

SMC Patient and Public Involvement Group (PAPIG)

The number of submissions from disease specific patient interest groups continues to show a pleasing increase. In 2006 we received 35 submissions from 24 organisations:

- Action on Pain
- Asthma UK
- Beating Bowel Cancer
- Breast Cancer Care
- Breakthrough Breast Cancer
- British Cardiac Patients Association
- British Lung Foundation
- Cancer BacUp
- Diabetes UK
- Ekbom Support Group
- HIV Scotland
- International Myeloma Foundation
- Migraine Action Association
- Mouth Cancer Foundation
- Multiple Sclerosis Society
- National Kidney Federation
- National Osteoporosis Society
- National Rheumatoid Arthritis Society
- Neuropathy Trust
- Parkinsons Disease Society
- Pain Concern
- Pain Association Scotland
- Roy Castle Lung Cancer Foundation
- UK Association Narcoleptics

This is an improvement on previous years (2003 – 9 submissions; 2004 – 17 submissions; 2005 – 21 submissions). In total, SMC had received 82 submissions from disease specific patient interest groups by the end of 2006.

SMC continues to ensure that each member of the committee receives a full copy of any patient interest group submission and a verbal summary of the most salient points of each submission is presented by one of the three public partners during the course of the meeting. Input both from SMC's public partners and from disease specific patient interest groups continues to keep the focus of all members of SMC on the patient perspective. If the medicine to which a patient interest group submission relates is not recommended by SMC, and the pharmaceutical company make a resubmission, the patient interest group is now notified of this and given the opportunity to provide material in support of their original submission.

We continue to raise awareness of SMC and its public involvement opportunities and during 2006 PAPIG began sending out 'letters of encouragement' to disease specific patient interest groups who have (i) not to date made a submission; and (ii) might wish to do so based on the fact that one or more of the medicines due for assessment in the next three months may be of interest to them. Our rationale for this is that such groups may not know of SMC and its public involvement opportunity. In addition, we will be introducing a system whereby patient interest groups can subscribe to SMC's monthly distribution circulation list and this will enable them to more easily identify new medicines which may be of interest to them as they are placed on SMC's work schedule.

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Continuing to spread the word about SMC to the voluntary health sector, we have placed an article in Voluntary Health Scotland Newsletter and provided an A4 information sheet for distribution to all patient interest groups to supplement existing materials and to enable them to provide their membership, via website or newsletter, with this information.

We have provided input to an Eli Lilly sponsored patient interest group workshop, facilitating a session entitled 'What makes a good patient interest group submission to SMC'

Considerable time and effort has gone into the development of a dedicated, jargon-free section for public involvement on SMC's revised website. The public involvement section, which is due to become available early 2007, will have four areas: namely, (i) Information about SMC; (ii) Information about PAPIG; (iii) How to Make Your Voice Heard – information for disease specific patient interest groups; and (iv) Individual Feedback – an area for individuals to provide individual testimony to SMC. This latter section is a new public involvement opportunity enabling individual medicine users and their carers who are not aligned to a disease specific patient interest group, or do not wish to provide their testimony via this route, to respond to specific questions about their experiences with currently available medicines together with their needs and preferences in relation to new medicines targeted at their specific health problems. PAPIG will use this input to help inform their discussions at SMC. This new opportunity will be reviewed after a year.

SMC has continued to offer representatives from disease specific patient interest groups the opportunity to attend as observers. This opportunity has now been extended to include groups that have not to date made a submission. During 2006, observers from Asthma UK Scotland and Depression Alliance Scotland attended and a representative from Epilepsy Scotland was unable to attend on the day. Mr Richard Norris, Director of the Scottish Health Council also attended as observer.

More pharmaceutical companies are now completing the Summary Information for Patient Interest Groups document in order to provide these groups with information over-and-above that contained in the publicly available Summary Product Information (SPC).

As part of the SMC Evaluation Project, work was commissioned to evaluate the effectiveness of SMC's public involvement strategy. This report will be available during the early part of 2007.

Wendy Nganasurian
on behalf of PAPIG

Membership of PAPIG:

- Mrs Wendy Nganasurian Public Partner, (Chair)
- Mrs Barbara Black Public Partner
- Mr Jim Eadie ABPI Scotland, SMC Member (from April 2006)
- Mrs Moira Howie Eli Lilly, SMC Member (to March 2006)
- Ms Angela Munday SMC Member
- Ms Helen Tyrrell Voluntary Health Scotland, Public Partner (to December 2006)
- Mr Mike Wallace ABPI, SMC Member