At the heart of any collaboration between the pharmaceutical industry and advocacy groups lie the interests of the public, the patient, and service user. More than ever, over the last two years this collaboration has become a much debated topic. For the first time, the 2006 ABPI Code revisions included a clause on relationships with patient organisations. A 2007 British Medical Journal (BMJ) opinion poll has heavily criticised the industry for jeopardising the independence of advocacy groups through its provision of support. But both advocacy groups and the industry reap significant benefits from a true partnership, communicating a common voice on health issues to key decision makers. So how should we set about improving working practice between the two sectors?

A practical guide by Janis Troup
1. KNOW THE WORLD YOU’RE IN
The common term advocacy group (AG) is used here to encompass patient groups, charities, voluntary organisations, professional groups, non-government organisations (NGOs) and other ‘third sector’ organisations.

Over 168,000 charities are registered in the UK and well over 18,000 (more than one in 10) of these have a definitive health remit. Whether as a registered charity or not, within some areas of health there is already a plethora of organisations all competing for support and publicity to further their causes.

Some will be focused on communicating with lay audiences, some with healthcare professionals, some with policymakers, some with a permutation of different audiences. Some will be large groups working in a similar manner to commercial companies, while some will be intentionally small or still in their infancy.

Within the AGs, chief executive officers (CEOs) and directors will have different backdrops. Some groups will be led by healthcare professionals (possibly in their spare time) others by permanent, but often part-time and/or voluntary staff. An appreciation from the outset of how an AG operates will be critical to building the foundations of a longstanding relationship.

2. IDENTIFY APPROPRIATE PARTNERSHIPS
The most appropriate partner or partners will only become apparent once you’ve reviewed the environment you are in and done some groundwork. Be confident and comfortable in the true purpose of developing AG relationships. The sentiment of, “I need some product endorsement – and quickly”, is just not acceptable and will not establish the foundation of the trust required to build an effective partnership.

No group in its right mind will act as your ‘promoter’ and nor should they. They must protect their own integrity in working with any commercial organisation.

Consider the context of the bigger picture in terms of your professional relations, communications and education programmes at hand. Be familiar with different AG objectives and aware of existing projects and programmes that different groups may be pioneering. Look at your messages and identify common ground with different organisations. There is never any harm in proposing and discussing new strategies and directions for AGs, but don’t try to change their plans merely to support your own – it won’t get your relationship together off on the right foot.

3. RIGHT FOOT FIRST
Given the ongoing degree of negative publicity concerning relationships between industry and advocacy groups, it is little wonder that some organisations are at best wary, or at worst highly cynical about working with the industry.

The fundamental step will be to establish from within your organisation whether any relationships with particular groups already exist. If they do, then take relevant advice on the best approach for initial contacts, ie, who?, how?, when? Like any opinion leader programme, consistency of contact is ideal.

Larger AGs that have significant experience of partnerships will often have a dedicated member of staff (or department) assigned to managing industry-supported programmes or projects. With smaller AGs, or those still in their infancy, the director or CEO will likely be your first point of call.

In the early stages of the relationship an initial face-to-face meeting is critical. Be prepared to discuss your corporate mission, followed by clear and transparent objectives relating to your specific programme objectives. Discuss how your company operates in terms of AG relationships and begin to understand or re-confirm how the group itself likes to work. Throughout all communications try to avoid unnecessary ‘corporate speak’ – it can be confusing and open to misinterpretation.

Mutual recognition and respect of each other’s objectives and goals is the critical primary step, before even engaging in discussions on specific support for project or programme ideas.

Irrespective of size, all advocacy groups will have direct experience of, or a view about, working with the industry.

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4. RESPECT EACH OTHER’S RULES
Dependent upon the nature of the AG, some will be more familiar with the ABPI and its Code of Practice than others, and the group’s level of understanding and appreciation of the ABPI will need to be established early on in your contact with them.

The 2006 revisions to the ABPI Code approve the development of working relationships with advocacy groups, stating that industry involvement must be transparent and clear. Guidance, for example, on arrangements for meetings supported by the industry is the same as that for healthcare professionals as part of any other communications programme.

Pharmaceutical companies must make publicly available the list of all patient organisations ie, any AGs, to which they provide funding. This can be by way of information on the company’s website or through its annual report. A contractual agreement must be in place between any AG and company that clearly states the terms of the relationship and the level of funding by specific activity. ‘Core funding’, a term previously used to denote a ‘donation’ to a charity, is a thing of the past. Declarations of funding must relate to ‘an educational grant’ for a specific project.

By the same token, AGs are advised to abide by their rules, not least to protect their integrity but also to guard against bad press.

New draft guidelines from the Association of Medical Research Charities (AMRC) stress the need for charities to be more open and transparent about collaboration with the pharmaceutical industry. The AMRC is supportive of such collaboration as an essential factor for the development and availability of new treatments. The draft guidelines, An Essential Partnership: Principles and Guidelines for Working with Industry, offer AGs guidance on working with the industry, focusing on clarity of expectations and awareness of potential pitfalls. The aim is to achieve improved consistency of approach.

Comprehensive guidance for AGs is also available from the Charity Commission and the National Council for Voluntary Organisations. Again, guidance is consistent with the ethos and working practice of the ABPI.

Promotion of prescription-only medicines remains a hot topic of debate. The ABPI revised Code continues to prohibit such activity. Yet, definitions of information that can be provided to the public have been updated to give improved guidance and clarify how a company may respond to patients’ needs for reference information on medicines. Whereas an AG may have a voice on issues concerning a product or be more than prepared to provide proactive information on a particular treatment to the public, it will undoubtedly guard against
any activity that may be seen as product promotion – whether this is with or without industry funding.

5. AGREE PROGRAMMES OF COLLABORATION
So, once the basic principles are established and all parties are comfortable with working practices, the projects and potential programmes can be discussed and agreed in detail, and then a contract drawn up.

It is not uncommon for an established AG to have a standard year-on-year programme of communications, education or research activities that invite corporate sponsorship. The cards-on-the-table approach should allow the AG to present its ‘shopping list’ to you and likewise for you to present yours to them.

In the same way that company-led healthcare communications work most effectively as an integrated programme, ideally the same approach should be adopted in working with AGs. Appraise each other’s ‘shopping lists’, but review how individual projects, be it a leaflet, newsletter, website, guidance publication or meeting, can become part of a comprehensive programme to positively change behaviour or raise awareness with the relevant audience.

Whereas effective education and communication with the target audience is the priority, let’s make no mistake that the benefit to both parties is increased exposure. The result should be a ‘win, win, win’ for all – patient, AG and industry.

6. THINK MORE BROADLY THAN THE BANK TRANSFER
If the industry is to combat the negative views around collaboration with AGs, it needs to think more broadly than the cheque book or bank transfer. Yes, there are always going to be activities whereby the AG will wish to have funding in its pocket, for example to produce new publications or revise the current website, but the industry can also offer so much more.

Think about the small AGs, or those in their infancy, that can be supported with knowledge and experience from an established pharmaceutical company. Often these small groups may be created by healthcare professionals, who although passionate about the cause will freely admit to their lack of experience in running a business, which is what it’s really all about. Small and larger organisations will always appreciate offers of skills’ training; perhaps in business plan development, management skills, IT support or just regular, informal chats for ideas about how to operate or grow the group. Whether you personally have those skills to offer or not, you are likely to be able to establish who within your organisation, or which agencies, could offer such a vital service.

7. LOBBY WITH INTEGRITY
To a large degree, bad press surrounding AG and industry relationships has probably been fuelled by the two sectors joining forces to argue preliminary or final appraisal determinations issued by the National Institute for Health and Clinical Excellence (NICE). This has presented an opportunity for the critics to accuse the industry of using AGs as its mouthpiece to increase its influence on decisions that have not gone their way.

In May 2007, Professor Sir Michael Rawlins, chair of NICE commented that charities were in danger of becoming “beholden” to the pharmaceutical industry and should be cautious over pharmaceutical funding.
Yet, who can point the finger at two organisations fighting a common cause on behalf of patients’ rights? The principle is not wrong. That is, assuming both parties are comfortable with the extent of positive and, at times, less positive media attention that such activity can create.

The level and exact nature of any collaboration between AGs and the industry concerning lobbying activities will vary. Often, the most appropriate approach is for both parties to establish a two-way communications programme so that they are effectively and confidentially appraised of their positions. This allows for consistency of message where those positions are concordant and for the AG to be knowledgeable on relevant clinical data and educational activities concerning a particular product or technology.

The AG should never feel under any obligation to fight the ‘product/technology’ cause in the public arena. AGs may have a policy whereby media or political statements are solely concerned with patients’ rights, and refer interested parties to the manufacturer for treatment-specific comment.

Given events so far in 2007 concerning NICE, there is little doubt that strength of voice, whether organised collaboratively or independently, is influencing final decision-making concerning the availability of new and more established treatments on the NHS.

8. EVALUATE ON ALL SIDES
Our marketing environment is heavily focused on demonstration of achievement. The success of collaboration with one or more AGs in a specific field will demand internal assessment, but also the AG should be encouraged to be open with its views on the success of projects and programmes. Helping the AG to illustrate to its audiences or patients the level of impact a particular initiative has had will be critical in building up its support with its community.

Discuss and agree at the outset of a programme the most appropriate metrics. Be open about the critical success factors that you will need to meet. This will help in allowing the partnership to develop over years, rather than be diminished to the level of a ‘one-off’.

9. A LASTING RELATIONSHIP
There will be times when you wish to work with an AG on a finite project. If so, ensure clarity on this point from the start. Ideally, in the interests of your company, the aim should be more about developing a longstanding relationship with the AG. Careful consideration around Points 1-8 should ensure that this is more than feasible, but timing will be of the essence.

Ongoing communication with the AG will be extremely important during your company planning cycles. Keep AGs appraised of, and familiar with, operational plan development. Ensure proposals accepted internally aren’t just sprung on the AG immediately prior to your deadlines for implementation. AGs, large or small, will usually have formalised planning cycles. Limited and sporadic communication with AGs may mean that you miss the boat on a significant opportunity for collaboration.

10. DEFEND BEST PRACTICE AT ALL COST
Successful collaboration between the pharmaceutical industry and AGs will centre on mutual recognition and clarity of the benefits to each party. This in turn leads to working according to best practice guidelines and drawing on the experience of others. Communication to the outside world about effective working relationships is essential to beat the critics.

There’s still a battle to be won. The 2007 BMJ opinion poll, following its editorial debate in May, saw only 16 per cent of 230 respondents agree that patient groups should accept money from the pharmaceutical industry. The 84 per cent against based their views most commonly on the fact that vulnerable groups are psychologically obliged to ‘return the favour’ and as a result the quality and content of information is influenced in support of the industry holding the purse strings.

But surely, AGs have guidance and rules to protect them in ‘doing the right thing’. After all, funding has to come from somewhere. As long as those patients and other audiences that AGs are aiming to reach respect and understand clearly their working relationships with sponsors, then they should welcome the support that the pharmaceutical industry can and does provide.

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**Communication to the outside world about effective working relationships is essential to beat the critics and right bad press**

**Always the right angle**

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**A practical guide by Janis Troup**

10 ways to improve your collaboration with advocacy groups