



# Patient Panel Newsletter

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## National Volunteer Week 1st-12th June 2016

Did you know that over 21million people volunteer at least once a year in the UK which contributes an estimated £23.9 billion to the national economy?

Supporting CEBD research in the many different ways that you do means that you're one of these active volunteers so you might be interested in finding out more about [National Volunteer Week](#) which is taking place 1st-12th June.

Organised by [NCVO](#) (the National Council for Voluntary Organisations) the aim of this event is to celebrate the work that volunteers do and to encourage more people to try volunteering. We're really pleased that the next Patient Panel meeting on 11th June (see over for more details) falls within National Volunteer Week and will recognise this on the day.

## Update on Recent Funding Applications

We're really sorry to have to let you know that the funding application for the [NIHR Programme Grant](#) (in collaboration with Miriam Santer, Southampton) investigating self-care strategies for eczema patients, as discussed at the last patient panel event, was unsuccessful. Feedback from the funders was encouraging though and the study team are currently investigating a number of options and are considering whether to re-submit the application at a later date.

On a more positive note, a number of outline grant applications have been submitted recently including a database study investigating links between diet and eczema and a clinical trial investigating the treatment of [acne in mature women](#). A further collaborative application with a study team in Southampton investigating which are the best emollients to use for the treatment of eczema has also been submitted to the [NIHR HTA funding stream](#). We will continue to keep you informed of the progress of these studies and many thanks to all those panel members who have helped to support their development.

## Meet a Member of CEBD Staff—Douglas Grindlay

Douglas Grindlay is the information specialist at CEBD. Douglas returned to work in the CEBD in July 2014, having worked in the Centre for Evidence-based Veterinary Medicine in the Nottingham Vet School for four years, where he helped to establish evidence-based research and resources in veterinary medicine. Douglas previously worked in the CEBD for many years, running the former National Library for Health Skin Disorders Specialist Library.

Douglas is a qualified librarian and information specialist with a background working in scientific research and government health policy. Douglas carries out a range of activities at CEBD relating to systematic reviews and database searching, including teaching search skills to staff, students and clinicians. Douglas also compiles CEBD Evidence Updates—monthly e-mails that highlight the latest guidelines and systematic reviews in dermatology—and works on mapping the evidence in major skin diseases.

Douglas time is now shared with the Orthopaedics and Trauma Group in the Nottingham School of Medicine, contributing to the newly established Centre for Evidence Based Hand Surgery, which is inspired by, and closely modelled, on the CEBD.

Away from work, Douglas is a keen gardener and enjoys playing music on his keyboard and violin.



## Meet a Panel Member—Maxine Whitton

My name is Maxine Whitton. I am retired and have 2 children and 3 grandsons. I was born in Jamaica but have lived in London since 1959. I came to England to live with my father and to study French as I wanted to be a French teacher. I graduated from UCL with an Honours Degree in French and did a year's postgraduate training to become a teacher. For a few years I taught French, my chosen career, but I soon became disillusioned with the lack of interest and apathy of the students and decided to give up. I got married and after my son was born got a part-time job as a Library Assistant at the North East London Polytechnic, now the University of East London (UEL). I was encouraged to do a Postgraduate course in academic librarianship which led to my second career as an academic librarian in the Biosciences Department of UEL. I really enjoyed this job, which in many ways prepared me for doing the Cochrane review as I searched the literature for information for the lecturers and gained a lot of experience of medical and scientific terms and databases. I also used the opportunity to find out all I could about vitiligo which is still my passion today.

I have had vitiligo for over 60 years but it did not become widespread until after my second child was born. I became very distressed when it started to spread over my body including my face and hands and there seemed to be nothing that could stop it spreading. A life changing meeting of people with vitiligo held at St Thomas's hospital led to the establishment of the Vitiligo Group, now the [Vitiligo Society](#). I had just taken early retirement from UEL so threw myself into managing the Society where I spent 28 years in various roles - as Committee member, Vice-Chair, then Chair and finally Patron. I stepped down in

2013 and now only contribute articles on research for the newsletter. Over the years I have found that helping other people with this disease helped me to cope.



I have always believed that the contribution of patients and carers to healthcare and research is important. I became involved in many organisations e.g. [INVOLVE](#) and the All Party Parliamentary Group on Skin. I was also a member of the first patient panel of NICE and later joined the patient panel at Whipps Cross, my local hospital. I was recruited by Hywel (co-director of CEBD) as a patient representative on the [UK Dermatology Clinical Trials Network](#) where I stayed for 9 years. I learnt a lot about research then. Hywel also inspired me to get involved with [Cochrane](#) where I am both a member of the [Consumer Network](#) as well as an author for the [Cochrane Skin Group](#), leading three reviews on treatments for vitiligo (please see the article on the next page for more information about Cochrane Systematic Reviews). I plan to scale down my work but not to retire just yet as I still enjoy meeting people and being involved, albeit in a small way now.

We're really pleased to be able to let you know that Maxine will be attending the Patient Panel meeting in Nottingham on 11th June (see below for more details).

To hear Maxine speak about her involvement in the vitiligo reviews for the Cochrane Skin Group [click here](#).

To see Maxine and others discuss the different ways that patients and carers can get involved in research then please see this really useful HealthTalk [on-line video](#).

## CEBD Patient Panel Training Event Saturday 11th June

Many thanks to the panel members who have confirmed their attendance at the next CEBD Patient Panel meeting which is taking place at the [Hemsley Building](#), University of Nottingham on Saturday 11th June. The programme for the day has been finalised and will include an update on new and on-going studies and training sessions on taking part effectively in teleconferences and the use of big datasets in clinical research.

We're expecting 14 panel members on the day so there are still a few places available—if you'd like to attend please contact [Carron Layfield](#) for more information. The final programme and further details of the day will be circulated to those attending in the next couple of weeks.

## Focus on Cochrane Systematic Reviews

[Cochrane Systematic Reviews](#) identify and explore research based evidence (usually in the form of clinical trials) for and against the effectiveness and appropriateness of treatments. They present the results in an accessible format for health care providers, consumers, researchers and policy makers so that relevant information is easy to find. (Please note that as an organisation Cochrane refer to patients/ carers as consumers so this terminology is used here).



Teams involved in writing Cochrane Systematic Reviews are careful to look at the results of all studies in an area (both published and unpublished) no matter what the outcome of the studies, or where in the world they were carried out. The teams are usually made up of health care professionals, medical researchers and consumers. Looking at research evidence in this way means that it is easier to see the bigger picture and work out which treatments really work the best. Cochrane Systematic Reviews are published quarterly via The Cochrane Library and plain English summaries of the review are often published alongside them. Once published, Cochrane Systematic Reviews are updated every few years to make sure that new studies in the area of interest are considered. There are over 50 collaborative review groups covering most medical specialities. CEBD is home to the editorial base of the [Cochrane Skin Group](#) which is dedicated to summarising how effective treatments for skin disease are. The Managing Editor for the group is Prof Hywel Williams (CEBD Co-director) and is pictured above with the rest of the editorial base team.

### **Why it's important for consumers to get involved in helping to write a Cochrane Systematic Review**

A consumer perspective on systematic reviews is important. Lead review authors are generally health care professionals and consider a question for a review because of their own experiences as a provider of health care in a clinical environment or through research. The purpose of consumer input during the review process is to:

- ensure that a review question is relevant to people requiring health care
- identify outcomes from healthcare interventions that are important for consumers – these may be different from those identified by service providers
- improve access to reviews by ensuring that the review can be read by a wide audience and that language is sensitive to consumers
- weigh up the benefits of a healthcare intervention against the potential harms – only consumers can identify the issues that are most important for themselves and their families or carers
- help decide priorities for new reviews.

### **Ways to get involved in helping to write a Cochrane Systematic Review.**

Consumers can get involved in a wide variety of ways, many of these involve ensuring that the reviews are written in a way that is easy to understand, using plain English and a lack of jargon wherever possible. These include commenting on Cochrane reviews before final publication (as a consumer peer reviewer or referee), helping to prioritise review topics suggested, contributing to writing lay summaries of systematic reviews and being actively involved in writing reviews as part of a team. The Cochrane Skin Group have a list of consumers who are able to help in this way and we are really grateful to the growing number of CEBD Patient Panel members who are involved in supporting reviews. If you'd be interested in getting involved please e-mail CEBD Patient Panel Co-ordinator [Carron Layfield](#) for more information.

In addition to training and support provided by CEBD, The Cochrane Collaboration has its own consumer network, the Cochrane Consumer Network (CCNet) which can provide assistance with communication, training and guidance in getting involved. The website is <http://www.cochrane.org/consumers/homepage.htm> and a huge amount of information and help can be accessed from here.