

Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

British Journal of Dermatology—Patient Associate Editor Opportunity

We're really pleased to be able to make you aware of an opportunity to become involved in dermatology publishing as a Patient Associate Editor with the [British Journal of Dermatology](http://www.bjd.org.uk) (BJD) - two posts are available.

This is your chance to join the BJD's editorial team to influence academic publishing and help further promotion of their plain language summaries. BJD is one of the only dermatology journals that publishes free to read, [plain language summaries](#) with every issue.

The role of Patient Associate Editor will involve being an active participant in championing why patients should be involved in research and how BJD is working towards this goal. You will also disseminate plain language summaries through patient support networks, invite submissions for a

patient perspective section and provide input into journal development. Please read [this editorial](#) regarding the background and BJD's vision for this role.

As with all the BJD Associate Editor posts, this is an unpaid role but any travel, accommodation or out of pocket expenses for journal work will be reimbursed. The estimated time commitment for this role is two hours per week (on average), with a term of office of two years.

The appointment process requires a letter of application outlining why you would be suitable for this role and a copy of your CV. The **deadline for applications is 26 July 2019** and the shortlisted candidates will be invited for an in-person interview at the BJD offices in London with an anticipated start date of September 2019.

The role description is attached and further information can be obtained from Shehnaz Ahmed, Managing Editor in the BJD editorial office (shehnaz@bad.org.uk).

DIPSOC study update – what will happen next?

The [DIPSOC study](#) (developing diagnostic criteria for psoriasis in children) has finished recruiting! We have successfully reached our recruitment target of 320 children and young people (160 with psoriasis and 160 with other skin rashes).

Patients were recruited from 12 different paediatric dermatology departments in England, Wales and Scotland. We would like to thank everyone who contributed feedback on the study design and patient information sheets. A special thanks goes to Panel Member Carolyn Hughes who is part of the research team. Children, young people and parents from our dermatology clinic in Nottingham and the Young Persons Advisory Group (Nottingham) also shared their ideas and suggestions. The study design, information sheets and other participant paperwork were very well received by patients, parents and research sites. This exemplifies the benefits of strong patient and public involvement in research.

So what next? The DIPSOC study aims to test how well a list of expert-derived diagnostic criteria (skin changes to look for and questions to ask about in the medical history) perform at separating psoriasis from other scaly red rashes. Using a statistical model we will develop the best predictive criteria. We are about to start analysis of the study data and the results should be ready for early 2020. The next step is to transform the diagnostic criteria into a questionnaire to be completed by young people or parents. The questionnaire will support research into psoriasis in children and young people outside the hospital environment.

We will soon be starting some research interviews with parents of children with a skin rash (Spring 2020). If you are interested in taking part please [get in touch](#).





Something a little bit different?

We are currently developing ideas for a school-based outreach project between a local professional orchestra, Sinfonia Viva, and CEBD. Led by Research Assistant Stephanie Lax (who has a personal interest in the creative arts and is currently working on the [Eczema Care Online Programme Grant](#)), the aim of this work is to raise awareness of skin disorders and our research at CEBD, encourage empathy amongst peers and educators, and generally try to tackle broader issues about self-image and inclusivity.

[Sinfonia Viva](#) specialise in taking musical themes on a topic developed by children in workshops, turning them into fully orchestrated pieces of music, and then putting on multimedia performance events. Each project they do is different in content and scope, and what a skin-based project might look like is very much up for grabs. We are very keen to hear from you about this — if you'd like to be involved further or would just like to share your thoughts and ideas (and indeed any reservations you might have about such a project) then please [get in touch](#).

Young People's Research Advisory Groups

As you may be aware, due to safe guarding issues the CEBD Patient Panel is limited to adults only. A number of our panel members provide input into projects as parents of children affected by eczema and other skin conditions; when we need direct input from young people and children we work with our local [Young People's Advisory Group \(YPAG\)](#) in Nottingham as illustrated by the DIPSOC project overleaf.

Funded by the National Institute for Health Research and other NHS linked organisations, there are currently eleven YPAGs across the UK. The main remit of the Groups is to support the development and delivery of paediatric research in the UK, and local groups meet every 6-8 weeks with an annual national event. The Groups are an excellent opportunity for children and young people (aged 8-19) to get involved in research. If you know anyone who would be keen to get involved please do get them to encourage them to contact their [local group](#) and find out more.

CEBD Patient Panel Event Sat 12th October

We've had a great response to the next CEBD Patient Panel event, which is taking place at [The Orchards Hotel, Nottingham](#) on Saturday 12th October, with only a few places remaining available.

The day will include a celebration of 10 years of the panel and we're really pleased to be able to let you know that CEBD Co-director Prof Hywel Williams will be presenting a 'Reflection on dermatology research over the past 10 years' as part of this. He is also composing some music to share with us all on the day!

This is your day so if there is anything in particular you'd be interested in hearing about, or any training you'd like to undertake, please do let us know and we'll do our best to accommodate these requests.

Please do get in touch with [Carron Layfield](#) if you'd like to attend so that she can reserve a place for you. Do remember that travel expenses will be reimbursed and travel/accommodation can be pre-booked if needed.

Update on Blistering Skin Disorders Priority Setting Partnership

The first meeting of the blistering skin diseases [priority setting partnership](#) took place in early May at Nottingham University. There was an excellent turnout of 20 people, including five patients, one of whom was Ingrid Thompson who is a member of the CEBD Patient Panel. It was a very useful and productive meeting with excellent input from the patient representatives. Some key decisions were made, including setting the scope to include the diseases bullous pemphigoid, pemphigus vulgaris and mucous membrane pemphigoid, whilst aiming to focus on treatment. The project Steering Committee are now working together on the next phase of the project to identify future research priorities and help drive research forward in this area, building on the previous success of the [BLISTER](#) trial in bullous pemphigoid.

Other things of interest.....

- If you are contributing to an NIHR project and have concerns on how this may affect any benefits you receive then there is a [specialist advice line available](#) (set up by Bedford Citizens Advice Bureau) to get help and advice.
- Are you aware of the NIHR [Patient Ambassador Programme](#) ? This is an excellent initiative to promote the importance of clinical research in delivering better healthcare in your local area.
- From April 2020 there will be a new [NIHR Centre for patient and public involvement, engagement and participation and research dissemination](#) which will be delivered by a company called LGC rather than [Involve](#).