

Example Reflection
**“Patient & public interactions in
clinical research via ABPI”**



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Personal Reflection

What?

Patient & public interactions in clinical research via ABPI:

I am an active member of the ABPI Medical Expert Network (MEN). This group is comprised of 18 Pharmaceutical industry Medical Directors and focuses primarily on medical affairs affecting pharma in UK, and each of us volunteer to lead on annual strategic objectives recommended to be aligned with the ABPI Board of Management objectives.

Throughout 2013 I have taken the lead proactively on the objective shaping the ABPI patient engagement strategy, especially patient and public involvement in clinical research. This is so that patients and the public can gain greater understanding of the opportunities to become involved in pharmaceutical sponsored clinical research at all levels from basic bench research to post-marketing & real-world clinical data collection.

I worked closely with a staff member at ABPI to first conduct a survey of UK-based companies to ask what clinical research initiatives and activities they were currently undertaking with patients and/or the public. The two of us then wrote a position paper reporting this and I presented the findings back to both the MEN group and then at an Innovation Board partnership forum in June. This involved composing a presentation slide summary and open discussion with the invited audience of representatives from patient groups, Government, MHRA and ABPI member companies.

I also am an active member of the Patient Organisation Forum of ABPI, representing my views and those of MEN. This meets around four times per year in London at ABPI, and is in its formative stages, sharing information of how the UK pharmaceutical industry conducts clinical research, from early-phase to post-marketing. I have been particularly keen to explain that research doesn't stop once the Marketing Authorisation is gained, and so patients & the public also need to be educated and to be aware of basic health economic and market access issues to medicines.

Following the Innovation Board presentation I fed back the discussion points to MEN, and was subsequently invited by ABPI Scotland to present at an ALLIANCE / ABPI Scotland patient engagement seminar in September.

Why?

I recognise the importance of patient and public engagement with the clinical research agenda of the ABPI. The NHS too has patients as its central focus - "no decision about me without me", and indeed this phrase has been modified by patient groups to "no research about me without me". I am passionate about this subject also because of my clinical training, experience, and personal experiences.

To date the interactions and events have gone well, though we are at an early stage of our interactions with patients and the public. What went less well was the extent of contribution of information on existing patient & public engagement from UK pharmaceutical companies – and I feel that this is most likely due to time commitments and workload of colleagues.

Whilst engaging professionally in this activity I have consciously avoided representing just my own views, and have shared and consulted with others to represent a broader perspective. I have also been responsible not to focus on any one therapeutic area or class of medicines to avoid any perceived commercial bias.

So what?

I have reflected upon this activity because it demonstrates both partnership with patients and maintaining their trust.

I have learned from my initial involvement that I have had as part of the Patient Organisation Forum that patients (and public – especially carers) are on a journey of discovery, some already being very knowledgeable about how clinical research is conducted in pharma, and some with very basic knowledge.

Furthermore I have learned that there appears to be a lack of focus too on UK market access, health economic and political issues, where patients and the public can play a very important role in future decision making. I have used my knowledge and experiences, both professional and personal to aid interaction and information sharing with patient groups. I feel very positive about the direction that the strategy is developing.

What next?

Clearly my previous clinical and research experience has helped with this activity, as I can see the picture from both the clinical and commercial perspectives. I have already accepted to continue my involvement with this ABPI strategy on behalf of MEN, and have been invited to a number of patient group meetings in 2014, e.g. with the UK representatives of the European Patients' Academy on Therapeutic Innovation (EUPATI). I also recognise that this may take up quite some time, and I will be careful to balance this against my other responsibilities.

I plan to host further discussion within my company about possible greater involvement with relevant patient groups and perhaps public engagement. I will discuss this with my colleagues and formulate a position paper in 2014.