

Patient-centred innovation to improve healthcare
Becky Purvis • November 2013

Patient-centred innovation to improve healthcare

What do we need to do to drive innovation in healthcare in the UK?

Patient-centred innovation and policy making in the health sector

How can innovation and policy making work together to improve health outcomes in a practical way?

Patient-centred innovation to improve healthcare

AMRC is a membership organisation of leading medical and health research charities funding research in the UK.

Working with our members, we aim to support the sector's effectiveness and advance medical research by developing best practice, improving public dialogue about research and science, and influencing government to ensure the best research can go ahead and be translated into new treatments.

Patient-centred innovation to improve healthcare

Medical research charities exist because the public choose to donate their money to support research to develop new treatments and cures.

In 2012, AMRC members invested over £1.2 billion into health research in the UK.

These charities are often hubs of expertise – bringing together patients, researchers, clinicians and carers

Patient-centred innovation to improve healthcare

Patient-centred innovation and policy making in the health sector

Dementia Priority Setting Partnership

Involving patients Alzheimer's Society led a Dementia Priority Setting Partnership with the James Lind Alliance to identify some of the priorities for dementia research.

Getting patients

Taking patients Through extensive engagement with people with dementia and their carers, health and social care practitioners, and organisations that represent these groups, over 4,000 questions on the prevention, diagnosis, treatment and care of dementia have been whittled down to a top 10 list.

Alzheimer's Society's Research programme remains committed to funding high quality research into the cause, cure, care and prevention of dementia. We undertook this exercise to focus and stimulate research to improve the quality of life of people living with dementia, and we are currently considering how we and other funders may take these questions forward.

Patient-centred innovation to improve healthcare

Patient-centred innovation and policy making in the health sector

Arthritis Research UK USER committee
Arthritis Research UK's USER committee is made up of healthcare professionals who are not research-active, and informed lay members. It looks at the practicality of doing research and questions the assumptions of researchers, as part of deciding which research should be funded. Patients have an expert knowledge of their condition. In one case, a patient reviewer was the only person to spot that a researcher had assumed that people would only have one artificial joint – many people with arthritis have more than one replacement joint, and so the suggested blood tests would provide unclear results.

Making research travel easier for older Parkinson's sufferers
Older people with mobility and cognitive problems face significant logistic and cost barriers to taking part in research. A recent trial funded by Parkinson's UK participants are helped and a friendly who was aided at would rush hour. back from said they give

Patient-centred innovation to improve healthcare 

People with serious conditions consider risks and benefits differently
 A group of patients with serious and/or rare conditions and family members of someone with a serious and/or rare condition explored the risks and benefits of hypothetical case studies and heard from a number of expert and advocate witnesses about how the regulatory system currently works, its strengths, and its potential weaknesses. The findings demonstrated that people with serious conditions are willing to take great risks for the potential cure or improvement of their condition.

At the end of the study the group made a number of recommendations:

- Regulators should include psychosocial factors in their decision making.
- Regulators should be more permissive for those treatments for people with rare and/or serious conditions.
- Patients should be more involved in all stages of the process, from setting the research agenda, to post-marketing authorisation decisions.
- Patients should be better supported to make their own decisions.

Patient-centred innovation to improve healthcare 



Patient-centred innovation to improve healthcare 

Pat sec "One of PenCLAHRC's successes has been to engage patients and the public; almost 15% of projects have been initiated by patients and carers who have also been involved throughout the projects and have attended meetings and training courses. One patient described all these possibilities as an *'Aladdin's Cave'* of opportunity.

NIH and Three commitments underpinned this work:

- funding public and patient involvement adequately
- building on what was already there
- and getting patients to help develop the partnership.

What also contributed was an on-going evaluation to assess levels and types of engagement which demonstrated that initial concerns about whether patients would make a valuable contribution have been completely overturned. There was recognition among academics and NHS staff that their CLAHRC has helped patients and the public become better informed about research and its benefits and has produced more patient-focused research."

Patient-centred innovation to improve healthcare 

How can innovation and policy making work together to improve health outcomes in a practical way?

How can we take these pockets of good practice and make them common practice?

Patient-centred innovation to improve healthcare 

How can innovation and policy making work together to improve health outcomes in a practical way?

Health & Social Care Act 2012
 Duty on the Secretary of State for Health, NHS Commissioning Board (NHS England) and Clinical Commissioning Groups to "promote the use of research and research evidence"

What does this look like?

Patient-centred innovation to improve healthcare 

How can innovation and policy making work together to improve health outcomes in a practical way?



Our vision for research in the NHS

Patient-centred innovation to improve healthcare 

How can innovation and policy making work together to improve health outcomes in a practical way?

- 91% of all those surveyed identified barriers they had experienced to taking part in research including lack of time (62%), funding (30%), practical support (27%) and difficulties navigating regulation (24%)
- 72% of people tell us they want to be offered opportunities to be involved in clinical trials of new treatments
- 53% of healthcare professionals told us they are asked by their patients about research opportunities less than once a year
- Near universal agreement that the NHS should support research into treatments for patients
- But only 22% of GPs felt it was very important for them to be involved in research

Patient-centred innovation to improve healthcare 

How can innovation and policy making work together to improve health outcomes in a practical way?

Every patient is offered opportunities to be involved in research
 All NHS staff see the importance of research
 The NHS conducts high-quality research and adopts new treatments

Patient-centred innovation to improve healthcare 

How can innovation and policy making work together to improve health outcomes in a practical way?

- Develop a quality mark to signify where patients have been involved in the design of a study
- Provide information about taking part in research and opportunities to self-refer
- Encourage NHS commissioners to implement our research charter to ensure their actions are informed by evidence
- Include research knowledge and use of evidence in basic training for all NHS staff
- Require clinicians to consider every patient's suitability to take part in research as part of their care
- Ringfence time for research in NHS contracts
- Clarify who pays for research costs
- Public research results and make data accessible to those who need them

Patient-centred innovation to improve healthcare 

What do we need to do to drive innovation in healthcare in the UK?


 ASSOCIATION OF MEDICAL RESEARCH CHARITIES

b.purvis@amrc.org.uk