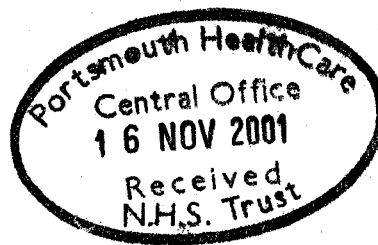


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13 November 2001

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Dear Anne

### Patient Involvement in Commission for Health Improvement's work

It was good to meet with you last week at the Start -up meeting.

Following your question about how we include positive patient experiences in our work. I have spoken with our Head of Patient and Public Involvement, David Gilbert who suggested I forward the attached draft strategy.

As you can see, the strategy is very much a working document at the moment and does not explicitly refer to the capture of positive patient experience at the organisation where we are conducting an investigation.

I have passed your comments on to David who is happy to discuss your concerns further if you wish, David's contacts are  or

I hope this is helpful.

Regards

**Code A**

Julie Miller  
 Investigation Manager

c.c Max Millett, Chief Executive, Portsmouth Healthcare NHS Trust  
 Liz Fradd, Director of Nursing, CHI  
 David Gilbert, Head of Patient and Public Involvement, CHI

**COMMISSION FOR HEALTH IMPROVEMENT**

Report for the Patient and Public Project Board meeting on  
3 October 2001

Developing a strategy for patient and public involvement

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**Aim and Purpose**

The enclosed paper provides Board members with a draft outline of a patient and public involvement strategy for CHI. It includes the following sections:

1. About the strategy
2. About the approach
3. Main themes for development
4. Process for taking the work forward

We welcome comments on all the above sections. Particular questions are:

- *Does the strategy and approach to developing it seem sensible and feasible?*
- *Are there any major gaps or omissions?*
- *What additional principles or criteria should guide the work?*
- *What sections need to be strengthened?*
- *Are the main themes for development the right ones?*
- *What additional outputs should be included within these themes?*
- *How should we consult with patients and the public and other stakeholders to develop the strategy?*
- *What involvement would members of the Board like to have in this work?*

This paper will be revised in the light of the Board's comments and taken forward as an agenda item during the next Commissioners' meeting on the 11<sup>th</sup> of October.

In addition, as part of the Project Board meeting, I will provide feedback on a consultation event with national Community and Voluntary Organisations that will

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have taken place on the 28<sup>th</sup> of September. This will have provided some initial external feedback on the draft strategy.

### 1. About the strategy

Commissioners have made it clear that they want CHI to be patient-centred and inclusive. The Patient and Public Project Board is committed to the development of a patient and public involvement strategy in order to deliver this aim.

It is vital that CHI can articulate what the principle of putting the '*patient experience at the heart of CHI's work*' means in practice. There are several possibilities, including:

- CHI looks at the patient experience and at what matters to patients when it does reviews, investigations and studies.
- CHI ensures that it makes a difference to the quality of care and treatment for patients and the patient experience of care.
- CHI involves patients (and the public) in all that it does.
- CHI is an exemplar and model for good practice in this field of work for the NHS.

The strategy should be clear on what it will produce and the criteria by which success will be judged:

1. **Outcomes** – The main objective will be how CHI has improved things for patients and the public and other key stakeholders (both in the NHS and with regard to CHI). Though hard to measure (because of the complexity of evaluation in this field and the short time scale), the impact of the strategy on patients and the public and other key stakeholders will be monitored and independently evaluated. This would include demonstration of benefits through CHI's work in the field of the NHS and in terms of patient and public involvement, awareness and understanding of the work and recognition of CHI as a model of good practice. The principle underlying any judgement of how well we have done here includes changing healthcare for patients, with patients and the public as a main vehicle for that change – in other words: 'change for, and via' patients and the public.
2. **Relationships with stakeholders** – how CHI has engaged and been open with patients and the public and those that represent their interests. This would include assessing the effectiveness of processes to engage with these interests during development of the strategy itself, to what degree external stakeholders have contributed to successful implementation of the strategy and perceptions of CHI's work in this area.
3. **Working with marginalized and vulnerable groups and individuals** – There is a view that if we get it right for marginalized and vulnerable groups, then we get it right for all. A key test for the strategy will be how well CHI has engaged with individuals and communities who have traditionally been thought of as 'hard to reach'. People who are labelled as being 'vulnerable and marginalised' are not homogenous, nor do they necessarily have 'special needs'. But they often face multiple barriers to getting good quality care and

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treatment over and above those having to do with their health condition and in relation to working with CHI. Therefore the strategy should cover individuals from at least the following groups:

- Patients – those with acute or chronic conditions – people who are ill are already vulnerable due to their condition who may be anxious and confused as well as ill.
  - People of different genders, age and sexual orientation – people who may use mainstream services but face particular issues due to their personal characteristics.
  - People from black and ethnic minorities and/or from different cultures and/or with different religious backgrounds – may have particular issues surrounding access to services and communication and cultural sensitivity.
  - People with mental health problems, physical disabilities, learning disabilities or with sensory deprivation – these people may have issues concerning access to mainstream services and concerning specialist services that attempt to cater to their particular needs.
  - People from different socio-economic or demographic circumstances (e.g. poor, unemployed, rural, etc) – people may have specific issues concerning access to services, communication and quality of care.
  - People from extremely marginalised groups within society – e.g. refugees and asylum seekers, travellers, street-workers, people who are homeless, who have drug dependency or substance abuse problems, etc. – Here the issues may be about access to services.
4. **Internal structures, systems and processes** – It will be crucial to identify how CHI has developed better internal systems in order to deliver this work. This would include awareness and understanding of the work across CHI, individual behaviours in line with the principles of the work, clearly defined roles and responsibilities for those undertaking the work, and coherent systems across the organisation
  5. **New tools and techniques** – The development of conceptual frameworks and practical tools to help deliver the work need to be assessed. This would include coherent methods to engage with patients and the public and with people from marginalized and vulnerable groups within both its corporate and statutory functions (see 'main themes for development' below)

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## 2. About the approach

The strategy will provide a long term, coherent and systematic approach and direction to the way we involve patients and the public in all we do – both as part of our statutory functions and corporately. We will build on the aims and objectives of the work and state in more detail the rationale, principles and values that underpin it and how success will be measured. The strategy will provide a theoretical and practical foundation for successful implementation of the work.

There are some key principles which will underpin the approach CHI will take in developing its strategy:

- **Developing a common understanding of the work** – People inside and outside the organisation have different understandings of the phrase ‘patient and public involvement’ and different expectations of what CHI should do. It is important to be clear about what the work on patient and public involvement means – what it is, and what is not. For example, we need to be clear that work on the ‘patient experience’ is different to work on ‘patient and public involvement’.
- **Mainstreaming the work** – It is vital to integrate the work on patient and public involvement with CHI’s corporate objectives and everyday practice in order for the work to be central to its business and to prevent the work being marginalized. This entails getting senior level support for the work and staff ownership and being clear about roles, responsibilities and resources – identifying ‘who needs to do what’ to get the job done. This will ensure that the ‘project’ turns into everyday practice.
- **Culture change** – Some of this work may feel threatening to some staff, either because they do not understand it, do not agree with it, or it may require changes in the way they work. Some of the changes may require some risks to be taken corporately and judgements will have to be taken as to the acceptability of these risks particularly with regard to developing new tools. Supporting staff and other organisations entails raising awareness, creating understanding of the benefits of the work and building capacity.
- **Links and boundaries** – People may think that work on patient and public involvement covers a multitude of areas. We need to define where the boundaries lie between the Policy and Development team and others and which areas we should lead on, and in which we should play a supporting role. At the same time, we need to ensure there are good links between people, teams and directorates doing work that concerns patient and public involvement. The main themes for development (see below) reflect this consideration and define who leads in which areas.
- **Practical considerations** – There may be some practical constraints to undertaking the work. Some of these may be due to resource constraints. Others have to do with the trade offs that may be a consequence of this. For example, limited time may require us to be clear about what is ‘good

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enough' in terms of breadth and depth of the work we undertake. It may be tempting for 'difficult work' to drop off the agenda. CHI also faces more general issues concerning the balance between a developmental and inspectorial mode and between supporting self-assessment and monitoring - these may have particular implications for this work.

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### 3. Main themes for development

There will be several arenas for work on patient and public involvement. Of the eight outlined below, it is suggested that the Patient and Public Project is responsible for leading on the first four and that it acts in support of, and contributes some initial investment in, the work of other directorates with regard to the last four.

#### **1. Involving patients and the public in developing policy and planning in CHI**

A key principle will be that CHI's policy and planning work – both its overall policy and planning and patient and public involvement work – should be guided by patients, carers and the public. Systems should be put in place within CHI that allow the voice of patients and the public to be heard and acted upon. These systems should be ongoing, coherent, consistent and effective.

Examples of objectives would be: effective patient and public engagement with decision-making processes through for example strategic, reference and working groups; keeping in close contact with developments with regard to good practice in patient and public involvement; using a variety of effective methods to reach marginalized and vulnerable groups so that they can contribute to change.

Early work has included meeting with key external stakeholders in order to learn from best practice and in order to inform the consultation process for developing the strategy. An external consultation event will have taken place by Oct 3<sup>rd</sup>.

#### **2. Supporting developments in patient and public involvement in the NHS**

A key objective would be to contribute towards developments in patient and public involvement across the NHS by working with national and local organisations concerned with patient and public involvement.

This might be done through supporting other organisations, through advice and guidance, to involve patients and the public in their work; responding in timely fashion to consultations and initiatives; working to ensure the success of new structural arrangements to promote patient and public involvement.

Early work has included attending meetings and conferences, making presentations and networking, keeping up to date with involvement initiatives and new structural arrangements in England, Wales and Scotland, leading responses to consultations on the new involvement mechanisms in England, liaising with the National Assembly for Wales on forthcoming guidance on involvement and co-ordinating a response to proposals for new complaints procedures.

#### **3. Patient and public involvement within statutory functions**

A key objective will be that, as part of its reviews, investigations and studies, CHI will look at the patient experience and at what matters to patients. This includes

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ensuring that CHI has a consistent theoretical approach to the dimensions of the patient experience and how it measures these and also how it looks at patient and public involvement.

The way that CHI does this should include ensuring that effective quantitative and qualitative methods are used to engage with patients and the public, with marginalized and vulnerable groups and with community and voluntary organisations, concerning the quality of care and patient experience. CHI should also be looking at the capacity of local organisations to involve patients and the public in healthcare and will seek to get the views of a wide range of local stakeholders on this issue.

Early work has included working with analysts to reformulate the dimensions of care we look at during reviews; working with development managers on restructuring our approach to review issues and key documentation required; working with project redesign to introduce new tools (on assessing how well organisations are carrying out patient and public involvement) and improving the stakeholder process (by, for example having a more systematic approach to gaining the views of community and voluntary organisations);

### **4. Contact with individual members of the public**

There need to be robust internal systems that ensure that CHI deals with contacts with individual members of the public. At present, there seems to be an inconsistent and potentially fallible system. A key early priority is to improve things.

Early work has included identifying problems in internal systems (e.g. the way that the stakeholder line is functioning, problems with the text phone), arranging ways to test out accessibility of the building and mapping out what contacts we have with different members of the public and how well we are doing. This last issue was a key priority to emerge from the recent internal working group.

### **5. Openness and accountability**

The Policy and Development team through the Patient and Public Project will support others within CHI – in particular the Corporate and Commission Team – to promote patient and public involvement in corporate governance and accountability issues. Particular input may concern support to attend and participate in CHI events and meetings, ensuring that all is done to promote openness in decision-making and what discussions are held in public

Early work has included discussions with the corporate and commission team about the strategy and principles, specific discussions on how we might support people to come and to contribute to Commissioners meetings. We will also be looking at the implications of any possible changes to where Commissioners Meetings are held, and principles governing private and open sessions to ensure maximum transparency to patients and the public.

### **6. Internal culture**



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The Policy and Development team through the Patient and Public Project will support others within CHI – in particular with HR – to promote a ‘patient-centred’ and ‘inclusive’ environment in terms of the *people* that CHI employs and has contact with and the *environment* in which they work. The former may include work on the role of lay reviewers, equal opportunity policies, staff awareness and induction, training and development and sharing learning. A key aim would be to promote involvement as part of the work of all CHI staff.

Early work has included discussions with HR and the lead on learning and development **Code A** around raising staff awareness, staff and reviewer training and the role of the lay reviewer. We have led sessions on patient and public involvement during induction and are contributing to other developments (such as competency work, performance improvement, learning organisation) so that the strategy for involvement is consistent with these initiatives.

The Internal Working Group is now established and has met twice. It will meet approximately every four to six weeks. The group will be consulted at each key stage of the development of the strategy and will provide a sounding board and source of support. Specific tasks and priority issues will be taken to members of the group and members may either undertake this work or provide advice as to how it might be done (e.g. carrying out an accessibility audit of CHI’s offices, development of contact database). Terms of reference for the group need to be clarified and other members brought on board. Decisions need to be taken as to whether there should be external participants and the relationship between this group and the Project Board requires clarification.

## 7. Communications

The Policy and Development team through the Patient and Public Project will support others within CHI – particularly the Communications Team – to develop effective communications with patients and the public.

Early work has included discussions regarding communication with the public during reviews and investigations, development of a contacts database, discussions concerning how CHI reports can be made more user-friendly, developing research methods concerning what sort of performance information the public want, and around public awareness of CHI.

## 8. Monitoring and evaluation

A key aim would be to develop methods to monitor, evaluate and share the learning from CHI’s work from a patient-centred perspective. Also, to evaluate the work CHI does specifically concerning patients and the public and to learn from others about good practice.

Early work has included thinking through outcomes for the strategy (see above) and thinking through ways that CHI can integrate this work with ongoing monitoring and evaluation work (e.g. developing the tender for evaluating CHI)

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#### 4. Process for taking the work forward

The Strategy development process will be taken forward in the following way with possible timings in brackets:

- Foundation work – identification of approach and areas for strategy development (now until end October);
- Early work (for more details see sections under ‘main themes for development’) (July – October)
- Continuing work on priority themes (e.g. on theme 4 – contact with individual members of the public) (October – ongoing)
- Draft involvement strategy (November)
- Consultation (Dec – Jan 2002)
- Revised involvement strategy (Feb 2002)
- Baseline assessment and development of implementation plan (Mar 2002) - Approaches to undertaking this work have been discussed, and main questions have been agreed. It has been decided that this work should be carried out once the themes have been agreed and the draft involvement strategy has been developed.
- Implementation (March 2002 onwards)