ABPI Patient Organisation Forum, 13 September 2013

Does the Code of Practice inhibit or support partnership working between industry and patient organisations?

Background and context

The ABPI Code of Practice for the Pharmaceutical Industry (the Code) prohibits pharmaceutical companies from promoting prescription only medicine to the public. In 2006, a new clause concerning relationships with patient organisations was introduced to the Code. Whilst companies are permitted to work with such groups, their involvement must be made clear, and the requirements for arrangements for meetings are similar to those for health professionals (Clause 23 – Relationships with Patient Organisations). Patient organisations have raised concerns that in practice the Code has become overly restrictive and as a consequence, opportunities for collaborative working are being missed. It had been raised at the ABPI Patient Organisation Forum (POF) that the spirit behind the original intention of the Code, which is to provide a framework within which relationships could operate in a transparent and ethical manner, whilst strongly supported, was being lost in translation when applied at a grass roots level.

A discussion paper was created, based on interviews with patient organisations and industry representatives, to help better understand some of the underlying issues and inform the Forum discussion. Four themes of issues were identified: interpretation, awareness, accessibility and meetings.

Summary of key discussion points

Heather Simmonds, Director, PMCPA, started the meeting with an overview of the ABPI Code, the role of the PMCPA in administering it on behalf of the ABPI and the sections that were relevant to the patient organisations. Heather’s slides can be viewed on the Patient Organisation Forum section of the ABPI website.

Matthew Speers later joined the Forum. Along with Heather, Matthew is leading a strategic review of the Code requested by the ABPI Board of Management to ensure that it remains fit for purpose in a changing world. The review will look at the enhanced role of patient organisations and the need to have clear guidance for interactions and partnerships with industry. The Forum was invited to input into the review, any recommendations from which will be included in a new edition of the Code dated 1 January 2015.

The Forum - addressing the question ‘Does the Code of Practice inhibit or support partnership working between industry and patient organisations?’ - looked at the four themes identified in the preparation and the following comments were noted:
Interpretation

- The group asked about whether there could be more clarity in the various definitions used within the Code.
- Members of the Forum talked about how to interpret the Code with regards to legal contracts. A suggestion was made to have a standard contract available.
- Also considered were the differences in definition between ‘patient organisation’, ‘charity’ and ‘expert patient’, and the implications of these differences when applied to partnership working.
- There was agreement on a lack of understanding/awareness of what each party needs to comply with. For example, patient organisations that are registered charities are regulated by the Charity Commission.

Accessibility

- Patient organisations felt that an industry code imposed on them was difficult to understand.
- The group was not aware of how the Code operates and wondered if there could be a summary of it for charities.
- It was thought by some members of the group that companies can raise more awareness of the existence and understanding of the Code.
- Patient organisations would like training on the Code. (The PMCPA run training courses on the Code; for more information contact the PMCPA).
- Could there be input from patient groups in the drafting of the Code?

Awareness

- Patient groups were not aware that the Code was administered by a separate organisation.
- Patient groups were not aware that they could go to the PMCPA for advice and queries about the Code.
- PMCPA remarked they rarely receive complaints from patient organisations. It was agreed this was symptomatic of a lack of awareness and understanding of the Code and the role of the PMCPA.

Meetings

- Patient groups were informed that meetings need internal approval in pharmaceutical companies.
- It was considered whether there should be consistency in how industry and patient organisations run meetings. Since many of these meetings are informal, it was thought that another level of bureaucracy was probably inappropriate and unnecessary.
- Does there need to be consistency with regards to how industry and patient groups set up a meeting? A list of do's and don'ts would be useful.
- Could there be further guidance for industry about attending conferences that patient organisations also attend?

Conclusion and next steps

The group found the discussion useful in helping to identify and understand constraints caused by the Code, faced by companies and patient groups when trying to work together. There was better understanding of the issues and initial suggestions to how to improve communication and awareness of the code for companies and patient groups.

Heather thanked the Forum for their comments and suggestions, offering to come back soon to the group to pick up the points raised and to try and find solutions. Heather also said that she would seek to engage the Forum in the strategic review of the Code that is currently underway for the ABPI Board.

Environmental Update

An Environmental update was given by Paul Catchpole, ABPI Director of Value & Access. Paul spoke about Value-based pricing (VBP) and biosimilars. The Forum was then joined by Yasemin Dill, Research Officer at the International Alliance of Patients Organisations (IAPO) who gave a presentation on biosimilars.