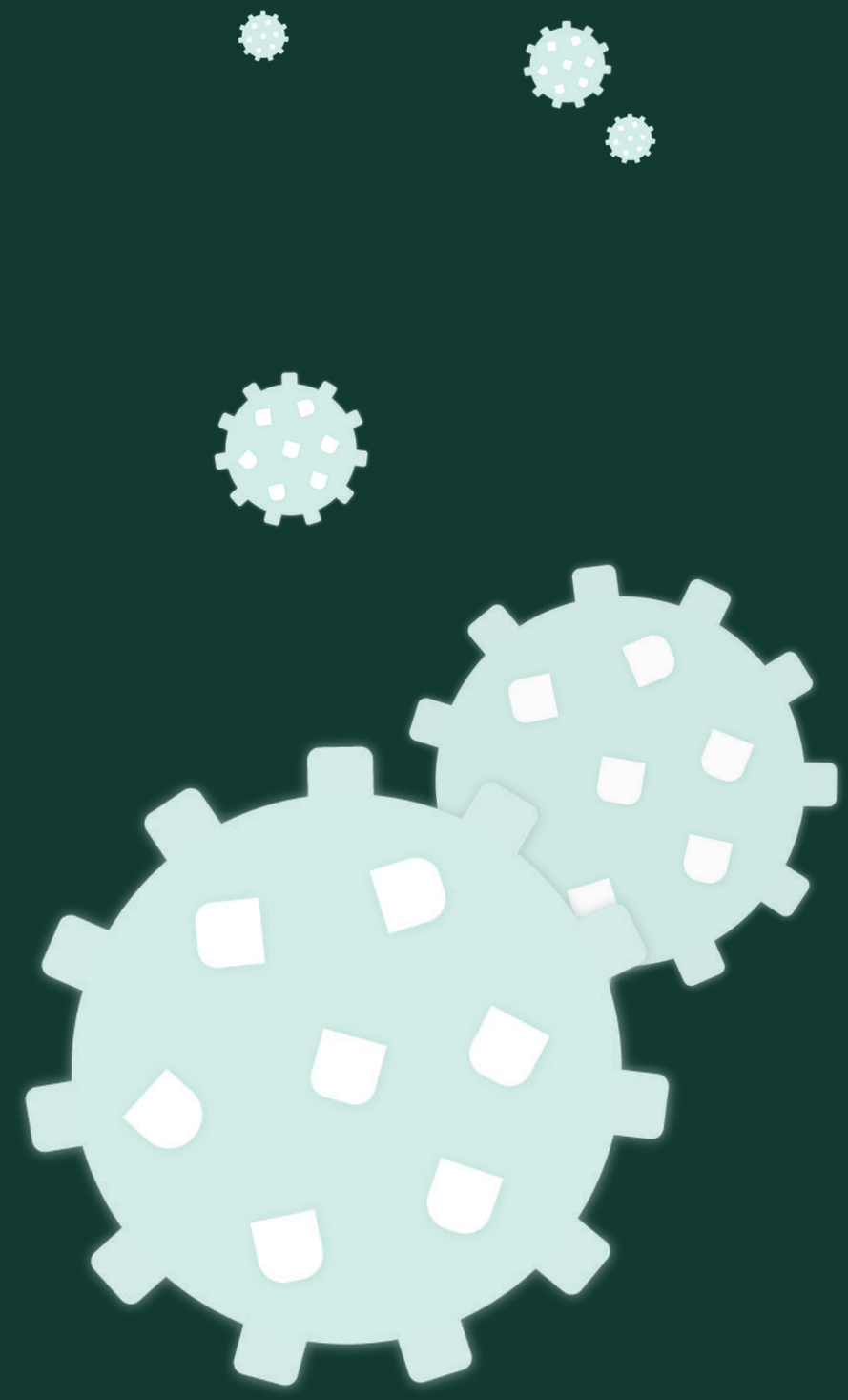
Jessie-May Volz | N11044004

Supporting Autoimmune Disease Diagnosis

Research Report



Word Count: 4337

Executive Summary

This research project aims to understand and contribute to existing research surrounding autoimmune disease diagnosis with the end goal being to create a product intervention which could support patients and physicians with this process.

Autoimmune disease encompasses a highly complex group of diseases which present with vague, fluctuating symptoms, and clinical presentation, that require consistent monitoring combined with unreliable testing before diagnosis is possible. This introduces significant challenges for both patients and physicians while seeking diagnosis. Physicians struggle to prove or distinguish disease presentation using test and unreliable symptoms, family and personal medical history reports, while patients struggle to effectively communicate their experiences, leading to frustrations on both sides, eventually resulting in feelings of dismissal, lack of trust from both parties, and in severe cases can lead to trauma presenting where it shouldn't be required.

To properly identify what the problem was and where further investigation was required, an initial literature review was conducted, alongside benchmarking. Together they provided a significant overview of research and market gaps. Two major gaps emerged: the end users experiences and pov were largely missing from existing research which focused more on the scientific limitations, and currently there are no existing products which could effectively support this process, though other diagnostic tools can provide a great starting point to identify market expectations regarding, product strengths and weaknesses. With that in mind triangulation was conducted by creating 2 surveys (for end users (72 participants) and clinicians (4 participants)) and holding 2 interviews with 3 end users.

With triangulation complete several key findings emerged; the complexity of autoimmune disease is well understood by both end users and scientists, going beyond what was found in the secondary research, to include the highly cyclical process end users complete to be diagnosed – including visiting multiple doctors, and completing numerous tests as the disease develops. Communication and psychological barriers emerged as highly important findings, with both physicians and end users reporting the challenges communication presented, while the end users reported not only communication challenges, but also significant psychological barriers is accesses their diagnosis. Benchmarking identified the final key finding. Currently there are no existing products which can support patients or physicians with autoimmune disease, or looking broader chronic illness disease support.

As the goal of this research is to create a product invention, it was valuable to compress the findings into opportunities for design development. 5 major design implications emerged; capturing the varying experiences, improving communication between physician and patient, accompanying an end user through the iterative diagnosis journey, reducing the negative psychological impact the process can produce for end users, and creating a product that would be support the patient. These opportunities present important implications that could be applied to the product intervention.

Together the findings of this report establish a foundation for translating the identified needs into design requirements and concepts. The subsequent design phase will explore how an intervention can support the flow of information between patients and healthcare professionals while remaining usable, clinically relevant, and appropriate for an ongoing diagnostic journey.

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Authenticity Statement

This is to certify that to the best of my knowledge, the content of this report is my own work. This report has not been submitted for any subject or for other purposes. I certify that the intellectual content of this report is the product of my own work and that all the assistance received in preparing this report and sources have been acknowledged.

- Jessie-May Volz | N11044004 | 11th September 2026

AI Use Statement

I have utilised Generative AI in this report (ChatGPT & Otter AI) to assist in various ways. The way I have used AI includes; to assist in transcribing interview recordings, to review grammar, punction and spelling, to help reduce word count and improve flow throughout the document.

- Jessie-May Volz | N11044004 | 11th September 2026

Section 1

The Topic



Figure 1: Project Outline

Project Structure

Introduction

The immune system is a vital tool in the human body that creates antibodies that can defend against disease and infection (Britannica, 2026). In people with autoimmune diseases the immune system produces antibodies that attack healthy cells, tissues and organs causing damage and inflammation throughout the body (ASCIA, 2025). These diseases are incurable and lifelong with treatment options focused on relieving symptoms, minimising organ and tissue damage, and preserving organ function (ASCIA, 2023).

Approximately 5% of people globally are affected by these diseases, making them one of the most significant chronic health problems people are facing today (ASCIA, 2023). The percentage of people with autoimmune disease is currently growing at a rate of around 12.5% annually with things like environmental exposures, modern lifestyle, dietary factors, genetics, and covid-19 and other infections all believed to be contributing to this increase (Duval, 2025). Despite their prevalence the diseases and symptoms are largely invisible making it difficult to be taken seriously by friends, colleagues, and most importantly doctors (Berman, 2025). In addition to the symptoms being hard to get recognised they also often have a significant overlap with other diseases, making misdiagnosis, and dismissal common (ASCIA, 2025).

The development and presentation of autoimmune disease is complex and can include flares, and remission periods where the symptoms severity changes between low and extremely high (Watson, 2026). Adding to the challenges to get diagnosed.

Despite the challenges, early diagnosis is crucial to prevent irreversible damage, improve the patient's quality of life, and reduce long term healthcare costs (Murray, 2025). This project aims to create a product intervention that can support patients and doctors with getting autoimmune diseases diagnosed.

Literature Review

Autoimmune diseases are chronic and difficult to diagnose, often presenting with vague difficult to communicate symptoms which often develop slowly, change as the disease progresses, fluctuate through periods of flare and remission, or remain asymptomatic until they escalate (Pisetsky, 2023). Classification of autoimmune diseases are vague and highly debated meaning there is no universally agreed number with estimates range from approximately 80 to 160 (Pisetsky, 2023). Research across different populations and time periods has identified a significant mortality burden associated with autoimmune diseases (Thomas et al., 2010) (Li et al., 2024) (Mitratza et al., 2020). Thomas et al. (2010) found autoimmune diseases collectively ranked in the top ten most frequent underlying cause of death among females under 75, while noting that their collective impact was hidden by the vague classification systems. More recent research has similarly identified a measurable though largely unrecognised mortality burden among autoimmune diseases (Mitratza et al., 2020) (Li et al., 2024).

The cause of autoimmune disease is not yet definitively understood, although environmental factors, infections, and genetics are known to influence susceptibility. Rather than inheriting a specific condition, family history can indicate an increased likelihood of developing any autoimmune disease (Marrack et al., 2001). The combination of varied disease presentation, progression, and causation contribute to significant diagnostic challenges. On average, diagnosis takes between 3–5 years, with patients typically seeing approximately 3.95 physicians before receiving an accurate diagnosis (AARDA Survey Study, 2017). Additionally, 76% of diagnosed patients reportedly experience a misdiagnosis at some point, while 62% report being described as “chronic complainers” by physicians (AARDA Survey Study, 2017; , Lutton, 2025).

A further challenge is the gap between what is understood about autoimmune disease and what can realistically be tested for in routine healthcare. Some autoimmune diseases have more than 100 different autoantibody specificities, most of which cannot be routinely tested (Pisetsky, 2023). Clinical manifestations can also vary significantly between patients, ranging from life-threatening conditions to minor abnormalities, with test results commonly revealing false positive or false negative results (Pisetsky, 2023).

Consequently, autoimmune diagnosis is an iterative process involving symptoms and clinical history, laboratory results, antibody testing, imaging, disease progression, and repeated or alternative investigations. Neither a positive nor negative result necessarily concludes the investigation; rather, each result contributes information that must be considered alongside other results and clinical experience (Sciascia et al., 2023).

Diagnostic Jouney

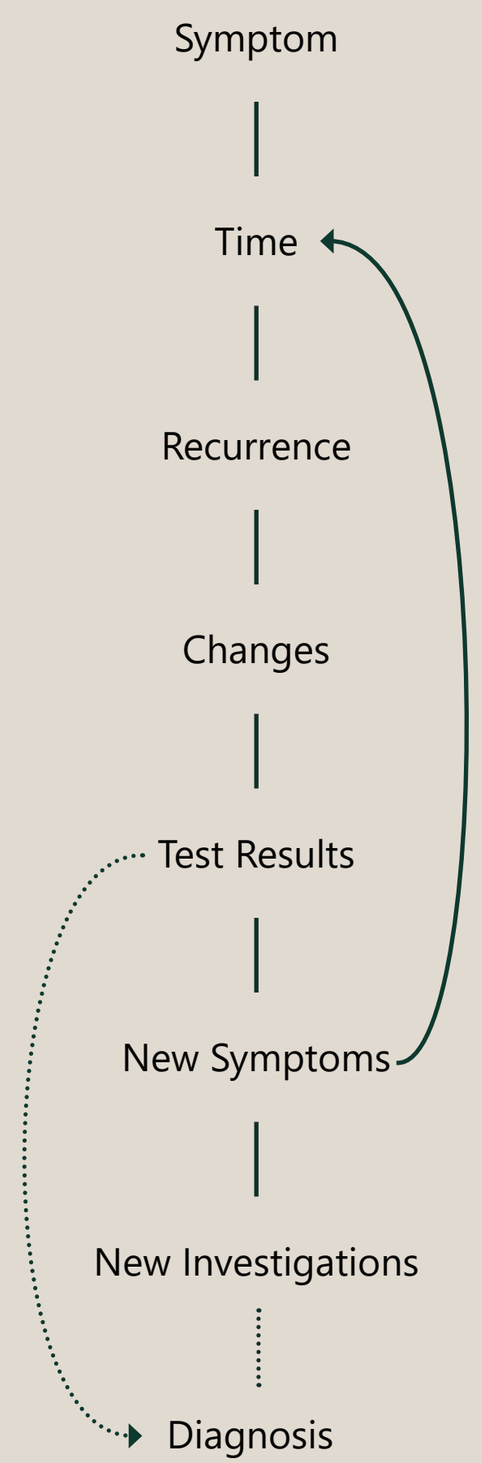


Figure 2: Diagnostic Process (Sciascia et al., 2023)

Benchmarking

Benchmarking is an important tool for identifying market gaps and opportunities, recognising industry best practices, avoiding replication of existing products, and understanding customer expectations (Alcàntara, 2024). As few products were identified that directly support autoimmune disease diagnosis, benchmarking was expanded to examine existing home diagnostic and health-monitoring products. This allowed strengths from adjacent healthcare products to be identified and considered for their potential application to autoimmune disease diagnosis.

Five product categories were identified, alongside a sixth category of "uncategorised diagnostic tools". A minimum of three commonly used products, tools, or devices were assessed within each category. Layered radial graphs were used to compare the strengths and weaknesses of each category and identify the strongest-performing products.

Apps

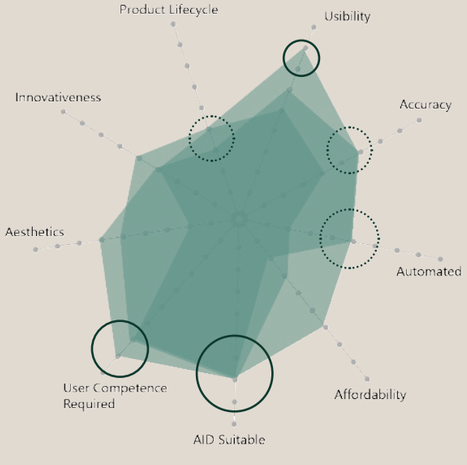


Figure 3: Benchmarked Apps

Strengths: Tracked multiple symptoms, familiar & accessible.

Weaknesses: low automation, user must input, subscription models, low accuracy.

Sleep Apnea Products

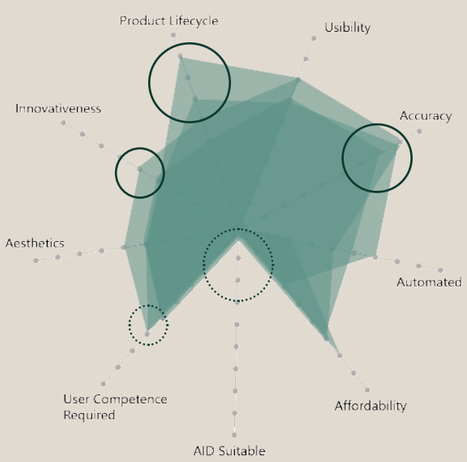


Figure 4: Benchmarked Sleep Apnea Products

Strengths: Innovative rental based lifecycle, clinically accurate results at home.

Weaknesses: limited AID application, require instructions, aesthetically intimidating.

Skin Diagnostic Tools

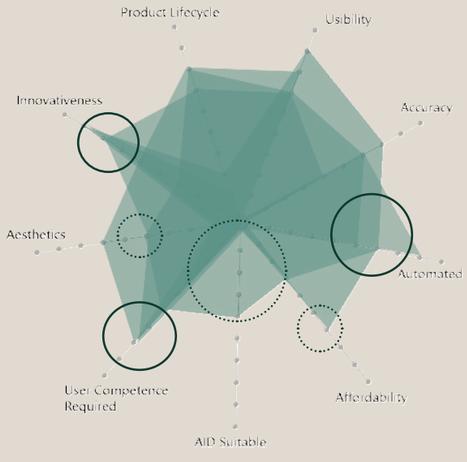


Figure 5: Benchmarked Skin Diagnostic Tools

Strengths: Highly automated, user-friendly, diagnostic innovation potential.

Weaknesses: designed for single symptoms, largely not yet commercially available.

Wearables

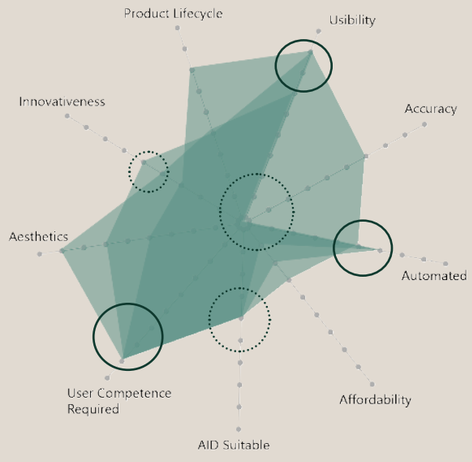


Figure 6: Benchmarked Wearables

Strengths: Familiar products, highly automated, subtle.

Weaknesses: lacking proof of accuracy, measures biometric data, but doesn't allow for input of other symptoms.

Diabetes Products

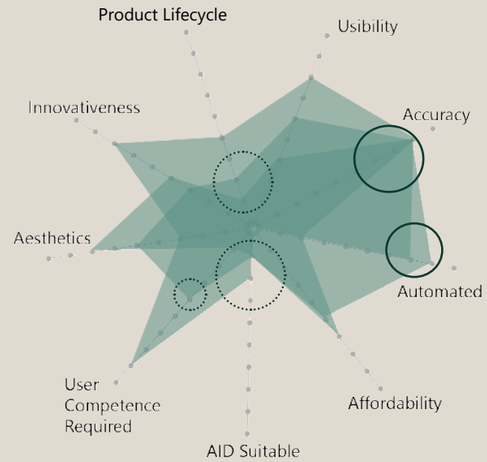


Figure 7: Benchmarked Diabetes Products

Strengths: Clinical accuracy, largely automated, consistent monitoring.

Weaknesses: Specialised for diabetes measuring, limited product lifecycle, user training required.

Benchmarking

Following the initial category comparison, an assessment matrix was created to consider identify the strongest-performing product from each category. After the initial matrix found the top products in each category, the top performing product from each was compared using the say matrix. This was useful to identify the strengths of each product category. The matrix compared nine criteria: usability, affordability, automation, user competence required, accuracy, suitability for autoimmune disease, aesthetics, innovativeness, and product lifecycle. Criteria were weighted according to their relevance to the project, with usability weighted most heavily (×2), followed by affordability (×1.75), automation and user competence required (×1.5), and the remaining criteria weighted equally (×1). The weighting ensured that products were assessed according to their suitability for the intended problem rather than simply their overall technical performance.

	Usibility (x2)	Affordability (x1.75)	Automated (x1.5)	User Competence Required (x1.5)	Accuracy (x1)	Suitable for AID (x1.5)	Aesthetics	Innovativeness	Product Lifecycle
Apps	18	12.25	9	12	7	8	5	6	6
Sleep Apnea Devices	16	7	10.5	10.5	9	1	5	5	6
Skin Diagnostic Tools	18	12.25	10.5	7.5	8	1	2	9	3
Wearables	18	7	9	13.5	7	5	5	4	8
Diabetic Devices	16	-	12	13.5	9	2	4	8	7

Table 1: Benchmarking Comparison Matrix

Insights

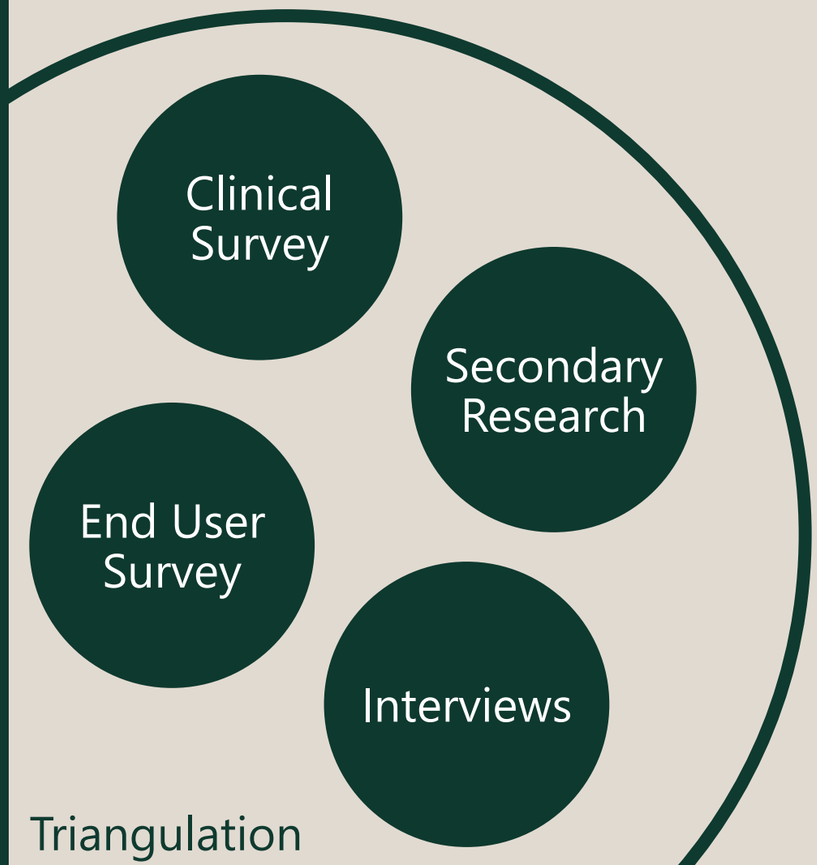
No directly comparable products supporting autoimmune disease diagnosis were identified through benchmarking. However, adjacent diagnostic and health-monitoring products demonstrated several characteristics that could be transferred to an autoimmune diagnostic tool. Across the benchmarked categories, the strongest opportunities were usability, automation, and accuracy. Products that required minimal instruction or user input were generally more accessible, while automated data collection reduced the reliance on users consistently remembering and recording information.

Conversely, existing products were generally designed around a single condition or a limited set of measurable symptoms. This limits their suitability for autoimmune disease, where symptoms can be diverse, fluctuate over time, and differ substantially between individuals. The benchmarking therefore identified an opportunity for a product that combines the usability and automation of existing consumer health technologies with the broader symptom tracking required to support autoimmune disease diagnosis.

Section 2
Research

Methods & Methodolgies

This research into autoimmune disease diagnosis used triangulation to corroborate findings, develop a more comprehensive understanding of the research problem, and identify contradictions between sources (Hassan, 2026). Two surveys, three interviews across two sessions (one individual interview and one concurrent interview with two participants), and secondary research were conducted for this purpose. Secondary research was conducted first to establish an understanding of the topic and inform the development of the primary research questions.



Triangulation

Surveys

Surveys provide access to a broad target audience and enable the collection of large quantities of structured quantitative and qualitative data to support research. They allow researchers to reach a large user group within a short timeframe and produce results that are relatively easy to compare and analyse (Miller, 2026). To ensure rigor two surveys were conducts, hosting mostly multiple choice, and short answer response questions to allow participants to provide additional information as desired and reducing the risk of the predetermined questions limiting participant responses.

Structure

Two surveys were conducted targeting the two key stakeholder groups: physicians and people diagnosed with autoimmune disease. Social media platforms, including Facebook and Reddit communities, were used to recruit participants. The patient survey was shared across seven autoimmune disease-related communities, reaching approximately 6,500 people globally. The survey was not geographically restricted. The physician survey was initially posted in three medical-related communities but received limited responses, so recruitment was expanded through third-party connections within my professional network. In total, the clinical survey was shared with approximately 2,000 people. However, because some communities included broader audiences, not all individuals reached would necessarily have had a clinical background.

	Posted to	Time open for	Responses
Patient Survey	6500 people across; 6 reddit posts and 1 Facebook post	Approximately 15 days	72
Clinical Survey	2000 people across; 3 reddit posts and 2 third party connections	Approximately 10 days	4

Table 2: Survey Structure Breakdown

Limitations

Despite their benefits, surveys also have several limitations, including sampling and response bias, questionnaire design limitations, and the reliability of participant responses (Makori, 2025). For the patient survey, there were acknowledged limitations relating to the distribution of participants across different autoimmune diseases. The survey was posted into several disease-specific communities, resulting in a significant bias towards certain diseases. For example, people with multiple sclerosis (MS) accounted for 25% of responses, creating a disproportionate representation of MS-related experiences within the dataset.

For the medical survey, a significant limitation was the reliability and verification of participant responses. To ensure participant privacy, it was not possible to collect evidence of professional certifications or qualifications. Consequently, anyone could have accessed and completed the survey regardless of their clinical background, potentially affecting the reliability of the results. The quality and depth of the responses appeared consistent with those expected from medical professionals, with several demonstrating knowledge beyond what would typically be expected from a general participant. However, this could not be independently verified and therefore remains an acknowledged limitation.

Interviews

Interviews provide insights into participants' experiences from their own perspectives, generating more in-depth information than can typically be obtained through structured survey responses or secondary research. They also provide participants with the opportunity to elaborate on their experiences, potentially revealing insights not previously considered by the researcher (Kalpokas & Hecker, 2025). Semi-structured interviews use predetermined, open-ended questions to guide discussion while allowing flexibility for participants to introduce unexpected topics or insights (Ayres, 2008). This approach was used for the interviews conducted in this research.

Structure

Two interviews involving three participants were conducted to understand the lived experiences of people diagnosed with autoimmune disease. The first interview was conducted individually, while the second was conducted concurrently with two participants. Four questions were formally asked:

"Walk me through your autoimmune disease diagnosis journey"

"What were your experiences with healthcare professionals while being diagnosed?"

"How did you remember and communicate your symptoms?"

"Is there anything you wish you had known or had that could have made your journey to diagnosis easier?"

Both interviews were conducted in person, with the individual interview lasting 17 minutes and the concurrent interview lasting 48 minutes.

	Participants	Duration	Location
Individual Interview	1	17 Minutes	In Person
Concurrent Interview	2	48 Minutes	In Person

Table 3: Interview Structure Breakdown

Limitations

This interview approach also presented several limitations, including interviewer and social desirability bias. This was particularly relevant because the interviews were conducted in person, meaning my body language, tone, or other non-verbal behaviours may have unintentionally influenced participant responses (LIS Academy, 2026). Additionally, thematic analysis is inherently interpretive and can be influenced by the researcher's perspective, potentially affecting how themes are identified and interpreted (Kalpokas & Hecker, 2025a).

Summary

Primary research was conducted as rigorously as possible while acknowledging the inherent limitations of the research and analysis methods. Triangulation was therefore an important component of the methodology, allowing findings from different methods and stakeholder groups to be compared and corroborated. This helped strengthen the reliability of the findings and identify potential biases or contradictions where possible.

Analysis & Findings

Analysis Method

The data collected through the surveys and interviews included multiple-choice, short-response, and long-response questions. These responses were analysed to identify recurring themes, patterns, and relationships relevant to the experience of autoimmune disease diagnosis.

Data Analysis

Survey data was analysed according to response type. Quantitative responses were analysed using univariate analysis to identify response frequencies and multivariate analysis to examine relationships between variables. Qualitative responses were thematically coded to identify recurring concepts and patterns across participants.

Interview data underwent thematic analysis. Interviews were manually coded using sticky notes in Miro, with each interview analysed separately to allow themes to emerge independently. Once the initial themes were established, Excel was used to conduct two forms of analysis: frequency analysis, which measured how often each code and theme occurred, and code co-occurrence analysis, which examined the likelihood of one code appearing when another code was present. This allowed both the prevalence and relationships between themes to be identified.

Clinical Surveys

The clinical survey explored the experiences of healthcare professionals diagnosing autoimmune disease, including diagnostic challenges, current workflows, approaches to patient symptom reporting, and potential areas for improvement.

Three of four respondents reported that they consider autoimmune disease almost always when assessing patients, despite experiencing significant challenges in diagnosis. The primary challenges identified were variability in presentation, overlapping symptoms, and patient expectations surrounding diagnosis.

Respondents identified evidence of symptoms and accurate family history as useful in supporting diagnosis. However, only half reported recommending tools for patients to record or communicate their symptoms, and these approaches were informal. Majority of respondents indicated that having accurate personal and family medical histories would be valuable, highlighting the importance of reliable patient-generated information within the diagnostic process.

How many patients do you see per week that you could conisder investigating Autoimmune Diseases

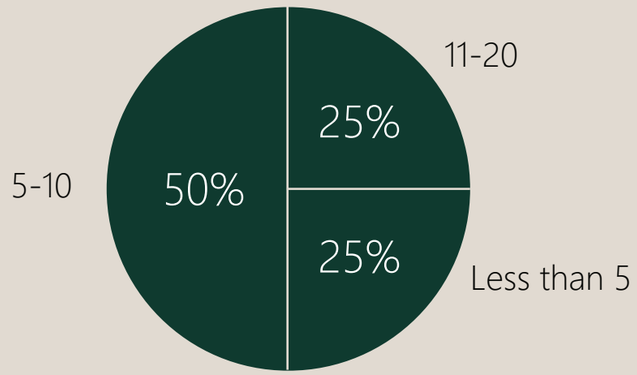


Figure 8: Q3.2 clinical survey resutls

What would make diagnosing Autoimmune disease easier? (Thematic Analysis of Answers)

Clinically Relevant	Better Tests	2
Communication	Diagnosis Expectations	2
	Family History	2
	Medical History	6
Symptoms	Symptom Records	6
	Symptom Timeline	3

Table 4: Thematics analysis coding table clinical survey results

Under Reported symptoms

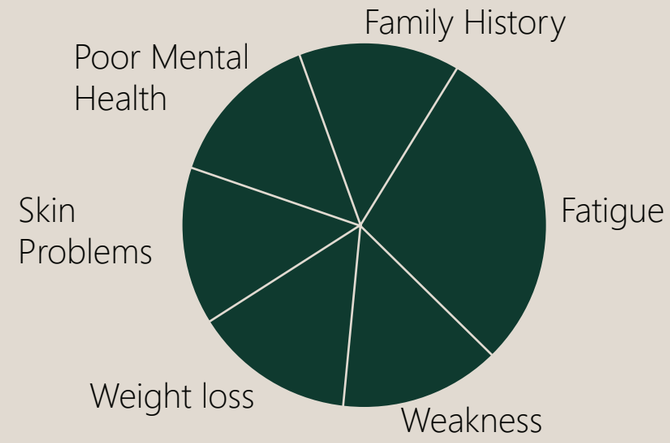


Figure 9: Q7 clinical survey resutls

Do you recommend patients use tools?

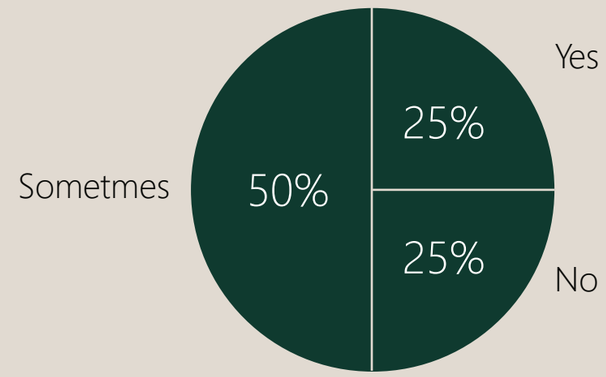


Figure 10: Q9 clinical survey resutls

What tools do you recommend?

"Symptom Diary"
"Report aggravating conditions"

Disease Distribution

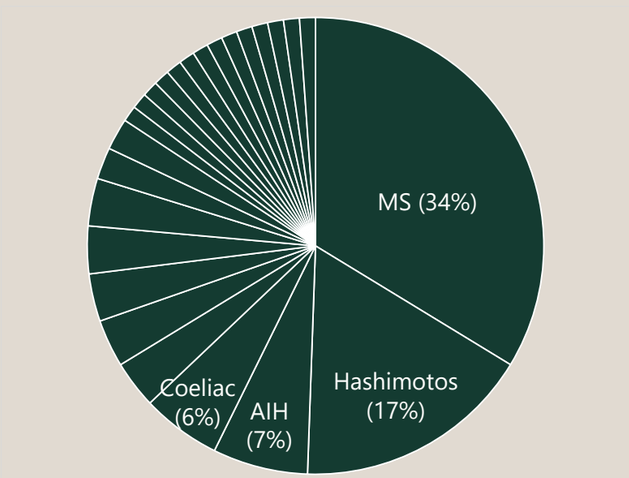


Figure 11: Q2 end user survey resutls

How did you Interpret Your Symptoms?

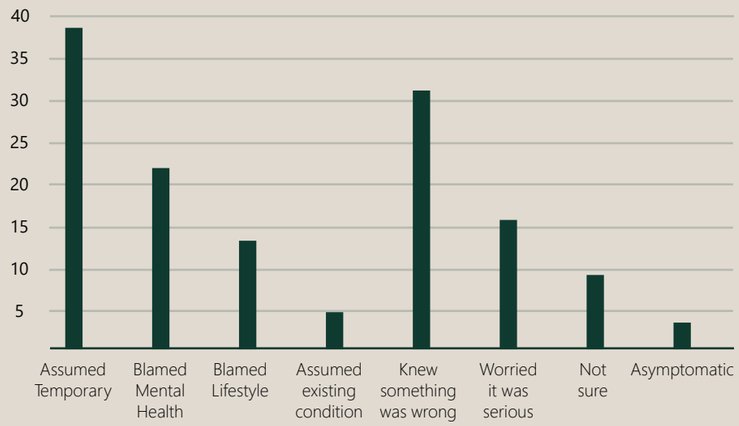


Figure 13: Q5.1 end user survey

What prompted you to see a physician?

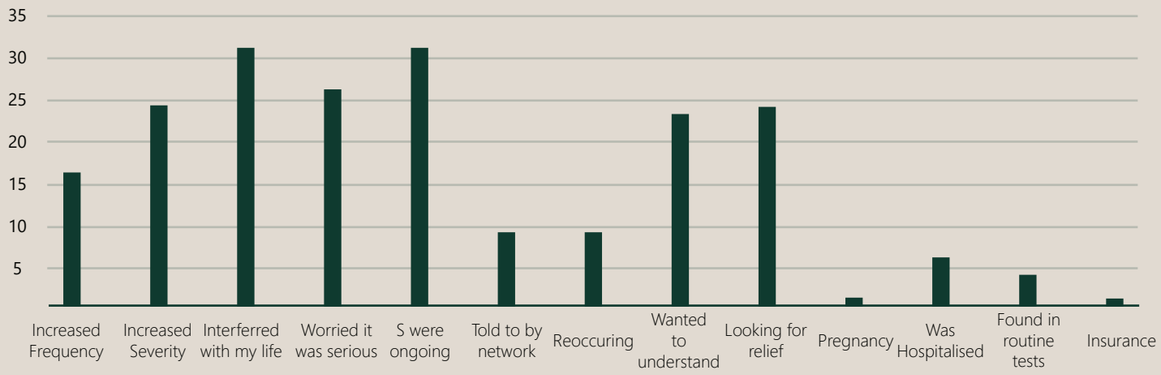


Figure 14: Q5.3 end user survey

Did you feel your condition was dismissed?

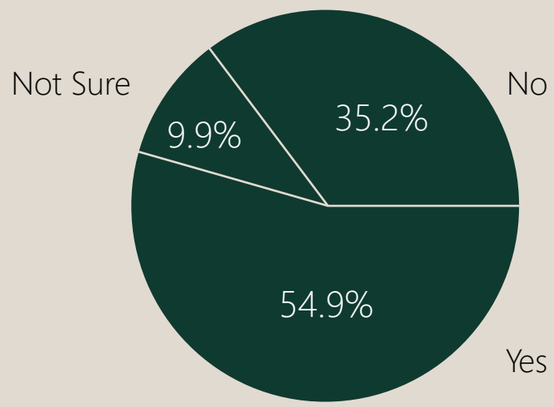


Figure 12: Q6 end user survey resutls

What Triggered your Diagnosis

Seeing the Dr	2nd Opinion	10
	Routine Visit	2
	Hospitalised	10
	Luck	7
Advocacy	Chasing Diagnosis	2
	Dr Google/GPT	3
	Self Advocacy	3
Symptom Report	Reporting symptoms & Timeline	14
	Wearable Tracking	1
	Physical Proof	1
Medical Actions	Female GP	1
	Naturopath	1
	Regualr Tests	13

Table 4: Thematics analysis coding table end user survey, diagnosis trigger

Initial Symptom Severity

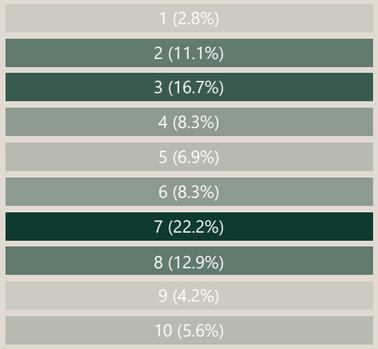


Figure 15: Q5.2 end user survey resutls

End User Surveys

The end user survey provided a broader understanding of the lived experience of seeking an autoimmune disease diagnosis. A total of 72 participants reported experience across 25 autoimmune diseases and more than 30 different symptoms.

A recurring pattern of dismissal emerged. Participants reported initially dismissing their own symptoms because they believed they were temporary, related to mental health, or not serious enough to warrant medical attention. More than half also reported experiencing dismissal from healthcare professionals. Participants commonly only sought medical assistance when symptoms interfered with daily life, persisted longer than expected, or became more severe.

The reported trigger for receiving a correct diagnosis was particularly significant. More than half of participants identified seeing multiple doctors or becoming sufficiently unwell and requiring hospitalisation as the point at which diagnosis progressed. A further group identified tracking and communicating symptoms, including their timeline, as contributing to receiving a diagnosis.

"*I started trying to bring *husband or my dad with me. But that didn't seem to be helpful. It actually kind of made things worse because they didn't listen to me, and they listened to them." (interview 2, 29:49)*

"I'd spent like four days in the hospital, and then I was like, "Can I go back to work? And he's [doctor] like, "Yeah, you'll be completely fine. Just eat bland foods for six weeks." (interview 1, 4:58)

"I have felt actually a lot of relief after the diagnosis because I was like, "Oh, I'm not crazy. Okay, I'm not losing my mind" (interview 1, 15:40)

"it became so stressful that I developed PTSD from the hospital system." (interview 2, 28:39)

"I had like weird swelling in like my stomach, and you know, doctors would just say, "Oh, she's just fat. and put me on diet, and I didn't get diagnosed till I was what 40s." (interview 2, 6:35)

"I decided to go to the doctors, and I went and described all my symptoms, and she sent me away with four anti nausea pills, and that was it." (interview 1, 2:16)

Interview Findings

Three participants were interviewed across two sessions. Thematic analysis identified several recurring themes, including gender, psychological effects, dismissal, symptom communication, and food-related symptoms.

Gender emerged as a notable relational theme. The male participant described a positive experience with a male doctor who "seemed to be really driven" to identify the cause of his symptoms. In contrast, both female participants described experiences of dismissal when consulting male doctors. One participant reported that the severity of her condition was underexplained even after receiving a diagnosis, while another stated that bringing her husband or father to appointments resulted in doctors listening to them rather than her. These accounts indicate that diagnostic difficulties may go beyond symptom complexity and testing limitations to include how patients' accounts are received within clinical interactions.

Psychological effects were also prominent themes within the interviews, despite not emerging during the initial research. One participant described being told that if nothing appeared in her blood tests, her symptoms were "in [her] head", later describing relief following diagnosis because she was "not crazy". Another participant reported developing PTSD from her experiences with the hospital system and subsequently avoiding treatment. These accounts demonstrate that the diagnostic process can have significant emotional consequences beyond the physical experience of disease.

Food-related symptoms were another recurring theme. Two participants had conditions affecting the gastrointestinal system, while the third was seeking diagnosis for a gastrointestinal autoimmune condition. Both participants reported attributing symptoms to diet, mental health, or weight before receiving an appropriate diagnosis. Both also attempted at home healing with restrictive diets to identify triggers and experienced prolonged symptoms before hospitalisation and eventual diagnosis.

Summary of Findings

Across the primary research, three consistent findings emerged: diagnostic difficulty is influenced by variable symptoms and incomplete patient information; dismissal can occur from both patients and healthcare professionals; and symptom tracking and clear communication can contribute to progressing diagnosis. The interviews additionally identified psychological and interpersonal factors that were less apparent in the survey data. Together, these findings highlight that the diagnostic challenge extends beyond identifying disease itself to effectively capturing, communicating, and interpreting a patient's changing experience over time.

Section 3

Discussion

This research was conducted to develop a deeper understanding of the challenges surrounding autoimmune disease diagnosis and identify areas for intervention. Together, the findings establish four major points: diagnosing autoimmune disease is inherently complex; the journey from symptom to diagnosis is highly iterative; patients face significant psychological and interpersonal hurdles while seeking diagnosis; and existing products provide limited support for this process.

Discussion

Complexities in diagnosing autoimmune disease were identified in both primary and secondary research. Existing literature establishes the vague and fluctuating nature of autoimmune diseases, where presentation can vary between individuals and change within the same individual over time and across different levels of severity (Sciascia et al., 2023). Primary research supports these findings, with clinicians reporting variability and overlapping symptoms, while patients described long and complicated diagnostic journeys involving multiple healthcare professionals. Combined, these findings suggest that autoimmune diagnostic complexity is not limited to understanding the disease itself, but also extends to capturing, documenting, and communicating how the disease changes over time.

Existing literature established diagnosis as an iterative process involving the ongoing reassessment of symptoms, clinical history, and test results (Sciascia et al., 2023). The interviews support this finding while extending it through the lived experience of the diagnostic process. Rather than progressing linearly, participants described a cyclical journey in which symptoms were initially dismissed, became more severe, led to seeking healthcare, and could result in further dismissal before another healthcare professional, hospitalisation, or symptom documentation progressed the diagnosis. This provides additional insight into how the iterative process identified in the literature is experienced by patients in practice.

One of the largest gaps identified in the existing research was the psychological and interpersonal toll of seeking diagnosis. While the literature largely focused on disease complexity, diagnostic delays, and clinical challenges, the interviews revealed experiences of dismissal, gender-related differences in healthcare interactions, self-doubt, psychological distress, loss of trust, and treatment avoidance. These findings suggest that the diagnostic process is not solely a clinical challenge, but can also influence how patients perceive themselves, their symptoms, and the healthcare system.

Benchmarking similarly identified gaps in existing products, with no directly comparable products identified for autoimmune disease diagnosis support. Existing products demonstrated transferable strengths, including usability, automation, and at-home clinical data collection; however, they were generally focused on a single condition or limited biometric measurements. Primary research further demonstrated that current patient methods for tracking symptoms are largely informal and rely heavily on accurate recall and communication.

Conclusively, this research extends existing knowledge from a predominantly disease-focused understanding of autoimmune diagnosis towards a more user-focused understanding of the diagnostic experience. It therefore identifies an opportunity to support the capture, organisation, and communication of patient experiences throughout this complex and iterative process.

Described Journey

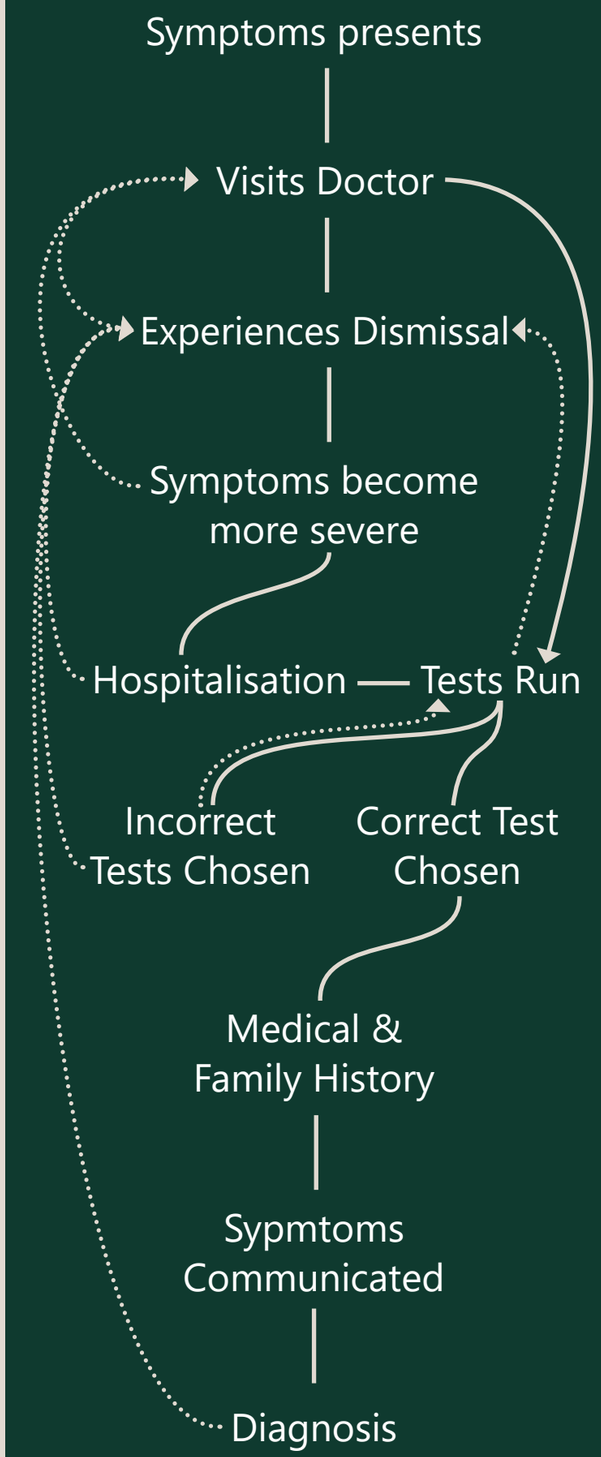


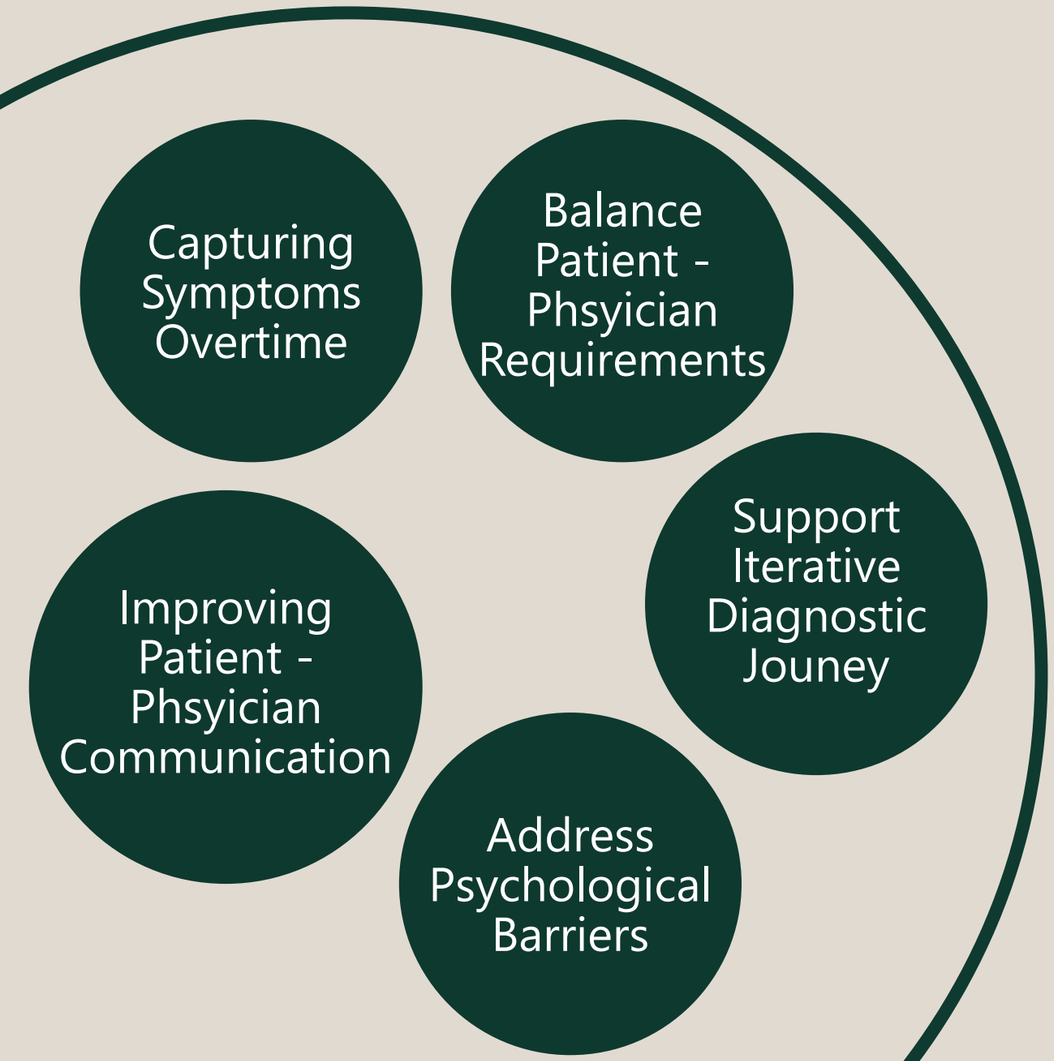
Figure 16: Diagnosis journey as described in interviews & Surveys

Section 3

Design Implications

Design Direction

The combined research has presented five key areas where a product intervention could support the autoimmune disease diagnostic process: capturing symptoms over time, improving patient–physician communication, supporting the iterative diagnostic journey, addressing psychological barriers experienced while seeking diagnosis, and balancing patient and clinician requirements.



Capturing Symptoms Over Time

The research strongly identified that symptoms related to autoimmune disease can fluctuate, change in severity, develop over time, and be difficult to accurately remember, record, or report (Sciascia et al., 2023). Accurate information about these changes can be valuable to physicians when assessing a patient. This creates a strong direction for a product, implying it should enable consistent and accurate documentation of symptoms over an extended period while remaining unobtrusive to the user's daily life. The interaction required to capture information should therefore minimise cognitive burden, particularly during periods when symptoms may be severe.

Improving Patient–Physician Communication

The primary research identified fatigue and brain fog as commonly reported symptoms, while secondary research highlighted limitations in what can be tested and the variability of clinical presentation (ASCIA, 2023). This reinforces the importance of accurately communicating the patient's lived experience alongside clinical test results. This presents an opportunity to create a product that can transform complex and potentially extensive patient experiences into concise, structured information that can be quickly understood by healthcare professionals. Rather than replacing the role of the physician, the product should improve the quality and accessibility of information available to support clinical decision-making.

Supporting the Iterative Diagnostic Process

All conducted research highlighted the non-linear pathway towards an autoimmune disease diagnosis. Patients may experience changing symptoms, multiple healthcare consultations, repeated investigations, and periods of uncertainty before a diagnosis is reached (Sciascia et al., 2023). Because of this, the product should support an ongoing diagnostic journey rather than treating diagnosis as a single event. Information should therefore remain useful across multiple appointments and stages of investigation, allowing new symptoms, changes, and relevant medical information to be incorporated over time.

Design for Patients and Clinicians

One of the most important findings was the recognition that both patients and physicians are key stakeholders in the diagnostic process. A product that is suitable for one but not the other would have limited value. The opportunity is therefore to develop a dual-purpose product that allows patients to interact with it seamlessly and with minimal effort, while presenting information in a format that allows clinicians to efficiently access and interpret relevant information. Patient usability and clinical usefulness must consequently be considered together throughout the design process.

Psychological Experience

Primary research highlighted the psychological impact that can result from existing diagnostic processes. An important consideration for a product intervention is therefore to minimise interactions that could contribute to self-doubt, feelings of dismissal, shame, or loss of trust. Findings around gender and dismissal should also inform this opportunity, without making the product gender-specific. Instead, the design should support patients in confidently communicating their own experiences and ensure that their reported information remains central to the interaction with healthcare professionals.

Summary of Findings

Collectively, these implications define an opportunity for a product that captures the changing experience of autoimmune disease, organises this information into a clinically useful format, and supports communication between patients and healthcare professionals throughout the diagnostic journey.

Conclusion

Autoimmune disease encompasses a highly complex and diverse group of diseases, which can present with fluctuating symptoms that are difficult to communicate and interpret. Existing diagnostic processes are highly iterative, requiring ongoing clinical assessment, multiple healthcare professionals, and a variety of tests that can produce unreliable or inconclusive results.

The research identified gaps between the clinical understanding of autoimmune disease and the lived experience of diagnosis, highlighting additional psychological and communication challenges alongside the well-established clinical challenges. Benchmarking further identified a lack of directly comparable products designed to support the autoimmune diagnostic process, despite existing health technologies demonstrating transferable strengths in usability, automation, and information collection.

From this research, an important design opportunity emerged: to develop a product intervention that helps patients capture their changing experiences, organise them into meaningful information, and communicate them effectively to healthcare professionals. Rather than attempting to replace existing diagnostic processes, the opportunity is to support the flow of information between patients and clinicians throughout the iterative diagnostic journey.

These findings provide a foundation for translating the identified needs and opportunities into design requirements and concepts, with consideration given to usability, consistent information capture, clinical relevance, and the needs of both healthcare professionals and patients.

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