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# EB EXPERT WORKSHOP REPORT

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19 NOVEMBER 2022 & 12 JANUARY 2023



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# ABOUT DEBRA IRELAND

DEBRA Ireland is a national Irish charity, established to provide support services to those living with the genetic skin condition Epidermolysis Bullosa (EB) and their families. We also drive research into developing treatments and cures for EB, and improving quality of life.

Established in 1988 by families who were living with EB, our family focus has never changed since. This is reflected by the fact that family members and individuals who live with EB sit on our Board and Research Committee.

We provide hope and support to approximately 300 people living with EB in Ireland, and aim to do everything we can to alleviate the difficulties they experience. We aim to provide care by bringing family support directly to the home. We also aim to identify and support trying to find a cure.

Additionally we also carry out advocacy work to be a voice for people who live with EB and their families.



# ABOUT THE EB EXPERT PANEL

The EB Expert Panel are individuals with EB, family members of those with EB or family members who have lost a loved one to EB. The panel advises the DEBRA Ireland Research and Family Support teams. This report contains the outputs of the first EB Expert Panel workshop. This workshop occurred in person on 19th November 2023, with an online version taking place at a later date for those unable to attend. This workshop is envisioned to occur twice a year, allowing the panel to have their voice heard within various DEBRA projects.

This is known as Patient and Public Involvement (PPI) and improves the quality of work DEBRA Ireland do for the EB community in Ireland and worldwide. It allows the ever-changing needs of this community to be at the forefront of our team's minds as they work towards improving the quality of life of those who live with EB in Ireland.

We would like to sincerely thank all members of the EB Expert Panel for voicing their opinions. We look forward to working with you further.





# OPENING REMARKS

## SINÉAD HICKEY - RESEARCH

Sinéad opened the workshop, by introducing herself and the other members of DEBRA staff who would be managing the EB Expert Panel and facilitating the workshop; Eve O'Donnell, Kate Gibney, Sarah Mullins and Marina Shatskikh. She thanked those attending for giving up their time to make a difference to the work DEBRA do and to have their voice heard within the organisation. She explained that although the Research and Family Support teams were experts in science and social care, they are not experts in what it is like to live with EB. DEBRA staff members work for the EB community in Ireland, and therefore they need the help of the EB Expert Panel to shape what they do and to ensure they are making an effective impact.

Sinéad went on to explain how the panel will work. The EB Expert Panel will meet for a workshop twice a year in person to discuss bigger topics and projects as a group. The panel will then be contacted on an ad hoc basis by members of the Research and Family Support teams to work on smaller projects in the interim. All members of the panel will be offered varying levels of payment for tasks they complete based on the time and effort of the task. Getting involved in one project does not mean an individual must get involved in every project. The DEBRA team will support individuals in their role as an EB Expert and will be there to ensure they are enjoying their time on the panel.

After her opening remarks, Sinéad went over some house rules for the workshop and asked everyone in the room to introduce themselves during an ice breaker. She then introduced Sarah Mullins, DEBRA Ireland's Research Officer, to describe how the EB Expert Panel can get involved in research and to begin the discussion tables.





# RESEARCH

## SARAH MULLINS - RESEARCH

Sarah began her presentation by explaining that involving EB Experts in research was known as Public and Patient Involvement (PPI). To describe how PPI works she used a comparison of baking a cake. If a researcher was baking a cake for the EB community and they asked an EB Expert how they should make the cake and what flavour it should be, then this would be PPI as the EB Expert is actively involved in making decisions about the cake for their community. However, if a researcher just baked a chocolate cake and simply presented it to an EB Expert and asked them if they liked it, then this would not be PPI, as the EB Expert was not involved in any decisions. Sarah went on to explain that PPI in research is research carried out 'with' or 'by' EB Experts, rather than 'to', 'about' or 'for' them. Research is one of the vital areas that needs direction from EB Experts to ensure that the resources DEBRA invests in research is making the greatest impact and meeting the needs of those who live with EB and their families.

Sarah then went on to give examples of what good PPI might look like in a research project. Examples included helping researchers/DEBRA with a grant application, helping to decide what topics should be researched and providing advice on the best ways to recruit people to take part in a research study. Sarah then gave examples of what would not be considered PPI in a research project, such as donating skin cells for lab-based projects, completing a survey or taking part in a clinical trial. She then gave the panel some real-life examples of PPI some members of the EB Expert Panel had taken part in already, such as advising researchers in UCD and DCU, and helping with research communications in DEBRA.

Sarah then went through DEBRA's current research priorities and criteria and asked the EB Experts to think about their own priorities in this area, which led on to the research activity.







# RESEARCH DISCUSSION OUTCOMES

The online group were also asked the below question and asked to provide their response via Menti.com, producing the below results.

## 1. What is the biggest impact EB has had on your life?



Similar to the in person workshop, the word cloud displays individual responses to the above question and EB Experts could input as many words as they wished.

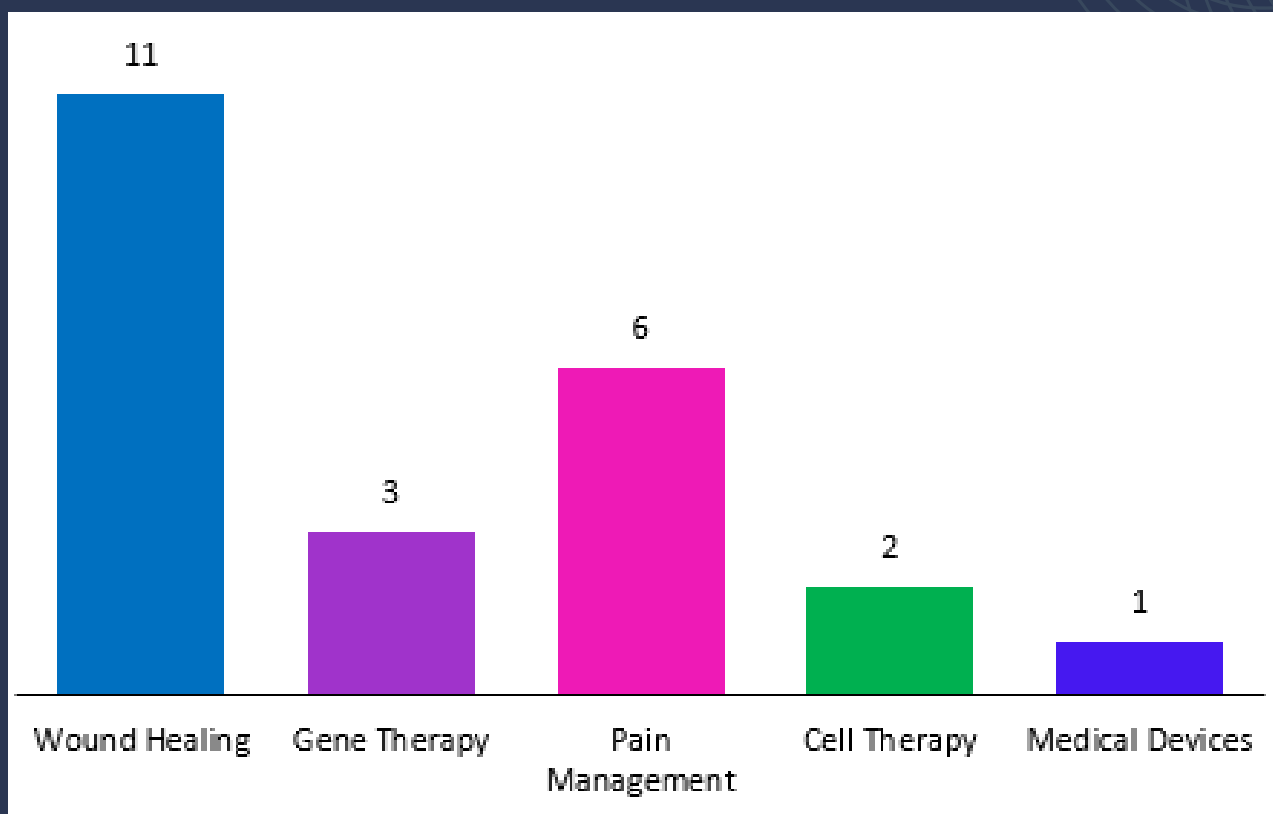
The responses above include 8 participants who attended the online workshop.





# RESEARCH DISCUSSION OUTCOMES

## 2. Which of these areas of research do you think is most important?



The bar chart displays individual responses to the above question. EB Experts could only choose one area of research which they believed to be the most important topic. The above responses include all participants who attended the in-person workshop and most online participants. Unfortunately, a number of online participants had technical issues.

After displaying the results to the in-person group, each table then broke into their discussion groups. There were four discussion groups in total, each facilitated by a member of the DEBRA Ireland team who would guide the discussion and feedback the top points of the discussion to the room. Due to the small number in attendance at the online workshop, a single discussion was had amongst all participants.



# RESEARCH DISCUSSION OUTCOMES

Discussion Tables Topic - A cure is the ideal solution for EB. Based on what you have heard today, what do you think we should focus on in Research?

## Summary of Research Priorities for both in-person and online Discussion Groups

- Medical devices – particularly shoes and socks
- Research into the correlation between blood circulation and wound healing
- Research into psychological impacts of EB—assessment of mental health impacts to develop adequate solutions and decrease isolating nature of EB
- Better solutions for itch associated with EB
- More research into impacts of EB on nails and eyes
- More research/guidelines in caring for newborn baby with EB
- Pain management
- Cure is important and research for this should remain ongoing, but a focus needs to be placed on the here and now equally



# RESEARCH DISCUSSION OUTCOMES

Based on the opinions of the EB Expert Panel, the Research Team revised DEBRA Ireland's research priorities and criteria. This will determine what the team and Research Committee will focus on when making decisions to fund and/or support EB research projects.

## DEBRA Ireland's Revised Research Priorities

- Wound Healing
- Pain Management
- Gene Therapy
- Medical Devices - with a particular focus on an EB shoe
- Psychosocial/Mental Health studies
- Cell Therapy

## DEBRA Ireland's Revised Research Criteria

All research we fund/support must have direct patient impact by either...

- Furthering the development of a potential treatment
- Identifying potential targets for a potential treatment
- Contribute to the overall knowledge of EB to help develop future treatments
- Improve quality of life for those with EB and their families





# FAMILY SUPPORT

## KATE GIBNEY & EVE O'DONNELL - FAMILY SUPPORT

Kate and Eve described how the EB Expert Panel can get involved in the work of DEBRA's Family Support team. Eve reminded attendees that DEBRA Ireland was established by families for families, and that the Family Support team are dedicated to continuing this ethos. The panel will be a vital part of this, providing Family Support with input and direction for various projects. Eve explained that putting the voices of families at the centre of what they do has always been part of their ethos but Family Support now wish to do this in a more formal way through the panel. Family Support aim to encourage new voices and new opinions through structuring this process. Eve explained that DEBRA Ireland is a small charity and a small team who cannot always do everything we would like to, but the panel will allow Family Support to ensure the projects they do work align with what the panel want.

Family Support has a number of specific projects they would like the panel to provide input on for the coming year. Input will vary depending on the project and could take point at the beginning, middle or end depending on the needs of the team. The first project Family Support would like to work on is the Online EB Hub, which is at the early stages of being developed. Kate went on to explain that the Hub will be an online platform where families will be able to easily access information and support on EB. Kate explained the Hub may be a section of the DEBRA Ireland website or it may be a standalone app - decisions such as this will be made collaboratively with the panel. The psychological and social impact of EB has shaped the decision to create a support hub for EB in Ireland, as the Family Support team recognise there are many more aspects of life that can be impacted by EB in addition to the physical challenges. It is hoped that the Hub will provide quick and easy to access supports, while being modern and simple to use. Kate then went on to give an example of a Hub and asked panel members to think about what they would like to see in the Online EB Hub. She then explained that this is what would be discussed within the various discussion tables.



# FAMILY SUPPORT DISCUSSION OUTCOMES

Discussion Tables Topic - What information and support should be included in an online hub? What would you use the hub most for? Do you use any other similar platforms?

## Summary of Opinions for both in-person and online Discussion Groups

- Information on products and practical tips/advice – medications, shoes, padding
- Research – updates on current projects in lay-man terms for ease of understanding
  
- Networking:
  - o Enable communication among community members (alongside in person events)
  - o Big brother/sister mentorship/peer support
  - o Enable exchange of advice/lived experience
  
- Psychological section:
  - o Information for self-care and support groups
  - o List of counsellors and availability of an EB psychologist
  - o Resources for carers



# FAMILY SUPPORT DISCUSSION OUTCOMES

## Summary of Opinions continued

- Teenager-specific information - involve teens in the design
- Resources for all life stages e.g. school, work, puberty, new mothers, family planning, etc
- Section for EB types - more needed for Simplex.
- Healthcare section: Information for healthcare providers, hospital advice for person with EB
- DEBRA specific: List of supports offered, event calendar
- Include login functionality to maintain privacy & personalise.
- Needs to be easy to use and visually appealing, use of different medias

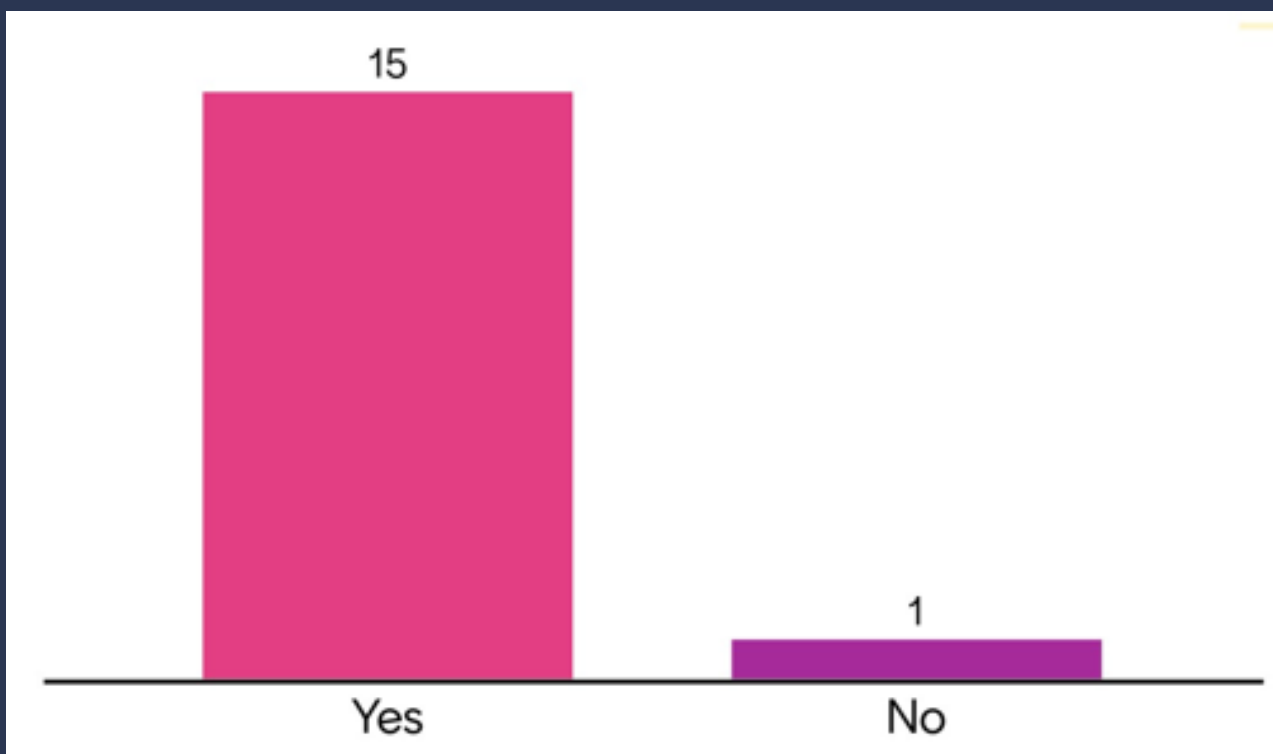




# FAMILY SUPPORT DISCUSSION OUTCOMES

After the discussion groups, the Family Support team asked the EB Expert Panel to think about the following questions and answer them individually on Menti.com, producing the below results.

1. Do you feel an online hub will be helpful to you?



The bar chart displays individual responses to the above question. EB Experts could only choose one answer - Yes or No.

From observing the results, it is clear that the vast majority of the panel believe they would find the Online EB Hub to be a helpful support for them. Unfortunately, due to a technical difficulty, response for online participants could not be collected.



# FAMILY SUPPORT DISCUSSION OUTCOMES

After the discussion groups, the Family Support team asked the EB Expert Panel to think about the following questions and answer them individually on Menti.com, producing the below results.

2. Thinking about what we have discussed today, what aspect of the hub would be most helpful to you?



The word cloud displays individual responses to the above question. EB Experts could input as many words as they wished. Words which are biggest in size were inputted more frequently by respondents. Similarly to the previous question, a technical difficulty prevented the collection of responses from the online group.





# BRAND REFRESH

## SINÉAD HICKEY - RESEARCH

Sinéad explained to the group that on occasion they may be asked to participate in other areas of DEBRA such as Communications, Fundraising and Advocacy. This will not be in the remit of the EB Expert Panel and will be on a voluntary basis. It is completely up to individuals if they wish to get involved in these extra tasks and it will not impact their participation within the panel in any way if they do not wish to participate in any extra requests.

The DEBRA Ireland Communications team asked for Sinéad to speak to the panel about a project they have coming up to refresh the DEBRA Ireland brand and website. Over the next six months, the Communications team will be working on two projects that will refresh how DEBRA Ireland looks, feels and sounds. These projects are updating the brand, which are the visuals and language DEBRA use, and updating our website [www.debraireland.org](http://www.debraireland.org).

Forms were provided for any interested individuals who wished to get involved, and Sinéad explained that the Communications team would contact them directly about working on both projects. This communication would come from the Communications Manager, Ale. Sinéad explained no experience in similar projects was needed as the Communications team were just looking for the views and thoughts of those who link in with DEBRA Ireland.

Sinéad also explained that any requests for help on projects specific to the EB Expert Panel would come from Sarah ([sarah@debraireland.org](mailto:sarah@debraireland.org)) or Kate ([kate@debraireland.org](mailto:kate@debraireland.org)). These will all be paid opportunities and will not come from any other member of the DEBRA Ireland team.





# CLOSING REMARKS

## EVE O'DONNELL - FAMILY SUPPORT

Eve thanked everyone for attending the first workshop and said she hoped they enjoyed themselves and that they would continue to engage with the team as EB Experts. She then explained the plan going forward was to hold a similar workshop once or twice a year and to approach the panellists individually for smaller tasks between workshops. The frequency of individual tasks will depend on time, frequency and availability of the EB Expert. Most of these sort of tasks should not take up a lot of time and the majority of them will be remote and will not require travel.

All input provided will be invaluable to the team so Eve emphasised how grateful the Family Support and Research teams are for everyone's participation. She also reminded the panel that being an EB Expert did not mean they have to say yes to every opportunity that arises and that the DEBRA team totally understand if they cannot participate in everything that is asked of them. She reminded the panel that for anything they do say 'yes' to, they will be fully supported by either herself, Kate, Sarah or Sinéad.

Eve then asked members to fill out a feedback form related to the workshop, this will allow the team to make changes to these events going forward if needed.



# FURTHER INFORMATION

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For further information on the EB Expert Panel or any information within this report, please contact Sarah:

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