the wren project

The Wren Project
Annual Impact Report
March 2023





CEO Introduction



The Wren Project wants to see a world where nobody diagnosed with an autoimmune disease has to face that journey alone, or without mental health support.

Our vision is to build support and community for all four million people in the UK diagnosed with autoimmune disease.

The Wren Project has grown exponentially in the past two years. We are now a steady team of seven, working across the country to support Wrens in periods of distress and loneliness with their autoimmune disease. We have built a wonderful and growing base of highly-trained volunteers that are the heart and soul of our charity and make the work we do possible.

We are the only charity that represents all autoimmune conditions together in the UK, and are already showing there is strength in numbers. We know that people with invisible and rare diseases need to be heard and supported. No other organisation explores what connects all patients with autoimmune disease, and their wider communities, rather than their differences. It gives us a large evidence base of impact and insight from people with all autoimmune diseases which we can use to improve and develop our services, rather than data about just one specific disease or type of disease.

We already raise awareness of the impact of living with long-term and incurable illnesses for Wrens' mental and psychological health, and wellbeing. Going forwards we will be engaging and promoting Wren's voices. Alongside building our digital presence, we will amplify Wren's voices through our strategic collaboration with stakeholders, building our networks, working with partners, signposting best practice elsewhere, building our own evidence base, and contributing to the wider research and policy landscape.

We aim to build our strategic communications and stakeholder engagement, to develop our fundraising and also become advocates for best practice, and evidence-based, integrated care for our community. Wren is a collaborative, valuable partner for those seeking to influence decision makers and we are uniquely placed to do so as a result of our growing expertise, research and networks.

The challenges we face today are new and demanding. As we continue to grow and expand our reach and goals, we must keep all areas of the Project rising together and focussed on our core: maintaining quality. We offer a highly-valued personalised, individual service to people that are in high distress and a growing Wren-led support structure for graduates of the service. As we increasingly make our stamp in the UK, we will not waiver from our commitment to build support and community for all four million people in the UK diagnosed with autoimmune disease. As we expand over the next year, we will continue to build and define a community of, and led by, people across the autoimmune category.

I am so proud of what we are all achieving, and the positive impact we are having on people's lives.

1660 listening appointments

£291,043 raised

397 referrals received

Why the Wren Project is needed

The Wren Project addresses the inadequate, inaccessible, or inexistent access to emotional and psychosocial support for people diagnosed with autoimmune disease. The term autoimmune is poorly understood, with little understanding of the 80+ diseases covered. Diseases range from those well-known – such as MS – to the rarely heard of, such as myasthenia gravis and Sjogren's syndrome.

Living with an unknown disease is isolating and exhausting, requiring repeated explanation to friends, employers, and even doctors. Beyond the physical disability, symptoms such as anxiety, depression, loneliness, body dysmorphia, and grief are acute and life-altering, and often seen as secondary to the medical, especially in the overstretched NHS.

83% of Wrens who come to the project tell us they are suffering from distress.
We are the only space where the emotional and social consequences of living with an incurable illness is given priority above medical symptoms and treatment plans. Our free, ongoing, non-judgemental, 1-1 listening support offers help in times of crisis and self-defined acute distress.

We are a community that understands. We work together to make people feel less lonely.



"Suddenly waking up one day and being diagnosed with a basketful of AI conditions, and being persistently labelled as 'complicated' (health-wise) was, and unfortunately is still, difficult.

In my experience, some medical professionals have become desensitised to the point they fail to identify and acknowledge the mental impact for a patient being newly diagnosed with an autoimmune (AI) condition.

From a patient's perspective, it is difficult to grasp an intangible and unpredictable condition that you can neither understand or see, especially when a patient has been diagnosed with a multitude of conditions - my case. This is why the Wren Project's entire existence is imperative.

For me, the Wren Project project has been like a lexicon: emotionally, I find it difficult to understand and come to terms with the various types of bedside manners during a time when I'm playing cat and mouse with conditions I do not understand. The Wren Project has provided a non-judgemental safe space to try and make sense of it all and for this, I am eternally thankful.."

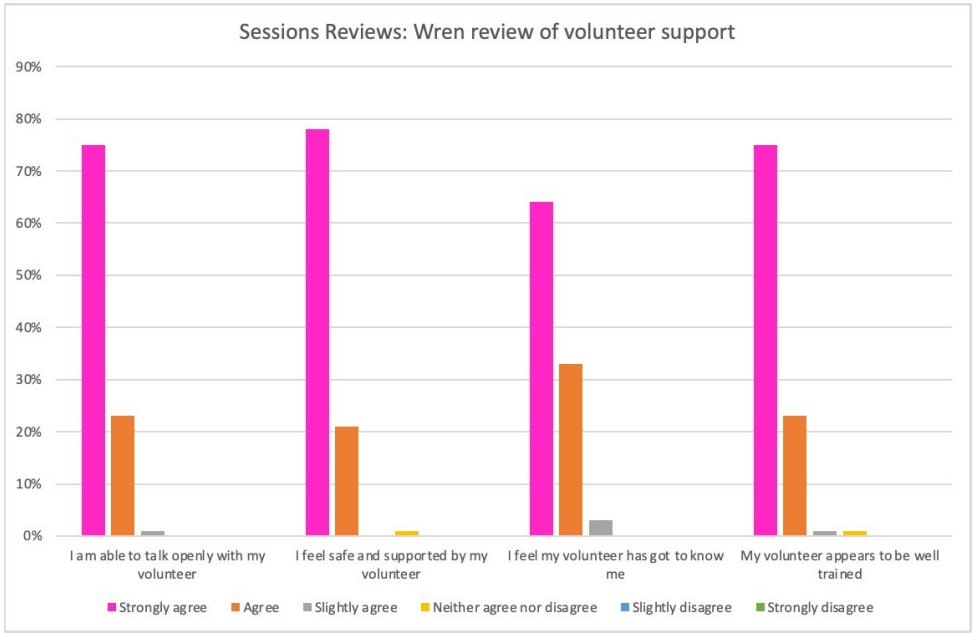
- *Wren*

Impact - session review

We measure impact through an initial assessment and a review session every three months, where we ask Wrens to reflect on levels of loneliness, distress, resilience, and ability to manage their disease.

We also ask Wrens to review the support provided by each listening volunteer. In many ways, this is the most important aspect of our support that we measure. Autoimmune diseases are lifelong and incurable; they might flare, go into remission, respond well to medication, but they cannot be cured. It is uncertain and unpredictable, and we cannot guarantee a positive outcome. What we can do is provide the best possible support, with highly trained volunteers creating a space of empathy, trust, and active listening.

These graphs show the responses provided from each session review - which we conduct every 3 months. Wrens' feedback of sessions demonstrates both the extremely positive experience of Wrens with our listening volunteers, as well as with the Wren Project team overall

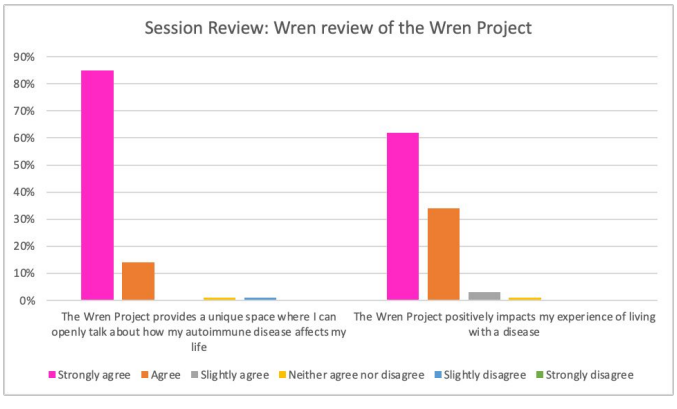


99% agree or strongly agree that they can talk openly with their volunteer

99% agree or strongly agree that the Wren Project provinces a unique space to talk about how autoimmune disease impacts life

99% rate their experience at the Wren Project as excellent or good

"The wren project has provided the routine support I need through probably the most difficult experience I have faced in my life. Living with an autoimmune disease is like staring into the dark hoping for some element of support, to know I have someone to talk to on a regular basis helps place the situation into perspective far greater than being left alone." - Wren





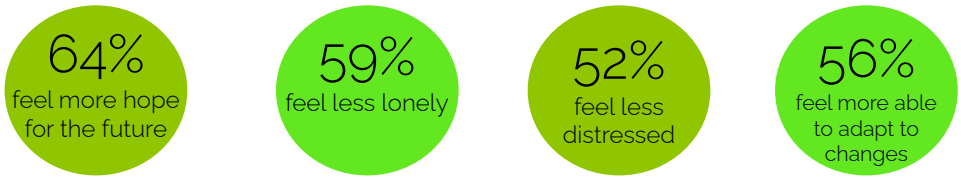
Impact - wellbeing review

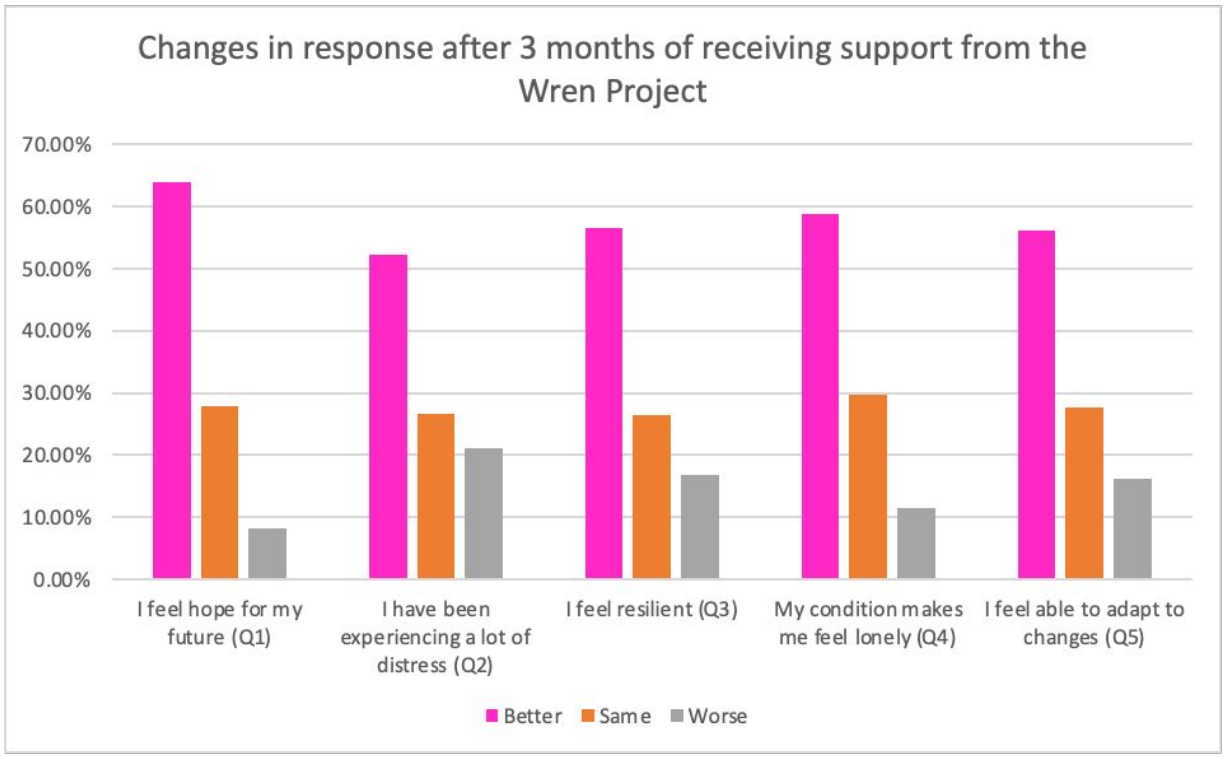
Our three monthly reviews invites Wrens to reflect on their holistic wellbeing, and especially their levels of. loneliness, distress, resilience, and ability to manage their disease. These are areas identified as most relevant for people with autoimmune disease yet lacking an adequate response from healthcare services. We measure these areas not because we believe we can magically solve related challenges, but so we can try to understand how our Wrens feel. We use this metric to understand the issues that Wrens face, not as a measure of success. The Wren Project stands by our value of truthful - we want Wrens to be truthful, to feel no pressure to put a positive spin on their experience, or claim they feel better to cheer others up. This metric helps to highlight how a Wren is honestly experiencing a lifelong, chronic condition.

Our reviews show that the Wren Project has a positive impact on a Wren's life in every domain for which we measure.

In the past twelve months, we have supported 189 remarkable Wrens with one-to-one, ongoing active listening support.

Of Wrens who received three months of support:





"My sessions have given me the opportunity to talk through decisions about my health and wellbeing without judgement. It is a relief to be able to talk to someone who did not know me prior to my diagnosis and so never makes comparisons to what I used to be able to. I feel empowered to consider different options regarding health treatments and life decisions at my own pace in a safe space." - Wren

Volunteers - the heart of the Project

Volunteers are integral to the Wren Project, meeting with Wrens via video call every fortnight to speak about their autoimmune disease, the impact it has on their life, and how they are coping.

Volunteers are trained in active listening, understanding autoimmune disease, and online support. Volunteers are supervised by members of staff, attend monthly group supervision, and have additional support when needed from experienced mental health professionals. Prior knowledge of autoimmune disease or mental health support is not required; our volunteers are trained to listen without offering judgement or giving advice. This active, empathic listening provides space for individuals to feel heard as they navigate a distressing and life-changing diagnosis..



"Volunteering to help people with autoimmune conditions like Addison's disease has given me a greater insight into how closely related the autoimmune community is and how we can all support each other. Practically it's very regular, a few hours a month. Having a routine is good for me and my conditions so it fits in well. I came to volunteer for the Wren Project because it's an experience I have gone through without support and if I can help someone through the tough time of being diagnosed with a condition I am glad to make it even a little easier."
- Chelsea, listening volunteer

"After each shift, I have the feeling that my morning was incredibly worthwhile. The session might go very well, or it might be more challenging, yet the feeling is the same. I feel fulfilled. Honestly, it is a privilege to know that someone trusts me enough to feel they can share some of their most difficult feelings or inner thoughts. It is extremely rewarding and to say it brings joy does not convey the right message. It is a deep feeling of doing something that has meaning."

- *Muriel, listening volunteer*



72 volunteers trained

10 supervisor volunteers trained

8 cohorts of volunteers

The Wren Journey

Initial assessment.
The Wren Project contacts Lily to conduct a referral call. We ask questions to understand how Lily's autoimmune disease affects her life, and explain how the Wren Project works, before assessing if the Project seems a good fit for Lily.

Referral.
Wrens learn about the Wren Project through doctors, partner organisations, universities, social media, or word of mouth. Lily learnt of the Wren Project through Thyroid UK after receiving a diagnosis of Graves disease.

Fortnightly sessions.
Every fortnight, Lily and her volunteer meet via video call for fifty minutes. These sessions offer Lily the chance to talk about the impact of her disease on life. Our volunteers are trained to support by active listening in a safe and confidential space.

3 month assessment.
After 6 sessions, the Wren Project discusses with Lily how she feels the support is going. We repeat the initial assessment and Lily is invited to reflect on her relationship with her volunteer.

Further sessions & 6 month assessment.
Guided by Lily's needs and sense of self, the sessions continue if appropriate, or come to an end. The Wren Project offers support for an average of 6 months.

Invitation to join the Wren Community
After 'graduating' 1-1 sessions, Lily is invited to join the Wren Project's ongoing community - to meet and connect with other Wrens, share experiences, and build a lasting network of peers living with autoimmune disease.

Invited to train as volunteer.
If Lily is interested, and feels in a strong place, she is encouraged to train to become a volunteer herself and support new Wrens grappling with autoimmune disease.



Matt's story:

"I was diagnosed with Severe Eosinophilic Asthma after a long, protracted process. I was rocked by the diagnosis, its severity, and the cost to the NHS for my treatment. I was told that I would need to take immunosuppressants every other month for the rest of my life. My experience of the Wren Project was AMAZING. I felt instantly supported and welcomed. It was the start of a long journey of self-acceptance that I'm still on but it has been a powerful force for change in my life. It has shown me that I don't need to hide what I think are my worst features and that I'm worthy of acceptance with my condition. It feels odd to say it now, but before the Wren Project's intervention I definitely felt as if I didn't really have much to offer society, to a workplace, or to my partner. I have since learned that none of that is true, and the Wren's input was the catalyst for that."

Aminah's story:

"Having suffered with Crohn's since I was 13/14, the disease seemed like an intrinsic part of myself – the psychological impact of which had taken a backseat throughout my life in an effort to minimise the impacts of a chronic illness. The Wren Project, for the first time in my life, provided me with a safe space to unashamedly focus on the condition and explore the full effect of it in various aspects of my life. Through articulating, validating and processing the experiences I have been through, I was able to be fully vulnerable and find a newfound appreciation for my own resilience but also an appreciation of the importance of dedicating time and space to talk about the impact of an autoimmune disease. It was truly an invaluable experience and I encourage more people to dedicate the time they deserve to exploring their own autoimmune diseases."



The Wren Journey

Lucy Brett
Graduate Wren
Director of Communications at the Wren Project



"My autoimmune disease hit me as an ambitious, busy working mum in my 30s and came with comorbidities which left me disabled, and in chronic severe pain. The diagnosis was devastating, although no mental health or psychological support was offered. And the havoc it wreaked across my life, and my family's life, was immense..

I've found autoimmune diseases like this constantly shift the goal posts and make plans and ambitions impossible. One day you might be planning a new career or holiday of physical activity, the next you are coming to terms with trying to climb out of bed, or get into your clothes.

I felt powerless. And sometimes uglier emotions too. Anger and resentment fuelled by fear, self-hate fuelled by all the stigma around disability and mental health and the extraordinary toll of some treatments. Wren offered a safe place, a kind and honest open space for me at my lowest ebb. They supported me when I received further upsetting diagnoses and the model of active listening helped me to explore all those feelings without judgement.

I felt heard by my volunteer and through the sessions finally had the time and space I needed to help me focus on what had happened to me and try to make sense of how I would or could move forwards. That's why, later, after my sessions with my volunteer ended I felt so passionate about joining the Wren team and using my professional background, as as a writer and communications strategist to help them work towards their ambitious plans to support all people with autoimmune conditions in the UK.

By making sure the Wren Project lives by its values of care, kindness, inclusivity, collaboration and trust, I hope our new communications strategy will help the whole team - staff and volunteers – keep supporting Wrens with our excellent services and increasing our reach. There is so much passion and ambition here, and we know from climbing autoimmune disease figures, alongside wider societal pressures on individuals, that we are all working in a space where Wren has never been needed more."

The Wren Nest



The Wren Nest is an online, twice monthly group meet-up for graduate Wrens that have finished one-to-one listening support. It was set up in response to requests by Wrens for social connections and community. It is run by the Wren Project, with each session facilitated by graduate Wrens. The space is informal and relaxed, with conversations covering diagnosis, identity, work and career, relationships, living with an incurable disease, medication and relation/friend/family-ships.

The Wren Nest aims to build a community for graduate Wrens to find a sense of belonging. Where other organisations often offer disease specific groups, the Nest brings people with a variety of autoimmune diseases together. Attendees will not necessarily share a diagnosis, but will share a direct direct experience and understanding of how autoimmune disease can impact life.

"It was important to have a space for Wrens to talk to each other, to share common ground, understanding, or to find new coping mechanisms. I think it's important to have a place for Wrens to check in when they've finished sessions, so that they're not just left on their own.

To be a part of it feels very rewarding, it feels like I'm making a difference in people's lives which in turn makes a difference in mine.

As someone with autoimmune disease, it also helps me to release how I feel. It feels important to know there's a day where others are going to understand how you feel and listen to you."

- Jade, Graduate Wren & Nest facilitator



The Wren Nest is open to all Wrens who have completed their individual listening sessions. We have an average of ten attendees per Nest, and we review every six months, with a focus group to ensure the Nest remains relevant.

85% felt listened to by the group

70% felt the Nest is a suitable continuation of support

70% felt that the Nest has made them less lonely

"To me this is a very special community. In some ways, I felt isolated which was difficult to address to other people. I feel like I found a second home. I feel very grateful."

- Wren Nest Attendee

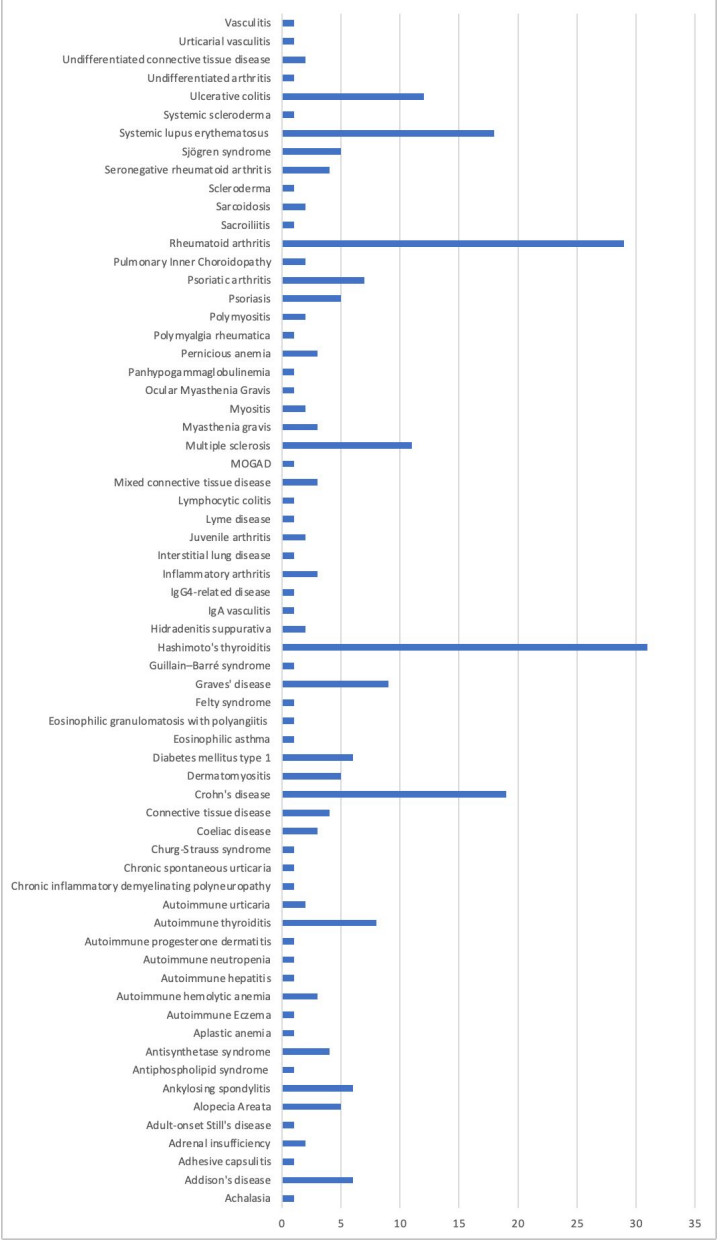
"Other groups are more social and trying to stay positive, whereas here I can talk about the true impact of my disease." - Wren Nest Attendee

An autoimmune community

In the UK, four million people currently live with autoimmune diseases, with cases rising by 3-9% each year. There are more than 80 different types of autoimmune diseases. 27% of people diagnosed with autoimmune diseases will develop additional autoimmune diseases.

The Wren Project is unique in that our support does not focus on one autoimmune disease; we provide ongoing support for people with any and multiple autoimmune diseases. By delivering our listening sessions through video platforms, we support people across the UK.

Our goal is to build an autoimmune community for all four million people diagnosed with autoimmune disease in the UK.



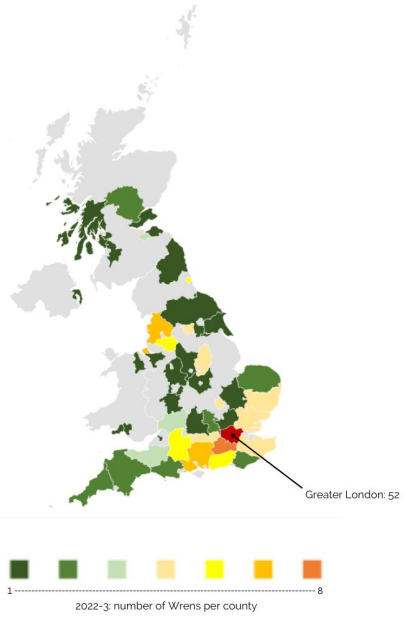
Between 1st March 2022 and 31st Jan 2023, we have received 397 referrals.

- 93% of are self-referrals. This community is actively looking for support.
- 66% continued to ongoing listening support sessions

Of those:

- 70% live with 1 autoimmune disease
- 30% live with 2 or more autoimmune diseases.

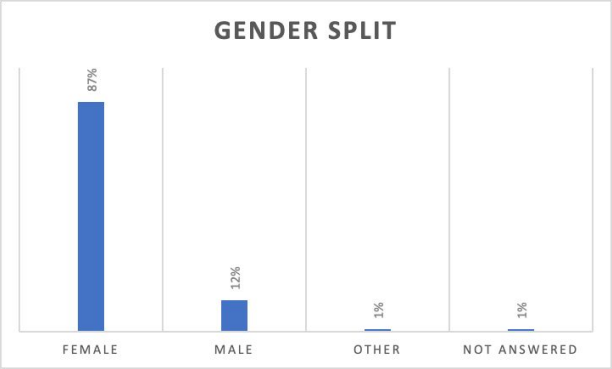
Geographic reach of the Wren Project



Our support is remote. Through video call platforms, we can connect with people across the UK, allowing us to reach more marginalised communities who might not have local, or established, access to other forms of support.

Wren demographic

The demographic background of Wrens reflects broader patterns of autoimmune disease in the UK: who is affected, and at what stage of life.

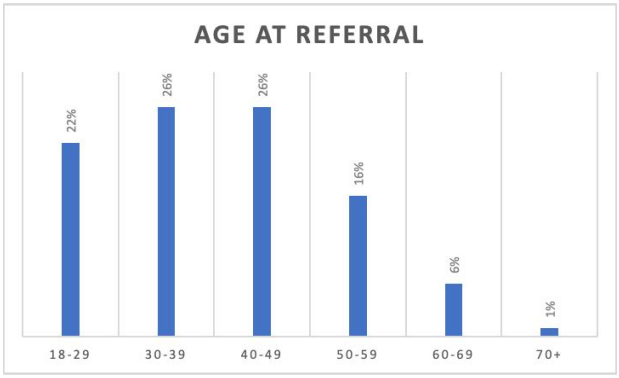


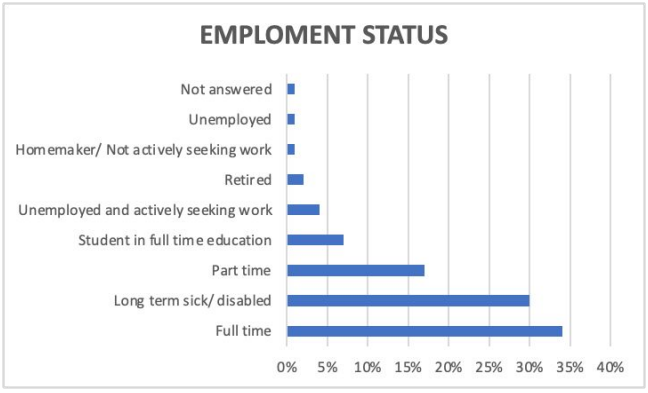
87% of Wrens are women.

This reflects the national demographic: in the UK, women constitute 75% to 80% of people diagnosed with autoimmune disease.

Most autoimmune diseases are diagnosed between the age of 20 and 50, but this also varies according to disease and gender.

The majority of Wrens refer to us between the age of 30-49, a significant time of life in terms of work, family, and social life. Support from the Wren Project provides space to acknowledge how disruptive and difficult a diagnosis can be and the toll it can take on everyday life.

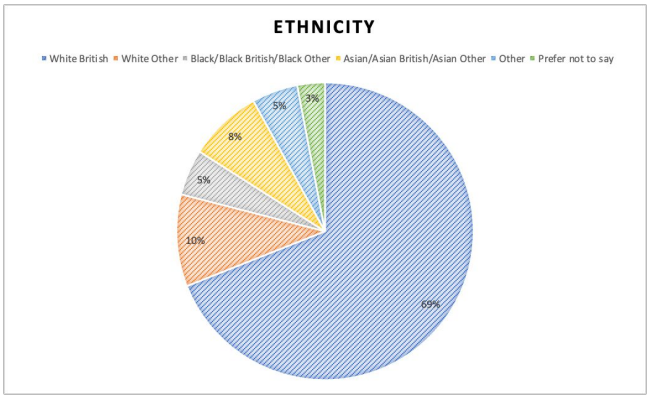




Only 34% of Wrens are in full-time employment; living with an autoimmune disease can significantly impact an individual's ability to sustain full time employment.

Our appointments span over the week, through the day and evenings offering Wrens who are employed or have other responsibilities or medical appointments the opportunity for appointments without needing to take time off.

18% of Wrens identify as non-White; ethnicity impacts risk of autoimmune disease, but this varies from condition to condition.



Partnerships

Our focus is specific: emotional wellbeing and community building. We provide ongoing listening support, without offering solutions or medical advice, and we refer to our partners if needs of Wrens are specific and beyond our remit. We work alongside disease-specific and specialised services, which provide helplines, treatment advice, research, and advocacy.

43% of our referrals hear about us from partner organisations.

The Wren Project's reputation as the only charity to offer consistent mental health support for people with autoimmune disease is robust and growing. Partnerships with other organisations in the autoimmune disease, medical and mental health fields are mutually beneficial to:

- **Increase the range of support available to our community.** Disease specific charities often receive frequent calls to their helplines yet lack capacity to provide long-term, emotional support. We receive referrals from partner organisations, and we refer to them when the needs of Wrens are disease specific and require specialised knowledge, beyond our remit.
- **Enhance research and understanding of autoimmune disease.** We work with partner organisations on research projects, aiming to advance holistic care for patients with autoimmune disease.
- **Improving quality of care for our community.** Autoimmune diseases are often treated in isolation, yet 27% of people living with an autoimmune disease will develop a second condition in their lifetime. We are the first organisation to look at autoimmune disease collectively. By working alongside all autoimmune disease charities, we aim for more joined-up integrated healthcare systems and holistic understanding of disease.