

Afternoon discussion groups

Topic: Can the research drivers and interest of patients, industry and the NHS be reconciled?

1. Drivers for research identified by the discussion groups:

Several of the groups brainstormed the drivers from the different perspectives outlined in the discussion question.

One group felt that it was important to understand these research drivers at the outset, and not make assumptions about or fall into simplistic thinking on the issue. Do we explicitly discuss these drivers enough in public forums, and what are the best ways for understanding them?

RESEARCH DRIVERS

<p>Industry Market Share Value/profit for shareholders Long term diseases 'Magic' drug License Innovation – Easy wins Prestige International stage Competitiveness Goodwill? Targeting major disease areas = market share More obscure areas = niche markets Saving lives? Responsive to market conditions</p>	<p>Government ? Majority interest NICE – NHS – Governance Value for money Improving human 'satisfaction' Health/treatments/guidelines Standardisation of care Clinician autonomy Is the government acting as a detrimental impact on research drivers Political impact/decision making on research drivers</p>
<p>Patient Quality of life Cure/care - best possible treatment/care Choice Participation 'Missing' rare conditions Complementary therapies Create a better future For parents/carers involvement in research can be a way of coping and a "vent" for emotions Creating a collective voice What it means for me – for my family in genetic disease Declining trust in medical expertise Knowledge and control Redressing the balance – perceived to be over-managed by medicine</p>	<p>NHS and the wider research community Making decisions about where the money goes Sharing what we already know Improving existing treatments - implementation NICE guidance – Clinical practice Public Health Policy Preventing ill health Rationing resources – best use of what we know Economic benefit to UK Spotting the opportunity (existing cohort/people) Changing demographics Increasingly difficult for clinicians in research within the NHS Improving your CV and publication rate</p>

Reconciliation of drivers – do different stakeholders believe patient input is important, and how do they demonstrate this?

2. Themes from the discussion group feedback

2.1 Developing the evidence base for patient input to the research process

- Research into how to make the patient input process better, does this interest research charities, and why do they not fund more work in this area?
- How to get researchers to explore, invest and educate to understand what it is like to be a “subject” of research.
- Members of the public are not involved in monitoring the implementation of research findings, and should be.

2.2 Process for patient and public involvement in research

- There should be a database of those willing to become involved in public dialogue.
- Why do people/organisations and the drug industry not want patients on drug safety boards?
- How to select and train lay consultants/advisors
- Channels needed for patients to give views
- There is insufficient funding for patient and public involvement (PPI)
- How to ensure appropriate and prompt reimbursement to consumer?
- There is an education gap: *how* do people become involved? Information is needed.
- Patients *are* the public: these groups are talked about as if they are entirely separate categories of people
- There are numerous practical difficulties for patients and the public getting involved in any discussions about research.
- Public involvement / consultation can be at several levels of complexity.
- How unbiased and independent are patient organisations? Note the level of pharmaceutical industry funding of many patient organisations.

2.3 The process of funding decisions

- Training mechanisms to get greater consistency and quality on funding decisions
- Why not make results of the research widely available as a condition of research funding?
- Information about balance of benefit and harm caused by treatments is needed: industry is not interested in (and may suppress) measuring and/or reporting harmful effects
- There is a need for a formal process (with funding) to enable people to work together.
- Easier publication and removal of perverse incentive of Research Assessment Exercise
- Checks and balances – positive influence of dissonance

2.4 Views on the research agenda and priorities

- What about 60% of patient questions that are about alternative/complementary treatments?
- Only positive outcomes of treatment trials are reported / published: negative data tend to be suppressed
- Some treatments, commonly used elsewhere, are neither available nor researched in the UK, e.g. speliotherapy (eastern Europe and Russia)
- Patients and the public want basic research as well as research about treatments

- There is a mismatch between NHS research priorities and what people want (or too much emphasis in some areas, with the effect of relative neglect of others)
- Freedom of data: (i) patients should be able to insist that data about themselves are stored and made available for future research
(ii) public access to all trial data
(iii) full access to data on adverse effects of treatments
- There is a need for more qualitative research and/or a variety of methods including qualitative approaches e.g. National Cancer Research Institute model

3. Key questions that the discussion groups put to the panel

1. What are the best ways for understanding the research drivers?
2. The impact of political decision making on research drivers
3. The importance of checks and balances in relation to research drivers – positive use of disagreement
4. The research community needs new models for collaboration/dialogue
5. We all start with altruism, but do we measure it differently?
6. Who needs to drive the agenda now?
7. Get industry more committed to patient involvement
8. Hypothecated tax on drugs – towards patient involvement
9. Adequate compensation
10. AMRC and relevant R & D organisations need a funded education initiative to get principal investigators (in clinical trials) to appreciate need for, and know how to involve patients
11. Patients doing it themselves - challenge the role of expertise - this will ensure patients drivers satisfied
12. Why isn't research funded in a community context e.g. community arts funding
13. Equipment industry – how to keep them involved, and what are their drivers?
14. Uncertainty on how PPI can be used efficiently and effectively at all levels
15. e.g. Via Research Assessment Exercise
16. Making industry more effective, take it internationally
17. Mixed economy, seeking consensus, keeping everyday clinicians involved including OT/therapists
18. A need for public education and information about involvement in research
19. Adequate and appropriate funding is needed for PPI
20. Freedom of data sharing, trials, adverse effects, industry data
21. Mismatch between the research that is funded, and what public patients want
22. How can NHS/Industry ensure adequate cover for less common conditions?
23. If PPI effective within 'NICE', how does that feed into industry?