

Why I came into CC SG?

I was an National Eczema Society trustee when the Cochrane Skin Group was mooted: it seemed 'a good thing' though I barely understood what it was about.

I was first asked re hand-searching - this not really for me.

Hywel did a rescue act; suggesting I might be involved in other ways.

And, of course, I have had eczema all my life... an almost all-consuming business... perhaps 'passion' is not so inappropriate.

I was intrigued by the idea that the medical profession might be interested in what I, a patient, client, 'sufferer' - perhaps a 'co-involved person' - might have to say. After all, once in hospital, when asking what I thought were sensible questions about how I could best manage my eczema, I was told by the consultant, 'you mind your business and let me mind mine, and we will get on a lot better'. So involvement was a new concept.

That was some time ago, and I know that I am speaking now to the converted. I do not think that would be said again, but, I doubt if we can yet say that this thought, this attitude, does not still exist. So I wonder how we can be most effectively **co-involved**.

My work - and I trust it is accepted as such! - with Cochrane, while it is interesting, informative and, mostly, rewarding, also makes me sad.

There seem to be a number of **missing links**. I wonder what can we do to build these links? Thinking for example, of the National Eczema Society, I wonder

- How could the Skin Group build on patients'/groups' experience of interactions with the medical profession?
- Could the Skin Group study the value of these patient groups and thereby discover which questions, as well as findings, have relevance to their experience of health care?
- Could Cochrane help to forge more co-operative links between health-care professionals and the patient?

Within Cochrane, so much long-term, detailed and painstaking work on all sorts of issues - of more-or-less immediate relevance to us - is going on, but all too often it seems not to filter down to the Primary Care level, where most of us seek help.

I worry too, that, with the preoccupation with **quantitive** measures, we may fail to evaluate the **qualitative** experience of the patient. I would hate to think that we risked throwing the baby out with the bath-water! Taking an effective account of the patient's actual experience and use of medication is notoriously difficult. It is as time-consuming as other aspects of research, but we ignore it at the expense of imperilling the validity of our work.

One review mentioned a study which included 'a regular ten-minute counselling session'. No detail: nor any mention that this could be an important **variable**, with implications for the study.

I cannot help mentioning Chris Bridgett's behavioural approach to eczema & scratching. I do not recollect any mention that his study took into account the significance of each patient being interviewed each week for perhaps 10-20 minutes. This was, and increasingly is, an unusual allocation of face-to face patient time. And, again, an important element in evaluating his study.

One of my most revered consultants regards it as a standing joke when I say that hydrous ointment suits me and my skin. I ask why he, as others, so commonly

prescribe the dreaded 50:50, when all it seems to do is to absorb into my clothes rather than into my skin, without hydrating it.... an experience common to others. To him it still remains a joke... If he told me that there was a problem with certain emollients blocking the pores, I would perhaps understand: I would certainly feel that he had listened to me, the consumer. There seems to be a gap between the skilled and the patient, who becomes de-skilled, Would not an evaluation of the patient experience be helpful here too? Is it too difficult?

Relevance of Reviews to the consumer: We are asked to what extent we think that a study has relevance to us... When I have commented that I would have liked to see some particular element considered, some Review Groups have said 'Yes..., we see your point, but we are constrained by the content of the studies available'. So, how can the **co-involved** be more effectively involved, and help to direct studies to the areas where, like the lager advert, some do not reach? Perhaps only by commenting in the Implications for Research section.

Patient groups. While much information is available, and patient groups are doing much to help consumers access information, there are still gaps, 'missing links'. Sad to say, I have learnt more from the National Eczema Society than from any doctors. except one consultant, who, in the 1990s, took the trouble to explain to me the different strengths and purpose of various topical steroids - although by then I had a whole rainbow selection of different coloured tubes. Patients are still only rarely taught the difference between a steroid preparation and an emollient, a cream and an ointment.

Could the Skin Group help to tackle this 'missing link' of this most basic information?

Could the Skin Group study the contribution of patient groups? It seems that patient groups, such as the NES, or Vitiligo Society, are often the most able to help those who need the information, but are the least used by health care professionals.

### **Why am I still here?**

I am still interested in, and keen about, what Cochrane and the Skin Group seeks to do. After all a main tenet is that of the 'Informed patient'.

Thoughtful feedback: some of the 5 or 6 Review Groups I have now worked with are most responsive, and come back with comments and discussion about my comments. I was so pleased to be sent a copy of Urba's report form on my comments on his Tinea capitis review - I had never felt so rewarded before! I wonder if we could receive these reports on a regular basis? We may learn even more from negative reports. This would encourage rather than discourage consumers.

Meeting with other consumers, especially at the International Colloquia, is always stimulating & encouraging.

And, of course, all the Cochrane folk I meet are wonderful, friendly and dedicated!

I would not be here unless I had some optimism about all this! Thanks, Hywel for keeping me involved!

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