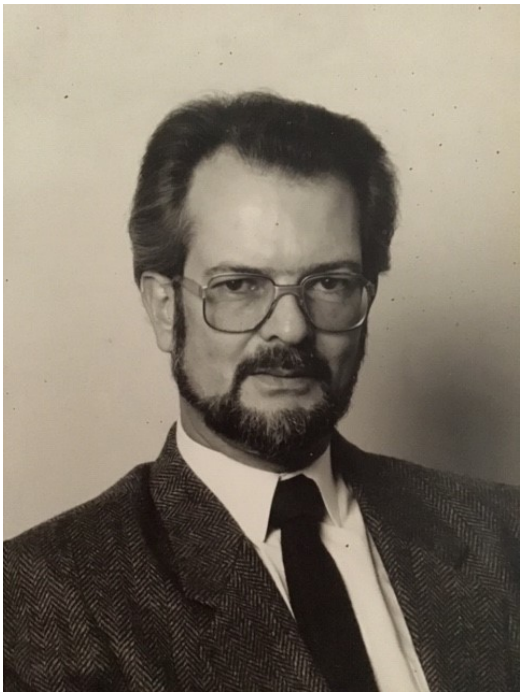
Vernon's Observations

"The first impression that I gained about the study was of open communication…"

Vernon's observations on his participation in the ASCOT study are reproduced with permission from: **Trafford VN; A patient's experience of ASCOT. In: Poulter NR, Sever PS (eds), *Anglo-Scandinavian Cardiac Outcomes Trial*, 1st Edition. Sherborne Gibbs Limited, 2005**.



Professor Vernon N Trafford writes about his experiences of participating in ASCOT

In October, 1998, I was identified by my, then, surgery as having a medical profile that made me eligible for consideration as a member of the ASCOT study. My application was accepted, and since late 1998 I have been a patient participant in this study.

My reason for writing this account is to provide some feedback on six years of my experience. Since personal participation and direct observation are major methods in my own research they have been used to assemble the experiences and impressions that follow. You will appreciate that I did not set out to be an internal researcher of the ASCOT study, but rather came to appreciate the opportunity simply to observe as a volunteer participant and observer! My observations were of course limited solely to the occasions when I attended the clinic, and participating in what transpired at those times.

The first impression that I gained about the study was of open communication that was informative and written in plain English. This was so evident in the initial 'briefing' undated letter that my surgery received and passed to me. It laid out the aims and purposes of the study in simple language and adopted a personal and user-friendly style of writing. The provision of contact names and addresses, followed by the subsection: What happens if something goes wrong? would have appealed to its readers for its professional honesty. The letter also dealt with basic ethical issues of confidentiality and withdrawal in a sensitive way. Thus, it conveyed genuine awareness by the researchers to address issues that prospective participants might have.

My next impressions relate to the administration of clinic visits. When I signed up to the Study I was in full time employment, although I am now retired. Arranging appointments involves balancing the preferred time band for the next visit against my professional commitments. Occasionally it has been necessary for me to reschedule agreed visit dates. This has never

appeared to have been a problem for the clinic nurse taking my phone call. As a consequence of this phone manner, a caring relationship is conveyed that other patients have appreciated and remarked on during informal post-consultation 'tea and toast sessions.'

Although the primary purpose of the Study underpins why patients visit the clinic, another impression is evident in the clinic. Arriving at the ground floor door and buzzing for entry prompts a friendly greeting. This is continued at the reception desk, where if there has been a delay in the appointment schedule, it is always explained ~ with a slight apology as well. This culture of friendly and open relationships towards patients is recognized and valued by those patients. Comments like *'They put you at ease, don't they?'* and *'I don't mind coming here, it's not like a hospital'*, or *'Why can't dentists' surgeries be like this and not be so off-putting?*' are evidence of the potentially calming and reassuring manner of staff in the clinic. Thus, before patients meet with either a nurse or doctor, they may well have become more relaxed than at similar visits to their own surgery. The effect of this upon their subsequent tests is likely to have a positive correlation.

Without exception, the nurses who I have met at the clinic display a very professional interest in me as they check my patient file. This process often becomes a form of reinforcement of two medical strands relating to my own health and to the aims of the Study. As a result, it conveys an understanding of how I fit into the wider strategy of the Study. On those occasions when my medication has been altered, the explanations for changing the treatment have been along two parallel lines ~ control of my hypertension and how that fits into the hypotheses being tested in the Study. Since my veins are deeply set, the taking of blood usually takes longer in my case than with other patients. This frequently becomes a time when nurses or doctors have spoken with me about the Study. This sharing of information about the Study with patients is another indicator of the openness that creates a sense of 'belonging to' rather than just 'knowing about' the Study. Other patients have remarked on *'...feeling a part of...,'* or *'My nurse / doctor told me about ...'* and *'I feel that I know about the ASCOT study...'* As a result of this harmonious atmosphere, patients positively identify with the Study ~ as was illustrated by the Summer Tea event.

The intermediate reports that are published and made available reinforce this sense of belonging. They are, again, written in a most assessable language and provide some feedback to patients. Along with the other documentation on personal health they form a secondary source of knowledge about the Study.

My clinic visits vary from 40 minutes to one and a half hours. I am not aware of having met the same patients, nonetheless I have spoken with many of those who are at the clinic during my own visits. Just being there implies a commonality of purpose and physical condition that we all accept ~ and then recognize in other patients. Frequently, eye contact will prompt a smile and a word or two ~ unlike the social distance that strangers normally project towards others. Volunteered information during these short conversations suggests that other patients *are 'glad to be of some help',* and *'happy that the time is useful',* or 'getting *better treatment than at the surgery'.* It is noticeable that the age, gender and ethnicity of patients do not intrude on impromptu discussions. These self-disclosures are voluntary, and frequently seem to enter quite personal aspects of health that would not normally be shared with strangers. An impression that many

patients have of the clinic is of it being *'an efficient, caring and a happy place'*. It is this climate of friendliness that appears to influence how patients relate to each other in a more friendly manner inside the clinic than outside as strangers.

The conduct of medical examinations cannot be faulted, by me, for its compliance with patient / clinician relationships. This started with the use of Written Consent Forms that detailed the obligations of both parties to the ensuing involvement in the research. It includes regular updating on, assurances about, the Study, plus the disclosure of research outcomes that are in the public domain. Any questions about my health or the Study are always answered in a professional and positive way. Perhaps my special interest in being a patient originates from also being a researcher, but overhearing other conversations between patients and clinic staff ~ while sitting in the reception area or in the 'tea and toast room' ~ confirms that my reaction is similar to those of other patients.

When patients receive a greetings card at Christmas it reinforces their sense of identity with the Study. This action elevates the staff of the clinic from being *'distant nurses and doctors'* to *'people I know and who have remembered me at Christmas time'.* This act really is appreciated.

I did not set out in 1998 to undertake research into the operations of the ASCOT clinic. However, it is apparent that nurses and doctors have jointly created a unique atmosphere and working style at the clinic. The direct effect of this is to have made visiting the clinic and taking part in consultations into an experience to which patients respond positively. Levels of patient anxiety regarding attending and being examined seem to be lower than at medical or dental surgeries. Patient comments concerned with *' lack of trust in the competency of staff'* or *'being hurt by the nurse or doctor'* are not expressions that are voiced or even hinted at. It is the confident and assured body language of patients both before and following their consultations that confirm these two conclusions. The conviction by patients that they receive high quality health care and advice at the clinic endorses the professional culture that has been established.

The inevitable pressures of research within the longitudinal ASCOT project itself are likely to be unfamiliar to the majority of the patients. However, the unhurried and relaxed manner of the clinic belies the quality of the activity that has occurred. Reconciling personal and individual respect for such a diverse research population of patients with the methodological demands of an international research project poses theoretical and practical difficulties. My six years of being a patient has exposed me to how they have been reconciled. I am impressed by the way in which all staff in the clinic have approached and handled that task. In my limited access to 'data' I have neither heard nor seen anything that criticizes the nurses, doctors or physical location of the clinic. I also concur with the above views of patients that I have overheard.

I am very pleased to have been admitted into the ASCOT research study and hope that my observations will provide a patient's view on what has transpired at the clinic over the past six years.