

I think I have to focus on a couple of EUREKA moments for me during my involvement in SISAQOL-IMI.

Firstly, when I joined Work Package 3, and reading through the review of a huge number of Single Arm Trials (60 plus), being totally surprised at the complete Laissez- Faire attitude which seemed to prevail throughout, with companies and researchers choosing what to test, what to report and what to ignore; including aspects of treatment or PRO results/side-effects I thought vital to patients. It was a real eye opener for me.

I quickly realised the enormity of the SISAQOL task and the absolute need for it to be successfully completed.

I could see the dedication of all the professionals involved in doing this work – and I was a bit overawed by the world class qualifications clearly evident, plus the ability of each to make their point of view known within every subject heading which was being discussed.

The second big moment came during the reviews and the presentations of WP4 results on the means of providing and displaying trial results, both for the professional and for the lay community. Lisa was doing a fantastic job on the stage and fielding comments coming at her from all over the audience. I realised then I've got something important to say in support of these display outputs – HEY I have some pretty decent qualifications myself.

Diagnosed with Prostate cancer, going through horrible hormone therapy, many weeks of radiation therapy only then to face - twelve months later - a diagnosis of Myeloma, an incurable blood cancer. This resulted in more months of chemotherapy, with some serious side effects, then High Dose chemotherapy and a stem cell transplant. Countless daily injections and tablets, revisiting all of life's previous vaccinations and even, during my recovery period, being offered aromatherapy, to calm the mind. Quality of life issues, and overcoming side effects were then, and still are for me today, vital aspects of daily life. These are great qualifications for reviewing some large parts of SISAQOL output, especially PROs. Some of my friends in the patient group probably have even better qualifications.

I should interrupt my wee outburst, to highlight how well this patient group has been guided and managed by our boss and mentor – Silène. We are deeply in debt for her help and guidance. The Consensus Meeting's - Patient Meetings, alone, are just one example of her excellent forums for the subjects discussed and reviewed and commented on. I'm sure the professionals in attendance at those meetings would agree to that.

Going back to my theme. There are aspects of SISAQOL activity, for example the statistics elements, where we are out of our depth, but I do believe we have made the patient viewpoint clearly and strongly in suitable areas.

I would conclude by using my patient status and my recognition of the huge input everyone in SISAQOL is contributing to making this very necessary project a huge success, to say - on behalf of patients everywhere - a very well-deserved Thank You. You will always have my deepest respect and admiration.

I have thoroughly enjoyed every minute of my involvement with SISAQOL.

*David Ness 4/2/25*