

Patient collaboration uncut!

Do's and Don'ts of patient and industry collaborations

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Here are some tips from industry stakeholders* who have been involved in successful patient collaborations, to help you navigate your next patient partnership.

Do



Communicate clearly and widely within your organisation about 'best practices' for working with patients and patient organisations. For example:

- Patient review of drafted patient materials
- Early involvement of patients in clinical trials
- Allowing a patient to help plan, manage and co-host an industry event for patients



Pursue collaborations in which the industry partner is genuinely interested in the added value patient partners can bring to the table



Select the right patient for each project/task – consider their knowledge, business skills and fit for the task in hand



Consult the ABPI Sourcebook and other useful resources listed at the end of this document for help with how to find your way through compliance and ethics challenges



Ensure there's transparency throughout the partnership, as well as clearly defined roles and agreed evaluation criteria

Do



Consider ways to make engagement easier for patients, such as allowing extended time for travel and inviting carers to assist them at events



Consider options if the patient is unable to fulfil their commitments due to their illness or treatment



Reimburse patients fairly for their time and services



Contact the ABPI with suggestions on what more is needed in the Sourcebook or future updates of the Code – some suggestions at the meeting included more guidance for the role of carers in industry collaborations



Measure the impact of patient collaborations on employees

“Employee job satisfaction increased among Norgine employees once the company adopted a patient-centric mindset throughout the company”



Engage people throughout the company in patient-focussed initiatives. Patient collaborations work best if a patient-focussed mindset is adopted at every level of the company



Communicate with patients. Find out why they refuse payment for their services. Ask them what logistical arrangements would make it easy for them to work with you. Ask for their feedback on how collaborations could work better



Remember – there’s growing evidence that patients and charities want to work with industry to ensure they have a say in developing the treatments that have such a great impact on their lives

Don't



Collaborate with patients as a 'token' gesture of inclusion. There must be genuine interest in the value patient involvement can add to industry initiatives



Regard 'patients' as a homogeneous group of people



Forget that working with individual patients is vastly different to working with a patient organisation



Assume that paying patients for their time and services is a breach of compliance or ethics



Use fear of compliance as a scapegoat for avoiding patient collaborations



Don't use complicated jargon, especially in key documents such as contracts



Don't forget carers as part of the collaboration, they often have valuable insights and a different yet relevant perspective on needs

Don't



Don't be shy to reach out to others within the industry to seek advice



Don't assume that a patient knows and understand everything about our industry – take the time to explain process and regulatory



Don't be put off – there will be challenges to overcome but the outcome will be worth the persistence



Resources recommended by the speaker panel

- Association of the British Pharmaceutical Industry (ABPI) [Sourcebook](#)
- Boehringer Ingelheim: [What are lay summaries?](#) Making clinical study results accessible
- Boehringer Ingelheim: [More than scleroderma](#)
- European Federation of Pharmaceutical Industries and Associations ([EFPIA](#))
- European Patient's Academy ([EUPATI](#))
- [EURORDIS](#) Charter for Collaboration in Clinical Research in Rare Diseases
- Patient Focussed Medicines Development (PFMD) [tools](#)
- [Pharmaforum: Fair Market value for patients](#) by Guy Yeoman and Trishna Bharadia
- St Emlyn's [blog](#)
- [WEGO](#) Health network
- [Patient Engagement for the Life Sciences](#) by Guy Yeoman & Mitchell Silva

*Faculty included:

- Jill Percy – Director, ABPI Code Engagement
- Dr Liz Clark – VP Medical Affairs, Norgine
- Trishna Bharadia – Health Advocate & Patient Engagement Consultant
- Dr Lucy Major – Senior Patient Involvement Manager, Cancer Research UK
- Claire Myerson – Cancer Insights Panel Member, Cancer Research UK
- Annie Gilbert – Global Patient Advocacy Relations Manager, Boehringer Ingelheim International GmbH
- Dr Juhi Tandon – Clinical Director, Cognitant
- Caroline Benson – Co-Founder of Cuttsy+Cuttsy and PM Society PEIG Lead

If you would like to find out more, please go to:
<https://pmsociety.org.uk/category/patient-engagement>