



Epidermolysis Bullosa Patient Insights

Quantitative Research Presentation

June 2023 / JN4286

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Synergy
Healthcare Research

About Synergy



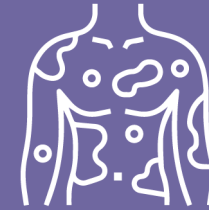
Full-service research agency with a broad range of expertise in healthcare

We carry out market research in a wide range of therapy areas among health professionals, payers and patients. We are big enough to carry out the largest projects and small enough to care about even the smallest projects.



Award-winning patient research

We have particular expertise conducting research amongst patients –including twice winning the BHBIA BOBI Award for Best Patient Centric Approach. Our most recent award in 2022 was for research looking into the impact of delayed diagnosis amongst multiple myeloma patients, working with Myeloma UK. We also won in 2020 for research with Psoriasis UK and LEO Pharma on the 'Wake up to Psoriasis' campaign.



Extensive experience researching dermatology and rare disease

We have conducted numerous research projects exploring the management of skin disease, including psoriasis, eczema, actinic keratosis and skin cancer. We also have significant expertise conducting research in rare diseases, with recent research covering haematological, metabolic and genetic rare diseases. Research will be designed and interpreted in the context of our extensive knowledge of this therapy area to provide deeper insights and more powerful recommendations.



Award winning expertise in a wide range of research approaches

Our expertise in a wide range of research approaches is demonstrated by awards presented to Synergy in categories encompassing most types of research including:

- Best Customer Insight
- Best Business Impact
- Sales Force Effectiveness Research
- Communication Research
- Excellence in Data Collection & Fieldwork

Foreword



The *2023 EB Insight Study* is our most comprehensive patient-centric research to-date, providing us with a baseline of invaluable data from those who know and understand Epidermolysis Bullosa 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 our 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 – DEBRA Vice Chair of the Board

Executive Summary

Conclusions and recommendations

EB has a high symptom burden, with many of the symptoms experienced by most patients having a high impact on daily life

That being said, life with EB is highly variable – the type of EB does not necessarily correlate with severity, and the worst days can be considerably worse than an average day – **beware of making assumptions** about what patients are going through and what they are capable of at any one time

Symptoms are again highly variable and cause significant impact on QoL – the 'lows' of patients with variable or seasonal symptoms can feel particularly low, and they can struggle to be understood by HCPs

Foot blistering is particularly impactful and may need to be an area of focus

EB has a significant impact on mental health, and for carers and DEB patients in particular – consider more carer focused solutions

Teenagers and young adults with EB need more tailored support across the board – potential gap resulting from service transition

Difficulties with HCP interactions evidences need for HCP education (see next section)

Effective symptom management, treatments or therapies severely lacking for EB – all patients using something different or nothing at all, rely on recommendations from others

Delayed presentation and referral are obstacles to timely diagnosis – particularly for SEB and patients with seasonal symptoms

A significant amount of EB patients are not under specialist care – whilst some feel they don't need this, the remainder are coping on their own or potentially held in local primary / secondary care

Even when under specialist care, access is difficult for some patients to achieve re travelling and frequency of appointments **not tailored to patient needs**

Whilst many aspire towards a cure for EB, when time frames and limited funds are taken into account **the development of new treatments take priority**

GPs appear to have reasonable spontaneous awareness of the signs and symptoms of EB – but difficulty exists around recognising these in practice and referring EB correctly, in both primary and secondary care, despite many HCPs having seen an EB patient

Destigmatise the complexity of managing EB and ensure links with specialist services are possible to increase HCP confidence in shared care arrangements, even for more complex patients

There is a need for better communications with specialist centres around role of primary care and local secondary care – primary care expect to manage antibiotics and pain management for EB patients, but need for clarity around who is responsible for bandages, bloods and needles, and what is covered by specialised commissioning

Need for education around ability to refer directly to specialist services and when this should be done – currently, some patients are being managed entirely within local secondary care

Prescriptions for specialist bandages need to specify exact type of dressing and justify why it is being prescribed to overcome any formulary barriers

- Assistance may also be needed for pharmacy re: how to order stock

In theory HCPs are receptive to more information about EB, but this should target the most effective channels and sources to ensure engagement

Positive reactions to a 'GP' pack of information – HCPs more likely to use information with NHS and specialist centre endorsement

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Methodology & Sample

Methodology

20 minute UK online survey with EB patients / carers

15 minute UK online survey with GPs & Dermatologists

Conducted April-May 2023

Preceded by qualitative depth interviews with 19 EB patients/carers and 9 EB specialists conducted Jan-Feb 2023

HCP Quantitative Sample

50 Dermatologists

Derms

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

88% Consultants 12% SpRs

All not working at an EB specialist centre

100 GPs

GPs

58% have seen at least 1 EB patient / last 5 years

Patient Quantitative Sample

318 Total Respondents

Patients

215 Patients

Carers

103 Carers (90 current carers, 13 past carers)

EB Types

61% EB Simplex

SEB

31% Dystrophic EB

DEB

4% Junctional EB

JEB

2% Kindler EB

KEB

15% Recessive Dystrophic (51% of DEB)

DEB

12% Dominant Dystrophic (40% of DEB)

3% were unsure of diagnosis

Patient & Carer Sample Demographics

SEB

DEB

JEB

KEB

DEBRA membership

90% Members

10% non-members

Age of patient

Baby / Toddler

6%

Child

12%

Teenager / Young Person

7%

Adult (21-40)

29%

Adult (40-60)

25%

Adult (61+)

21%

Ethnicity

92% White

5% Asian / Asian British

<1% Black / Black British

<1% Arab

<1% Mixed / Multiple ethnic group

3% Other / Prefer not to say

Locations

England

80%

North England

15%

East England and the Midlands

25%

South England

40%

Scotland

14%

Wales

4%

Northern Ireland

2%

Patient Gender

63% Female

34% Male

<1% Non-Binary

Carer Gender

81% Female

18% Male

<1% Non-Binary

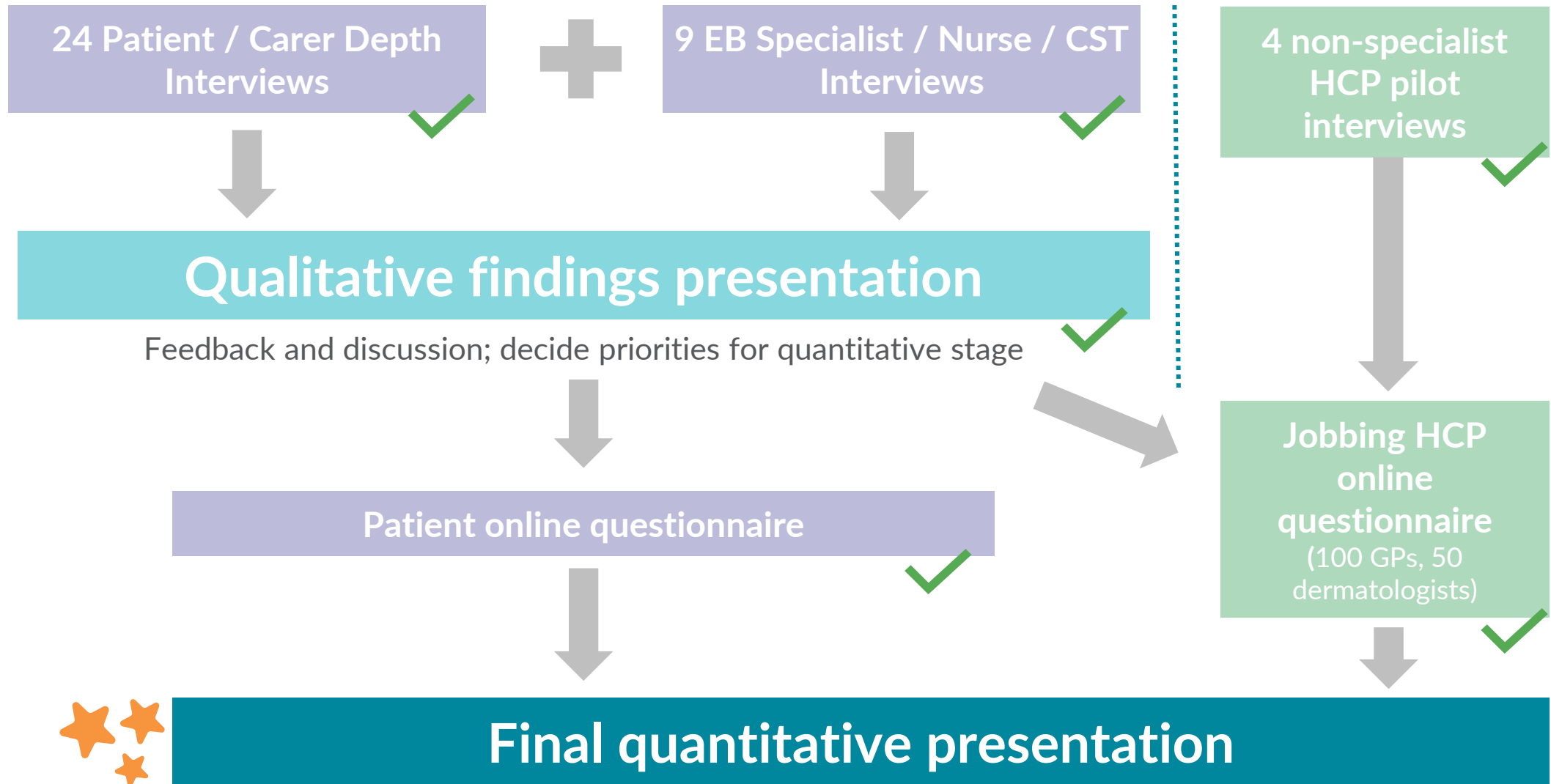
HCP Sample Demographics

| Location | GPs | Dermatologists |
|----------------------|-----|----------------|
| England | 95% | 84% |
| Greater London | 23% | 18% |
| North East/West | 17% | 10% |
| Yorkshire / Humber | 7% | 4% |
| East / West Midlands | 19% | 12% |
| East | 8% | 10% |
| South East/West | 31% | 30% |
| Scotland | 2% | 12% |
| Wales | 2% | 2% |
| Northern Ireland | 1% | 2% |
| Gender | GPs | Dermatologists |
| Female | 53% | 50% |
| Male | 45% | 46% |

| Dermatologist Setting | |
|--|-----|
| Specialist Dermatology Centre | 0% |
| University Teaching Hospital | 74% |
| Non-University Teaching Hospital / DGH | 26% |
| Dermatologist level of interest in EB | |
| Lead for our hospital for EB | 0% |
| Greater interest in EB than any other area of dermatology | 4% |
| Greater interest in EB along with a number of other areas of dermatology | 36% |
| Less interested in EB than other areas of dermatology | 60% |

| GP – level of interest in dermatology | |
|---|-----|
| GPwER (GP with extended role) in dermatology and skin surgery | 1% |
| GPwSI (GP with special interest) in dermatology | 5% |
| Lead GP for dermatology in my practice | 6% |
| Other special interest / role in dermatology | 13% |
| None of the above | 80% |
| Area practice | GPs |
| Urban | 40% |
| Suburban | 52% |
| Rural | 8% |

Where we are now:



Objectives

Marketing Objective:

Improve DEBRA's understanding of and engagement with the EB community



Provide proactive support

Enable DEBRA to proactively intervene to provide support across the EB patient pathway



Inform language

Enable DEBRA to discuss EB in a way that resonates with patients; and improve patient-centricity and organisational tone-of-voice



Form advocacy positions

Inform lobbying, research funding, forming alliances
Developing robust community support



Show progress DEBRA has made with EB

Increase member engagement and credibility for fundraising
Provide confidence for future partnerships



Increase relevance

Help DEBRA engage in current debates, influence key stakeholders such as MPs and the NHS, and form alliances with other organisations

Detailed research objectives – patients and carers living with EB



What it's like to live with EB

- **Details of what its like to live with EB:** how long patients have had the condition, where they are affected, what the physical symptoms are like and the limitations caused by these
- **Triggers for symptoms / worsening symptoms**
- **Patient Journey:** initial diagnosis, HCP support offered, treatments offered (and the impact of these), and general perception of healthcare support provided
- **Non-HCP support provided**
- **Daily routine looks like living with EB:** what's involved, how long does it take
- **Understand unique challenges of each EB subtype**



Impact of EB

- **Impact of EB on daily life:** such as mobility, eating, sleep and hygiene, social life, education, career, aspirations, and travel
- **Mental health of both patients, carers, and other loved ones:**
 - Explore key triggers for mental health
 - Explore the symptoms that have the greatest impact on mental health
- **Coping mechanisms:** Physical and emotional techniques used
- **Pain relief:** uses and concerns patients have regarding frequency of pain relief
- **Understand satisfaction with treatments and current support**
- **EQ-5D questionnaire**
- **Cost of living crisis**



Aspirations for the future

- ***Provide insights into patients' aspirations for the future, including***
 - *Improvements that would improve their QoL*
 - *Aspirations in terms of treatments and understanding of EB*
- **Understand patients' priorities for future funding:** i.e. drug repurposing, researching a cure, or immediate relief and care



Patient views of DEBRA

- *Assess services and support patients would like to see DEBRA provide*
- *Assess patient perception of DEBRA's performance*
- **Understand patient need for further provision of support, including:**
 - Online members forum
 - Local support and connection with people like themselves
 - More inclusive communication and events

Detailed research objectives – HCPs



Identification and Diagnosis

- Assess HCP awareness and knowledge of EB
- Explore issues around identification, diagnosis and support of patients with EB
- Identify current barriers to quick identification and diagnosis



Patient Care

- Where are the gaps in terms of support HCPs can offer patients
- **Barriers and Obstacles in system:** what is preventing optimal EB patient care e.g., GPs not aware able to refer out of area for EB, incorrect dispensing of dressing prescriptions
- **Extent of HCP involvement in EB patient care**
 - Understand HCP perception of which EB patient issues should be managed locally vs by specialist consultation (e.g. conditions unrelated to EB such as flu)



Reactions to possible support options

- **Outreach clinics:** HCPs attitudes to outreach clinics
- **GP Pack:** Explore GP reactions to Patient guided packs and determine optimal source and format
- **Understand HCP satisfaction with current EB care**



Communications and Reactions to DEBRA

- **Assess dermatologist and primary care awareness and opinions of DEBRA**
- **Communication:** Identify most-used HCP sources of credible information including journals & websites; understand extent to which clinical best practice guidelines valued / used

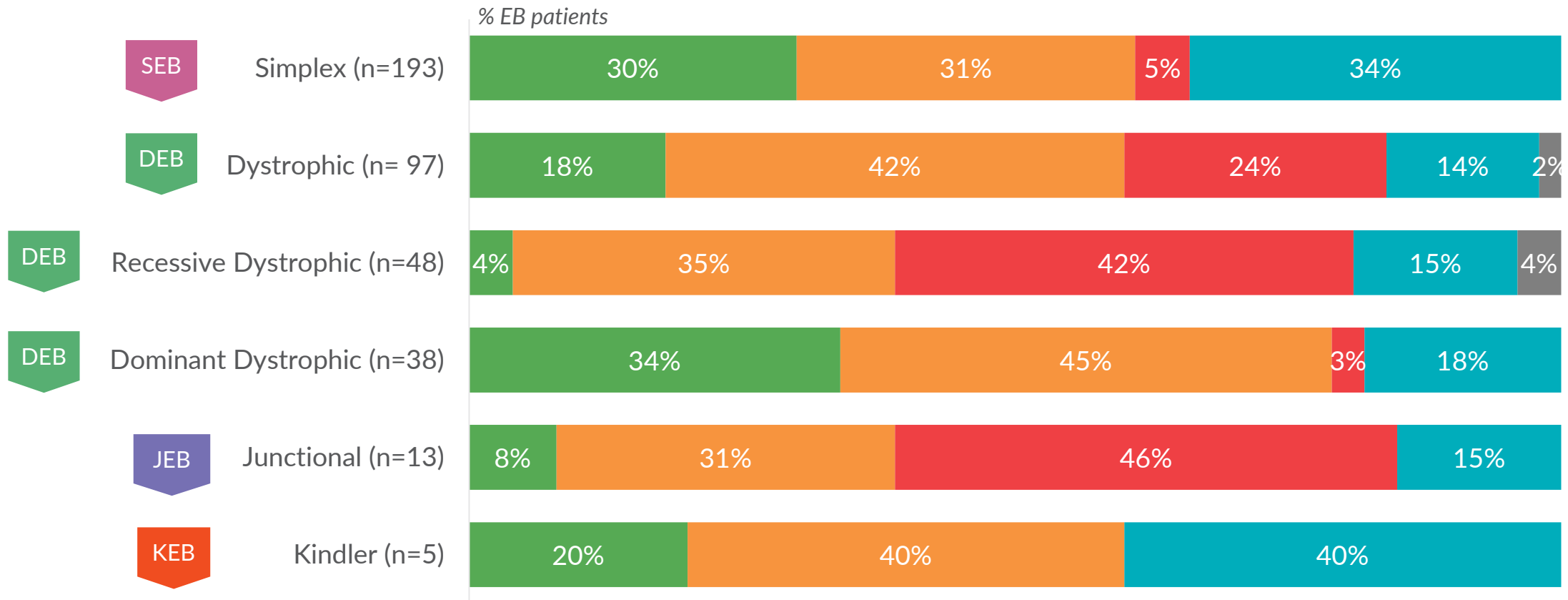
Patient & Carer Research Key Conclusions

Diagnosis and life with EB

Only 30% EB Simplex patients have 'mild' EB; for a third it depends / varies
 42% Recessive Dystrophic patients have severe EB vs only 3% Dominant Dystrophic

Would you consider your (/the person you care for / cared for's) EB to be...

■ Mild ■ Moderate ■ Severe ■ It depends / varies ■ Not sure



Base 318 (215 Patients, 103 Carers)

D1 Would you consider your (/the person you care for / cared for's) EB to be...

Many EB patients experience delays in their diagnosis – though this could be due to delayed presentation



Although c.
three quarters
EB patients
experienced
symptoms
from birth



only
38%
were diagnosed
at birth

The remainder
were diagnosed
as a toddler
(16%), child
(15%) or adult
(17%)

65%

received their EB diagnosis within
1 year of experiencing first symptoms

9%

within 1-5 years

13%

took between 5 and 20 years

14%

took 20 years or longer



On average EB Simplex is diagnosed later and takes longer from first symptoms than other EB types

Mean age of diagnosis (years):

SEB

11.9

DEB

3.7

JEB

8.2

KEB

0.6



Once patients
presented to a HCP,
for 3/4 it took **6
months or less** to
receive a diagnosis

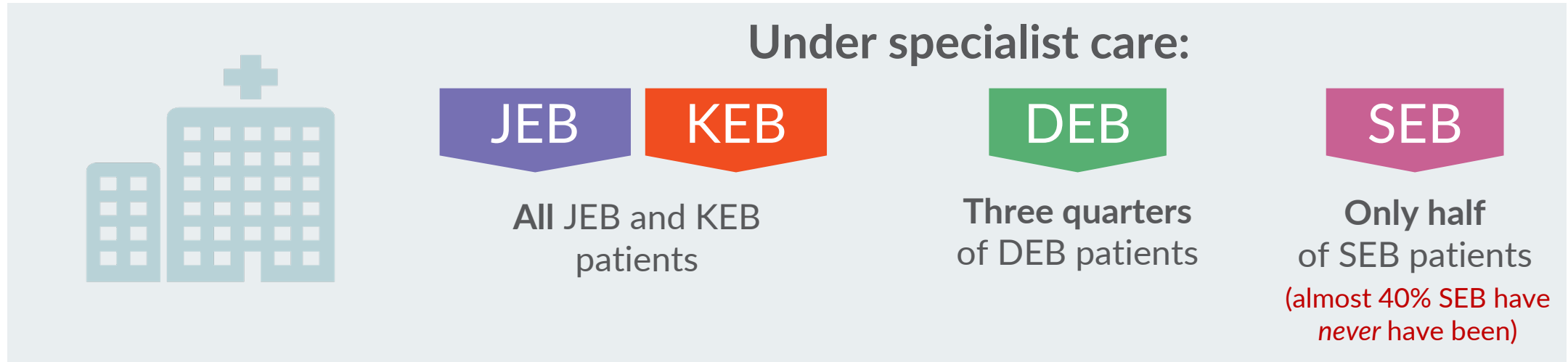
(76% of the n=186 who could remember
how long the diagnosis took)

For the remaining quarter, it
took longer than 6 months

95%

Have a diagnosis
from a HCP

Two fifths of EB patients are not under the care of an EB specialist hospital



Overall **40%** EB patients are not currently under EB specialist care, including **12%** who previously were but no longer are

Only 23% of those not under care agree they don't need access and are coping fine as they are

54%

Around half of EB patients attend medical appointments or see HCPs about their EB or relevant issues once to few times a year

Two fifths see HCPs more rarely, less than once a year, whilst for a minority it's very frequent at once a month or more

DEBRA members, younger patients, ethnic minority patients and patients in the south of England are most likely to be under EB specialist care

Patients who are older, white, and from Scotland or North England are more likely to have disengaged from specialist care or not be under specialist care at all

Just over half EB patients/carers would like more contact with the specialist service – but individual needs and situations vary considerably



90% of EB patients and carers feel HCPs do not understand EB

*particularly **SEB** and those with severe or variable disease severity*

85% have had to educate GPs on EB themselves

particularly carers of young children and females

54% do not feel listened to by healthcare professionals

Whilst **54%** would like more contact with specialist services...



48% agree travelling to specialist centre is difficult and can cause EB to flare up

Particularly those with severe disease, of an ethnic minority, or in North England

48% agree travelling to specialist centre is not always necessary, and 45% agree by the time they get to see a HCP their problem has become irrelevant



28% agree they struggle to afford to travel to appointments

32% feel access to specialist services isn't needed, they're coping fine as they are – *particularly older adults (61+), those with **SEB**, mild disease, and those not under the care of a specialist centre*



Specialist services need to be responsive to patient situations

EQ5D QOL assessments were completed twice – once to assess the patient's health **today**, and again for when their EB is **at it's worst**

Mobility

I have no problems in walking about
I have slight problems in walking about
I have moderate problems in walking about
I have severe problems in walking about
I am unable to walk about

EQ5D-5L

Self-care

I have no problems washing and dressing myself
I have slight problems washing and dressing myself
I have moderate problems washing and dressing myself
I have severe problems washing and dressing myself
I am unable to wash or dress myself

Usual activities (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities
I have slight problems with performing my usual activities
I have moderate problems with performing my usual activities
I have severe problems with performing my usual activities
I am unable to perform my usual activities

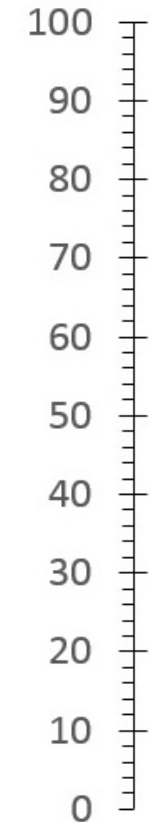
Pain / discomfort

I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

Anxiety / depression

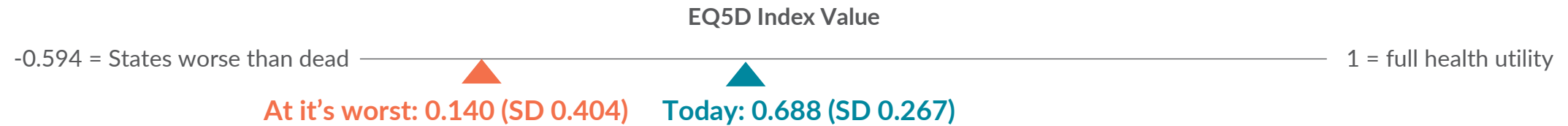
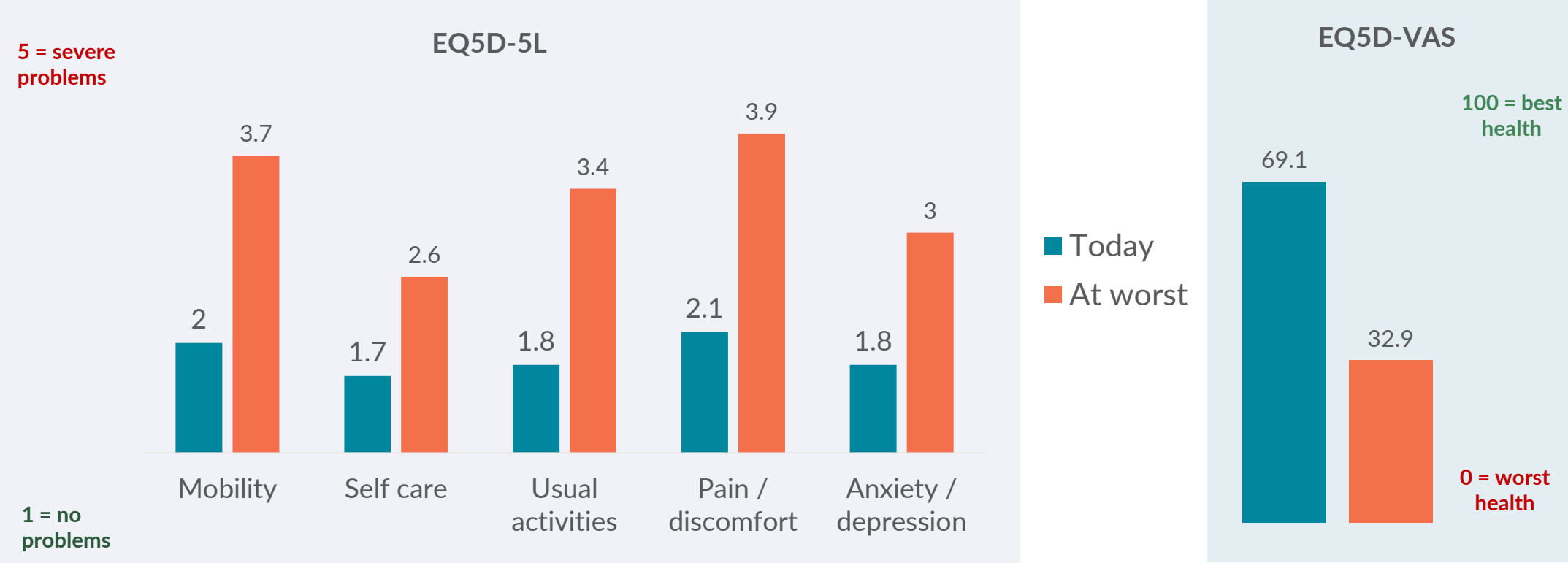
I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed

Best imaginable health state



Worst imaginable health state

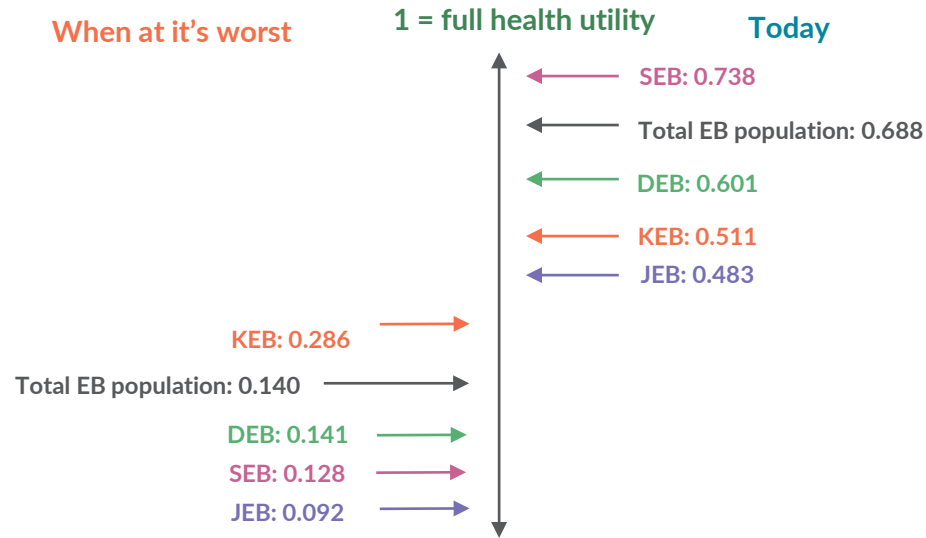
EB patients experience problems across all EQ5D dimensions, particularly pain and discomfort; volatility of life with EB is evidenced by disparity between EQ5D measures on a typical day vs when EB is at its worst



Base 302 (All patients & current carers, excluding outliers)
Q36 Which of the following best describes your / the person you care for's level of problems with...
Q37 & Q38 On a scale from 0 to 100 (where 100 is the best health you could imagine and 0 is the worst health you could imagine) please indicate below how you feel / how you would describe the health of the person you care for, today / when EB is at it's worst
Index value calculated using EQ5D-5L to 3L crosswalk and UK Dolan values

EB can be volatile, impacting many aspects of patient's lives

EQ5D-5L



-0.594 = states worse than dead

Whilst on a **typical day** the health of **SEB patients** and those with **variable severity** is relatively high, when **at its worst health is impacted considerably**, and SEB patients can struggle severely with mobility

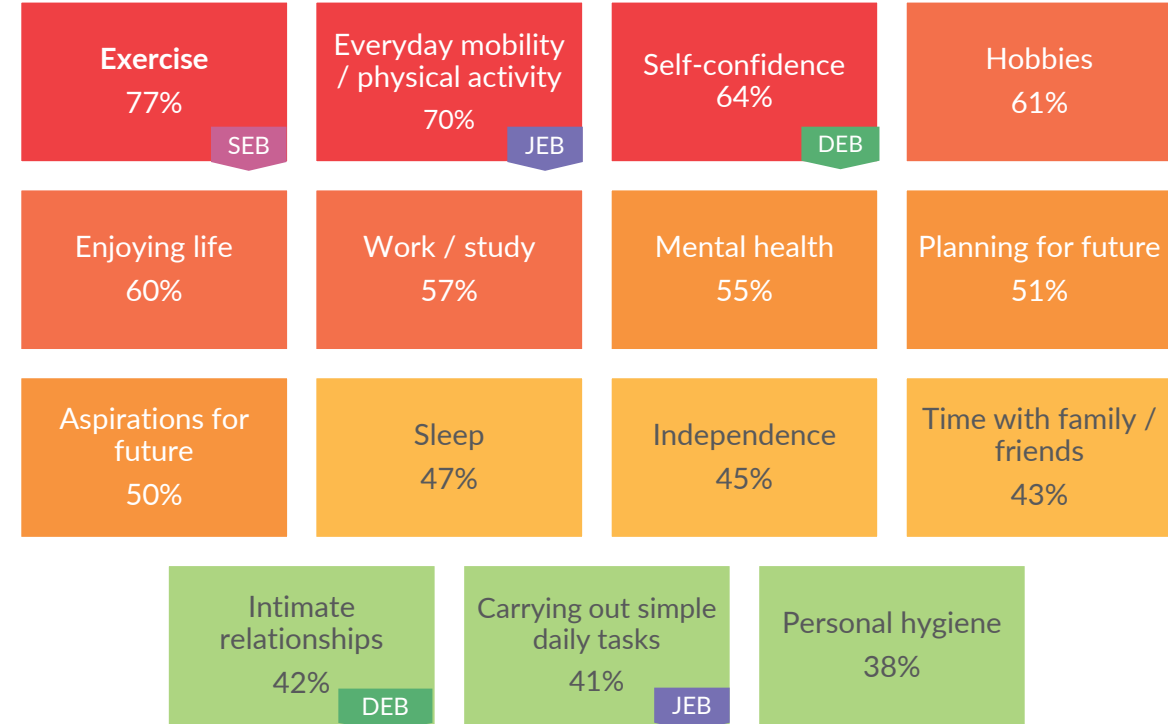


For **JEB** and severe patients, across all dimensions **a typical day is more similar to their worst day with EB** – mobility, self-care, usual activities and pain are consistently impacted

At their worst, **DEB patients** are more likely to experience problems with anxiety/depression



Many different aspects of life of patients' lives are impacted by EB...



On a typical day...

- 81% patients spend time on blister / wound care, taking one hour on average
- 85% spend time on personal hygiene e.g. taking an average 1.2 hours
- 67% spend time on resting / recovery, for an average 4.1 hours
- Severe patients spend more time on blister / wound care, personal hygiene, food preparation, getting dressed and resting daily
- JEB patients spend more time on food preparation daily

Whilst on a typical day the health of SEB patients and those with variable severity is relatively high, when at its worst health is impacted considerably, and SEB patients can struggle severely with mobility

For JEB and severe patients, across all dimensions a typical day is more similar to their worst day with EB – mobility, self-care, usual activities and pain are consistently impacted

At its worst, DEB patients experience the poorest health and are slightly more likely to experience problems with anxiety/depression

Patients

Carers

| Mean (1 = no problems, 5 = severe problems) | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|---------------|---------------|---------------|---------------|---------------|-----------------|---------------|---------------|---------------|----------------|---------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Base | 302 | 189 | 90 | 10 | 4 | 214 | 88 | 83 | 105 | 30 | 82 |
| Mobility - Today | 2.0 | 2.0 | 2.2 | 3.0 | 2.5 | 1.9 | 2.4 | 1.3 | 2.2 | 3.3 | 2.1 |
| Mobility - At its worst | 3.7 | 4.0 | 3.2 | 3.7 | 3.0 | 3.7 | 3.8 | 2.9 | 3.8 | 4.5 | 4.1 |
| Self care - Today | 1.7 | 1.5 | 2.0 | 2.9 | 2.3 | 1.5 | 2.2 | 1.1 | 1.7 | 3.4 | 1.6 |
| Self care - At its worst | 2.6 | 2.4 | 3.0 | 3.3 | 3.0 | 2.4 | 3.0 | 1.8 | 2.7 | 4.2 | 2.6 |
| Usual Activities - Today | 1.8 | 1.7 | 1.9 | 2.7 | 2.5 | 1.6 | 2.2 | 1.2 | 1.9 | 2.9 | 1.9 |
| Usual Activities - At its worst | 3.4 | 3.6 | 3.3 | 3.6 | 3.3 | 3.4 | 3.7 | 2.7 | 3.6 | 4.5 | 3.7 |
| Pain / discomfort - Today | 2.1 | 1.9 | 2.4 | 2.6 | 2.3 | 1.9 | 2.5 | 1.5 | 2.2 | 3.2 | 2.1 |
| Pain / discomfort - At its worst | 3.9 | 4.0 | 3.8 | 4.2 | 3.0 | 3.8 | 4.0 | 3.2 | 3.9 | 4.7 | 4.2 |
| Anxiety / depression - Today | 1.8 | 1.6 | 2.0 | 1.6 | 2.8 | 1.8 | 1.8 | 1.4 | 1.8 | 2.7 | 1.7 |
| Anxiety / depression - At its worst | 3.0 | 2.9 | 3.4 | 2.8 | 3.5 | 3.1 | 3.0 | 2.4 | 3.1 | 4.3 | 3.1 |
| Mean (0 = worst health, 100 = best health imaginable) | | | | | | | | | | | |
| VAS - Today | 69.1 | 73.1 | 60.9 | 66.6 | 60.5 | 70.3 | 66.4 | 80.9 | 64.4 | 50.5 | 70.2 |
| VAS - At it's worst | 32.9 | 34.2 | 28.7 | 33.4 | 42.0 | 33.7 | 31.2 | 49.5 | 28.7 | 19.4 | 27.1 |
| Index Value (-0.594 = States worse than dead, 1 = full health utility) | | | | | | | | | | | |
| Index Value - Today (SD) | 0.688 (0.267) | 0.738 (0.251) | 0.601 (0.267) | 0.483 (0.347) | 0.511 (0.313) | 0.737 (0.257) | 0.571 (0.255) | 0.866 (0.128) | 0.662 (0.225) | 0.279 (0.272) | 0.696 (0.247) |
| Index Value - At its worst (SD) | 0.140 (0.404) | 0.128 (0.402) | 0.141 (0.423) | 0.092 (0.413) | 0.286 (0.208) | 0.161 (0.416) | 0.088 (0.371) | 0.447 (0.329) | 0.115 (0.350) | -0.325 (0.232) | 0.026 (0.361) |

Base 302 (All patients & current carers, excluding outliers)

Q36 Which of the following best describes your / the person you care for's level of problems with....

Q37 & Q38 On a scale from 0 to 100 (where 100 is the best health you could imagine and 0 is the worst health you could imagine) please indicate below how you feel / how you would describe the health of the person you care for, today / when EB is at it's worst. Index value calculated using EuroQoL recommended EQ5D-5L to 3L crosswalk and UK Dolan values

N.B. caution interpreting percentages with a low base

20% experience difficulties during the PIP/DLA process
Two thirds of EB patients and carers have found EB harder to manage during the cost of living crisis



Two thirds of EB patients and their carers have been impacted by the cost of living crisis

12% are experiencing a **severe impact**

27% are experiencing a **moderate impact**

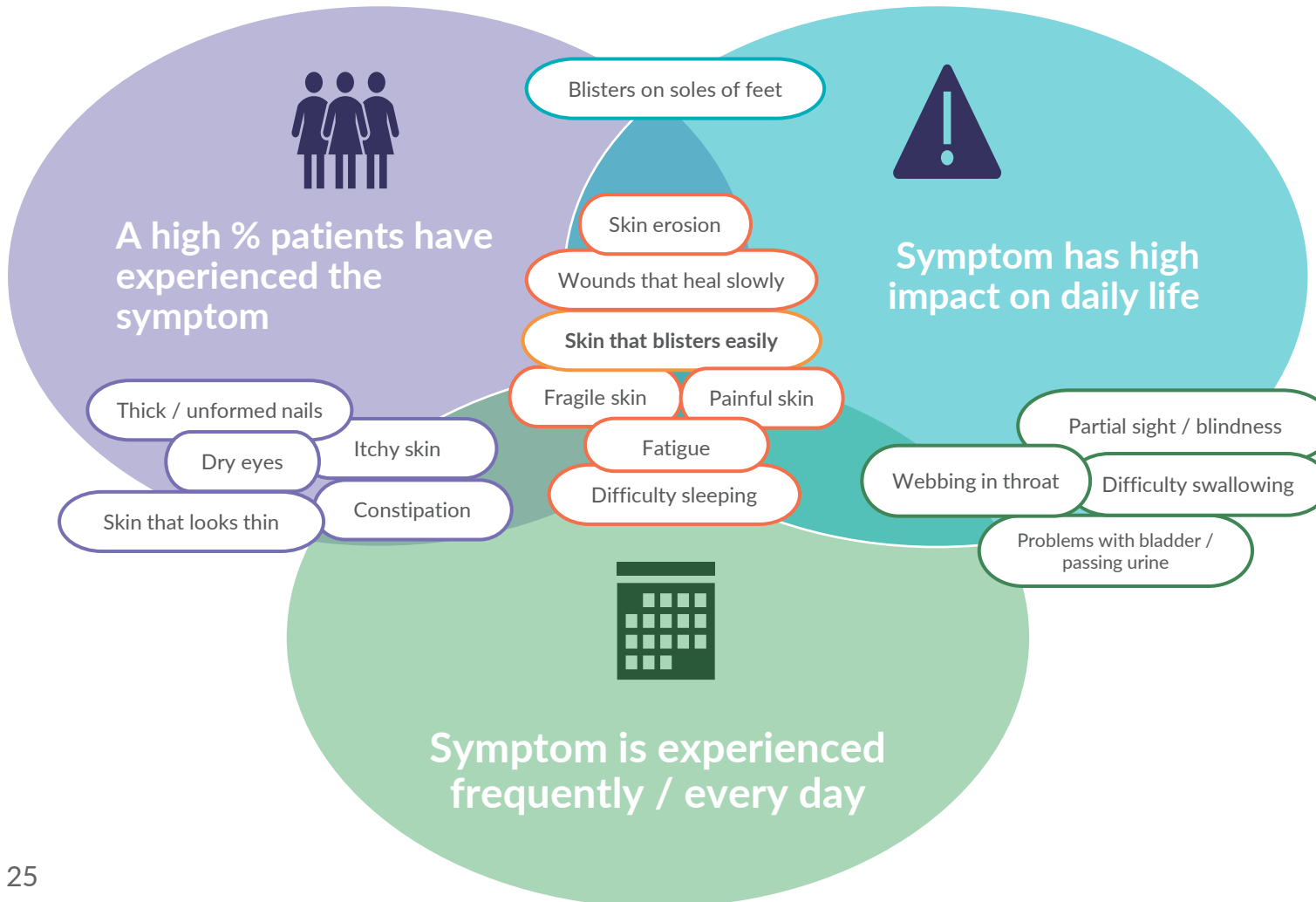
Impact less likely for mild EB and **SEB**, more likely for severe EB, younger patients and those of an ethnic minority

Symptoms of EB



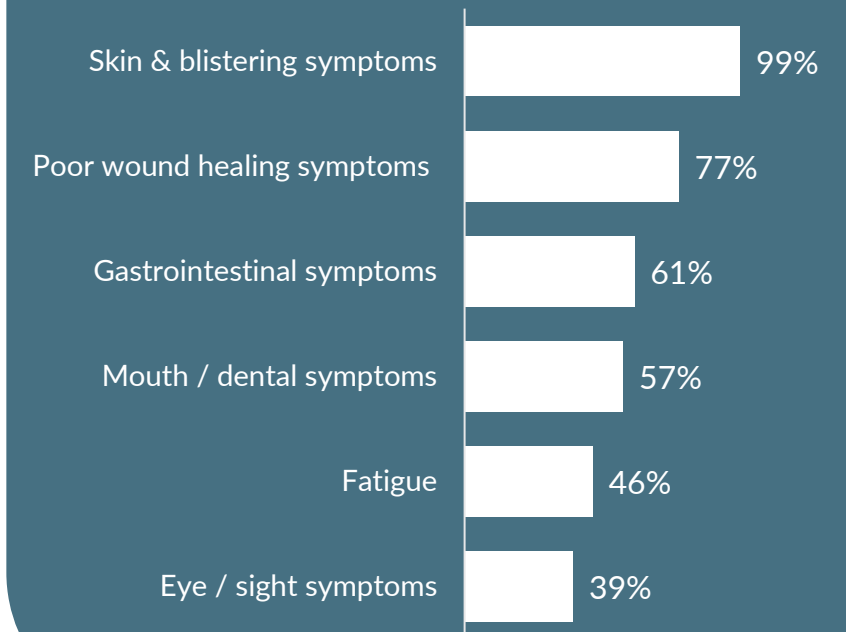
Most EB patients frequently experience skin that blisters easily and is fragile, highly impacting daily life

EB symptoms manifest differently in terms of **incidence**, **frequency** and **impact** on life



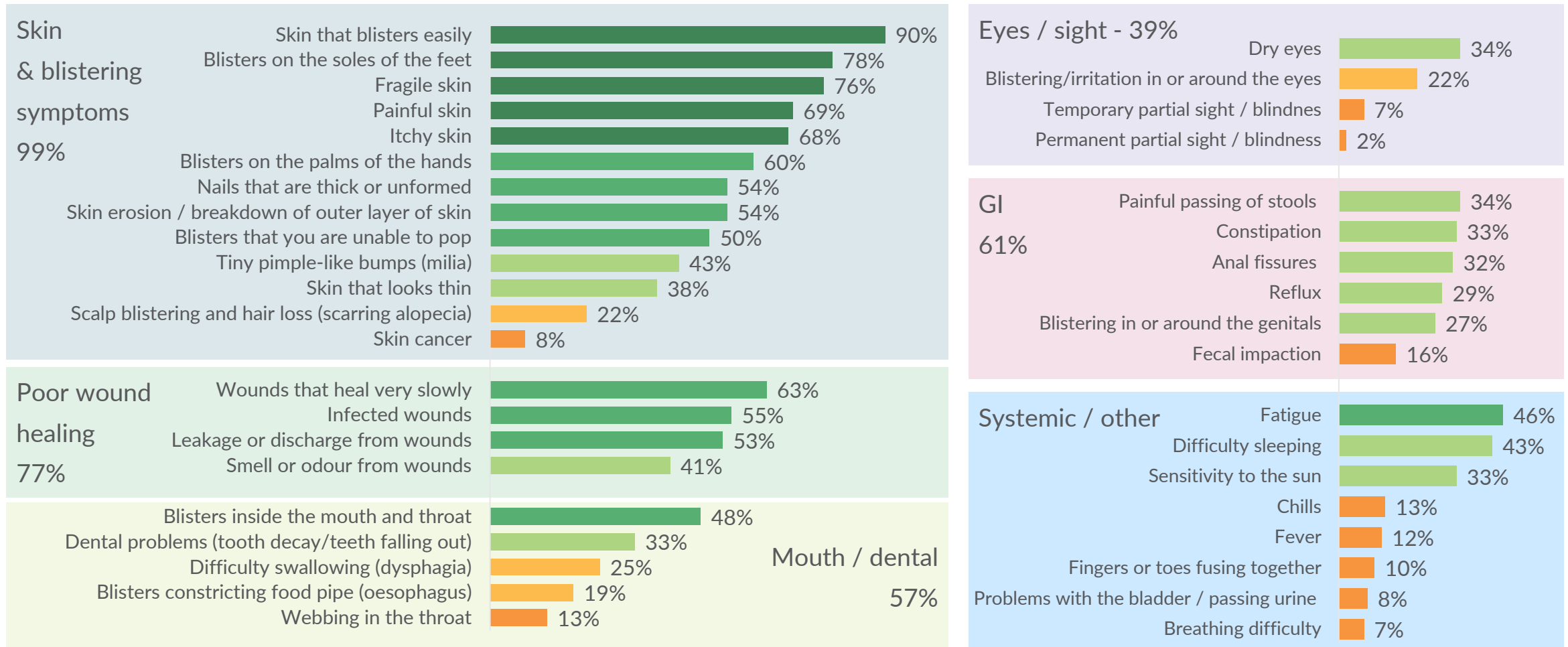
EB has a high symptom burden, with EB patients experiencing a mean 14 (median 13) different symptoms

- Whilst a third (33%) have experienced between 1 and 10 symptoms, 43% have experienced between 11 and 20 symptoms, and a quarter (24%) 21 symptoms or more



EB patients experience a wide variety of symptoms, with 9/10 having skin that blisters easily, 8/10 blisters on soles of feet & fragile skin, and c. two thirds with painful or itchy skin and slow healing wounds

Which of the following symptoms of EB have you / the person you care(d) for have you ever experienced? (prompted)



Skin, blistering and wound healing symptoms vary widely by EB type and severity

| % EB patients who have experienced each symptom | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|------|------|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Base | N=318 | N=193 | N=97 | N=13 | N=5 | N=215 | N=103 | N=83 | N=108 | N=39 | N=85 |
| Skin & blistering symptoms | 99% | 100% | 99% | 100% | 100% | 100% | 98% | 100% | 99% | 100% | 100% |
| Skin that blisters easily | 90% | 92% | 89% | 92% | 60% | 89% | 90% | 84% | 92% | 97% | 89% |
| Blisters on the soles of the feet | 78% | 96% | 52% | 46% | 40% | 81% | 72% | 71% | 75% | 69% | 93% |
| Fragile skin | 76% | 68% | 88% | 92% | 100% | 73% | 83% | 53% | 83% | 97% | 80% |
| Painful skin | 69% | 64% | 79% | 85% | 80% | 66% | 76% | 52% | 75% | 92% | 69% |
| Itchy skin | 68% | 56% | 90% | 77% | 100% | 67% | 69% | 55% | 77% | 85% | 61% |
| Blisters on the palms of the hands | 60% | 70% | 47% | 46% | 20% | 60% | 59% | 48% | 63% | 64% | 66% |
| Nails that are thick or unformed | 54% | 40% | 75% | 85% | 100% | 51% | 60% | 51% | 61% | 62% | 46% |
| Skin erosion / breakdown of outer layer of skin | 54% | 43% | 74% | 69% | 80% | 51% | 61% | 42% | 57% | 90% | 46% |
| Blisters that you are unable to pop | 50% | 58% | 37% | 54% | 60% | 51% | 49% | 40% | 49% | 51% | 61% |
| Tiny pimple-like bumps (milia) | 43% | 31% | 73% | 15% | 40% | 40% | 50% | 43% | 48% | 54% | 34% |
| Skin that looks thin | 38% | 22% | 65% | 46% | 100% | 38% | 39% | 24% | 44% | 69% | 32% |
| Scalp blistering and hair loss (scarring alopecia) | 22% | 11% | 39% | 62% | 0% | 17% | 31% | 10% | 24% | 64% | 11% |
| Skin cancer | 8% | 3% | 16% | 15% | 20% | 10% | 5% | 10% | 8% | 21% | 1% |
| Poor wound healing symptoms | 77% | 70% | 90% | 92% | 80% | 77% | 79% | 65% | 81% | 92% | 79% |
| Wounds that heal very slowly | 63% | 53% | 79% | 85% | 80% | 61% | 67% | 52% | 64% | 87% | 61% |
| Infected wounds | 55% | 49% | 69% | 77% | 20% | 53% | 61% | 34% | 58% | 79% | 62% |
| Leakage or discharge from wounds | 53% | 44% | 73% | 62% | 0% | 51% | 57% | 39% | 58% | 85% | 46% |
| Smell or odour from wounds | 41% | 30% | 66% | 46% | 0% | 36% | 50% | 22% | 41% | 87% | 39% |

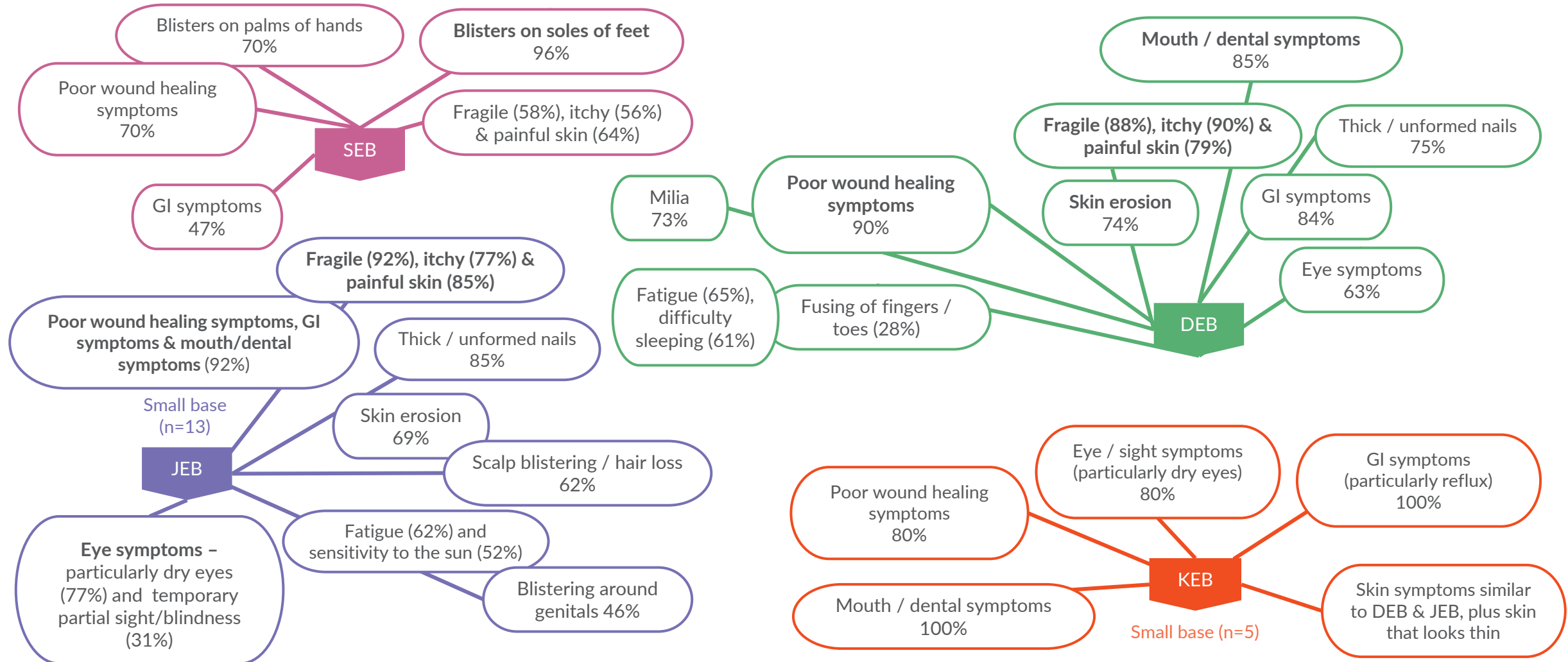
SEB patients are less likely than other EB types to experience mouth/dental, eye, and GI symptoms

Patients

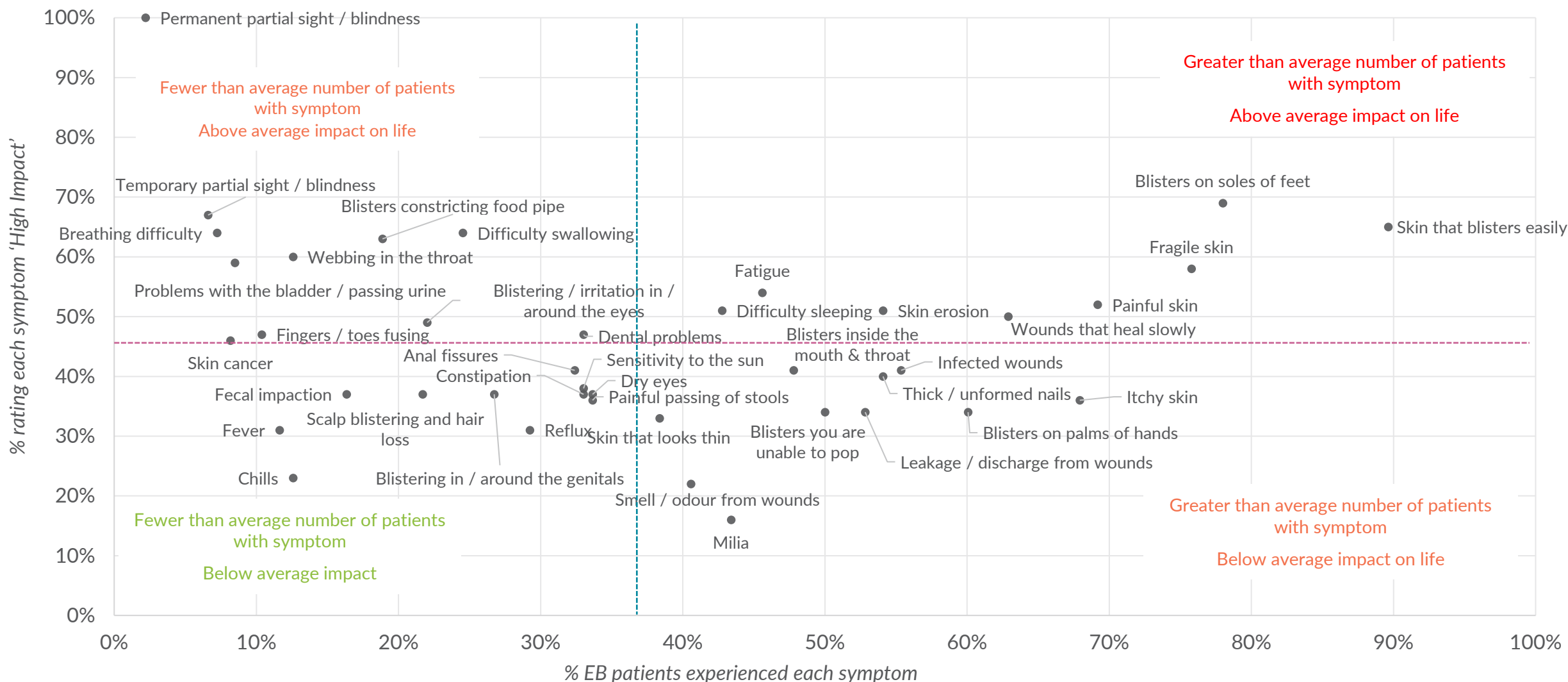
Carers

| % EB patients who have experienced each symptom | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|------|------|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Base | N=318 | N=193 | N=97 | N=13 | N=5 | N=215 | N=103 | N=83 | N=108 | N=39 | N=85 |
| Mouth / dental symptoms | 57% | 40% | 85% | 92% | 100% | 53% | 63% | 40% | 65% | 90% | 48% |
| Blisters inside the mouth and throat | 48% | 30% | 78% | 69% | 100% | 44% | 56% | 29% | 56% | 79% | 41% |
| Dental problems, such as tooth decay or teeth falling out | 33% | 19% | 55% | 69% | 100% | 31% | 37% | 17% | 37% | 69% | 27% |
| Difficulty swallowing (dysphagia) | 25% | 6% | 59% | 38% | 80% | 21% | 31% | 7% | 31% | 64% | 15% |
| Blisters constricting or narrowing food pipe (oesophagus) | 19% | 1% | 53% | 31% | 80% | 14% | 29% | 4% | 20% | 62% | 12% |
| Webbing in the throat | 13% | 1% | 33% | 15% | 80% | 10% | 17% | 1% | 16% | 33% | 9% |
| Eye / sight symptoms | 39% | 23% | 63% | 77% | 80% | 35% | 48% | 22% | 46% | 62% | 36% |
| Dry eyes | 34% | 18% | 56% | 77% | 80% | 32% | 38% | 20% | 40% | 54% | 29% |
| Blistering and/or irritation in or around the eyes | 22% | 9% | 42% | 54% | 40% | 19% | 29% | 7% | 25% | 51% | 19% |
| Temporary partial sight or blindness | 7% | 1% | 14% | 31% | 20% | 6% | 9% | 1% | 7% | 21% | 4% |
| Permanent partial sight or blindness | 2% | 1% | 5% | 8% | 0% | 0% | 7% | 0% | 1% | 8% | 2% |
| GI symptoms | 61% | 47% | 84% | 92% | 100% | 55% | 72% | 39% | 69% | 85% | 62% |
| Painful passing of stools (poo) | 34% | 18% | 60% | 69% | 60% | 27% | 48% | 19% | 37% | 69% | 27% |
| Constipation | 33% | 20% | 55% | 62% | 60% | 25% | 50% | 14% | 36% | 64% | 33% |
| Anal fissures - sores, tears or ulcers near the anus / back passage | 32% | 21% | 54% | 62% | 20% | 33% | 31% | 24% | 38% | 51% | 25% |
| Reflux | 29% | 19% | 41% | 69% | 100% | 27% | 34% | 14% | 34% | 49% | 28% |
| Blistering in or around the genitals | 27% | 23% | 31% | 46% | 40% | 23% | 35% | 13% | 24% | 56% | 29% |
| Fecal impaction | 16% | 9% | 28% | 23% | 60% | 14% | 20% | 8% | 19% | 28% | 14% |
| Fatigue | 46% | 35% | 65% | 62% | 20% | 45% | 48% | 29% | 50% | 74% | 45% |
| Difficulty sleeping | 43% | 35% | 61% | 46% | 20% | 41% | 46% | 25% | 47% | 72% | 41% |
| Sensitivity to the sun | 33% | 26% | 41% | 54% | 100% | 31% | 38% | 22% | 38% | 46% | 32% |
| Chills | 13% | 7% | 22% | 23% | 40% | 12% | 15% | 4% | 18% | 26% | 8% |
| Fever | 12% | 8% | 19% | 31% | 0% | 8% | 18% | 4% | 13% | 31% | 8% |
| Fingers or toes fusing together | 10% | 2% | 28% | 15% | 0% | 6% | 20% | 4% | 6% | 46% | 5% |
| Problems with the bladder / passing urine e.g., urethral stricture | 8% | 7% | 7% | 31% | 40% | 9% | 8% | 5% | 14% | 10% | 4% |
| Breathing difficulty | 7% | 4% | 12% | 31% | 0% | 7% | 8% | 2% | 8% | 15% | 6% |

Different EB types are characterised by the presence and impact of certain symptoms – but symptoms can also vary significantly within each EB type



Skin that blisters easily, blisters on soles of feet and fragile skin have both a higher than average incidence and impact on daily life



Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14c Please tell us how much impact EB has / had on each of these aspects of your / their daily life.

Blisters on soles of the feet are more likely to high impact on SEB patients' lives, whereas fragile skin, itchy skin, skin erosion and skin cancer are more likely to highly impact DEB patient's lives
Generally greater severity correlates with greater impact of symptoms (1/2)

| % EB patients within each group with each symptom that rated it 'High Impact' | Total | SEB | DEB | JEB | KEB | Respondent Type | | Severity | | | |
|---|-------|-----|-----|------------|------------|-----------------|-------|----------|----------|--------|------------|
| | | | | | | Patient | Carer | Mild | Moderate | Severe | It depends |
| Base (variable for each row) | | | | Small base | Small base | | | | | | |
| Skin that blisters easily | 65% | 68% | 63% | 70% | 33% | 60% | 76% | 37% | 69% | 94% | 74% |
| Blisters on the soles of the feet | 69% | 73% | 52% | 100% | 100% | 64% | 79% | 41% | 68% | 88% | 85% |
| Fragile skin | 58% | 47% | 71% | 80% | 60% | 53% | 69% | 30% | 59% | 91% | 59% |
| Painful skin | 52% | 51% | 56% | 78% | 25% | 47% | 64% | 19% | 48% | 81% | 66% |
| Itchy skin | 36% | 24% | 50% | 22% | 60% | 32% | 45% | 17% | 35% | 65% | 35% |
| Blisters on the palms of the hands | 34% | 31% | 42% | 60% | 0% | 29% | 46% | 13% | 37% | 65% | 32% |
| Nails that are thick or unformed | 40% | 33% | 44% | 89% | 60% | 37% | 46% | 19% | 42% | 52% | 54% |
| Skin erosion / breakdown of outer layer of skin | 51% | 41% | 64% | 43% | 50% | 45% | 61% | 20% | 48% | 77% | 62% |
| Blisters that you are unable to pop | 34% | 40% | 17% | 33% | 33% | 37% | 29% | 21% | 34% | 28% | 44% |
| Tiny pimple-like bumps (milia) | 16% | 14% | 20% | 0% | 0% | 17% | 14% | 6% | 25% | 20% | 10% |
| Skin that looks thin | 33% | 26% | 32% | 60% | 60% | 29% | 40% | 15% | 23% | 60% | 33% |
| Scalp blistering and hair loss (scarring alopecia) | 37% | 29% | 38% | 57% | 0% | 35% | 40% | 0% | 31% | 48% | 56% |
| Skin cancer | 46% | 0% | 63% | 100% | 0% | 38% | 80% | 25% | 44% | 75% | 0% |
| Wounds that heal very slowly | 50% | 41% | 58% | 78% | 25% | 47% | 55% | 30% | 51% | 78% | 46% |
| Infected wounds | 41% | 38% | 46% | 56% | 0% | 38% | 48% | 14% | 36% | 60% | 53% |
| Leakage or discharge from wounds | 34% | 25% | 44% | 67% | 0% | 31% | 39% | 13% | 25% | 60% | 46% |
| Smell or odour from wounds | 22% | 18% | 29% | 0% | 0% | 21% | 25% | 11% | 14% | 32% | 30% |

Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

Generally greater severity correlates with greater impact of symptoms (2/2)

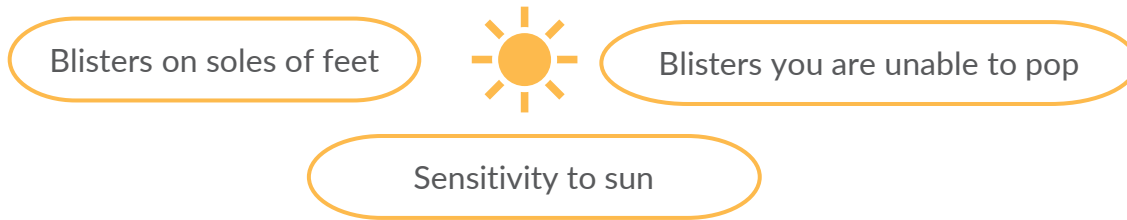
| % EB patients within each group with each symptom that rated it 'High Impact' | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|------|------------|------------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Base variable for each row | | | | Small base | Small base | | | | | | |
| Blisters inside the mouth and throat | 41% | 28% | 51% | 29% | 40% | 44% | 35% | 13% | 41% | 46% | 51% |
| Dental problems, such as tooth decay or teeth falling out | 47% | 50% | 50% | 22% | 60% | 43% | 54% | 29% | 40% | 58% | 57% |
| Difficulty swallowing (dysphagia) | 64% | 55% | 66% | 67% | 75% | 63% | 66% | 33% | 64% | 59% | 85% |
| Blisters constricting or narrowing food pipe (oesophagus) | 63% | 100% | 64% | 100% | 25% | 57% | 69% | 33% | 57% | 67% | 70% |
| Webbing in the throat | 60% | 0% | 66% | 100% | 25% | 59% | 61% | 0% | 59% | 62% | 63% |
| Dry eyes | 37% | 24% | 40% | 78% | 50% | 35% | 41% | 0% | 33% | 68% | 44% |
| Blistering and/or irritation in or around the eyes | 49% | 39% | 56% | 67% | 0% | 53% | 45% | 17% | 44% | 58% | 56% |
| Temporary partial sight or blindness | 67% | 50% | 64% | 75% | 100% | 58% | 78% | 100% | 75% | 50% | 67% |
| Permanent partial sight or blindness | 100% | 100% | 100% | 100% | 0% | 0% | 100% | 0% | 100% | 100% | 100% |
| Painful passing of stools (poo) | 41% | 43% | 38% | 71% | 0% | 38% | 48% | 25% | 41% | 53% | 43% |
| Constipation | 36% | 26% | 39% | 63% | 33% | 36% | 36% | 44% | 33% | 40% | 30% |
| Anal fissures - sores, tears or ulcers near the anus / back passage | 37% | 18% | 46% | 71% | 33% | 40% | 34% | 50% | 31% | 43% | 32% |
| Reflux | 31% | 19% | 36% | 50% | 40% | 24% | 42% | 17% | 32% | 41% | 25% |
| Blistering in or around the genitals | 37% | 41% | 38% | 20% | 0% | 41% | 32% | 36% | 38% | 35% | 36% |
| Fecal impaction | 37% | 12% | 58% | 33% | 33% | 29% | 50% | 57% | 33% | 30% | 33% |
| Fatigue | 54% | 48% | 65% | 29% | 100% | 54% | 53% | 42% | 52% | 70% | 53% |
| Difficulty sleeping | 51% | 45% | 58% | 67% | 0% | 52% | 49% | 38% | 55% | 50% | 51% |
| Sensitivity to the sun | 38% | 38% | 36% | 29% | 60% | 44% | 26% | 17% | 41% | 35% | 44% |
| Chills | 23% | 14% | 33% | 0% | 0% | 24% | 20% | 0% | 26% | 10% | 43% |
| Fever | 31% | 20% | 44% | 0% | 0% | 22% | 39% | 33% | 21% | 27% | 43% |
| Fingers or toes fusing together | 47% | 0% | 54% | 50% | 0% | 50% | 45% | 0% | 33% | 59% | 25% |
| Problems with the bladder / passing urine e.g., urethral stricture | 59% | 62% | 57% | 50% | 100% | 68% | 38% | 75% | 60% | 25% | 67% |
| Breathing difficulty | 48% | 43% | 50% | 50% | 0% | 40% | 67% | 50% | 44% | 25% | 60% |

Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

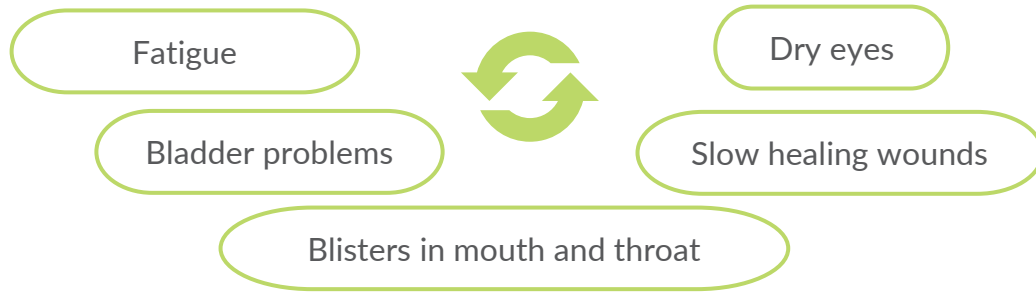
Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

EB Symptom frequency & triggers

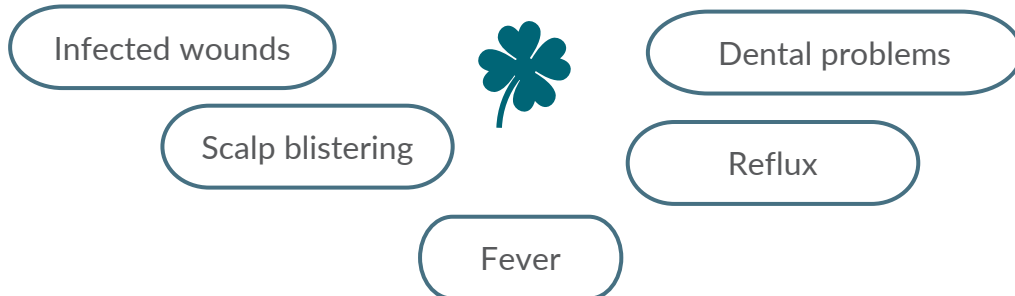
Some symptoms are more likely to occur seasonally...



Some are more likely to occur frequently, or every day...



And some occur only intermittently, or rarely...



EB symptoms can be triggered by...



In addition to physical exertion (51%), removal of stuck bandages / clothes (50%), rough / poorly fitting clothes (44%)



The symptoms that impact the most patients and are experienced every day / most days, include skin that blisters easily, is fragile, painful or itchy frequently or daily, in addition to skin erosion & thick/unformed nails and fatigue



Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable
Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

Treatments

A large, stylized graphic of a leaf or plant branch, rendered in a lighter shade of blue than the background, positioned behind the title.

Most EB patients use specialised bandages (from HCP); widespread painkiller use (and concerns about this); severe patients think current treatments don't work; widespread use of mobility aids

Patients

76%

use bandages and dressings to treat their EB - mostly specialised (less use in mild)



c.85-90% dressings come from HCP

65%

Value treatment recommendations from other EB pts

79%

Keen to know more about clinical trials

69%

use painkillers (less in mild patients; opioids used more by severe patients)



Around 2/3 patients worry about side effects of painkillers; worry they will stop working; say they don't work well

Severe EB more likely to strongly agree

42%

use specialist clothing or shoes - more in severe

21%

use steroids more in severe, less SEB and mild

39%

Think treatments don't work well

33%

Struggle to afford treatments for EB

Moderate and severe EB more likely to strongly agree

50%

have used a wheelchair or mobility aid at some point



¼ mild patients have used aids - rising to 9/10 severe patients

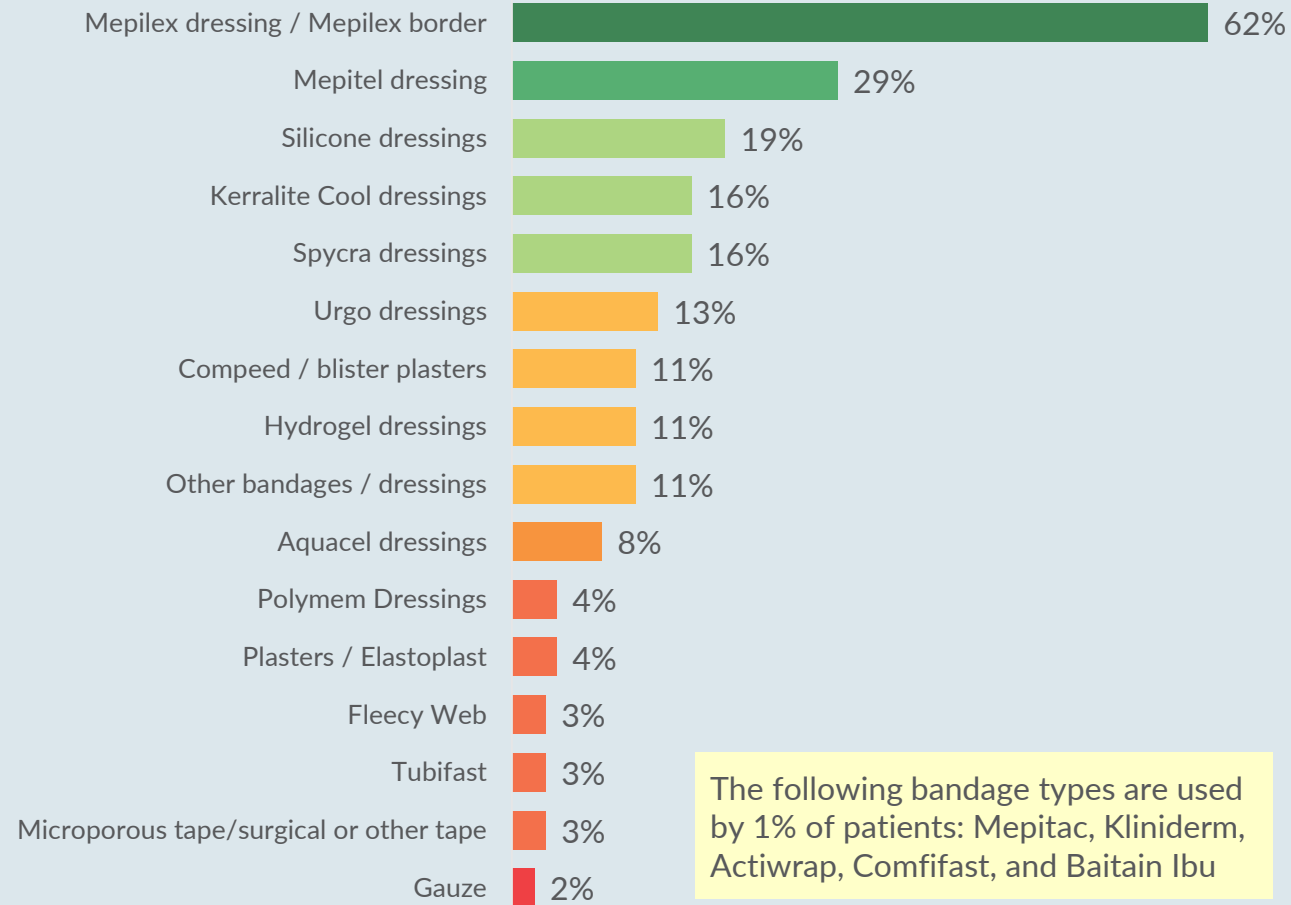


C. Two thirds of EB patients use Mepilex dressings, OTC painkillers and moisturising creams to manage symptoms; just under half use syringes or needles, a third use specialist clothing or socks

Patients

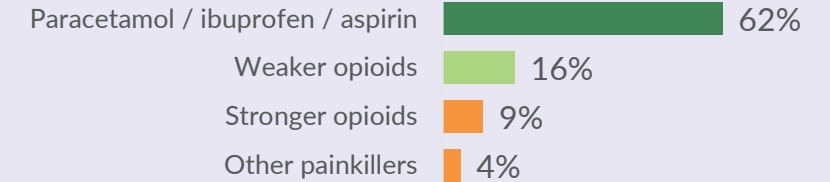
Carers

Bandages and dressings – 76%



The following bandage types are used by 1% of patients: Mepitac, Kliniderm, Actiwrap, Comfifast, and Baitain Ibu

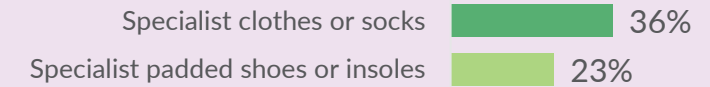
Painkillers – 69%



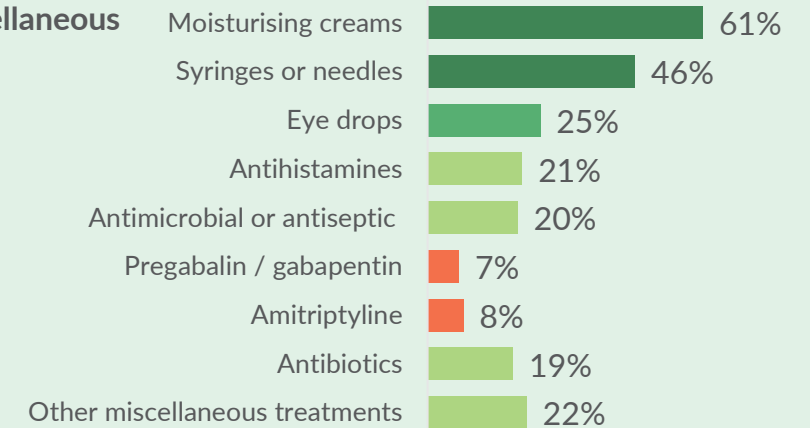
Steroids – 21%



Specialist clothing – 42%



Miscellaneous



Base 318 (215 Patients and 103 carers)

Q19 Which of the following medicines or therapies do you currently take or use to help manage your EB symptoms?

C. Two thirds of EB patients use Mepilex dressings, OTC painkillers and moisturising creams to manage symptoms; just under half use syringes or needles, a third use specialist clothing or socks and a quarter use eye drops; other treatments and medications are only used by a minority, evidencing lack of standard of care treatment

Patients

Carers

| % Patients and carers selecting options | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 83 | 108 | 39 | 85 | 103 | 215 |
| Pain Killers [NET] | 69% | 69% | 72% | 69% | 80% | 65% | 79% | 46% | 70% | 85% | 84% |
| Paracetamol / ibuprofen / aspirin | 62% | 63% | 63% | 69% | 80% | 43% | 61% | 72% | 78% | 74% | 57% |
| Weaker opioids | 16% | 17% | 16% | 15% | 0% | 5% | 15% | 28% | 22% | 12% | 18% |
| Stronger opioids e.g. morphine / hydrocodone | 9% | 4% | 19% | 38% | 0% | 0% | 6% | 41% | 7% | 23% | 3% |
| Other painkillers | 4% | 3% | 7% | 0% | 0% | 0% | 5% | 13% | 4% | 6% | 3% |
| Bandages, wound dressing, and plasters {NET} | 76% | 70% | 89% | 77% | 80% | 73% | 83% | 58% | 81% | 79% | 86% |
| Mepilex dressing / Mepilex border | 62% | 53% | 78% | 69% | 80% | 55% | 75% | 41% | 65% | 69% | 74% |
| Mepitel dressing | 29% | 19% | 49% | 46% | 20% | 21% | 46% | 8% | 31% | 56% | 33% |
| Silicone dressings | 19% | 17% | 22% | 31% | 40% | 16% | 26% | 12% | 19% | 36% | 20% |
| Kerralite Cool dressings | 16% | 20% | 10% | 15% | 20% | 16% | 17% | 13% | 17% | 5% | 25% |
| Spycra dressings | 16% | 19% | 12% | 8% | 0% | 12% | 25% | 6% | 20% | 15% | 21% |
| Urgo dressings | 13% | 8% | 20% | 46% | 0% | 7% | 25% | 5% | 16% | 31% | 8% |
| Compeed / blister plasters | 11% | 14% | 6% | 0% | 0% | 13% | 8% | 17% | 7% | 5% | 13% |
| Hydrogel dressings | 11% | 11% | 10% | 15% | 0% | 9% | 15% | 7% | 9% | 15% | 14% |
| Aquacel dressings | 8% | 5% | 12% | 15% | 20% | 4% | 16% | 0% | 7% | 18% | 11% |
| Other bandages / dressings | 7% | 7% | 5% | 8% | 0% | 9% | 1% | 11% | 3% | 0% | 11% |
| Nothing / no treatments / medicines / therapies | 6% | 6% | 6% | 8% | 0% | 8% | 2% | 14% | 5% | 3% | 2% |
| Other bandages / dressings / plasters | 4% | 5% | 4% | 0% | 0% | 4% | 5% | 4% | 6% | 3% | 5% |
| Polymem Dressings | 4% | 2% | 7% | 15% | 0% | 2% | 8% | 1% | 6% | 13% | 0% |
| Plasters / Elastoplast | 4% | 6% | 1% | 8% | 0% | 6% | 1% | 10% | 5% | 0% | 1% |
| Steroids [NET] | 21% | 10% | 38% | 38% | 60% | 17% | 30% | 6% | 24% | 44% | 30% |
| Steroid tablets | 4% | 1% | 8% | 23% | 0% | 3% | 6% | 0% | 6% | 13% | 0% |
| Steroid cream applied on your skin | 20% | 10% | 34% | 38% | 60% | 16% | 28% | 6% | 20% | 44% | 20% |

C. Two thirds of EB patients use Mepilex dressings, OTC painkillers and moisturising creams to manage symptoms; just under half use syringes or needles, a third use specialist clothing or socks and a quarter use eye drops; other treatments and medications are only used by a minority, evidencing lack of standard of care treatment

| % Patients and carers selecting options | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 83 | 108 | 39 | 85 | 103 | 215 |
| Specialist clothing / shoes [NET] | 42% | 46% | 35% | 62% | 40% | 35% | 56% | 24% | 46% | 51% | 51% |
| Specialist clothes or socks | 36% | 41% | 27% | 54% | 40% | 27% | 54% | 23% | 35% | 49% | 46% |
| Specialist padded shoes or insoles | 23% | 25% | 20% | 31% | 40% | 20% | 29% | 10% | 26% | 26% | 33% |
| Moisturising creams / gels | 61% | 52% | 77% | 77% | 80% | 53% | 77% | 46% | 64% | 77% | 65% |
| Syringes or needles | 46% | 43% | 51% | 77% | 40% | 36% | 65% | 30% | 47% | 62% | 52% |
| Eye drops | 25% | 12% | 43% | 77% | 80% | 21% | 34% | 12% | 30% | 44% | 24% |
| Other miscellaneous treatments | 22% | 17% | 28% | 38% | 60% | 15% | 36% | 13% | 22% | 36% | 22% |
| Antihistamines | 21% | 16% | 30% | 46% | 20% | 14% | 37% | 12% | 20% | 46% | 20% |
| Antimicrobial or antiseptic treatments | 20% | 20% | 23% | 23% | 20% | 18% | 25% | 13% | 14% | 44% | 24% |
| Antibiotics | 19% | 15% | 28% | 31% | 40% | 13% | 32% | 5% | 19% | 51% | 20% |
| Amitriptyline | 8% | 7% | 11% | 8% | 0% | 7% | 10% | 1% | 11% | 18% | 6% |
| Pregabalin / gabapentin | 7% | 3% | 13% | 15% | 20% | 11% | 5% | 0% | 5% | 26% | 6% |

N.B. caution interpreting percentages with a low base

EB and mental health

MH issues are widespread and support is not always offered to those who need it; poor coping strategies evident

Symptoms that have widest impact on MH
(that is, affect the most people and have an above-average impact on MH):

Blisters on the feet
Skin that blisters easily

Fatigue
Painful skin
Slowly healing wounds
Itchy skin
Thick / unformed nails

Symptoms that also have a large impact on MH
(but affect fewer people)

Skin cancer (although, rare)
Partial sight / blindness
Fingers / toes fusing
Bladder problems
Scalp blistering and hair loss
Dental problems

55%

state EB has had a high or moderate impact on their mental health

MH worse in: mod / severe / seasonal disease; in teenagers and young adults / middle aged; women; ethnic minorities; those not working

70%

State EB has had a negative impact on their self-confidence

65%

Sometimes feel a burden to others

50%

Have experienced abuse or bullying

6/10

Have not been offered MH support on the NHS

SEB and mild less likely to be offered

Only 15%

state EB has had no impact on MH

Only

3/10

Of those in who EB has had high / moderate impact on MH have been offered NHS support

Poor coping strategies are evident:

78%

Just get on with it

50%

Avoid physical activity

40%

Use humour

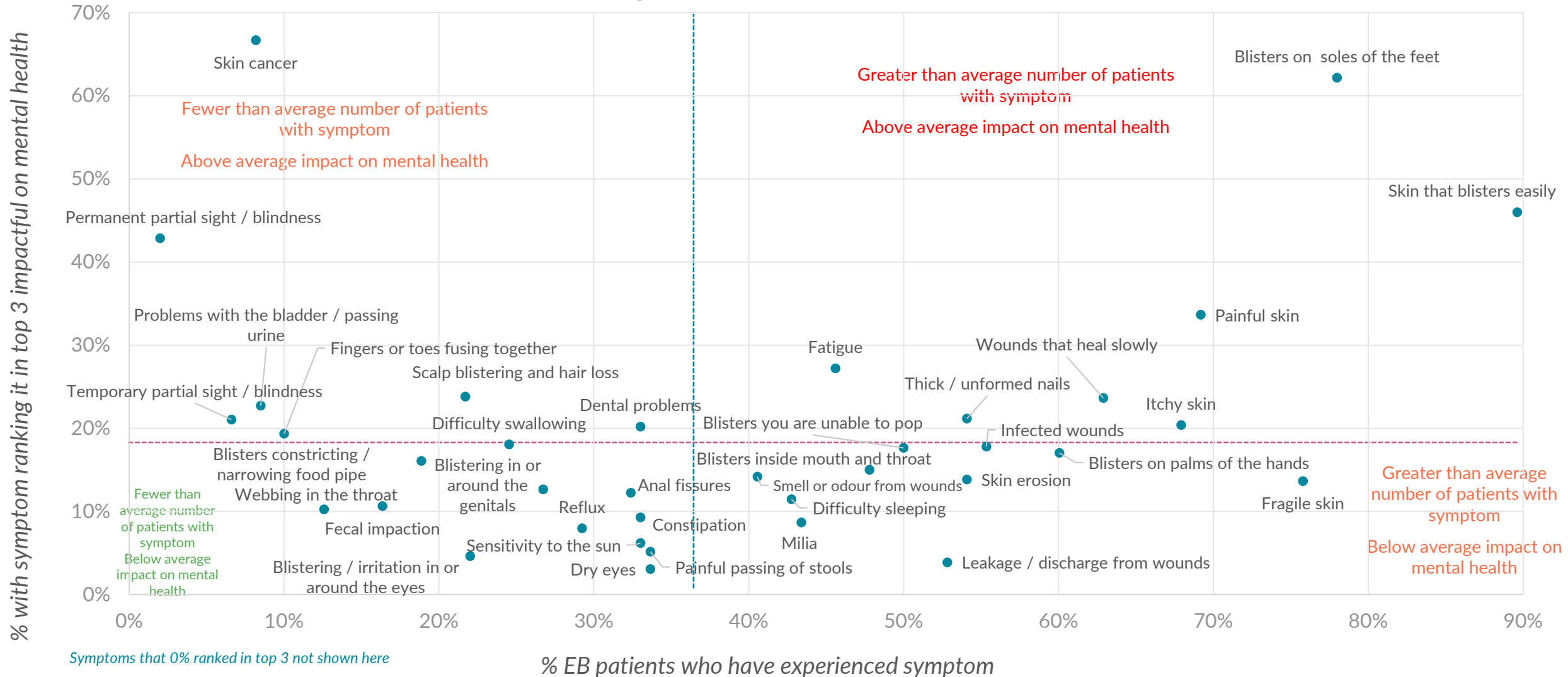
44%

Keep in mind 'it could be worse'

particularly mild and moderate patients

Severe patients rely on escapism, whereas mild patients try to keep active

Symptoms that many patients have, such as skin that blisters easily and blisters on soles of feet, are highly impactful on mental health



Base 291 patients/carers reporting symptoms who did not skip the question

Q24 Which symptoms have the greatest impact on your mental health? Please rate the top three that have the most impact on your mental health, selecting the most impactful first.

Large variations in how frequently symptoms present across EB types – severe patients more likely to have more frequent symptoms (1/2)

| % EB patients with each symptom who have experienced each symptom every day / most days / frequently | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|------|------|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Base variable for each row | | | | | | | | | | | |
| Permanent partial sight or blindness | 100% | 100% | 100% | 100% | 0% | 0% | 100% | 0% | 100% | 100% | 100% |
| Fragile skin | 81% | 71% | 94% | 90% | 100% | 79% | 86% | 71% | 84% | 100% | 75% |
| Nails that are thick or unformed | 78% | 75% | 79% | 100% | 100% | 76% | 81% | 71% | 79% | 76% | 87% |
| Fatigue | 78% | 69% | 84% | 100% | 100% | 78% | 77% | 67% | 78% | 96% | 71% |
| Skin that blisters easily | 74% | 67% | 86% | 90% | 67% | 67% | 88% | 51% | 79% | 97% | 76% |
| Problems with the bladder / passing urine e.g., urethral stricture | 74% | 77% | 71% | 50% | 100% | 90% | 38% | 100% | 80% | 25% | 67% |
| Painful skin | 73% | 63% | 85% | 100% | 100% | 66% | 85% | 33% | 77% | 94% | 85% |
| Fingers or toes fusing together | 72% | 0% | 81% | 100% | 0% | 58% | 80% | 33% | 50% | 94% | 25% |
| Dry eyes | 70% | 62% | 66% | 100% | 100% | 75% | 60% | 59% | 72% | 74% | 68% |
| Difficulty sleeping | 69% | 63% | 73% | 100% | 100% | 67% | 72% | 52% | 69% | 79% | 71% |
| Itchy skin | 68% | 57% | 79% | 89% | 80% | 64% | 75% | 50% | 70% | 90% | 65% |
| Skin that looks thin | 68% | 58% | 74% | 60% | 80% | 66% | 74% | 50% | 70% | 80% | 67% |
| Breathing difficulty | 67% | 43% | 83% | 50% | 0% | 67% | 67% | 0% | 67% | 75% | 80% |
| Skin erosion / breakdown of outer layer of skin | 66% | 48% | 86% | 86% | 100% | 57% | 83% | 34% | 63% | 97% | 74% |
| Difficulty swallowing (dysphagia) | 63% | 55% | 63% | 100% | 75% | 57% | 72% | 33% | 52% | 77% | 77% |
| Webbing in the throat | 63% | 50% | 63% | 100% | 50% | 64% | 61% | 0% | 65% | 77% | 38% |
| Wounds that heal very slowly | 61% | 50% | 70% | 100% | 25% | 57% | 69% | 42% | 58% | 97% | 58% |
| Constipation | 60% | 47% | 64% | 86% | 100% | 57% | 64% | 75% | 46% | 78% | 57% |

Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

Large variations in how frequently symptoms present across EB types – severe patients more likely to have more frequent symptoms (2/2)

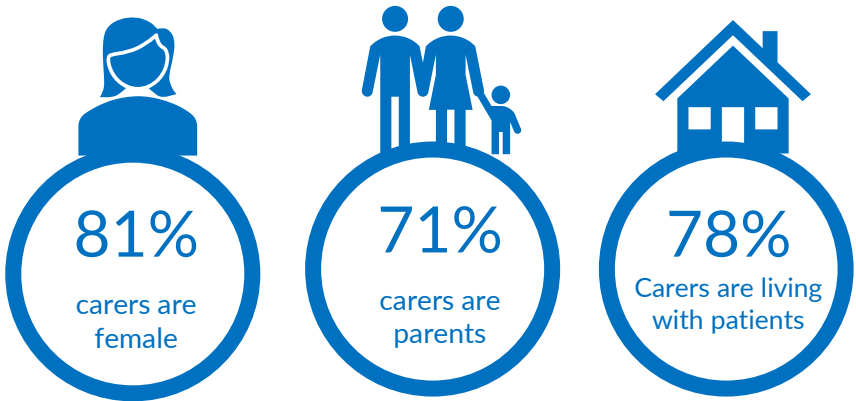
| % EB patients with each symptom who have experienced each symptom every day / most days / frequently | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|------|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Base variable for each row | | | | | | | | | | | |
| Blisters on the soles of the feet | 58% | 58% | 56% | 100% | 100% | 53% | 72% | 41% | 59% | 92% | 60% |
| Leakage or discharge from wounds | 58% | 41% | 77% | 100% | 0% | 51% | 71% | 41% | 52% | 93% | 51% |
| Reflux | 58% | 47% | 56% | 88% | 100% | 60% | 55% | 58% | 57% | 59% | 58% |
| Blisters inside the mouth and throat | 57% | 35% | 68% | 86% | 100% | 58% | 56% | 48% | 53% | 82% | 51% |
| Temporary partial sight or blindnes | 57% | 50% | 57% | 50% | 100% | 50% | 67% | 100% | 63% | 50% | 33% |
| Painful passing of stools (poo) | 56% | 59% | 54% | 63% | 67% | 48% | 66% | 56% | 50% | 60% | 61% |
| Scalp blistering and hair loss (scarring alopecia) | 55% | 29% | 65% | 71% | 0% | 54% | 57% | 25% | 54% | 70% | 44% |
| Tiny pimple-like bumps (milia) | 53% | 48% | 54% | 100% | 50% | 59% | 44% | 47% | 56% | 60% | 52% |
| Chills | 53% | 43% | 62% | 33% | 50% | 60% | 40% | 0% | 47% | 60% | 71% |
| Blisters constricting or narrowing food pipe (oesophagus) | 52% | 0% | 54% | 100% | 25% | 47% | 58% | 0% | 57% | 67% | 20% |
| Dental problems, | 51% | 47% | 44% | 67% | 100% | 49% | 54% | 43% | 53% | 58% | 44% |
| Fecal impaction | 47% | 29% | 58% | 67% | 67% | 39% | 60% | 43% | 33% | 70% | 50% |
| Blistering and/or irritation in or around the eyes | 46% | 39% | 46% | 67% | 100% | 50% | 41% | 33% | 56% | 53% | 25% |
| Anal fissures - sores, tears or ulcers near the anus | 45% | 28% | 56% | 57% | 0% | 45% | 45% | 40% | 44% | 58% | 38% |
| Sensitivity to the sun | 43% | 36% | 46% | 71% | 60% | 35% | 58% | 17% | 49% | 59% | 41% |
| Blistering in or around the genitals | 42% | 41% | 45% | 40% | 50% | 41% | 44% | 27% | 31% | 55% | 48% |
| Blisters on the palms of the hands | 41% | 36% | 49% | 100% | 100% | 30% | 64% | 10% | 47% | 83% | 38% |
| Blisters that you are unable to pop | 40% | 38% | 43% | 50% | 67% | 36% | 50% | 9% | 43% | 72% | 44% |
| Smell or odour from wounds | 40% | 30% | 46% | 100% | 0% | 28% | 58% | 11% | 27% | 74% | 39% |
| Infected wounds | 29% | 19% | 39% | 67% | 0% | 27% | 32% | 4% | 27% | 57% | 28% |
| Skin cancer | 27% | 0% | 31% | 100% | 0% | 10% | 100% | 0% | 11% | 75% | 0% |
| Fever | 22% | 13% | 22% | 67% | 0% | 28% | 17% | 0% | 14% | 36% | 14% |

Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

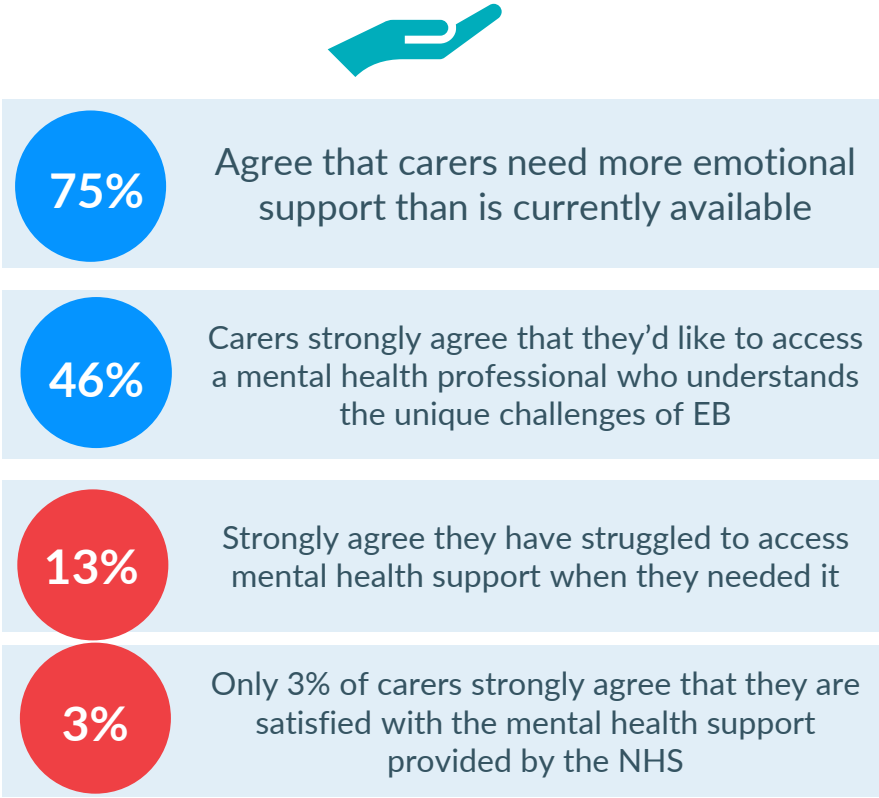
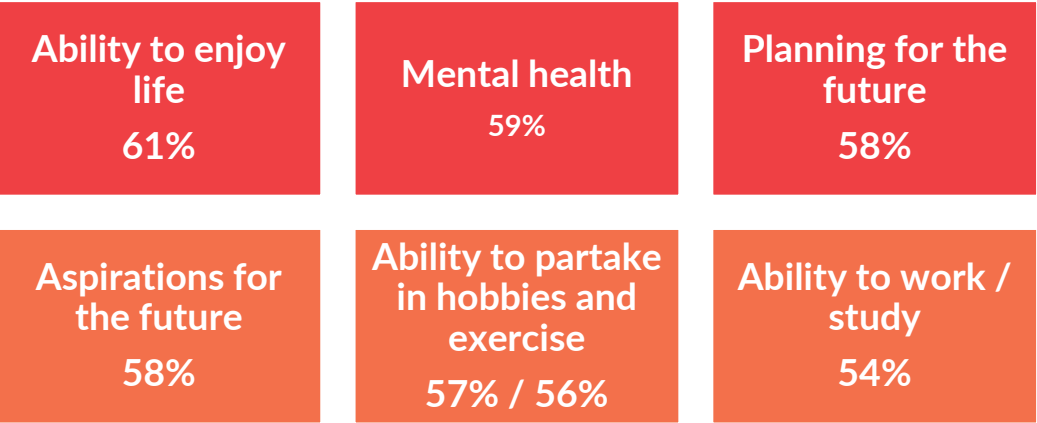
Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

Carers for people with EB

Carers for EB patients experience strain on their mental health and are often unable to access appropriate support



Carers say caring for someone with EB has a moderate to high impact on their....



The lives of carers of patients with moderate/severe & variable presentation EB are more heavily impacted, particularly their ability to plan for the future and their mental health – **these carers need more support and respite**

However, the carers of milder and SEB patients are still impacted and less able to enjoy their lives

- On a typical day carers spend an average:
- 1.3 hours assisting with blister / wound care
 - 1.2 hours assisting with personal hygiene
 - 1.1 hours checking on the pt. in the night
 - 0.6 hours assisting the pt. with getting dressed
- Carers for patients with severe symptoms spend much more time assisting with these activities



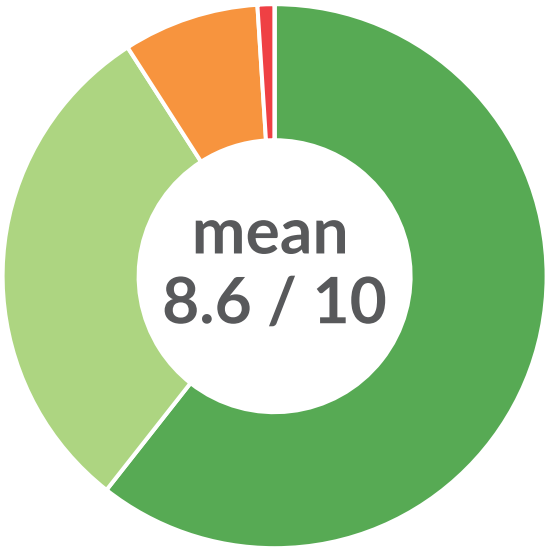
Attitudes to DEBRA

The majority of EB patients and carers have positive perceptions of DEBRA’s performance; 90% members score DEBRA 7+ /10

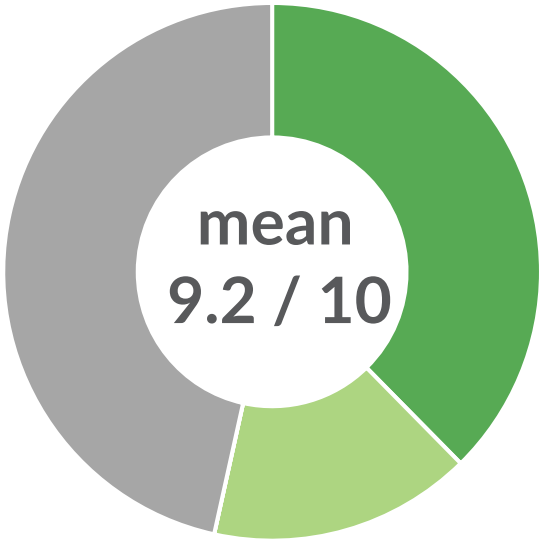
If you had to give DEBRA UK a score from 0-10 for how well they are doing, where 0 = very poor and 10 = extremely well, what score would you give them?

90%

of survey participants were already DEBRA members



DEBRA members



non-members

| | | % respondents | |
|---|-----------------------|---------------|-------------|
| | | Members | Non-members |
| ■ | 9-10 | 60% | 38% |
| ■ | 7-8 | 30% | 16% |
| ■ | 5-6 | 8% | 0% |
| ■ | 0-4 | 1% | 0% |
| ■ | Don't know / not sure | 0% | 47% |

Base 318 (215 patients and 103 carers)
Q41 Are you a member of DEBRA?
Q42 If you had to give DEBRA UK a score from 0-10 for how well they are doing, where 0 = very poor and 10 = extremely well, what score would you give them?

Fewer patients with mild symptoms of EB are DEBRA members than patients with moderate to severe or variable symptom presentation

| % Patients and carers who are a member of DEBRA | Total | SEB | EB Type DEB | JEB | KEB | Respondent Type Patient | Carer | Severity Mild | Moderate | Severe | It depends |
|---|-------|-----|----------------|------|------|----------------------------|-------|------------------|----------|--------|------------|
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Yes | 90% | 89% | 93% | 100% | 100% | 89% | 92% | 80% | 93% | 95% | 94% |
| No | 10% | 11% | 7% | 0% | 0% | 11% | 8% | 20% | 7% | 5% | 6% |

| Mean DEBRA rating (Q42) | Total | SEB | EB Type DEB | JEB | KEB | Respondent Type Patient | Carer | Severity Mild | Moderate | Severe | It depends |
|-------------------------|-------|-----|----------------|-----|-----|----------------------------|-------|------------------|----------|--------|------------|
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Mean | 8.7 | 8.8 | 8.4 | 8.6 | 9.0 | 8.7 | 8.6 | 8.8 | 8.6 | 8.4 | 8.7 |

N.B. caution interpreting percentages with a low base

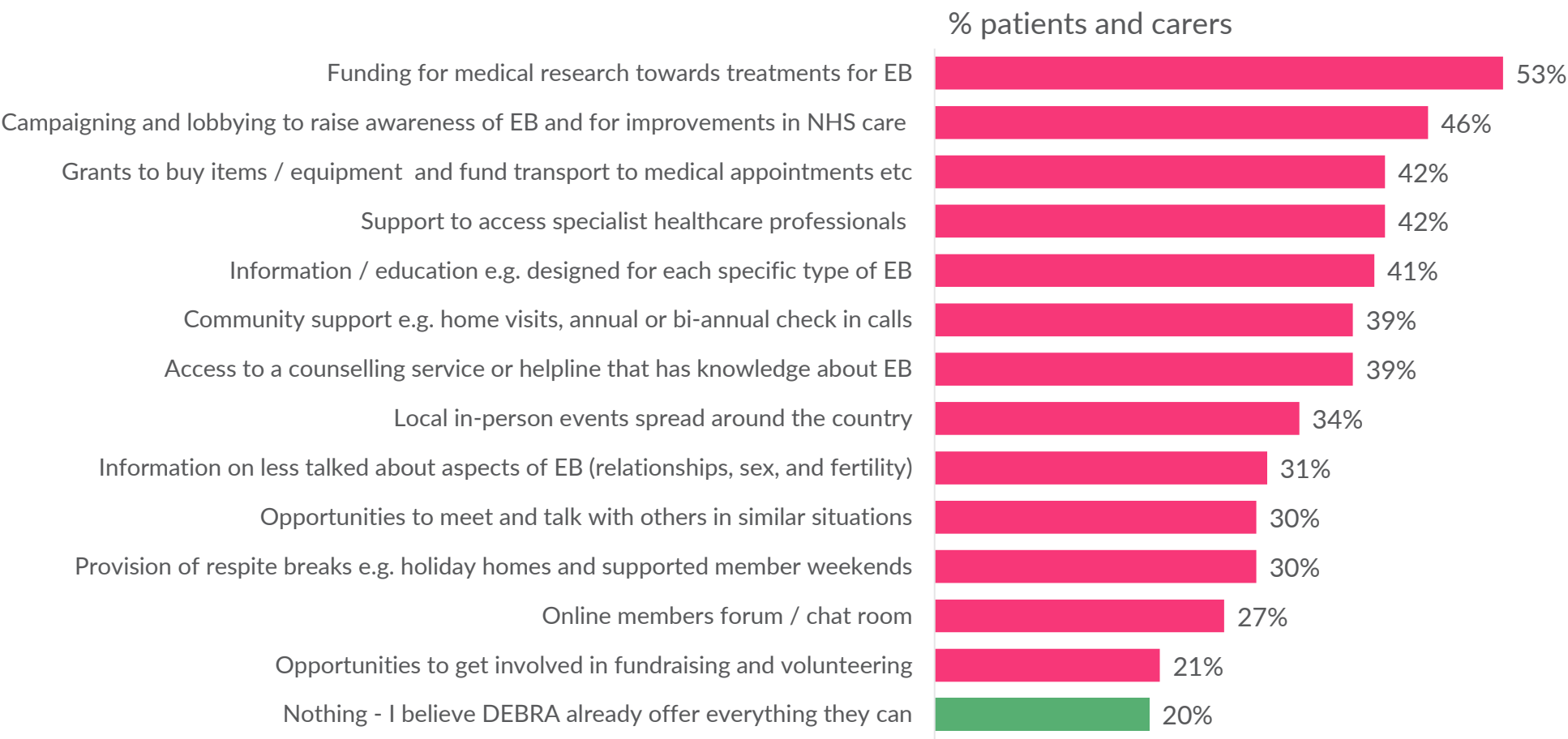
Base 318 (215 patients and 103 carers)

Q41 Are you a member of DEBRA?

Q42 If you had to give DEBRA UK a score from 0-10 for how well they are doing, where 0 = very poor and 10 = extremely well, what score would you give them?

EB patients and carers would most like to see DEBRA funding research towards treatments and campaigning and lobbying to raise awareness of EB and improve NHS care

What activities or services would you like DEBRA UK to provide? (prompted, multicode)



Whilst all are positive towards funding research and campaigning, mod/severe/JEB want grants & community support

DEB, ethnic minorities, teenagers and young adults would most like to see access to counselling

Carers of babies most satisfied with current support overall, less so for carers with children – who want to see provision of respite breaks & online forum

Children and younger adults more likely to want in-person events around the country, and info on sex / fertility

Females less positive towards funding and campaigning

DEBRA non-members would like to see similar provision as members, expect being less likely to want campaigning / lobbying (28%), access to counselling service (28%), provision of respite breaks (16%)

Base 318 (215 patients and 103 carers)
Q43 What activities or services would you like DEBRA UK to provide?

Moderate & severe patients/carers more likely to want to see DEBRA provide community support; Severe and JEB particularly positive towards DEBRA funding medical research, campaigning to raise awareness, opportunities to meet others and provision of respite breaks; mild & SEB least likely to want grants; JEB most likely to want supported access to specialist HCPs; DEB & severe most likely to want to see counselling service / helpline

Patients Carers

| % Patients and carers selecting option | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Total | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Funding for medical research towards treatments for EB | 53% | 47% | 60% | 69% | 60% | 49% | 60% | 49% | 56% | 69% | 45% |
| Campaigning and lobbying to raise awareness of EB and for improvements in NHS care for people with EB | 46% | 41% | 55% | 62% | 20% | 44% | 50% | 41% | 47% | 59% | 45% |
| Grants to buy items / equipment (e.g. specialist clothing, wheelchairs) and fund transport to medical appointments etc | 42% | 38% | 47% | 62% | 60% | 37% | 51% | 31% | 51% | 56% | 35% |
| Support to access specialist healthcare professionals e.g. occupational therapy, podiatry, physiotherapy | 42% | 40% | 43% | 54% | 40% | 42% | 41% | 40% | 49% | 41% | 35% |
| Information / education e.g. designed for each specific type of EB, educational videos about EB | 41% | 42% | 38% | 46% | 20% | 40% | 41% | 42% | 40% | 44% | 39% |
| Community support e.g. home visits, annual or bi-annual check in calls from DEBRA support team, mentoring for families who have children with EB | 39% | 31% | 49% | 54% | 80% | 37% | 43% | 33% | 47% | 51% | 29% |
| Access to a counselling service or helpline that has knowledge about EB | 39% | 32% | 52% | 38% | 40% | 38% | 40% | 34% | 41% | 56% | 34% |
| Local in-person events spread around the country | 34% | 32% | 38% | 31% | 20% | 30% | 41% | 28% | 37% | 33% | 35% |
| Information on less talked about aspects of EB (relationships, sex, and fertility) | 31% | 29% | 34% | 31% | 20% | 32% | 29% | 34% | 33% | 28% | 28% |
| Opportunities to meet and talk with others in similar situations e.g. online group meetings for people with EB / carers via Zoom, in person meet ups for people with EB / their carers | 30% | 27% | 34% | 46% | 60% | 27% | 36% | 24% | 35% | 46% | 21% |
| Provision of respite breaks e.g. holiday homes and supported member weekends | 30% | 28% | 33% | 46% | 20% | 25% | 41% | 28% | 33% | 44% | 22% |
| Online members forum / chat room | 27% | 27% | 26% | 31% | 40% | 25% | 33% | 29% | 31% | 28% | 21% |
| Opportunities to get involved in fundraising and volunteering | 21% | 18% | 27% | 31% | 40% | 19% | 25% | 25% | 23% | 28% | 12% |
| Nothing - I believe DEBRA already offer everything they can | 20% | 22% | 19% | 15% | 0% | 23% | 15% | 27% | 15% | 13% | 24% |
| None of the above | 1% | 2% | 0% | 0% | 0% | 1% | 2% | 1% | 0% | 0% | 4% |

Base 318 (215 patients and 103 carers)

Q43 What activities or services would you like DEBRA UK to provide?

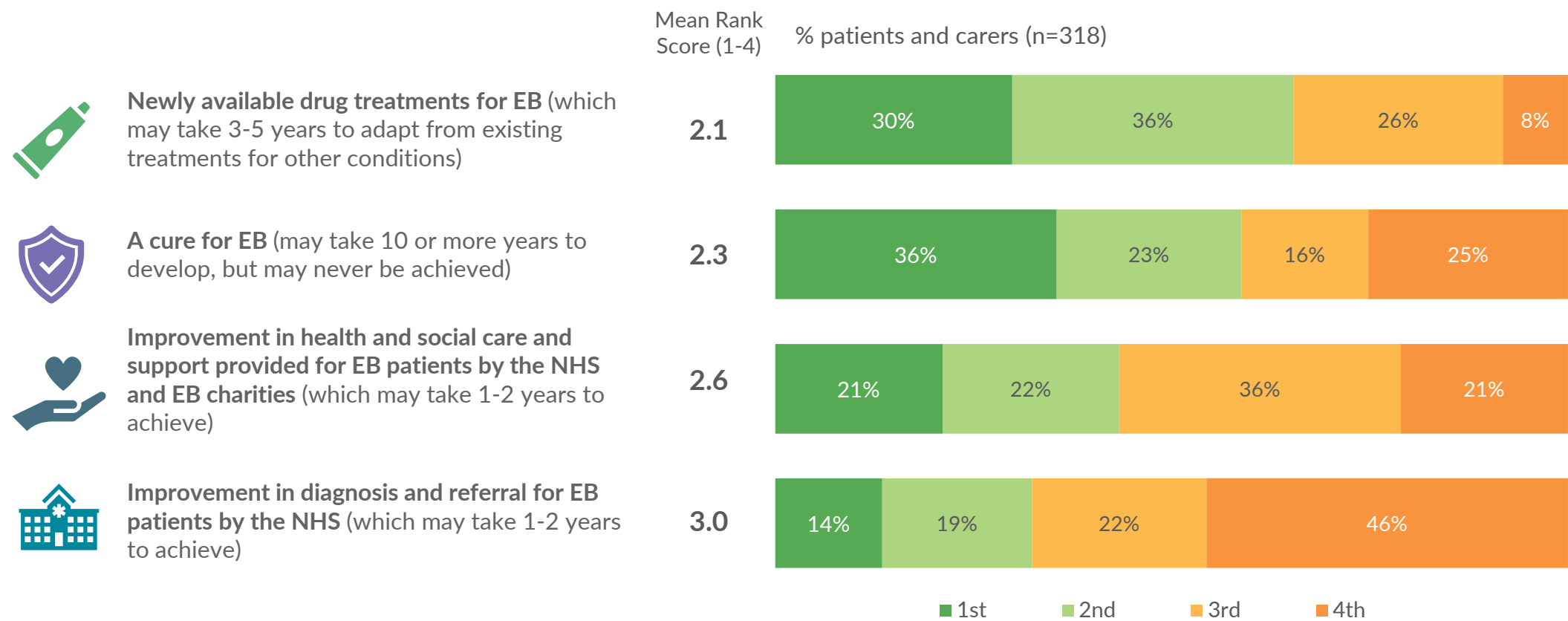
N.B. caution interpreting percentages with a low base

Only 5% of carers for children feel DEBRA offers everything they can compared to 40% of carers for babies; teenagers, younger adults and those of an ethnic minority would like access to a counselling service

| % Patients and carers selecting option | Total | Under care of specialist centre? | | Patient Age | | | | | | Patient Gender | | Patient ethnicity | | Location | | |
|--|-------|----------------------------------|---------------|----------------|-------|-------------------------|-------------|-------------|-----------|----------------|--------|-------------------|-----------------|---------------|-----------------|---------------|
| | | Yes | No / not sure | Baby / toddler | Child | Teenager / young person | Adult 21-40 | Adult 41-60 | Adult 61+ | Male | Female | White | Ethnic minority | North England | East & Midlands | South England |
| N= | 318 | 193 | 125 | 20 | 38 | 23 | 93 | 79 | 65 | 108 | 201 | 292 | 24 | 46 | 81 | 126 |
| Funding for medical research towards treatments for EB | 53% | 56% | 47% | 35% | 63% | 61% | 60% | 41% | 52% | 64% | 47% | 52% | 58% | 61% | 47% | 57% |
| Campaigning and lobbying to raise awareness of EB and for improvements in NHS care for people with EB | 46% | 48% | 42% | 30% | 42% | 48% | 54% | 41% | 48% | 56% | 41% | 47% | 29% | 52% | 48% | 50% |
| Grants to buy items / equipment and fund transport to medical appointments etc | 42% | 46% | 35% | 30% | 50% | 65% | 48% | 34% | 32% | 44% | 42% | 40% | 58% | 43% | 42% | 46% |
| Support to access specialist healthcare professionals e.g. occupational therapy, podiatry, physiotherapy | 42% | 42% | 40% | 20% | 39% | 43% | 48% | 35% | 46% | 45% | 40% | 43% | 25% | 33% | 32% | 52% |
| Information / education e.g. designed for each specific type of EB, educational videos about EB | 41% | 42% | 38% | 30% | 45% | 48% | 46% | 35% | 37% | 34% | 44% | 41% | 33% | 43% | 35% | 43% |
| Community support e.g. home visits, annual or bi-annual check in calls from DEBRA support team, mentoring for families who have children with EB | 39% | 42% | 34% | 35% | 34% | 57% | 46% | 33% | 32% | 43% | 37% | 38% | 50% | 37% | 27% | 44% |
| Access to a counselling service or helpline that has knowledge about EB | 39% | 41% | 34% | 30% | 37% | 52% | 46% | 33% | 34% | 41% | 38% | 37% | 58% | 41% | 40% | 40% |
| Local in-person events spread around the country | 34% | 35% | 31% | 20% | 42% | 39% | 47% | 20% | 28% | 31% | 35% | 35% | 17% | 35% | 33% | 32% |
| Information on less talked about aspects of EB (relationships, sex, and fertility) | 31% | 34% | 27% | 15% | 24% | 48% | 48% | 16% | 28% | 30% | 32% | 30% | 42% | 22% | 30% | 38% |
| Opportunities to meet and talk with others in similar situations | 30% | 36% | 21% | 35% | 39% | 39% | 37% | 19% | 23% | 34% | 28% | 29% | 42% | 28% | 25% | 37% |
| Provision of respite breaks | 30% | 32% | 27% | 25% | 45% | 48% | 31% | 23% | 23% | 32% | 29% | 30% | 33% | 28% | 26% | 35% |
| Online members forum / chat room | 27% | 28% | 26% | 20% | 42% | 22% | 35% | 19% | 22% | 29% | 27% | 27% | 25% | 30% | 27% | 26% |
| Opportunities to get involved in fundraising and volunteering | 21% | 22% | 20% | 15% | 21% | 35% | 28% | 13% | 18% | 25% | 18% | 22% | 17% | 22% | 20% | 25% |
| Nothing - I believe DEBRA already offer everything they can | 20% | 18% | 25% | 40% | 5% | 13% | 15% | 32% | 20% | 12% | 24% | 21% | 13% | 20% | 20% | 18% |
| None of the above | 1% | 2% | 1% | 0% | 5% | 0% | 1% | 1% | 0% | 0% | 2% | 1% | 0% | 0% | 4% | 0% |

Overall EB patients and carers feel it is most important for funds to be spent on newly available drug treatments for EB, closely followed by a cure; improvement in diagnosis and referral seen as least important

Which of the following options do you believe is the most important to spend money on?



Severe & JEB are slightly more likely to prioritise new drug treatments over improvements in care, diagnosis & referral; JEB place particular emphasis on cure

JEB

For JEB, improvement in care, diagnosis and referral are much less important than a cure or new treatment development

| Mean (1st = 1, 4th = 4) | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Total | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Newly available drug treatments for EB (which may take 3-5 years to adapt from existing treatments for other conditions) | 2.1 | 2.1 | 2.1 | 1.9 | 3.2 | 2.2 | 1.9 | 2.2 | 2.2 | 1.9 | 2.1 |
| A cure for EB (may take 10 or more years to develop, but may never be achieved) | 2.3 | 2.4 | 2.3 | 1.6 | 1.6 | 2.3 | 2.2 | 2.5 | 2.3 | 2.3 | 2.2 |
| Improvement in health and social care and support provided for EB patients by the NHS and EB charities (which may take 1-2 years to achieve) | 2.6 | 2.6 | 2.5 | 3.1 | 2.2 | 2.5 | 2.8 | 2.4 | 2.6 | 2.6 | 2.6 |
| Improvement in diagnosis and referral for EB patients by the NHS (which may take 1-2 years to achieve) | 3.0 | 2.9 | 3.1 | 3.4 | 3.0 | 2.9 | 3.1 | 2.9 | 3.0 | 3.2 | 3.1 |

N.B. caution interpreting percentages with a low base

Base All respondents (n=318)

Q39B Please think about your aspirations for EB in the future.

Imagine that you are in charge of funding decisions for EB – you get to decide what to spend money on. But, there are a limited amount of funds to go around; it is not possible to spend money on everything. Which of the following options do you believe is the most important to spend money on?

Conclusions and Recommendations

- **EB has a high symptom burden, with many of the symptoms experienced by most patients having a high impact on daily life**
- **That being said, life with EB is highly variable** – the type of EB does not necessarily correlate with severity, and the worst days can be considerably worse than an average day – **beware of making assumptions** about what patients are going through and what they are capable of at any one time
- **Symptoms are again highly variable and cause significant impact on QoL** – the ‘lows’ of patients with variable or seasonal symptoms can feel particularly low, and they can struggle to be understood by HCPs
- **Foot blistering is particularly impactful** and may need to be an area of focus
- **EB has a significant impact on mental health**, and for carers and DEB patients in particular – consider more carer focused solutions
- **Teenagers and young adults with EB need more tailored support across the board** – potential gap resulting from service transition
- **Difficulties with HCP interactions** evidences need for HCP education (see next section)
- **Effective symptom management, treatments or therapies severely lacking for EB** – all patients using something different or nothing at all, rely on recommendations from others
- **Delayed presentation and referral are obstacles to timely diagnosis** – particularly for SEB and patients with seasonal symptoms
- **A significant amount of EB patients are not under specialist care** – whilst some feel they don’t need this, the remainder are coping on their own or potentially held in local primary / secondary care
- **Even when under specialist care, access is difficult for some patients to achieve** re travelling and frequency of appointments **not tailored to patient needs**
- Whilst many aspire towards a cure for EB, when time frames and limited funds are taken into account **the development of new treatments take priority**

HCP Research Key Conclusions

There is a need to raise awareness and understanding of EB among GPs and dermatologists, despite many having seen an EB patient in the past

57%

GPs have seen an EB patient in the last 5 years
(mean 4 patients)

82%

derms have seen an EB patient in the last 5 years
(mean 5 patients)

42%

were unsure what type of EB their patient had

4%

were unsure what type of EB their patient had



Over 2/3 of dermatologists suggest that awareness of EB in both primary care and general dermatology is too low

Only **3% GPs** and **18% dermatologists** have a good knowledge and awareness of EB



Around a quarter of GPs and derms felt they could benefit from a reminder



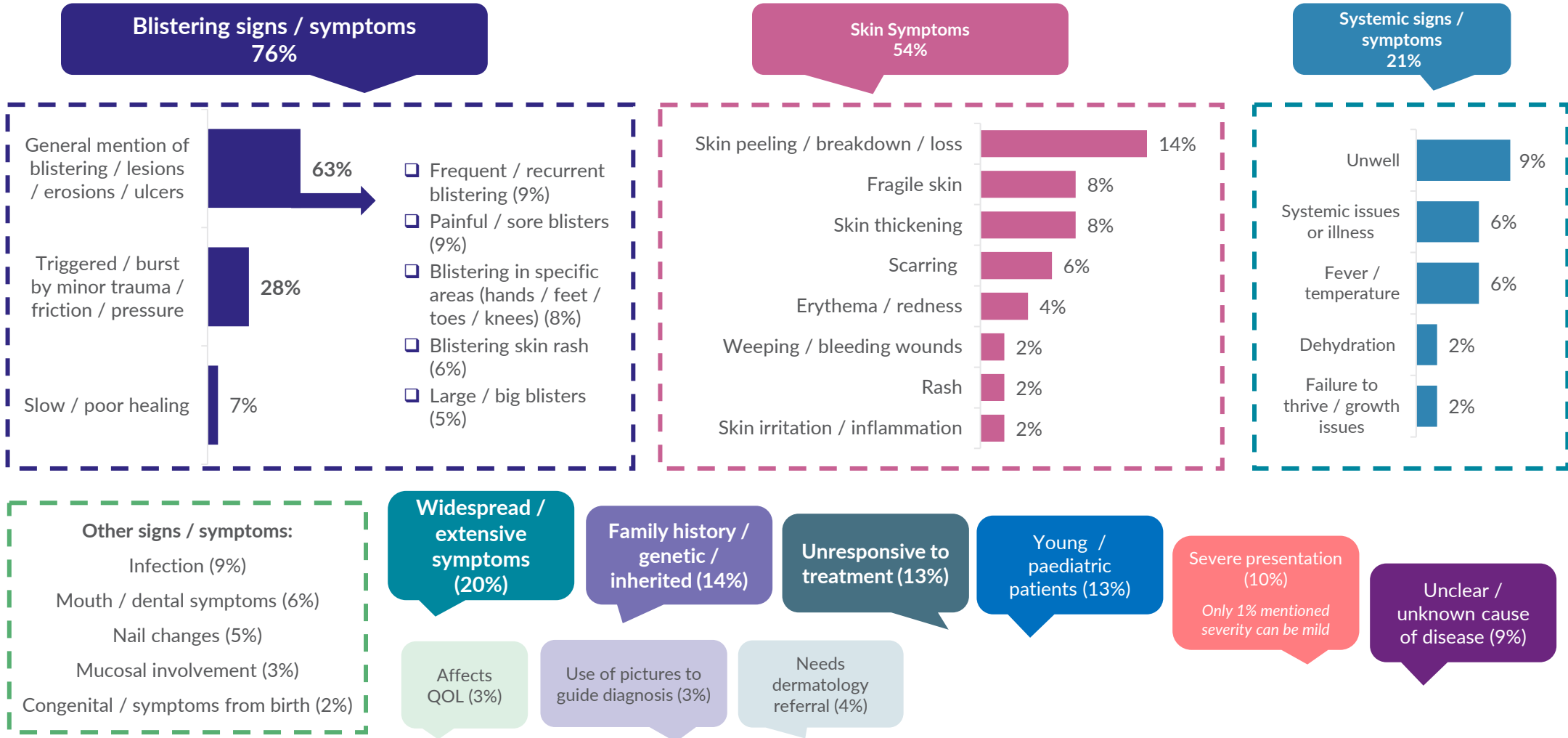
3/4 dermatologists feel EB is too rare to be familiar with



2/3 dermatologists are not sure they would recognise EB symptoms if they saw them

GP spontaneous awareness of signs and symptoms of EB

What signs or symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB / a possible diagnosis of EB? (free text, spontaneous) (2% = 2 GPs)



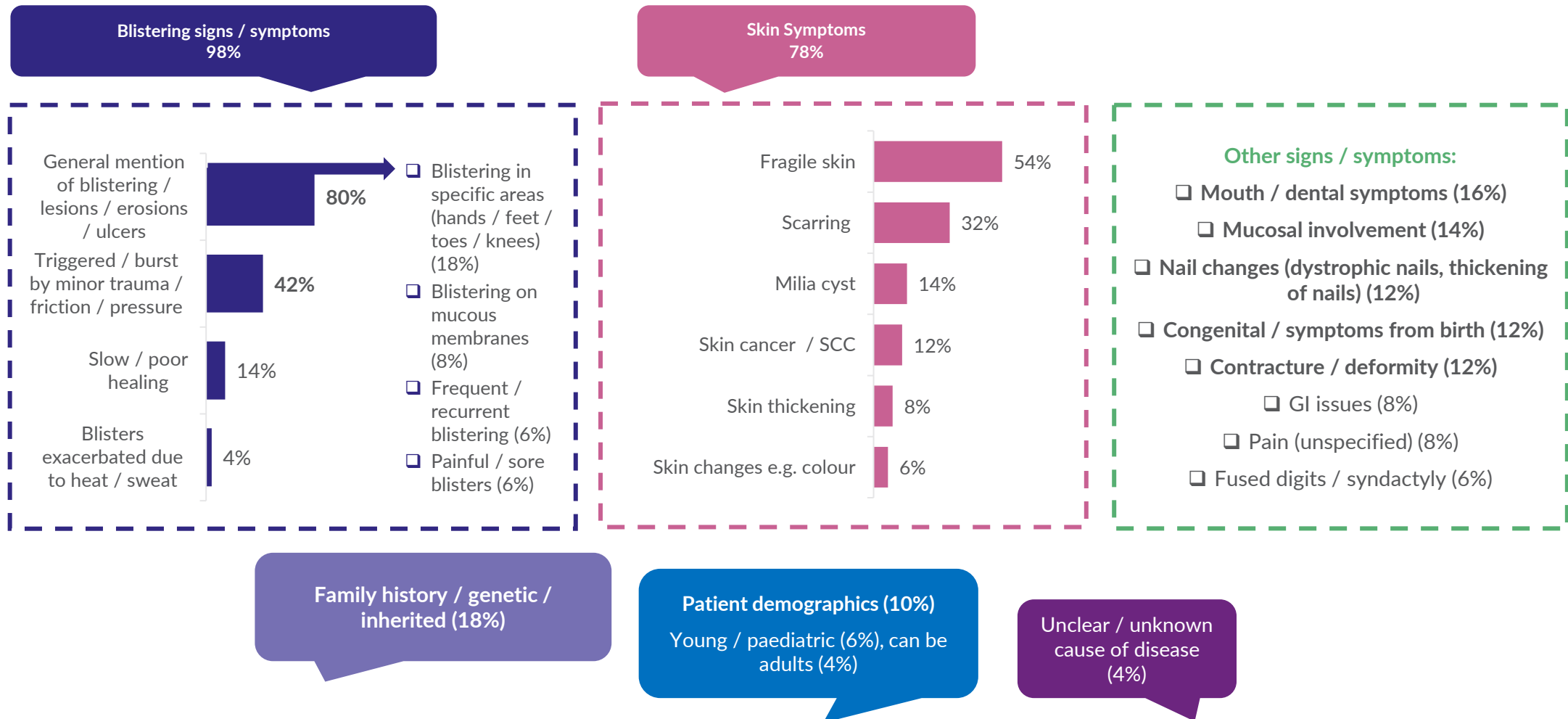
Mentions <2% not shown

Base: 100 GPs

Q1 What signs or symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB / a possible diagnosis of EB?

Dermatologist spontaneous awareness of signs and symptoms of EB

What signs or symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB / a possible diagnosis of EB? (free text, spontaneous) (4% = 2 dermatologists)



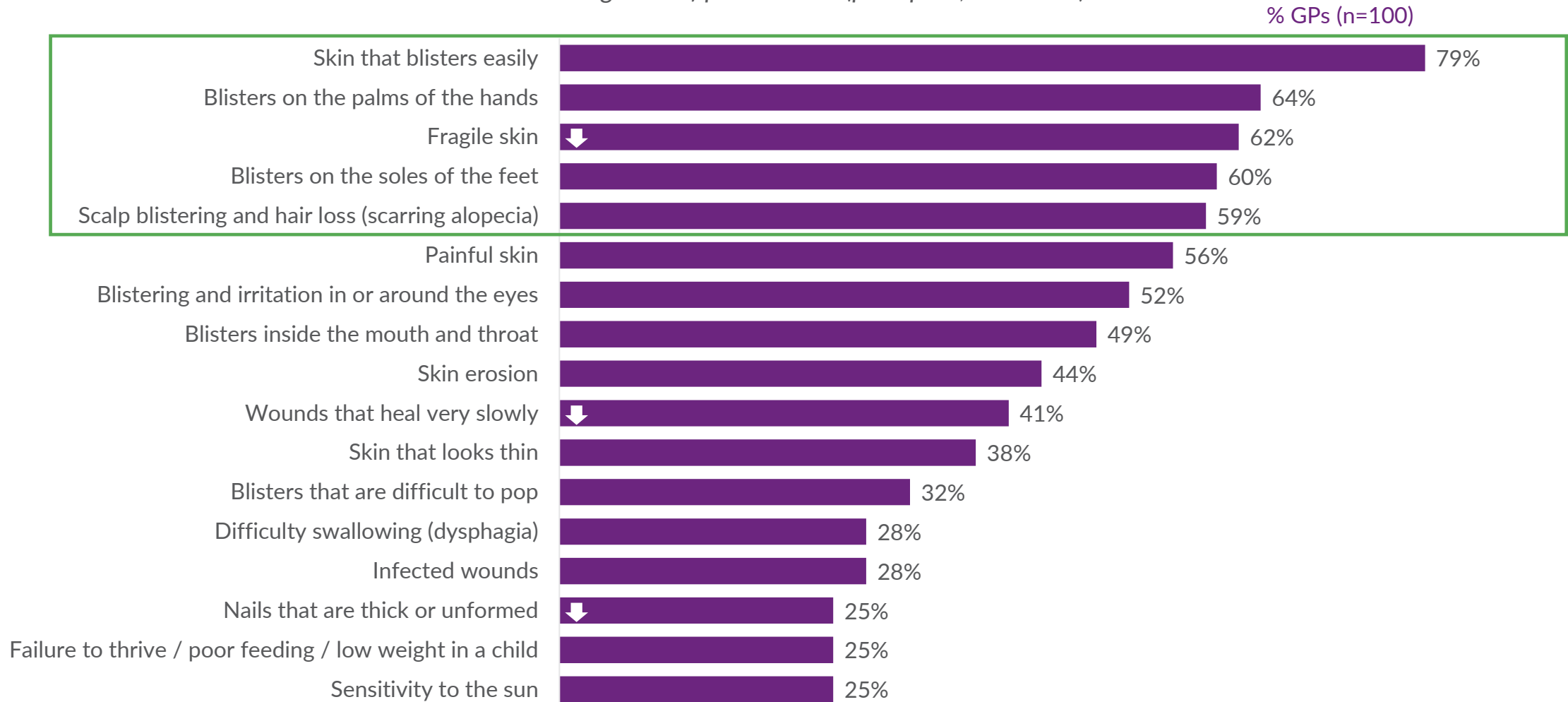
Mentions <4% not shown

Base: 50 Dermatologists

Q1 What signs or symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB / a possible diagnosis of EB?

GPs most associate EB with skin that blisters easily, fragile skin, blisters on palms/soles of feet and scalp blistering upon prompting

Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB? (prompted, multicode)



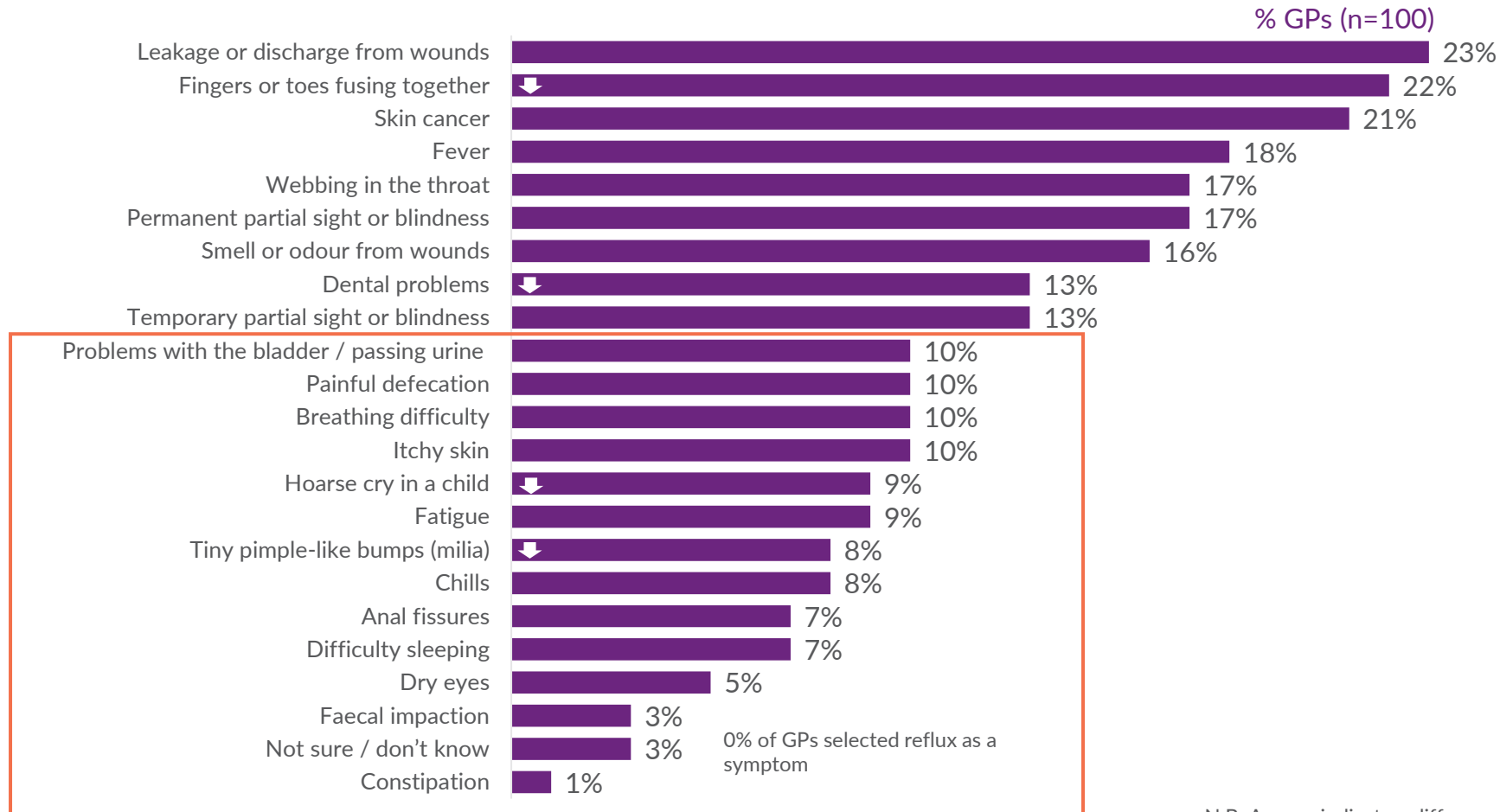
N.B. Arrows indicate a difference in response vs dermatologists

Base = 100 GPs

Q12: Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB?

GPs least associate EB with...

Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB? (prompted, multicode)



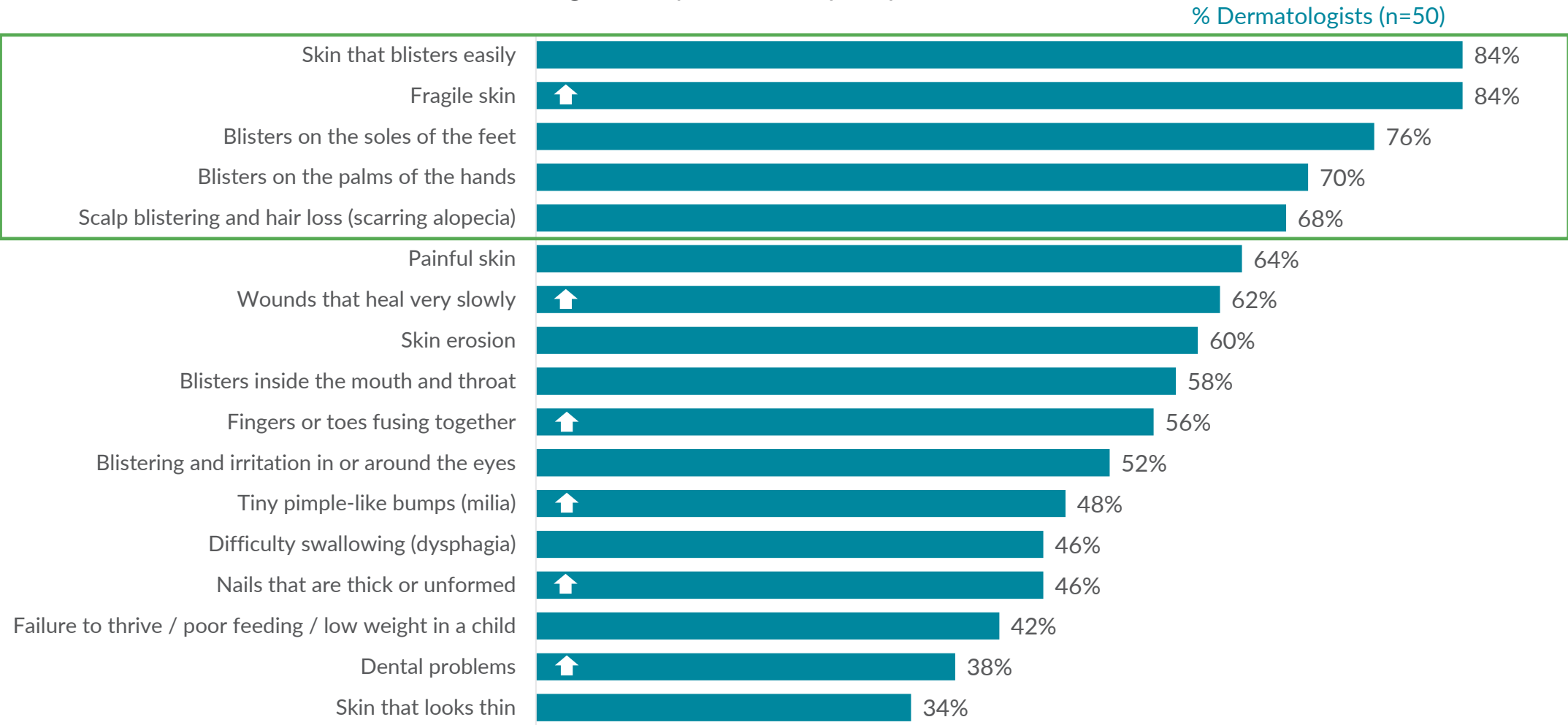
N.B. Arrows indicate a difference in response vs dermatologists

Base = 100 GPs

Q12: Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB?

Dermatologists most associate EB with skin that blisters easily, fragile skin , blisters on palms/soles of feet and scalp blistering upon prompting

Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB? (prompted, multicode)

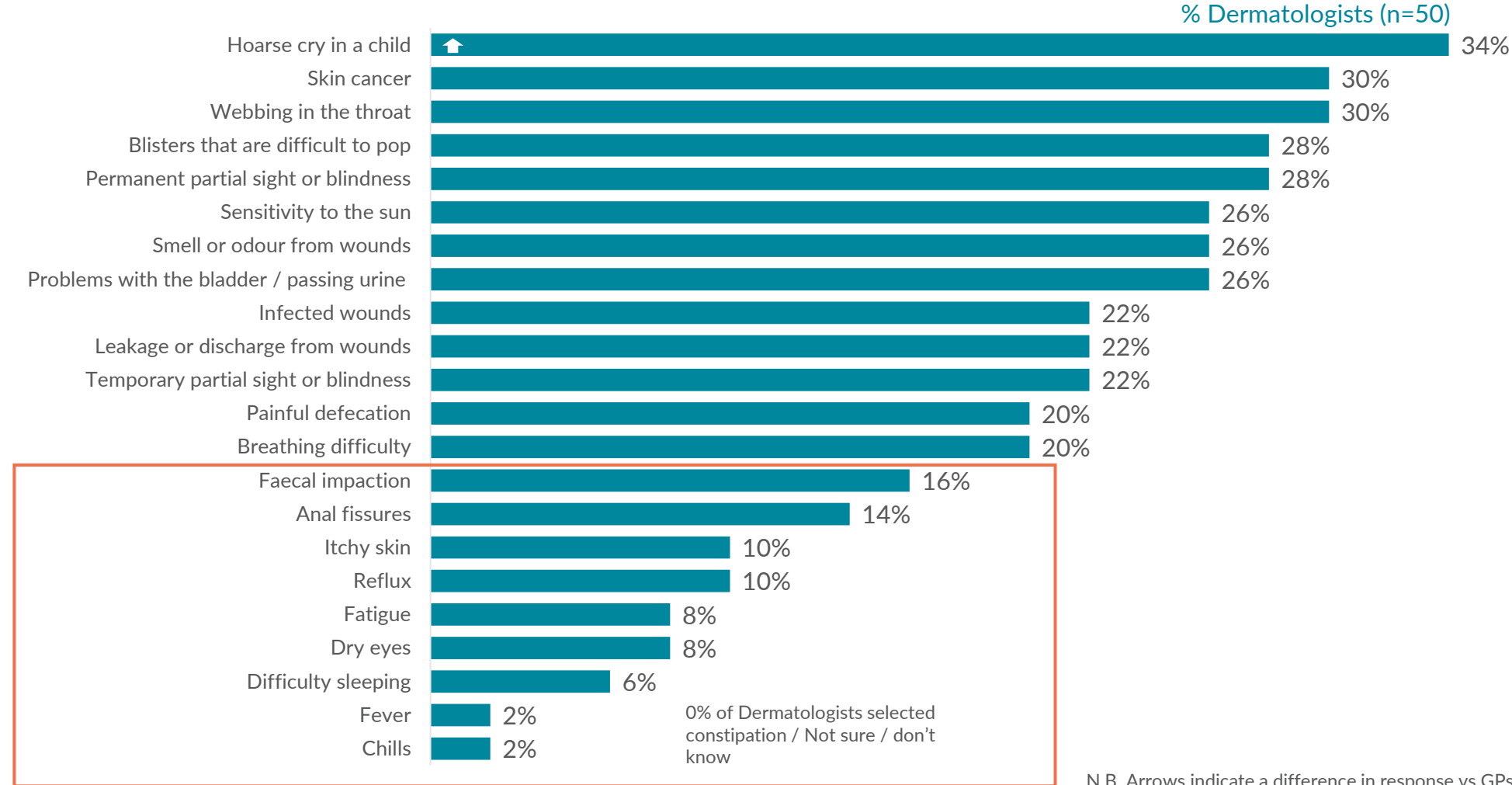


N.B. Arrows indicate a difference in response vs GPs

Base = 50 Dermatologists
Q12: Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB?

Dermatologists least associate EB with...

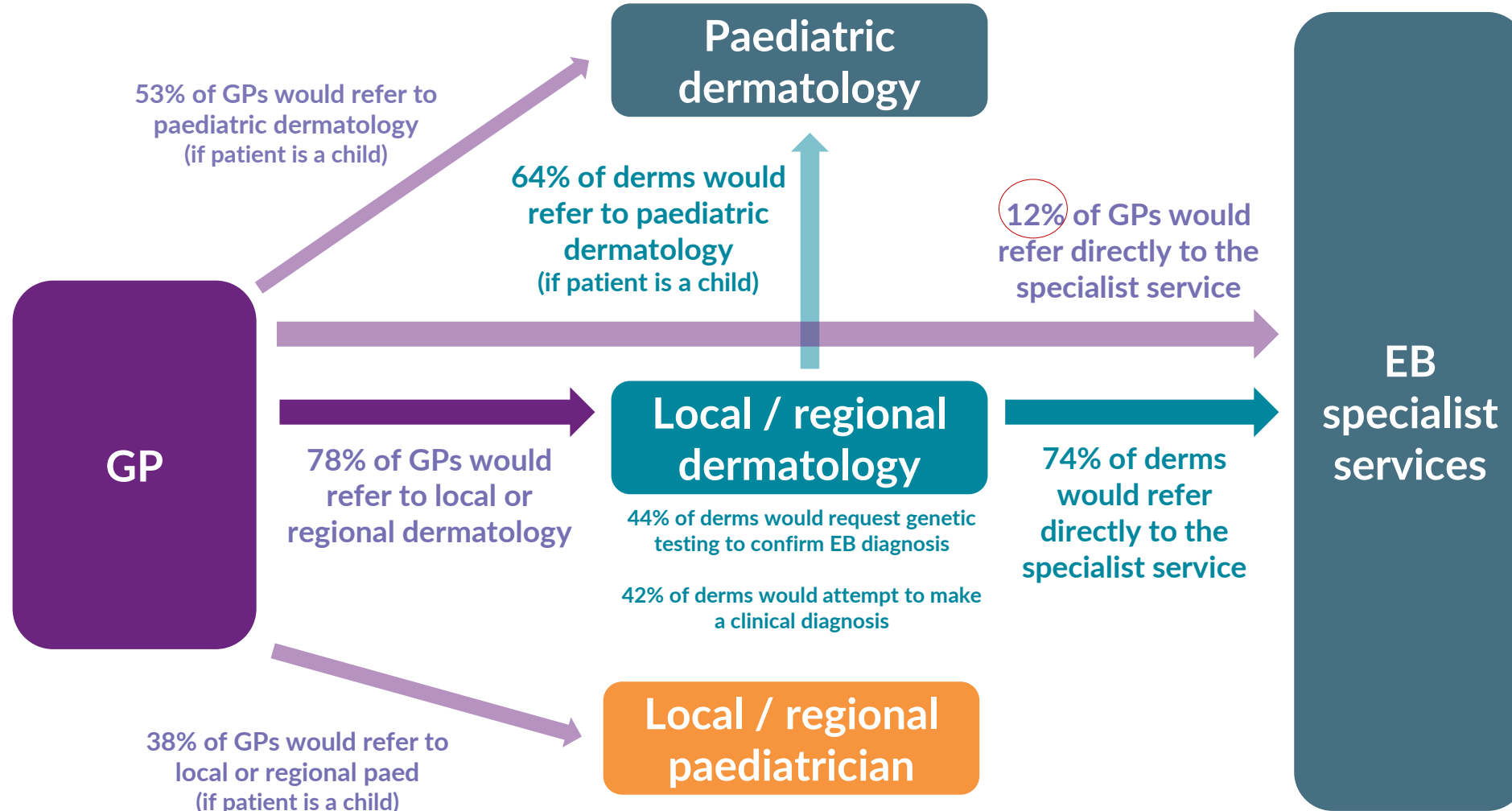
Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB? (prompted, multicode)



N.B. Arrows indicate a difference in response vs GPs

Base = 50 Dermatologists
Q12: Which of the following symptoms would suggest to you that a patient should be referred to diagnostic services or secondary care for investigation of possible EB?

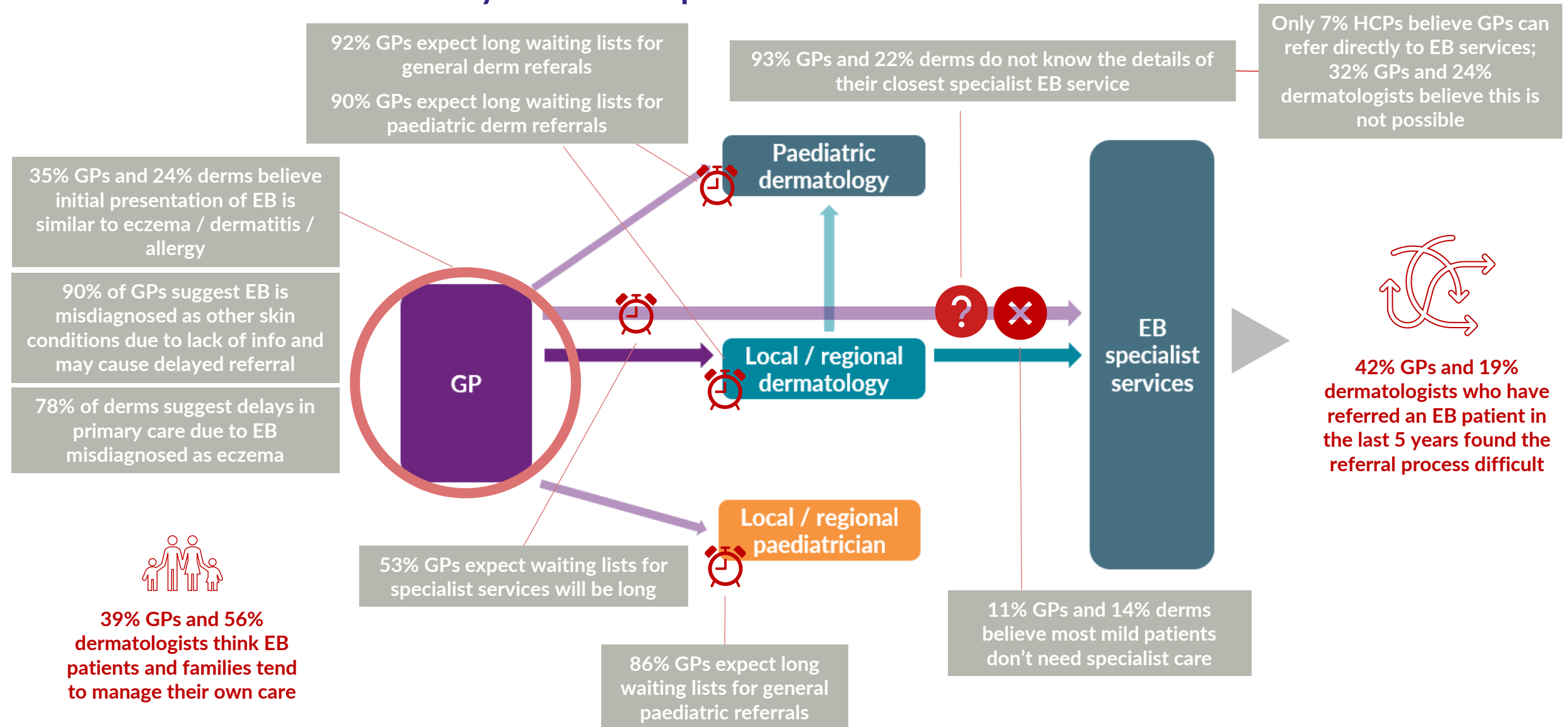
If you were to identify a potential EB patient, what actions would you take? (prompted, HCP able to select multiple options)



Base = 50 Dermatologists, 100 GPs

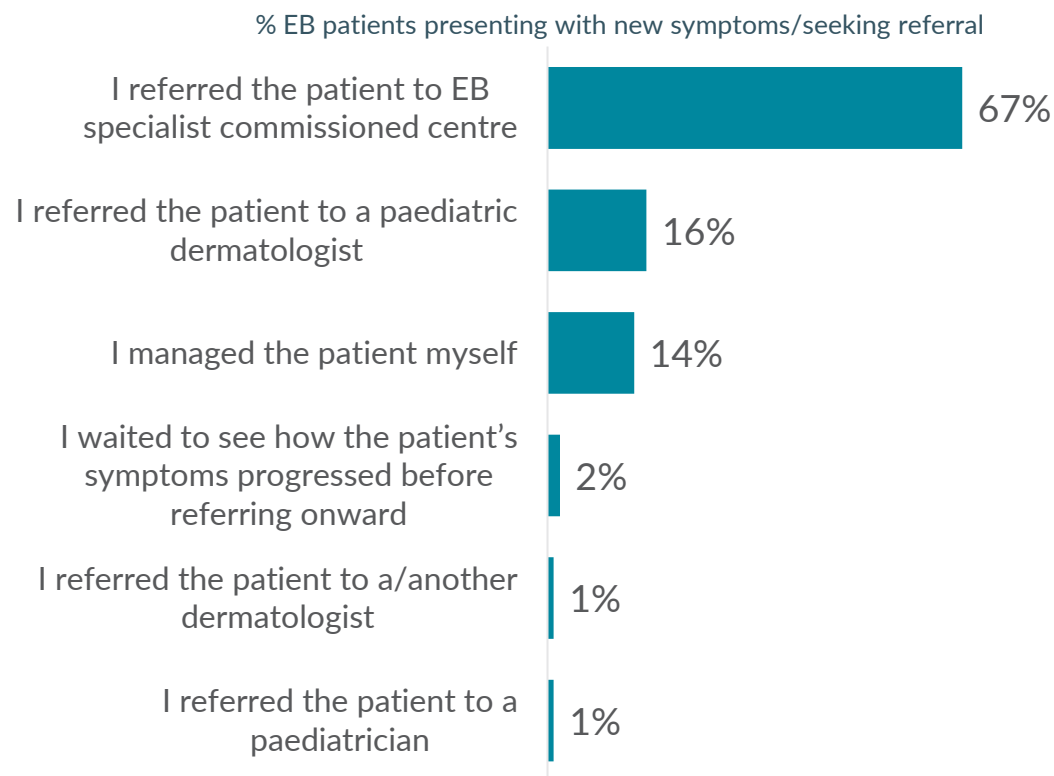
Q15: If you were to identify a potential EB patient, what actions would you take?

Barriers and delays to EB specialist services referral

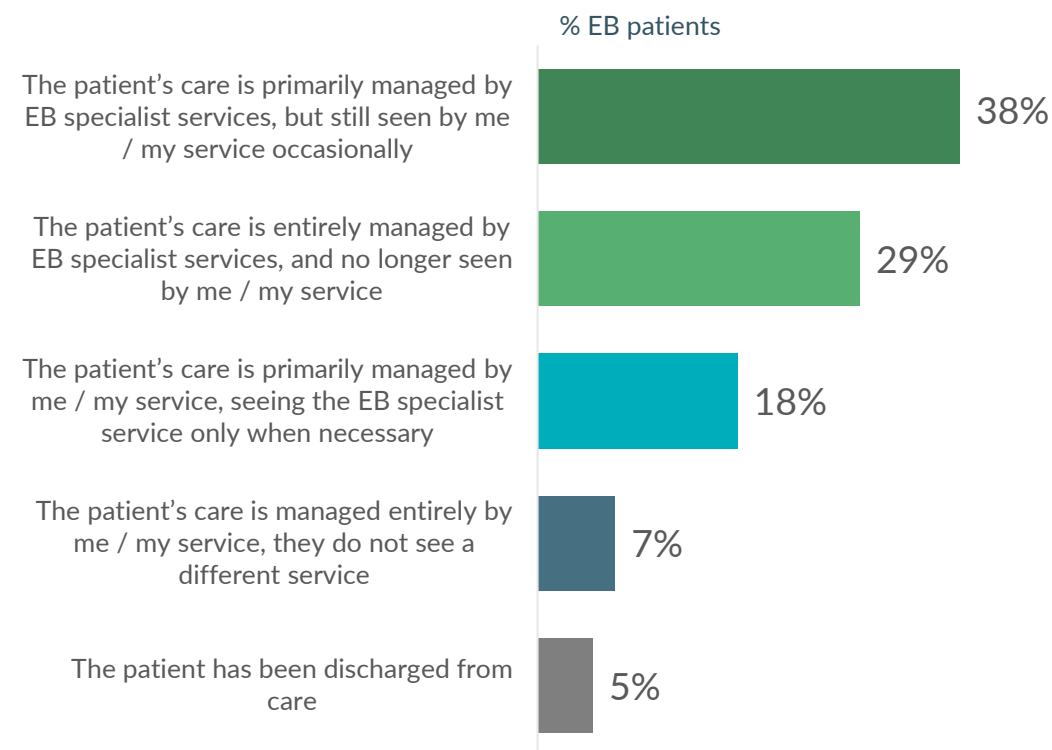


Dermatologists suggest the care of a minority of EB patients is managed entirely without the oversight of specialist services

Of the patients presenting with new EB symptoms or seeking a referral when you first saw them – which of the following actions did you take? (prompted)



How have the EB patients seen by dermatologists in the last 5 years been managed? (prompted)



Base: 25 dermatologists with EB patient(s) in last 5 years either presenting with new EB symptoms or seeking a referral into tertiary specialist care / 40 dermatologists who have seen an EB patient / last 4 years (1 x outliers excluded)

Q5 Of the ___ patient(s) you said you have seen with EB in the last 5 years who were either presenting with new EB symptoms or seeking a referral into tertiary specialist care when you first saw them – which of the following actions did you take?

Q7 Of the ___ patient(s) you have seen with EB in the last 5 years, how many have been managed as follows?

A disconnect exists between the role HCPs think their *service* should have in managing EB patients, and what they would be *personally comfortable managing*

A purple speech bubble containing the text "GPs".

GPs

Whilst over 4/5 GPs feel primary care should have a role in EB patient care and would be willing to take part in shared care arrangements

- 70% of GPs think even mild EB patients need specialist care
- 86% GPs would need to know more about EB before feeling comfortable to manage care of an EB patient
- Just under half would be comfortable managing mild patients, but over half have reservations about managing more severe cases

A teal speech bubble containing the text "Derms".

Derms

Dermatologists are more comfortable with the idea of shared care of EB patients

- 95% agree that local secondary care should be involved in managing EB
- Most would be happy managing mild cases

However: two thirds would still not be comfortable with severe cases, and 52% agree the needs of EB patients are too complex for local secondary care to meet



86% of Dermatologists would feel positively towards the set up of an EB outreach clinic in their area

Even if specialist dressings are recommended, derms and GPs can be reluctant to prescribe; perception that specialist services should provide and manage this



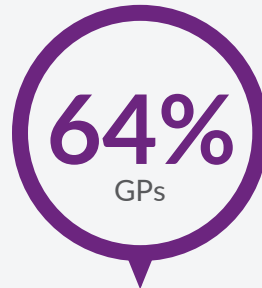
3/4 HCPs agree primary care would manage pain medication and antibiotics for EB patients (GPs in particular, though some dermatologists envisage a greater role for themselves)

Lack of awareness around who manages specialist bandages – just over half of GPs and two thirds dermatologists say it will be specialist services



Uncertainty exists around who:

- Takes bloods for EB patients - 58% GPs say it would be primary care, but a quarter of dermatologists believe they would play this role
- Manages provision of needles – lack of consensus



claim to have an approved dressings list / formulary

prescribing outside of this list is difficult for the majority, especially dermatologists (84%)

Dermatologists agree

- specialist dressings may not be stocked by community pharmacies causing problems with fulfilling prescriptions for patients (82%)
- that recommendations for them don't always include all information needed to prescribe (76%)
- and that they are under cost pressure to prescribe generic dressings (64%)



agree GPs are not always happy to supply specialist dressings

would opt to prescribe similar generic dressings, even if specialist dressings were recommended



would always question requests for large quantities of dressings

54% GPs and 46% dermatologists believe the cost of specialist dressings is not always covered by specialised commissioning



Communicating with GPs and dermatologists about EB



83%

info on common signs and symptoms of EB

76%

when to involve tertiary / secondary care

69%

best practice guidelines for EB

69%

guidance on making referrals to specialist care



80%

info on approved treatments / support they may have to prescribe

78%

best practice guidelines for EB

76%

guidance on making referrals to specialist care

74%

advice about managing dressings

To keep up to date:

GPs use GP notebook, NICE updates & GP study days – webinars & websites
Dermatologists use BAD and associated journals, DermNet NZ & NICE updates – conferences/events, local/regional meetings



Two thirds of GPs would find a patient-directed pack of information very useful, with preference for this to be a website page (50%) the patient could direct them to or a hard copy / leaflet the patient could provide (41%)

If HCPs need to seek information about an unusual dermatological presentation...



- **GPs** would send a picture to dermatology (68%) or search a dermatology website (50%)
- **Dermatologists** would ask colleagues or search a dermatology website (64%)
- A quarter of **dermatologists** would search symptoms on Google (28%), only 9% GPs admit to this

In this situation HCPs are more likely to use information which is endorsed by specialist centres & the NHS (and for GPs, to be UK-specific)

PIF TICK would not have an impact for the majority



HCPs most likely to engage with EB information in format of CPD accredited training courses and online webinars / content; for dermatologists, in person meetings

Conclusions and Recommendations

- GPs appear to have reasonable spontaneous awareness of the signs and symptoms of EB – but difficulty exists around recognising these in practice and referring EB correctly, in both primary and secondary care, despite many HCPs having seen an EB patient
- Destigmatising the complexity of managing EB and ensure links with specialist services are possible to increase HCP confidence in shared care arrangements, even for more complex patients
- There is a need for better communications with specialist centres around role of primary care and local secondary care – primary care expect to manage antibiotics and pain management for EB patients, but need for clarity around who is responsible for bandages, bloods and needles, and what is covered by specialised commissioning
- Need for education around ability to refer directly to specialist services and when this should be done – currently, some patients are being managed entirely within local secondary care
- Prescriptions for specialist bandages need to specify exact type of dressing and justify why it is being prescribed to overcome any formulary barriers
 - Assistance may also be needed for pharmacy re: how to order stock
- In theory HCPs are receptive to more information about EB, but this should target the most effective channels and sources to ensure engagement
- Positive reactions to a 'GP' pack of information – HCPs more likely to use information with NHS and specialist centre endorsement

EB Patient Survey

Detailed findings

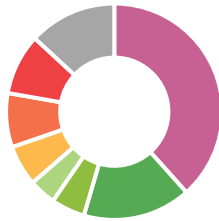
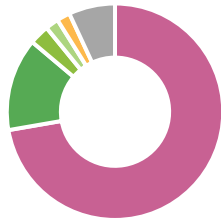
EB diagnosis & management

Delays to diagnosis evident - although c. three quarters EB patients experienced symptoms from birth, only 38% were diagnosed at birth



95% patients have an EB diagnosis from a healthcare professional

When did EB patients experience their first symptoms, and get diagnosed?



| % EB patients | Age of first symptoms (n=318) | Age of diagnosis (n=298 diagnosed) |
|---------------------------|-------------------------------|------------------------------------|
| From birth | 73% | 38% |
| 0-2yrs | 14% | 16% |
| 2-5yrs | 3% | 5% |
| 5-10yrs | 2% | 4% |
| 10-16yrs | 2% | 6% |
| 16-30yrs | - | 8% |
| 30+ yrs | - | 9% |
| Not sure / can't remember | 7% | 13% |



Only 65% patients received their EB diagnosis within 1 year of experiencing symptoms

- 9% received a diagnosis within 1-5 years of experiencing symptoms
- For 13%, it took between 5 and 20 years
- For 14% it took 20 years or longer



Once patients presented to a healthcare professional, it took 6 months or less to receive a diagnosis for three quarters of EB patients (76% of the n=186 who could remember how long the diagnosis took)

- For the remaining quarter, it took longer than 6 months

On average EB Simplex patients experience first symptoms and are diagnosed later than other EB types

Base 318 (215 Patients, 103 Carers)

S1 What is your age? S3 What is the age of the person you are supporting / were supporting when they died?

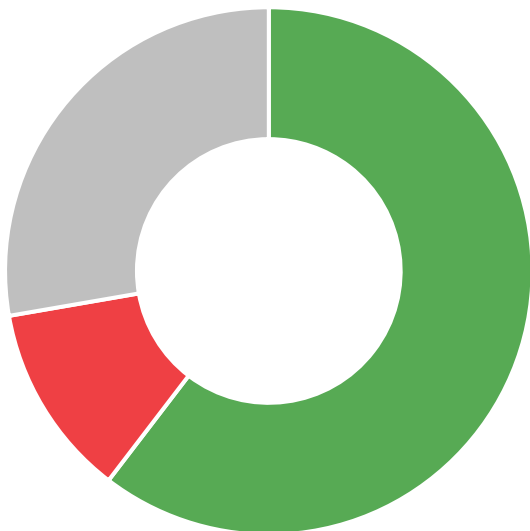
Q3 How old were you / the person you care for / the person you cared for when you / they first started to experience symptoms of EB? Q5 Have you / the person you care(d) for been told you have EB / been given an EB diagnosis by a healthcare professional? Q7 What age were you / they when you / they were diagnosed by a healthcare professional? Q8 How long did it take from when you / they first saw a healthcare professional about your / their EB symptoms, to getting diagnosed with EB?

On average EB Simplex patients experience first symptoms and are diagnosed later than other EB types

| | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|------|------|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Mean patient age (years) | 38.1 | 39.9 | 36.4 | 24.2 | 34.2 | 48.5 | 16.3 | 41.0 | 40.4 | 25.3 | 39.2 |
| Mean age of first symptoms (years, at birth = 0) | 0.8 | 1.1 | 0.1 | 0.6 | 0.0 | 1.1 | 0.2 | 0.9 | 1.1 | 0.3 | 0.7 |
| % experiencing first symptoms from... | | | | | | | | | | | |
| Birth | 73% | 65% | 87% | 77% | 100% | 69% | 80% | 65% | 74% | 97% | 66% |
| 0-2yrs | 14% | 17% | 8% | 8% | 0% | 13% | 16% | 18% | 11% | 0% | 19% |
| 2-5yrs | 3% | 4% | 1% | 0% | 0% | 4% | 1% | 7% | 1% | 0% | 2% |
| 5-10yrs | 2% | 3% | 0% | 8% | 0% | 2% | 1% | 4% | 1% | 0% | 2% |
| 10-16yrs | 2% | 3% | 0% | 0% | 0% | 2% | 0% | 1% | 2% | 3% | 1% |
| 16-30yrs | <1% | <1% | 0% | 0% | 0% | <1% | 0% | 0% | 1% | 0% | 0% |
| 30+ yrs | <1% | 0% | 0% | 0% | 0% | <1% | 0% | 0% | 1% | 0% | 0% |
| % EB patients who have received an official diagnosis | 95% | 94% | 96% | 100% | 100% | 95% | 94% | 92% | 97% | 95% | 95% |
| Mean age of diagnosis (years, birth = 0) | 8.8 | 11.9 | 3.7 | 8.2 | 0.6 | 12.3 | 2.5 | 8.0 | 10.1 | 9.0 | 3.3 |
| Mean time in years from first symptoms to diagnosis | 6.9 | 9.6 | 2.8 | 4.7 | 0.6 | 10.0 | 1.6 | 8.9 | 5.6 | 3.0 | 9.1 |

All JEB and KEB patients are under specialist EB care, but only half of SEB and three quarters of DEB patients are (almost 40% SEB have *never* been seen)
Overall 40% EB patients are not currently under EB specialist care

Is the EB patient under the care of an EB specialist hospital?



The following were named as EB specialist centres:

- Guys & St Thomas Hospitals, London
- Great Ormond Street Hospital, London
- Solihull Hospital
- Birmingham Children's Hospital
- Glasgow Royal Hospital for Children/Queen Elizabeth University Hospital

| % patients | | Total | N=193 SEB | N=97 DEB | N=13 JEB | N=5 KEB | Mild N=83 | Moderate N=108 | Severe N=39 | It depends N=85 |
|------------|--|-------|--------------|-------------|-------------|------------|--------------|-------------------|----------------|--------------------|
| ■ | Yes – under the care of one of these hospitals | 60% | 50% | 77% | 100% | 100% | 39% | 69% | 82% | 61% |
| ■ | Was previously under the care of one of these hospitals, but not seen at any of them anymore | 12% | 12% | 13% | 0% | 0% | 20% | 10% | 3% | 9% |
| ■ | No – not under the care of any specialist hospital for EB | 28% | 38% | 9% | 0% | 0% | 41% | 20% | 15% | 29% |

DEBRA members, younger patients, ethnic minority patients and patients in the south of England are most likely to be under EB specialist care
Patients who are older, white, and from Scotland or North England are more likely to have disengaged from specialist care or not be under specialist care at all

Base 318 (215 Patients, 103 Carers)

Q9 Are you / is the person you care for / Was the person you cared for under the care of a specialist EB centre for your / their EB?

DEBRA members, younger patients, ethnic minority patients and patients in the south of England are most likely to be under EB specialist care
Patients who are older, white, and from Scotland or North England are more likely to have disengaged from specialist care or not be under specialist care at all

| % patients / carers | Total | DEBRA Member | | Patient Age | | | | | | Patient Gender | | Patient ethnicity | | Location | | | | | | |
|--|-------|--------------|-----|----------------|-------|-------------------------|-------------|-------------|-----------|----------------|--------|-------------------|-----------------|----------|----------|-------|------|---------------|-----------------|---------------|
| | | Yes | No | Baby / toddler | Child | Teenager / young person | Adult 21-40 | Adult 41-60 | Adult 61+ | Male | Female | White | Ethnic minority | England | Scotland | Wales | NI | North England | East & Midlands | South England |
| N= | 318 | 286 | 32 | 20 | 38 | 23 | 93 | 79 | 65 | 109 | 201 | 292 | 24 | 253 | 45 | 14 | 6 | 46 | 81 | 126 |
| Yes – under the care of one of these hospitals | 61% | 64% | 34% | 95% | 89% | 78% | 62% | 49% | 38% | 64% | 58% | 58% | 88% | 66% | 38% | 57% | 0% | 57% | 63% | 72% |
| Was previously under the care of one of these hospitals, but not seen at any of them anymore | 12% | 10% | 25% | 0% | 0% | 17% | 13% | 18% | 11% | 10% | 13% | 13% | 0% | 10% | 20% | 14% | 0% | 0% | 15% | 11% |
| No – not under the care of any specialist hospital for EB | 28% | 26% | 41% | 5% | 11% | 4% | 25% | 33% | 51% | 26% | 29% | 29% | 13% | 23% | 42% | 29% | 100% | 43% | 22% | 17% |

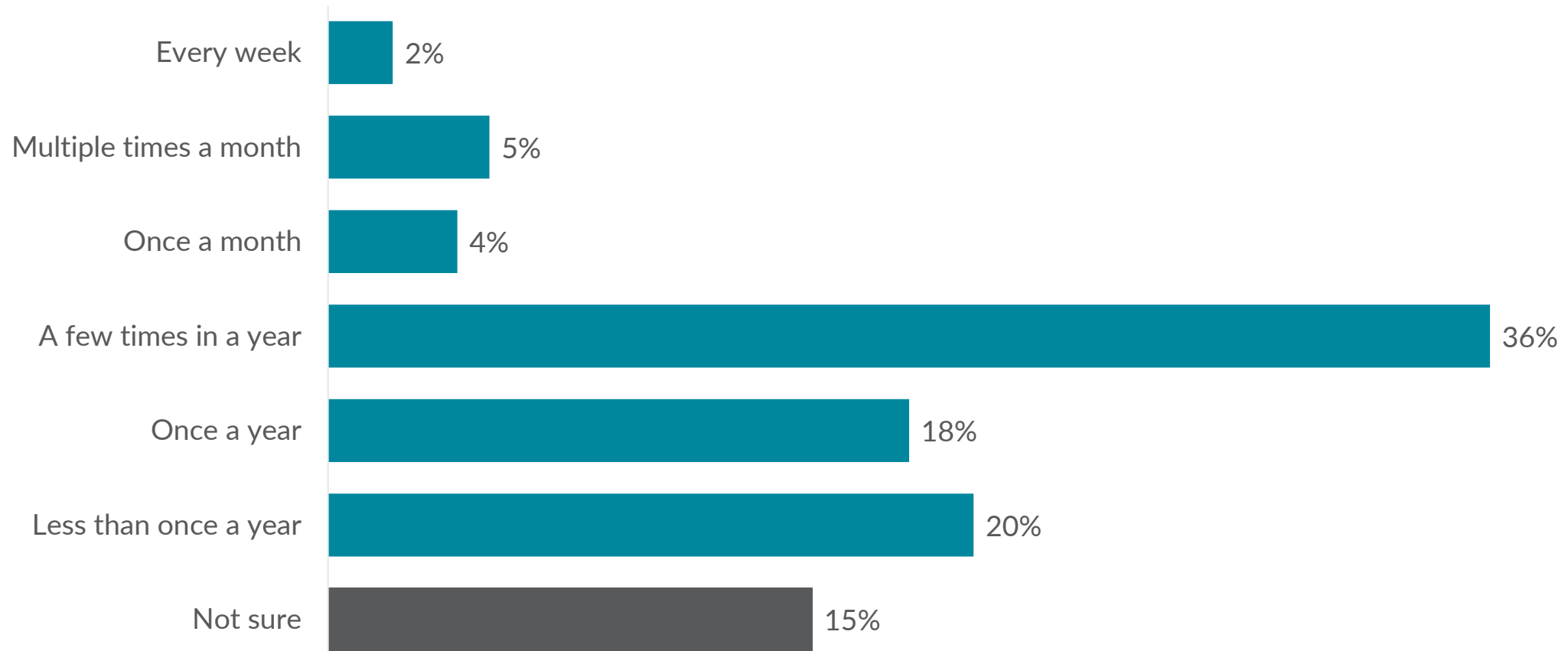
NB a specialist hospital in Northern Ireland was not named in the question

Base 318 (215 Patients, 103 Carers)

Q9 Are you / is the person you care for / Was the person you cared for under the care of a specialist EB centre for your / their EB?

C. half of EB patients attend medical appointments / see HCPs about their EB or relevant issues once or a few times a year; for two fifths this is less than once a year, and for a minority it is more frequent (once a month or more)

On average how frequently do you attend medical appointments or see healthcare professionals about your EB or issues relating to your EB?



Base 305 (215 Patients & 90 Current Carers)

Q15B On average how frequently do you attend medical appointments or see healthcare professionals about your EB or issues relating to your EB? /
On average, how frequently do you support the person you care for to attend medical appointments or see healthcare professionals about their EB or issues relating to their EB?

Typically, EB patients attend medical appointments / see HCPs about their EB or relevant issues a few times a year

| % Patients / carers selecting option | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--------------------------------------|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 305 | 190 | 91 | 10 | 5 | 215 | 90 | 83 | 106 | 30 | 84 |
| Every week | 2% | 2% | 4% | 0% | 0% | 1% | 6% | 0% | 3% | 10% | 1% |
| Multiple times a month | 5% | 3% | 8% | 30% | 0% | 1% | 13% | 0% | 3% | 20% | 6% |
| Once a month | 4% | 1% | 7% | 30% | 20% | 1% | 11% | 1% | 4% | 7% | 6% |
| A few times in a year | 36% | 27% | 53% | 40% | 60% | 32% | 44% | 22% | 49% | 37% | 32% |
| Once a year | 18% | 21% | 13% | 0% | 20% | 19% | 16% | 20% | 18% | 7% | 19% |
| Less than once a year | 20% | 27% | 7% | 0% | 0% | 27% | 3% | 37% | 12% | 10% | 17% |
| Not sure / not applicable | 15% | 20% | 9% | 0% | 0% | 19% | 7% | 19% | 11% | 10% | 19% |

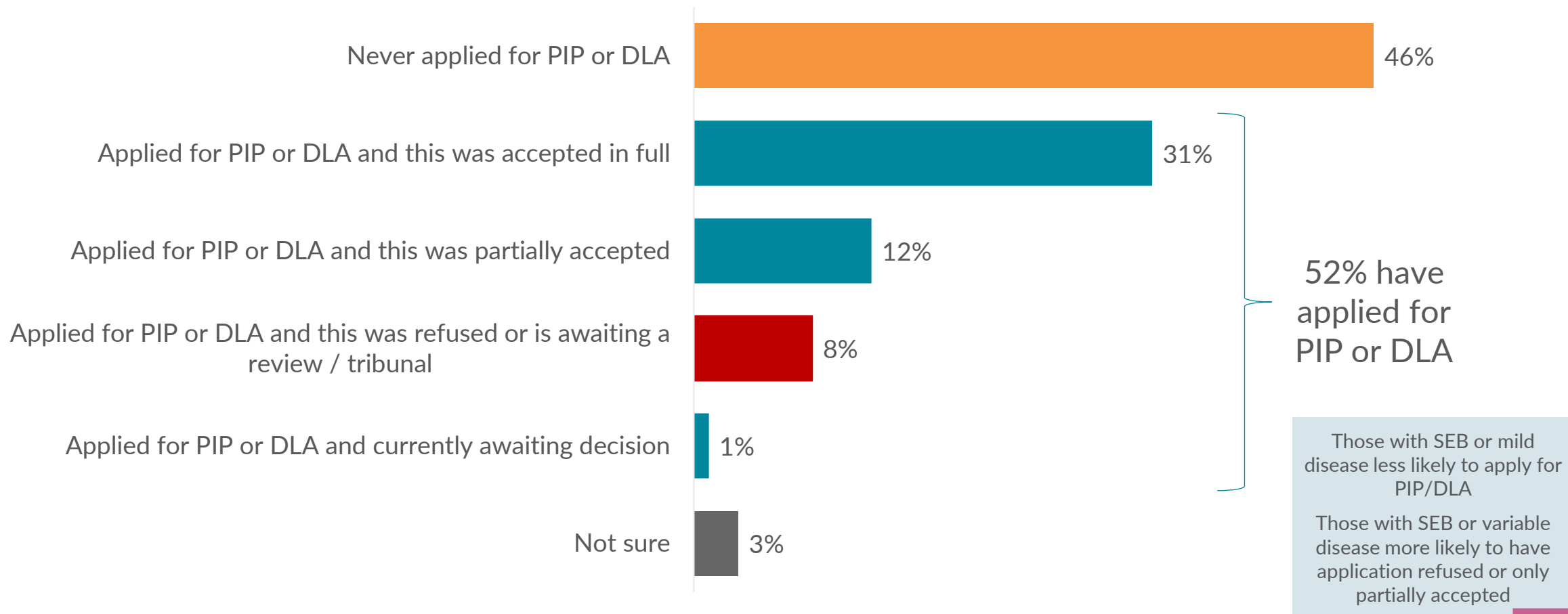
N.B. caution interpreting percentages with a low base

Base 305 (215 patients and 90 current carers)

Q15B On average how frequently do you attend medical appointments or see healthcare professionals about your EB or issues relating to your EB? / On average, how frequently do you support the person you care for to attend medical appointments or see healthcare professionals about their EB or issues relating to their EB?

52% patients have applied for PIP or DLA; 8% have had their application refused or sent for review, and a further 12% were only partially accepted

Which of the following apply to you regarding applications for PIP (personal independence payment) or DLA (disability living allowance)?



Base 318 (215 patients and 103 carers)

Q17 Which of the following apply to you / the person you care(d) for regarding applications for PIP (personal independence payment) or DLA (disability living allowance)?

Those with SEB or mild disease less likely to apply for PIP/DLA
Those with SEB or variable disease severity more likely to have application refused or only partially accepted
97% severe patients have applied for PIP/DLA; JEB/DEB applications most likely to be accepted in full

| % patients / carers selecting option | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Never applied for PIP or DLA | 46% | 50% | 39% | 18% | 0% | 57% | 20% | 82% | 41% | 0% | 36% |
| Applied for PIP or DLA and this was accepted in full | 31% | 24% | 42% | 82% | 20% | 20% | 53% | 8% | 35% | 86% | 22% |
| Applied for PIP or DLA and this was partially accepted | 12% | 13% | 9% | 0% | 60% | 10% | 16% | 1% | 13% | 9% | 22% |
| Applied for PIP or DLA and this was refused or is awaiting a review / tribunal following refusal | 8% | 10% | 3% | 0% | 20% | 9% | 6% | 6% | 6% | 3% | 14% |
| Applied for PIP or DLA and currently awaiting decision | 1% | 1% | 2% | 0% | 0% | 1% | 1% | 1% | 3% | 0% | 0% |
| Not sure | 3% | 2% | 4% | 0% | 0% | 2% | 3% | 1% | 2% | 3% | 5% |

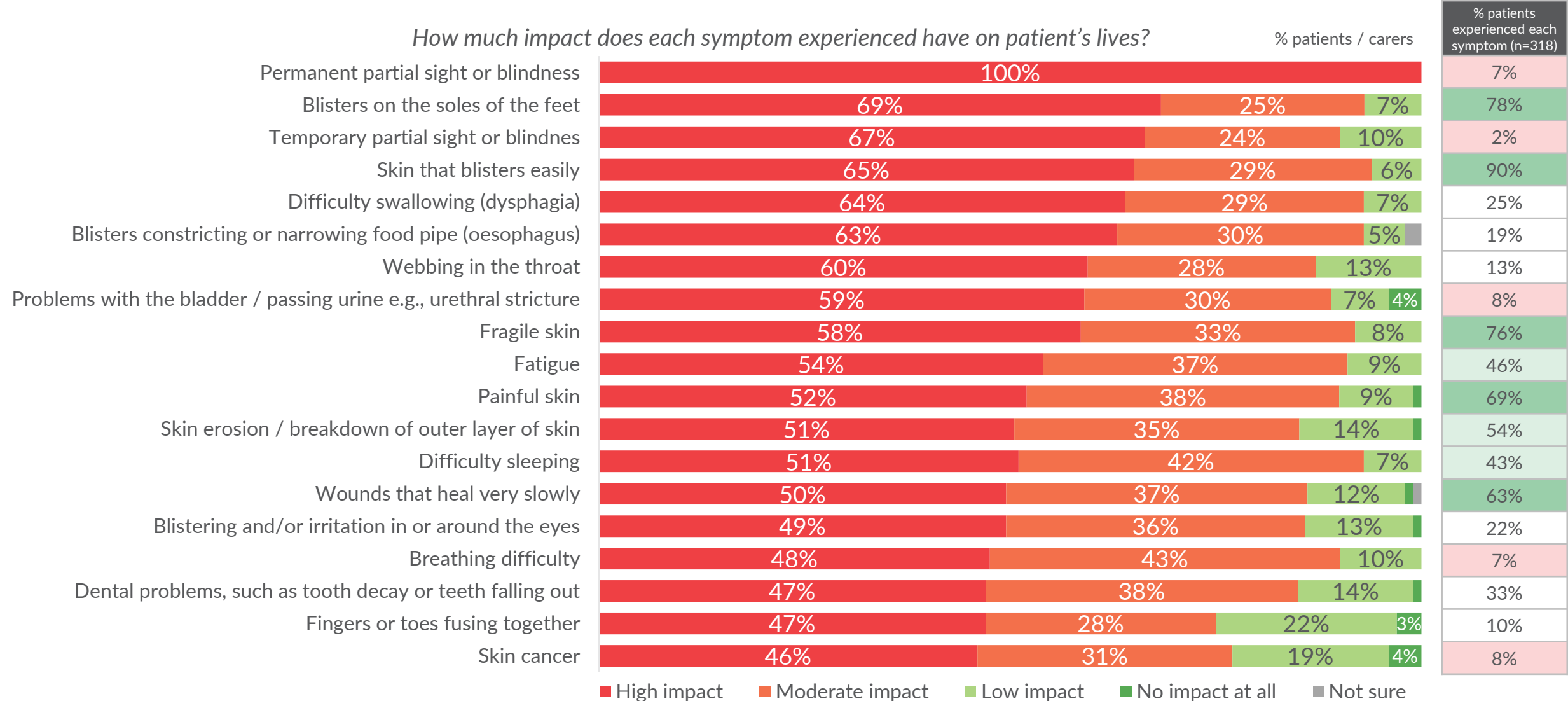
N.B. caution interpreting percentages with a low base

Base 318 (215 patients and 103 carers)

Q17 Which of the following apply to you / the person you care(d) for regarding applications for PIP (personal independence payment) or DLA (disability living allowance)?

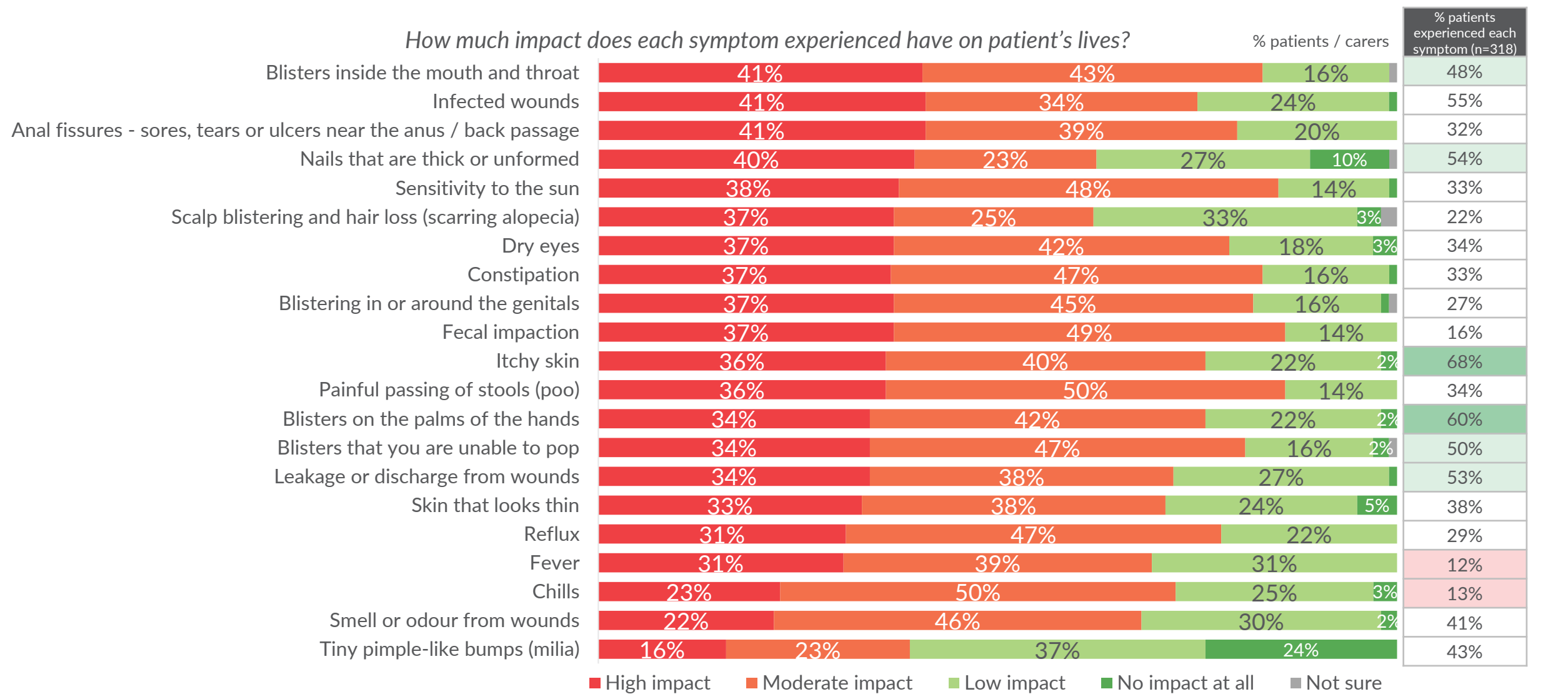
EB Symptoms & Impact on QOL

Skin that blisters easily, blisters on soles of feet and fragile skin are experienced by at least ¾ patients and for the majority this highly impacts their daily lives;
Some symptoms highly impact day to day life but are only experienced by a minority of patients



Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable N.B. Percentages <3% not labelled for clarity
Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

Even the less impactful EB symptoms have a high or moderate impact on the daily lives of c. two thirds of patients who experience them



Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

N.B. Percentages <2% not labelled for clarity

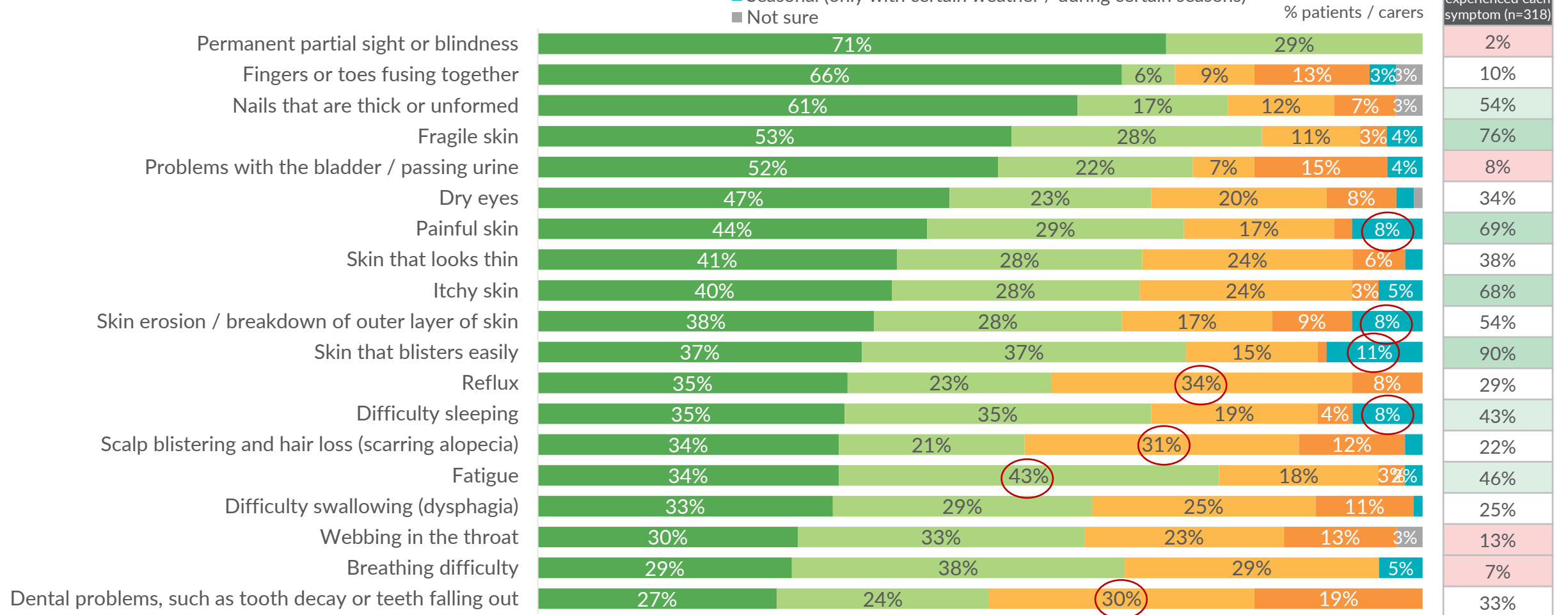
Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

Skin symptoms can be seasonal for some, but for c. three quarters they are frequent or daily Three quarters of those with fatigue experience it frequently (1/2)

Patients Carers

How frequently do patients experience each symptom?

- Every day / most days
- Frequently (often, but not every day)
- Intermittent / variable (can go for weeks or months without experiencing)
- Rarely (can go several months or years without experiencing)
- Seasonal (only with certain weather / during certain seasons)
- Not sure



Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

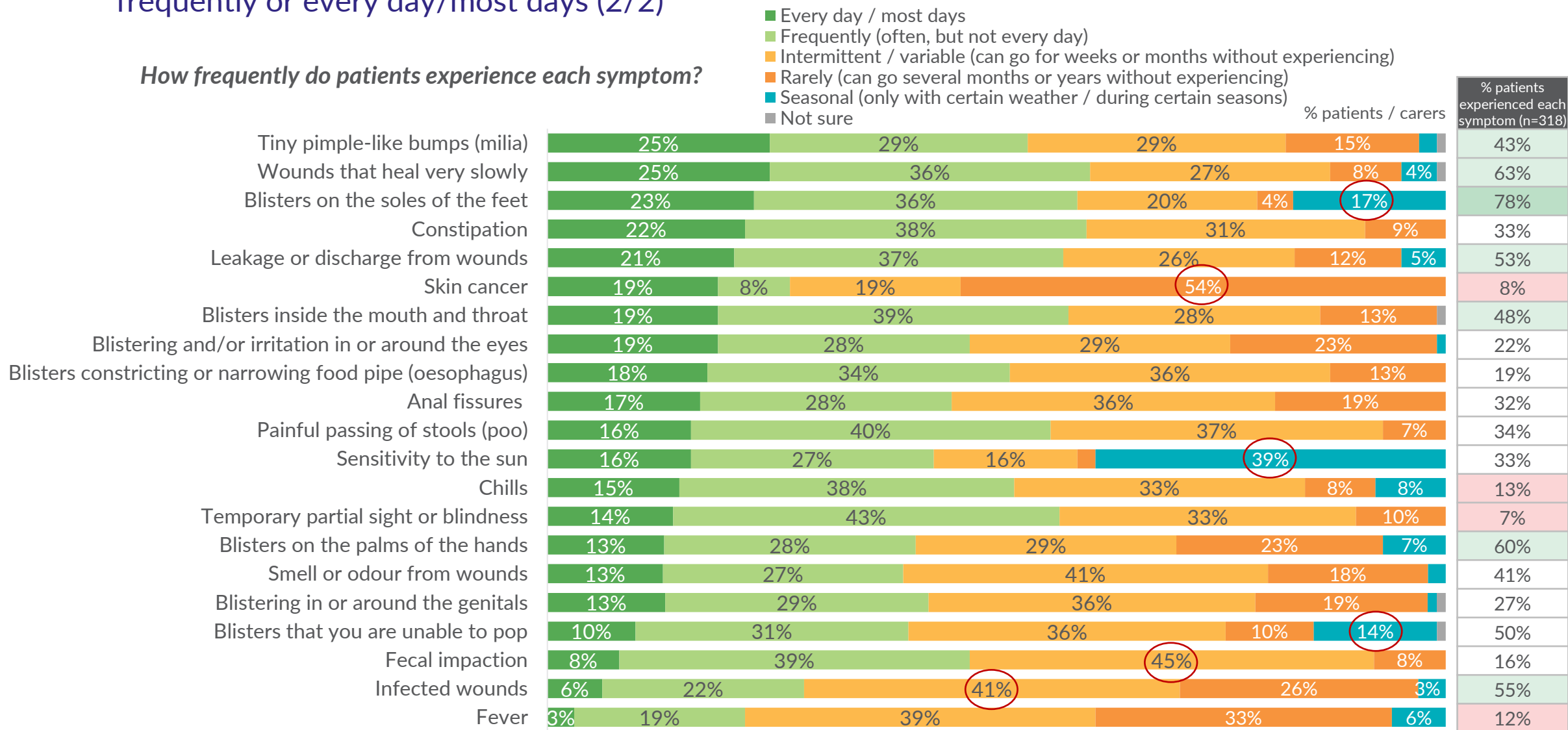
N.B. Percentages <3% not labelled for clarity

Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

Blisters on soles of feet, blisters you are unable to pop and sensitivity to the sun can be seasonal Three fifths of those with slow healing wounds and blisters in mouth/throat experience this frequently or every day/most days (2/2)

Patients Carers

How frequently do patients experience each symptom?



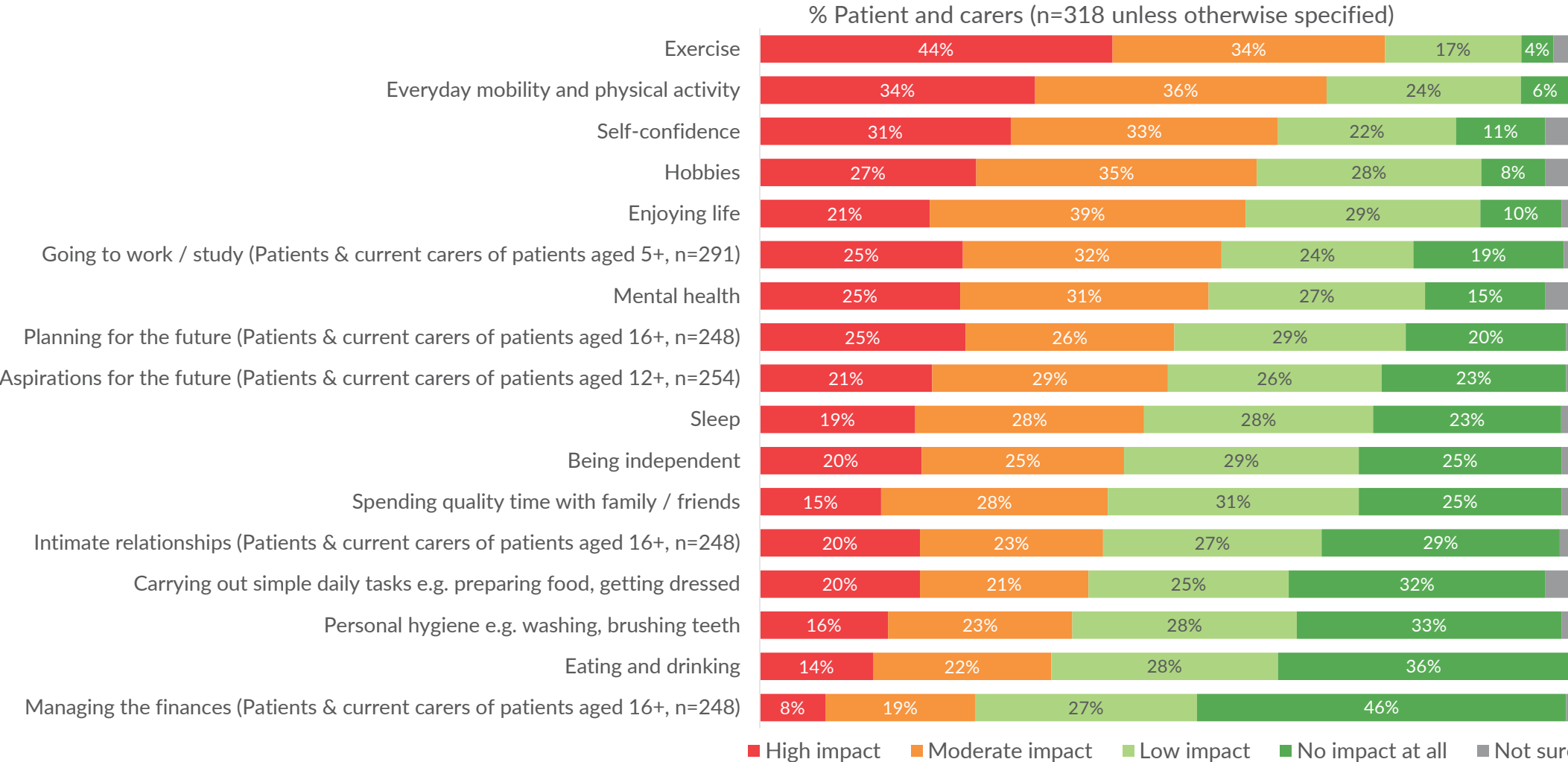
Base Patients & Carers (excluding past carers of patients under 2); Base for each symptom variable

N.B. Percentages <3% not labelled for clarity

Q14A For each of the symptoms you / the person you care(d) for have experienced, please tell us: How much impact they have had on your / their daily life? Q14B How frequently the symptom affects you / them?

EB highly impacts patients' ability to exercise and be mobile and active; over half state EB has moderate/high impact on their self-confidence, hobbies, enjoying life, working/studying, and mental health; planning and aspirations for future are moderately/highly impacted for c. half

Please tell us how much impact EB has / had on each of these aspects of you / the person you care for's life (prompted)



Greater EB severity correlates with extent of impact EB has on all aspects of life

For 80% SEB patients exercise is moderately or highly impacted, but there is less impact on ability to care for themselves

For DEB patients self-confidence, intimate relationships and managing finances is particularly affected

For JEB, every-day mobility, simple tasks and sleep are most impacted

Impact correlates with disease severity; for SEB there is less impact on ability to care for themselves

Patients

Carers

| % selecting high or moderate impact | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Exercise | 77% | 80% | 73% | 91% | 60% | 78% | 77% | 55% | 82% | 89% | 87% |
| Everyday mobility and physical activity | 70% | 68% | 73% | 82% | 80% | 67% | 77% | 35% | 81% | 100% | 75% |
| Self-confidence | 64% | 56% | 77% | 64% | 80% | 64% | 63% | 42% | 69% | 97% | 64% |
| Hobbies | 61% | 60% | 64% | 64% | 60% | 60% | 62% | 33% | 71% | 89% | 65% |
| Enjoying life | 60% | 56% | 66% | 64% | 60% | 57% | 67% | 30% | 66% | 94% | 69% |
| Going to work / study (n=291) | 57% | 53% | 66% | 67% | 75% | 53% | 68% | 28% | 68% | 97% | 56% |
| Mental health | 55% | 51% | 63% | 55% | 60% | 54% | 57% | 34% | 58% | 89% | 59% |
| Planning for the future (n=248) | 51% | 46% | 64% | 50% | 75% | 48% | 70% | 21% | 55% | 100% | 61% |
| Aspirations for the future (n=254) | 50% | 44% | 69% | 33% | 75% | 47% | 72% | 22% | 57% | 95% | 58% |
| Sleep | 47% | 36% | 66% | 73% | 20% | 41% | 59% | 24% | 48% | 91% | 49% |
| Being independent | 45% | 38% | 59% | 64% | 60% | 38% | 60% | 10% | 49% | 97% | 51% |
| Spending quality time with family / friends | 43% | 42% | 47% | 55% | 60% | 39% | 54% | 17% | 47% | 91% | 45% |
| Intimate relationships (n=248) | 42% | 32% | 66% | 50% | 50% | 40% | 55% | 21% | 48% | 83% | 43% |
| Carrying out simple daily tasks e.g. preparing food, getting dressed | 41% | 31% | 58% | 64% | 80% | 34% | 55% | 10% | 48% | 97% | 36% |
| Personal hygiene e.g. washing, brushing teeth | 38% | 25% | 59% | 55% | 100% | 33% | 50% | 12% | 40% | 97% | 36% |
| Eating and drinking | 36% | 19% | 64% | 55% | 100% | 31% | 47% | 11% | 44% | 83% | 31% |
| Managing the finances (n=248) | 27% | 22% | 37% | 17% | 50% | 26% | 30% | 6% | 26% | 65% | 36% |

Base 318 (215 Patients and 103 carers) – bases variable where stated

Q14C Please tell us how much impact EB has / had on each of these aspects of you / the person you care(d) for daily life.

N.B. caution interpreting percentages with a low base

On a typical day, the most time each day is spent resting / recovering, with about an hour each for hygiene and blister care, but much longer for severe patients

*Please think about a typical day. On average, how much time do you spend on each of the following activities?
(prompted)*

| | % who spend 0 hours per day on activity | Of those who do undertake each activity, mean hours a day spent on each activity | |
|------------------------------------|---|--|--|
| Time spent resting / recovering | 33% | 4.1 | Severe and variable spend more time resting |
| Time spent on hobbies | 32% | 1.7 | Mild spend slightly more time on hobbies |
| Time spent on personal hygiene | 15% | 1.2 | Severe spend more time on hygiene |
| Time spent on blister / wound care | 19% | 1.0 | Significantly more time spent on blister / wound care for severe |
| Time spent on food prep | 55% | 1.0 | JEB and severe spend more time |
| Time spent getting dressed | 21% | 0.6 | Severe and variable much more time |

Base All patients able to answer (172)
Q15 Please think about a typical day. On average, how much time do you spend on each of the following activities?

Severe patients spend much longer undertaking activities of daily living

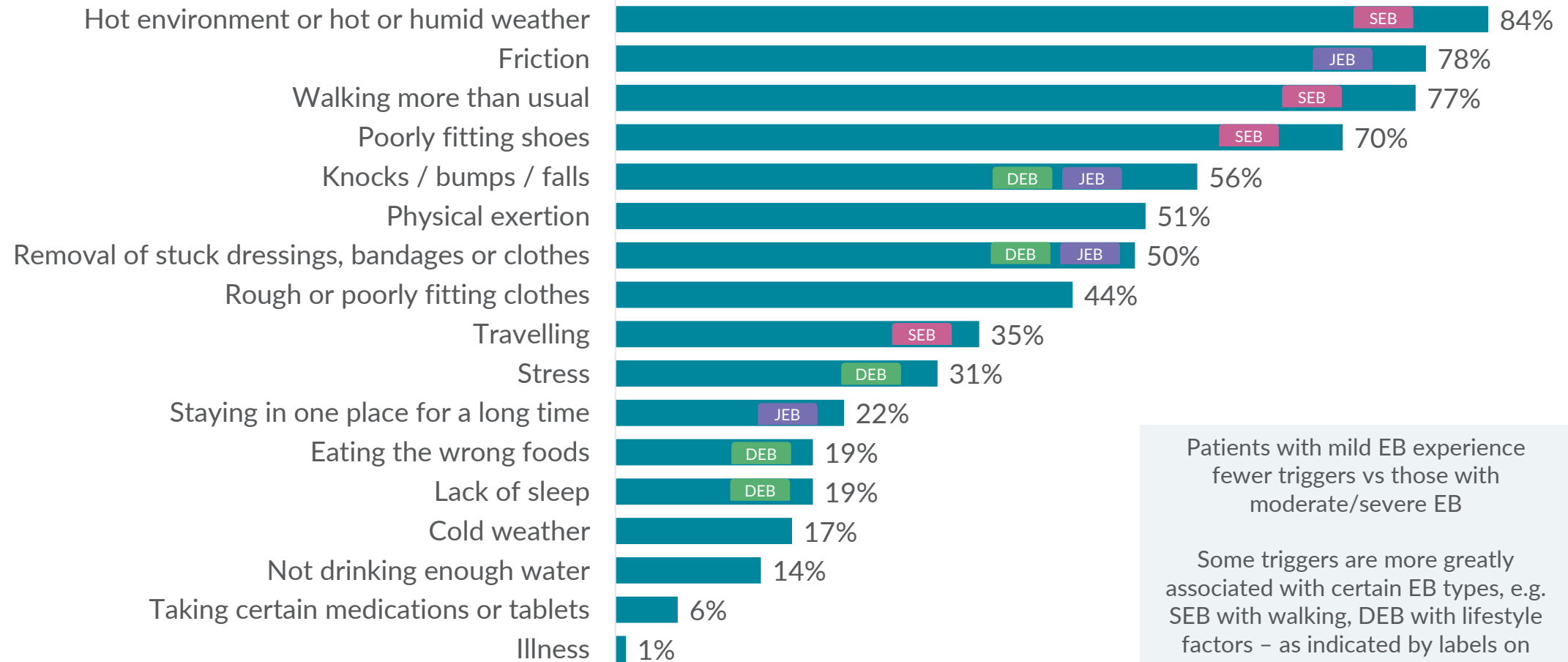
| Of those undertaking the activity, mean hours spent | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 172 | 104 | 53 | 5 | 3 | 172 | | 49 | 63 | 12 | 47 |
| Time spent resting / recovering | 4.1 | 4.4 | 4.0 | 4.3 | 2.8 | 4.1 | - | 3.4 | 3.4 | 6.3 | 5.1 |
| Time spent on hobbies | 1.7 | 1.8 | 1.6 | 2.1 | 1.5 | 1.7 | - | 2.0 | 1.6 | 1.2 | 1.7 |
| Time spent on personal hygiene – bathing, washing, going to the toilet, eye care | 1.2 | 1.1 | 1.4 | 1.3 | 1.0 | 1.2 | - | 1.0 | 1.0 | 2.2 | 1.2 |
| Time spent on blister / wound care including removing and applying dressings or bandages | 1.0 | 0.8 | 1.5 | 1.4 | 0.4 | 1.0 | - | 0.5 | 0.8 | 2.6 | 1.1 |
| Time spent on food preparation – e.g. if needing to puree food | 1.0 | 0.9 | 1.1 | 1.7 | 0.9 | 1.0 | - | 0.9 | 1.0 | 2.0 | 0.8 |
| Time spent on getting dressed | 0.6 | 0.7 | 0.5 | 0.5 | 0.6 | 0.6 | - | 0.3 | 0.5 | 0.7 | 0.9 |

Base All patients who spend time on an activity (172)

Q15 Please think about a typical day. On average, how much time do you spend on each of the following activities?

EB most commonly triggered by heat, friction, walking more than usual and poorly fitting shoes

What, if anything, triggers your EB symptoms to flare up or to get worse? (multicode)



Patients with mild EB experience fewer triggers vs those with moderate/severe EB

Some triggers are more greatly associated with certain EB types, e.g. SEB with walking, DEB with lifestyle factors – as indicated by labels on graph

Base 318 (215 patients, 90 carers)

Q16 What, if anything, triggers your EB symptoms to flare up or to get worse?

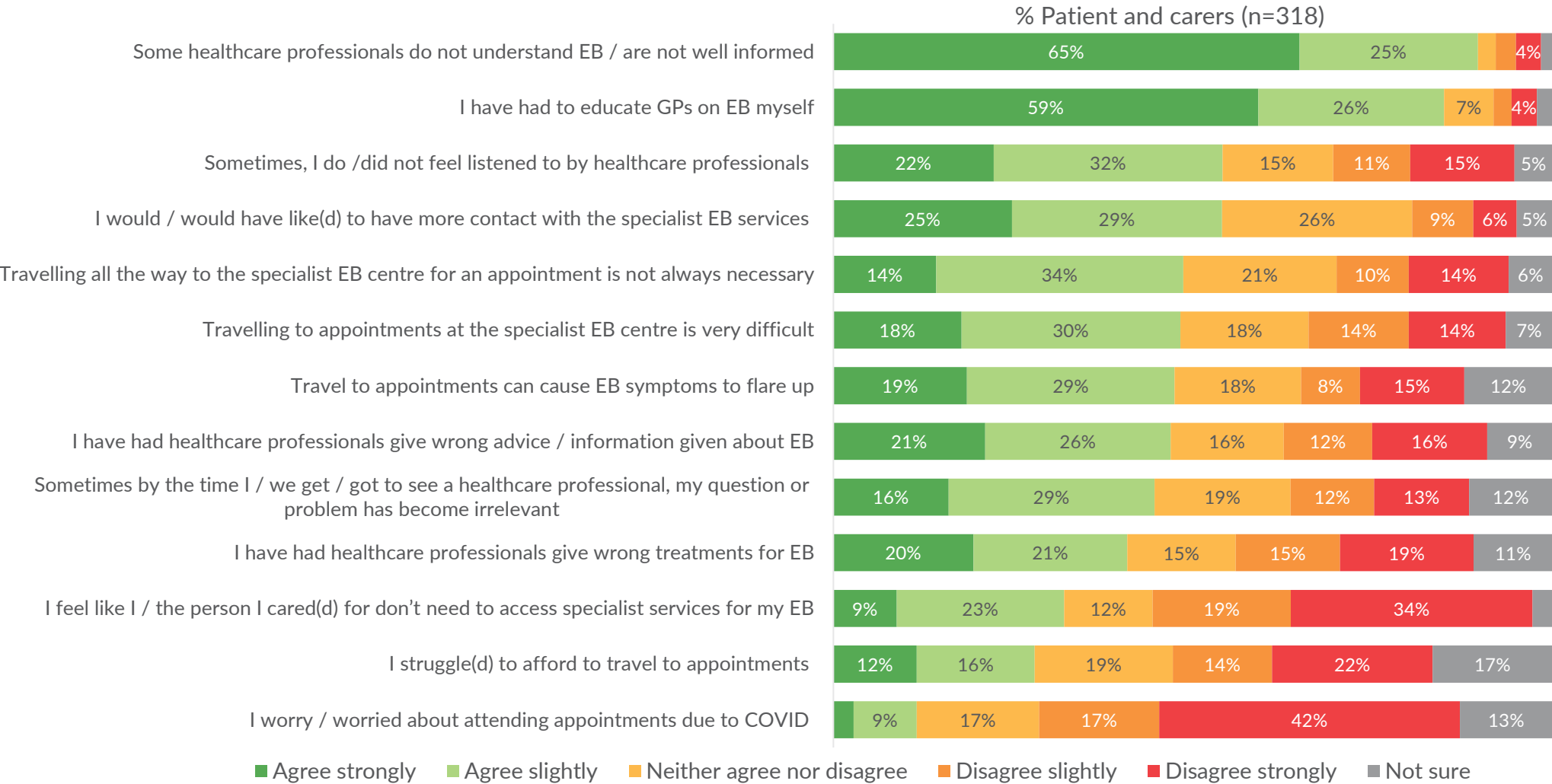
Overall, patients with mild symptoms experience fewer triggers for EB (except walking/shoes), and some triggers are more greatly associated with certain EB types, e.g. SEB with walking / shoes, DEB with lifestyle factors

| % Patients and carers selecting option | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Hot environment or hot or humid weather | 84% | 94% | 68% | 85% | 80% | 83% | 86% | 75% | 83% | 87% | 94% |
| Friction – due to clothing, furniture or other | 78% | 78% | 79% | 92% | 60% | 78% | 79% | 72% | 84% | 85% | 75% |
| Walking more than usual | 77% | 88% | 63% | 62% | 60% | 79% | 74% | 67% | 81% | 62% | 89% |
| Poorly fitting shoes | 70% | 75% | 65% | 54% | 60% | 74% | 62% | 70% | 73% | 59% | 73% |
| Knocks / bumps / falls | 56% | 36% | 91% | 85% | 60% | 50% | 70% | 47% | 65% | 82% | 42% |
| Physical exertion | 51% | 56% | 43% | 46% | 40% | 52% | 49% | 35% | 59% | 56% | 55% |
| Removal of stuck dressings, bandages or clothes | 50% | 38% | 71% | 85% | 40% | 44% | 63% | 25% | 56% | 85% | 52% |
| Rough or poorly fitting clothes | 44% | 44% | 47% | 54% | 20% | 39% | 55% | 29% | 50% | 64% | 42% |
| Travelling | 35% | 40% | 29% | 38% | 40% | 34% | 37% | 17% | 41% | 56% | 36% |
| Stress | 31% | 21% | 53% | 31% | 20% | 32% | 30% | 18% | 37% | 49% | 28% |
| Staying still in one place for a long time – e.g. long periods of sitting or lying down | 22% | 16% | 29% | 77% | 20% | 19% | 28% | 7% | 22% | 54% | 21% |
| Eating the wrong foods | 19% | 12% | 34% | 31% | 20% | 19% | 20% | 6% | 24% | 46% | 14% |
| Lack of sleep | 19% | 11% | 36% | 23% | 0% | 17% | 24% | 6% | 24% | 46% | 13% |
| Cold weather | 17% | 7% | 36% | 15% | 60% | 19% | 15% | 6% | 22% | 26% | 18% |
| Not drinking enough water | 14% | 7% | 23% | 31% | 60% | 10% | 21% | 6% | 15% | 33% | 9% |
| Taking certain medication or tablets | 6% | 3% | 12% | 15% | 0% | 4% | 11% | 0% | 6% | 28% | 1% |
| Other (please specify) | 3% | 2% | 4% | 0% | 20% | 2% | 4% | 0% | 3% | 5% | 5% |
| Illness | 1% | 1% | 2% | 0% | 0% | 1% | 1% | 2% | 1% | 0% | 0% |
| Nothing / no triggers | 1% | 0% | 2% | 0% | 0% | 1% | 1% | 2% | 0% | 3% | 0% |
| Not sure | 0% | 0% | 0% | 0% | 0% | 0% | 1% | 0% | 0% | 0% | 0% |

Attitudes to care

90% of EB patients and carers feel HCPs do not understand EB and 85% have had to educate GPs on EB themselves; c.half do not feel listened to by healthcare professionals and would like more contact with specialist services

To what extent do you agree or disagree with each of the following statements? (prompted)



Severe, ethnic minority patients and those in North England are more likely to struggle with travelling to appointments, with ethnic minority patients finding them less useful / necessary; SEB & patients with mild symptoms, adults over 61 and c. a quarter those not currently under specialist care more likely to feel they are coping fine without specialist services
SEB, severe & variable severity patients most likely to feel HCPs are not well informed about EB
Carers of young children are most likely to have had to educate GPs on EB themselves and women are more likely to experienced HCP mistreatment or lack of awareness

Severe patients are more likely to struggle with travelling to appointments; SEB patients and those with mild disease slightly more likely to feel they are coping fine without specialist services; SEB patients most likely to feel HCPs are not well informed about EB

Patients

Carers

| % Patients and carers selecting strongly agree | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Some healthcare professionals do not understand EB / are not well informed | 67% | 72% | 65% | 54% | 20% | 66% | 69% | 60% | 67% | 72% | 72% |
| I have had to educate GPs on EB myself | 61% | 66% | 54% | 54% | 80% | 61% | 63% | 60% | 60% | 56% | 67% |
| I would / would have like(d) to have more contact with the specialist EB services | 26% | 26% | 24% | 31% | 40% | 25% | 27% | 14% | 27% | 38% | 28% |
| Sometimes, I do/did not feel listened to by healthcare professionals | 23% | 24% | 22% | 0% | 20% | 20% | 29% | 16% | 25% | 26% | 27% |
| I have had healthcare professionals give wrong advice / information given about EB | 22% | 24% | 20% | 8% | 0% | 25% | 16% | 19% | 22% | 15% | 27% |
| I have had healthcare professionals give wrong treatments for EB | 20% | 21% | 19% | 15% | 0% | 23% | 15% | 22% | 18% | 13% | 24% |
| Travel to appointments can cause EB symptoms to flare up | 19% | 23% | 13% | 23% | 20% | 17% | 24% | 4% | 19% | 33% | 26% |
| Sometimes by the time I / we get to see a healthcare professional, my question or problem has become irrelevant | 17% | 20% | 11% | 15% | 0% | 17% | 15% | 14% | 15% | 15% | 20% |
| Travelling to appointments at the specialist EB centre is very difficult | 13% | 14% | 13% | 15% | 20% | 11% | 18% | 6% | 12% | 28% | 15% |
| I struggle(d) to afford to travel to appointments | 12% | 10% | 15% | 15% | 20% | 12% | 12% | 4% | 13% | 18% | 15% |
| Travelling all the way to the specialist EB centre for an appointment is not always necessary | 11% | 13% | 9% | 8% | 0% | 10% | 13% | 6% | 13% | 8% | 13% |
| I feel like I don't need to access specialist services for my EB – coping fine as I am | 9% | 12% | 4% | 0% | 0% | 11% | 5% | 19% | 5% | 3% | 7% |
| I worry / worried about attending appointments due to COVID | 3% | 1% | 4% | 8% | 20% | 1% | 6% | 1% | 2% | 8% | 2% |

Carers of young children most likely to have had to educate GPs on EB; ethnic minority patients more likely to struggle with travelling to appointments, finding them not always useful / necessary; women more likely to experienced HCP mistreatment or lack of awareness; those in north England more likely to find travelling to specialist centre difficult; older adults (61+) and those not currently under specialist care (c. a quarter) more likely feel they are coping fine as they are without this

Patients

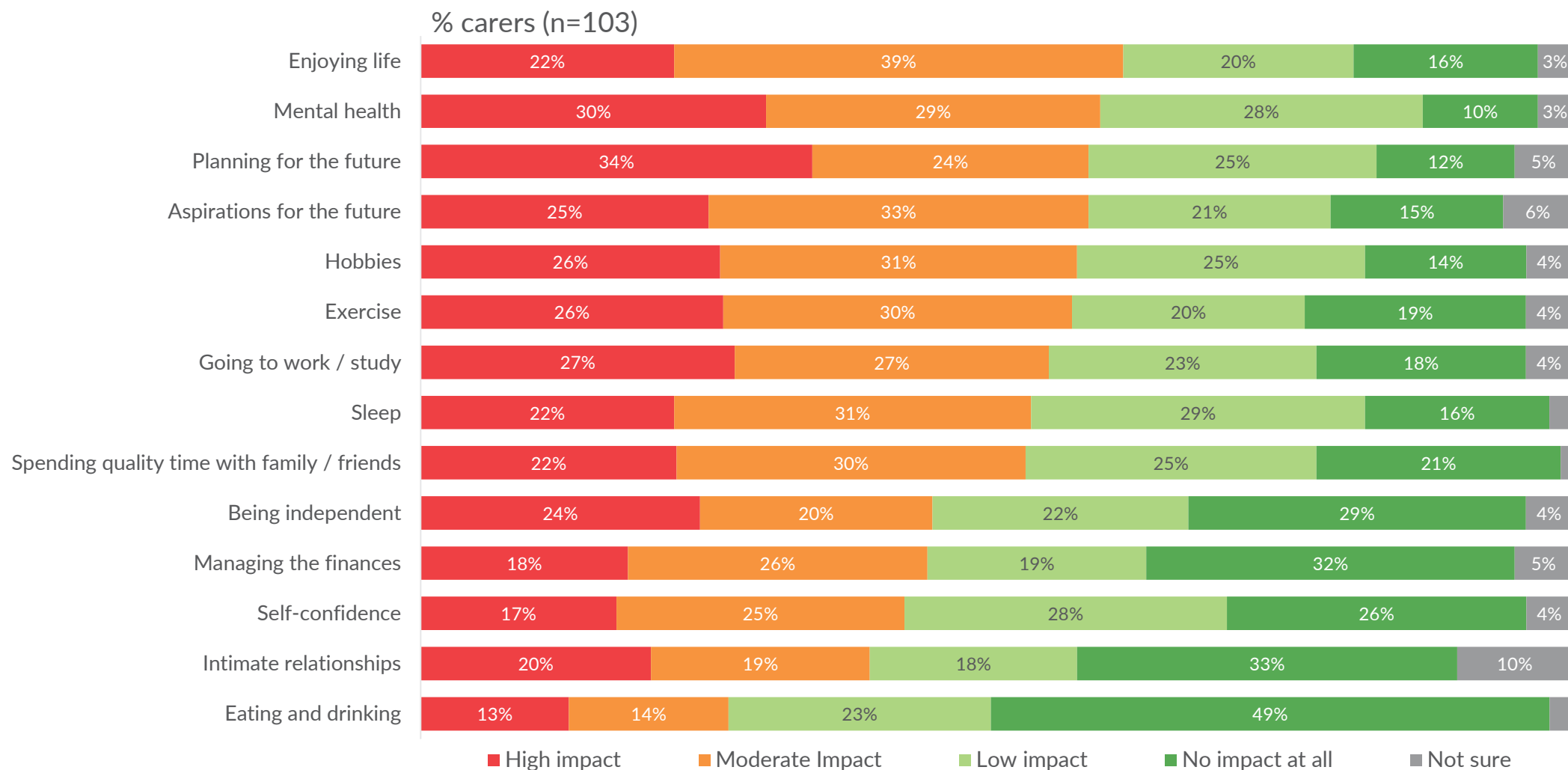
Carers

| %Patients and carers selecting strongly agree | Total | Under care of specialist centre? | | Patient Age | | | | | | Patient Gender | | Patient ethnicity | | Location | | |
|---|-------|----------------------------------|---------------|----------------|-------|-------------------------|-------------|-------------|-----------|----------------|--------|-------------------|-----------------|---------------|-----------------|---------------|
| | | Yes | No / not sure | Baby / toddler | Child | Teenager / young person | Adult 21-40 | Adult 41-60 | Adult 61+ | Male | Female | White | Ethnic minority | North England | East & Midlands | South England |
| N= | 318 | 193 | 125 | 20 | 38 | 23 | 93 | 79 | 65 | 108 | 201 | 292 | 24 | 46 | 81 | 126 |
| Some healthcare professionals do not understand EB / are not well informed | 67% | 64% | 73% | 70% | 76% | 77% | 55% | 71% | 71% | 60% | 71% | 68% | 63% | 63% | 71% | 64% |
| I have had to educate GPs on EB myself | 61% | 60% | 64% | 75% | 73% | 55% | 53% | 67% | 58% | 54% | 65% | 62% | 54% | 53% | 69% | 63% |
| I would like/would have liked to have more contact with the specialist EB services | 26% | 22% | 32% | 30% | 27% | 32% | 27% | 23% | 22% | 24% | 27% | 25% | 33% | 26% | 21% | 22% |
| Sometimes, I do/did not feel listened to by healthcare professionals | 23% | 23% | 23% | 25% | 32% | 27% | 21% | 15% | 29% | 21% | 25% | 24% | 17% | 19% | 18% | 27% |
| I have had healthcare professionals give wrong advice / information given about EB | 22% | 20% | 25% | 15% | 14% | 14% | 26% | 24% | 22% | 15% | 26% | 22% | 13% | 16% | 18% | 24% |
| I have had healthcare professionals give wrong treatments for EB | 20% | 18% | 24% | 20% | 11% | 9% | 18% | 26% | 27% | 12% | 25% | 21% | 8% | 14% | 22% | 19% |
| Travel to appointments can cause EB symptoms to flare up | 19% | 24% | 11% | 25% | 27% | 14% | 18% | 21% | 15% | 14% | 22% | 17% | 42% | 16% | 22% | 22% |
| Sometimes by the time I/we get to see a healthcare professional, my question or problem has become irrelevant | 17% | 15% | 19% | 15% | 14% | 18% | 18% | 18% | 15% | 15% | 17% | 15% | 33% | 19% | 16% | 16% |
| Travelling to appointments at the specialist EB centre is very difficult | 13% | 19% | 4% | 10% | 14% | 36% | 10% | 15% | 8% | 17% | 12% | 12% | 29% | 23% | 10% | 15% |
| I struggle(d) to afford to travel to appointments / | 12% | 14% | 9% | 10% | 16% | 14% | 11% | 17% | 5% | 12% | 12% | 11% | 17% | 14% | 10% | 11% |
| Travelling all the way to the specialist EB centre for an appointment is not always necessary | 11% | 16% | 2% | 20% | 19% | 5% | 8% | 10% | 10% | 11% | 11% | 10% | 25% | 7% | 10% | 17% |
| I feel like I don't need to access specialist services for my EB – coping fine as I am | 9% | 1% | 23% | 10% | 5% | 0% | 9% | 6% | 19% | 7% | 10% | 10% | 4% | 16% | 6% | 6% |
| I worry/worried about attending appointments due to COVID | 3% | 3% | 3% | 10% | 5% | 0% | 1% | 3% | 3% | 3% | 3% | 2% | 4% | 7% | 4% | 1% |

Impact of EB on carers

C.60% of carers for EB patients have found that their caring responsibilities have high/moderate impact their enjoyment of life and mental health

Please tell us how much impact EB has on each aspects of your daily life as a carer for someone with EB. (prompted)



Caring for patients with moderate, severe & variable disease has a greater impact on most aspects of carers lives – 85% of carers for severe patients say their mental health and ability to plan for the future is highly impacted SEB carers less impacted than other EB types in terms of MH, planning and aspirations for the future, managing finances and intimate relationships – but are still are just as impacted in terms of enjoying life

Caring for patients with moderate, severe & variable disease has a greater impact on most aspects of carers lives – 85% of carers for severe patients say their mental health and ability to plan for the future is highly impacted
SEB carers less impacted than other EB types in terms of MH, planning and aspirations for the future, managing finances and intimate relationships – but are still as impacted in terms of enjoying life

| %Patients and carers selecting 'High Impact' | Total | EB Type | | | | Severity | | | |
|--|-------|---------|-----|-----|------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Mild | Moderate | Severe | It depends |
| Total | 103 | 53 | 38 | 8 | 2 | 13 | 33 | 26 | 29 |
| Enjoying life | 61% | 58% | 61% | 75% | 100% | 23% | 61% | 77% | 62% |
| Mental health | 59% | 47% | 71% | 63% | 100% | 46% | 45% | 85% | 55% |
| Planning for the future | 58% | 42% | 74% | 75% | 100% | 46% | 55% | 85% | 41% |
| Aspirations for the future | 58% | 47% | 68% | 75% | 100% | 31% | 52% | 81% | 55% |
| Hobbies | 57% | 57% | 53% | 75% | 100% | 23% | 67% | 65% | 52% |
| Exercise | 56% | 57% | 45% | 88% | 100% | 23% | 67% | 62% | 52% |
| Going to work / study | 54% | 53% | 50% | 75% | 100% | 31% | 52% | 69% | 52% |
| Sleep | 53% | 47% | 53% | 88% | 100% | 23% | 52% | 77% | 45% |
| Spending quality time with family / friends | 52% | 43% | 58% | 75% | 100% | 23% | 52% | 73% | 45% |
| Being independent | 45% | 38% | 47% | 63% | 100% | 31% | 45% | 62% | 31% |
| Managing the finances | 44% | 32% | 50% | 75% | 100% | 23% | 33% | 65% | 41% |
| Self-confidence | 42% | 40% | 37% | 63% | 100% | 8% | 39% | 54% | 45% |
| Intimate relationships | 40% | 25% | 50% | 75% | 100% | 15% | 36% | 65% | 28% |
| Eating and drinking | 26% | 15% | 26% | 75% | 100% | 8% | 27% | 35% | 21% |

N.B. caution interpreting percentages with a low base

On a typical day, the most time each day is spent resting / recovering, with carers spending about an hour each for hygiene and blister care, but much longer for severe patients

| | % who spend 0 hours per day on activity | Of those who do undertake each activity, mean hours a day spent on each activity | |
|------------------------------------|---|--|--|
| Time spent resting / recovering | 38% | 2.2 | Severe and variable spend more time resting |
| Time spent on hobbies | 38% | 2.0 | Mild spend more time on hobbies |
| Time spent on blister / wound care | 9% | 1.3 | Significantly more time spent on blister / wound care for severe |
| Time spent on personal hygiene | 20% | 1.2 | Severe and KEB spend more time on hygiene |
| Checking on pt during the night | 41% | 1.1 | KEB checked on more in the night |
| Time spent on food prep | 58% | 1.0 | KEB spend more time |
| Time spent getting dressed | 28% | 0.6 | JEB, KEB and mild spend more time |

Carers of severe patients spend much longer on blister care and hygiene

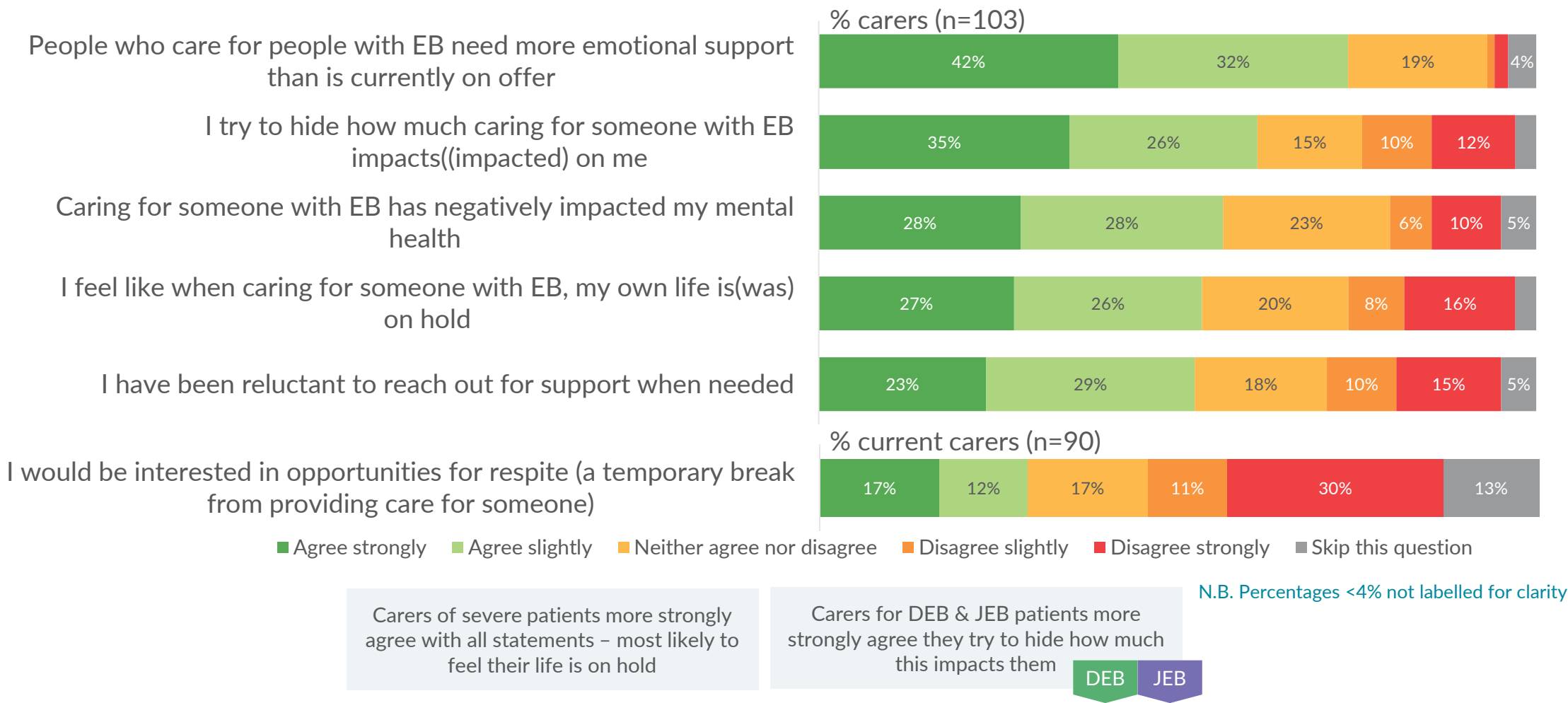
| Of those undertaking the activity, mean hours spent | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 76 | 41 | 28 | 5 | 2 | - | 76 | 11 | 26 | 16 | 22 |
| Time spent resting / recovering | 2.2 | 1.9 | 2.4 | 3.7 | 1.8 | | 2.2 | 0.9 | 2.0 | 2.8 | 2.6 |
| Time spent on hobbies | 2.0 | 2.2 | 1.9 | 2.0 | 0.3 | | 2.0 | 4.3 | 1.4 | 2.9 | 1.5 |
| Time spent on blister / wound care including removing and applying dressings or bandages | 1.3 | 1.2 | 1.5 | 1.8 | 0.6 | | 1.3 | 0.9 | 1.0 | 2.4 | 1.1 |
| Time spent on personal hygiene – bathing, washing, going to the toilet, eye care | 1.2 | 0.9 | 1.5 | 2.3 | 1.1 | | 1.2 | 1.1 | 0.6 | 2.0 | 1.2 |
| Time spent checking on patient including during the night [Carer A only] | 1.1 | 1.3 | 0.9 | 1.7 | 0.6 | | 1.1 | 1.9 | 0.8 | 1.3 | 1.1 |
| Time spent on food preparation – e.g. if needing to puree food | 1.0 | 0.9 | 1.1 | 1.0 | 1.7 | | 1.0 | 1.1 | 0.7 | 1.2 | 1.1 |
| Time spent on getting dressed | 0.6 | 0.6 | 0.6 | 0.9 | 1.1 | | 0.6 | 1.1 | 0.5 | 0.7 | 0.6 |

Base All carers able to answer (76)

Q15 Please think about a typical day. On average, how much time do you spend on each of the following activities?

Over 50% of carers for EB patients feel caring has put their life on hold and negatively impact their mental health; ¾ of carers feel they need more emotional support than is currently offered; respite polarising

To what extent do you agree or disagree with each of the following statements? (prompted)



Base 103 all carers
Q30 To what extent do you agree or disagree with each of the following statements?

Over 50% of carers for individuals with severe symptoms of EB feel their life is on hold due to their caring responsibilities – more interest in respite care

| % Patients and carers selecting strongly agree | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 103 | 53 | 38 | 8 | 2 | - | 103 | 13 | 33 | 26 | 29 |
| People who care for people with EB need more emotional support than is currently on offer | 42% | 42% | 37% | 38% | 100% | - | 42% | 23% | 39% | 54% | 41% |
| I try to hide how much caring for someone with EB impacts((impacted) on me | 35% | 26% | 42% | 50% | 0% | - | 35% | 31% | 27% | 54% | 24% |
| Caring for someone with EB has negatively impacted my mental health | 28% | 23% | 29% | 38% | 50% | - | 28% | 23% | 21% | 50% | 17% |
| I feel like when caring for someone with EB, my own life is(was) on hold | 27% | 23% | 29% | 50% | 0% | - | 27% | 8% | 15% | 54% | 21% |
| I have been reluctant to reach out for support when needed | 23% | 17% | 26% | 38% | 0% | - | 23% | 15% | 15% | 35% | 24% |
| I would be interested in opportunities for respite (a temporary break from providing care for someone) | 15% | 11% | 18% | 13% | 50% | - | 15% | 8% | 9% | 27% | 14% |

N.B. caution interpreting percentages with a low base

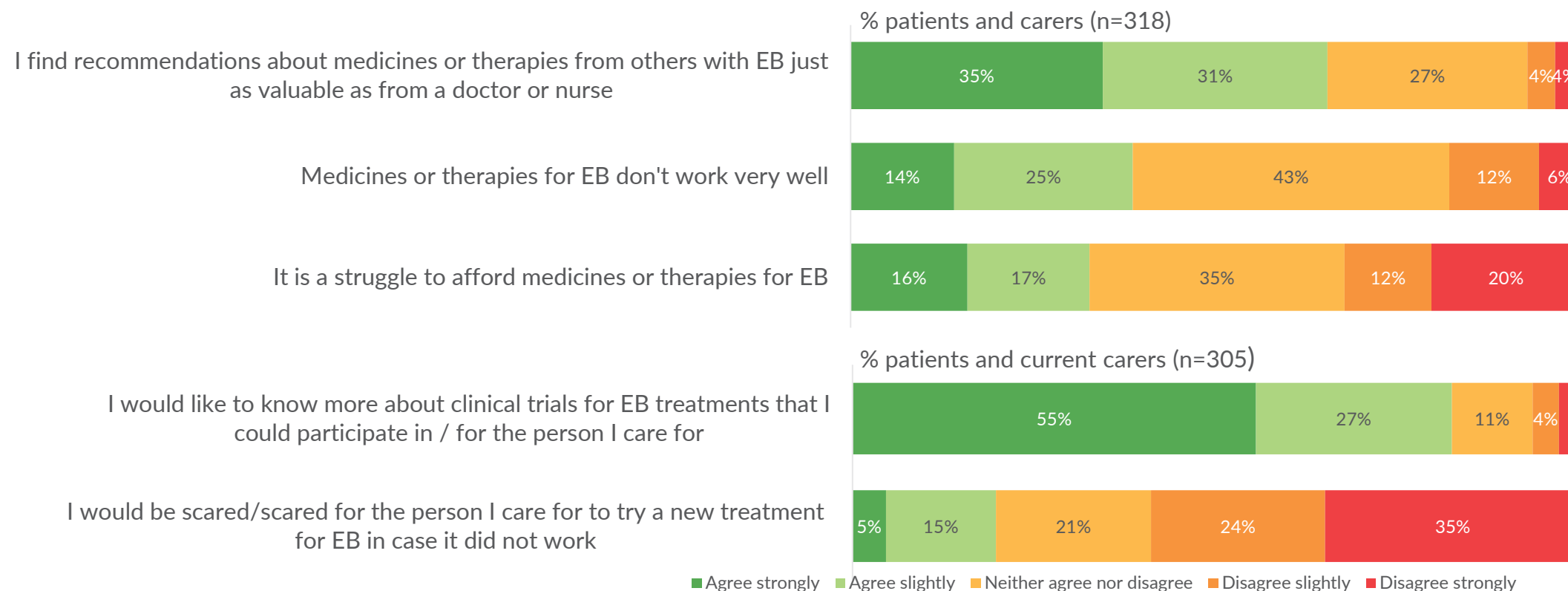
Base 103 all carers

Q30 To what extent do you agree or disagree with each of the following statements?

EB treatments

2/3 of patients and carers find recommendations from other EB patients as useful as advice from HCPs and 4/10 patients and carers feel medicines and therapies for EB don't work; 8/10 would like to know more about clinical trials, 8/10 say they would not be afraid to try new treatments

To what extent do you agree or disagree with each of the following statements about medicines or therapies for EB and symptom management? (prompted)



N.B. Percentages <4% not labelled for clarity

Base 318 (215 Patients and 103 carers)

Q22 To what extent do you agree or disagree with each of the following statements about medicines or therapies for EB, and symptom management?

Moderate / severe more likely to feel that they struggle to afford medicines or therapies for EB and that these treatments aren't very effective

C.20% of patients with moderate to severe symptoms or seasonal symptoms feel that they struggle to afford medicines or therapies for EB and that these treatments aren't very effective, by comparison only 2% of patients with mild EB symptoms

| %Patients and carers selecting strongly agree | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| I find recommendations about medicines or therapies from other people with EB just as valuable as recommendations from a doctor or nurse | 35% | 37% | 27% | 38% | 20% | 31% | 42% | 30% | 40% | 26% | 36% |
| Medicines or therapies for EB don't work very well | 14% | 15% | 12% | 23% | 0% | 12% | 19% | 2% | 18% | 18% | 18% |
| It is a struggle to afford medicines or therapies for EB | 16% | 15% | 21% | 0% | 40% | 14% | 19% | 2% | 19% | 21% | 20% |
| I would like to know more about clinical trials for EB treatments that I could participate in / I would like to know more about clinical trials for EB treatments that the person I care for could participate in | 53% | 59% | 43% | 46% | 60% | 54% | 50% | 42% | 52% | 49% | 68% |
| I would be scared to try a new treatment for EB in case it did not work / I would be scared for the person I care for to try a new treatment for EB in case it did not work | 4% | 4% | 5% | 0% | 0% | 3% | 7% | 1% | 6% | 5% | 5% |

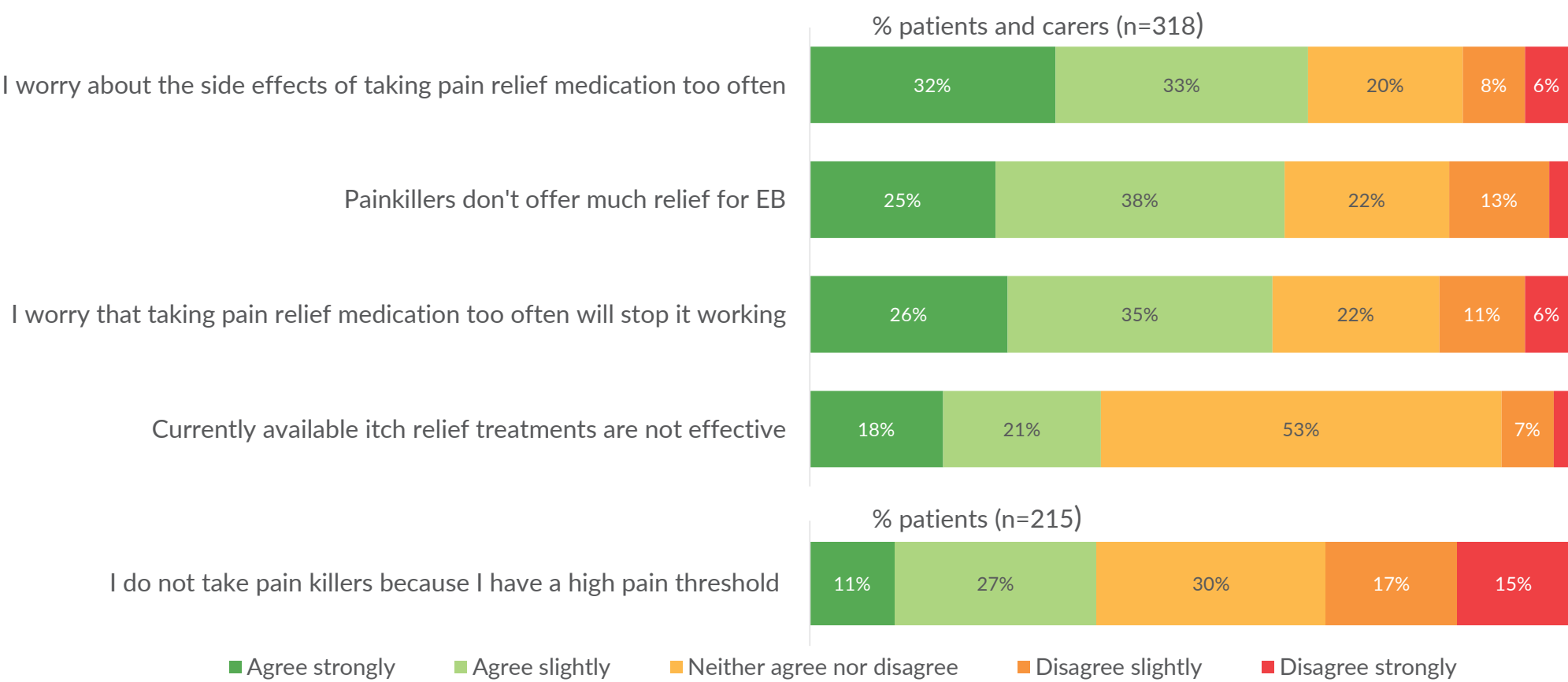
N.B. caution interpreting percentages with a low base

Base 318 (215 patients and 103 carers)

Q22 To what extent do you agree or disagree with each of the following statements about medicines or therapies for EB, and symptom management?

2/3 of patients and carers are worried about side effects of using pain killers too often but also suggest that painkillers don't offer much relief; 6/10 worry that using pain relief too often will stop it working

To what extent do you agree or disagree with each of the following statements about pain killers and itch treatment for EB? (prompted)



Severe more likely to worry about pain relief and find it ineffective; DEB more likely to feel itch relief is not effective

N.B. Percentages <4% not labelled for clarity

Base 318 (215 patients and 103 carers)
Q23 To what extent do you agree or disagree with each of the following statements about pain killers and itch treatment for EB? Carers: When giving your answers, please think about them in relation to how the person you care for uses or used painkillers and itch treatment.

Patients with variable or severe symptoms worry about the side effects of taking pain relief more frequently than patients with mild symptoms; 33% of patients with variable symptom severity also claim that painkiller don't offer much relief

| % Patients and carers selecting strongly agree | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 38 | 215 | 83 | 108 | 39 | 85 |
| I worry about the side effects of taking pain relief medication too often | 32% | 32% | 31% | 38% | 20% | 16% | 29% | 18% | 33% | 46% | 38% |
| I worry that taking pain relief medication too often will stop it working | 26% | 25% | 27% | 38% | 20% | 21% | 22% | 14% | 30% | 41% | 26% |
| Painkillers don't offer much relief for EB | 25% | 28% | 18% | 23% | 0% | 13% | 23% | 13% | 25% | 31% | 33% |
| Currently available itch relief treatments are not effective | 18% | 12% | 29% | 8% | 0% | 24% | 15% | 13% | 21% | 21% | 14% |
| I do not take pain killers because I have a high pain threshold | 8% | 8% | 7% | 0% | 0% | 16% | 11% | 17% | 7% | 3% | 1% |

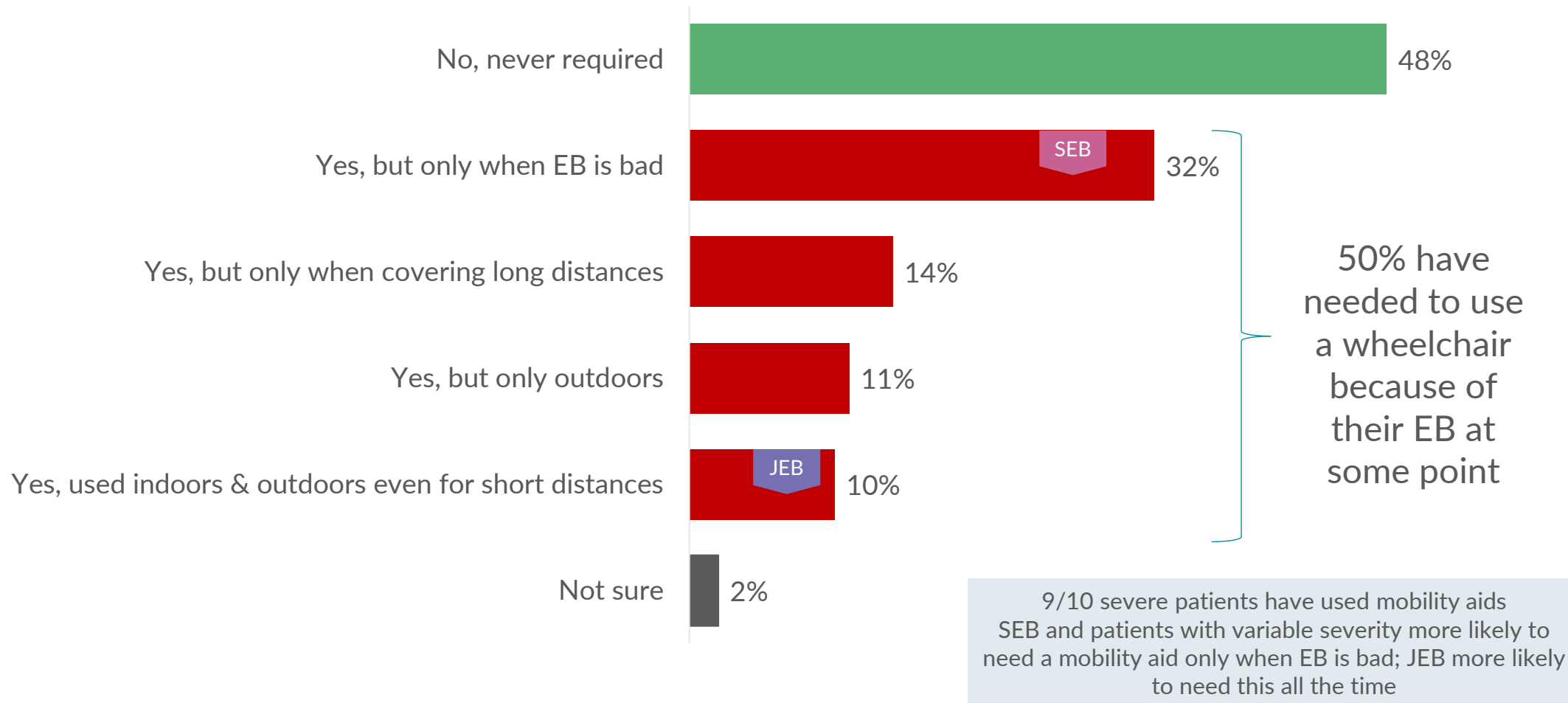
N.B. caution interpreting percentages with a low base

Base 318 (215 patients and 103 carers)

Q23 To what extent do you agree or disagree with each of the following statements about pain killers and itch treatment for EB? Carers: When giving your answers, please think about them in relation to how the person you care for uses or used painkillers and itch treatment.

50% have needed to use a wheelchair or mobility aid at some point

Have you ever needed to use a wheelchair, scooter or other mobility aid or equipment as a result of your EB?



Base 318 (215 patients and 103 carers)

Q23B Have you ever needed to use a wheelchair, scooter or other mobility aid or equipment as a result of your EB?

50% have needed to use a wheelchair or mobility aid at some point; rising to c.9/10 for severe patients

| % Patients and carers selecting option | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|------|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Total | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| No, this has never been required | 48% | 44% | 54% | 27% | 100% | 54% | 34% | 72% | 48% | 9% | 40% |
| Yes, but only used when EB is bad | 32% | 41% | 21% | 0% | 0% | 33% | 32% | 19% | 34% | 26% | 46% |
| Yes, but only used when covering long distances | 14% | 15% | 13% | 18% | 0% | 11% | 20% | 7% | 11% | 23% | 19% |
| Yes, but only used when going outside (no indoor use) | 11% | 10% | 13% | 27% | 0% | 9% | 14% | 5% | 10% | 17% | 13% |
| Yes, used frequently / both indoors and outdoors / even for short distances | 10% | 8% | 13% | 36% | 0% | 5% | 21% | 0% | 9% | 46% | 6% |
| Not sure | 2% | 2% | 1% | 9% | 0% | 2% | 1% | 2% | 2% | 3% | 1% |

N.B. caution interpreting percentages with a low base

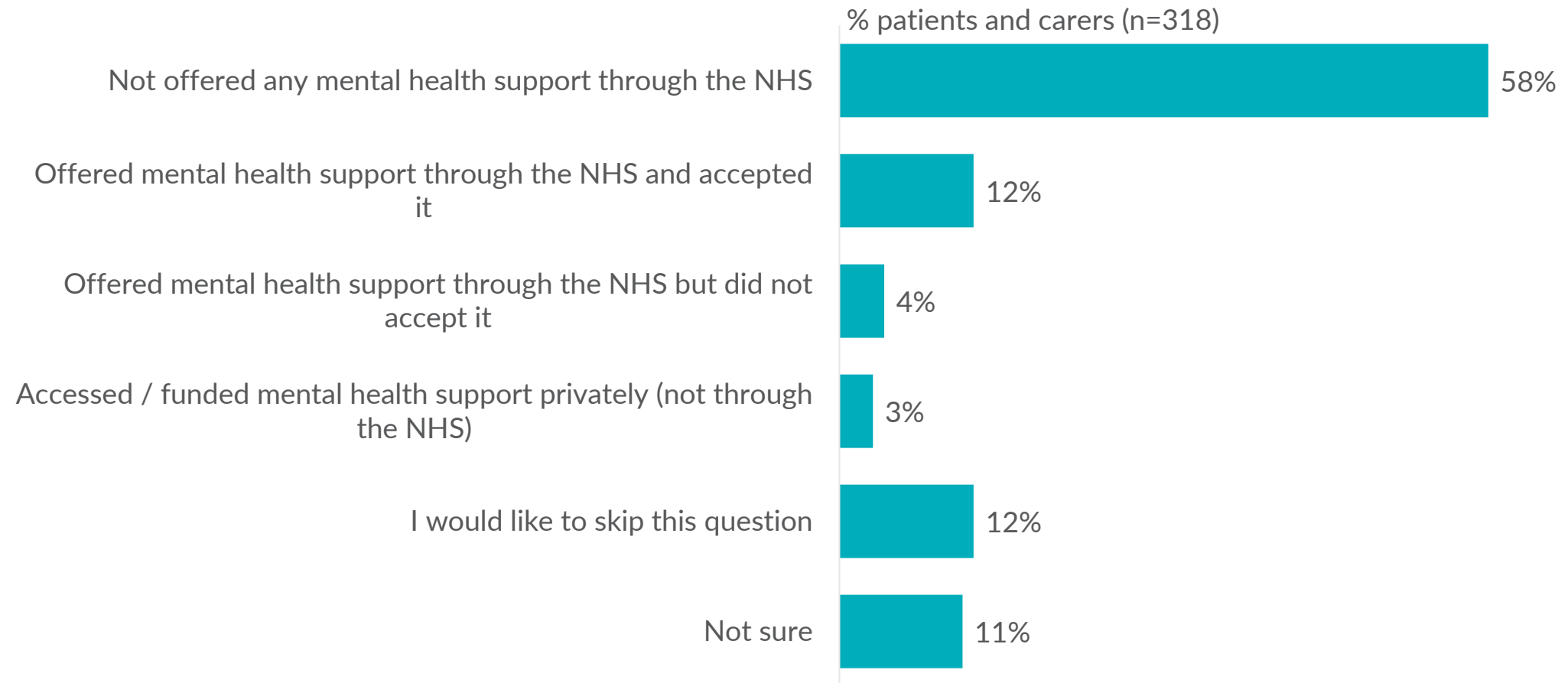
Base 318 (215 patients and 103 carers)

Q23B Have you ever needed to use a wheelchair, scooter or other mobility aid or equipment as a result of your EB?

Impact of EB on mental health

Almost 60% of EB patients have not been offered any mental health support via the NHS; only 15% of EB patients have accessed any mental health support

Which of the following statements describe the mental health support you have been offered in relation to your EB? (prompted)



Base 318 (215 patients and 103 carers)

Q27 Which of the following statements describe the mental health support you have been offered in relation to your EB?

KEB patients most likely to be offered support, SEB and DEB less likely: 14% of patients with severe symptoms have turned down mental health support despite it being offered

| % Patients and carers selecting option | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Not offered any mental health support through the NHS | 58% | 63% | 53% | 9% | 40% | 61% | 50% | 64% | 56% | 34% | 65% |
| Offered mental health support through the NHS and accepted it | 12% | 9% | 20% | 27% | 0% | 12% | 14% | 2% | 16% | 26% | 13% |
| I would like to skip this question | 12% | 12% | 11% | 18% | 40% | 13% | 11% | 22% | 10% | 9% | 8% |
| Not sure | 11% | 11% | 7% | 27% | 20% | 8% | 16% | 7% | 9% | 17% | 11% |
| Offered mental health support through the NHS but did not accept it | 4% | 2% | 8% | 18% | 0% | 3% | 8% | 1% | 6% | 14% | 2% |
| Accessed / funded mental health support privately (not through the NHS) | 3% | 3% | 3% | 0% | 0% | 5% | 0% | 4% | 5% | 3% | 1% |

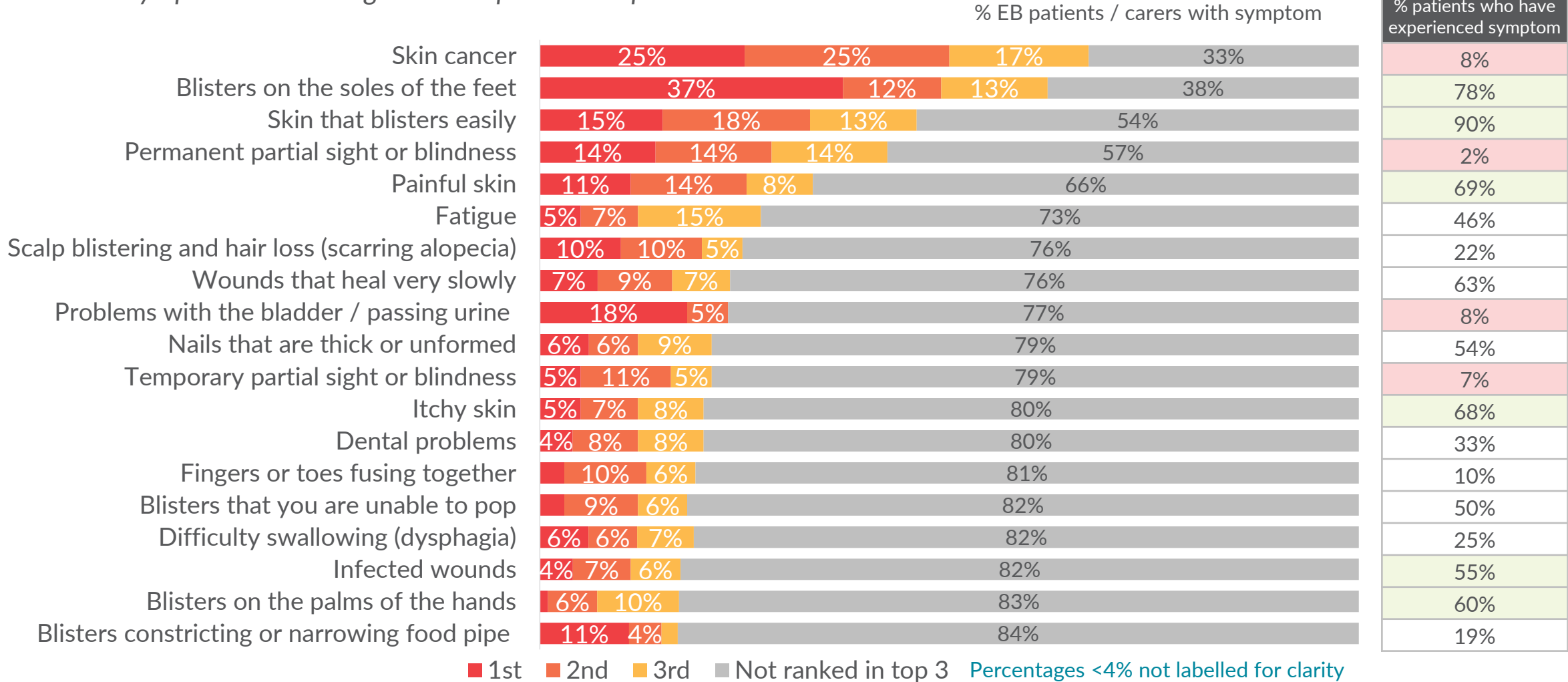
N.B. caution interpreting percentages with a low base

Base 318 (215 patients and 103 carers)

Q27 Which of the following statements describe the mental health support you have been offered in relation to your EB?

Skin cancer, blisters on the soles of the feet and skin that blisters easily are most impactful on EB patient mental health, in addition to permanent partial sight/blindness and painful skin; those with bladder problems rank this as highly impactful on MH

Which symptoms have the greatest impact on EB patient mental health?

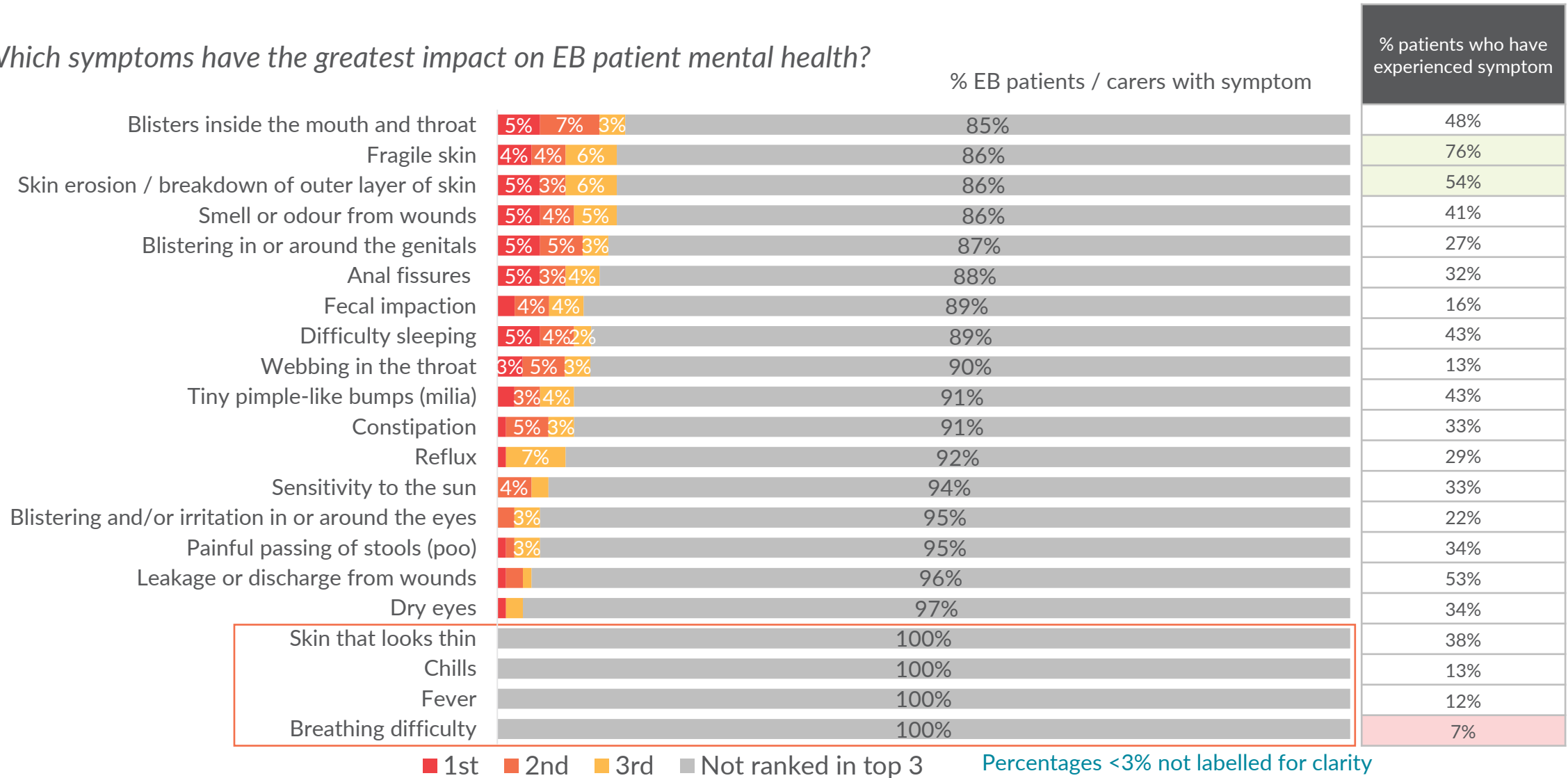


Base 291 patients/carers reporting symptoms who did not skip the question; base variable for each symptom

Q24 Which symptoms have the greatest impact on your mental health / Which symptoms do you believe have the greatest impact on the mental health of the person you care for? Please rate the top three that have the most impact on your / their mental health, selecting the most impactful first.

Some symptoms are less impactful on mental health – none of those with thin skin, chills/fever or breathing difficulty ranked it in top 3 symptoms impacting mental health

Which symptoms have the greatest impact on EB patient mental health?



Base 291 patients/carers reporting symptoms who did not skip the question; base variable for each symptom

Q24 Which symptoms have the greatest impact on your mental health / Which symptoms do you believe have the greatest impact on the mental health of the person you care for? Please rate the top three that have the most impact on your / their mental health, selecting the most impactful first.

Blisters on the soles of the feet most impactful on MH for SEB and mild; severe most impacted by sight loss (1/2)

| % Patients and carers selecting 1st place as most impactful symptom on mental health | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= VARIABLE DEPENDING ON NO. OF PEOPLE WITH SYMPTOM | 291 | 180 | 90 | 9 | 5 | 202 | 89 | 74 | 99 | 34 | 82 |
| Blisters on the soles of the feet | 34% | 44% | 2% | 0% | 0% | 39% | 24% | 53% | 26% | 15% | 37% |
| Skin cancer | 23% | 0% | 38% | 0% | 0% | 24% | 20% | 13% | 33% | 25% | 0% |
| Problems with the bladder / passing urine | 15% | 23% | 0% | 25% | 0% | 21% | 0% | 25% | 20% | 0% | 0% |
| Permanent partial sight or blindness | 14% | 0% | 20% | 0% | 0% | 0% | 14% | 0% | 0% | 33% | 0% |
| Skin that blisters easily | 13% | 18% | 7% | 0% | 0% | 13% | 15% | 10% | 13% | 13% | 17% |
| Painful skin | 11% | 11% | 10% | 9% | 0% | 8% | 15% | 5% | 14% | 6% | 14% |
| Blisters constricting or narrowing food pipe | 10% | 0% | 12% | 0% | 0% | 3% | 17% | 0% | 14% | 8% | 10% |
| Scalp blistering and hair loss | 9% | 0% | 8% | 25% | 0% | 8% | 9% | 0% | 12% | 4% | 11% |
| Wounds that heal very slowly | 7% | 7% | 7% | 9% | 0% | 6% | 7% | 5% | 7% | 12% | 4% |
| Nails that are thick or unformed | 6% | 3% | 7% | 0% | 20% | 6% | 7% | 17% | 5% | 0% | 0% |
| Itchy skin | 5% | 2% | 9% | 0% | 0% | 6% | 3% | 7% | 5% | 0% | 6% |
| Skin erosion / breakdown of outer layer of skin | 5% | 5% | 6% | 0% | 0% | 6% | 3% | 11% | 3% | 0% | 5% |
| Blisters inside the mouth and throat | 5% | 3% | 3% | 0% | 60% | 6% | 2% | 4% | 5% | 0% | 9% |
| Difficulty swallowing (dysphagia) | 5% | 0% | 7% | 0% | 0% | 7% | 3% | 0% | 9% | 4% | 0% |
| Temporary partial sight or blindness | 5% | 0% | 0% | 25% | 0% | 8% | 0% | 0% | 0% | 13% | 0% |
| Smell or odour from wounds | 5% | 4% | 6% | 0% | 0% | 3% | 8% | 0% | 5% | 6% | 6% |
| Anal fissures - sores, tears or ulcers | 5% | 3% | 8% | 0% | 0% | 6% | 3% | 15% | 0% | 0% | 10% |
| Blistering in or around the genitals | 5% | 7% | 3% | 0% | 0% | 8% | 0% | 9% | 4% | 5% | 4% |
| Fatigue | 5% | 3% | 6% | 0% | 0% | 7% | 0% | 8% | 7% | 3% | 0% |
| Difficulty sleeping | 5% | 6% | 5% | 0% | 0% | 7% | 2% | 5% | 6% | 4% | 6% |

Base 291 patients/carers reporting symptoms who did not skip the question; base variable for each symptom

Q24 Which symptoms have the greatest impact on your mental health / Which symptoms do you believe have the greatest impact on the mental health of the person you care for? TOP RANKING SYMPTOM

Blisters on the soles of the feet most impactful on MH for SEB and mild; severe most impacted by sight loss (2/2)

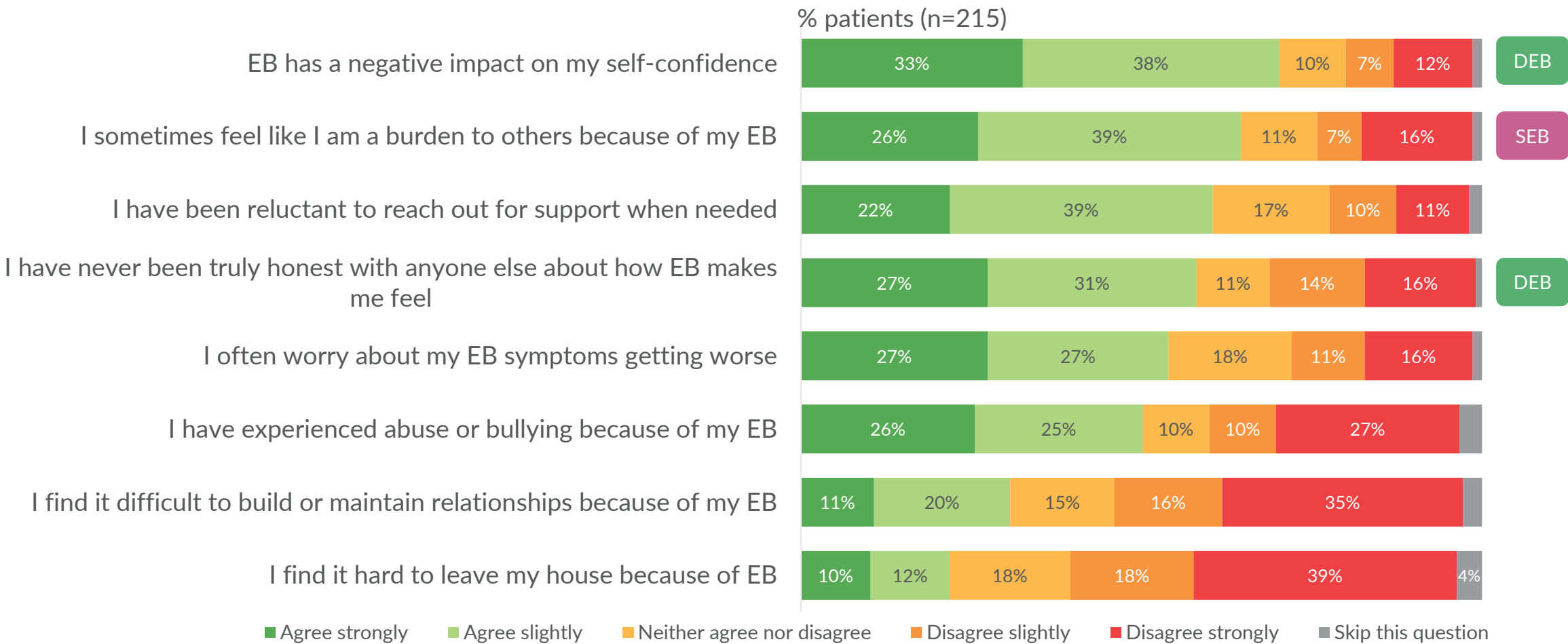
| % Patients and carers selecting 1st place as most impactful symptom on mental health | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= VARIABLE DEPENDING ON NO. OF PEOPLE WITH SYMPTOM | 291 | 180 | 90 | 9 | 5 | 202 | 89 | 74 | 99 | 34 | 82 |
| Fragile skin | 4% | 2% | 6% | 8% | 0% | 3% | 5% | 2% | 3% | 5% | 4% |
| Dental problems, such as tooth decay or teeth falling out | 4% | 3% | 4% | 0% | 20% | 6% | 0% | 7% | 5% | 4% | 0% |
| Infected wounds | 4% | 5% | 2% | 10% | 0% | 2% | 8% | 4% | 3% | 3% | 6% |
| Blisters that you are unable to pop | 3% | 4% | 0% | 0% | 0% | 3% | 2% | 6% | 2% | 0% | 2% |
| Webbing in the throat | 3% | 0% | 3% | 0% | 0% | 5% | 0% | 0% | 0% | 0% | 13% |
| Fingers or toes fusing together | 3% | 0% | 4% | 0% | 0% | 0% | 5% | 0% | 0% | 6% | 0% |
| Fecal impaction | 2% | 0% | 4% | 0% | 0% | 3% | 0% | 0% | 0% | 0% | 8% |
| Blisters on the palms of the hands | 1% | 2% | 0% | 0% | 0% | 1% | 2% | 0% | 3% | 0% | 0% |
| Tiny pimple-like bumps (milia) | 1% | 3% | 0% | 0% | 0% | 2% | 0% | 0% | 2% | 0% | 3% |
| Dry eyes | 1% | 3% | 0% | 0% | 0% | 2% | 0% | 0% | 0% | 0% | 4% |
| Leakage or discharge from wounds | 1% | 0% | 1% | 0% | 0% | 1% | 0% | 0% | 0% | 0% | 3% |
| Painful passing of stools (poo) | 1% | 0% | 0% | 11% | 0% | 0% | 2% | 0% | 0% | 4% | 0% |
| Constipation | 1% | 0% | 2% | 0% | 0% | 2% | 0% | 8% | 0% | 0% | 0% |
| Reflux | 1% | 0% | 3% | 0% | 0% | 2% | 0% | 8% | 0% | 0% | 0% |

Base 291 patients/carers reporting symptoms who did not skip the question; base variable for each symptom

Q24 Which symptoms have the greatest impact on your mental health / Which symptoms do you believe have the greatest impact on the mental health of the person you care for? TOP RANKING SYMPTOM. Zeros not shown.

C. 70% of EB patients feel their condition has a negative impact on their self-confidence and makes them feel like a burden to others; c. 50% of EB patients have experienced abuse or bullying due to their EB

To what extent do you agree or disagree with each of the following statements? (prompted)



N.B. Percentages <4% not labelled for clarity

Severe patients more likely to struggle to leave the house, worry about symptoms getting worse and feel they are burden to others

SEB patients more likely to feel like a burden because of their condition; DEB patients more likely to feel EB has impacted their self-confidence and have never been honest about how EB makes them feel; c. two thirds with severe EB find it hard to leave the house, worry about symptoms getting worse and feel they are a burden to others because of their EB

| % Patients and carers selecting strongly agree | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 215 | 140 | 59 | 5 | 3 | 215 | 0 | 70 | 75 | 13 | 56 |
| EB has a negative impact on my self-confidence | 33% | 28% | 41% | 20% | 0% | 33% | - | 23% | 41% | 54% | 27% |
| I sometimes feel like I am a burden to others because of my EB | 26% | 33% | 14% | 20% | 0% | 26% | - | 16% | 25% | 62% | 32% |
| I have been reluctant to reach out for support when needed | 22% | 18% | 32% | 0% | 0% | 22% | - | 7% | 32% | 31% | 23% |
| I have never been truly honest with anyone else about how EB makes me feel | 27% | 23% | 37% | 20% | 0% | 27% | - | 14% | 32% | 31% | 38% |
| I often worry about my EB symptoms getting worse | 27% | 20% | 44% | 60% | 33% | 27% | - | 13% | 29% | 69% | 34% |
| I have experienced abuse or bullying because of my EB | 26% | 23% | 31% | 40% | 0% | 26% | - | 23% | 28% | 46% | 21% |
| I find it difficult to build or maintain relationships because of my EB | 11% | 7% | 19% | 40% | 0% | 11% | - | 3% | 21% | 31% | 2% |
| I find it hard to leave my house because of EB | 10% | 9% | 17% | 0% | 0% | 10% | - | 1% | 9% | 62% | 9% |

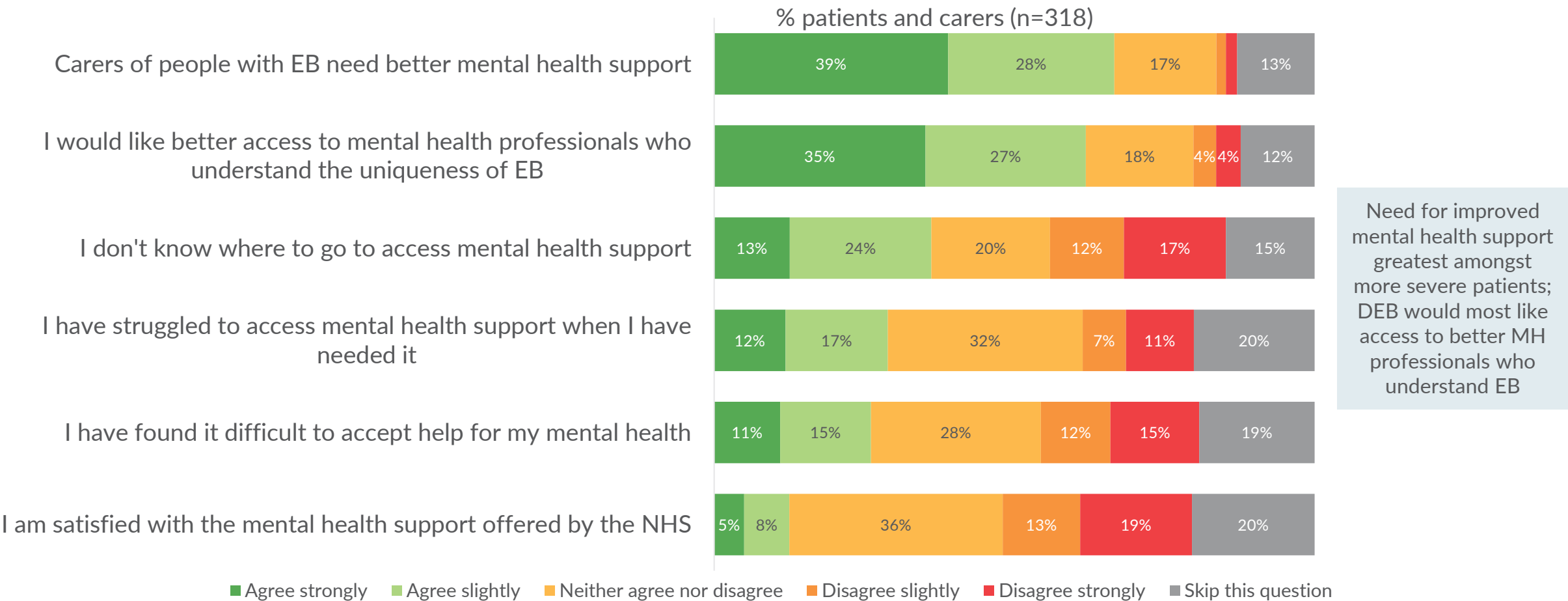
N.B. caution interpreting percentages with a low base

Base 215 Patients

Q26 To what extent do you agree or disagree with each of the following statements?

Only 13% of EB patients and carers are satisfied with mental health support offered by the NHS; c.65% believe carers need better mental health support and would like better access to MH support which understands the uniqueness of EB

To what extent do you agree or disagree with each of the following statements? (prompted)



N.B. Percentages <4% not labelled for clarity

Base 318 (215 patients and 103 carers)

Q28 To what extent do you agree or disagree with each of the following statements. CARERS: Please answer from your own perspective as a carer of someone with EB

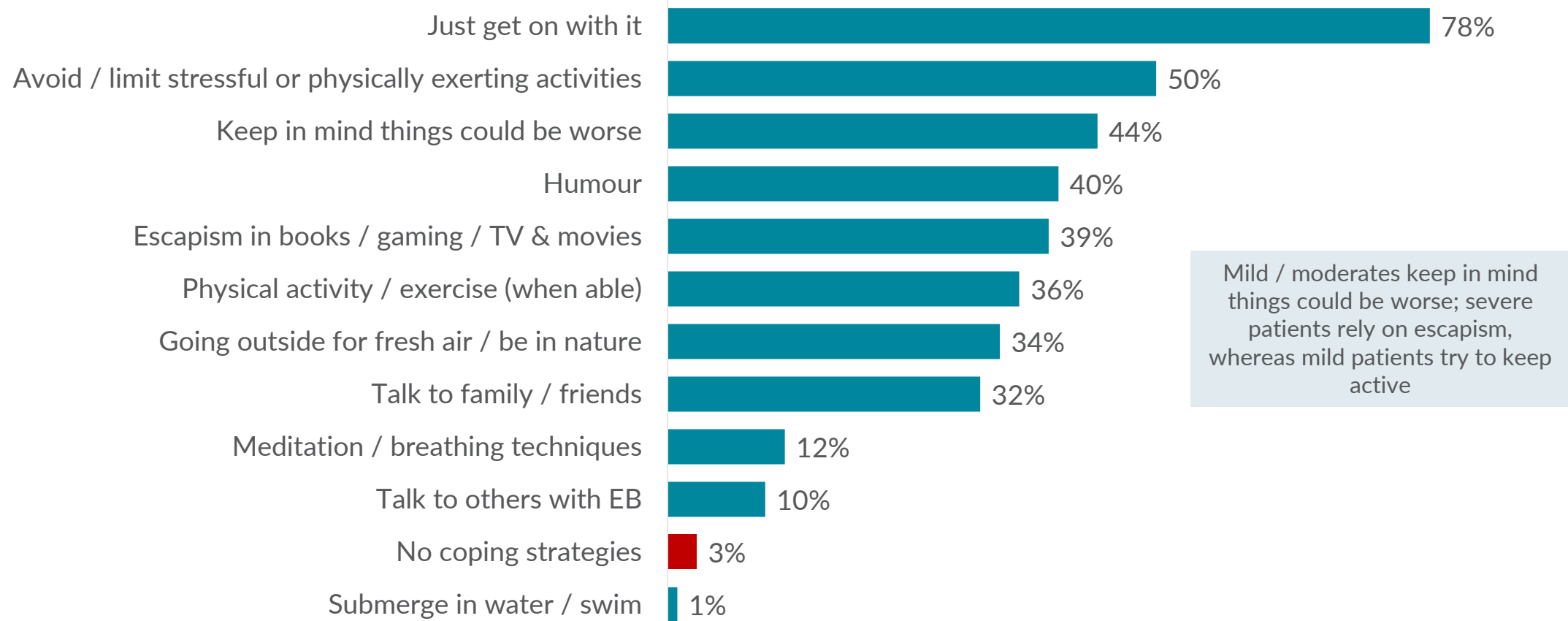
Need for improved mental health support greatest amongst more severe patients; DEB would most like access to better MH professionals who understand EB

| % Patients and carers selecting strongly agree | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| N= | 318 | 193 | 97 | 13 | 5 | 215 | 103 | 83 | 108 | 39 | 85 |
| Carers of people with EB need better mental health support | 39% | 38% | 38% | 31% | 60% | 38% | 42% | 25% | 37% | 69% | 41% |
| I would like better access to mental health professionals who understand the uniqueness of EB | 35% | 30% | 45% | 31% | 40% | 30% | 46% | 22% | 37% | 64% | 33% |
| I don't know where to go to access mental health support | 13% | 11% | 16% | 15% | 0% | 11% | 17% | 7% | 13% | 21% | 13% |
| I have struggled to access mental health support when I have needed it | 12% | 10% | 16% | 15% | 0% | 12% | 13% | 6% | 9% | 26% | 14% |
| I have found it difficult to accept help for my mental health | 11% | 7% | 18% | 15% | 0% | 9% | 15% | 8% | 8% | 26% | 9% |
| I am satisfied with the mental health support offered by the NHS | 5% | 3% | 9% | 8% | 0% | 6% | 3% | 4% | 5% | 8% | 4% |

N.B. caution interpreting percentages with a low base

The majority of patients with EB tell themselves to “just get on with it” as a way to cope with their EB – positive coping mechanisms less evident

Which coping strategies, if any, do you use to cope with living with EB? (multicode)



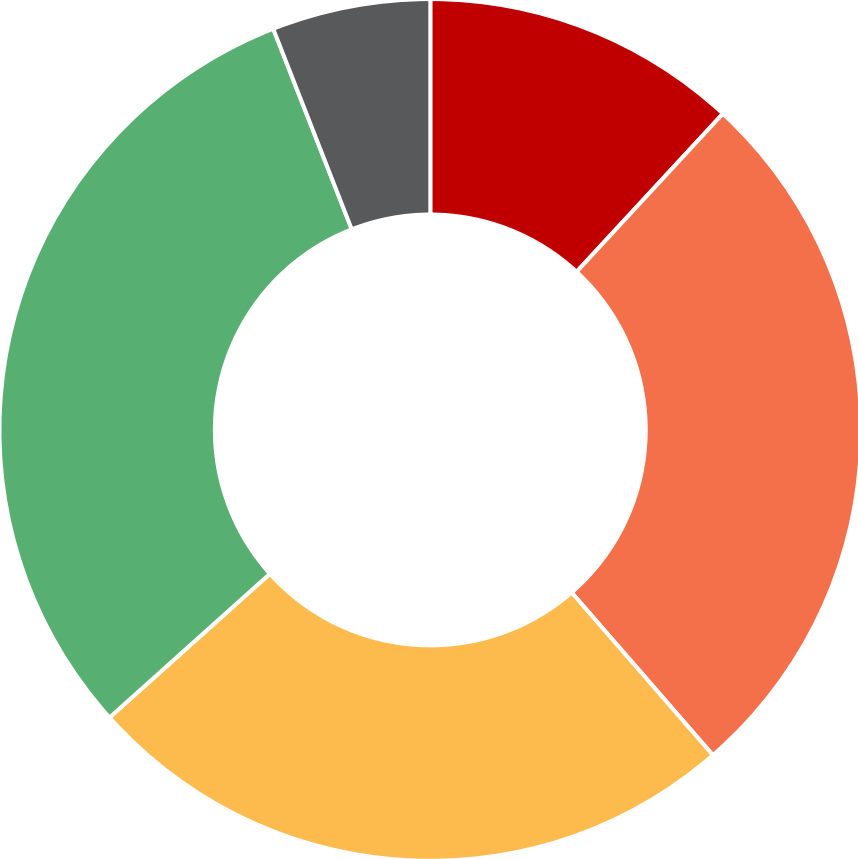
The majority of patients with EB tell themselves to “just get on with it” as a way to cope with their EB; mild / moderates keep in mind things could be worse; severe patients rely on escapism, whereas mild patients try to keep active

| %Patients and carers selecting strongly agree | Total | EB Type | | | | Respondent Type | | Severity | | | |
|---|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Total | 305 | 190 | 91 | 10 | 5 | 215 | 90 | 83 | 106 | 30 | 84 |
| Just get on with it | 78% | 76% | 81% | 90% | 60% | 81% | 70% | 84% | 75% | 73% | 77% |
| Avoid / limit activities or interactions that cause stress or are physically exerting | 50% | 53% | 47% | 40% | 20% | 51% | 49% | 48% | 46% | 53% | 57% |
| Keep in mind that things could be worse | 44% | 39% | 54% | 50% | 40% | 50% | 29% | 47% | 51% | 30% | 37% |
| Humour | 40% | 36% | 47% | 60% | 20% | 41% | 38% | 45% | 39% | 57% | 32% |
| Escapism in books / video games / TV and movies | 39% | 33% | 52% | 30% | 0% | 39% | 39% | 35% | 42% | 57% | 33% |
| Keep physically active / exercise when able to | 36% | 37% | 38% | 40% | 20% | 40% | 28% | 46% | 38% | 23% | 31% |
| Going outside to get fresh air / be in nature | 34% | 30% | 40% | 50% | 60% | 40% | 22% | 40% | 36% | 33% | 26% |
| Talk to family / friends | 32% | 31% | 36% | 30% | 60% | 33% | 31% | 40% | 26% | 40% | 30% |
| Meditation / breathing techniques | 12% | 13% | 10% | 10% | 20% | 15% | 4% | 12% | 14% | 7% | 11% |
| Talk to others with EB | 10% | 9% | 10% | 20% | 40% | 12% | 7% | 11% | 12% | 13% | 6% |
| Other (please specify) | 3% | 3% | 4% | 0% | 0% | 2% | 6% | 2% | 1% | 3% | 6% |
| No coping strategies | 3% | 3% | 1% | 0% | 20% | 3% | 2% | 2% | 4% | 3% | 1% |
| I would like to skip this question | 2% | 1% | 3% | 0% | 0% | 1% | 2% | 2% | 3% | 0% | 0% |
| Submerge in water / swim | 1% | 2% | 0% | 0% | 0% | 2% | 0% | 1% | 2% | 0% | 1% |

Cost of living crisis

Two thirds of EB patients and their carers have been impacted by the cost of living crisis

To what extent, if at all, has the cost of living crisis impacted your life and your ability to manage your EB / To what extent, if at all, has the cost of living crisis impacted your life and your ability to support the person you care for with EB?



| | % patients/carers |
|-----------------|-------------------|
| Severe impact | 12% |
| Moderate impact | 27% |
| Little impact | 25% |
| No impact | 31% |
| Not sure | 6% |

Impact less likely for mild EB and SEB, more likely for severe EB, younger patients and those from an ethnic minority

Base 305 (215 patients and 90 current carers)
Q39 To what extent, if at all, has the cost of living crisis impacted your life and your ability to manage your EB / To what extent, if at all, has the cost of living crisis impacted your life and your ability to support the person you care for with EB?

Cost of living crisis is less likely to have impacted mild EB and SEB patients / and their carers, and more likely for severe EB

| % Patients and carers selecting option | Total | EB Type | | | | Respondent Type | | Severity | | | |
|--|-------|---------|-----|-----|-----|-----------------|-------|----------|----------|--------|------------|
| | | SEB | DEB | JEB | KEB | Patient | Carer | Mild | Moderate | Severe | It depends |
| Total | Total | 305 | 190 | 91 | 10 | 215 | 90 | 83 | 106 | 30 | 84 |
| It has had a severe impact | 12% | 9% | 16% | 10% | 40% | 13% | 11% | 1% | 12% | 33% | 14% |
| It has had a moderate impact | 27% | 24% | 30% | 30% | 60% | 24% | 23% | 16% | 29% | 43% | 26% |
| It has had a little impact | 25% | 22% | 31% | 40% | 0% | 34% | 24% | 24% | 30% | 13% | 25% |
| No impact | 31% | 38% | 20% | 20% | 0% | 24% | 35% | 52% | 23% | 7% | 30% |
| Not sure / not applicable | 6% | 7% | 3% | 0% | 0% | 5% | 7% | 7% | 6% | 3% | 5% |

N.B. caution interpreting percentages with a low base

Base 305 (215 patients and 90 current carers)

Q39 To what extent, if at all, has the cost of living crisis impacted your life and your ability to manage your EB / To what extent, if at all, has the cost of living crisis impacted your life and your ability to support the person you care for with EB?

Younger patients and those of an ethnic minority are more likely to have been impacted by the cost-of-living crisis

| % Patients and carers selecting each option | Total | Under care of specialist centre? | | Patient Age | | | | | | Patient Gender | | Patient ethnicity | | Location | | |
|---|-------|----------------------------------|---------------|----------------|-------|-------------------------|-------------|-------------|-----------|----------------|--------|-------------------|-----------------|---------------|-----------------|---------------|
| | | Yes | No / not sure | Baby / toddler | Child | Teenager / young person | Adult 21-40 | Adult 41-60 | Adult 61+ | Male | Female | White | Ethnic minority | North England | East & Midlands | South England |
| N= | 305 | 184 | 121 | 15 | 38 | 23 | 89 | 78 | 62 | 103 | 198 | 279 | 24 | 44 | 80 | 119 |
| It has had a severe impact | 12% | 14% | 8% | 7% | 18% | 17% | 7% | 17% | 8% | 14% | 11% | 10% | 29% | 16% | 16% | 8% |
| It has had a moderate impact | 27% | 34% | 16% | 47% | 29% | 26% | 43% | 19% | 6% | 28% | 25% | 26% | 29% | 32% | 21% | 27% |
| It has had a little impact | 25% | 28% | 21% | 40% | 26% | 26% | 21% | 23% | 29% | 26% | 25% | 26% | 21% | 14% | 26% | 29% |
| No impact | 31% | 23% | 43% | 7% | 21% | 30% | 22% | 38% | 45% | 27% | 32% | 33% | 13% | 32% | 33% | 30% |
| Not sure / not applicable | 6% | 2% | 12% | 0% | 5% | 0% | 7% | 3% | 11% | 5% | 6% | 5% | 8% | 7% | 4% | 5% |

N.B. caution interpreting percentages with a low base

Base 305 (215 patients and 90 current carers)

Q39 To what extent, if at all, has the cost of living crisis impacted your life and your ability to manage your EB / To what extent, if at all, has the cost of living crisis impacted your life and your ability to support the person you care for with EB?

Patient Demographics

Patient Gender and Ethnicity

*What gender do you identify as? / What gender does (did) the person you (were) supporting identify as?
What is your ethnicity? / What is (was) the ethnicity of the person you are (were) caring for?*

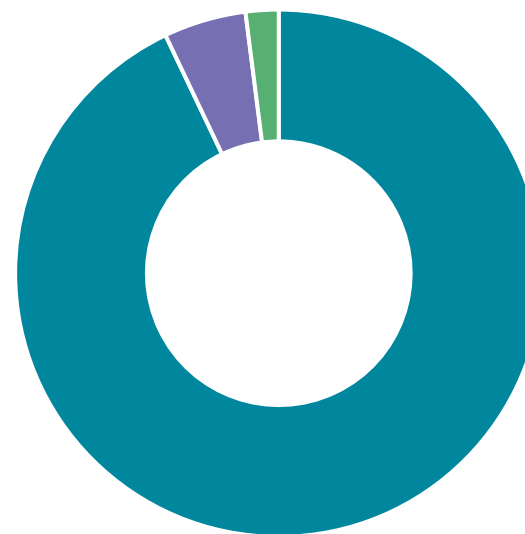
Patient Gender



% patients and carers

| | | |
|---|------------|-----|
| ■ | Males | 35% |
| ■ | Female | 64% |
| ■ | Non-Binary | 0% |

Patient Ethnicity



% patients and carers

| | | |
|---|-----------------------|-----|
| ■ | White / White British | 92% |
| ■ | Asian / Asian British | 5% |
| ■ | Other | 2% |

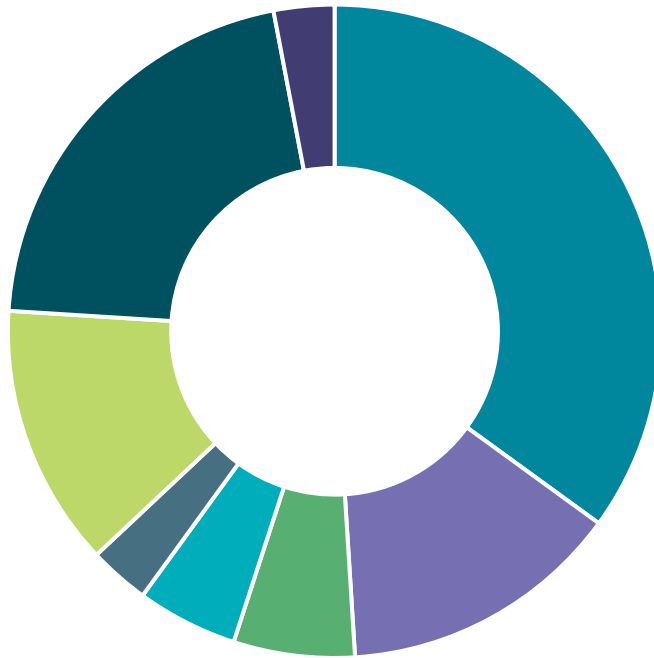
Base 318 (215 patients and 103 carers)

D4 What gender do you identify as? / What gender does (did) the person you (were) supporting identify as?

D5 What is your ethnicity? / What is (was) the ethnicity of the person you are (were) caring for?

Patient Employment Status

What is your employment status? / What is (was) the employment status of the person you are (were) supporting (before they died)?



| | % patients | SEB | DEB | JEB | KEB | Mild | Moderate | Severe | It depends |
|----------------------------------|------------|-----|-----|-----|-----|------|----------|--------|------------|
| Working full time | 35% | 41% | 24% | 17% | 25% | 45% | 36% | 0% | 35% |
| Working part time | 14% | 11% | 16% | 17% | 50% | 17% | 13% | 4% | 15% |
| Self employed | 6% | 6% | 8% | 0% | 0% | 8% | 5% | 12% | 3% |
| Student | 5% | 4% | 8% | 17% | 0% | 6% | 3% | 8% | 6% |
| Unemployed | 3% | 2% | 4% | 17% | 0% | 0% | 2% | 8% | 3% |
| Unable to work due to ill health | 13% | 8% | 23% | 17% | 0% | 0% | 9% | 68% | 10% |
| Retired | 21% | 25% | 14% | 17% | 25% | 20% | 27% | 0% | 24% |
| Stay at home parent / carer | 3% | 2% | 4% | 0% | 0% | 1% | 5% | 0% | 3% |

Base 318 (215 patients and 103 carers)

D6 What is your employment status? / What is (was) the employment status of the person you are (were) supporting (before they died)?

Patient Education Level

What is the highest level of education you have completed? / What is the highest level of education the patient you are (were) supporting has (had) completed?



| | % patients | SEB | DEB | JEB | KEB | Mild | Moderate | Severe | It depends |
|--|------------|-----|-----|-----|-----|------|----------|--------|------------|
| No qualifications | 8% | 0% | 20% | 16% | 17% | 32% | 16% | 12% | 13% |
| O levels / CSE / GCSE / Level 1 or 2 awards and diplomas / IVQ Level 1 or 2 | 25% | 0% | 29% | 10% | 33% | 25% | 23% | 4% | 25% |
| A levels / Level 3 awards and diplomas / INVQ level 3 | 12% | 0% | 9% | 15% | 0% | 10% | 12% | 0% | 13% |
| Foundation degree / Certificate of higher education / Level 4 or 5 awards and diplomas / NVQ Level 4 or 5 | 10% | 0% | 12% | 10% | 17% | 11% | 9% | 20% | 12% |
| Bachelor's degree / Graduate diploma / NVQ Level 6 | 22% | 75% | 21% | 32% | 33% | 13% | 28% | 48% | 25% |
| Higher degree e.g. Master's degree / Postgraduate certificate in education / Postgraduate diplomas and certificates / NV | 20% | 25% | 5% | 14% | 0% | 8% | 9% | 16% | 3% |

Base 318 (215 patients and 103 carers)

D7 What is the highest level of education you have completed? / What is the highest level of education the patient you are (were) supporting has (had) completed?

Household Income

What is your total household income?

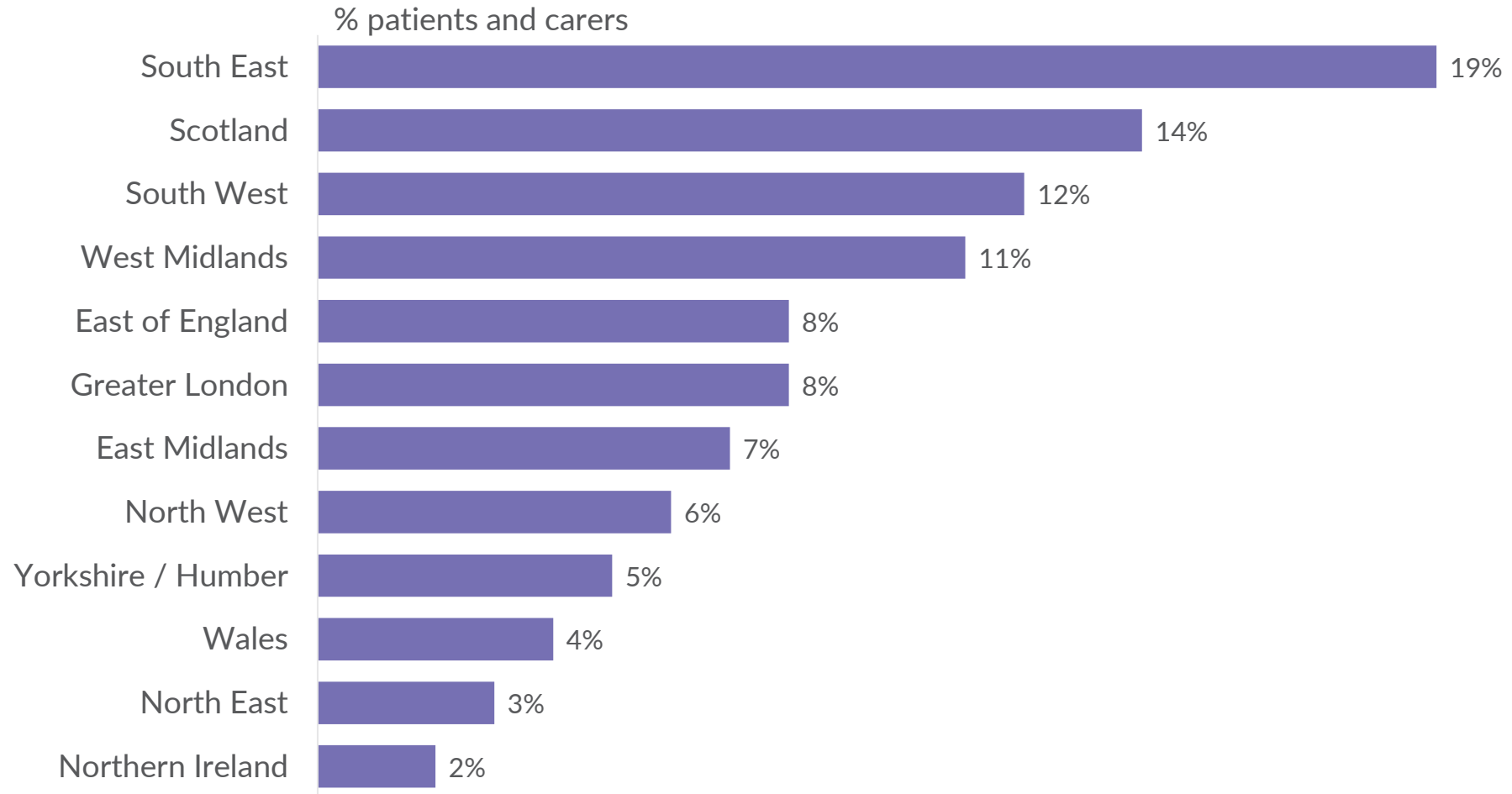


| | % patients | SEB | DEB | JEB | KEB | Mild | Moderate | Severe | It depends |
|-------------------|------------|-----|-----|-----|-----|------|----------|--------|------------|
| Below 10,000 | 7% | 6% | 9% | 8% | 20% | 20% | 13% | 20% | 31% |
| 10,000 to 20,000 | 14% | 13% | 12% | 31% | 40% | 18% | 47% | 23% | 15% |
| 20,001 to 30,000 | 13% | 13% | 11% | 15% | 20% | 8% | 6% | 6% | 5% |
| 30,001 to 40,000 | 13% | 13% | 14% | 0% | 0% | 14% | 16% | 11% | 10% |
| 40,001 to 50,000 | 6% | 8% | 5% | 0% | 0% | 16% | 8% | 14% | 10% |
| Above 50,001 | 27% | 28% | 27% | 8% | 0% | 15% | 7% | 19% | 15% |
| Prefer not to say | 20% | 19% | 20% | 38% | 20% | 8% | 2% | 7% | 10% |

Base 318 (215 patients and 103 carers)
D8 What is your total household income?

Where Patients Live

Where do you live? / Where does (did) the person (baby or toddler) you are (were) supporting live?



Base 318 (215 patients and 103 carers)

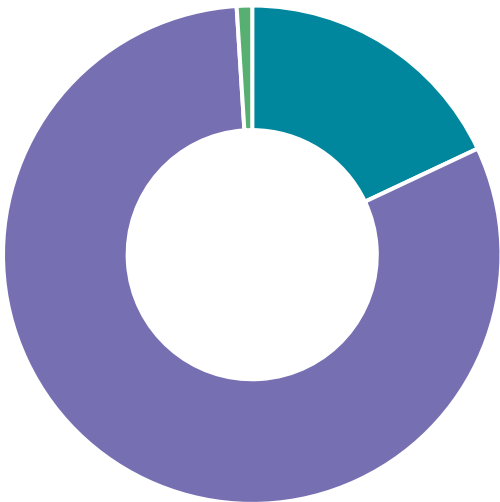
D9 Where do you live? / Where does (did) the person (baby or toddler) you are (were) supporting live?

Carer Demographics

Carer Gender and Ethnicity

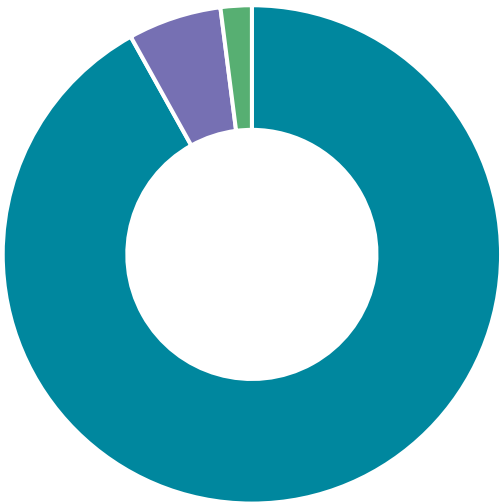
What gender do you identify as?
What is your ethnicity?

Carer Gender



| | % patients and carers |
|--------------|-----------------------|
| ■ Males | 18% |
| ■ Female | 81% |
| ■ Non-Binary | 1% |

Carer Ethnicity



| | % patients and carers |
|-------------------------|-----------------------|
| ■ White / White British | 91% |
| ■ Asian / Asian British | 6% |
| ■ Other | 2% |

Base 103 carers
D10 What gender do you identify as?
D11 What is your ethnicity?

Carer Employment Status

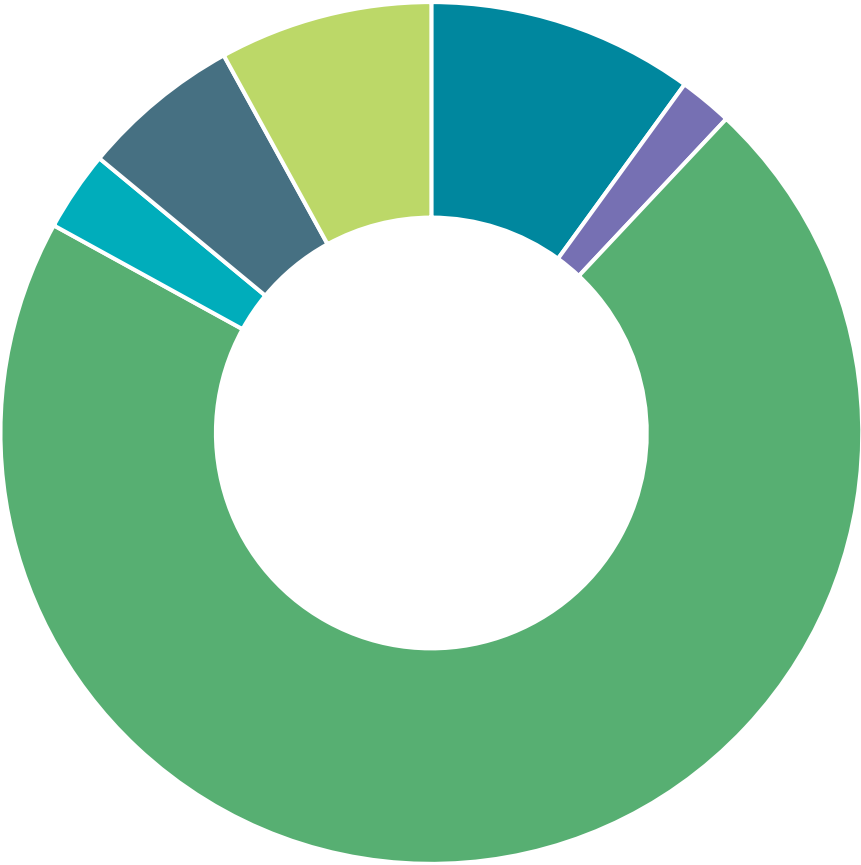
What is your employment status?



| | % carers | SEB | DEB | JEB | KEB | Mild | Moderate | Severe | It depends |
|----------------------------------|----------|-----|-----|-----|-----|------|----------|--------|------------|
| Working full time | 28% | 28% | 32% | 25% | 0% | 31% | 33% | 35% | 17% |
| Working part time | 26% | 28% | 24% | 13% | 50% | 46% | 18% | 19% | 31% |
| Self employed | 8% | 2% | 18% | 0% | 0% | 15% | 9% | 12% | 0% |
| Student | 3% | 4% | 3% | 0% | 0% | 0% | 0% | 4% | 7% |
| Unemployed | 3% | 2% | 0% | 13% | 0% | 0% | 3% | 4% | 0% |
| Unable to work due to ill health | 5% | 6% | 5% | 0% | 0% | 8% | 6% | 0% | 7% |
| Retired | 14% | 15% | 16% | 0% | 0% | 0% | 18% | 19% | 10% |
| Stay at home parent / carer | 13% | 13% | 3% | 50% | 50% | 0% | 9% | 8% | 28% |

Carer's Relationship to Patient

What is (was) your relationship to the person (baby or toddler) you (are) supporting(/ed)?



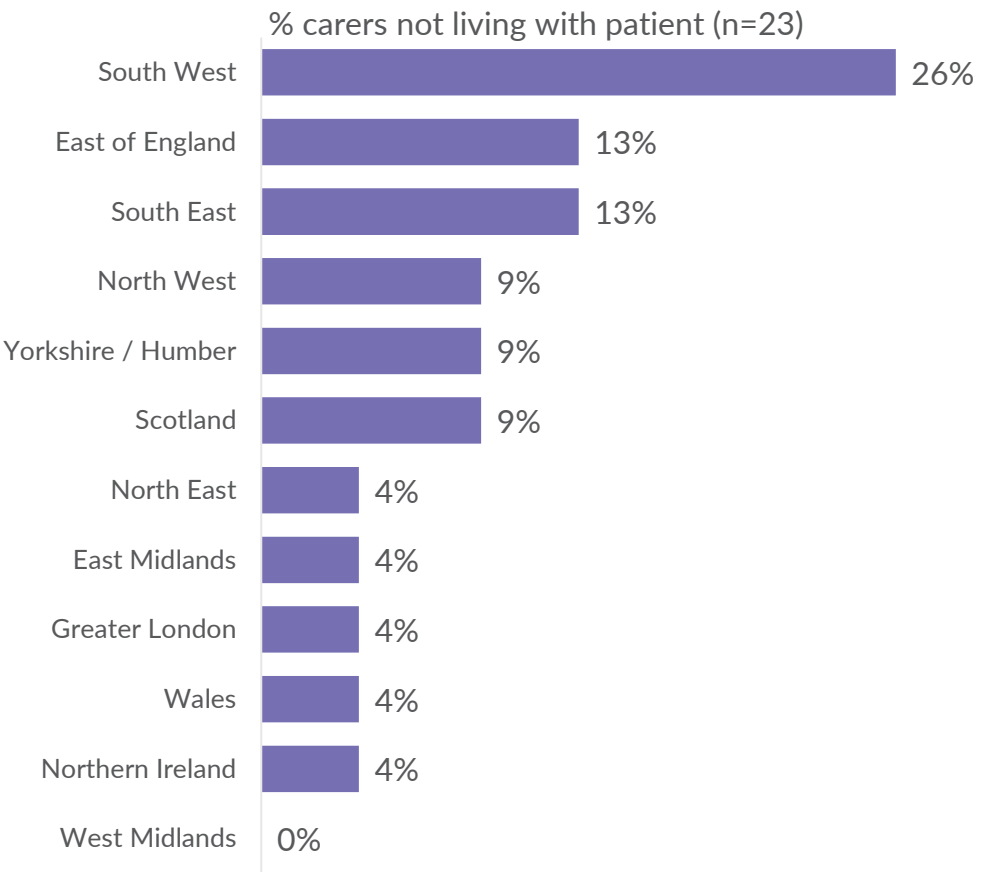
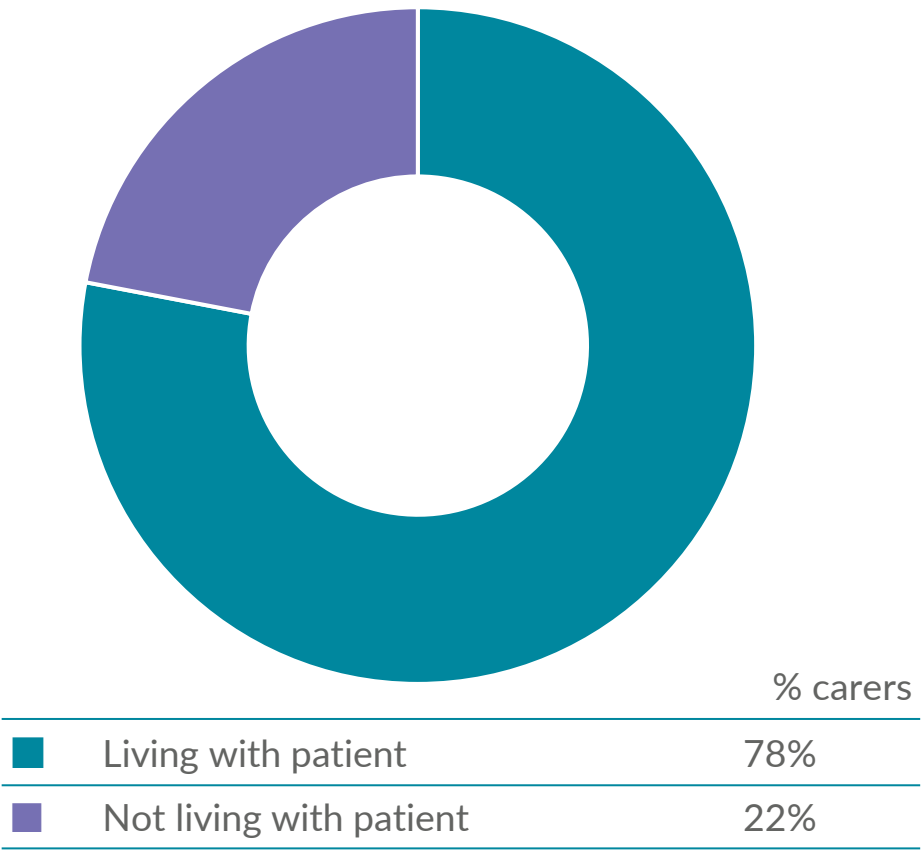
| | % carers |
|---|----------|
| My partner / spouse | 10% |
| My parent / parent of my partner | 2% |
| My daughter / son or the daughter/son of my partner | 71% |
| My brother or sister | 3% |
| My friend | 6% |
| Another family member | 8% |

Base 103 carers
D13 What is (was) your relationship to the person (baby or toddler) you (are) supporting(/ed)?

Where carers live

Do (Did) you live in the same household as the person you care(d) for?
Where do you live in the UK?

% carers living with pt.



Base 103 carers
D14 Do (Did) you live in the same household as the person you care(d) for?
D15 Where do you live in the UK?

Carer Level of Education

What is the highest level of education you have completed?



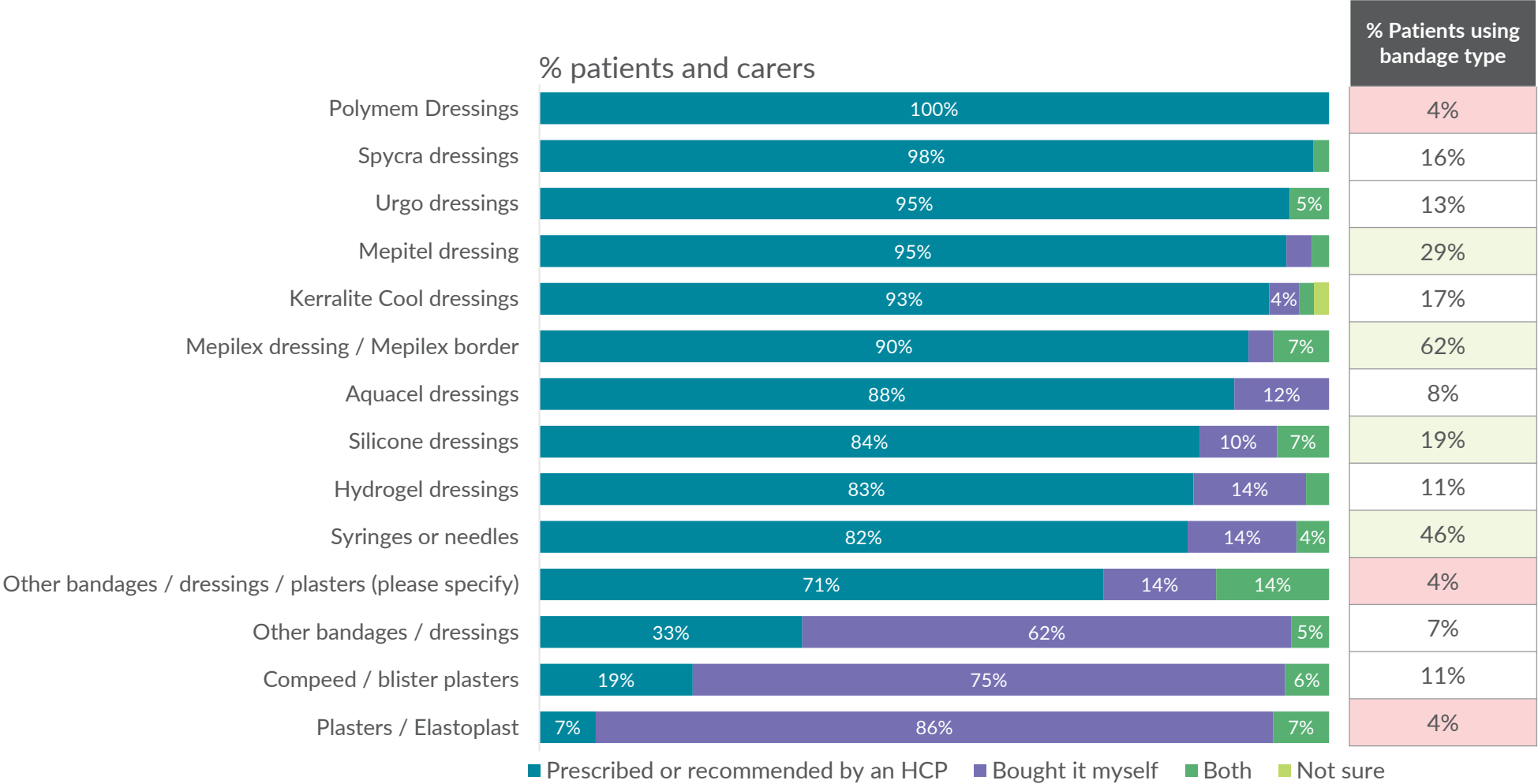
| | % carers |
|---|----------|
| No qualifications | 4% |
| O levels / CSE / GCSE / Level 1 or 2 awards and diplomas / IVQ Level 1 or 2 | 19% |
| A levels / Level 3 awards and diplomas / INVQ level 3 | 17% |
| Foundation degree / Certificate of higher education / Level 4 or 5 awards and diplomas / NVQ Level 4 or 5 | 15% |
| Bachelor's degree / Graduate diploma / NVQ Level 6 | 23% |
| Higher degree e.g., Master's degree / postgraduate certificate or equivalent | 19% |
| Prefer not to say | 3% |

Base 23 carers not living with patient
D16 What is the highest level of education you have completed?

Patient Appendix

Most dressings are prescribed or recommended by HCP; patients self-purchase standard plasters

For each of the following you use to help manage your EB symptoms, please indicate below if this is prescribed or recommended by your doctor or nurse, or if you buy it yourself that is, this is something you use that your doctor or nurse has not specifically recommended to you). (prompted, multicode)

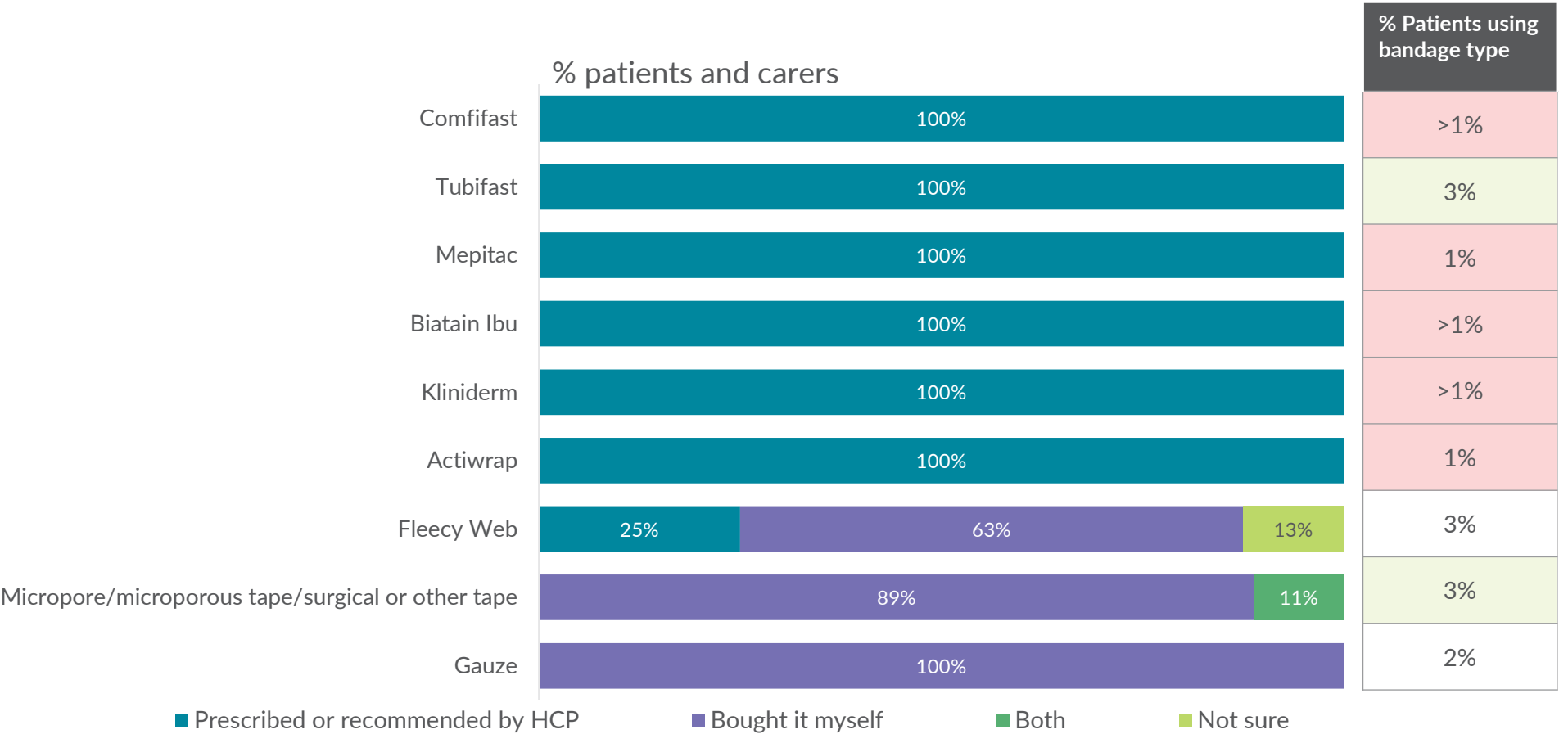


N.B. Percentages <4% not labelled for clarity

Base Variable by bandage/dressing type
Q20 For each of the following you use to help manage your EB symptoms, please indicate below if this is prescribed or recommended by your doctor or nurse, or if you buy it yourself (that is, this is something you use that your doctor or nurse has not specifically recommended to you)

20% of patients who use needles either purchase all or some of the needles necessary for their use: 10% of patients using Mepilex dressings purchase some or all of the dressings needed for their care

For each of the following you use to help manage your EB symptoms, please indicate below if this is prescribed or recommended by your doctor or nurse, or if you buy it yourself that is, this is something you use that your doctor or nurse has not specifically recommended to you). (prompted, multicode)



N.B. Percentages <4% not labelled for clarity

Base Variable by bandage/dressing type
 Q20 For each of the following you use to help manage your EB symptoms, please indicate below if this is prescribed or recommended by your doctor or nurse, or if you buy it yourself (that is, this is something you use that your doctor or nurse has not specifically recommended to you)

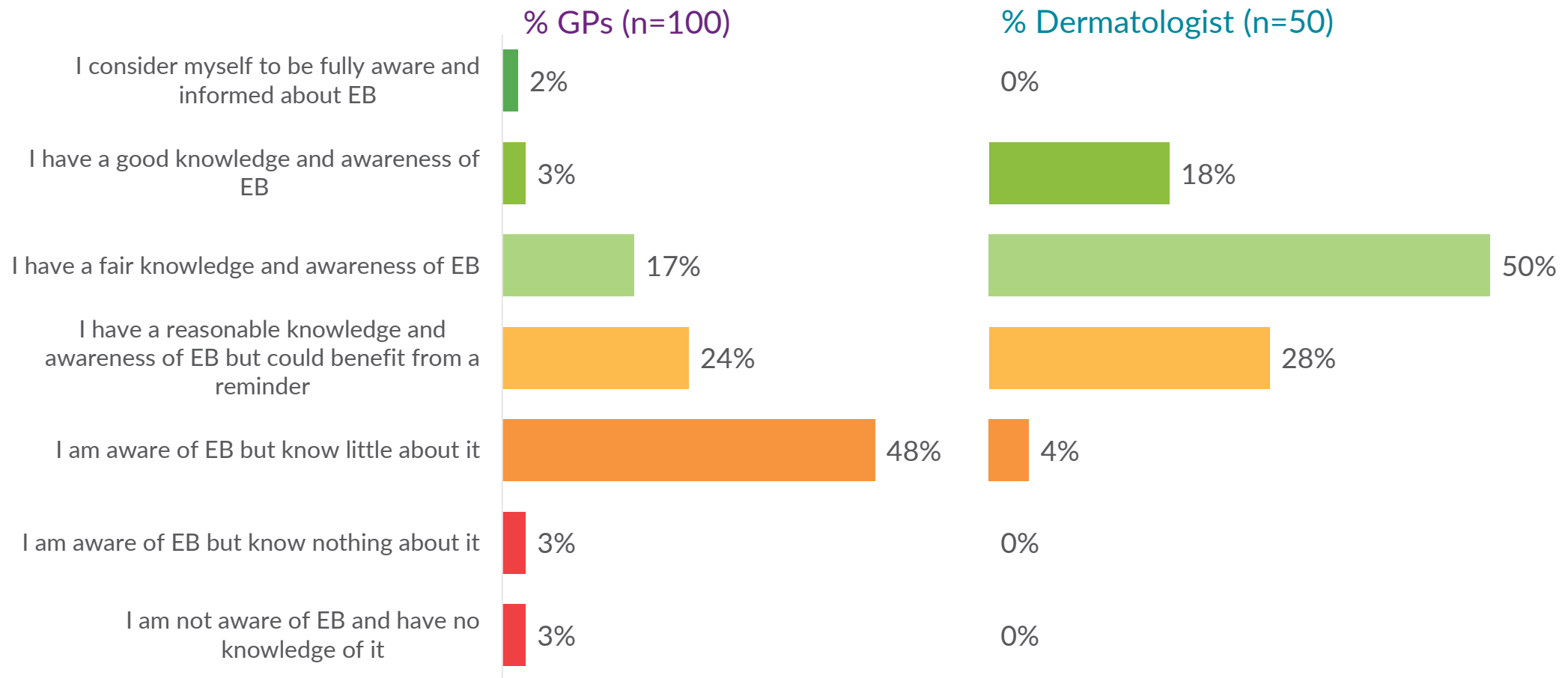
HCP Survey

Detailed findings

HCP awareness of and attitudes to EB

The majority of HCPs have little to fair knowledge of EB; dermatologists have greater knowledge and awareness than GPs, but none consider themselves fully informed

Which of the following statements best describes your understanding and awareness of EB? (prompted)



Base = 50 Dermatologists and 100 GPs

Q11: Which of the following statements best describes your understanding and awareness of EB?

93% GPs and 22% dermatologists don't know the details of their closest EB specialist service

Do HCPs know the details of their nearest EB specialist service? (prompted)



| | GPs (n=100) | Dermatologists (n=50) |
|------------|----------------|--------------------------|
| ■ Yes | 7% | 78% |
| ■ No | 80% | 20% |
| ■ Not Sure | 13% | 2% |

Base = 50 Dermatologists and 100 GPs

Q16 Do you know the details of your closest specialist EB service?

Only a minority of HCPs (7%) believe GPs can refer directly to EB services; a third of GPs and a quarter of dermatologists believe this is not possible

Can GPs refer directly to EB specialist services, even if the specialist service is outside the local referral area? (prompted)



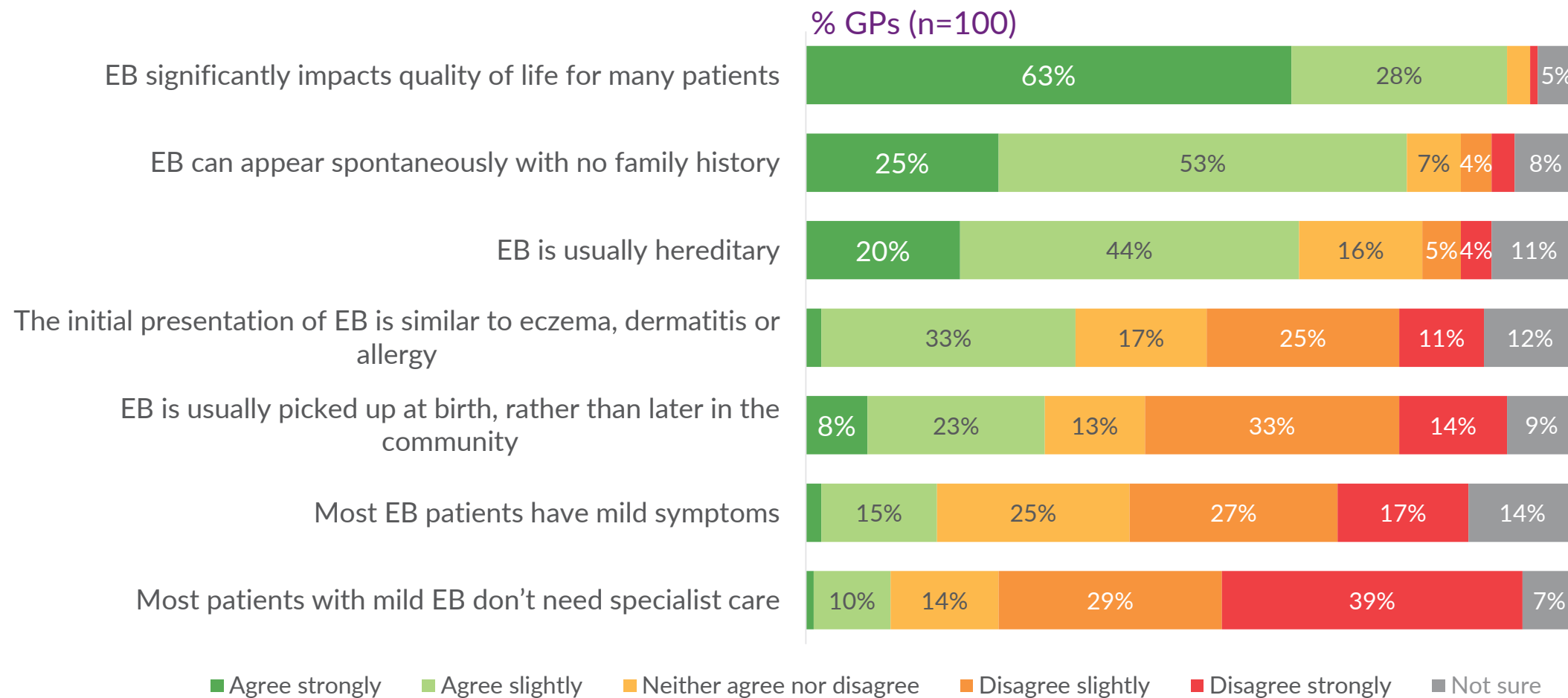
| | GPs (n=100) | Dermatologists (n=50) |
|------------|----------------|--------------------------|
| ■ Yes | 8% | 6% |
| ■ No | 32% | 24% |
| ■ Not Sure | 60% | 70% |

Base = 50 Dermatologists and 100 GPs

Q17 Can you / Can GPs refer directly to specialist EB services (i.e. without having to refer via a dermatologist (or paediatrician)), even if the specialist centre is outside the local referral area?

GPs appear to have fair awareness of EB disease characteristics, with 91% aware of impact on QOL and 78% aware of potential non-genetic presentation; however 35% agree initial presentation is similar to eczema / dermatitis / allergy, and 11% believe most mild patients don't need specialist care

To what extent do you agree or disagree with the following statements about EB? (prompted)



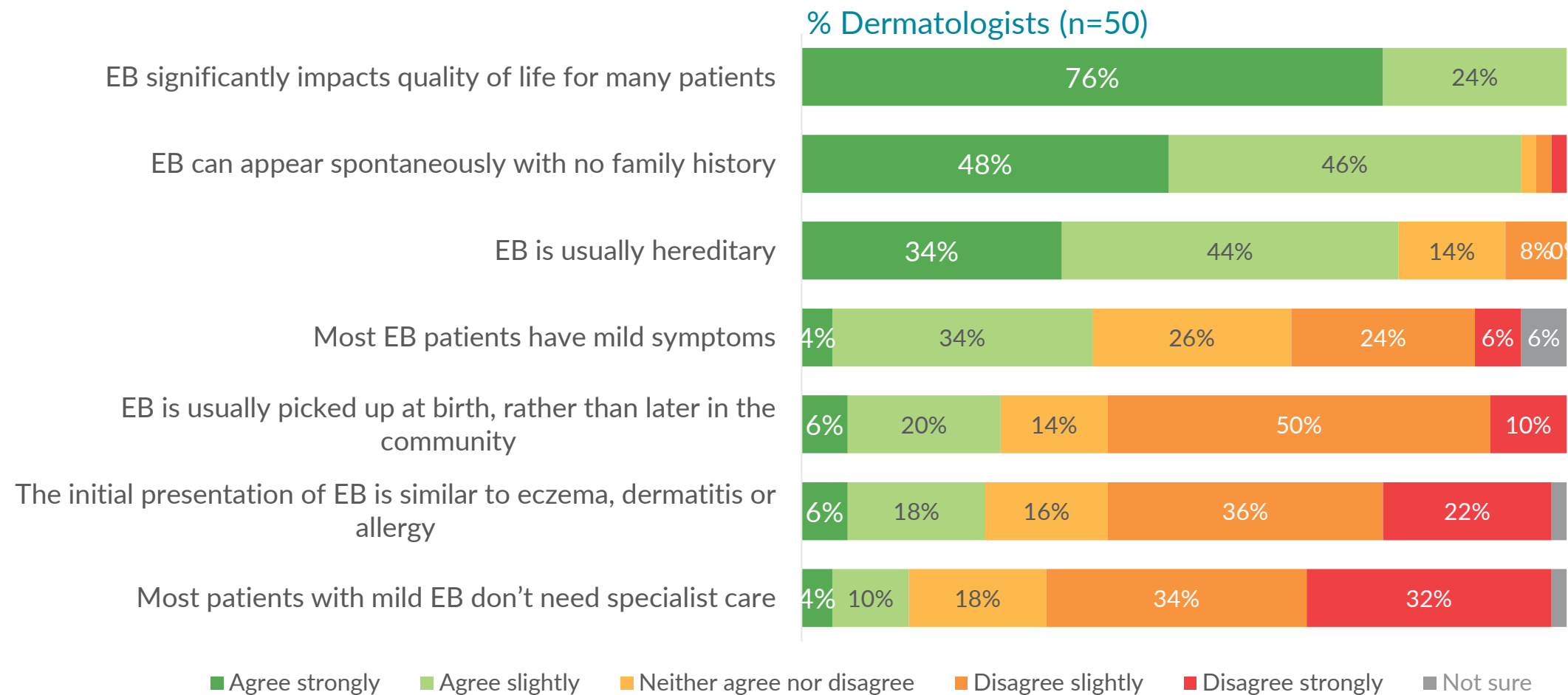
N.B. Percentages <4% not labelled for clarity

Base = 100 GPs

Q13: To what extent do you agree or disagree with the following statements about EB?

All dermatologists aware of EB impact on QOL; but a quarter agree EB presents similarly to eczema / dermatitis / allergy

To what extent do you agree or disagree with the following statements about EB? (prompted)



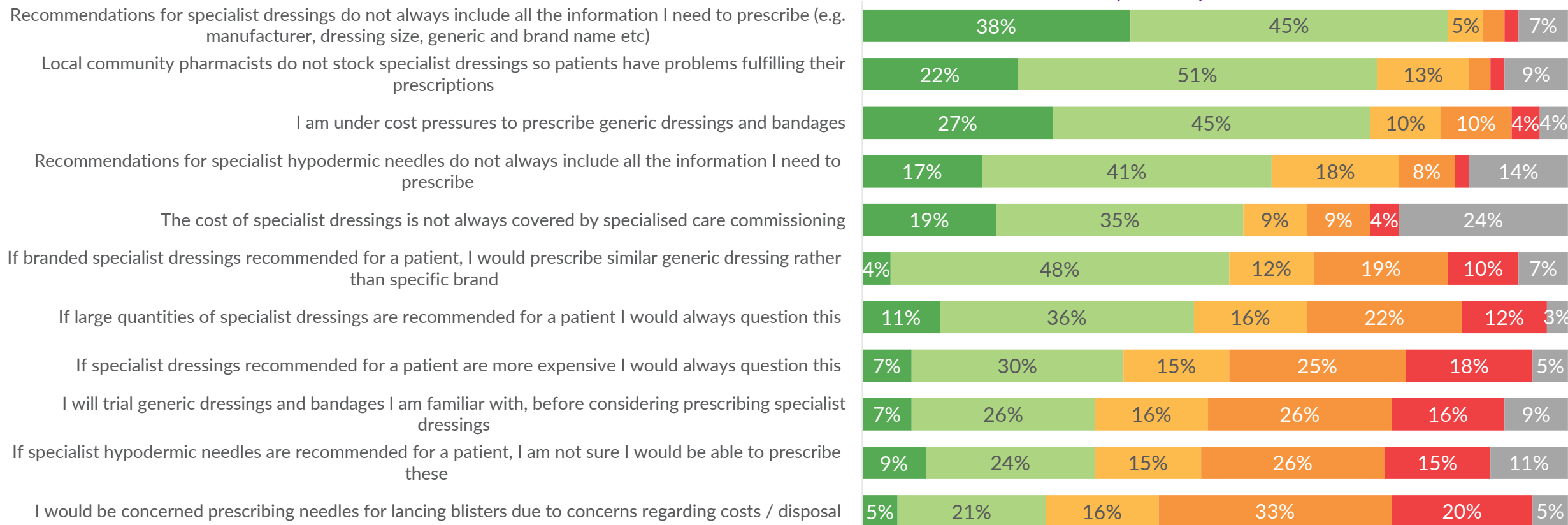
Base = 50 Dermatologists

Q13: To what extent do you agree or disagree with the following statements about EB?

N.B. Percentages <4% not labelled for clarity

If specialist dressings are recommended, just over half of GPs would opt to prescribe similar generic dressings instead; c.half would always question requests for large quantities of dressings, and over half believe the cost of specialist dressings is not always covered by specialised commissioning

To what extent do you agree or disagree with each other following statements about prescribing and dispensing of specialist bandages, dressings and other items? (prompted) % GPs (n=100)



■ Agree strongly ■ Agree slightly ■ Neither agree nor disagree ■ Disagree slightly ■ Disagree strongly ■ Not sure

N.B. Percentages <4% not labelled for clarity

Base = 100 GPs

Q20 To what extent do you agree or disagree with each other following statements about prescribing and dispensing of specialist bandages, dressings and other items?

44% dermatologist strongly agree that GPs are not always happy to supply specialist dressings
The majority of dermatologists also agree that specialist dressings may not be stocked by community pharmacies, that recommendations for them don't always include all information needed to prescribe, and that they are under cost pressure to prescribe generic dressings

To what extent do you agree or disagree with each other following statements about prescribing and dispensing of specialist bandages, dressings and other items? (prompted) **% Dermatologists (n=50)**

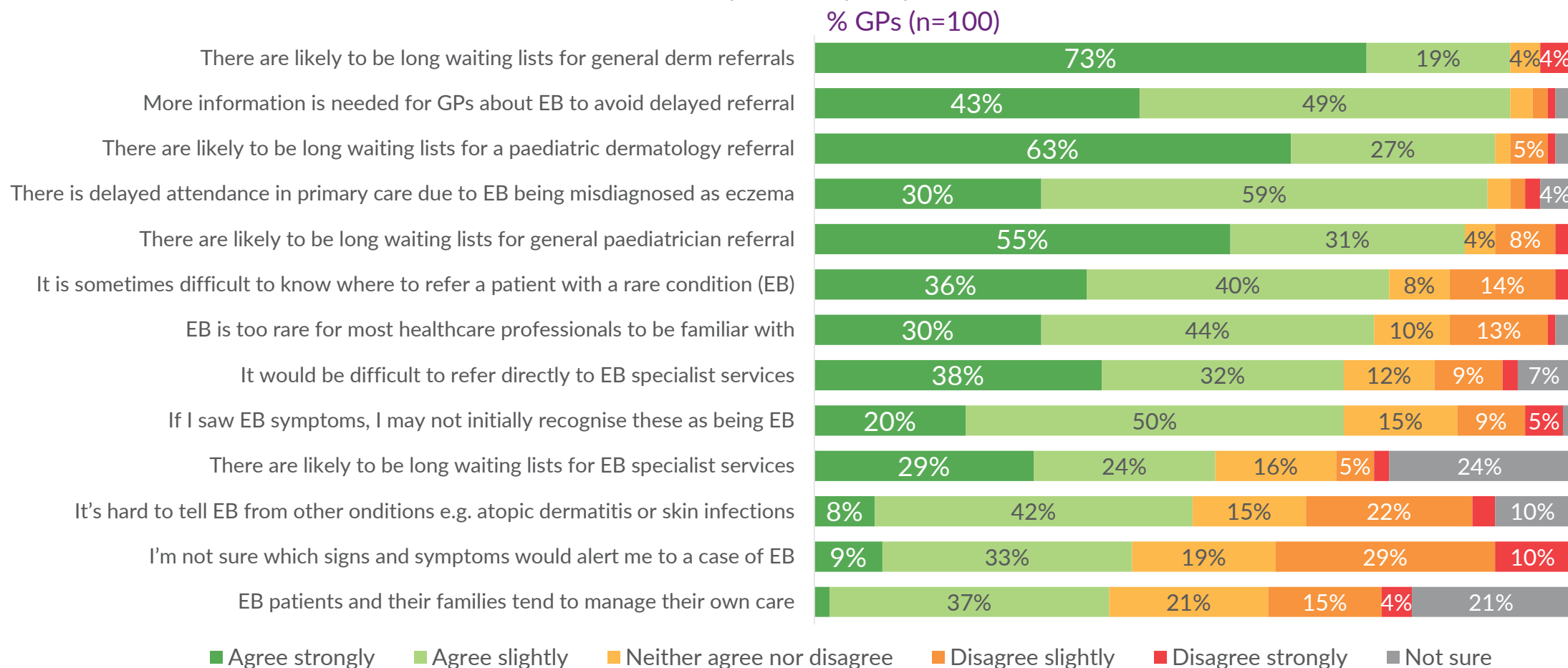


N.B. Percentages <4% not labelled for clarity

Base = 50 Dermatologists
Q20 To what extent do you agree or disagree with each other following statements about prescribing and dispensing of specialist bandages, dressings and other items?

Over 2/3 of GPs identify several potential difficulties with the EB referral process including long wait times; ~90% of GPs also suggest that EB is misdiagnosed as other skin conditions due to lack of information and may cause delayed referral

To what extent do you agree with the following statements about the factors which may cause delays to diagnosis and referral of EB patients? (prompted)



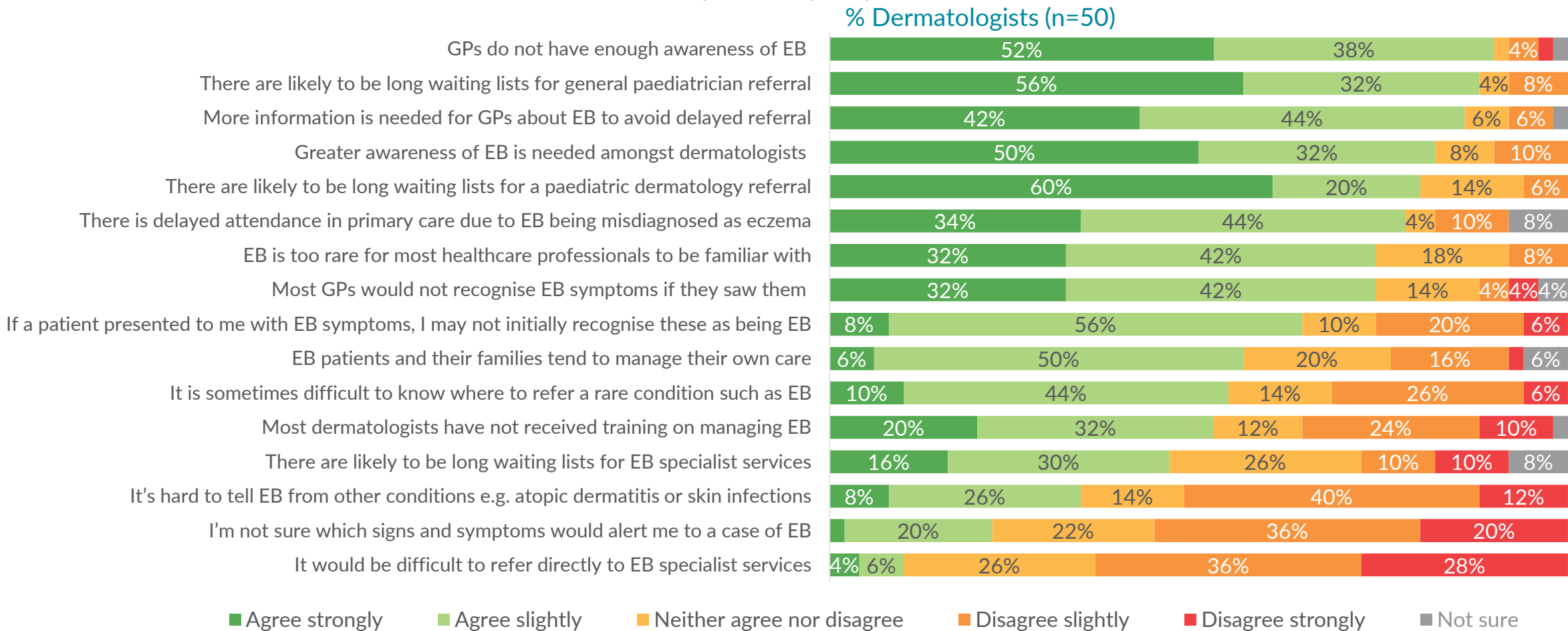
Base = 100 GPs

N.B. Percentages <4% not labelled for clarity

Q21 To what extent do you agree or disagree with the following statements about the factors which may cause delays to diagnosis and referral of EB patients?

Over 2/3 of dermatologists suggest that awareness of EB in both primary care and general dermatology is too low and paediatric referral waiting lists are likely to be long; three quarters feel EB is too rare for most HCPs to be familiar with and 2/3 are not sure GPs would recognise EB symptoms if they saw them

To what extent do you agree with the following statements about the factors which may cause delays to diagnosis and referral of EB patients? (prompted)



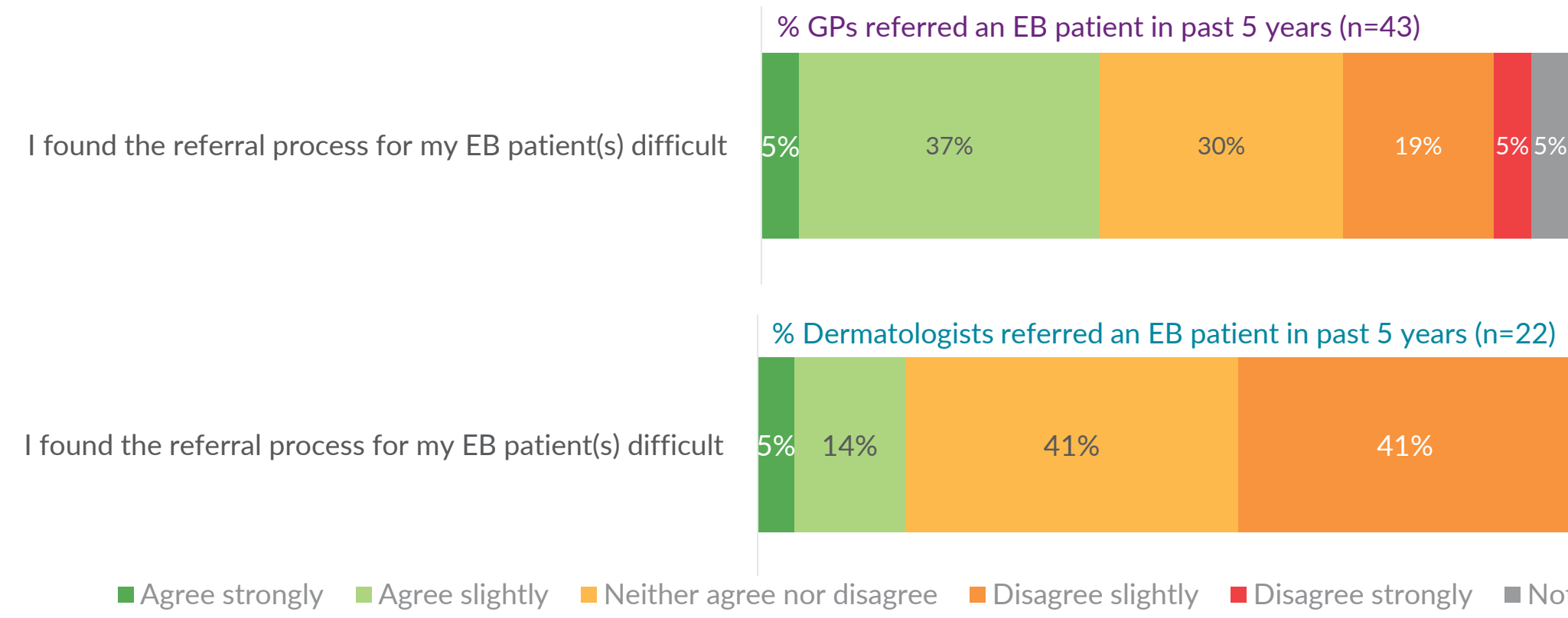
Base = 50 Dermatologists

Q21 To what extent do you agree or disagree with the following statements about the factors which may cause delays to diagnosis and referral of EB patients?

N.B. Percentages <4% not labelled for clarity

42% GPs and 19% dermatologists who have referred an EB patient in the last 5 years found the referral process difficult

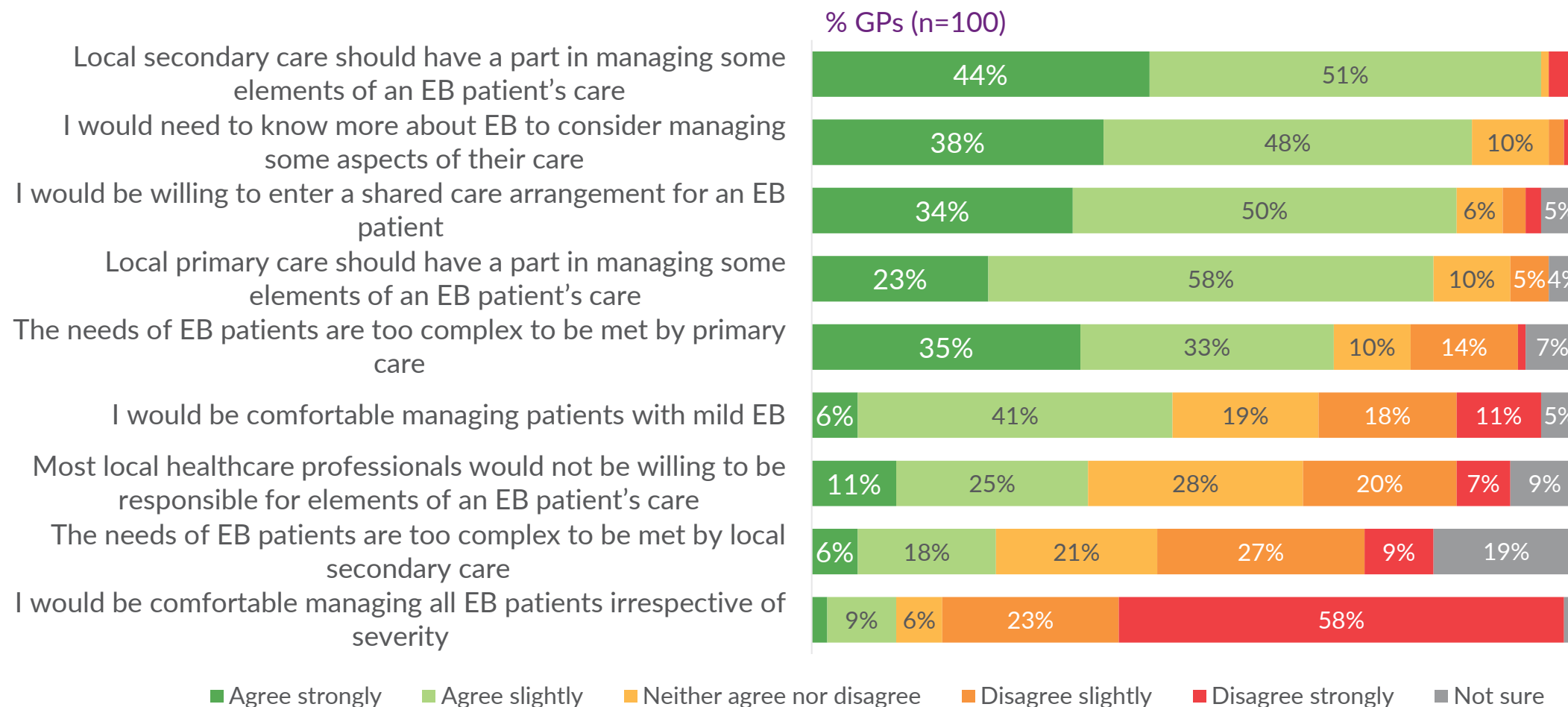
To what extent do you agree with the following statements about the factors which may cause delays to diagnosis and referral or EB patients? (prompted)



Base = 22 Dermatologists and 43 GPs
Q21 To what extent do you agree or disagree with the following statements about the factors which may cause delays to diagnosis and referral of EB patients?

Whilst over 4/5 GPs feel primary care should have a role in EB patient care and would be willing to take part in shared care arrangements, they would need to know more about EB before feeling comfortable to do this; just under half would be comfortable managing mild patients, but over 8/10 have reservations about managing more severe cases

To what extent do you agree with the following statements about management of EB patients (prompted)



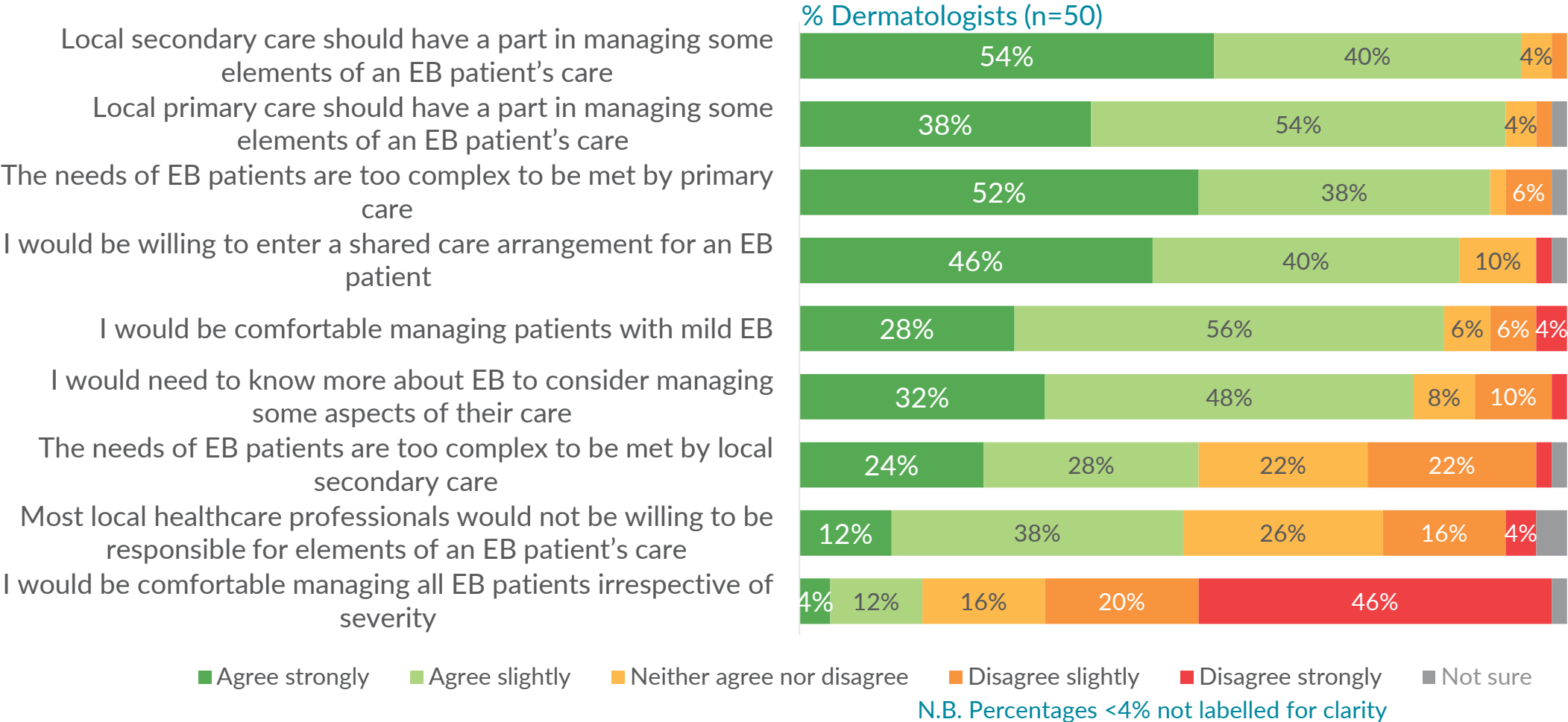
N.B. Percentages <4% not labelled for clarity

Base = 100 GPs

Q22 To what extent do you agree or disagree with the following statements about management of EB patients?

95% of Dermatologists agree that local secondary care should be involved in managing EB; most are happy managing mild, however, two thirds would not be comfortable with severe cases, and 52% agree the needs of EB patients are too complex for local secondary care to meet

To what extent do you agree with the following statements about management of EB patients? (prompted)



Base = 50 Dermatologists
Q22 To what extent do you agree or disagree with the following statements about management of EB patients?

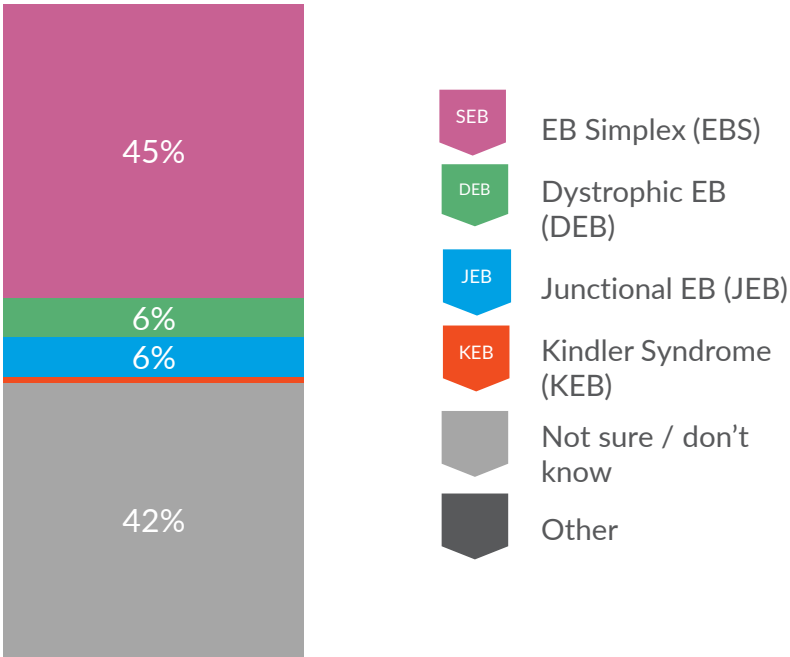
HCP management of EB

Half of EB patients seen by GPs are undiagnosed presentations

Only 58% GPs aware of the type of EB the patient they saw had

57% GPs have seen an EB patient in the last 5 years (mean 4 patients)

% EB patients with each type of EB / last 5 years (n=57 GPs)



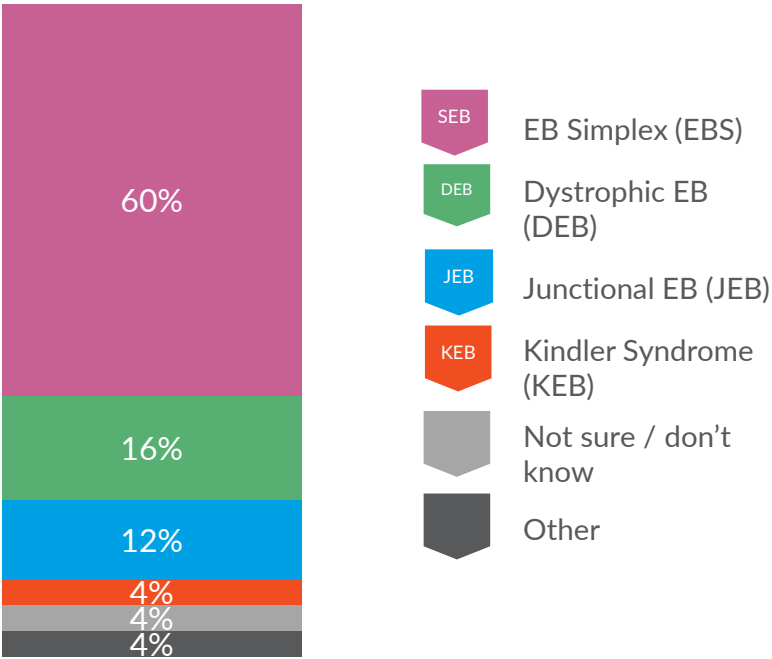
| | % patients | GP |
|--|------------|-----|
| Undiagnosed patient presented with new EB symptoms seeking diagnosis | 41% | 41% |
| Diagnosed EB patient seen for issues relating to their EB | 22% | 22% |
| Diagnosed EB patient looking for (re)referral into tertiary care services | 11% | 11% |
| Diagnosed EB patient seen for another issue unrelated to EB | 17% | 17% |
| Undiagnosed patient with awareness of condition (e.g. due to own research or family history) seeking tertiary specialist care referral | 9% | 9% |






Base: 57 GPs & 40 dermatologists who have seen an EB patient / last 4 years (2 x outliers excluded)
Q3 Of the __patient(s) you have seen with EB in the last 5 years, how many had each type of EB?
Q4 How many were first seen under each of the following circumstances?

EB patients seen by HCPs are majority EBS; 38% were new, undiagnosed presentations

82% Dermatologists have seen an EB patient in the last 5 years (mean 5 patients)

% EB patients with each type of EB / last 5 years (n=97 HCPs)

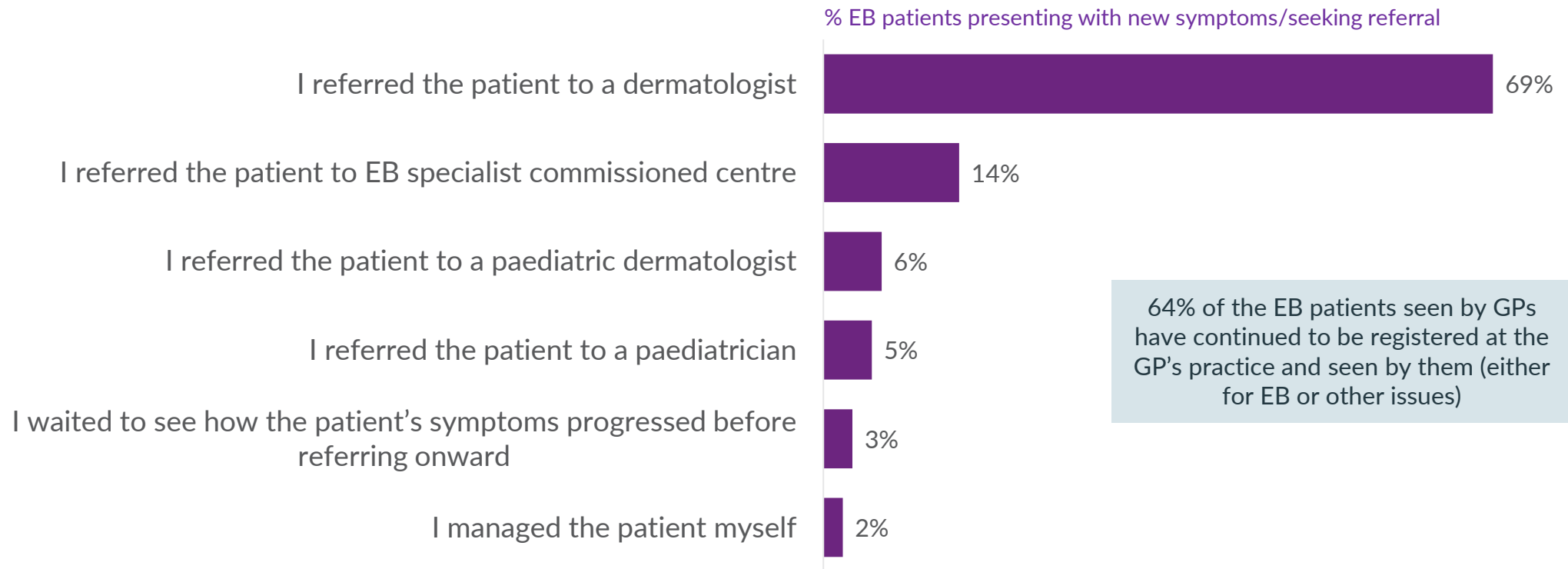


| % patients | | Derm |
|---|--|------|
|  | Undiagnosed patient presented with new EB symptoms seeking diagnosis | 28% |
|  | Diagnosed EB patient seen for issues relating to their EB | 33% |
|  | Diagnosed EB patient looking for (re)referral into tertiary care services | 21% |
|  | Diagnosed EB patient seen for another issue unrelated to EB | 7% |
|  | Undiagnosed patient with awareness of condition (e.g. due to own research or family history) seeking tertiary specialist care referral | 10% |

Base: 57 GPs & 40 dermatologists who have seen an EB patient / last 4 years (2 x outliers excluded)
Q3 Of the__patient(s) you have seen with EB in the last 5 years, how many had each type of EB?
Q4 How many were first seen under each of the following circumstances?

Two thirds of EB patients seen by GPs were referred to a dermatologist; only 14% were referred directly to an EB specialist centre

Of the patients presenting with new EB symptoms or seeking a referral when you first saw them – which of the following actions did you take? (prompted)



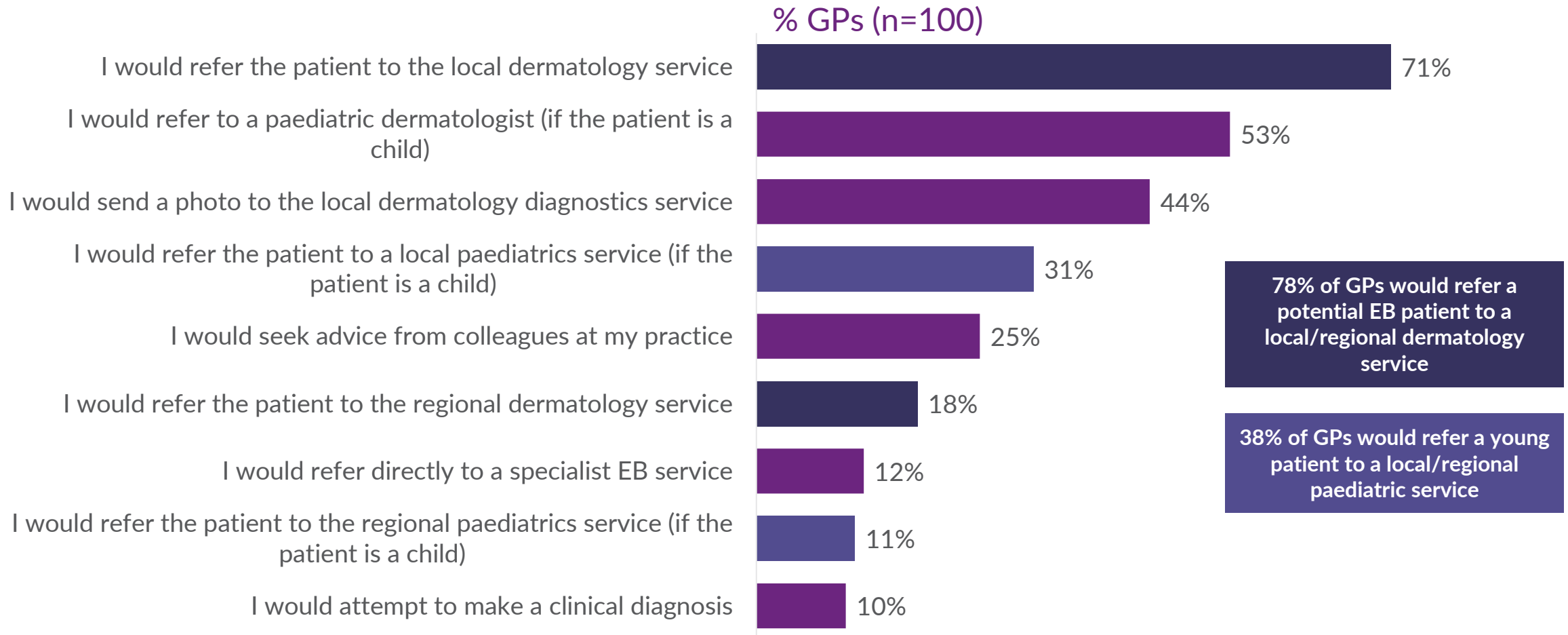
Base = 42 GPs with EB patient(s) in last 5 years either presenting with new EB symptoms or seeking a referral into tertiary specialist care (1 x outlier excluded)

Q5 Of the ___patient(s) you said you have seen with EB in the last 5 years who were either presenting with new EB symptoms or seeking a referral into tertiary specialist care when you first saw them – which of the following actions did you take?

Q6 Of the ___patient(s) you said you have seen with EB in the last 5 years how many continue to be registered at your practice and seen by you / colleagues, either for their EB or for other issues?

Only 12% of GPs would refer a potential EB patient directly to specialist EB services; the majority would refer to the local/regional dermatology service (78%) or paediatric dermatologist (53%)

If you were to identify a potential EB patient, what actions would you take? (prompted, multicode)

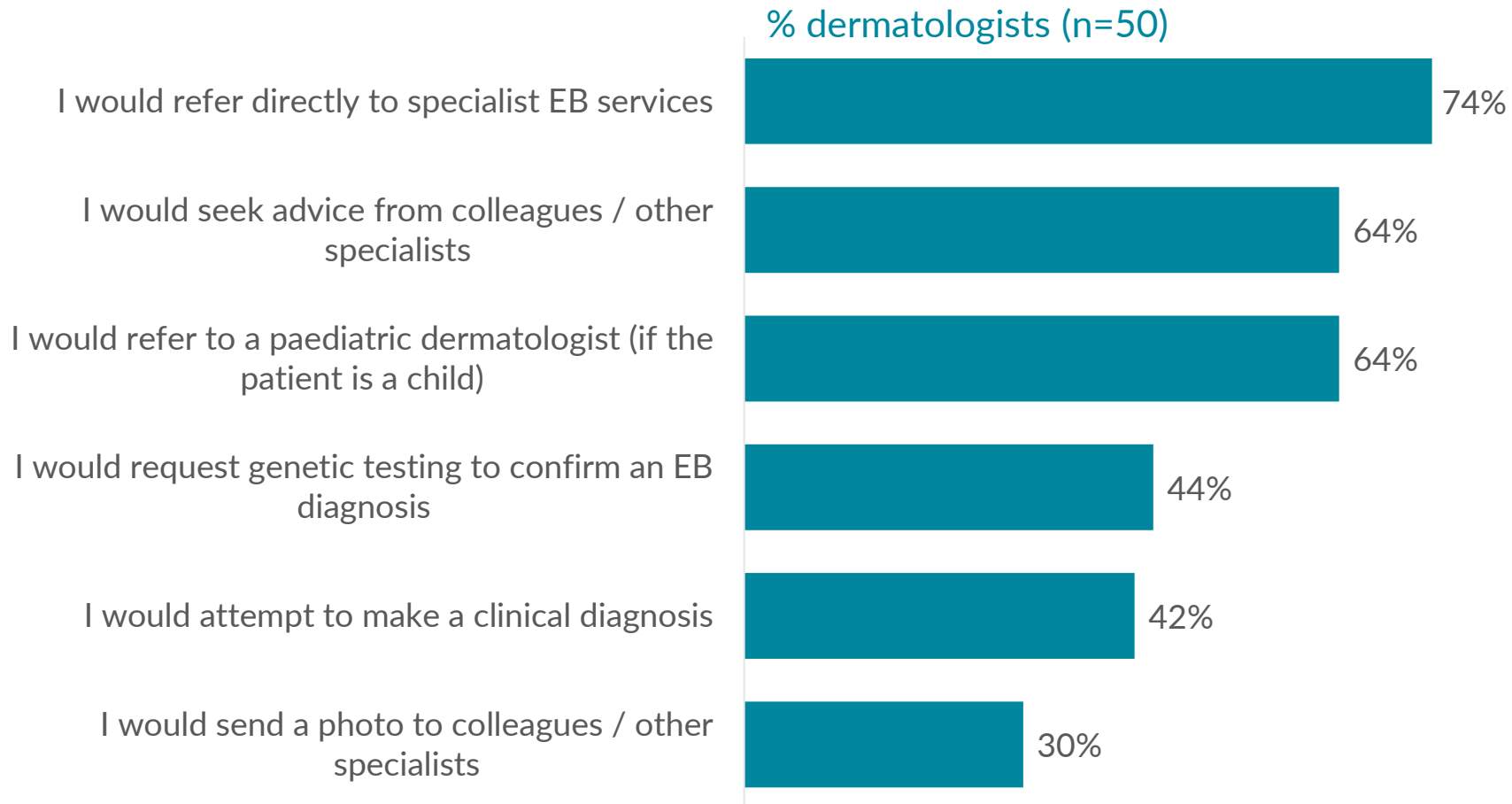


Base = 100 GPs

Q14: If you were to identify a potential EB patient, what actions would you take?

Three quarters of dermatologists would refer a potential EB patient directly to EB specialist services; two thirds would refer to a paediatric dermatology

If you were to identify a potential EB patient, what actions would you take? (prompted, multicode)



Of the 26% dermatologists who **did not** select they would not refer directly to a specialist centre:

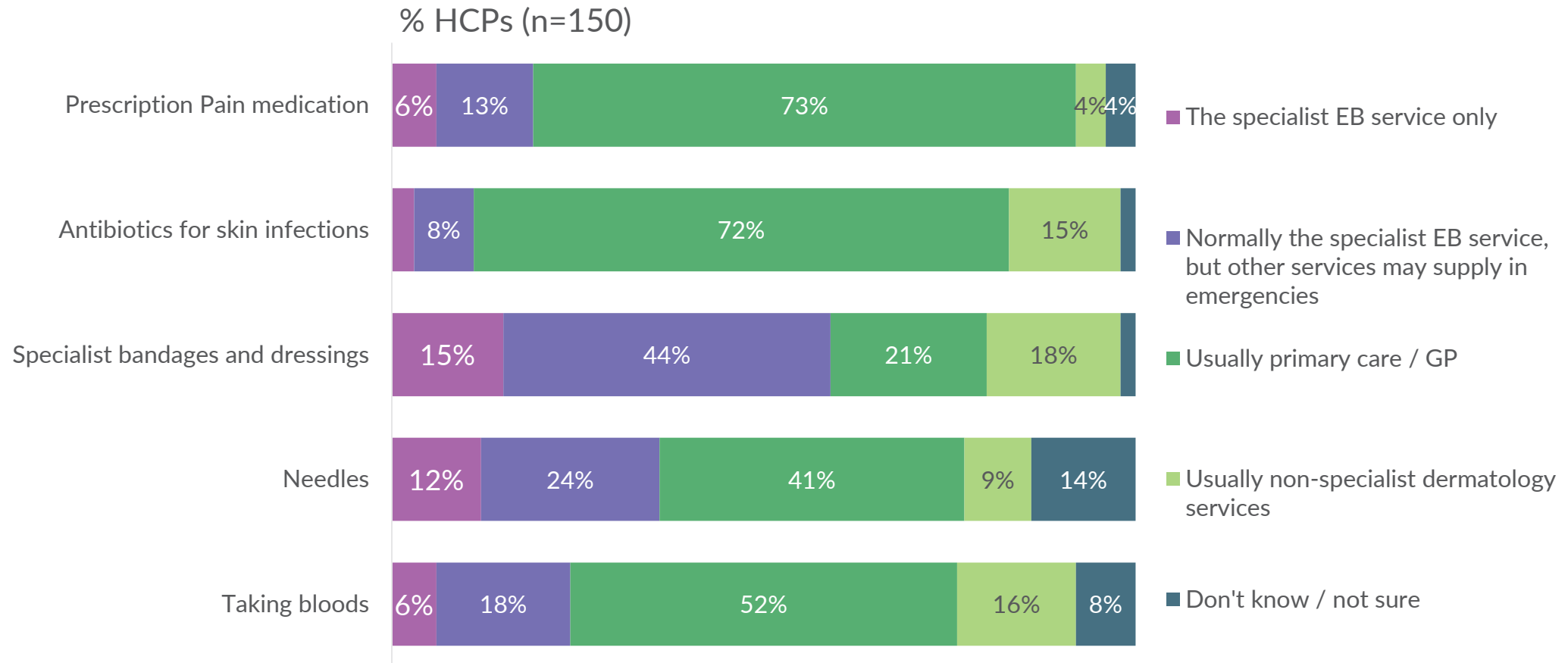
- 77% said they would seek advice from another colleague or specialists
- 77% said they would refer to a paediatric dermatologist

Base = 50 Dermatologists

Q15: If you were to identify a potential EB patient, what actions would you take?

C. three quarters HCPs say primary care would manage pain medication and antibiotics for EB patients, but 59% say specialist services normally manage specialist bandages and dressings; lack of certainty around who manages provision of needles and taking bloods

Who typically manages the following aspects of EB patients' care? (prompted)



Base = 50 Dermatologists and 100 GPs

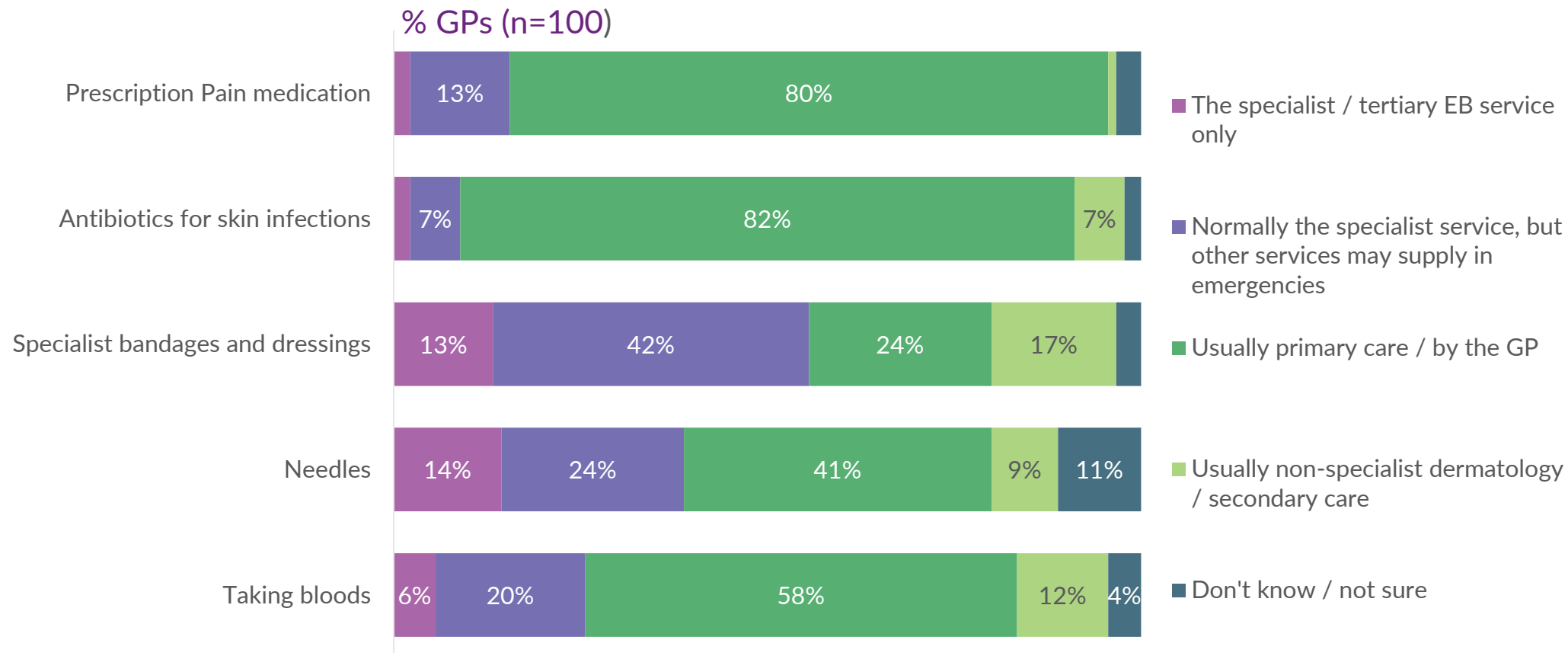
N.B. Percentages <4% not labelled for clarity

Q8: Thinking about the ___ EB patient(s) remaining under your care, who typically manages the following aspects of these patients' care?

Q8B: Thinking generally about the patients you see in your practice who have rare or unusual dermatological condition that are usually seen by specialists / tertiary services, who typically manages the following aspects of these patients' care?

4/5 GPs say primary care would manage pain medication and antibiotics for EB patients, and 58% suggest they would take bloods, but lack of certainty around who would manage needles and specialist bandages; just over half suggest specialist care would manage bandages/dressings

Who typically manages the following aspects of EB patients' care? (prompted)



Base = 100 GPs

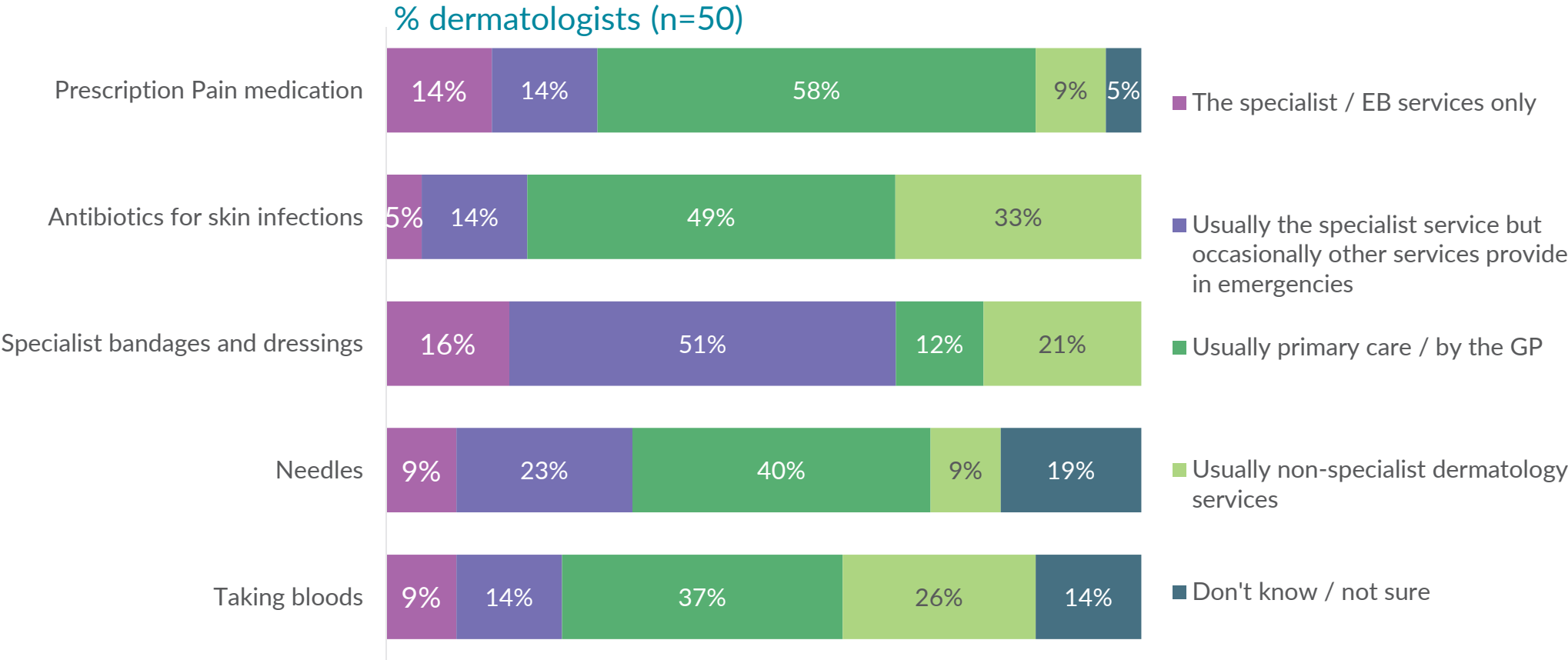
Q8: Thinking about the ___ EB patient(s) remaining under your care, who typically manages the following aspects of these patients' care?

Q8B: Thinking generally about the patients you see in your practice who have rare or unusual dermatological condition that are usually seen by specialists / tertiary services, who typically manages the following aspects of these patients' care?

N.B. Percentages <4% not labelled for clarity

Vs GPs dermatologists envisage a slightly greater role for non-specialist dermatology and specialist care in managing pain medication, antibiotics and taking bloods for EB patients; two thirds say specialist services will manage specialist bandages and dressings

Who typically manages the following aspects of EB patients' care? (prompted)



Base = 50 Dermatologists

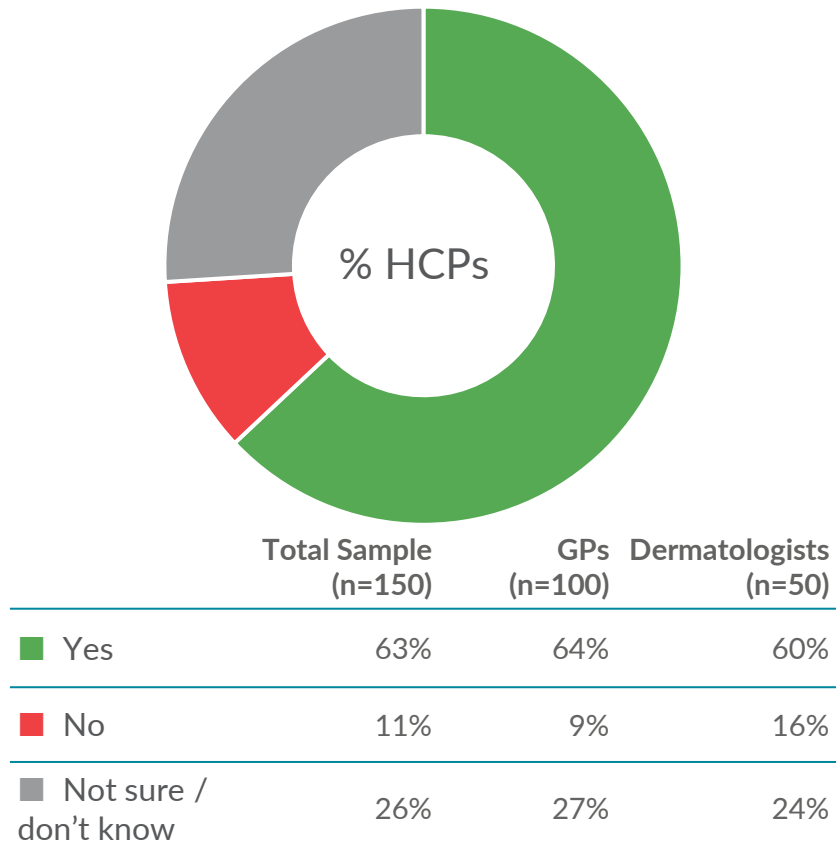
Q8: Thinking about the ___ EB patient(s) remaining under your care, who typically manages the following aspects of these patients' care?

Q8B: Thinking generally about the patients you see in your practice who have rare or unusual dermatological condition that are usually seen by specialists / tertiary services, who typically manages the following aspects of these patients' care?

N.B. Percentages <4% not labelled for clarity

Two thirds HCPs claim to have an approved dressings list / formulary; prescribing outside of this list is difficult for the majority, especially dermatologists (84%)

Do you have an approved dressings list / wound care / dressings formulary in your local area?

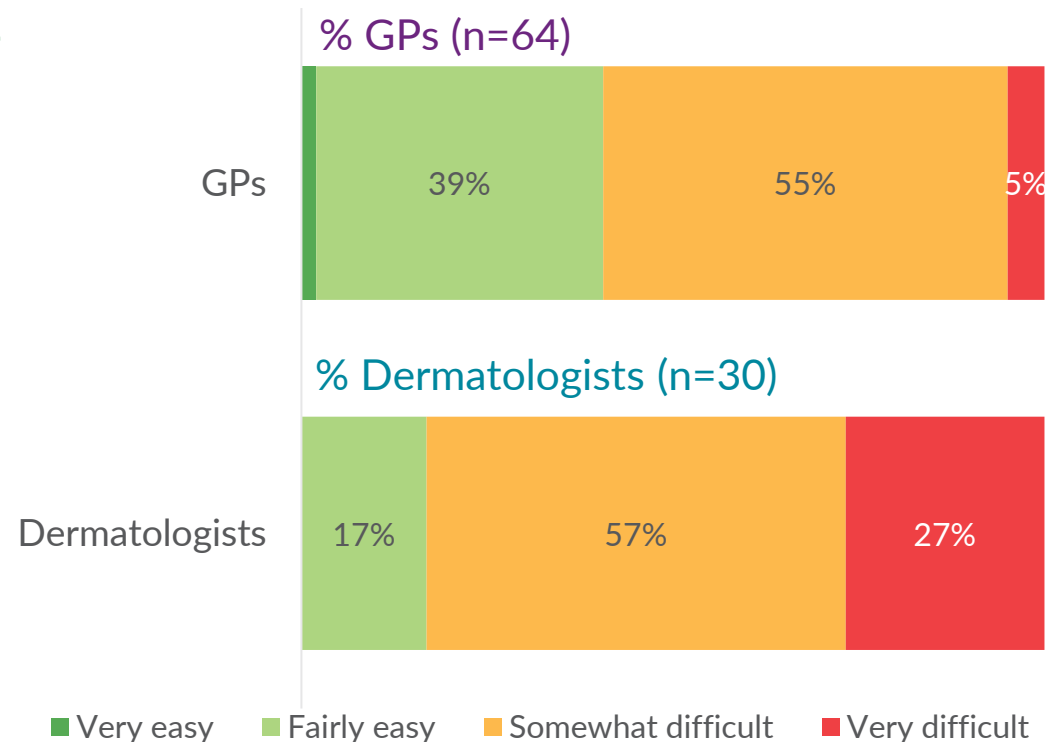


Base = 50 Dermatologists and 100 GPs

Q18 Do you have an approved dressings list / wound care formulary / dressings formulary in your local area?

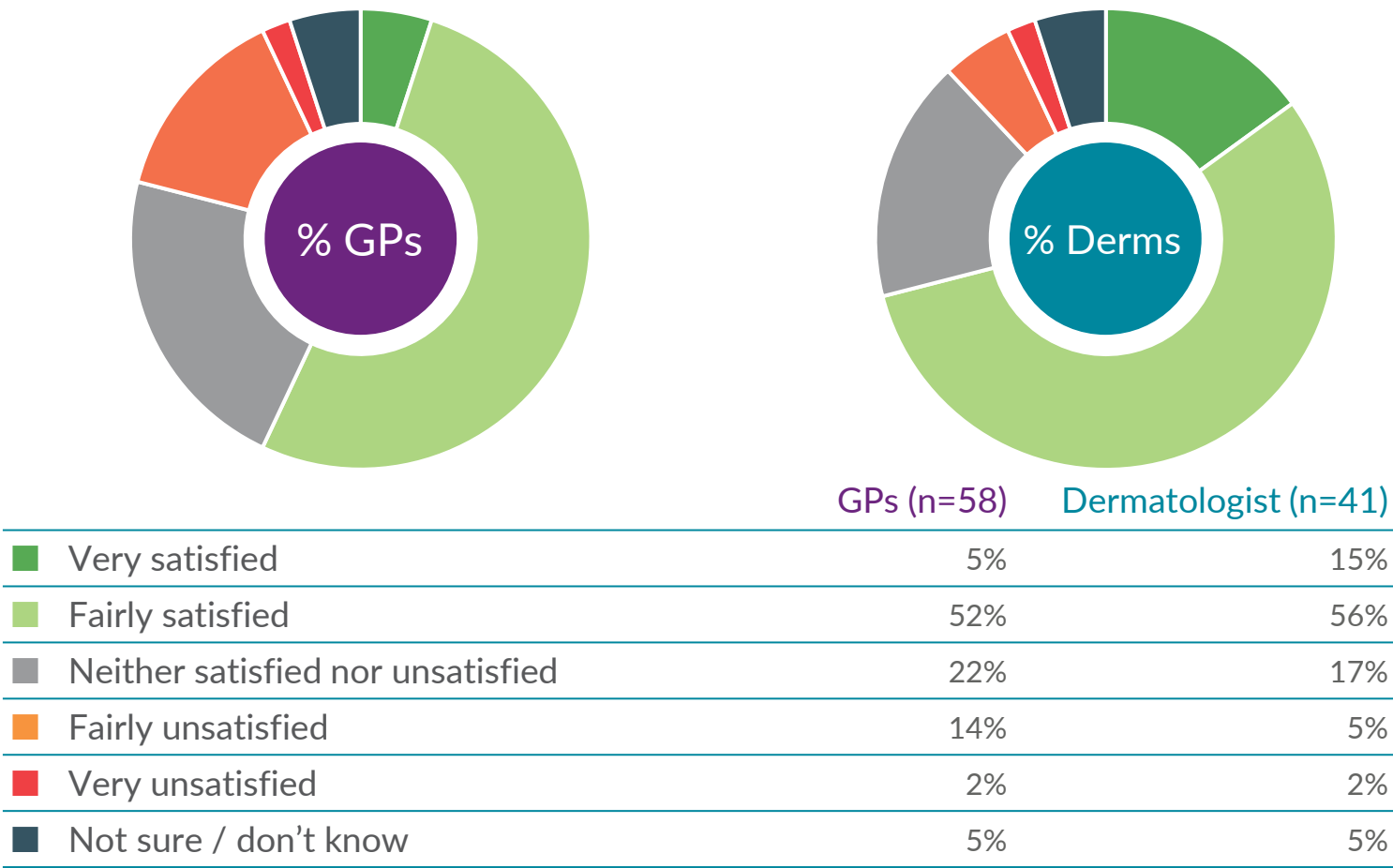
Q19 How easy or difficult would it be to prescribe dressings NOT on the dressings formulary if needed / when requested by specialist service?

How easy or difficult would it be to prescribe dressings NOT on the dressings formulary if needed / when requested by specialist service?



Over half of HCPs are satisfied with the current healthcare provision available to EB patients – but few are very satisfied, room for improvement

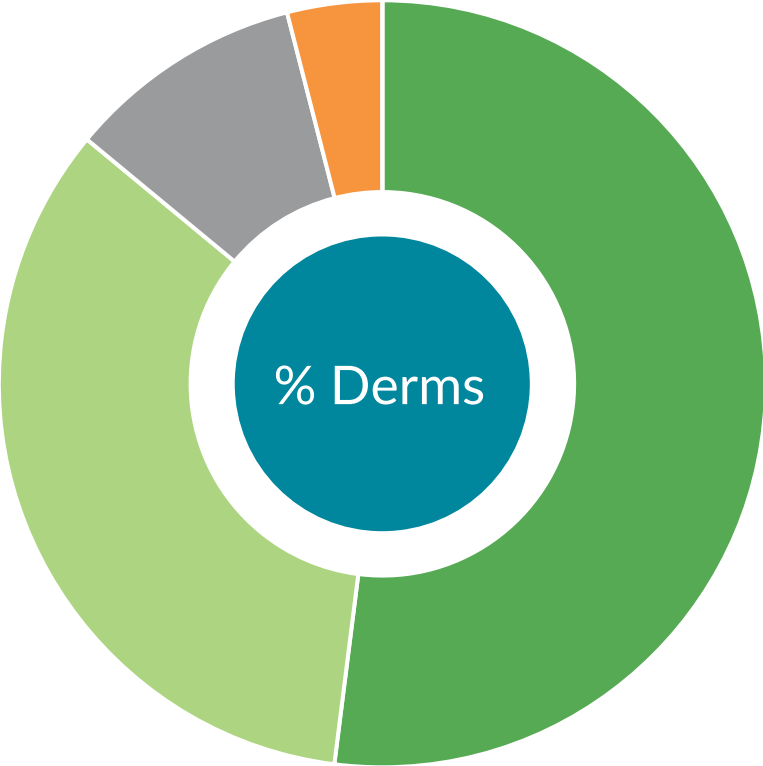
Thinking about the ___ patient(s) you have seen with EB in the last 5 years, how satisfied have you been with the current healthcare provision available to EB patients? (prompted)



Base = All with EB patient in last 5 years (41 Dermatologists and 58 GPs)
 Q10: Thinking about the ___ patient(s) you have seen with EB in the last 5 years, how satisfied have you been with the current healthcare provision available for EB patients?

86% of Dermatologists would feel positively towards the set up of an EB outreach clinic in their area

*How positively or negatively would you feel towards the set up of an EB Outreach Clinic in your area?
(prompted)*

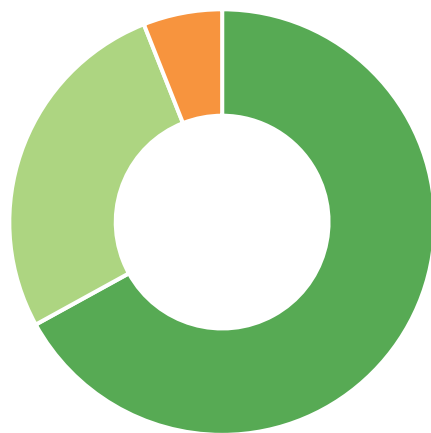


| Dermatologist (n=50) | | |
|----------------------|-------------------------------|-----|
| <div></div> | Very positive | 52% |
| <div></div> | Fairly positive | 34% |
| <div></div> | Neither positive nor negative | 10% |
| <div></div> | Fairly negative | 4% |
| <div></div> | Very unsatisfied | 0% |
| <div></div> | Not sure / don't know | 0% |

Communicating with HCPs about EB

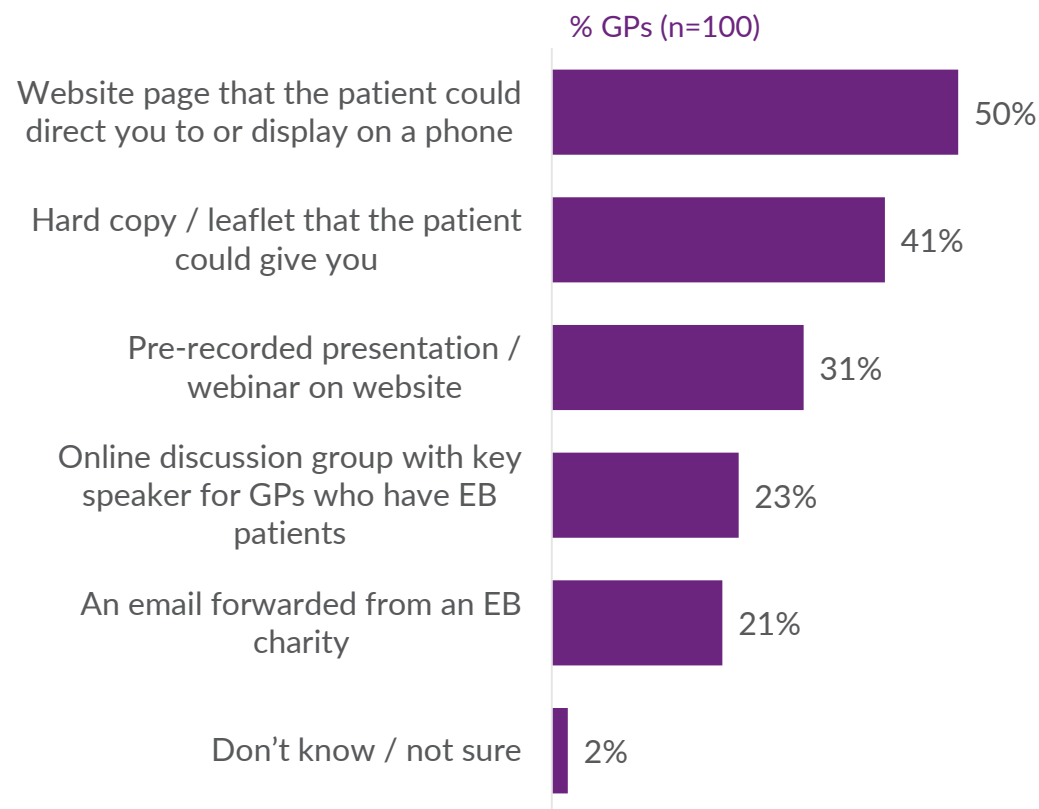
Two thirds of GPs would find a patient-directed pack of information very useful, with preference for this to be a website page the patient could direct them to or a hard copy / leaflet the patient could provide

How useful would GPs find a patient-directed GP pack of information about EB?



| | GPs (n=100) |
|-------------------|-------------|
| Very useful | 67% |
| Somewhat useful | 27% |
| Not very useful | 6% |
| Not useful at all | 0% |

In what format would a patient-directed GP pack be best presented? (prompted, GPs selected up to 2)



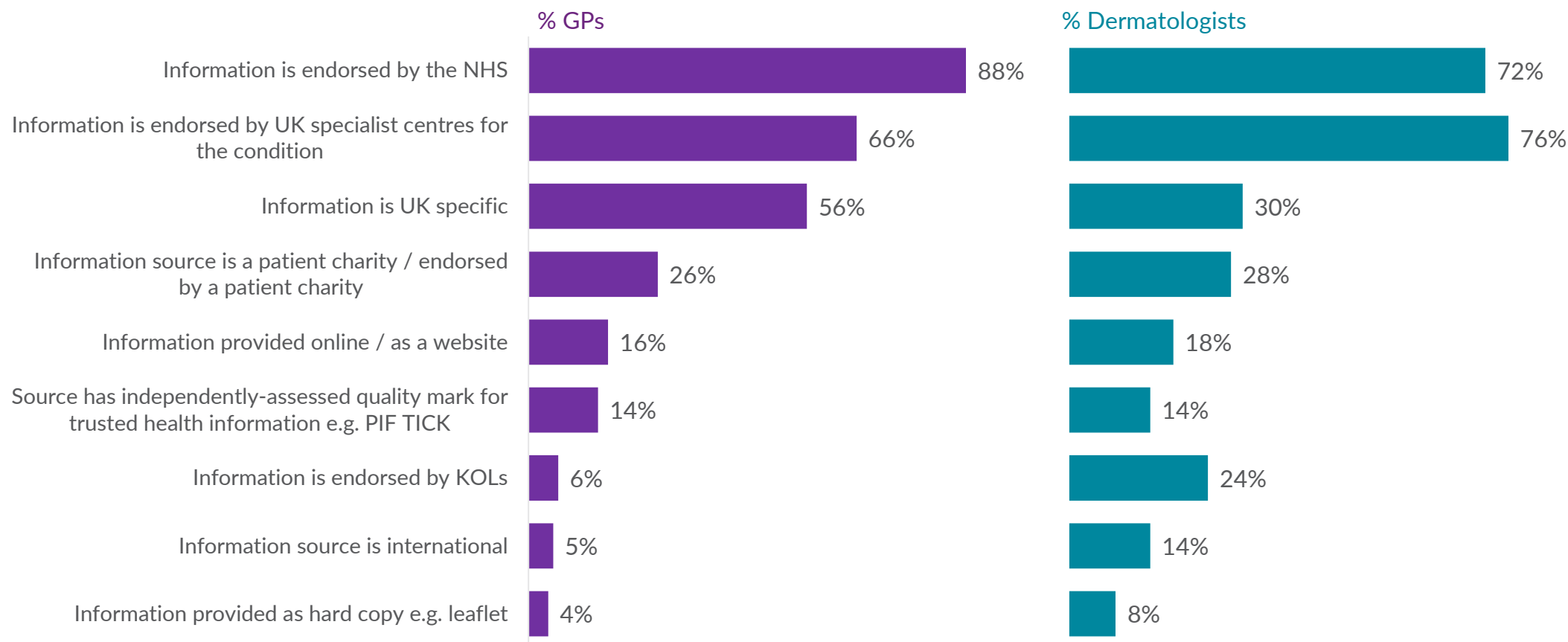
Base = 100 GPs

Q28 If you had a patient with EB under your care, how useful would you find a patient-directed GP Pack of information about EB?

Q29 And in what format would this patient-directed GP pack be best presented to you?

When searching for information about a condition such as EB, HCPs are more likely to use information which is endorsed by specialist centres & the NHS; independent endorsements e.g. PIF TICK would not have an impact for the majority

When you need to search for more information about a condition, for example EB, which of the following would make you more likely to use and trust the information you find? (prompted, multicode)

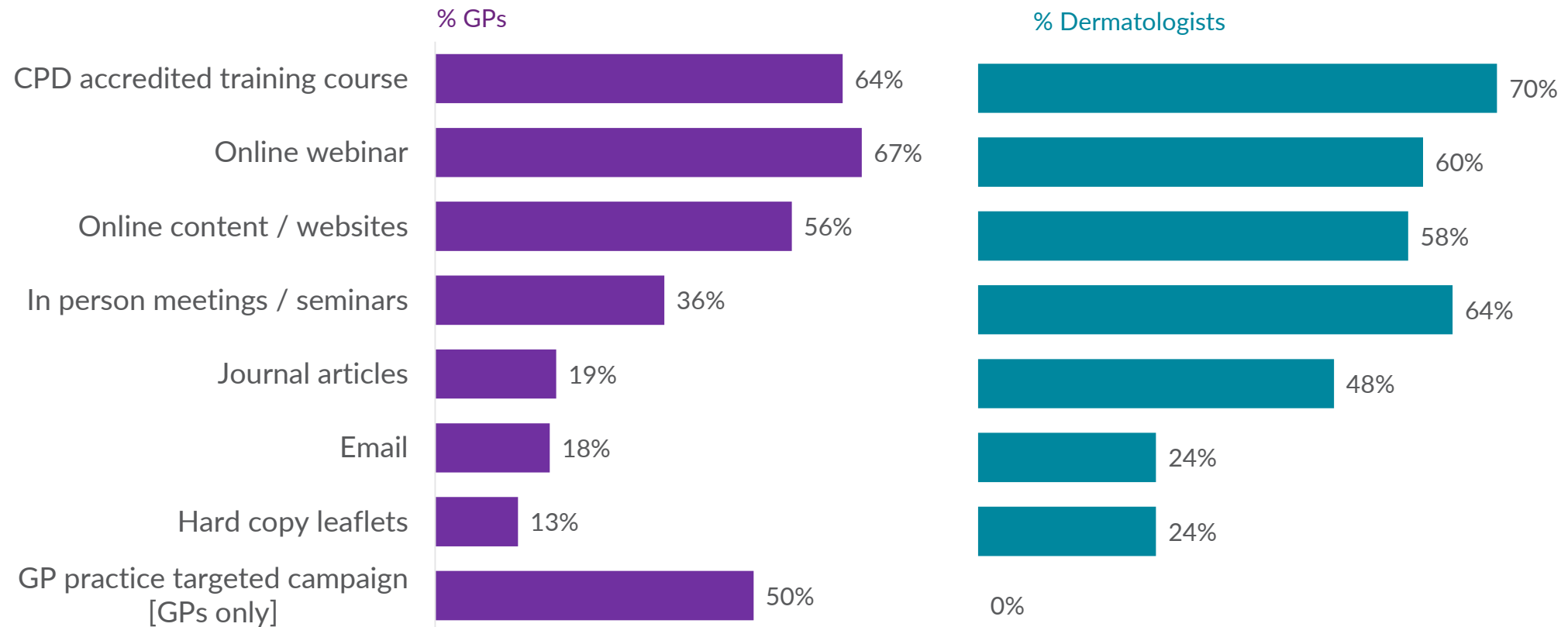


Base 50 Dermatologists and 100 GPs

Q26 When you need to search for more information about a condition, for example EB, which of the following would make you more likely to use and trust the information you find?

HCPs are most likely to engage with EB information in the format of CPD accredited training courses and online webinars / content, and for dermatologists, in person meetings

If you were to receive further information or education about the condition of EB, which of the following formats of information would you be most likely to engage with? (prompted, multicode)

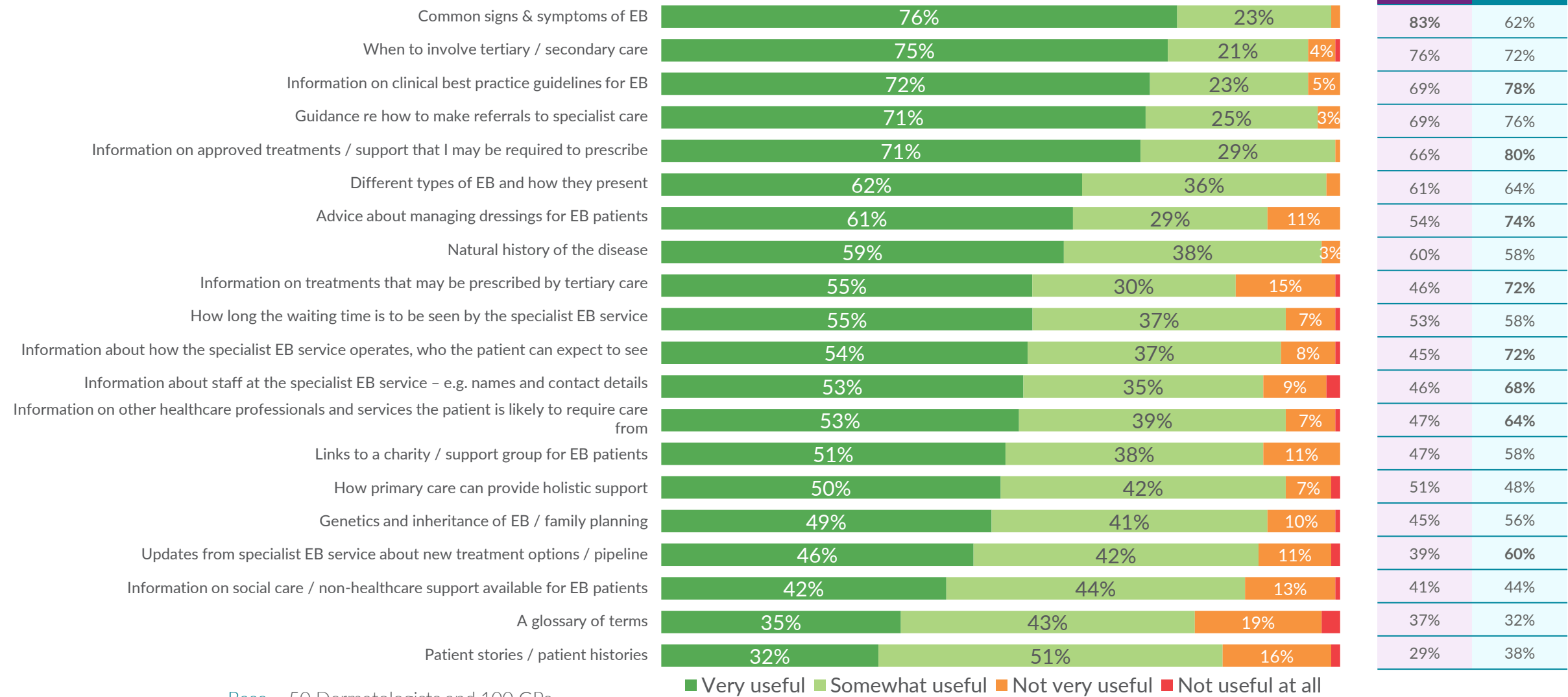


Base = 50 Dermatologists and 100 GPs

Q27 If you were to receive further information or education about the condition of EB, which of the following formats of information would you be most likely to engage with?

HCPs are highly positive towards being provided with different types of information about EB, with common signs/symptoms and when to involve tertiary /secondary care being most useful; dermatologists desire more specific information

If you were to come into contact with an EB patient in the future, how useful, if at all, would you find having been provided with the following information about EB?

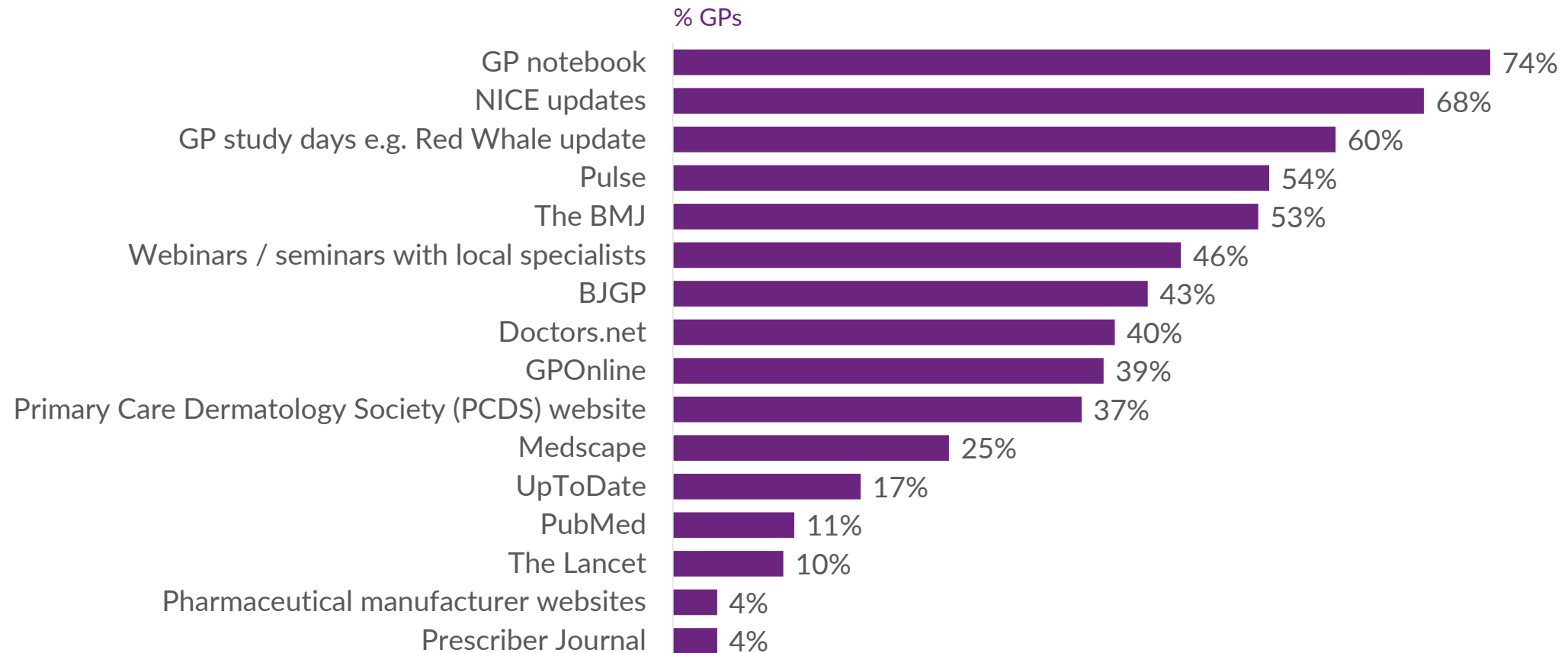


Base = 50 Dermatologists and 100 GPs

Q31 If you were to come into contact with an EB patient in the future, how useful, if at all, would you find having been provided with the following information about EB?

GPs most commonly use GP notebook, NICE updates and GP study days to stay up to date with developments in general practice; 37% use the Primary Care Dermatology website

Specific sources used to keep up to date with the latest developments in general practice (prompted, multicode)

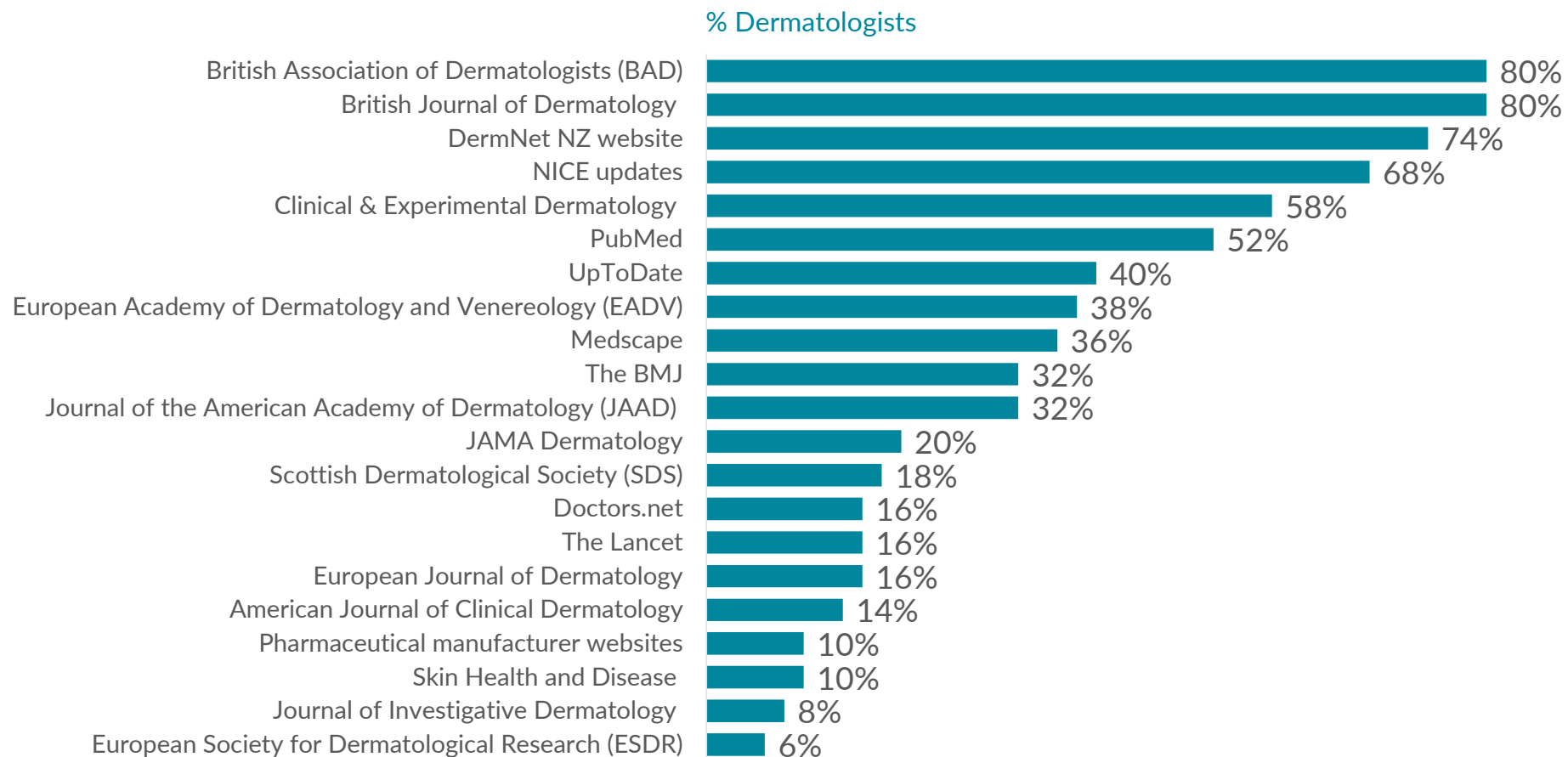


Base = 100 GPs

Q24 What sources of information, if any, do you use to keep up to date with latest developments in dermatology / general practice?

Dermatologists most commonly use British Association of Dermatologists and associated journals, DermNet NZ website and NICE updates to keep up to date in dermatology

Specific sources used to keep up to date with the latest developments in dermatology (prompted, multicode)



Base = 50 Dermatologists

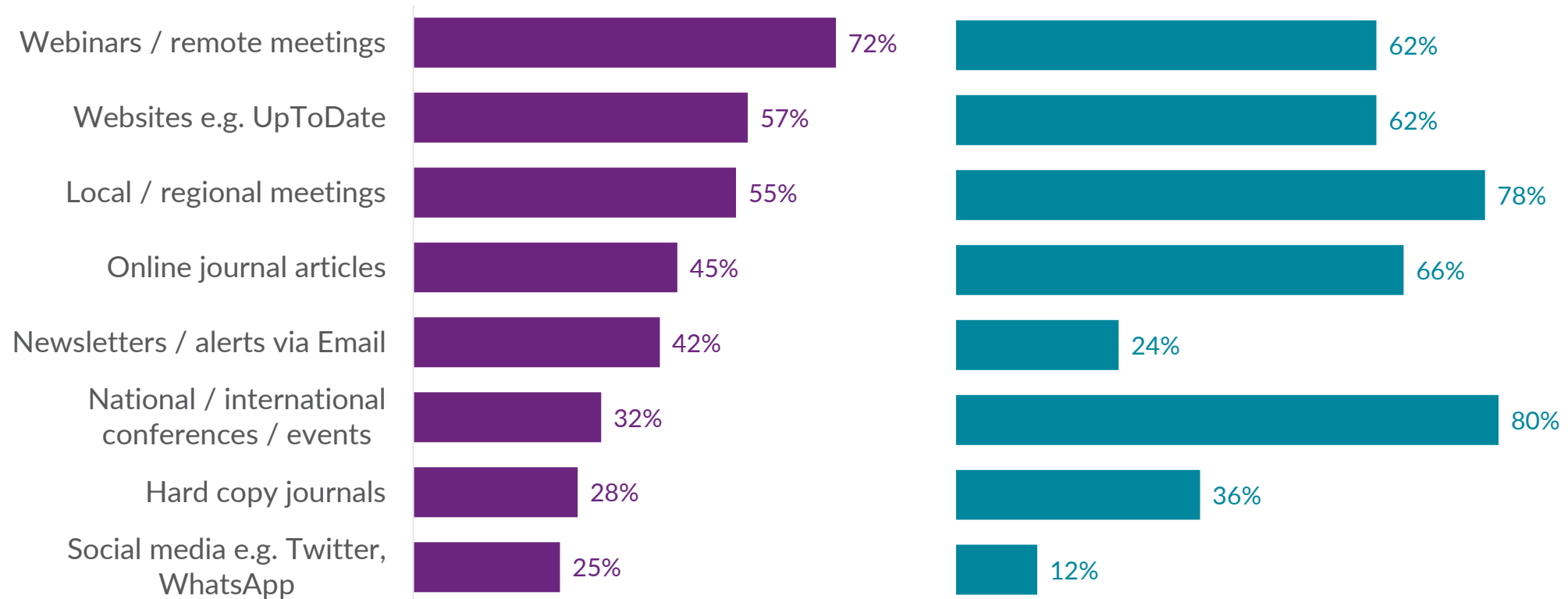
Q24 What sources of information, if any, do you use to keep up to date with latest developments in dermatology / general practice?

The majority of GPs use webinars and websites to keep up to date in general practice, whereas dermatologists primarily use conferences/events and local/regional meetings

Channels most used to keep up to date with the latest developments in... (prompted)

General practice (n=100 GPs)

Dermatology (n=50 dermatologists)



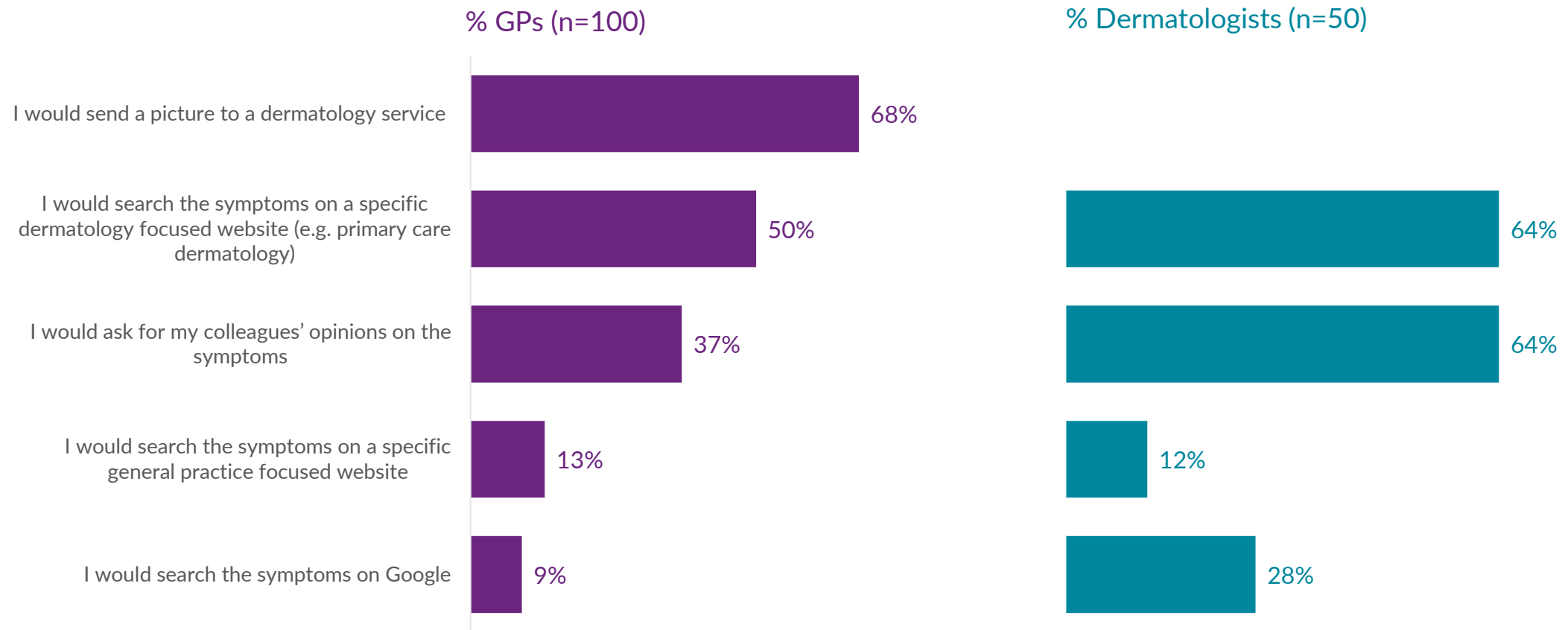
Base = 50 Dermatologists and 100 GPs

Q23 Via which channels do you most frequently keep up to date with the latest developments in dermatology / general practice?

If HCPs need to seek information about an unusual dermatological presentation, GPs would send a picture to dermatology or search a dermatology website; dermatologists would ask colleagues or search a dermatology website

A quarter of dermatologists would search symptoms on Google

Where would HCPs first look for information about symptoms when presented with an unusual dermatological condition? (prompted, multicode)



Base 50 Dermatologists and 100 GPs

Q25 If a patient presented to you with an unusual dermatological condition where you were unsure of the diagnosis, where would you initially go to seek information about the symptoms?



THE BUTTERFLY SKIN CHARITY

Help stop the pain of EB