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Editor

‘The expert patient may be a good thing and involving patients during the development of protocols for clinical research sounds reasonable. However, the definition of a patient expert needs to be explored and clarified, be based on meaningful criteria and free from jargon and political correctness.’

How do we define the expert patient?

‘There are still far more experts around than is healthy’ (Sackett, 2000)

If you are contemplating a change in your clinical service or finally getting round to that research project, then a ‘must-have’ is patient involvement. The idea of patients as experts is a political imperative (Department of Health, 2001) and looks like becoming a requirement for grant submissions at least in the UK (Diabetes UK, 2003).

The concept of the expert patient is not new. Despite the fact that the jargon is unsurprisingly indigestible – with language such as ‘user-led self-management’ – and the inevitable ‘development in line with resources’, i.e. no money, the idea seems to have become accepted with the minimum of fuss. Although, patient involvement and self-management programmes seem to make intuitive sense, and probably encourage multidisciplinary team working and perhaps even reduce red tape as *the patient is always right*, there has been little debate on the criteria for becoming an expert patient. Certain preconditions might be useful (Tattersall, 2002):

- Basic education in the management of the disease
- Availability of objective ways to monitor the condition
- An ability (and approval) to change treatment
- A special sort of personality – the charisma factor.

The difficulty is defining ‘expertness’ per se. The assumption is that ‘experts’ have earned their title through the personal experience of living and dealing with the disease on a day-to-day basis. In a sense, this is curious – they would fail the ‘Mastermind’ test; anyone can become an expert and have specialist subject knowledge irrespective of their background. In addition, the inclusion/exclusion criteria for ‘expertness’ are not at all well-defined: should an individual have achieved a certain level of HbA_{1c}, be free of long-term complications or be taking the correct number and type of tablets? What about the person who has survived many years of diabetes by adopting a completely idiosyncratic approach to their condition – would they still qualify as an expert?

A further complicating factor on selecting a patient to become an expert relates to opportunity. Traditional teaching suggests that only motivated, informed and stable patients will benefit from intensive insulin therapy. In fact, in a recent study involving young people (aged 6–16 years) with type 1 diabetes, patients and parents with the lowest level of diabetes knowledge and adherence at baseline had the greatest benefit from a programme of intensive insulin therapy (Wysocki et al, 2003). This should mean that training will be an essential prerequisite on the road to becoming an expert but it does raise the thorny issue of which course?

The expert patient may be a good thing and involving patients during the development of protocols for clinical research sounds reasonable. However, the definition of a patient expert needs to be explored and clarified, be based on meaningful criteria and free from jargon and political correctness. Until then, perhaps the best advice to anyone contemplating becoming an expert is still that of Sackett – retire and move onto something else!

Department of Health (2001) *The expert patient: a new approach to chronic disease management for the 21st century* (www.ohn.gov.uk/ohn/people/expert)

Diabetes UK (2003) *Structured education programmes for people with diabetes* (www.diabetes.org.uk/research/grants/downloads/HSR_Ad.pdf)

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Wysocki T et al (2003) Self-management competence as a predictor of outcomes of intensive therapy or usual care in youth with type 1 diabetes. *Diabetes Care*; 26: 2043-47