debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

No one should have to live like this.

The devastating impact of EB.

The 2023 EB insights study was commissioned and conducted on the behalf of DEBRA UK by Synergy Healthcare Research. The study was co-funded by Amryt Pharma and Krystal Biotech, neither company had any influence over the content.

The survey was conducted between January and May 2023.
Date of publication: September 2023

AMRYT PHARMA

Krystal

Introduction

The EB insights study was commissioned by DEBRA UK, the national charity and patient support organisation for people living with the genetic skin blistering condition epidermolysis bullosa (EB). This study was conducted between January and May 2023 by Synergy Healthcare Research, a London based research agency which specialises in conducting market research amongst healthcare professionals and patients.

People living with all types of EB, and their carers were surveyed to find out what it is like to live with the condition, the symptoms they get, and how they currently manage them, and the impact it has on their daily lives. The survey also explored their aspirations for the future in terms of healthcare and treatments.

The study also included interviews with healthcare professionals (HCPs) both those working directly with EB patients and non-EB specialist HCPs to assess their awareness and knowledge of the condition, and to identify any barriers or obstacles that currently prevent optimal EB patient care being delivered.

Date of publication: September 2023

Foreword

The 2023 EB insights study is our most comprehensive patient-centric research to-date, which provides us with a baseline of invaluable data from those who know and understand EB best: the EB community.

Over 200 people with different types of EB, over 100 carers, 50 dermatologists, and 100 GPs contributed to the study. Hearing the voices of those with and those impacted by EB is critical to our understanding of this debilitating condition.

Responses to the study came from across the UK, from a split of genders and across a range of ages. This diversity of thought confirms and informs our direction of travel in our fight against EB, leaving no-one with EB behind. Further, it will underpin a step-change in our planning and actions.

For example, the responses will guide our frontline services to ensure they are in line with the needs of the EB community and focus our research on the areas that matter most to EB patients. The study also provides us with a body of quantitative and qualitative data which serves as a foundation for our national advocacy and lobbying endeavours, while offering pharmaceutical companies the data they need to make targeted progress on treatments. And, ultimately, the findings of this study will inform our search for cures.

This is just the starting point; we will continue to involve the EB community in the next phases to ensure that we get services right for people with EB today and that we increase support and funding to enact change for people with EB tomorrow.

Carly Fields
Vice-Chair of the Board - DEBRA UK
September 2023

> **“The responses will guide our frontline services to ensure they are in line with the needs of the EB community and focus our research on the areas that matter most to EB patients.”**

Sample and demographics

This subsequent report, written by DEBRA UK, highlights the key findings from the EB insights study and the changes needed to improve patient outcomes. Please note that all findings in this report refer to the numbers and percentages of the people who participated in the EB insights study, not the wider EB community.

A breakdown of the number of respondents to the study is below:

Healthcare Professional (HCP) sample demographics

Location	GPs	Dermatologists
England	**95%**	**84%**
Greater London	23%	18%
South East/West	21%	30%
East/West Midlands	19%	12%
North East/West	17%	10%
East	8%	10%
Yorkshire/Humber	7%	4%
Scotland	**2%**	**12%**
Wales	**2%**	**2%**
Northern Ireland	**1%**	**2%**

50
Dermatologists

46% Male

50% Female

4% Didn't state

88% Consultants

12% SpRs (Specialist Registrars)

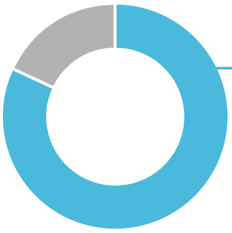
100% not working at an EB specialist centre

Dermatologist setting

74% University Teaching Hospital

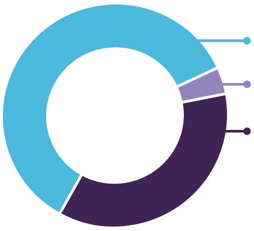
26% Non-University Teaching Hospital/DGH

0% Specialist Dermatology Centre



82% have seen at least 1 EB patient / last 5 years

Dermatologist level of interest in EB

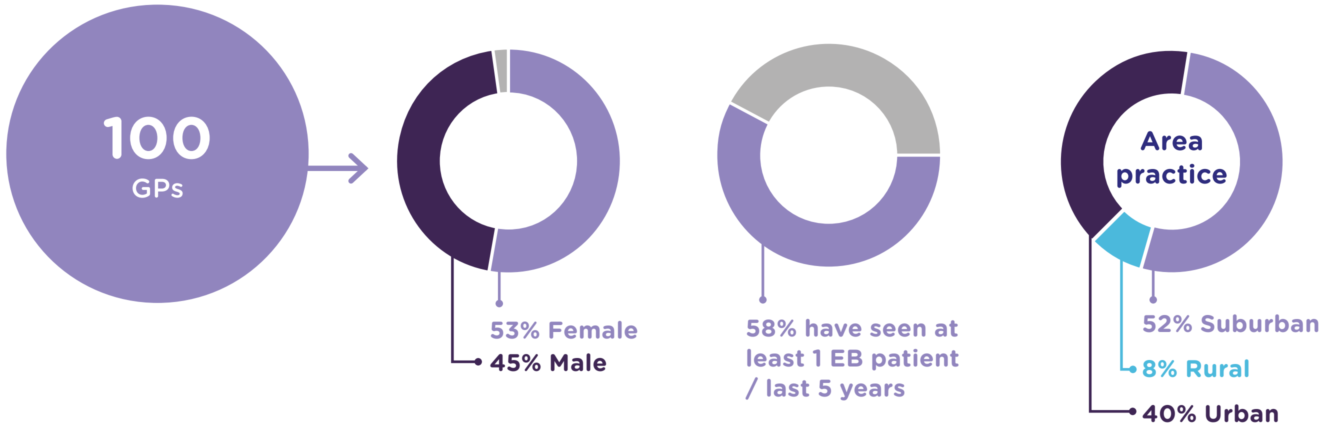


60% Less interested in EB than other areas of dermatology

4% Greater interest in EB than any other area of dermatology

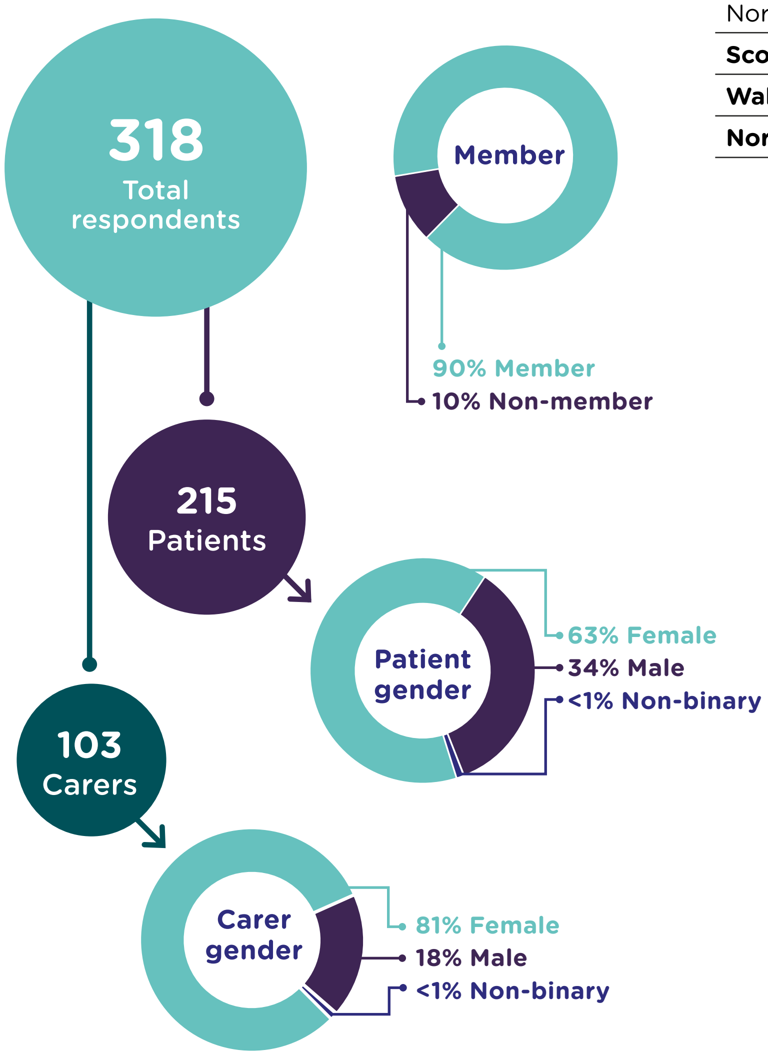
36% Greater interest in EB along with a number of other areas of dermatology

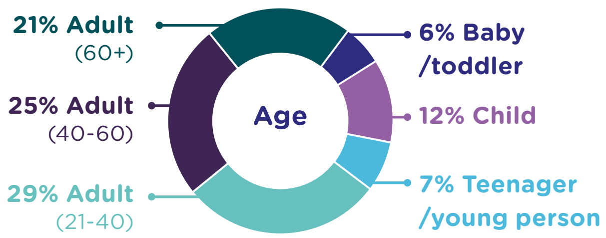
0% Lead for our hospital for EB

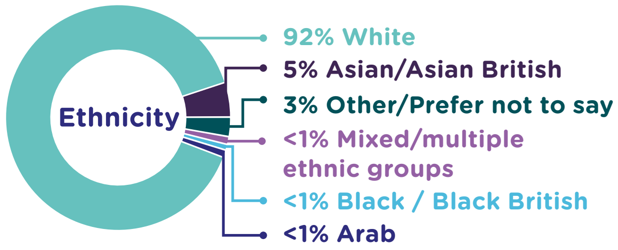


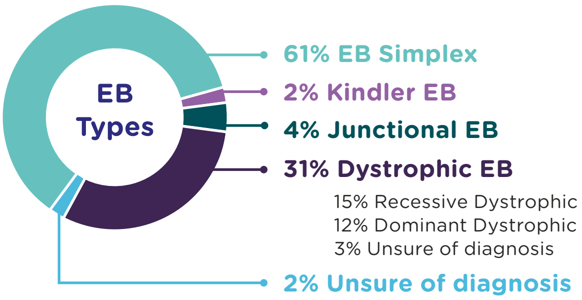
Patient and carer sample demographics

Location	
England	**80%**
South England	40%
East England and the Midlands	25%
North England	15%
Scotland	**14%**
Wales	**4%**
Northern Ireland	**2%**









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Key finding & calls to action 2023/24

The UK-wide EB insights study has provided further evidence of the devastating impact that EB has on the lives of people living with or directly affected by the condition. It has also provided evidence that the current cost-of-living crisis is only exacerbating the challenges that many people living with EB already faced, particularly when it comes to accessing specialist EB healthcare.

From the EB insights study, we have identified the following 7 x key issues as having the greatest impact on the EB community that we at DEBRA, as the patient support organisation for people living with EB, must address in our future plans:

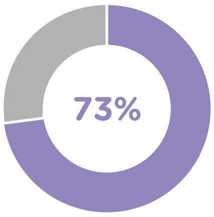
1. There is a need for improved awareness & understanding of EB:

a.

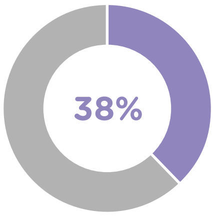
GPs and dermatologists need to have improved awareness and understanding of all types of EB including the symptoms to look out for, the impact that the condition has on the individual and their family/carer, and the support that is already available through the NHS, to ensure they can correctly diagnose it and refer patients to the specialist EB healthcare that is available through the NHS.

EB is a rare condition and consequently awareness is generally low amongst GPs and dermatologists who face difficulties in diagnosing the condition in practice: 35% of GPs and 24% of dermatologists surveyed believe the initial presentation of EB is like eczema, dermatitis, or an allergy and some of the less obvious symptoms of EB are currently not seen as an indicator that the patient could have EB, e.g., 10% or less of GPs surveyed associated problems with the bladder, painful defecation, breathing difficulty, itchy skin, and fatigue as symptoms of EB. Although 73% of EB patients surveyed experienced EB symptoms from birth only 38% received a diagnosis at birth and only 65% received a diagnosis within a year of first experiencing symptoms. For 14% it took 20 years or longer to be diagnosed.

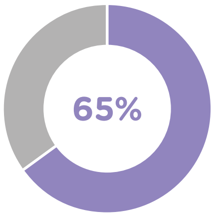
11% of GPs and 14% of dermatologists surveyed believe most 'mild' patients, which typically is patients with EB Simplex (EBS), do not need specialist care, which could explain why 50% of EBS patients are not under the care of the specialist EB healthcare centres and are thus missing out on the support that these centres can offer. Patients with EBS are diagnosed later and longer from first symptoms than other types of EB. By getting a late diagnosis many EB patients surveyed experienced delays in getting a referral for specialist care. Of the EB patients surveyed, 40% were not under the care of an EB specialist centre but 77% of these patients believed they should be. 93% of GPs and 22% of dermatologists surveyed did not know the details of their closest specialist EB healthcare centre.



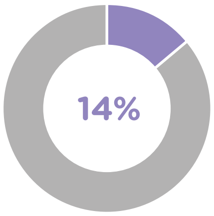
73% experienced symptoms from birth



Only 38% received diagnosis from birth



65% received diagnosis within first year of symptoms



14% received diagnosis after 20 years or longer

To increase awareness and understanding of all types of EB amongst GPs and dermatologists and to encourage more referrals to EB specialist healthcare centres, DEBRA will re-launch its members pack to include resources that DEBRA members can use themselves to help educate HCPs on EB, to include: the symptoms of all types of EB and what to look out for, the specialist EB healthcare available within the NHS and how to access it, plus a specific letter template they can use to request a referral to EB specialist healthcare. We will enhance and make more visible the HCP targeted content on the DEBRA website, creating a dedicated HCP zone including information on the referral process and details of the EB specialist healthcare centres. We will launch an EB awareness campaign in Q1 2024 specifically targeting GPs and dermatologists with the objective of raising awareness and understanding of EB to facilitate quicker diagnosis and referral to the specialist EB healthcare support that is already available through the NHS. And throughout our 2024 campaigns targeting multiple different audiences, we will continue to represent people with all types of EB as we started with the “A Life Free of Pain” appeal.

b.

The EB patients and carers interviewed want to see DEBRA campaigning to raise awareness of EB and improve NHS care.

After funding research towards treatments, this was the next priority with 46% of EB patients/carers wanting DEBRA to focus on this as a priority.

46% want DEBRA to focus on raising awareness of EB and improving NHS care

Raising awareness of EB amongst HCPs, including GPs and dermatologists, will be a key activity for DEBRA in 2024 both through member driven activity such as the new member packs and through a dedicated HCP awareness campaign.

We will also invest in raising awareness of EB and of DEBRA and our membership offer both to existing members but also to people who may not be aware that they have EB, so that they are aware of the condition, of DEBRA, and of the support that is available for people living with EB both through DEBRA and the NHS. Improving the EB healthcare provision will also form a key part of our 2024 government lobbying campaign, which we will deliver in partnership with a specialist public affairs agency.

c.

There is a need for information / education designed for each type of EB. 41% of EB patients/carers surveyed requested this.

41% believe there is a need for information / education designed for each EB type

Much of this information is already available but we need to make it much more visible and easier to access and we will do this by relaunching our member packs and by creating an intelligent search tool on the new DEBRA website, which will launch in 2024 and make it much easier to access the specific EB information related to the type of EB the person has and their life stage.

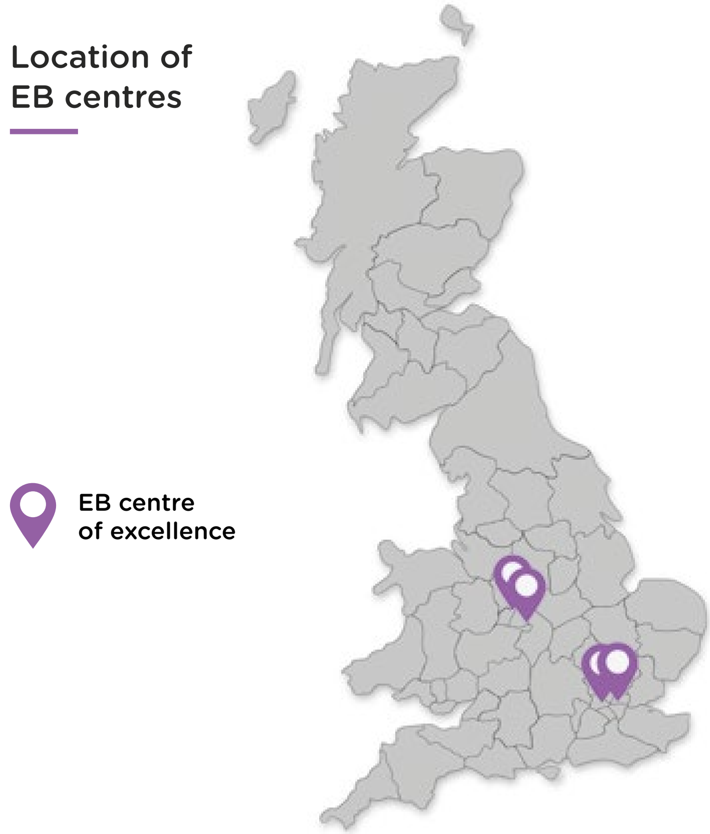
2. There is a geographical imbalance of EB specialist healthcare:

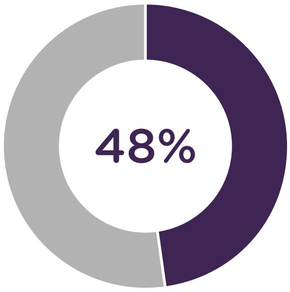
a.

The geographical location of the UK's EB specialist healthcare centres makes it difficult for many patients to attend appointments due to the associated transportation and accommodation costs. The location of the specialist centres can also make it more difficult to support members with EB Simplex who may not have symptoms at the time of their annual appointment and who would be better served with regional clinics. These barriers must be removed to make it easier for people living with all types of EB to access the specialist EB healthcare which is already available through the NHS.

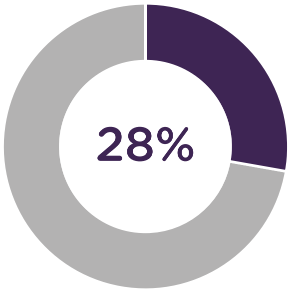
The four UK EB healthcare centres of excellence, which DEBRA supports either with part funding or community support staff being a part of the multi-disciplinary team, are in Birmingham and London, there are no centres in the Southwest England, the North of England, Wales, Scotland, or Northern Ireland, which means many people with EB must travel significant distances to attend appointments. For 48% of EB patients surveyed, travelling to a specialist centre is difficult, and 28% struggle to pay the transportation costs.

DEBRA will continue to work with the NHS to explore opportunities to address the geographical imbalance of specialist EB healthcare in the UK. We will explore with them the opportunity for more virtual clinics and regional satellite clinics to ease the burden on those patients who currently must travel significant distances to attend an appointment. We will also more widely publicise the travel grants that are available through DEBRA to support people living with EB to attend appointments at the specialist EB healthcare centres, and not just to existing DEBRA members but also more widely so that members of the EB community who may not be aware of DEBRA and of the support we offer, can also access this support.





48% of patients find travelling to a specialist centre difficult



28% struggle to pay for transportation costs

3. The cost-of-living crisis is exacerbating the financial burden of living with EB:

a.

The cost-of-living crisis is impacting people living with EB and additional support must be provided to ensure members of the EB community get the financial help they need to improve their quality of life.

64% of EB patients surveyed have been impacted by the cost-of-living crisis, with 33% struggling to purchase treatments, particularly those who do not qualify for free prescriptions. Only 52% of EB patients surveyed have applied for PIP/DLA and 20% experienced problems with the process.

64% of patients have been impacted by the cost-of-living crisis

DEBRA will continue to publicise the grants that are available to DEBRA members to support them with daily living including purchasing specialist equipment and seamless soft clothing for newborns. We will publicise the benefits of DEBRA membership more widely so that members of the EB community who are not currently aware of DEBRA can also access this support. As part of the new member packs and HCP awareness campaign, we will provide clear guidance based on the published Best Practice Guidelines to GPs and dermatologists as to the optimal dressings that should be prescribed for patients with the different types of EB to avoid generic alternatives being prescribed that do not offer the same benefits. And as part of our government lobbying campaign for 2024 we will ask for consideration to be given to extending free prescriptions to all members of the EB community, not just those that qualify through means testing. This is needed because of the amount of bandaging and dressings that are required to manage the symptoms of EB throughout the patient's life, which can create a huge financial burden.

Through the new member packs and enhanced website content, we will provide improved information about the financial support and advice that DEBRA's Community Support Team can provide, the grants that are available to members through DEBRA, and we will improve the signposting to resources that can help members navigate the process for applying for a Disability Living Allowance (DLA) or a Personal Independence Payment (PIP). We will also share tips and suggestions from other members who have successfully secured this support.

b.

The EB patients and carers surveyed want to see DEBRA offering grants to buy specialist items / equipment, funding for transport to medical appointments etc, and support to access healthcare professionals.

This was the highlighted as a key priority by 42% of respondents to the insights study.

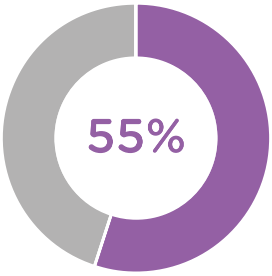
Grants are already offered via DEBRA to support our members with many areas of daily living including the cost of specialist equipment and transportation costs, however we need to make sure that these grants are more widely publicised through more frequent communications across all available channels so that more members are aware of the support that is available to them. We also need to be reach people with EB who may not be aware of DEBRA so that they can also become members and thus have access to the same level of support. To achieve this, in 2024 we will invest in awareness activity targeting people outside of our existing membership with the objective of connecting with people who may not know they have EB, and people who have EB but who are unaware of DEBRA and the support we offer. This will be built into our communications plan for 2024.

4. The current mental health provision for EB patients/carers is inadequate:

a.

The current mental health provision available through the NHS for people living with EB and their carers is inadequate and needs to be improved.

55% of EB patients surveyed stated that EB has had a high or moderate impact on their mental health and yet only 3/10 had been offered NHS mental health support. 70% state EB has had a negative impact on their self-confidence, and 50% have experienced bullying or abuse. The mental health provision also appears to be lacking for carers of people living with EB too, with 75% saying they felt more emotional support was needed.



55% of patients state EB has a high or moderate impact on their mental health

50% have experiences bullying or abuse

DEBRA has recently partnered with Togetherall to provide on-line mental health support 24/7 for DEBRA members and we will promote this resource both to existing members and the wider EB community as a DEBRA membership benefit to ensure as many people with EB as possible can benefit from this resource. In addition to Togetherall we will explore opportunities to partner with other organisations to offer tailored face to face mental health support / counselling for the EB community and improved mental health support for the EB community will also form part of our government lobbying campaign for 2024.

5. EB patients/carers want treatment recommendations from other EB patients:

a.

The EB patients surveyed found peer to peer recommendations for EB treatments to be as beneficial as the recommendations they receive from HCPs and so it is vital that these peer-to-peer conversations can easily take place.

65% of patients surveyed valued treatment recommendations from other EB patients, and as the patient support organisation for people living with EB, we will do whatever we can to help the EB community come together and connect to share ideas and recommendations, and to talk to one another.

Annually we host a DEBRA member's weekend where members can physically get together however we recognise that geographically this can be a challenge with just one national event and the insights showed that 34% of EB patients and carers surveyed would like local in-person events throughout the country. We will explore the opportunity to offer more regional member events in 2024, which we will more widely publicise to ensure that members of the EB community who are not currently aware of DEBRA and of the benefits that free DEBRA membership offers them, can also benefit. Also, to facilitate more day-to day interactions within the EB community we will launch a social collaboration platform specifically for the EB community, which is what 27% of EB patients/carers surveyed specifically requested.

6. EB patients/carers want effective treatments as a priority:

a.

The EB patients and carers surveyed want to see DEBRA funding research towards treatments as the top priority.

53% of EB patients surveyed want DEBRA to be funding research into future treatments and 39% stated that existing EB treatments don't work well.

53% of patients want DEBRA to be funding research into future treatments

39% state that existing EB treatments don't work well

Research into future treatments for EB is at the centre of our research strategy and has been the key focus for our fundraising activities in 2023 which has helped fund the first DEBRA UK drug repurposing clinical trial which will commence towards the end of 2023. This focus will continue into 2024. We do however need to secure the right balance between researching effective treatments for tomorrow and improving treatments and care for today and thus in parallel to our drug repurposing programme we will continue to investigate and share with the EB community, guides, and information to support them with their symptom management today, e.g., sharing information on specialist equipment, clothing, and shoes and we will continue to explore opportunities for specialist product development with suitable partners that could benefit the EB community.

7. EB patients want more interaction with DEBRA's community support team:

a.

There is a need for more community support including home visits, annual or bi-annual check in calls.

39% of EB patients/carers surveyed requested this.

To strengthen our community support offer we will aim to achieve a minimum 1 check-in call every year for every DEBRA member.

We will ensure that our strategic plan for 2024 includes activities that directly address the key issues that have been highlighted through the 2023 EB insights study and we will continue to ensure that through forums such as our involvement network, the voices of the EB community continually inform our direction and plans.

In 2025 we plan to repeat the EB insights study which will help us measure the progress that has been made in addressing the key issues that affect the EB community .

Scan to read the full 2023 EB insights study

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Help stop the pain of EB

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We are here to make a difference

Find out how to become a DEBRA member, make more of your membership or contact us for support.

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🌐 www.debra.org.uk/membership

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