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Nottingham

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# Centre of Evidence Based Dermatology

Impact Review Jan 2019 - Dec 2020



# Welcome

After a year like 2020, I feel loathe to reflect on what the future might hold for the CEBD, but one thing remains unchanged and that is our amazing and dedicated staff, who continue to be the beating heart of our team. They are an amazing and inspiring group of people, who bring their varied skills and talents to work daily, and I've enjoyed learning about their more eclectic interests during our period of lockdown – whether that be wildlife photography, gardening, dressmaking, woodwork, playing music or simply reading a good book.

I hope you enjoy flicking through this, our new online version, of our bi-ennial impact report, which contains all the usual highlights and is a great celebration of some of our major achievements over the last couple of years. We have completed two landmark randomised controlled trials – one on the prevention of eczema ([BEEP](#)), and another evaluating treatments for vitiligo ([HI-LIGHT](#)). We are also delighted to have contributed to completion of the core outcome set for eczema ([HOME](#)) and development of a new tool for measuring eczema control ([RECAP](#)).

You might like to take a few moments to watch one of our [videos](#), or read our latest [blog](#), or learn something new though one of our free [online training courses](#).

Looking to the future, we are proud to now be included in the National Institute for Health Research's School of Primary Care Research and look forward to working more closely with our primary care colleagues both in Nottingham and throughout the country.

Whichever direction the future takes us, we will continue to work to our areas of strength and ensure that people with skin disease are at the heart of everything that we do – taking us on their journey and addressing research needs of importance to them.

With very best wishes,



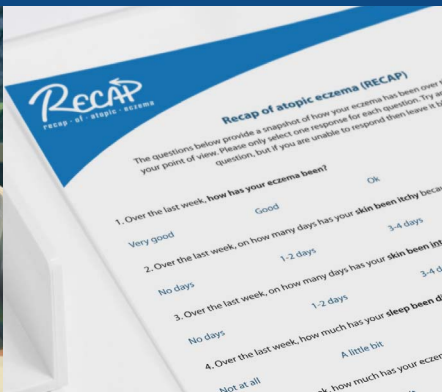
**Professor Kim Thomas**  
Co-Director of the Centre of  
Evidence Based Dermatology



# Highlights 2019



Dr Robert Boyle discusses research integrity in the field of infant formula clinical trials in the Dispatches documentary, *The Great Formula Milk Scandal* broadcast on Channel 4.



The RECAP instrument is selected by the HOME initiative to become part of their Core Outcome Set for clinical eczema trials.



Dr Mitesh Patel receives the prestigious *GP Trainee of the Year Award 2019* from the Royal College of General Practitioners.



CEBD patient panel member Amanda Roberts is highly commended at the 2019 SPCR Showcase for making an *Exceptional Contribution to Patient and Public Involvement*.



Medical student Charlotte Goodrum is the winner of the University of Nottingham's Bart Prize, awarded for outstanding achievement in the third year of the BMedSci degree course.



The Harmonising Outcome Measures for Eczema (HOME) initiative complete the first ever Core Outcome Set (COS) for dermatology, with their COS for atopic eczema clinical trials.



# Highlights 2020



CEBD patient panel member Dr Peter Smart is appointed as Cochrane Skin's first patient editor.



The UK DCTN BLISTER trial is shortlisted for the Inspirational Research Stories Competition at the CRN East Midlands @5 celebration event.



The BEEP study, evaluating whether emollient use in the first year of life can prevent eczema development, is published in the Lancet.



The HI-LIGHT Vitiligo Trial results, assessing the use of topical corticosteroids and ultraviolet light as treatments, is published. Watch our [animated video](#).



Dr Douglas Grindlay launches the CEBD Coronavirus Dermatology Resource collating research articles, guidelines, and relevant patient information relating to the coronavirus.



Cochrane Skin's first living systematic review "Systemic pharmacological treatments for chronic plaque psoriasis: a network meta-analysis" is published.

# About the Centre of Evidence Based Dermatology

The [Centre of Evidence Based Dermatology](#) has a well-earned reputation for independent research into the treatment, prevention and diagnosis of skin disease that informs evidence-based practice across the world.

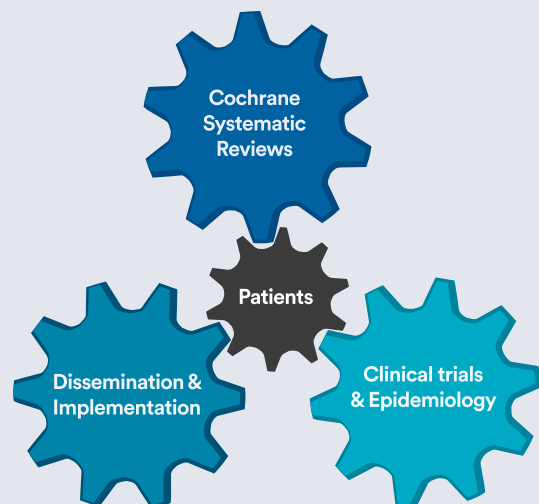
As part of the School of Medicine at the University of Nottingham, we collaborate with colleagues locally, nationally and internationally to deliver a programme of work that combines a range of methodological and epidemiological approaches.

The Centre is home to the editorial base for [Cochrane Skin](#) and the co-ordinating centre of the [UK Dermatology Clinical Trials Network](#). A broad dissemination and knowledge mobilisation strategy helps to ensure that our research outputs are impactful and effective in changing clinical practice and making a positive difference to patients' lives with our excellent range of [dermatology resources](#) freely available and accessible to all.

The Centre produces around 50-60 peer-reviewed publications per year. One of the highest income generators for non-commercial dermatology research in the world, the majority of our research is funded through the National Institute for Health Research (NIHR) or medical charities. We also teach evidence-based dermatology through a range of online and face to face [courses and conferences](#) and help to build future research capacity in dermatology through a range of fellowships and our post-graduate students.

## Research strategy

To perform high-quality, independent research into the prevention, diagnosis and treatment of skin disease. We do this by focusing on questions that have been identified and prioritised by patients and clinicians, working with some of the best researchers in the world to address these questions, and by ensuring that our research is reported clearly and transparently to a variety of audiences.



The three interdependent cogs show how CEBD's key elements fit together, with patients being the driving force at the centre of everything we do.





# 2019 and 2020 - Impact by numbers

**153**

Peer-reviewed  
publications

Page 20



**10**-year  
anniversary  
of CEBD  
patient panel  
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**437,404**  
views of hidradenitis  
suppurativa training video

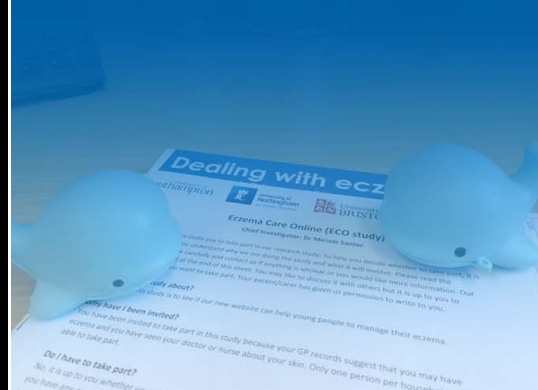
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**677** participants  
recruited into our  
two Eczema Care  
Online (ECO)  
trials in 1 year,  
despite COVID-19

Page 12



**3** UK DCTN  
virtual journal  
clubs held



**5** years as Director  
of the NIHR HTA  
Programme for  
Prof Hywel Williams

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**1st** Complete  
Core Outcome Set  
for dermatology

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# The BEEP study

The Barrier Enhancement for Eczema Prevention (BEEP) study was a randomised controlled trial that tested whether advising parents to apply emollient daily for the first year of life can prevent the onset of eczema in high-risk children in 1394 families.

The BEEP trial convincingly demonstrated that applying emollients (moisturisers) from birth was not a useful strategy for preventing the development of eczema in children born to families with a family history of atopic disease. Eczema was present in 23% (139/598) infants in the intervention group and in 25% (150/612) in the control group at 2 years of age. The UK working party diagnostic criteria were assessed by a research nurse who was blinded to treatment group allocation. Other measures of eczema (visible eczema (blinded)), parent report of a clinical diagnosis, or parent completion of the diagnostic criteria also showed no difference between groups.

**Emollients do not reduce the severity of eczema that develops or delay the onset of development;** There was no difference between groups in eczema severity either by a blinded assessment of clinician-reported signs (EASI) or parent-reported symptoms (POEM). Time to onset of eczema was similar across groups.

**Applying emollient for the first year of life does not prevent other allergies;** in fact, there was a small increase in food allergy in the emollient group (challenge proven food allergy to milk, egg or peanut in 7.5%



versus 5.1% in the control group). This will be further investigated in an ongoing prospective individual patient data meta-analysis of similar studies ([SciPAD](#)).

**There were more parent-reported skin infections in the emollient group;** during the first year when emollients were applied, 15% of infants in the emollient group had skin infections compared to 11% in the control group.

Long-term follow-up questionnaires continue to be sent to all families at 3, 4 and 5 years and will be reported in 2022. The results of the BEEP study were [published in the Lancet](#) and a video of Professor Hywel Williams discussing the findings can be found on the [BEEP Study website](#) alongside further information about the trial.







# The HI-LIGHT Vitiligo Trial

**Vitiligo is a condition that causes loss of colour in the skin. These white patches can sometimes grow rapidly and cause distress, especially for people with darker skin tones.**

Vitiligo can be a difficult condition to treat. Two of the most commonly recommended treatments are topical corticosteroid creams and light treatment (which usually requires specialist support from hospital). Recently, it has been possible to buy handheld light therapy devices at a reasonable cost, making it possible to treat vitiligo at home, without the need to attend hospital.

We conducted a large randomised controlled trial to answer two key questions:

- Question 1: Is handheld light therapy using narrowband UVB light better than using a topical corticosteroid?
- Question 2: Is using light therapy and topical corticosteroid together, better than using topical corticosteroid on its own?

A total of 517 adults and children participated in the trial, which involved using the treatments for up to 9 months.

The results showed that using both treatments together was better than using just steroid cream on its own,



**Thanks to the [HI-LIGHT Vitiligo Trial](#), we now have a better understanding of the effectiveness, safety and acceptability of these two treatments and the results are being shared with clinicians responsible for the care of people with vitiligo.**

and combination treatment was also likely to get a treatment response more quickly.

Overall, almost two thirds of people using both treatments together achieved at least some improvement by 9 months (27% felt that the treatment had been successful in reducing the noticeability of the patches, and another 35% felt it had been partially successful for them). People who used the treatments most often saw the biggest improvements in their vitiligo, but this was a big commitment that required a lot of time and dedication.

The most commonly reported side-effect of treatment was accidental burning of the skin (like sunburn), and some people reported thinning of the skin.

Unfortunately, for many people, the vitiligo returned once treatment was stopped, suggesting that ongoing maintenance treatment might be needed.

If people with vitiligo wish to purchase their own light therapy device for home treatment, we would recommend asking for advice from a dermatologist prior to use. We have made available the [treatment schedules](#) and [training videos](#) from the trial on our website as helpful resources for clinicians.

Development and testing of new vitiligo treatments with a greater treatment response and longer-lasting effects are very much needed for this under-served patient group.



# COVID-19 response

The [Centre of Evidence Based Dermatology](#) has continued to operate throughout the pandemic. In addition to our usual work undertaking national clinical trials and systematic reviews, we have also provided specialist resources and dermatological expertise to help tackle the virus.

## Advice on Handwashing

Hand hygiene has been the cornerstone of public health campaigns, which have emphasized the vital role of handwashing in reducing the spread of COVID-19. However, many people with eczema, as well as parents who have children with eczema, are finding frequent handwashing with soap and water problematic in that it worsens their hand eczema. Additionally, healthcare workers on the front line are also experiencing an epidemic of irritant contact dermatitis ie dry, inflamed and itchy skin as a result of frequent hand washing.

To help those suffering with these problems, we produced a video on COVID-19 and handwashing, in which Professor of Dermato-Epidemiology Hywel Williams gives practical advice (hand washing with soap, followed by emollient use) and explains the evidence on which this is based. At the time of the outbreak, some were advocating emollients for hand washing which could have paradoxically protected the virus. This advice led to changes in guidance issued by the British Association of Dermatologists as well as patient organizations.

“I would like to use the video on our Trust intranet to hopefully help those staff that are struggling at the moment.”

Charlotte Wakeley, Occupational Health Department at Barnsley Hospital NHS Foundation Trust



**Watch the video**  
COVID 19 and handwashing

## CEBD Coronavirus Dermatology Resource

With each passing day, more is known about the virus, resulting in an ever-expanding body of literature. This includes information on skin manifestations of COVID-19, changes to service delivery and therapeutic management of skin diseases, and how enhanced hand hygiene and PPE use may impact the skin.

To help people find important information and to navigate these topics, we launched the CEBD Coronavirus Dermatology Resource in March. Compiled by CEBD Information Specialist Dr Douglas Grindlay, this continually updated resource contains research articles relating to the coronavirus and dermatology as well as links to guidelines, evidence-based resources and relevant patient information.

“The CEBD Coronavirus Dermatology Resource is great!”

Professor Paolo Gisondi, Università di Verona, Italy

“Your COVID resource is really fantastic.”

Professor Catherine Smith, KCL, UK

## Influencing policy

At the request of the Chief Medical Officer's office, Professor Williams also initiated a group of dermatology experts from the British Association of Dermatologists to establish policy for people on immunosuppressive drugs. This group, led by Dr Ruth Murphy, developed a detailed [advice grid](#) which is aligned to similar advice from other specialties using immunosuppressive medicine such as rheumatology and gastroenterology. This information will be of benefit to both patients taking immunosuppressive medicines and healthcare professionals to help them make better decisions regarding isolation versus social distancing.

# The HOME initiative

**Core Outcomes** are critical aspects of a disease that should always be measured in a clinical trial. For atopic eczema trials, 2020 marks the year the Harmonizing Outcome Measures for Eczema (HOME) initiative achieved consensus for this Core Outcome Set.

## Clinical Trials Core Outcome Set

At HOME VII, the seventh meeting of the HOME initiative, the process of recommending instruments for the four agreed core domains was finalised. This is the first complete Core Outcome Set for the field of dermatology, and one of only a handful across the whole of medicine.

HOME VII was held in Tokyo, Japan in April 2019. It was attended by 75 participants from 16 countries. The group recommended core outcome instruments for health-related quality of life, disease control and itch intensity (Table 1) which [completed the Core Outcome Set](#) for atopic eczema clinical trials. In addition to trialists using the same outcome instruments, data need to be collected and presented in a way that would permit meta-analysis. The group therefore agreed that, as a minimum, trials should present the core outcomes at baseline and the primary endpoint (usually end of treatment). Furthermore, [HOME published recommendations](#) that the mean and standard deviation be reported for each group at these time points.



The use of core instruments reported in a way that can be used in meta-analysis should greatly improve the evidence base for eczema treatments. The challenge now for HOME is to ensure that the COS is implemented widely.

Domain of interest	Recommended Outcome Instrument
Clinician-reported signs	Eczema Area and Severity Index (EASI)
Patient-reported symptoms	Patient-Oriented Eczema Measure (POEM)
	Peak 24hr itch Numerical Rating Scale-11 (NRS-11)*
Health-related quality of life	Dermatology Life Quality Index (DLQI)*
	Children's Dermatology Life Quality Index (CDLQI)*
	Infants Dermatology Quality of Life Index (IDQoL)*
Disease control	Recap of Atopic Eczema (RECAP)* or Atopic Dermatitis Control Test (ADCT)*

**Table 1: Complete Core Outcome Set for atopic eczema clinical trials (\*recommended at HOME VII)**

## Clinical practice set

HOME also aims to provide recommendations for good-quality instruments for use in routine care. The recommendations for this clinical practice set are similarly based on validity and feasibility, but unlike the clinical trials set, multiple instruments can be recommended per domain as no data is expected to be combined. Two consensus meetings (HOME VI, HOME VIII) have taken place to agree preferred

instruments; PO-SCORAD and POEM were recommended for inclusion within this clinical practice set at the [HOME VI meeting](#). POEM has subsequently been incorporated into the [NHSx playbook](#) to support its use in clinical practice through our [Eczema Tracker app](#).

HOME VIII, organised by Prof Eric Simpson and Dr Yael Leshem, took place in October 2020. Although HOME meetings usually occur face-to-face, HOME VIII was held

as an online meeting, which took place on two dates to accommodate participants in different time zones and enable global participation. A total of 80 participants from 18 countries took part. The group agreed on recommendations for instruments to measure disease control (RECAP, ADCT) and itch intensity (Peak 24-hr NRS-itch, Average and Peak 1-week NRS-itch (PROMIS® Itch Questionnaire)).



# Introducing RECAP

## Understanding how to measure patients' experiences of eczema control

Long-term control is one of the four core domains within the Harmonising Outcome Measures in Eczema (HOME) initiative Core Outcome Set for atopic eczema clinical trials.

Working alongside our patient, healthcare professional and international colleagues, we aimed to develop an instrument to capture a patient's perspective of eczema control. The result of this work was a new questionnaire, [Recap of atopic eczema \(RECAP\)](#).

RECAP is a 7-item questionnaire that can be filled in by people with eczema or their caregivers to capture the experience of eczema control. A [video overview](#) of the development process is available to watch online.

As RECAP has been designed with a range of stakeholders the questionnaire is designed to be easy to fill in and form part of routine appointments and research. RECAP has been translated into a number of different languages (to date English, Dutch, German, and Chinese) and we welcome those who would like to create a translation to get in touch.

“Using RECAP allows you to see how well your eczema treatment is working. Using information recorded using this questionnaire is really important for clinical trials, as it can be really difficult to remember and describe how your eczema has been in the past, this questionnaire makes this really quick and easy.”

Adult with eczema, UK

“As a mum, I feel helpless watching my son suffer from eczema. I'll try anything to provide relief. RECAP allows me to quickly and objectively measure his eczema in my quest for a solution.”

Parent of child with eczema, Australia

In 2019, RECAP was recommended by the global initiative Harmonising Outcome Measures in Eczema (HOME) as a core instrument to be measured in all eczema clinical trials. A year later, at the HOME VIII meeting RECAP was also recommended for inclusion in the clinical practice core instrument set.



# Eczema Care Online

For the last three years, we have been working with clinicians and researchers from across the UK to develop an online toolkit that will support people in managing their eczema.

## What is Eczema Care Online?

The Eczema Care Online toolkit has been developed using behavioural science techniques, along with lots of feedback from people with eczema. We have made sure that it includes information that people want to know about managing their eczema and is based on the latest up-to-date evidence.

Two versions of the Eczema Care Online Toolkit were created:

- A version for parents of young children with eczema
- A version for teenagers and young adults with eczema

We are currently testing both of these online toolkits in clinical trials. Despite the COVID-19 pandemic, the trials have continued to be successful in recruiting participants. In December 2020 enrolment in these trials closed with a total of 340 parents of young children with eczema and 337 teenagers and young adults with eczema.

## What does this mean for people with eczema?

We hope that both of the online toolkits we have developed will prove to be a great help for people looking for a source of support in managing eczema.

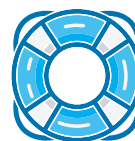
Alongside this, we are also keen to ensure that these resources will be made available to those who could benefit from them through the NHS and eczema charities. We hope the toolkits will help people to get the most from their prescribed eczema treatments and make them feel they are supported in making decisions about managing their eczema, or in the case of parents, their child's eczema.

## Underlying research

Developing the Eczema Care Online Toolkit involved speaking to people who have eczema, to establish what their information needs are. Additionally we have reviewed the evidence available about the effectiveness of different eczema treatments and their safety.

Further information about how we did this research and what we found can be found within the [publication](#) section of our website.

For a more informal overview, [blogs](#) have been written to accompany these publications.



**Eczema Care Online**  
**Self-help toolkit** ➔

Visit us:

[Eczema Care Online website](#)





# Top 10 publications

Daily emollient during infancy for prevention of eczema: the BEEP randomised controlled trial.

[Lancet. 2020](#)



Defining and measuring “eczema control”: An international qualitative study to explore the views of those living with and treating atopic eczema.

[J Eur Acad Dermatol Venereol. 2019](#)

Incidence, prevalence, and mortality of bullous pemphigoid in England 1998-2017: a population-based cohort study.

[Br J Dermatol. 2020](#)

Randomised controlled trial of topical corticosteroid and home-based narrowband UVB for active and limited vitiligo - results of the HI-Light Vitiligo trial.

[Br J Dermatol. 2020](#)



Development and initial testing of a new instrument to measure the experience of eczema control in adults and children: Recap of atopic eczema (RECAP).

[Br J Dermatol. 2019](#)

Algorithm based smartphone apps to assess risk of skin cancer in adults: systematic review of diagnostic accuracy studies.

[BMJ. 2020](#)



Ultrasound, CT, MRI, or PET-CT for staging and re-staging of adults with cutaneous melanoma.

[Cochrane Database Syst Rev. 2019](#)

A behaviour change package to prevent hand dermatitis in nurses working in health care: the SCIN cluster RCT.

[Health Technol Assess. 2019](#)

Measuring atopic eczema symptoms in clinical practice: The First Consensus Statement from the Harmonising Outcome Measures for Eczema in Clinical Practice Initiative.

[J Am Acad Dermatol. 2020](#)

An economic evaluation of the randomised controlled trial of topical corticosteroid and home-based narrowband UVB for active and limited vitiligo (The HI-Light Trial).

[Br J Dermatol. 2020](#)



# Our research

## Summary of recently completed and ongoing research

Project	Research Type	Funded by	Duration (status)
<b>Eczema</b>			
Validating the POEM and understanding patient and carer perspectives of long-term control of eczema	Outcome Measure	British Skin Foundation PhD studentship	2016-2019 (complete)
Knowledge sharing in atopic eczema: understanding and enhancing mindlines and patientlines to improve experience and outcomes of primary care consultations and self-management practices	Fellowship	NIHR Knowledge Mobilisation Fellowship	2016-2019 (complete)
Methotrexate versus Ciclosporin in the Treatment of Severe Atopic Eczema in Children (TREAT Trial): An economic evaluation	RCT, Economic Evaluation	NIHR RfPB	2017-2019 (complete)
Best Emollient for Eczema (BEE) study	RCT	NIHR HTA	2017-2020 (in follow-up)
Barrier Enhancement for Eczema Prevention (BEEP) study	RCT	NIHR HTA	2014-2022 (ongoing)
Food allergy (add-on study to BEEP)	RCT	Imperial College Healthcare Charity	2017-2019 (complete)
Skin care interventions for preventing eczema and food allergy: a systematic review and individual participant data meta-analysis	Systematic Review	NIHR RfPB	2017-2020 (complete)
Eczema Care Online study	Programme Grant	NIHR PGfAR	2017-2023 (ongoing)
The TEST (Trial of Eczema allergy Screening Tests) study: feasibility RCT with economic evaluation and nested qualitative study.	RCT	NIHR School for Primary Care Research	2017-2019 (complete)
Phototherapy for Atopic Dermatitis	Systematic Review	American Academy of Dermatology	2020-2021 (ongoing)
Systematic Review On Immunomodulatory Agents For Atopic Dermatitis	Systematic Review	American Academy of Dermatology	2020-2021 (ongoing)
Harmonizing Outcome Measures for Eczema (HOME) initiative	Outcome research	None	2008-present (ongoing)
<b>Other skin diseases</b>			
Assessing the feasibility of implementing the Fast Raman device for testing tumour clearance during Mohs micrographic surgery of basal cell carcinoma	Diagnostics	NIHR RfPB	2018-2021 (ongoing)
Informing the development of clinical trials in autoimmune blistering skin diseases	Database study	NIHR RfPB	2019-2020 (in write-up)
Pemphigus and pemphigoid Priority Setting Partnership (PEM PSP)	PSP	Nottingham Hospitals Charity	2018-2021 (ongoing)
CORALS (Core Outcomes for Research in Lichen Sclerosus)	Outcome research	UK DCTN Themed Call award	2018-2020 (ongoing)
Is urinary incontinence associated with lichen sclerosus in females? A systematic review and cross-sectional study	Systematic review, cross-sectional study	BSF and British Association of Dermatologists	2019-2020 (ongoing)
Spironolactone for Adult Female Acne (SAFA) study	RCT	NIHR HTA	2018-2021 (ongoing)
Treatment of Hidradenitis Suppurativa Evaluation Study (THESEUS)	Cohort study	NIHR HTA	2019-2022 (ongoing)
Refining Outcome Measures for trials in Alopecia areata (ROMA)	Outcome research	UK DCTN Pump Priming Award	2017-2019 (ongoing)
Developing diagnostic criteria for psoriasis in children (DIPSOC)	Diagnostics	NIHR DRF	2016-2020 (In write-up)
Vitiligo Noticeability Scale validation study	Outcome research	NIHR RfPB	2019-2021 (ongoing)





# Training and events

## Annual Evidence Based Update Meeting

Each spring, CEBD holds a one-day Annual Evidence Based Update Meeting chaired by Professor Hywel Williams. The topic changes each year, with the event summarising the most recent evidence in the form of systematic reviews, expert opinion sessions and recently completed trials. Delegates have the opportunity to ask an expert panel clinical questions in a unique Q&A session. The meeting is CPD accredited (5 points) and also now co-badged with the BAD.

“Excellent update and really nice to have a review based on current evidence. Gives confidence in managing these tricky patients.”

Annual Evidence Based Update Meeting delegate, 2019

The 2019 topic, organised in collaboration with The British Hair and Nails Group, was hair disorders. Speakers included Dr B Farjo (surgery for hair disorders), Prof P Joly (results of an alopecia areatis totalis study), J Chambers from

Alopecia UK (involving patients in alopecia research) and Dr V Joliffe (hair cosmetics). Sadly, the 2020 meeting on keratinocyte cancers was cancelled due to COVID-19, but the topic has been carried forward as a virtual meeting to 2021.

## Summer School

The 2019 one-day summer school ‘Better Paper Writing Skills’ aimed to give delegates the skills to write clearly and meaningfully for a scientific audience. Sessions included how to respond to referees comments, and a workshop on ‘Tips for getting your paper accepted’ was delivered by Dr John Ingram (Editor, British Journal of Dermatology). Unfortunately, the 2020 summer school covering ‘Communication Skills’ was postponed due to COVID-19 and is now re-scheduled for 11th June 2021.

## Better Evaluation of Evidence and Statistics (BEES) course

BEES is a popular three-day course held annually. The course uses the principles of epidemiology and statistics to improve delegates’ critical appraisal skills to both better inform their clinical practice and ability to design and participate in clinical research. The course is CPD accredited (15 points), and in 2019 we were delighted that BEES was approved for co-badging by the British Association of Dermatologists (BAD) Education Unit.

“Was the best course I’ve been on to date. Thank you for making such a challenging and potentially boring topic (stats) interesting and enjoyable.”

BEES delegate, 2019

“Excellent teaching methods. Well taught to a variety of backgrounds. Good pace and content.”

BEES delegate, 2020

“I really enjoyed this interactive workshop by knowledgeable speakers in a friendly, supportive environment which was extremely useful.”

Summer school delegate, 2019

[Visit our Courses and Meetings webpage for details on upcoming training opportunities and events.](#)

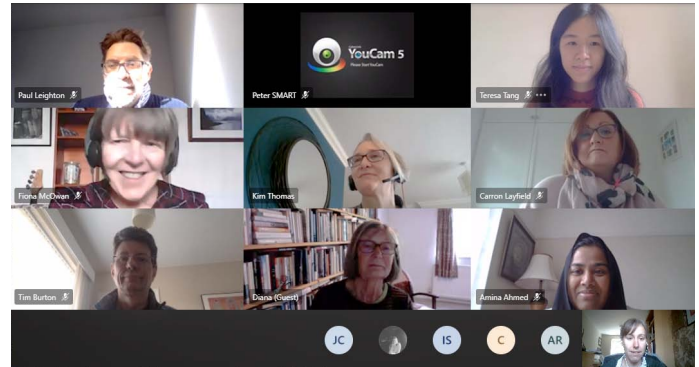
# Patient and public engagement

## CEBD Patient Panel

The CEBD Patient Panel is now a well-established group of more than 30 members across the UK, who live with a range of skin conditions. Panel members contribute to CEBD research in a wide variety of ways and have helped support over 40 projects to date; we were really proud when the group was highlighted in a BMJ Open Blog in 2019.

Publication of the National Standards for Public Involvement in Research gave us an opportunity to reflect on how we work together. An initial consultation with panel members, asking them how we measured up against these standards, resulted in the development of an action plan to improve ways of working. This is being delivered by a team made up of both CEBD staff and panel members, and we have introduced a number of improvements over the past couple of years including:

- an induction pack and buddy scheme for new members
- a code of conduct and purpose statement
- a 'we asked, you said, we changed' template for providing feedback
- a co-production approach to our annual patient panel meetings
- a Facebook page to enable panel members to better keep in touch with each other



The 2019 annual panel meeting celebrated ten years of the group and included sessions on shared learning experiences from both panel members and other patient involvement groups and a reflection on dermatology research over the past ten years from CEBD Co-director Hywel Williams. Due to COVID-19, our 2020 event was held online; although initially nervous about this approach, it was well received and gave a number of panel members the opportunity to take part who have not done so for a while due to travel limitations.

You can find out more about the CEBD patient panel on the [how to get involved section](#) of the CEBD website.

We would like to thank the following groups who have helped us reach the wider patient and carer community: the National Eczema Society, The Vitiligo Society, the Psoriasis Association, the Psoriasis and Psoriatic Arthritis Alliance (PAPAA), The Hidradenitis Suppurativa Trust, PEM friends, and the Nottingham Support Group for Carers of Children with Eczema (NSGCCE).

## Wider engagement activities

Working with the University of Nottingham outreach team, we led dermatology outreach and engagement work at a Family Discovery Day in June 2019. These events aim to engage children who attend schools where traditionally only low numbers of students progress to University, in an effort to introduce children at a young age to higher education. Activities undertaken included making models of the skin using sweets or craft materials to demonstrate how eczema affects the skin and a game that involved designing a sun hat to illustrate how patients are randomised in clinical trials.



**“This really engages parents – it was great to see different families getting involved and we have had great feedback.”**

Teacher, Sneinton St Stephen's C of E Primary School

**“My favourite thing was learning about the skin layers and making them with sweets.”**

Pupil, Robert Mellors Primary School

**“I've learnt no matter how smart you are there's always more to learn.”**

Pupil, Brookhill Leys Primary School



# Nottingham Support Group for Carers of Children with Eczema

The Nottingham Support Group for Carers of Children with Eczema (NSGCCE) is an initiative supported by volunteers, CEBD and local healthcare professionals.

CEBD work closely with NSGCCE as we have a shared and long-standing commitment to improve the care received by people with atopic eczema. Established more than 25 years ago, the NSGCCE continues to offer independent information and informal support to those affected by eczema. The Group have an effective online presence, providing information via their website, raising awareness via social media and encouraging patients to share their experiences via a blog site.

## Producing useful resources

As a result of a survey of carers of children with eczema in paediatric dermatology clinics in Nottingham, we have produced a one-page infographic 'How to Control Your Child's Eczema'. We continue to produce our Patient Information Leaflets (PILs), written by healthcare professionals and parents, which are reviewed on a rolling programme to ensure the information they contain is updated with new information. We receive requests from around the country to use these and a GP practice in Coventry hopes to translate them; PILs on Topical Steroids and Exercise are currently proving the most popular.

## Patient advocacy

Where a change in policy may affect service delivery for those with eczema, we work to make sure the voice of patients is heard. Recent examples include the change of provision at Nottingham's Treatment Centre and preparative consultations for COVID-19.

## Supporting research

We strongly support and encourage eczema research teams. Currently we are helping with the Best Emollient for Eczema (BEE) study, Eczema care Online (ECO) management programme and various others including pharmaco-

epidemiology work and the development of citizen science trials which really excites us. We ensure all patient material is practical, useable and reflects the reality of patient's lives.

## Connecting with others

Our twitter account @eczemasupport now has over 6700 followers. In a given month, our account will have 104.5K impressions, with nine link clicks per day and three retweets per day on average. In addition to providing links to our PILs, we tweet about current medical news, provide links to research information and Cochrane reviews. Our tweets mainly focus on eczema, but we also engage in discussions about other aspects of atopy, general childhood health and patient involvement in research.

## COVID-19

Appreciating that the coronavirus pandemic may present new challenges for managing a child's eczema, we produced a video with CEBD on evidence-based advice offering handwashing which changed the advice being given by other organisations at the time. We also provided fast turn-around responses to other COVID-19 eczema-related questions via a new Q&A section on our website.



“Not that many years ago, my son couldn't pick up a spoon without crippling pain from no skin on his hands; thanks to the help of @eczemasupport, he's picked up his stick and played his first game of lacrosse wearing an England Squad bib #ProudDadMoment”

Tweet by Dr Neil Currie, Senior Lecturer, University of Salford, UK

“So glad my son is healing from this! Almost a whole month out of school due to this. Thank you for these tips!”

Tweet by Tamra Simmons, Peabody award-winning filmmaker and CEO, USA



For more information please visit the [NSGCCE website](https://www.nsgcce.org.uk)



# Reflections on directing the NIHR HTA Programme

by Professor Hywel C. Williams

On September 30th 2020, I stepped down as the Director of the NIHR HTA Programme after five very busy years. To set the scene, The NIHR Health Technology Assessment (HTA) Programme sits within the National Institute for Health Research (NIHR) - the UK's largest funder of health and social care research funded by the UK Government. HTA is the largest NIHR Programme and in 2018/19, it supported 584 live projects worth £0.5 billion - that's 268 active clinical trials, 74 new projects, 86 final reports, 40,567 participants recruited, 1,635 peer reviewers, 1,915 topic suggestions received and 67 calls advertised with an annual spend £76 million. Quite a responsibility then to direct such a programme, so what are my reflections?

The first is that I remain convinced that **our National Institute of Health Research is by far the best research system in the world**. Seriously, no other global research system has all of these key components joined up: a faculty of skilled researchers, funding programmes, research governance systems and an amazing infrastructure to deliver research - and with NHS patients clearly at the centre.

**Clinical research is now everyone's business in the NHS.** A unique aspect of the HTA Programme has been to work with patients and the public and health care professionals to identify questions that our NHS needs answering, rather than just reacting to researcher-led proposals, although the two streams work together in a creative tension to close any gaps.

The second is to tell you what a fantastic bunch of people I have had the privilege to work with. The support team at NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), our leaders at the Department of Health and Social Care (DHSC), and all who served on our funding committees have their hearts in the right place. **Egos are left at the door in our funding committees, and there is a real shared vision of wishing to make things better for our NHS patients.**

Third, such a responsible role has given me an opportunity to change things – hopefully for the better. Some of the things that I have taken a particular interest in promoting through teamwork include:

- Ensuring strong and genuine patient and public involvement in all our committees
- Redressing inequalities in research - like encouraging recruitment where the burden of disease is greatest and increasing diversity in our funding committees
- Reducing research waste by ensuring all our topics are prioritised, well designed and that all are reported fully in a timely fashion in the public domain, and by introducing the concept of enhanced dissemination
- Celebrating our commissioned work stream - tackling market failures as well as new technologies so that they can be used by our NHS
- Encouraging use of up-to-date methodology such as data-enabled trials or studies within a trial and core outcomes to be used where they exist
- Promoting more cross-programme working so that good ideas are not lost by falling between the programmes

I have tried to be as fair as I can to all research communities with no hidden agendas and my communications have been through [monthly YouTube videos](#) and are accessible to all. I can honestly say that I have played with a straight bat from start to finish and **it has been a privilege to serve the British public in this way.**



# Meet the team



Row 1: Prof Hywel Williams, Prof Kim Thomas, Dr Emma Axon, Arabella Baker, Dr Jonathan Batchelor, Radu Boitor  
 Row 2: Dr Bob Boyle, Dr Esther Burden-Teh, Dr Jo Chalmers, Prof Fiona Cowdell, Sue Davies Jones, Liz Doney  
 Row 3: Dr Sonia Gran, Dr Douglas Grindlay, Dr Karen Harmen, Dr Jane Harvey, Dr Laura Howells, Dr Lisa Kirby  
 Row 4: Dr Stephanie Lax, Dr Carron Layfield, Dr Paul Leighton, Jo Llewellyn, Barbara Maston, Victoria Maddox  
 Row 5: Maggie McPhee, Dr Ruth Murphy, Dr Mitesh Patel, Dr Monica Persson, Laura Prescott, Dr Jane Ravenscroft  
 Row 6: Helen Scott, Dr Maulina Sharma, Dr Rosalind Simpson, Dr Sandeep Varma, Margaret Whittingham  
 Not pictured: Linda Pycroft, Dr Natasha Rogers



## Appendix: Publications Jan 2019 - Dec 2020

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