

Patient Empowerment in Primary Care: an evaluation of the Expert Patient

*A summary of findings compiled for the Consultant
Physicians who participated in the study*

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Who this summary is for

This summary has been prepared for the consultants who have contributed to the study by being interviewed and allowing a researcher to observe clinics. Whilst each report includes findings from data drawn from the total study we have also attempted to highlight any pertinent data from your particular patient group.

We would like to thank you again for your help with the study and hope you will find this summary interesting. An overall report which has been prepared for Primary Care Trusts can be found at:

<http://perseus.herts.ac.uk/uhinfo/index.cfm?DBE6BC6A-0498-E5D6-6976-4A274729A00F>

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What was the study about?

The study was a response to both the implementation of pilot Department of Health Expert Patient Programmes (Department of Health, 2001) (EPP) within primary care and the increasingly common phenomenon of active and informed patients, termed throughout this report as expert patients. We were interested in finding out what helps or hinders patient expertise in self-management of long term conditions, and particularly wanted to explore the differences between lay and professional led self-management courses, and how health professionals responded to expert patients.

Who was involved in the study?

Overall, more than 100 health professionals were involved. These included nurses undertaking post registration courses in the care and management of a long term condition, practice nurses, diabetes nurse specialists, general practitioners, consultant physicians, physiotherapists and other rehabilitation practitioners. Nurses and therapists contributed to both interviews and focus groups, and practice and specialist nurse clinics were observed. All doctors were interviewed and the consultant physician clinics were observed.

In addition more than 100 adults with a physical long term condition were interviewed, participated in a focus group or agreed to have their clinic

consultation observed. A lay led Expert Patient course (also known as Living Well course) and a professional led self-management course (Back Fitness) were observed. The study took place in 6 Hertfordshire Primary Care Trusts and 1 Acute Trust.

How were the findings reached?

We transcribed all the interviews and focus group discussion and analysed them along with the notes that were taken during the observation. This was a qualitative research study as we were interested in seeing whether any recurring themes about peoples' experiences and thoughts emerged. Consequently what we report here are the major themes which may not necessarily reflect your experiences but we have attempted to indicate which themes were most common and also give examples of any opposite cases. In order to improve the validity we have presented the major findings to a selection of professional and patient groups to ensure that we were interpreting the data appropriately. Data has and will continue to be anonymised at all times.

Findings

1. Patient Experience

Diagnosis

For many of the generic patients who were interviewed or took part in a focus group there were similar stories of a lengthy period of time between first alerting their GP of signs and symptoms and the diagnosis. However, this did not appear to be an issue for the majority of patients with skin conditions, with most being diagnosed reasonably promptly in primary care or referred to the consultant.

It was observed in the dermatology clinic that a number of patients with atypical mole syndrome (AMS) had learned the pattern recognition skills required for suspecting a diagnosis of melanoma. However, alongside these skills one patient shared that they lived in a constant state of "*worry and having to look all the time*".

Developing knowledge about the condition

The majority of generic patients stated their knowledge of the condition was rarely obtained from a health professional which conflicted with the

observation of both consultant and nurse-led clinics where a significant amount of time was spent in teaching the patient about the condition. A contrasting case was presented by a patient with AMS who was very clear that the bulk of her knowledge had been gained from her consultant dermatologist and extended further by participation at medical “*mole dinners*”. A range of knowledge sources were cited from the generic patients, the most frequently mentioned were:

- Support group (however it should be noted that the focus groups were recruited via support groups).
- Daily Mail health page – this was a surprisingly frequent citation, with GPs and Practice Nurses (PN) also mentioning it (generally because there was an increase in consultations linked to the topic covered in the previous day’s edition).
- Internet – although this was not mentioned as frequently as many of the health professionals anticipated.
- Books, friends, work colleagues.

None of the patients with skin conditions who attended the clinic or were interviewed indicated any involvement with Support Groups, however one was planning to attend an Expert Patient Programme and hoped that would provide a source of knowledge (please see later).

Being an “expert patient”

The Department of Health describe an expert patient as someone that will self-diagnose, offer suggestions about treatment and seek help appropriately (Jones, 2003). Using that description as a baseline we wanted to find out more about their characteristics and from the significant number of expert patients in the study (including those with skin conditions) were able to discern shared characteristics:

- **View of health:** Despite varying degrees of disease severity, expert patients tend not to think of themselves as unwell, rather they term their situation as living with a condition and getting on with life.
- **Self-presentation:** Perceived it as very important to exhibit an appearance of cheerfulness or stoicism. In practical terms this often

meant they felt it necessary to hide feelings of anxiety or “feeling low” when dealing with some professionals.

- **Inner resourcefulness:** Often recounted years of persistence in getting investigations done or referrals to specialist centres, often identified themselves as having a fighting spirit.
- **Intelligent:** Generally described themselves as intelligent.
- **Self-educating:** Invested time, money & energy in obtaining books, attending conferences or courses about their condition.
- **Sense of responsibility:** often saw it as a duty to put something back into society as they had received so much from the health care system. This usually took the form of active involvement in support groups or teaching health professionals (the latter exemplified by the previously discussed patient with AMS). There was a great willingness to provide active lay contributions within statutory health services.
- **Logical and well-organised:** spent much time in preparing for consultations, often kept detailed files and records about treatments.
- **Knew the system:** described the importance of knowing the Consultant’s secretary or GP Surgery staff, could circumvent barriers other patients often come up against.
- **Risk assessment skills:** Could give well-informed and balanced reasons for adapting their treatment strategies between consultations.
- **Relationship with professionals:** saw it as vital to develop a rapport with professionals, displayed good communication skills and identified it as crucial not to appear to be a “challenging” patient.

During the observation of the dermatology clinics, expert patients were identified as specifically exhibiting the following behaviours:

- Were able to give a succinct history
- Talked knowledgeably about their condition (most common in people with AMS)
- Had developed strategies to increase their observation skills. For example, one male patient with AMS took photographs of himself

which he then used as a constant comparison to the ones provided by the consultant at the clinic.

Experience of professionals

Most patients’ strongest views were about doctors, either describing the relationship they had with them as particularly helpful or very unhelpful.

A summary of generic patients’ perceptions of good and bad characteristics of a professional is shown below.

Positive characteristics	Negative characteristics
<ul style="list-style-type: none"> • Makes you feel good in yourself • Encourages you to try things out • Removes barriers • Helps you reach your goals • Knows your feelings & experiences • Open to requests • Open to complimentary therapy • Gives you choices • Asks your opinion • Honest but kind advice • Good listener • Gives information • Accessible • Helps you keep things in proportion • Helps you to take responsibility for own health • Chases things up • Keeps in touch with you when things are bad • Caring • Sees you as a partner in care 	<ul style="list-style-type: none"> • Lacks time for you • Brutally frank • Just deals with one problem at a time, not holistic • Does not know you • Lack of continuity • Inhibits emotional release • Makes you feel neurotic • Dishonest • Poor communicator • Lacks clinical competence • Inflexible • Treats you with a lack of respect • Lack of interest • Does not suggest a plan

During the observation of the dermatology clinic it was apparent that the doctor-patient relationship was framed by the positive characteristics described above.

View of services

Many generic patients (particularly those with CHD) described a perceived necessity to access private in addition to NHS care, with reasons ranging from waiting times to accessing a more personalised service.

Many of the generic patients had suggestions regarding service delivery improvement:

- **Patient centred approaches:** The most recurring theme was the need for individualised approaches by professionals, promoting patient involvement throughout the care pathway, being non-judgemental and open to patient suggestions such as complimentary or alternative medicines, and enabling the feeling that the patient, not the professional is in charge of the condition (all of which appeared to form the ethos of the dermatology clinic). For many generic patients the worst experiences were described as being admitted to a General Hospital and having to cope with staff who had limited knowledge of their condition and being refused permission to continue their normal self-care practices. Although this was not picked up in the observation of the dermatology clinic as an issue, further research with patients whose skin conditions require intensive self-management would be helpful to explore whether the same applied to this group of patients.
- **Professionals' responses:** Another issue for many generic patients were perceived inappropriate responses to the patient's expression of emotional distress. Many cited nurse specialists as providing a good example of appropriate responses; easily accessible, takes time to listen and offering practical advice where appropriate.
- **Support groups:** The majority of generic interviewees saw voluntary organizations as the most effective source of support, particularly emotional, but would like to see greater knowledge & dissemination of information by professionals about the groups and closer links with statutory services.
- **Nutritional advice:** Several generic interviewees (not exclusively those living with diabetes) felt that health services were poor in delivering nutritional advice in long-term conditions and felt this should be improved.
- **Other advice:** It was suggested by some interviewees that written information should be provided about the different services available and how to access them, and also clearer advice on financial issues in long-term conditions.

- **Public involvement:** whilst there was a willingness to become involved in statutory organizations two barriers were identified. Firstly, jargon used at, for example PCT open meetings was perceived by some as a problem, and secondly there was a perception by some interviewees that patients were “hand picked” for patient forums.

2. Professionals’ responses to expert patients

A number of major themes emerged from the data;

- **Time resource:** many professionals described expert patients as taking more time to some extent in consultations. However, both the doctors and physiotherapists described this as an initial investment that would save time in the long-term. In contrast many nurses saw the time resource issues as an on-going burden, apart from the nurse specialists who described part of their role as giving more time to the patient. The period of observation suggested that the consultant clinics were far busier than the nurse led clinics. In addition there was another key difference in that the consultant-patient interaction often involved a “third party”. One consultant actively typed up notes on a computer during the consultation which sometimes affected the flow of discussion. Another consultant would routinely have a nurse present which far from detracting from the patient-professional interaction often facilitated a three way discussion. It was also observed that patients actively listened to any teaching points between consultant and nurse, appearing to absorb the information or use it as reinforcement for their self-management activities.
- **Litigation:** whilst doctors and physiotherapists were comfortable with their liability in the self-managing expert patient, the vast majority of nurses had particular concerns in this area. The concerns appear to stem from the perception that even in cases where the patient is competent, fully informed and has chosen to self-manage; errors made by the patient will be blamed on the nurse involved. The majority of nurses described their working practices as adhering strictly to protocols and sometimes felt unable to “allow” patients to self-manage

aspects of their condition as the nurse themselves perceived they did not have permission for this from either the organization within which they worked or from the doctor with whom they worked. The nurse specialists were noticeably more comfortable with liability (although it did cause some concern) which appeared linked to their comparatively autonomous role within a multi disciplinary team with its shared understanding and history of informed patients self-managing their long-term condition.

- **Perception of the expert patient as challenging:** Physiotherapists and doctors did not feel that expert patients triggered any feelings of threat to them and this appeared to be linked to these professionals ease with their role definition and area of particular expertise. However, whilst active and informed patients were not seen in terms of a threat, it was observed in the consultant clinics that patients with a lot of pre-researched questions did leave the physicians with a sense of “*being interrogated*” or that the patient was “*demanding*”. A significant number of nurses did describe active and informed patients as particularly challenging and intimidating who caused feelings of unease with the nurses’ own knowledge. This appeared to be a particular issue for the more recently qualified nurses who were still developing experiential knowledge and a recently qualified physiotherapist described her anxiety when dealing with particularly informed patients. Interestingly, a significant number of generic expert patients would actively ensure they did not appear challenging and would do their best to put the professional at ease.

“...if you’ve got a long-term situation, well it’s to your own advantage to create a rapport...you think of them as your friends rather than your foes.”

“...you just gauge the person you’re speaking to, and you have to go softly softly... it’s just a little bit of rapport and bits and pieces...the medics are only human, they want to do a good job”

Patient M6 interview

- **Responses to emotional needs of patients:** Many generic patients described the negative emotional consequences of living with a long-

term condition, but as stated earlier actively suppressed these in consultations. For patients who did discuss their feelings with medical practitioners there were frequent descriptions of what they perceived as inappropriate responses. Examples of these were being referred for counselling or prescriptions for anti-depressants, whereas the patients stated all they really wanted was to be listened to just for that one consultation and for their feelings to be acknowledged.

I got quite upset to my doctor who then said "Oh I didn't know you were like that" because I started to cry in the surgery, he said "I always thought you were such a, you know, someone with common sense, I didn't know you got upset like this" and put me on tranquillisers

Patient F3 interview

The data from the patients was reinforced by the GPs in the study who often described the most challenging patient to be the over-emotional and tearful one. In contrast it was observed in all the consultant clinics that there was an acknowledgement of emotional issues and patients' non-verbal cues regarding their emotional state were picked up and responded to in the majority of consultations. One consultant articulated the importance of dealing with the emotional issues of long term conditions:

"I think one of the problems in skin disease, particularly with long-term conditions, is unless you get that baggage out on the table, you're banging your head against a brick wall often. Acne's a good example of that. I've had girls come in and youngsters come in who have got really quite trivial acne who want very strong treatments and actually, when you explore it, it's maybe that they're not happy at home, they're not happy at school, they don't go out of the house not so much because of their acne but because of other wider issues and you have to have all that baggage out into the open really because just treating the skin condition without treating the way that that skin condition affects their life because of everybody around them, you're not going to make them better."

Consultant 02 interview

Nurses were clearly comfortable in dealing with the emotional consequences of the condition and were often identified by patients as being the most responsive to this need. The nurse specialists articulated this response as a key component of their role although there were

reservations from them as to whether they had the appropriate counselling skills when people had complex needs in this area.

3. Lay or professional led self-management education?

Although specific skin condition self-management education was not part of the study sample, it was noted that some dermatology patients were accessing the Expert Patient Programme.

The EPP is a 6 week self-management course for people with long term conditions and is now running in all PCTs. It is seen by the Department of Health as the cornerstone of their Chronic Disease Management policy. The key characteristic is that it is facilitated by a lay person who has long term condition and has received training as an EPP lay tutor, and is generic rather than condition specific. Data from the observation of the course and interviews suggest that the key strengths are:

- credibility for participants as it is led by a lay person who has a long-term condition;
- it can reduce feelings of isolation firstly by validating the emotional issues chronic illness may bring, meeting with people who understand the consequences of chronic illness, and lastly some participants reported it had improved their social life by introducing them to new people;
- learning from each other strategies that are useful in self-management (examples are changes to diet, or joining Support Groups) or what services are available in their PCT (an example is “Prescription for Fitness”);
- establishing self-care practices such as appropriate levels of exercise as a habit;
- suggesting and validating communication strategies in the patient-professional relationship such as preparing a checklist of queries before a consultation.

However, the strength of the EPP appears to be dependent on four factors. Firstly, the attributes of the lay tutors are very important; charisma, being non-judgemental and inclusive was cited as key

characteristics of an effective tutor. Secondly, participants who found the EPP most helpful were at a certain stage of their condition; neither newly diagnosed nor established self-managers. It was also imperative that they had actively chosen to attend to the EPP rather than being persuaded by a professional and felt well enough to attend. Thirdly, the success of an individual EPP is dependent on how the group bonds, if group cohesion is weak it will negate the facilitation skills of the tutor. Lastly, positive feelings about an EPP can rapidly diminish if discussed with an ambivalent professional.

We also observed a professional-led course designed for people with chronic back pain who had been assessed and referred to the course by a doctor or physiotherapist. Although course content covered similar areas, the depth was noticeably greater in the Back Fitness Course (BFC), as were the facilitation skills of the psychologist leading it. However, there appeared less engagement by the BFC participants with both the material and group support. The data suggests that the credibility of lay tutors appears to outweigh the benefits of facilitation skills, for whilst the professional was acknowledged as very knowledgeable the BFC participants queried whether the facilitator knew what it was actually like to live with back pain. Commitment also appeared higher with EPP participants as they had chosen to attend the course rather than being referred by a professional. Although not within the scope of this study it would be worthwhile to carry out a longer term evaluation of the differences in outcomes between the two approaches to self-management training.

The current trend from the Department of Health is to develop condition specific EPPs, and there is some ongoing work on this in Hertfordshire PCTs. It may be worthwhile to explore whether specific skin condition self-management courses could compliment local EPPs.

Conclusion

A significant number of expert patients were identified during the observation of the dermatology clinics. People living with AMS provide a clear exemplar of being an expert patient and also provide a contrast to generic expert patients

within the study. Whilst the latter appeared to develop much of their knowledge from support groups, those with AMS were more likely to be self-taught in some degree of isolation from others living with the same condition. The needs of self-managing expert patients appeared to be met well within the dermatology clinic, annual reviews of AMS patients were discouraged in order to promote self-reliance and a window of six months was provided for self-referral (although research from other studies suggest that demand would not be increased if this window was lengthened). In contrast to many of the generic patients' narratives it was clearly observable and articulated within the interview data that the emotional needs consequential to living with a skin condition were being met. The professional/patient relationship within the dermatology clinic appeared based on a mutual partnership and often characterised by a sense of reciprocity.

The study had a limited number of patients with skin conditions when compared to other conditions such as diabetes but the data suggests it would be worth developing further research exploring the self-management expertise developed by those living with AMS.

References

- Department of Health (2001) *The expert patient - a new approach to chronic disease management for the 21st Century*. Stationary Office, London.
- Jones N. (2003): How are expert patients different? *EPP Update* 8 1, 3.