

Carron Layfield[#], Amanda Roberts^{*}, Jason Simons^{*}, Maxine Whitton^{*}, Carolyn Hughes^{*} and Anjna Rani^{*} on behalf of the CEBD Patient Panel

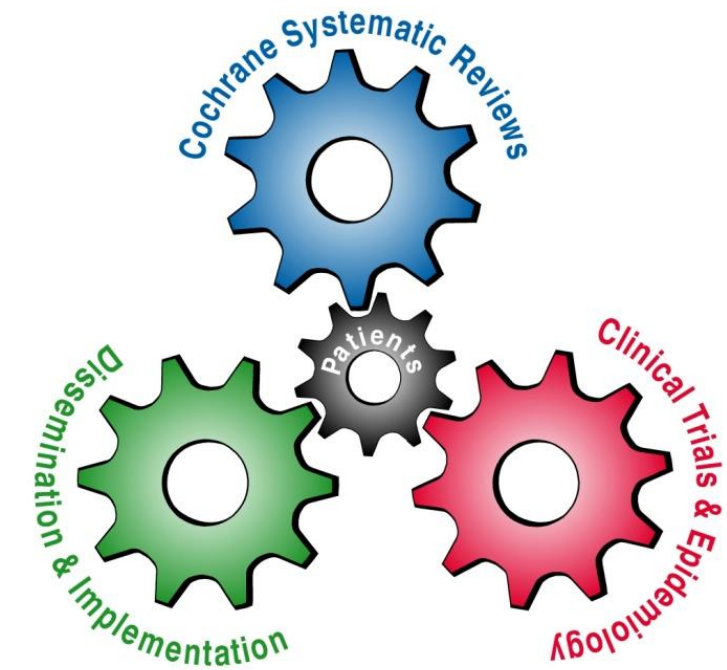
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Background

The Centre of Evidence Based Dermatology (CEBD) is part of The University of Nottingham. Its director is Professor Hywel Williams who is both a consultant dermatologist and an academic researcher. More information about CEBD can be found on our website www.nottingham.ac.uk/dermatology.

Research undertaken at CEBD is illustrated by interlocking cogs that work together, shown on the right. The driving force behind this concept is the needs of patients.



The 3 cogs are:

- The Cochrane Skin Group (CSG)
- The UK Dermatology Clinical Trials Network (UK DCTN)
- Dissemination and Implementation

CEBD has always had a strong record of patient and carer involvement in our research. The Patient Panel was established in 2009 to create a more effective research environment and to give support and training to those patients and carers involved. Panel activities are funded by the National Institute for Health Research (NIHR) Programme Grant 'Setting Priorities and Reducing Uncertainties' (RP-PG-0407-10177).

We began recruiting patients and carers into the panel by contacting those already involved in our work. We also advertised the panel on our own website and those of relevant patient support groups and charities. Three years on, the panel is now well developed and has over 20 active members involved in a variety of research activities.

Case Studies

Jason Simons



As a patient who was diagnosed with psoriasis 20 years ago, I would say that I am an "expert" when it comes to self-care and managing a long-term condition. I first became involved with CEBD in 2009 after responding to an advert in the psoriasis society member's magazine looking for panel members.

I have been involved in design of research studies and as a result of my work with CEBD I was invited to be a Patient representative for the NIHR Dermatology Specialty Group. I am very keen to ensure the voice of the patient is heard and is at the core of research design and practice. Personally, it has allowed me to meet other passionate people with skin conditions who really care about making a difference to others and the research process.

Carolyn Hughes

I joined the CEBD Patient Panel because I was interested in doing something positive that could help people with psoriasis and other skin diseases.

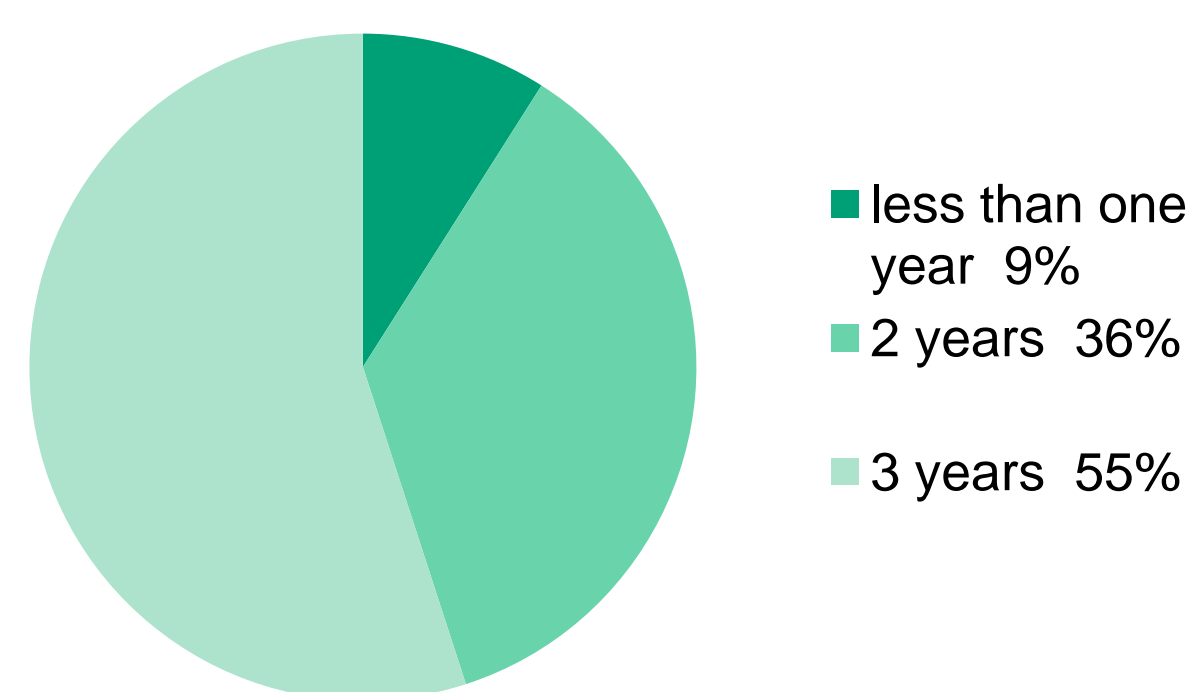
I joined the Cochrane Skin Group as a Consumer reviewer in 2009, and have read several Cochrane Review protocols and one full review, all focusing on treatments for psoriasis, which I have had since childhood. Getting involved in the Cochrane reviews is an interesting experience – for me it is an opportunity to understand more about the disease and available treatments, and it has given me a chance to comment on the reviews from my perspective – such as finding it easy to read and understand, or suggesting which technical terms might need to be further explained.



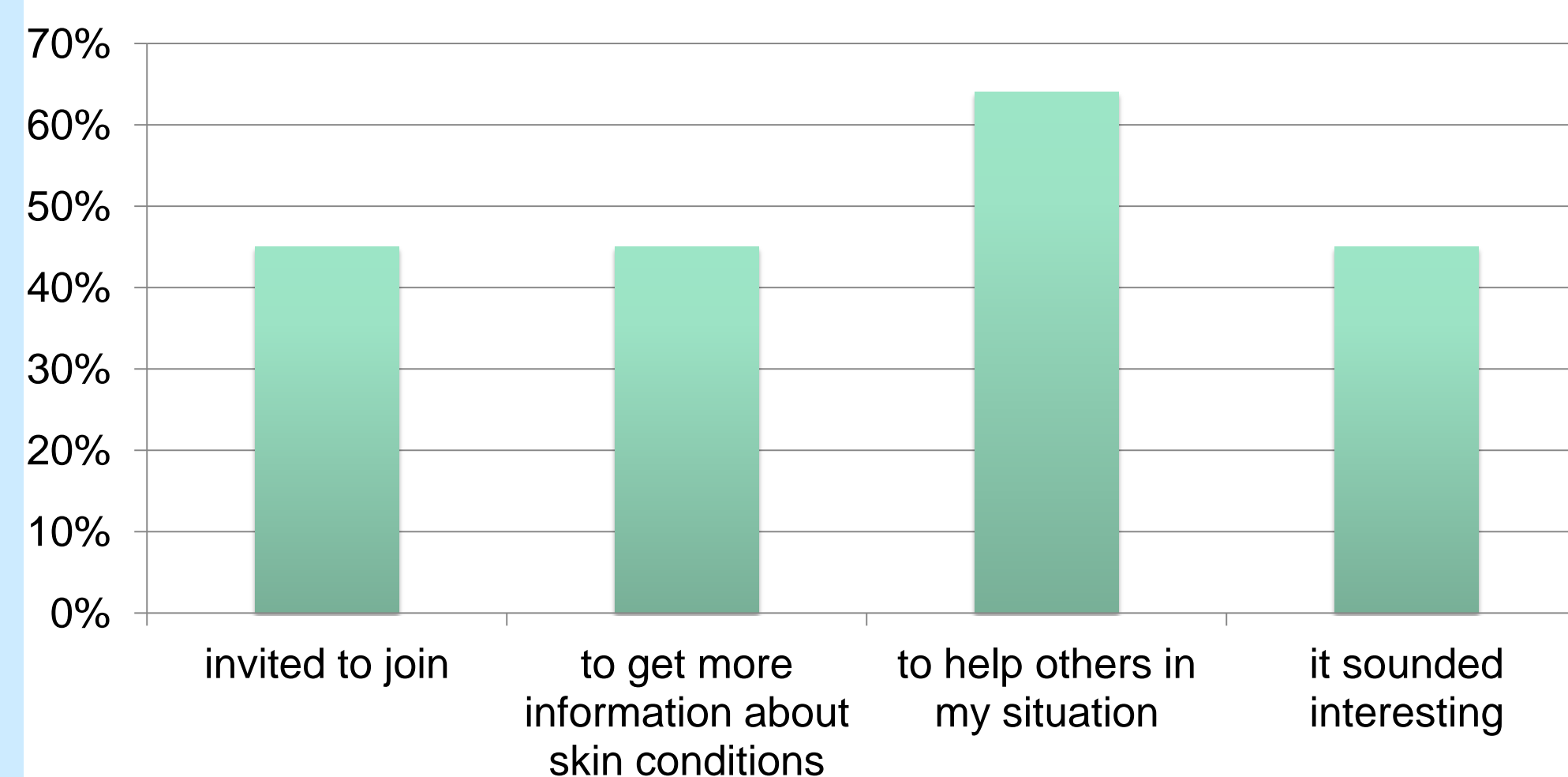
Panel Details and Activities

We recently surveyed panel members to establish why they joined the CEBD Patient Panel and whether joining the panel has led them to get involved in other activities giving rise to wider benefits for patient health. Over 50% of panel members responded to the survey with the results outlined below.

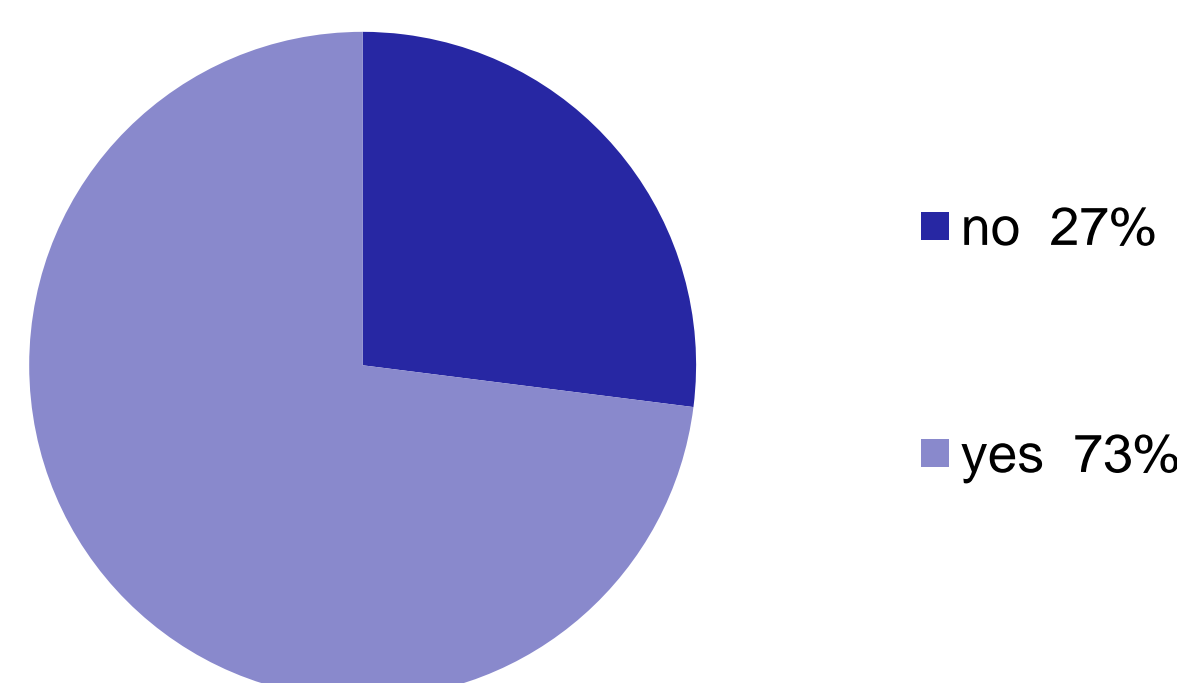
Length of involvement in panel



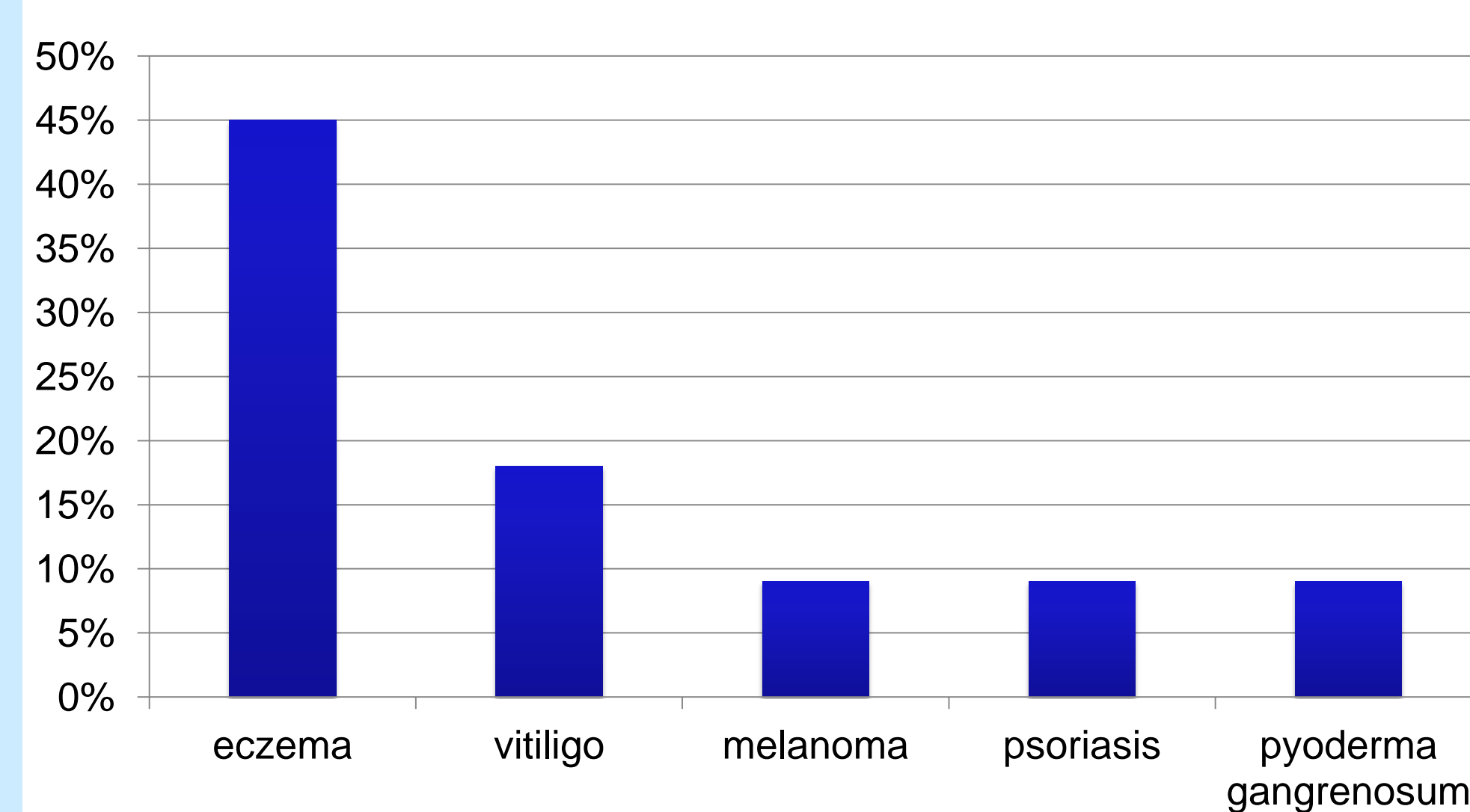
Reason for joining the CEBD Patient Panel



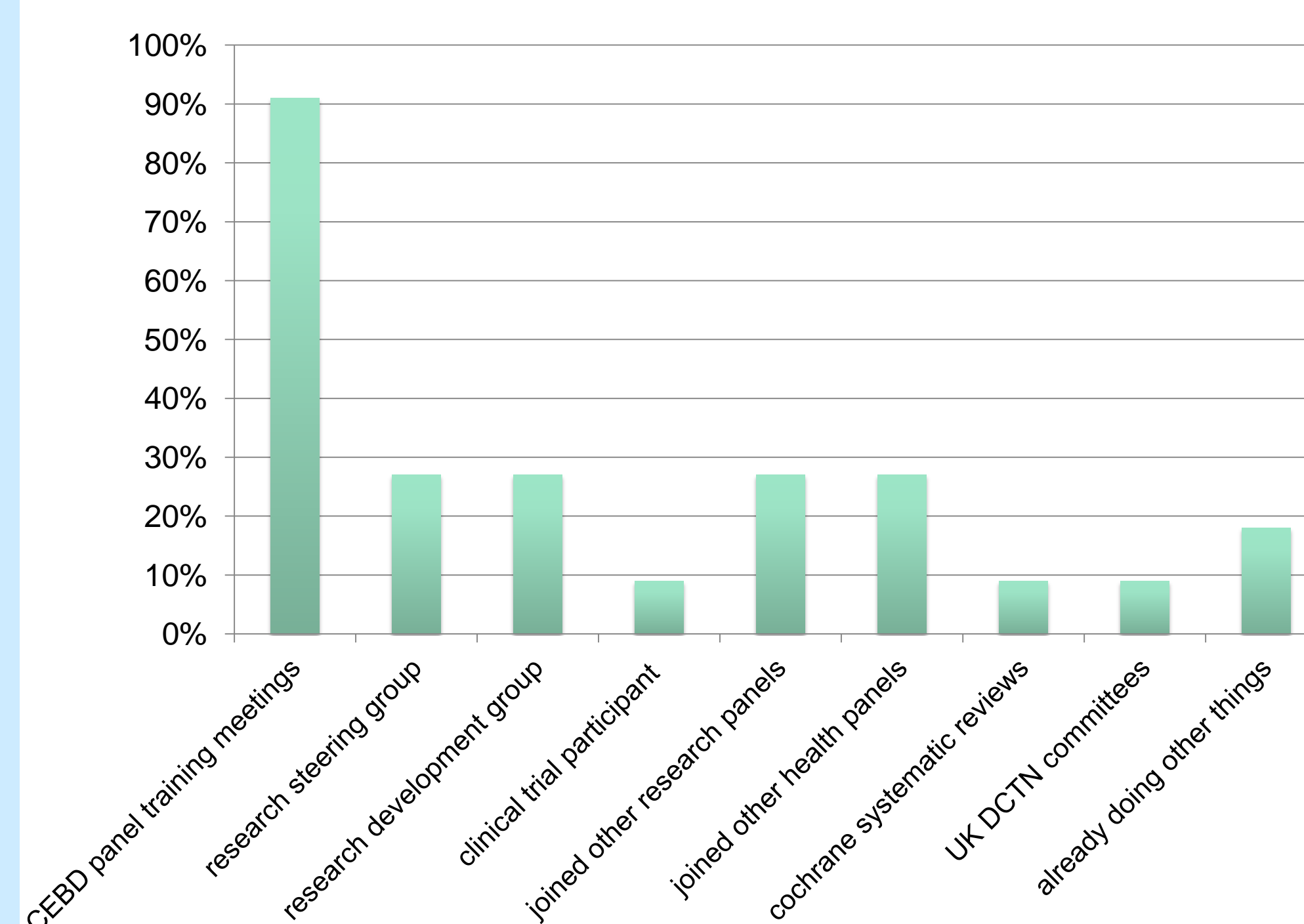
Previous involvement in research



Skin condition



Activities panel members are involved in



Training

Four CEBD Patient Panel training days have been held to date over the past three years with an average of twelve members attending each one. The days are split into presentations to inform and educate panel members and workshop sessions to assist with the development of CEBD research projects. Subjects covered to date include the design of clinical trials, Cochrane systematic reviews, jargon busting, clinical research and evidence-based medicine.



Feedback from patient panel members on the training events:

- 'Great friendly atmosphere'
- 'Thank you for making it easy to ask questions and interact with others in the group'
- 'Fantastic pack of information with additional information sheets I can take away and read'
- 'Good work, valuable get together'
- 'Very informative, enjoyable day'

Conclusions – Wider Benefits for Patient Health?

The many benefits of the patient panel to CEBD are obvious; we have a significant number of engaged and trained patients/carers affected by a wide variety of skin disorders who are involved in an extensive range of research activities. The commitment of our panel members is illustrated by their length of involvement in the panel and the variety of activities they are increasingly taking part in.

Members can benefit from participation in the CEBD Patient Panel in a number of ways. This includes learning new skills and the satisfaction of knowing they are helping others in their situation; the latter being the most common reason stated for joining the panel. Direct health benefits for panel members have been stated as coping better with their condition, an increased confidence in dealing with healthcare professionals and an increased understanding of their disease.

'A number of direct benefits for my skin but I actually found it was wonderful to be in a roomful of people and – for the first time in my life - not be self conscious about scratching!'

The survey we carried out revealed wider and unforeseen benefits to patient health on a range of levels. As they've gained confidence and experience, a number of patient panel members are becoming involved in research activities outside CEBD. This includes becoming involved in Nottingham University Hospital Trust panels and representing the interests of patients on the NIHR Dermatology Specialty Group. Such broader participation in research is of great benefit to NHS research as a whole and not just CEBD. A further benefit has been the impact the panel has had in raising the profile of dermatology research amongst relevant patient support groups and in general.

Acknowledgements

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