

## Patient and Public Involvement in Strategic Development of Health Research Capability. Some thoughts based on personal experience.

### **The Context.**

I am one of three PPI members on the E-Health Records Research Board (EHRRB) and the External Reference Group of the Research Capability Programme. (RCP). I attend meetings of the EHRRB Board and RCP External Reference Group provide written comments on discussion papers, contribute to additional workshop activities, make presentations at national workshops (as part of the communication strategy) and have submitted evidence for the Gateway Review process.

### **The E-health Records Research Board. (EHRRB)**

- The EHRRB is one of three partnerships under the oversight of the Office for Strategic Coordination of Health Research (OSCHR) and the OSCHR Board.

The other two are: - the Translational Medicine Board and the Public Health Research Board. Both have PPI representation.

- The role of the OSCHR partners is to take forward the recommendations of the Cooksey Review of Health Funding (2006) intended to facilitate more efficient translation of health research into health and economic benefits in the UK through better coordination of health research and more coherent funding arrangements to support translation.
- The OSCHR E-Health Records Research Board focuses exclusively on that aspect of the E-health agenda that relates to the use of electronic patient record data for research.
- The overall aim of EHRRB is to maintain strategic oversight of the E-health records research agenda in the UK and ensure that there is connectivity between a range of different funding initiatives across the UK. The EHRRB provides strategic oversight of E-Health Records research in the UK and acts as the External Reference Group for the NHS connecting for Health Research Capability Programme. England

### **The Research Capability Programme. (RCP)**

The purpose of the RCP is to enable research to achieve its full potential as a 'core' activity for healthcare alongside other uses of NHS data that lead to improvements in the quality and safety of care.

It will achieve this by providing:

- a common information infrastructure
- a customer focused set of services that ensures information is treated and handled in a safe and secure way
- access to a comprehensive range of technical resources and data sets under strict protocols of information governance.

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### The strategic dimension

A strategic dimension is inherent in both the broad scope and purpose of OSCHR, EHRRB, RCP and the detailed consideration of proposed developments.

- OSCHR, EHRRB, RCP are important contributory components of the governments *Best Research for Best Health Strategy*.
- The three partnership programmes within OSCHR are inter-related and have separate PPI membership. The remit includes public and private sector research activities.
- The work of the RCP programme is being taken forward in the context of other programmes and services developed by the National programme for Information Technology. These include Secondary Uses Service, Care Records Programme, NHS Number programme.
- From a PPI perspective there are concerns relating to data security, information governance and patient consent that surface in many different but related programmes that have formal or informal PPI representation.
- There are necessary links with the responsibilities of National Information Governance Board and PIAG.
- Government policy and practice relating to data sharing has relevance. Are databases containing personal health information susceptible to access for purposes relating to national security rather than health care? There is a worrying trend developing that allows national security to be used to justify access to data bases for purposes other than those originally intended.
- There is an international dimension. EU and other international law, directives and protocols concerning information governance and cross national sharing of electronic data bases have to be considered.

*A detailed account of the work of OSCHR, EHRRB AND RCP can be found in: Office for Strategic Coordination of Health Research. Chairman's First Progress Report. Nov 2008.*

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### **A strategic approach to PPI. Issues and Implications.**

#### **The EHRRB /RCP experience.**

- The interconnectedness of programmes is recognised at expert, secretariat level, This is not systematically replicated for PPI members. This places PPI members at a disadvantage in terms of knowledge and influence.
- Responsibility for public consultation relating to RCP stands referred to SUS. There are no formal or informal arrangements facilitating cross programme consideration of public consultation by PPI interests on SUS members of RCP, EHRRB or OSCHR.
- There are no formal/informal structures through which consideration of issues such as patient consent, data linkage, security of personal information, the governance of safe havens, anonymisation, pseudonymisation and communication with patients can be discussed by PPI members on a cross programme basis. This leads to the real possibility of conflicting PPI perspectives across programmes and unnecessary duplication of debates. Criticism by the Chair of the NIGB (Harry Cayton) of patient consent protocols raised by the RCP is a current example of potential for cross programme conflict.

#### **Implications for PPI capability and Capacity.**

The need for PPI members to address the broader strategic context raises questions concerning their mandate and their readiness to engage with the broader landscape of government policy.

- My own experience at local level of PCT forum and Local Implementation Team membership suggests that the demands and skills on PPI members at strategic level are different in kind from programme and service delivery topics.
- At local level PPI contributions can draw on patient experience and local knowledge within defined policy parameters. The PPI mandate is legitimised by patient experience and local knowledge. This is not so clear when considering strategic issues. There are possible tensions between the different forms of public involvement. Consultation/ political representation /service user, consumer perspectives.
- To consider and contribute to strategic thinking PPI members have to very quickly absorb and respond to huge amounts of detailed technical and policy information without easy access to support networks. This raises concerns about fitness for purpose of selection /recruitment process, skills, experience and capacity development for PPI.

**A possible way forward.** The creation of a national forum based on structured networks that bring together PPI members contributing to policy, programmes and services related to health research.

- This could facilitate systematic public consultation and engagement across programme and organisation boundaries from a PPI perspective.
- Promote a consistent PPI contribution to consideration of information governance and other issues
- Avoid unnecessary duplication of consultation, engagement and policy development activities across related programmes.
- Develop a programme of PPI recruitment and capacity building that has a distinctive strategic orientation.