Empowering Patient-Centric Research:

LEVERAGING AI TO ELEVATE PATIENT AND CAREGIVER PERSPECTIVES

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inspire™

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I. EXECUTIVE SUMMARY

Perspective from patients and caregivers (also called “patient or caregiver voice”) is essential to the development of person-centric therapies that prioritize quality of life (QoL) and real-world outcomes.Traditional methods of collecting patient and caregiver perspectives (e.g. unmet needs, hopes, fears, willingness for treatment) —through surveys, interviews, and focus groups—are episodic, resource-intensive, and often limited in scope.

This white paper demonstrates the use of generative artificial intelligence (genAI) to make patient and caregiver perspectives easily available and on-demand. The result is the scalable and continuous upstream inclusion of patient and caregiver perspective into drug development and care strategies. This significantly increases the likelihood that authentic patient unmet needs and treatment preferences are met by developed therapies.

Inspire has developed a methodology that uses generative AI to “bring to life” the patient and caregiver conversations from an online support group. These threads, gathered from dedicated patient communities, contain the natural conversations where patients and caregivers ask for information and share concerns and preferences. Inspire’s use of genAI makes those patient and caregiver perspectives contained in conversation threads “come alive” and answer questions about QoL and unmet needs. Crucially, these AI-generated insights are validated by the very patients and caregivers whose conversations were analyzed, ensuring accuracy and trustworthiness.

A recent project focused on the Interstitial Cystitis community on Inspire.com exemplifies this approach. A question bank of eight "industry-speak" questions was presented to Inspire's AI informed by the patient and caregiver perspective from Inspire’s Interstitial Cystitis community. The perspective-informed AI then generated answers as if it was speaking from the point of view of those patients and caregivers from the community conversations. These answers were subsequently reviewed and validated by members of the Interstitial Cystitis community, demonstrating the potential for AI to facilitate continuous, real-time patient feedback.

By leveraging AI, Inspire provides life sciences companies with access to patient and caregiver insights on a much larger scale than was previously possible. This technology enables an “always-on” patient voice—one that can inform clinical trial design, patient recruitment, retention strategies, and ultimately, the development of therapies that genuinely address patient needs.

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II. INTRODUCTION

The Importance of Authentic Patient and Caregiver Voices

In recent years, regulatory agencies like the FDA have emphasized the value of patient perspectives in the development of treatments in order to address clinical efficacy and quality of life (QoL). However, the capture and integration of patient perspectives, also called patient voice, remains a significant challenge. The collection of patient insights—through surveys, interviews, or focus groups—is labor-intensive, time-consuming, and often fails to capture the full breadth of patient experiences.

Traditional data collection methods often frame human experiences in highly clinical or technical terms that fail to resonate with the people who are patients and caregiver e.g.phrases like “quality of life” or “unmet needs” are artificial. The clinical or technical terms employed do not capture the raw and deeply personal nature of living with a chronic illness or supporting a loved one through a chronic illness. As a result, insights gleaned through these conventional channels are limited, both in scope and relevance. These limited insights may only reinforce existing knowledge and may fail to reflect the real concerns or needs of patients and caregivers.

This gap between industry language and human experience creates barriers to fully understanding what matters most to patients and caregivers. To truly prioritize person-centric care, the life sciences industry must broaden the scope of patient insights, making them easily accessible and integrated upstream in the development of therapies.

AI as the Solution

This white paper introduces an innovative approach to bridge that gap: generative artificial intelligence (genAI) designed to bring patient and caregiver voices to life. Inspire’s use of generative AI incorporates patient-to-patient conversation threads thereby unlocking the latent patient and caregiver voice from those authentic unstructured discussions. The unlocked patient and caregiver voices are then available for questions and interactions that yield actionable insights on QoL, unmet needs, and other critical aspects of patient care. By tapping into the authentic, unstructured discussions occurring on platforms like Inspire.com, this approach makes it possible to capture patient perspectives at scale, without the need for intrusive or resource-heavy data collection methods.

Moreover, AI allows for these insights to be continually available. This "always-on" access to patient voices—validated by the same patients and caregivers who contributed the original content—opens up new possibilities for drug development, clinical trial design, and patient engagement strategies. With this technology, the patient perspective is no longer a once-in-a-while input; it becomes an ongoing, integral part of every stage of care and therapeutic development.

III. PROBLEM STATEMENT

Industry Speak vs. Human Experience

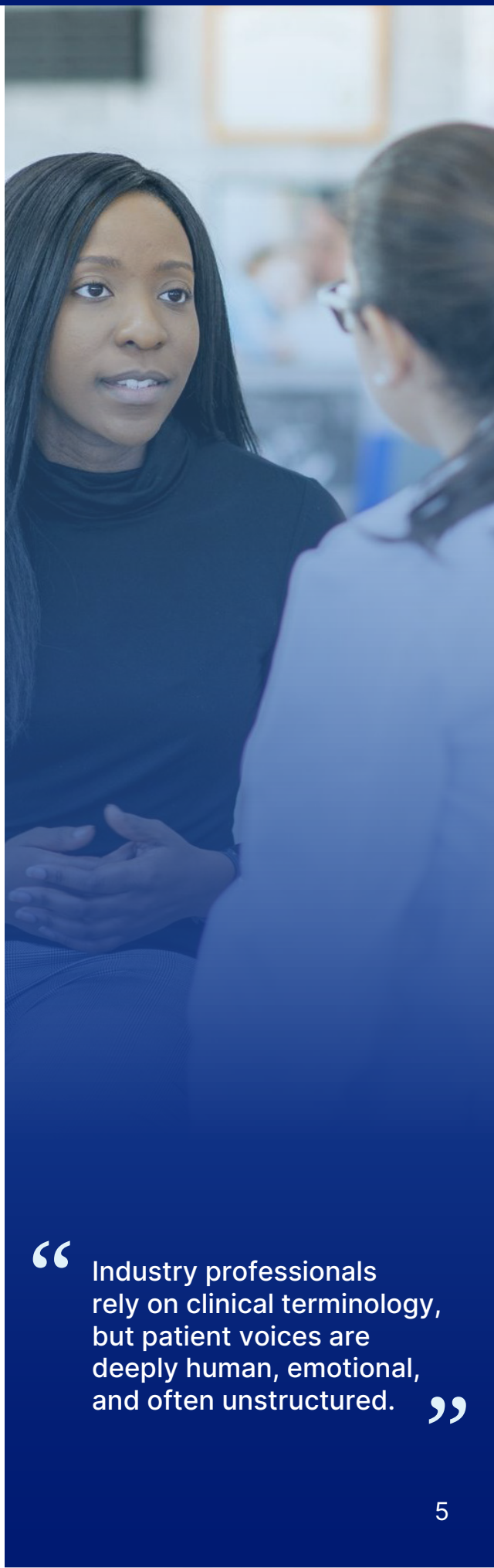
In the life sciences industry, there is a significant divide between the language used by researchers, clinicians, and the language of patients and caregivers. When conducting clinical research or developing new therapies, common industry terms like “quality of life” or “unmet needs” are frequently employed. However, these terms often fail to resonate with patients. No one naturally expresses their daily experiences with such terms. When asked “What is your quality of life?” or “Please rank your unmet needs,” patients might struggle to connect the question to their real, lived experiences. As one patient put it, “I don’t know, I’m kinda thirsty right now.”

This disconnect is a key challenge: industry professionals rely on clinical terminology, but patient voices are deeply human, emotional, and often unstructured. This mismatch leads to data that may be clinically useful but fails to capture the nuances of patient and caregiver experiences. The result is a narrow understanding of what truly impacts the lives of those living with chronic conditions.

Limited Access to Patient Voices

Capturing the full spectrum of patient and caregiver voices requires time, effort, and significant resources. Traditionally, the industry has depended on surveys, focus groups, or interviews, all of which are time-intensive and limited by the scale of engagement they can achieve. These methods often miss the spontaneous, genuine expressions of patient concerns and priorities that emerge in real-life conversations.

The data collected through these efforts can also be constrained by the specificity of the questions asked. Patients are seldom invited to share their thoughts in open-ended formats where their voices can emerge naturally, and as a result, insights are frequently siloed into predefined categories that may not reflect the true scope of their needs or concerns. This approach limits the application of patient insights to specific, narrow areas of research or development, preventing a holistic understanding of their experiences.



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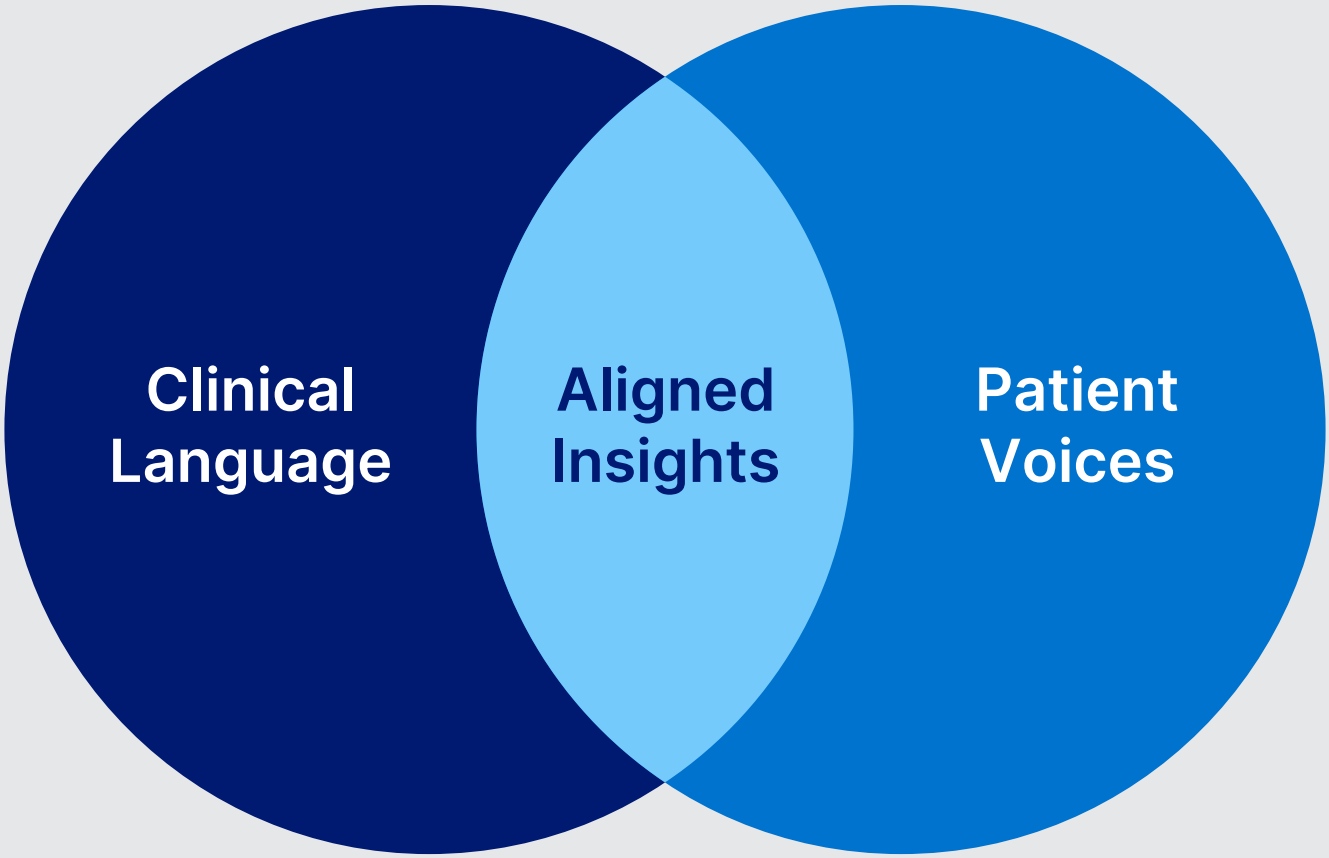


The Need for Broader, Easier Access

The combination of narrow and high cost collection methods to collect patient and caregiver voice results in a series of relatively infrequent one-off engagements, which is very far from the goal of centering patient and caregiver in therapeutic development. In order to center the patient and caregiver voice in therapeutic development, the industry must broaden the availability and upstream inclusion of patient insights. These insights must be continuously accessible, not restricted to one-off surveys or controlled studies. This requires a shift from static, manually collected data to a dynamic, scalable method of capturing patient and caregiver perspectives.

To make patient voices central to the development of life sciences solutions, the industry now has the ability to deploy technology that makes patient and caregiver voices more widely and easily available, without requiring labor-intensive or intrusive processes. The industry will not only collect more data, but also collect richer, more authentic data that reflects the realities of patients' lives—unfiltered by the constraints of industry-speak.

IV. INTRODUCING INSPIRE'S AI-POWERED SOLUTION

AI in Action

To address the disconnect between "industry-speak" and human experience, Inspire has developed a groundbreaking approach using generative artificial intelligence (genAI) to capture patient and caregiver voices more effectively. By leveraging genAI, Inspire ingests unstructured patient-generated conversation threads from its vast community platform and synthesizes meaningful, actionable insights for healthcare providers and life sciences companies.

Generative AI models have been shown to excel at processing natural language inputs, extracting patterns, and responding to complex questions in human-like ways[1]. By feeding these models with thousands of patient discussions, Inspire enables AI to provide answers to questions about quality of life (QoL) and unmet needs—questions that typically require resource-heavy, time-consuming human interventions.

However, unlike typical applications of AI, Inspire's solution goes a step further by involving patients and caregivers in validating the AI-generated answers. This human validation ensures that the AI's insights remain true to the lived experiences of those who contributed to the original conversations. Research in healthcare AI highlights the importance of maintaining a feedback loop where machine-generated data is refined through human input to avoid inaccuracies and bias[2].

Patient-Caregiver Validation

While AI can process large amounts of data, the human element remains essential for ensuring that insights reflect actual patient needs and priorities. Inspire has built a process that incorporates patient and caregiver feedback at critical points in the data generation cycle. After the AI produces responses to the questions—based on threads from condition-specific communities—these answers are presented back to the patients and caregivers from the relevant community. The community members are then asked to confirm the AI's interpretations and provide any necessary corrections or refinements.

This validation process not only enhances the accuracy of the AI-generated insights but also ensures that the data remains rooted in the personal experiences of patients and caregivers, which are essential for QoL-related metrics. Recent studies highlight the importance of human oversight in validating AI-generated medical insights, particularly in complex, patient-centered scenarios[3].

Case Study: Interstitial Cystitis Community

To demonstrate the efficacy of Inspire's AI-powered solution, a recent project focused on the Interstitial Cystitis (IC) community on Inspire.com. Interstitial Cystitis is a chronic and debilitating bladder condition that significantly impacts the quality of life of those affected. Inspire engaged this community to explore whether AI could help collect actionable data on QoL and unmet needs in a more efficient manner.

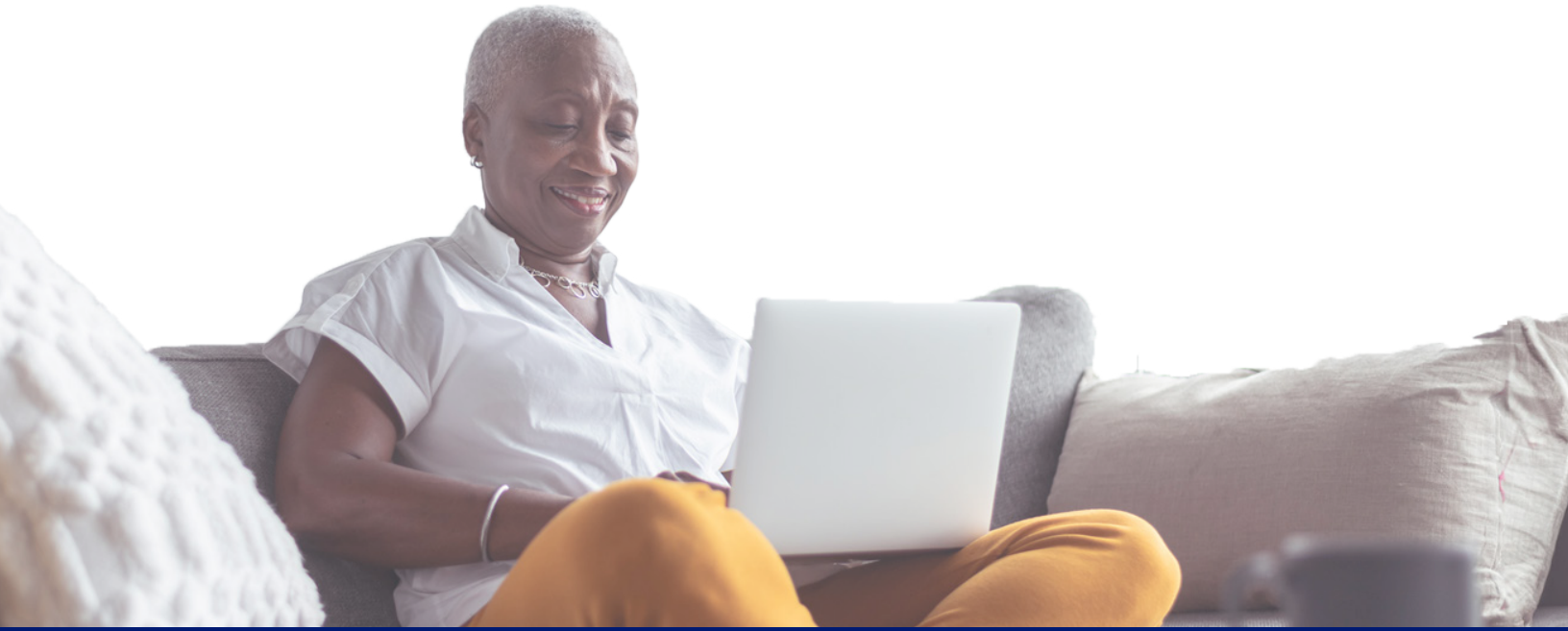
The process began by creating a question bank of eight questions that were framed in typical "industry-speak" language (e.g., "What are your unmet needs?"). The AI model was then trained using conversation threads from the IC community. By feeding these threads into the model, the AI generated answers that mimicked how a patient might respond, interpreting the discussions for insights on QoL and unmet needs.

After producing these AI-generated answers, Inspire conducted a follow-up survey with members of the IC community to review and validate the responses. Community members evaluated the AI's ability to reflect their experiences and suggested adjustments where needed. Research indicates that patient validation is critical in refining AI models, particularly when interpreting nuanced health conditions[4].

Results

The outcome of this project demonstrated the potential of AI to make patient voices continuously available. Community members reported that the AI-generated answers reflected their lived experiences with a high degree of accuracy, provided they had an opportunity to offer feedback. This real-world validation underscored the effectiveness of AI in scaling patient insights while maintaining their reliability.

Explore Inspire's approach to amplifying patient voices—visit inspireresearch.com to learn more.

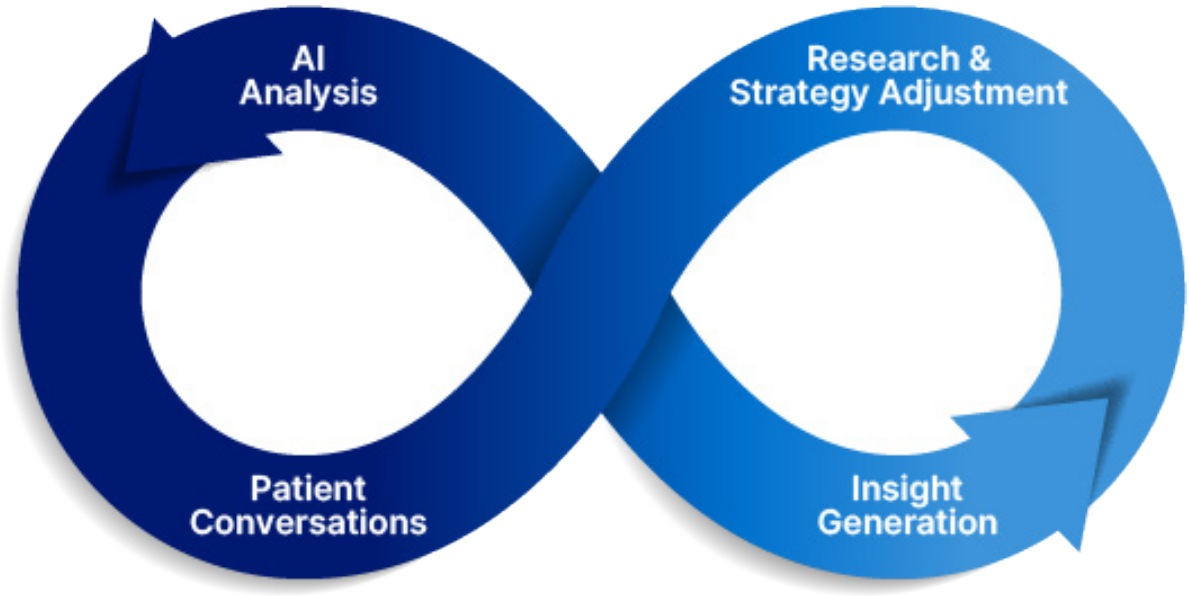


VI. THE BENEFITS OF AI IN PATIENT-CENTRIC RESEARCH

Scalability and Efficiency

Traditional methods of collecting patient and caregiver insights, such as surveys, interviews, and focus groups, are often limited in scale and require substantial resources. These methods provide valuable data, but they are constrained by the number of participants and the time required for data collection. In contrast, genAI enables researchers to scale these efforts significantly, offering the ability to analyze large volumes of patient-generated data across various conditions and communities[5]. By leveraging genAI to ingest naturally-occurring patient conversations, healthcare researchers can quickly derive insights from patient conversations, making the process both faster and more efficient than traditional data collection methods[6].

GenAI's ability to handle unstructured data, such as online patient discussions, enables a more comprehensive understanding of patient perspectives. These insights, which might otherwise remain inaccessible, provide life sciences companies with a richer view of patient experiences, particularly in relation to quality of life (QoL) and unmet needs[7]. This scalability ensures that patient insights are not restricted to small, narrowly focused studies but can be applied across larger and more diverse patient populations[8].



Always-On Access to Patient Voices

One of the most significant advantages of using AI in patient-centric research is the potential for "always-on" access to patient and caregiver voices. Rather than waiting for scheduled data collection or relying on retrospective studies, AI allows researchers to continuously gather and analyze patient insights from real-time conversations occurring in online communities[9]. This "always-on" access ensures that patient feedback is available whenever it is needed, providing up-to-date insights that can inform ongoing research, clinical trial designs, and treatment development strategies[10].

Furthermore, AI's ability to process large datasets in real time means that patient voices can be continuously integrated into the decision-making processes of life sciences companies, enabling more responsive and adaptive strategies. This continuous feedback loop allows researchers and clinicians to adjust their approaches based on the evolving needs and concerns of patients and caregivers, resulting in more patient-centered outcomes[11].

Broad Applications Beyond Interstitial Cystitis

While the case study focused on Interstitial Cystitis (IC), the applications of AI in patient-centric research extend far beyond this specific condition. AI can be applied across multiple therapeutic areas, capturing insights from patient communities affected by a wide range of diseases. By making patient voices more widely accessible, AI allows life sciences companies to incorporate patient feedback into the development of therapies and interventions for conditions ranging from chronic diseases to rare disorders[12].

For example, AI can be used to inform clinical trial designs by identifying patient reported barriers to participation, such as logistical challenges or concerns about specific trial protocols[13]. Additionally, AI can provide insights into the factors that influence patient retention, enabling sponsors to design trials that are more aligned with the preferences and needs of participants[14]. These insights are critical for optimizing recruitment and retention strategies, particularly in trials for conditions that are underrepresented in traditional research methodologies[15].

VII. IMPLICATIONS FOR HEALTHCARE AND DRUG DEVELOPMENT

Improving Quality of Life Data

The integration of genAI into patient-centric research provides a transformative approach to understanding and improving patient quality of life (QoL). Historically, QoL data has been difficult to capture comprehensively due to its subjective nature and the limitations of traditional data collection methods[5]. However, by utilizing AI to analyze real-world patient conversations, researchers can gain a deeper understanding of the factors that contribute to QoL beyond what is typically captured in clinical settings.

AI's ability to process unstructured data—such as patient conversations about daily challenges, emotional well-being, and unmet needs—allows researchers to capture insights that are often missed in clinical trials and surveys[6]. This richer QoL data can be used to inform the development of therapies that address not only clinical efficacy but also the broader impact of diseases on patients' lives, such as their ability to work, engage in hobbies, and maintain social relationships[7].

Supporting Clinical Trial Design

One of the most promising applications of AI in healthcare is its ability to inform the design of clinical trials. By analyzing patient-reported data, AI can identify key factors that influence trial participation, such as logistical barriers, the complexity of protocols, or concerns about side effects[8]. These insights allow sponsors to design trials that are more aligned with patient needs, which can significantly improve recruitment and retention rates.

For example, if AI reveals that a particular procedure in a trial protocol is viewed as too invasive or burdensome by patients, sponsors can modify the protocol to make it more patient-friendly[9]. Additionally, AI can help identify previously overlooked patient populations who may be willing to participate in trials, expanding the reach of recruitment efforts and ensuring more diverse representation in clinical research[10].

A Continuous Feedback Loop

AI also enables the creation of a continuous feedback loop between patients and researchers, facilitating real-time adjustments to clinical trial designs and ongoing studies. Instead of relying on static, pre-trial feedback, researchers can use AI to gather ongoing insights from participants as they progress through the trial[11]. This dynamic approach allows for mid-trial modifications to address emerging concerns, potentially improving patient adherence and overall trial outcomes.

Moreover, AI's ability to provide continuous feedback is particularly valuable in long-term studies, where patient needs and experiences may evolve over time[12]. By keeping an open channel for patient feedback throughout the course of a study, sponsors can ensure that trials remain relevant to the participants and maintain higher retention rates.

Informing Treatment Development

Beyond clinical trials, AI-driven patient insights have the potential to influence the development of new treatments. By identifying unmet needs and patient priorities, AI can guide pharmaceutical companies in developing therapies that better address the real-world challenges faced by patients[13]. For instance, if AI reveals that current treatments fail to adequately address pain management or mobility issues, drug developers can focus their efforts on creating therapies that target these specific needs.

The integration of patient insights into treatment development not only improves the likelihood of creating more effective therapies but also aligns with the growing emphasis on patient-centered care in the healthcare industry[14]. By ensuring that new treatments reflect the priorities and preferences of patients, pharmaceutical companies can enhance the overall impact of their therapies and improve patient satisfaction[15].

VIII. CONCLUSION

The future of patient-centric research and drug development is being transformed by the integration of artificial intelligence (AI). By leveraging AI to analyze patient-generated content, healthcare and life sciences organizations can capture the authentic voices of patients and caregivers more efficiently and at a larger scale than ever before. This transformation allows for deeper insights into patient quality of life (QoL), unmet needs, and the real-world impact of chronic conditions—insights that are often inaccessible through traditional research methods[5].

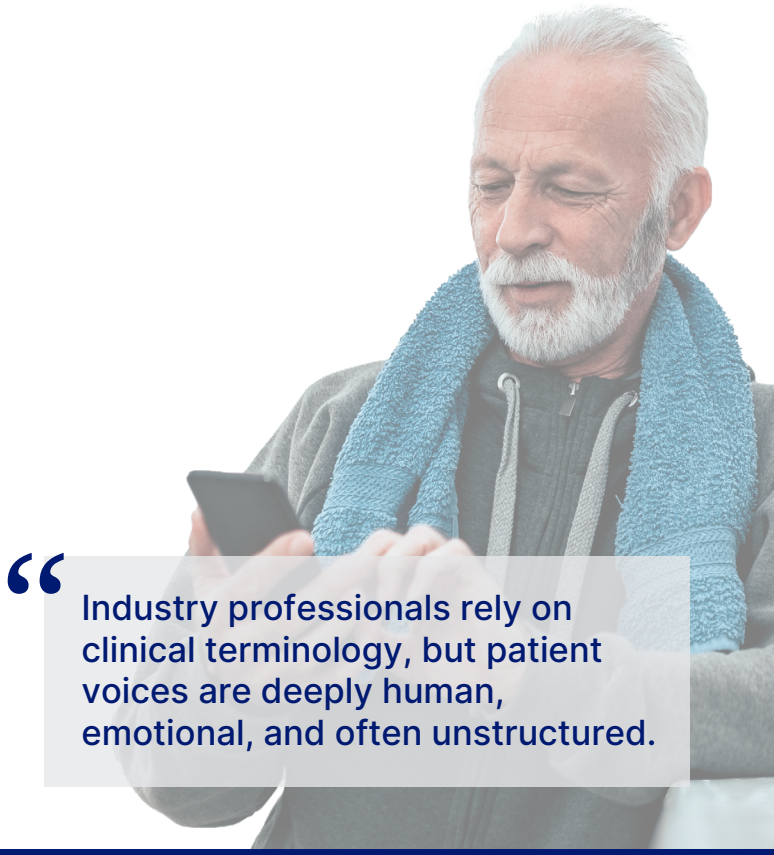
The case study on Interstitial Cystitis (IC) demonstrated the power of AI in generating actionable insights that are not only validated by patients but also scalable across different conditions and communities. With the ability to process unstructured data, AI provides an "always-on" platform for continuous access to patient perspectives, ensuring that life sciences companies can respond to patient needs in real time[6]. This dynamic, data-driven approach to understanding patients' experiences enables more responsive drug development processes, resulting in therapies that better address the real-world challenges of those living with chronic diseases[7].

As the healthcare landscape continues to evolve, AI will play an increasingly important role in informing clinical trial design, optimizing patient recruitment and retention, and ensuring that treatments are developed with a deep understanding of patient priorities. The scalability, efficiency, and responsiveness that AI brings to patient-centric research represent a significant advancement in making the patient and caregiver voice central to healthcare innovation[8].

Inspire's work in applying AI to real-world patient conversations is a testament to the potential of this technology in reshaping how the life sciences industry approaches patient engagement. With ongoing refinement and the incorporation of patient feedback, AI will continue to bridge the gap between industry language and human experience, ensuring that patient voices drive meaningful change in the development of new therapies and healthcare solutions[9].

Join Inspire in placing patient voices at the heart of healthcare innovation.

Contact us at inspireresearch.com



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