‘Oh, Come All Ye Faithful’: acquiring and maintaining a cohort

The lupus clinic at the Centre for Rheumatology, The Middlesex Hospital, University College London, started by Michael Snaith in 1977, recently acquired its 300th patient. Incidentally, we do not see patients as a one-off or, with very few exceptions, as an annual review, but rather contribute to their care weekly if necessary. The patients seem to have found us rather than us actively seeking them out. We do not as yet have our own web page and word of mouth remains a potent stimulus for patients to seek a referral to our lupus clinic.

Looking after 300 patients with lupus is very time-consuming and requires a great deal of hard work but is also fascinating, challenging and stimulating and constantly recalls the mantra plastered on the office wall of one of us ‘Expect the unexpected’! Passing this milestone has given us cause to contemplate what the advantages of establishing a cohort of patients might be and, assuming that there is a point to it, the optimal way of doing it and how best to keep the patients coming!

The benefits of a cohort are probably most obvious in a surgical specialty, where undertaking a complex but beneficial operation is likely to lead to referrals from far and wide. The expertise acquired by the surgeon is likely to impact quickly on patient outcome. Seeing a substantial number of patients with the same disease very quickly teaches the physician to appreciate the nuances of the condition and, with a disease like lupus, enhances their respect and concern for patients who suffer from it. It provides an invaluable teaching resource for both undergraduate and postgraduate students, and provides a useful focus for more basic researchers who know, for example in our unit, that Thursday is lupus clinic, which is the day to collect blood samples, complete clinical questionnaires and arrange for other research tests, including imaging etc. Reviewing the same patients over long periods of time provides instruction in the natural history of the condition.

Accepting the benefits of the cohort system, then, how might you proceed, assuming that you have a passion for ‘interesting disease X (IDX)’. It is undoubtedly easier to get started when newly appointed as a specialist/consultant. You should certainly be full of enthusiasm at this point and willing to see that extra
and (more for our Sjögren’s disease patients) colleagues from Nephrology, Dermatology, Respiratory Medicine and (more for our Sjögren’s disease patients) colleagues from the Eastman Dental Institute. In addition, our colleagues in Gastroenterology and Plastic Surgery are but a floor away. We would argue that this approach also benefits the patient, providing two opinions simultaneously and reducing out-patient attendances overall.

Establishing a cohort and a clinic for IDX is enormously facilitated by finding reliable and friendly administrative staff who want to get to know the patients on a regular basis and are ready to bend the rules a little by perhaps squeezing in the patient before the official referral letter arrives. Some colleagues extend their interest by performing outreach clinics in other towns and cities, although we find this is impractical and prefer to let the patients come to us.

How then to hold on to these patients? First and foremost, it is essential for the patient to feel that the clinic really does provide them with a personal service, with the knowledge that they can be seen at short notice if their disease flares, and especially if they feel that their family practitioner (rightly or wrongly) is unwilling to deal with the problem. During the first few consultations, the interested physician must spend time establishing what particular component of the IDX really troubles the individual. You can thus demonstrate very clearly your interest in the condition in general and in the individual patient’s version of it in particular. Seeing familiar faces from the receptionist to the specialist nurse and the clinic doctor is also likely to encourage more regular attendance. It is comforting to know that someone from the clinic will phone you if there is a worrying result and, even more important, that you can phone the clinic between appointments if the symptoms are getting worse or there is something on your mind.

There are obvious problems in organizing long-term follow-up for patients who live many miles away, including geographic and economic considerations. It may well be more practical for you to establish a shared arrangement with the local clinic, so that the patient is seen alternately at the specialist clinic and locally. Indeed you may even wish to point the patient in the direction of a local specialist who may have trained within your unit, with whom you have a good working relationship. There should also be other, more tangible benefits to the patient. One, which for many diseases is becoming a reality, is the knowledge that pharmaceutical companies offering exciting new drugs for the treatment of IDX are more likely to make their latest preparations available in a larger clinic where hundreds of patients with IDX are followed up, compared with a local clinic where perhaps a few dozen patients attend but are scattered throughout a much larger clinic population.

In summary, we believe that establishing a cohort carries advantages to all concerned. For the would-be specialist, it allows the build-up of a challenging and interesting group of patients, enabling him or her to acquire detailed knowledge of the natural history of disease, skilled management techniques and a basis for clinical and laboratory-based research. The patient benefits from being treated by experienced, interested staff who may, on occasion, provide the benefit of a definitive negative opinion, e.g. the ability to say for a patient with sufficient reassurance that the patient does not have IDX. The support staff who run the clinic often provide additional help to patients, who they get to know well over the months or years of follow-up. Patients attending these clinics are likely to be offered first refusal of new drugs introduced for IDX, and seeing two specialists simultaneously will often help to improve management by rationalizing drugs and making sure that investigations deemed important by one specialist (but not as vital to the other!) are not forgotten. The general practitioner benefits because specialist clinics often have shorter waiting lists than general clinics; help or urgent review can be provided swiftly in the clinic with the knowledge that a definitive second opinion for IDX is readily available. The District General Hospital rheumatologist can also benefit, by having access to a rapid further opinion and, if interested, is likely to be asked to provide shared care, enabling them, for example, to observe the effect of drugs that are not widely available.

Acquiring and monitoring a cohort is hard work and requires a major team effort, but in the long run it’s worth it.

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