

How patients supply more than a voice in Accelerating Medical Product development

Dr. Alastair Benbow
Chief Executive The Age of the Brain

A campaign to make us change the way we all think about our most vital asset-our brains

- Patient 'need' should be a rallying point for stakeholders in collaborations-more than cure!
- How do patient groups work together to maximise impact?
- How can patients directly contribute to the development of new clinical outcome measures such as patient-reported outcomes?
- What are the benefits of fostering collaboration between the US and the EU?

Patient need should be the rallying point for stakeholders in collaborations-as defined by patients or their representatives

- For years product development driven by ‘unmet medical need’ and others make decision on behalf of patients
- Patients should be involved in
 - Input to key development time points
 - Helping define outcome measures and value to them and society
 - Participate in the accumulation of real world evidence to support the value proposition
 - Help refine further evidence need
 - Contribute to broader service provision needs beyond a product
- Be central to a new ‘Ecosystem’- dynamic, aware of societal trends, using digital tools, real world big data, less geographic silos

How do patient groups work together to maximise impact?

Perceptions

- Patient groups are fragmented, small in size and impact, poorly understand drug development and its time frames, poorly funded
- Do they know what they want, how, where and when to contribute? Think too small and are easily influenced by big, bad pharma'

Reality

- Mostly true, geographic differences, less global unity, more politics and minimal impact on development

Give them a clear purpose

Build expertise, not in individuals but groups, share knowledge, link across geographies, create common standards, focus on patient need early

Clear rules of engagement, define common targets, develop competencies, create alliances in therapy areas, in individual diseases

How can patients directly contribute to the development of new clinical outcome measures such as patient-reported outcomes?

- Increasing interest in patient-reported outcomes and being widely used in measuring e.g. operative interventions but less well developed for new products
- A company by company approach unlikely to work, need joined up thinking by all stakeholders, patient, academia, industry, regulator and payor to establish standards, best practice etc.
- Patients must be at the heart of this
- Probably best led by academia and patient groups
- More than just generic quality of life

What are the benefits of fostering collaboration between the US and the EU?

- Global world, global development
- Science, academia and particularly, patient groups all currently stronger in EU and US than anywhere else
- Regulators in EU and US open to more, but controlled participation
- Politically the voice of the patient and their needs more important than ever before – less filtered, less focussed on distress, more practical
- Ultimately we will all be patients - it is critical that we to get this right