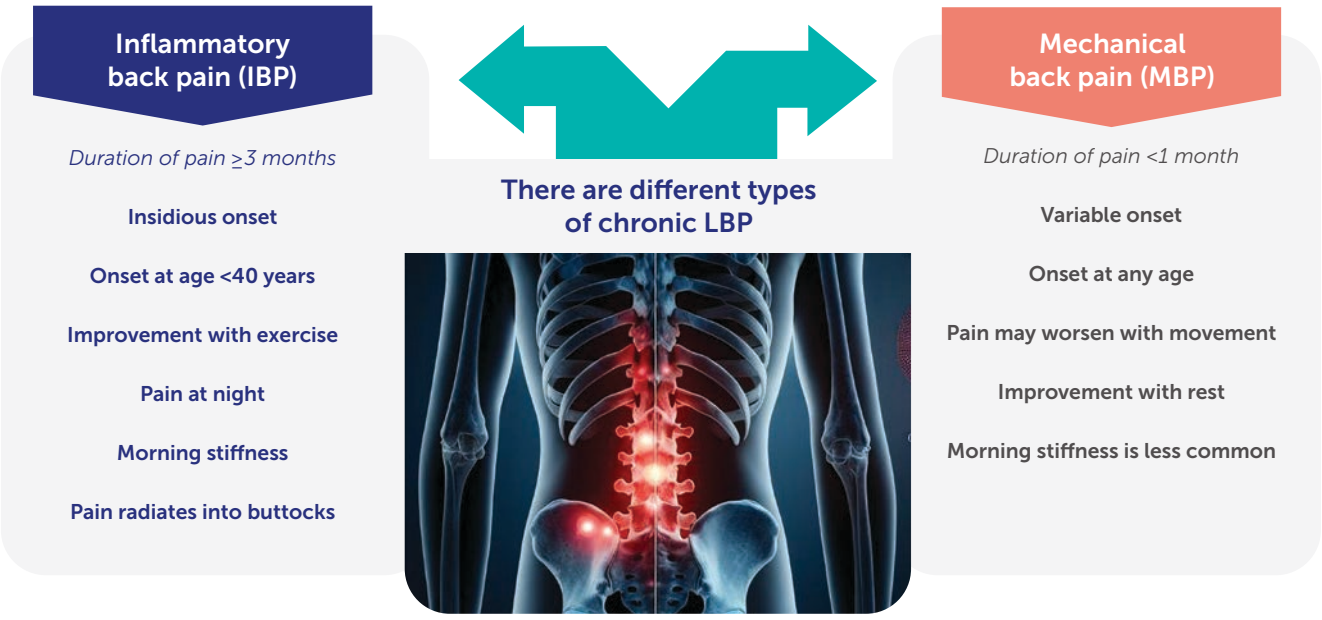


Figure 2. Differential Diagnosis of Chronic LBP.

screening parameter, but baseline HLA-B27 levels vary widely across geographies and ethnicities.[14] Additionally, the frequency of HLA-B27 positivity is much lower in nr-axSpA than in AS, requiring further imaging for confirmation.[1,16] Although IBP is regarded as the leading clinical symptom of axSpA, referring clinicians and rheumatologists lack consensus on key IBP features, and referral requirements lack concordance across specialties.[1,14] Moreover, before 2020, the field lacked an official set of diagnostic codes for nr-axSpA, causing patient records to be incorrectly coded or noncoded, further exacerbating diagnostic inaccuracy and delay.[17]

Lastly, current healthcare personnel shortages in rheumatology impose escalating demands on clinicians.[18] Patient loads, time constraints, and inefficiencies can cause workforce burnout,[19] reducing the availability of high-quality care for patients with rheumatic conditions.[20,21]

Fortunately, increased efficiency and standardization in screening for axSpA may help overcome these existing barriers. Screening tools that use simple criteria could facilitate the identification of patients at risk of axSpA, flagging them for additional follow-up. Specifically, one rationale proposes integrating a simple, automated IBP questionnaire into the EHR to quickly screen patients in an efficient and streamlined process that facilitates easy adoption for clinicians. Three pioneering collaborators took on this challenge.

> "Many patients have been misclassified as having chronic back pain, degenerative disc disease, or fibromyalgia. Furthermore, the variability in pain and symptoms often delays some patients from seeking timely help. Compounding this issue, the outdated belief that AS primarily affects men has led to many women being overlooked for diagnosis. Identifying these patients who are 'hiding in plain sight' is a responsibility shared across all specialties. Where technology can assist in this effort, as demonstrated by AARA, it should be utilized fully to shorten time to diagnosis and care."
>
> *–Dr Nehad Soloman, AARA*

An Innovative Healthcare Partnership to Close the axSpA Gap in Care

UCB is a leader in its commitment to the patients with axSpA due to its patient-centric focus on gaps in care. NextGen Healthcare is an EHR software innovator that works with over 60% of community-based rheumatology practices in the United States. AARA is a multicenter rheumatology practice comprising 12 clinics and ~55 clinicians and serving over 120,000 patients in Arizona and Texas. Together, these organizations collaborated in a first-of-its-kind approach to improve upon the current process of axSpA identification by leveraging simplified screening protocols and EHR data analysis capabilities. UCB provided robust disease state knowledge, AARA and the Chair of Data/Health Population Management, Dr Nehad Solomon, provided clinical direction and rheumatology expertise, and NextGen Healthcare provided technical prowess. This approach resulted in a 2-year project in which the team successfully integrated an IBP

screening tool into the new patient intake process using the existing EHR software. The team also designed customizable data analysis query sets (axSpA-ID) that leverage existing EHR data to automate the identification of established patients likely to have axSpA (AS and nr-axSpA), especially those patients who had not previously been identified.

Developing the Integrated Screening Approach

Screening Tool Integration and Outcomes

A simple 5-question IBP screening tool was adapted from the Assessment of SpondyloArthritis international Society (ASAS) questionnaire, which evaluates patients for key features distinguishing IBP from MBP, such as changes in back pain with exercise or rest.[13] The criteria for IBP are fulfilled if at least 4 out of 5 questions are answered affirmatively (**Figure 3**), and this triggers the EHR to send an automatic, customized alert to the clinician for review. Such alerts are intended to prompt clinicians for patient follow-up with additional testing such as labs and imaging. Notably, the alerts are designed to prevent message blindness by requiring acknowledgment before the clinician can progress within the system (**Figure 3**).

Query Set Development and Outcomes

The collaboration also led to the development of axSpA-ID query sets based on clinical features that support earlier recognition of patients with a high likelihood of axSpA diagnosis (**Figure 4**). These query sets are customizable, allowing clinicians and administrators to select the most pertinent parameters based on their clinical experience and the specific needs of their patient population. Clinicians can also set a desired query frequency to assess patients at predetermined timing intervals. The resulting EHR query report provides patient lists for follow-up based on the chosen clinical attributes.

> "A very important confounding factor in identifying axSpA is that many patients have comorbid musculoskeletal conditions, including degenerative disc disease and osteoarthritis of the spine, sacroiliac, and peripheral joints, as well as comorbid pain syndromes, such as fibromyalgia. The query system alerting our clinicians to the possibility of axSpA 'hiding' in these contexts heightens awareness and supports further investigation and evaluation."
>
> *–Dr John R.P. Tesser, AARA*

Results from testing suggest clinicians should include a minimum of 6 and a maximum of 39 clinical features in the query set to help identify established patients with potential axSpA. Furthermore, developmental testing revealed four specific queries that reached consensus among the team, and these are now recognized as available queries among all NextGen users. Notably, using queries within the EHR platform can identify established patients at risk for axSpA who may have previously been "hiding" in a population of individuals with undefined, chronic LBP.

Tool Validation and Clinical Impact

The team validated the impact of integrating the IBP screening tool into the EHR-supported patient intake process with RWE from AARA. In doing so, over 120,000 patients across all AARA practice locations were screened with the IBP tool as of March 31, 2024.[22] In an analysis of 19,875 new patients, defined

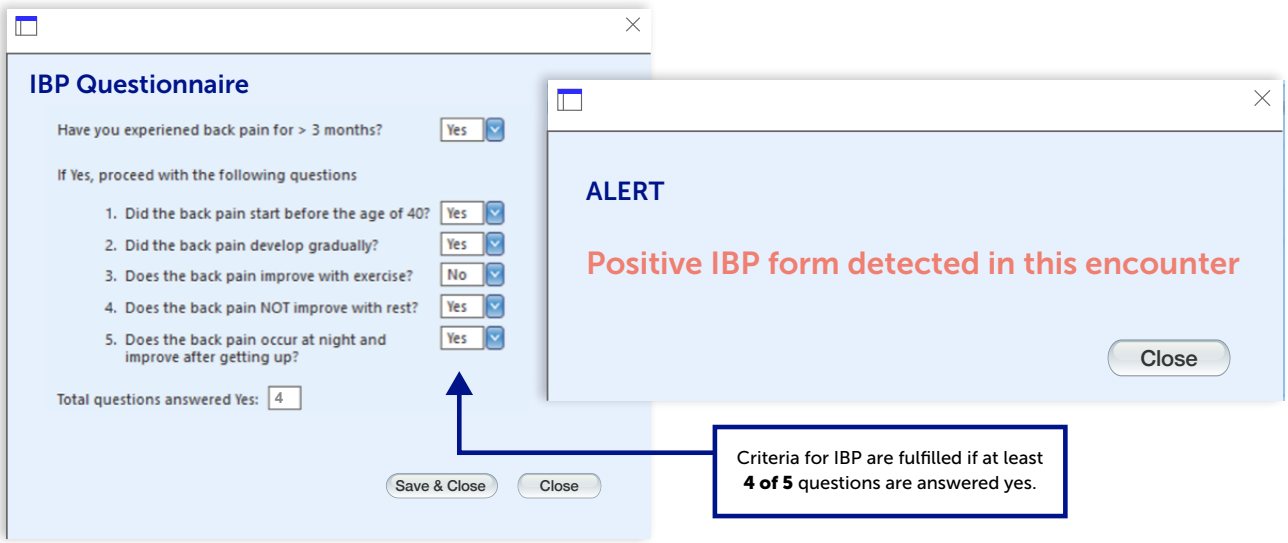


Figure 3. Key Features of the IBP Screening Tool and EHR Automation.

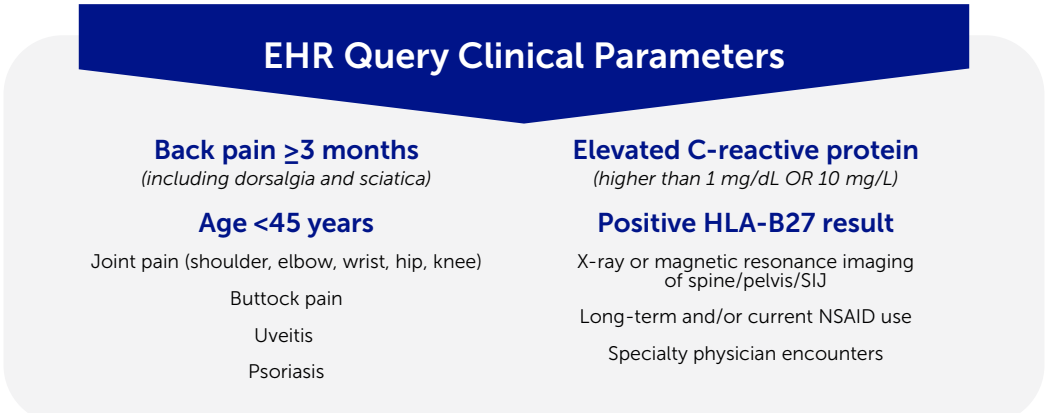
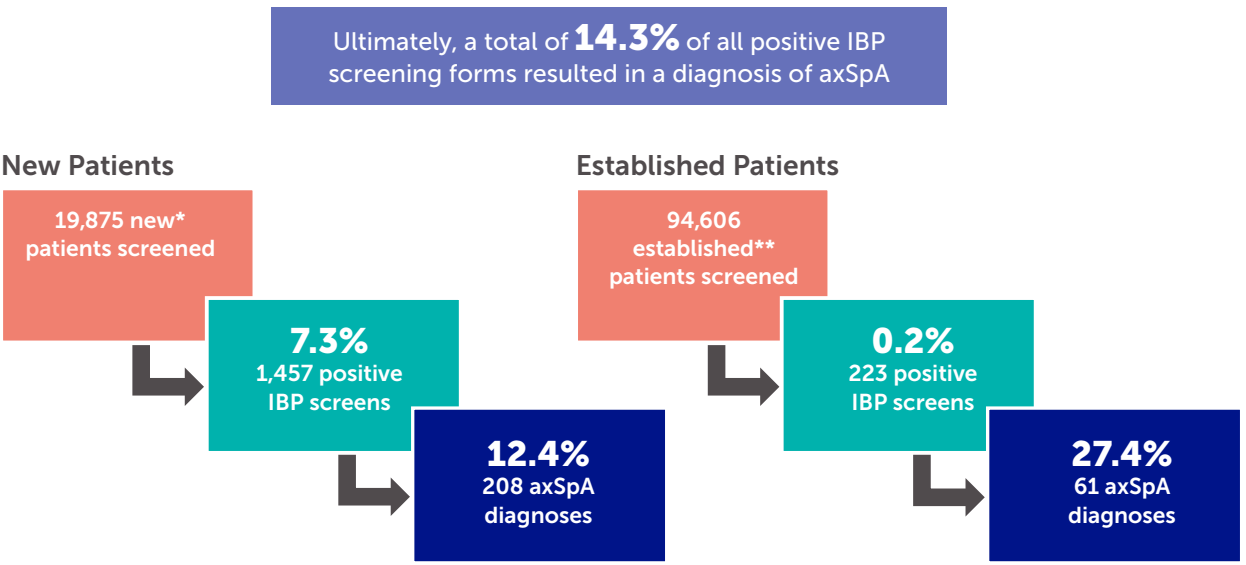


Figure 4. Examples of Clinical Features Supporting Early Identification of axSpA for Query Set Development.

as those with a first or second visit between October 2021 and October 2023, 1,457 had a positive IBP screening result, suggesting that 7.3% of new patients are at risk for axSpA (**Figure 5**). Of new patients with a positive IBP result, 180 (12.4%) were subsequently diagnosed with AS or nr-axSpA, representing ~1% of all new patients during the defined study period. These results demonstrate that the tool can successfully identify new patients with IBP who are subsequently diagnosed with axSpA.[22]

> "We successfully leveraged the power and flexibility of the NextGen system to enhance clinicians' ability to identify patients more efficiently. This underscores the critical importance of not only having technology that empowers clinics but also the dedicated team at NextGen Healthcare supporting that innovation."
>
> *–Matt McIntosh, NextGen Healthcare*

The results from new patient screening prompted the group to evaluate established AARA patients in a second analysis. In an axSpA-ID query set analysis of 94,606 established patients at AARA—defined as those with a third or subsequent visit before January 1, 2023—223 (0.2%) met the query set criteria. Of established patients who met the query set criteria, 61 (27.4%) had a subsequent diagnosis of AS or nr-axSpA. Thus, even in a top-performing clinic, delayed diagnosis of axSpA is a discrete possibility, and the query set successfully identified at-risk patients who were previously missed. Ultimately, a total of 14.3% of all positive IBP screening forms were associated with a diagnosis of axSpA (AS or nr-axSpA).[22]



**New patients were defined as those with a first or second visit between October 2021 and October 2023.*
***Established patients were defined as those with a third or subsequent visit before January 1, 2023.*

Figure 5. Outcomes Data From Screening Tool Validation.

Key Learnings From the Partnership Approach

Several meaningful learning opportunities occurred throughout the 2-year project (**Figure 6**). The first learning is that effective collaboration is central to a successful outcome. While clinicians and industry professionals often work together, the current project included an EHR software company as an essential partner. The consistent involvement of all three partners proved enlightening and valuable in several ways. The clinicians' perspectives and insights allowed for optimal consideration of features within the EHR platform (e.g., message blindness). The technical expertise from NextGen Healthcare was critical to align the desired outcomes with the clinical needs of AARA clinicians by maximizing existing EHR data. UCB supported various types of unbranded education throughout the 2-year period to create awareness and helped improve the utilization of the tool. Incorporating feedback from each partner was essential for the program's success, and this is a recommended component for anyone embarking on a similar project.

> "Even in a well-established practice like AARA, we continue to uncover patients 'hiding in plain sight' through the IBP questionnaire and targeted EHR queries."
>
> *–Dr Nehad Soloman, AARA*

The second learning is that ongoing feedback from all partners allows for an agile and iterative approach to developing actionable solutions at each stage. For example, when an advanced practice provider suspected that a patient may have nr-axSpA, an AARA provider inquired about the patient's IBP questionnaire result. At the time, the EHR did not send an alert when a positive IBP result was registered. This led to realizing efficiencies could be captured if patient intake data functioned strategically with the EHR. Discussing this shortcoming with NextGen Healthcare led to implementing the current automated alert system, providing a more streamlined approach for clinicians. While the screening tool can be integrated into the EHR, the process can be made even more efficient for clinicians when the tool is integrated with patient intake. However, this is not advised if the intake information does not transfer to the EHR.

A third learning is that integrating the IBP screening tool into the EHR requires minimal time investment from clinical staff while yielding compelling results. Furthermore, the full integration of screening across a multicenter practice created consistency across sites and clinicians. This is particularly important because patients can be found in a variety of specialties, as mentioned. Overall, this project demonstrated the value of the tool in Rheumatology practices to quickly and efficiently identify patients at risk for axSpA.

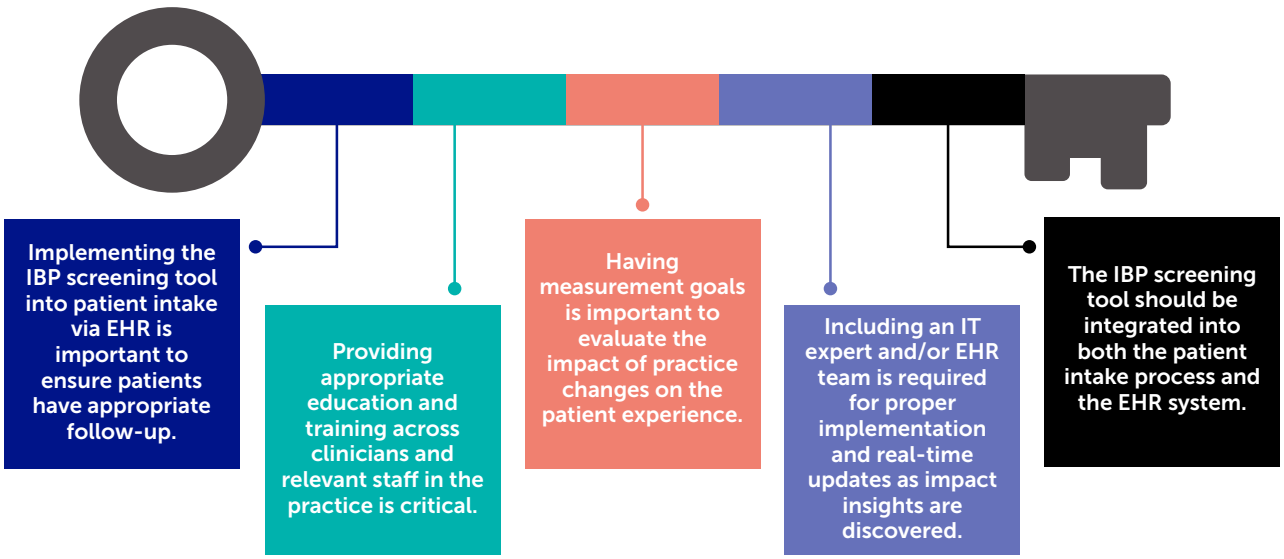


Figure 6. Key Learnings From the Innovative Partnership.

Conclusion

AS and nr-axSpA affect millions of patients, most of whom struggle with debilitating symptoms and incorrect diagnoses for several years before receiving proper treatment. Existing gaps in care negatively affect these patients and result in prolonged suffering and reduced quality of life. However, the entire healthcare community can work to overcome these gaps in care by leveraging existing systems to modernize and simplify the identification of axSpA, which may reduce diagnostic delays and lead to earlier therapeutic intervention. This white paper details a unique and effective process through an unprecedented partnership between industry professionals, digital innovators, and clinical experts that provided the critical pathway to improving the identification of patients at risk for axSpA. The EHR-integrated IBP screening tool and customizable query sets, developed through this innovative partnership, are already making a clinical impact in at-risk patients. In particular, this real-world study demonstrated that 14.3% of all positive IBP screening forms were associated with an axSpA diagnosis. By seamlessly integrating into clinical workflows, this novel approach has transformed how healthcare professionals identify and address care gaps within the rheumatology specialty. It has set a new standard for proactive patient identification, leading to improved patient outcomes while closing critical gaps in care.

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