

In 2014 my husband Norman and myself were proposed by the British Heart Foundation to become lay representatives on the above group. I had previously been invited to attend other meetings and consultations, but as they were mostly held in London, we felt the travelling involved was a bit onerous for a day meeting so reluctantly declined. We were therefore very happy to be able to take part in this important review process.

We had unfortunately missed the first two meetings as we were on holiday so it was therefore with a bit trepidation we attended our first meeting. We had of course read all the documents and minutes but it was difficult to go into something which had already started. Although previously I had been a Health Centre Practice Manager and was quite comfortable working alongside medical professionals, it was slightly intimidating to be in a room with Cardiology Professors, Cardiac surgeons & consultants, economists, British Heart Foundation Managers and of course the staff of SIGN. Our concerns turned out to be totally unfounded, as we were made extremely welcome and once the discussions started if we asked any questions the answers were given with clarity and with consideration of our non medical background. As we are there to represent patients with ACS we did feel some explanations had to be given to us, but did not feel we were holding up discussions or the proceedings with our questions.

After general discussions regarding the guidelines the group then broke into smaller groups to review in more detail and discuss the scientific evidence presented for the review of key questions. My husband and myself felt at this point we really could only observe as we had no knowledge or expertise to comment on the decisions the medical professionals were making, but even then they were quick to explain to us why they were making changes to procedures, either through new research, drug availability or new surgical techniques. We both found this part of the process extremely interesting and informative. At this point we still felt we could question decisions as to why any change was better for a patient, and were delighted to be given so much insight and explanations.

The lay representatives had separate meetings to discuss ideas for presenting the updated recommendations to the Provision of information. This section reflects issues likely to concern patients and carers and are matters we felt should be considered when Health Professionals treat and communicate with ACS patients and carers. The Patients representatives also worked together on the new SIGN guideline Patient Information booklet.

Patient representative meetings were more interactive as we all had experiences and views to express. These resulting discussions became very lively at times due to differing opinions but we worked together and felt we had produced a checklist which really reflected what a patient needed and deserved. As well as personal experience I believe as a BHF Heart Matters champion on the forum gave me an insight as to many other patient's needs and concerns. When our part in the review was completed many other steps were still to be taken, with our section of the guidelines and patient leaflet being reviewed and discussed with other groups for their opinions and observations.

I would have to be honest and say that we did not realise the importance or the extent and involvement in this national clinical guideline review process. Overall we found it not only extremely interesting but also gave us confidence that our care is not random, but results from researched and vigorously discussed recommendations for a patient's management.

After all these months being part of this process, we feel that a patient suffering an ACS will benefit by having their journey made easier due to their health care being further researched, reviewed and fully discussed by experienced and dedicated Health Professionals. They will also achieve an improved level of personal communication, advice and the provision of new and revised literature.

We completed our part in this Guideline review a few months ago, in December 2015, and are proud to have been part of it all. We would like to thank the British Heart Foundation for proposing us, all those involved for their consideration and courtesy to us, and also for the help, guidance and encouragement from the SIGN management team. We feel this has been an opportunity for patients voices to be heard.

Helen and Norman Anderson