

The King's Fund

Promoting Patient Choice:  
Process evaluation

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## Promoting Patient Choice: process evaluation

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### Appendices

Appendix one - introductory letter

Appendix two - outline questions

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### This report

This is a report on the process evaluation undertaken as part of the King's Fund's Promoting Patient Choice initiative. The report outlines:

- the background to the project
- the purpose and method of the evaluation
- findings from the seven sites. Information about the application stage, the development process and the evaluation and dissemination of the materials is included
- suggestions about generalisable lessons for the future.
- a series of recommendations

### Background

The Promoting Patient Choice initiative was set up by the King's Fund in 1991. Its aim is to encourage clinicians and patients to participate in shared clinical decision-making. One part of this project has been to award grants to seven sites across the country to enable them to develop a range of evidence-based information materials to help patients make treatment decisions.

Each of the sites has been encouraged to conduct its own evaluation of the materials produced and their impact on patients. Representatives from the sites also met with King's Fund staff to review the project as a whole in July 1997. In addition, the King's Fund were keen to evaluate the *process* of this element of the Promoting Patient Choice initiative. A freelance researcher who had no previous involvement in the initiative was employed to undertake this evaluation.

### Purpose

The evaluation addressed three key questions:

- Did the site meet the objectives it initially set? If not, what were the reasons for this?
- Would the materials have been developed without the financial assistance of the King's Fund?
- What impact have the materials had on patients and other clinicians?

The sites covered in the evaluation were:

- **Beaumont Street Practice, Oxford** - multimedia package on hormone replacement therapy
- **Bristol Urological Institute** - multimedia package and booklet on urge incontinence
- **Hull University/Castle Hill Hospital** - multimedia package on colorectal cancer

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- **Manchester University/Hope Hospital** - personal organiser on ulcerative colitis
- **Nottingham University/Nottingham City Hospital** - multimedia package for children on nocturnal enuresis
- **Queen's Medical Centre, Nottingham** - booklet on post-operative pain relief
- **Redbridge Health Care NHS Trust/ Redbridge and Waltham Forest Health Authority** - audio tapes, directory of services and booklets for Asian women on anxiety management

For brevity, sites are referred to as follows:

Beaumont Street Practice - Oxford

Bristol Urological Institute - Bristol

Hull University/Castle Hill Hospital - Hull

Manchester University/Hope Hospital - Manchester

Nottingham University/Nottingham City Hospital - Nottingham

Queen's Medical Centre - QMC

Redbridge Health Care NHS Trust/Redbridge and Waltham Forest Health Authority - Redbridge

### Research methods

The evaluation was carried out between August and October 1997. An initial letter was sent to project managers at each of the seven sites. At Redbridge, the research assistant had left the organisation. She was contacted at her new place of employment. These letters introduced the researcher and explained the purpose of the evaluation (appendix one). Letters were followed up with a telephone call to arrange a visit.

Visits took the form of semi-structured interviews with the project manager and the lead clinician. Outline questions for the interview are attached as appendix two. These were agreed with the King's Fund and shared with those interviewed at each of the sites.

This report has been compiled using information given during these interviews. A draft report was circulated for comment to those interviewed, and to Christine Farrell, Director of the Promoting Patient Choice project, and Mark Duman, its Project Officer, in order to check accuracy. This final report incorporates their amendments and comments.

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### FINDINGS

#### 1. The application process

##### 1.1. Initial publicity about the project

Sites heard about the project through three different means: Oxford and QMC heard through contact with staff at the King's Fund; Bristol, Hull and Manchester saw the advertisement in the British Medical Journal; Redbridge and Nottingham heard about the project through another member of staff who had seen the BMJ advertisement. Teams who did not see the advertisement felt they heard about the report almost by accident or good fortune.

##### 1.2. Original aims identified by the sites

All of the sites were clear about the initial aims and objectives of their projects at application stage. They were interested in offering more information about a particular condition, or in using a particular medium to facilitate increased patient choice.

In Bristol, Anthony Timoney had been involved in developing tools for computer aided learning for medical students. He wanted to see how patients would respond to the same technology - "the topic was picked almost at random". The project aimed to develop a multimedia package to inform women suffering from urge incontinence about their condition, and to help them to consider the options for treatment.

At Hull, Mark Hughes wanted to improve the quality and quantity of information for patients with colorectal cancer. They planned to produce a multi-media package, booklets and videos for patients, which they hoped would reduce patient anxiety.

The Manchester team planned to produce a video on ulcerative colitis, covering "the sort of thing doctors think patients want to know," in order to improve the quality of life for patients with this condition.

The Nottingham team aimed to develop an educational package for children about enuresis and its treatment. Their principal objectives were to identify the informational needs of children (and parents) with enuresis; to design and produce interactive multimedia packages which would provide this information, and to implement, evaluate and disseminate these packages to paediatric clinics and services.

The QMC team had already developed a strategy to improve pain management within the hospital. One of the ways they intended to do this was to introduce written information for all surgical inpatients. They felt that the Promoting Patient Choice project 'fitted in with our way of doing things', as it followed an audit cycle where initiatives could be evaluated, improved and re-evaluated. They wanted patients to play a major role in developing the

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written information, and to see whether the use of the information would help pain management in the post operative stage of the patient's stay in hospital.

The Redbridge team's overall aim was to promote improved mental health amongst Asian women living in the area. They planned to do this by producing booklets on depression and anxiety management in the four Asian languages most common in the area; to translate tapes on depression and anxiety management into these four languages and to produce a directory of mental health services for the area.

Those involved in the Oxford project would have preferred to develop a project based on the existing information boards used within the practice to help women make decisions about whether to take HRT. However, staff felt that the King's Fund would be interested in evaluation, and they knew that it would be difficult to undertake a randomised trial of the information boards. They therefore decided to evaluate the comparative impact of two pieces of information on HRT - an interactive video, imported from the States, and a booklet, to be written by the project team.

### 1.3. Sites' views on the role of the King's Fund in the application process

None of the sites had any contact with the King's Fund during the application process. For most, this was not perceived to be a problem, as application forms were felt to be clear and self-explanatory. One site felt that the time given to return application forms was short.

A number of sites cited their concern to balance the need to apply for a 'realistic' sum with the concern not to seem to be over costing the application. Some sites said they were not aware what a realistic figure was until they had completed the project.

The Redbridge team, who have had some contact with the King's Fund Grants Department, felt that an arrangement whereby a grants officer visits each applicant to advise about completion of the application and in particular about how much it might be realistic to apply for, would have been helpful. Three other sites were asked to comment on this idea. They felt it would have been a useful resource, particularly as they felt that the grant they applied for had not realistically reflected the true cost of the project.

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### 2. The development process

#### 2.1. Changes to aims and objectives

Some sites revised their original aims and objectives. They identified a number of reasons for doing so:

##### **a. Patient feedback**

Four sites reviewed and changed their original objectives following feedback from patients. The Manchester team recruited a medical student to ask patients what medium they would prefer. The overwhelming preference was for written information. The team wanted to produce something which could be easily updated, pocket sized and in which patients could make their own notes. They therefore agreed with patients that they would develop a personal organiser, rather than a video.

The QMC team had originally planned to produce written information, an audio tape and information for those who speak little English. Initial feedback from patients showed very clearly that the preference was for written information rather than an audio tape or computer based package. Plans were therefore revised accordingly.

The Nottingham team had hoped to involve children in identifying information needs about enuresis. However, children were embarrassed to discuss this subject. They therefore addressed their initial questions about information needs to parents.

The Redbridge team had great difficulty in reaching the Asian women with whom they wished to work. This meant that some of the proposed methodology changed, and that some areas of the project took longer than had been anticipated in the project plan.

##### **b. Other reasons**

When staff involved in the Bristol project began to look at when their 'booth' would be used by patients within a hospital visit, they felt that the most appropriate time for women to use a package looking solely at urge incontinence would be after a meeting with the doctor in the outpatients clinic, at which point the woman may have gained all of the information needed from the doctor. They therefore revised their original aims and agreed to develop a package which would look at incontinence as a whole. This would enable women to use the package prior to seeing the doctor in the outpatients clinic. When peer reviewers looked at the information, it was agreed that not enough of this was common to the conditions which cause incontinence. The team therefore reverted to their original aim of developing a package solely on urge incontinence.

#### 2.2. The importance of academic links

The involvement of an academic department was seen to have been very helpful in the development and evaluation of materials. In Oxford, one of principle investigators is an academic. Other members of the team commented that "without him, we may have wanted

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more help with questionnaire design, especially in the early stages to prevent reinventing the wheel."

In Manchester the gap between the departure of Hilary Gilbert and the arrival of Mark Duman could have been a problem, but Anne Kennedy felt that the support of academics within the University meant they were able to adhere to their timetable. She commented that "If I hadn't had the university's support and back-up I would have been lost."

The Bristol team originally had a link with the university, but this member of staff left as the project began. The team felt that an academic would have had more time to write grant applications, and that some bodies give money more readily to academic centres than to clinicians working outside them. They reported that a link with an academic centre could have given them access to a multidisciplinary team, so devising the evaluation would have been easier. They felt this could also have been helpful in the dissemination of information about the project.

Redbridge felt that an academic unit could have helped them with validation of translations and with developing evaluation tools. However, they feel that clinical departments should be encouraged to apply for this type of grant, and that their availability should not be limited to academic departments.

### 2.3 Sites' views on the role of the King's Fund during the development process

All of the sites found the support offered by the King's Fund during the development process was helpful - although some were more positive than others. Some of the sites praised the project officers' readiness to supply information and resources, and their accessibility by phone. Two sites reported being promised information which never arrived. This may have been due, at least in part, to the departure of Hilary Gilbert.

Nottingham, Manchester, Oxford and Bristol felt that they had needed very little support from the King's Fund and had therefore not asked for assistance. Redbridge had found Hilary Gilbert very helpful in clarifying the aims of the project, motivating people, assisting with methodology and providing feedback on other areas within the project plan. A number of sites found Mark Duman's assistance in identifying additional sources of funding and publicising the work of the project very helpful.

Hull, QMC, Nottingham and Redbridge felt that the King's Fund were particularly useful in helping the team gain access to other networks and contacts, for example with people working in the same area, and external reviewers.

The most important contribution the King's Fund made to all of the sites was seen to be the funding to enable the projects to take place. QMC said that although they would have undertaken the work, the grant enabled them to develop the project properly and to complete the work more quickly. Oxford also felt that they would not have been able to purchase the computer equipment or evaluate it without the grant. Hull, Manchester and Nottingham felt that this initial grant had enabled them to develop a product which they



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can build upon. They saw the initial grant as the most difficult one to obtain, and now feel that they have both a proven track record in development and implementation and an actual product which they can demonstrate to potential funders. They see this as a key factor to help them to develop the work into other related areas.

### 2.3 Project meetings

Views varied about the usefulness of project meetings held by the King's Fund to enable teams to discuss common problems and plans. Although there was common agreement that the initial meeting held by the King's Fund was helpful, five of the sites felt that subsequent meetings were repetitive (although Nottingham felt that this repetition was useful, as sites were looking at the same issues but from a different stage in their development). Manchester would have preferred one meeting at six months and one review meeting to look at lessons learned to date. Some sites felt that although the meetings were useful to keep people in touch with each other and with the King's Fund, in fact the project teams had little in common beyond their desire to 'promote patient choice' - their methods and their problems were different.

There were a number of comments about the administration of the meetings. QMC, Oxford and Bristol felt that it would have been helpful to have been told about project meetings at an application stage, and advised to build in associated travel costs to their application. QMC commented that clear agendas and stated aims for the meetings would have been useful. Bristol felt it would have been helpful to record action points agreed at meetings and to circulate these. The team felt that meetings generated a lot of ideas but that there was little time and resources within the sites to act on these.

The venue for the meetings was also commented upon by some of the sites. As this element of the Promoting Patient Choice initiative supported a number of projects in the north of the country, members of some of the project teams felt that the time spent travelling to meetings meant it was hard to justify attending all of them. Some sites suggested that locating at least some of the meetings in the north would have been helpful.

### 2.4. The gap in project officer support

Sites had very different reactions to the departure of Hilary Gilbert in January 1996, the absence through sickness of Christine Farrell and the subsequent delay in Mark Duman's appointment in May 1997. This seemed to depend upon the stage the project had reached.

The absence of Hilary Gilbert was probably felt most strongly by Redbridge, where Hilary's departure coincided with the departure of a key member of the team from the Health Authority. The team felt they had lost "an informed external perspective." During the gap, the researcher commented that she felt the project became a "local one."

Bristol felt that Hilary's departure caused a 'huge hiatus'. They did not receive the validated questionnaire about patient information they had been promised, so the team decided to put together their own questionnaire, which they felt involved them in what was

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possibly a reinvention of the wheel. The subsequent gap meant that peer reviews were delayed, which in turn put the project as a whole behind schedule. Oxford felt that the absence of project officer support may have led to further delays in delivery of equipment from the States.

The gap in project staff occurred when Anne Kennedy started work on the project in Manchester - this meant her induction into the 'King's Fund' element of the project was delayed.

Nottingham did not feel that the gap was a problem, commenting 'we were organised by the time Hilary left'. They felt that they could call Christine Farrell when they needed to, and that she had been very helpful. QMC were also less affected by the departure of Hilary Gilbert, but for different reasons - her departure coincided with the sickness of the project nurse, so to some extent the project was dormant at this stage. In Hull, the absence did not affect the project, as development had not yet begun.

For Redbridge, the arrival of Mark Duman brought about a perceived change in the role of the project officer, with an increased emphasis on the need for evaluation. Nottingham noticed that the King's Fund became more proactive within the project once again when Mark came into post.

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### 3. Implementation and dissemination

#### 3.1. Obstacles to the achievement of the aims of the projects

##### a. Time

The problem of time was common to a number of the sites. Although all of the sites had an initial project plan, with hindsight these were often overly optimistic. Delays in receiving responses to questionnaires caused problems at Redbridge. In Oxford, hardware which had to be sent over from the States was delayed by eighteen months because the company involved ran out of money. One key member of the team also went on maternity leave. The QMC project was also delayed because of staff absence - this time through illness. In Hull, the team realised that they would not be able to produce all of the materials within their timescale. They therefore abandoned plans to produce a video. Nottingham ran over their deadline by six months. Only Manchester completed the project within the timetables they had set themselves.

##### b. Technology

There were problems with the purchase and development of appropriate technology, perhaps because some of the sites were piloting the use of this technology in the communication of information and choices to patients. Hull opted to work with their in-house IT support staff, believing that this would be more cost-effective. In fact, the reverse was the case. The package they developed has no sound and a great deal of text. They will be working with an external consultant to develop a second version of the package. Hull also regretted purchasing a PC rather than a laptop.

Bristol also felt they learned lessons about the purchase of the appropriate technology. In addition, the team have been unable to make their booth as accessible as they would wish. It is currently situated within the consultant's office because of a shortage of appropriate private space, so use has been limited.

##### c. Copyright issues

Hull, Nottingham, Bristol and Manchester felt that was a lack of clarity about copyright. Although the initial publicity about the project produced by the King's Fund stated that the King's Fund would expect to hold the copyright of materials produced as a result of the grants, these sites felt that this was not made clear within the contract. This led to a significant amount of time being spent in an attempt to resolve this issue. The Bristol team reported that they had lost an opportunity for sponsorship because of this lack of clarity.

Despite these obstacles, most of the sites feel that they have achieved many of their original or revised aims. Manchester have produced a personal organiser; QMC a leaflet; Hull a multi-media package; Bristol a multi-media package and a leaflet; Nottingham a CD ROM; Redbridge two tapes, a directory of services and a booklet in four languages.

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### 3.2. Evaluation

All but one of the sites have evaluated, or are in the process of evaluating the materials they produced. Oxford adapted their original ideas to incorporate an evaluation. Manchester are now undertaking a controlled trial to evaluate the effectiveness of their personal organiser. QMC, Bristol and Nottingham are setting up randomised controlled trials to evaluate the effectiveness of their materials. Hull have undertaken some evaluation work, and plan further research once they have developed the second version of their multi-media package. They hope to explore whether the provision of information has reduced length of hospital stay and the use of analgesics. Now that the team at Oxford have received their equipment, a randomised controlled trial is beginning comparing effectiveness of the multi-media tool and the leaflet. Redbridge is the only site where no further evaluation is planned.

However, concerns about the role of evaluation within the project as a whole were raised by all of the sites. Manchester, Redbridge and Bristol felt that there had been little indication at the beginning of the project that a detailed evaluation would be a requirement, and had not included the resources for this in their bid. They felt they would have benefited from help on how to evaluate their materials, and how to access funds to enable them to do this.

Manchester, Nottingham and Bristol felt that it might have been helpful to phase the project, with an initial grant being offered to develop products, and a second grant being made available to a smaller number of sites to undertake a validated evaluation of effectiveness, and then to distribute the products.

QMC raised concerns about peer review, which was undertaken by clinicians. They suggested that patients should also be asked to peer review materials.

All of the sites stressed the importance of using a validated tool to evaluate the impact of the products. Some of the sites felt it would have been useful if the King's Fund could have identified or developed such a tool, thus preventing sites duplicating existing work, or developing evaluation tools which were not methodologically rigorous.

### 3.3. Production and marketing

For some of the sites, large scale production and marketing of their materials has presented a challenge. This is an area where sites feel they have little established expertise. Nottingham, for example, felt they had to learn about production and marketing as they undertook this. The Bristol team are concerned about how they might fund the production and distribution of their multi-media package. They questioned whether the grant awarded to them might have been better spent evaluating an existing multi-media package (such as the one developed by Julia Schofield Consultancy), rather than developing a new package and not disseminating it. This area is one where some sites feel that the King's Fund could have undertaken more research on behalf of all of the sites.

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### 3.4. Impact of the products

Although evaluation had not been completed in all of the sites, each site felt able to draw some conclusions about the impact of their work in a number of arenas.

#### a) Impact on patients

In addition to the information contained in their report, Nottingham noted that all of the children attending the enuresis clinic use the CD-ROM, and that they seemed to enjoy using it. Feedback from patients at QMC, Manchester and Redbridge has also been positive. Initial evaluation carried out with patients in Bristol also showed patients were positive about the booth. However, use of the booth has been limited as it has no dedicated space. This means it can only be used when the consultant's office is free.

In Hull, initial research showed that those patients who had used the multi media package were significantly more depressed, but felt more socially supported than those who had not used it. However, the project manager pointed out that the sample size was small and that further evaluation is needed. He felt that use of the package helped to prompt patients to talk more about their emotional response to cancer.

#### b) Impact within the organisation

The Boards at all of the projects within secondary care had an awareness about the materials and the King's Fund's involvement. In Redbridge, Morris Nitsun felt that the project had served to raise the profile of the psychology department within what is a large Trust. The QMC team felt that the project has had a major impact within the hospital, and that it had raised the profile of the Acute Pain Service. The methodology used to develop the leaflet has been taken up by other staff who are developing written information. The leaflet and the methodology used to produce it are being examined by a group of staff within the hospital who are looking at the production of written information. The team have also used the experience they gained from the development of this leaflet to review and rewrite other leaflets produced by the Service.

The project has also had a major impact in Hull, where multi-media information packages are being developed for patient with breast cancer, and for those needing stoma care. Interest has also been expressed by oncologists caring for people with cancer of the head and neck.

In Bristol, although the development of the booth has not encouraged other departments to develop computer based information for patients, it has generated increased interest in the use of this technology within the training of medical students. Although the Nottingham City Hospitals Trust initially showed less interest in the project, they became more positive about it when they were required to produce evidence for the hospital insurance scheme, which include the need to demonstrate 10 pieces of written information for patients where risks and options for treatment are clearly outlined.

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In Nottingham, clinicians are interested in developing a package similar to the one on enuresis for those with diabetes. However, projects in Manchester and Redbridge have not led to others within the organisation wishing to develop anything similar.

### **c) Impact on other professionals**

All of the sites which have produced materials to date feel that the projects have had some impact on others within their profession. Paediatricians from around the country have expressed an interest Nottingham's CD-ROM, as have psychologists. Psychologists have also expressed some interest in the booklet produced by the Redbridge team, as have some local GPs. The principle impact amongst professionals within the QMC project has been on nurses within the hospital, who have been particularly positive about the leaflet, and recognised the importance of offering written information to patients. There has been interest from gynaecologists, urologists and continence nurses from around the country in Bristol's booth.

Interest in the Hull and Manchester materials has been primarily local to date. All of the consultants caring for patients with ulcerative colitis at Hope Hospital want to use the Manchester team's personal organiser. Doctors throughout the North West region of the NHS have also expressed interest in using it.

Sites which are now undertaking evaluations of their products anticipate further interest from professionals once their results have been published.

### **d) Impact on patients' organisations**

For some sites, there was a clearly identifiable patients' organisation with whom they could liaise. In Nottingham, this was the Enuresis Resource and Information Centre (ERIC) - a national organisation. They are now marketing the product on behalf of the team. The link organisation for Manchester was the National Association for Colitis and Crohn's Disease (NACC). A representative from the local group was a member of the steering group of the project, and provided a link with other members of the local group and an additional patient input to the project. NACC nationally has not been keen to disseminate or publicise the organiser - perhaps because they produce their own literature.

The Redbridge team worked with two local organisations for Asian women to produce their materials - the Asian Women's Association and the New Commonwealth Women's mental Health project. The former has expressed an interest in the finished products and have been sent free copies of the booklet and directory. Voluntary organisations featured within the directory of local services have been sent a copy of this, and a number have purchased further copies and expressed an interest in the anxiety management booklet.

The Bristol team have had some contact with the Continence Foundation, but have not pursued them with regard to assistance in dissemination of the product.

There was no appropriate patients' organisation for the QMC or Hull teams to link with, although Hull are exploring the possibility of working on the second version of their multi-media package with a new colo-rectal cancer patients' group, called Crocus.

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### e) Impact on commercial producers

None of the sites reported any impact on producers or potential producers.

### 3.4. Press coverage

Sites received a varying amount of media interest in their work. Manchester reported that the interest they received had been minimal, but were happy with this, expressing a preference for receiving coverage after they have evaluated their product. This feeling was shared by Bristol. Redbridge received a 'fair amount' of press coverage which generated a great deal of interest - particularly the interview given by Morris Nitsun for Asian Radio.

Manchester, QMC and Redbridge felt that the press coverage generated by the King's Fund came too early in the project. People contacting these sites were hoping to get access to the finished product when in fact the project was at an early stage of development. Although Nottingham initially felt that press interest had come too soon, on reflection they judged the timing may have been right for them. Press coverage changed the direction of the project for Nottingham - at the beginning of the project the team had anticipated more interest from professionals than from parents and planned accordingly. The response from parents to press coverage had an influence on the dissemination of the CD-ROM. Nottingham saw press coverage as a motivating factor within the project: "it reassured us we were doing something people wanted and were interested in, and kept us focused about the timetable."

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### 4. Financial issues

All of the sites reported that they had incurred costs in addition to the grants they received to develop the products. Some sites felt unable to quantify these; others offered broad estimates.

Some of these additional costs related to staff time spent on developing the materials. Manchester had to secure an additional £10,000 to extend the contract of Anne Kennedy. In addition to this, they estimated that Andrew Robinson spent two hours per week on the project and that two professors each spent several hours per month on the project. Anne also worked for some time without pay whilst additional funds were raised.

The grant to QMC did not cover the time Fiona Dobson and Greg Hobbs spent on the project. Oxford estimated that they will incur an additional £3,000 in staff time on the project. Nottingham estimate that their project took an additional 1.5 person days per week over the eighteen months the project was running - none of this was covered by the King's Fund grant

Redbridge reported that the project cost an additional £6,500 in staff time. The project team had substantially underestimated the cost of translation. This meant that the project had to be substantially scaled down in size. The Hull team also estimated they spent far in excess of the grant they received in order to develop their multi-media package - Mark Hughes reported the additional cost was around £20,000 - almost all of this was for staff time. Bristol report that they would have been unable to complete the project without cross subsidising it from other projects.

Other additional costs relate to evaluation and production of materials. Additional funds have been obtained to undertake trials of materials in Manchester, QMC and Nottingham. The Nottingham project has received an additional £7,500 from the University to produce the CD-ROM. Manchester are also raising funds for the production of their personal organisers.

Some sites applied with varying success for additional funds to enable them to complete their project. All were clear that the project could not have been completed without access to additional funds or staff time.



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### 5. Sites' plans

A number of sites are now planning or undertaking trials to test the effectiveness of their products. QMC are planning an RCT to look at the effectiveness of their leaflet. The leaflet will then be amended, and the project written up. The leaflet may also be made available more widely through regional and national pain networks. Manchester are also planning a controlled trial, and have developed some options for dissemination. The team are applying to the NHS Executive for funding to produce a similar publication for irritable bowel syndrome. They intend to publish a paper on the method used to develop the organiser.

Nottingham are commencing an RCT of their CD-ROM, and are looking into translation of the programme for use abroad. Some members of the team have obtained funding for a similar package on diabetes, and are exploring whether similar packages could be produced about other conditions. The Bristol team are currently undertaking trials comparing their booth with a leaflet, and are exploring sponsorship options for disseminating the package. They are also exploring the possibility of making the information available on the Internet, once the technology is available to them to enable them to charge people for the package.

Hull plan a second, improved version of their package for patients with colorectal cancer. This will have more images and less text. They have begun to think about dissemination, which will be undertaken once further evaluation has taken place. They are also working on a package for stoma users.

Oxford are only now beginning their project, having obtained and set up the equipment from the States. Their trial will commence shortly, and completion is anticipated within nine months.

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### 6. What can we learn for the future?

#### 6.1. Sites' views about generalisable lessons

In addition to questions about the specific areas outlined above, sites were asked to identify the most significant lessons they felt they had learned which could benefit other, similar projects.

A number of the sites identified issues about the process of developing materials. Bristol felt that in future it would be important to set clear goals, agree on a story board and have this peer reviewed before purchasing equipment. These recommendations are outlined more fully in the team's report. Hull also felt that lessons could be learned about who to employ to develop programmes, and the importance of being clear about how equipment will be used before deciding what to purchase.

QMC and Manchester felt that the process they undertook to develop their materials could be adopted more widely. They stressed the importance of asking patients about their preferred medium for information, as both teams had altered their initial plans as a result of patient feedback.

Manchester and Bristol highlighted the need to consider evaluation and distribution from the outset of the project.

Oxford and Nottingham noted that the projects had taken considerably longer than they had anticipated. Bristol, Oxford and Redbridge stressed the importance of applying for a realistic budget to ensure completion of the project within the timescale set.

Redbridge recommended the employment of a researcher who speaks the appropriate languages for any future project involving translation of materials. They also stressed the need for more collaboration with other agencies (in their case the health authority), and the importance of recognising and planning for the variable interest of GPs in a project.

Hull emphasised the need to involve a project team in the development, evaluation and dissemination of materials. Mark Hughes felt that he had undertaken most of the work himself, with the help of a clinical psychologist. Given that this project took place alongside his work as a nurse counsellor, it is hardly surprising that the original aims of the project were not achievable within the time agreed.

#### 6.2. Sites' views about how the King's Fund could have improved their support to sites

Sites identified a number of areas where, if a similar project was to be undertaken by the King's Fund, additional support could be offered. Redbridge and QMC valued the access the King's Fund offered to other resources, but felt these could have been offered at an earlier stage in the project. Redbridge felt they would have benefited from advice about

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translation and translators - something the King's Fund Share project may have been able to help with. QMC felt that, with the King's Fund's excellent library service, it would have been helpful to circulate new articles from journals or the Internet that would be relevant to the Promoting Patient Choice Project. Manchester commented that they would have welcomed help to identify appropriate grey literature. Bristol, Manchester and Nottingham felt they would have benefited from advice and support about producing, marketing and disseminating their products.

### 6.3. Evaluator's views

Some general conclusions can be drawn which may be of some assistance if similar projects are undertaken in future.

#### a. The application process

It may be appropriate to advertise initiatives more widely, and to encourage more liaison between the King's Fund staff and applicants at the initial application stage. This would ensure that sites apply for realistic levels of grant aid. It might also be appropriate to ask applicants their reasons for choosing a particular medium for communicating choices to patients, as some of the sites which explored this with patients changed their original plans.

#### b. The development process

It is clear that most, if not all of the products would not have been developed without the King's Fund grant - the Fund has been seen by the sites as being willing to invest in ideas rather than in a proven track record. This is obviously vital if new and innovative developments are to be encouraged within the NHS. In addition to the grant aid, the King's Fund played an important role in the following areas:

- Networking

Both Hilary Gilbert and Mark Duman were able to assist in publicising the projects within the King's Fund's networks. They provided information and advice which it would have been difficult for the projects to access in other ways. For example, Mark Hughes was linked with the nursing development network. All of the sites reported receiving information or requests for information from a variety of sources who had heard about their work through the King's Fund. Nottingham commented that all of the national impact of their work could be attributed to the King's Fund.

- Continuity

The Fund helped sites to develop project plans and timetables, and reminded them of their aims and objectives, as well as of deadlines they had set themselves. A number of sites noted the importance of continuity within the relationship.

#### c. Project support

There are also areas where the Fund may wish to develop their role further. It would be helpful in future projects to have less meetings and to tell sites about the requirement to attend these at the application stage, so that funding can be built in to the budgets. This is

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particularly important for national initiatives. The Fund may wish to consider holding some meetings at a location more central to the sites which receive grants. It would also be helpful to encourage sites to be less optimistic in their time planning - most sites felt that the projects had taken much longer than they had anticipated.

### **d. The importance of teamwork**

Those sites where a team of people were involved in the development of products seemed to feel more satisfied with the outcome of their projects. This team may only have been made up of two people who took on work related to the project, as in Manchester, or a larger group, as in Nottingham. Sites where one member of staff did most of the work seemed to be find it harder to meet their objectives within the time they had set themselves. The support of an academic department also meant that some projects found tasks relating to evaluation easier.

### **e. Evaluation**

If any similar projects are developed, it would be helpful to state any requirements for evaluation clearly within the initial publicity and within the contract. The King's Fund may also wish to consider building on the work of the sites to develop a validated tool which could be used more widely to evaluate the effectiveness of patient information. It might also be worth considering the use of a two stage funding process for pilot projects in future, with phase one being used to develop information, and sites being asked to apply for an additional grant to evaluate their materials.

### **f. Production, marketing and dissemination**

Because of the nature of the organisations involved in the development of materials (non-profit making and local), sites which have begun to produce and disseminate large numbers of copies of the materials have found this stage to be particularly challenging. The Fund may therefore wish to explore ways in which it can help by advising on possible producers of multi-media technology who offer good value for money and service, and advice about dissemination. The copyright issue should also be clarified early in the application process.

### **g. Promoting patient choice**

Concerns were raised by a number of sites about the degree of choice available to patients regarding their treatment, or the information they receive about it. Hull noted that patients with colorectal cancer have very little choice about treatment, as the only option currently available to most patients is surgery. QMC and Manchester raised concerns about whether patients in all of the sites were offered choices about the medium through which they would prefer information and choice to be conveyed. This is clearly a question which will need to be addressed by future projects - some patients may be at home with multi-media packages, whereas research by Manchester and QMC shows that others, notably older people, prefer written information. There are, then, two levels of choice to be addressed, one about treatment options and the other about the medium through which these options are conveyed.

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### **h. Who should pay for better communication?**

There is no doubt that this element of the Promoting Patient Choice initiative has enabled sites to develop a number of innovative and useful products. Initial evaluation certainly shows their value for patients in offering additional information and clearer choices. However, the development has been costly - all of the sites agree that their organisations could not have funded such developments within their budgets. There seems to be a need for the generalisable lessons, particularly about the methods used for producing good quality information to be disseminated, in addition to the products themselves. There needs to be wider debate about who should pay for the development of more information of this kind.

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### 7. CONCLUSIONS

In conclusion, it seems appropriate to return to the three key questions which this evaluation set out to address.

#### **7.1. Did the sites meet the objectives they initially set? If not, what were the reasons for this?**

All of the sites met most of their aims and objectives. Each site (with the exception of Oxford where there were significant delays in starting the project) now has at least one product. The two main reasons for changing original aims and objectives were patient and peer feedback and finance. These are discussed in more detail in section 2.1. Problems with timescales, technology, copyright issues and a perceived lack of clarity around the requirements for formal evaluation were the major obstacles in achieving the aims of the projects. Once the sites had finalised their materials, large scale production and marketing have also proved challenging to those sites (such as Bristol and Nottingham) who are keen to distribute their products nationally.

#### **7.2. Would the materials have been developed without the financial assistance of the King's Fund?**

It is not surprising that sites viewed the grant as the most important contribution of the King's Fund. All of the sites commented that their projects could not have been undertaken in such a form without this grant. Perhaps crucially, three of the sites - Hull, Manchester and Nottingham - reported that this grant had enabled them to develop a product upon which they can build others. Without this initial grant, it is likely that the products now being planned or developed to promote patient choice in other areas, such as diabetes, breast cancer, stoma care and irritable bowel syndrome, would not be taking place.

#### **7.3. What impact have the materials had on patients and other clinicians?**

The results of the trials now taking place in Bristol, Manchester, Nottingham, Oxford, QMC and the further trials planned in Hull will show more clearly how these products have assisted patient choice. However, initial feedback from the sites shows that patients have been enthusiastic about the materials, and that their knowledge of their condition and the options for treatment has increased.

The products developed by the teams have inspired colleagues to develop products relating to other conditions, and led members of the existing teams to seek funding to develop further products. This was noticeable in Hull, Manchester and Nottingham. At QMC, the lessons learned by the team in the development of patient information are being shared with other staff, thus assisting in the improvement of information for patients about other conditions and treatments. QMC and Redbridge also noted that the project had helped to raise the profile of their service with other clinicians. In Bristol, the project has

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increased interest from other clinicians in the use of computers in the training of medical students.

When evaluations have been completed, sites plan to publish articles about their projects and to make further presentations at conferences. There is likely to be further interest from clinicians in a number of the products as a result.

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### 8. RECOMMENDATIONS

If a similar project is developed in future, it is suggested that the King's Fund build on the success of this project in the following ways:

- 8.1. Advertising initiatives more widely, with long lead times.
- 8.2. Offering telephone or personal contact (project finances permitting) to applicants to ensure that realistic budgets and timescales have been included.
- 8.3. Requiring applicants to check whether their preferred medium for communicating information is also the preferred choice of their patients.
- 8.4. Ensuring that one of the criteria used in deciding whether a site is successful in its grant application is the active commitment from a team of people to work on the project.
- 8.5. Continuing to fund teams with innovative ideas, who may not have a proven track record in their chosen medium.
- 8.6. Considering a phased grant, whereby the first part of the grant is awarded to develop materials with a limited evaluation of process and outcome, and the second to undertake more detailed evaluation of materials through trials.
- 8.7. Offering a higher level of support to those sites to links with an academic department, particularly with regard to issues around evaluation.
- 8.8. Ensuring that any requirement to attend meetings is included within initial information for applicants, and that meetings have clear aims and action points.
- 8.9. Advising sites about the purchase of appropriate equipment once they have finalised their aims and objectives, or offering more information about where to go for this advice.
- 8.10. Ensuring that sites have access to the expertise of staff from across the King's Fund from an early stage in the project, including the King's Fund library.
- 8.11. Identifying or developing a validated tool for evaluating the effectiveness of patient information, and encouraging sites to consider how they will use this from the outset of the project
- 8.12. Offering more advice about the production, marketing and distribution of products, or directing sites to appropriate sources of such advice.



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- 8.13. Ensuring that issues about copyright are clear when contracts are signed with sites.

With regard to the existing initiative, it is recommended that:

- 8.14. Lessons learned about the process of producing information about choices is disseminated, as well as the materials themselves
- 8.15. Debate is encouraged about who should pay for the production of information enabling patients to make informed choices about their treatment or care.

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Bec Hanley  
October 1997

**APPENDIX ONE  
INTRODUCTORY LETTER**

62 Exeter Street  
Brighton  
BN1 5PH

Tel/fax: 01273-553382

Dan Smith  
Bristol Urological Institute  
Southmead Hospital  
Westbury on Trym  
Bristol  
BS10 5NB

15th August 1997

Dear Dan

**PROMOTING PATIENT CHOICE EVALUATION**

I'm sorry I wasn't able to meet you at the Promoting Patient Choice review meeting at the King's Fund last month. I have been asked by the King's Fund to undertake an evaluation of some elements of the Promoting Patient Choice project. I should stress that I won't be evaluating the materials produced. Instead, Christine and Mark have asked me to address the following questions:

- Have the objectives of the Promoting Patient Choice project been achieved? If not, why?
- Would the materials have been developed without the King's Fund's financial assistance and support?
- What impact have the materials had on patients and other clinicians?

I would like to visit you and Anthony Timoney to hear your views on the project, and particularly on the questions outlined above. I will telephone you in the next week or so to arrange a convenient time, but thought that you might like something in writing in advance of my telephone call so that you'll know what I'm ringing you about!

I look forward to speaking with you soon. Please contact me if there is anything you would like to discuss in the meantime.

Yours sincerely

Bec Hanley

## APPENDIX TWO

### OUTLINE QUESTIONS FOR DISCUSSION

1. What were your initial aims when you decided to apply for the Promoting Patient Choice project?
2. How far do you think you achieved these?
3. If you didn't achieve all of your objectives, what were the reasons for this?
4. What, in your opinion, was the role of the King's Fund in the project?
5. What did you feel about the support offered by the King's Fund:
  - during the application process?
  - during the development process?
  - during meetings?

How could they have been more helpful?
6. Did they give you enough of a 'steer', if you wanted one?
7. Did Hilary Gilbert's departure and the subsequent gap cause you any problems?
8. What resources did the King's Fund offer you (time, information, support, money)? Were these helpful? How could they have been improved?
9. What was the impact of the final product on:
  - patients?
  - the organisation?
  - other professionals locally and nationally?
  - voluntary organisations?
  - producers?

What are you basing your opinion on?
10. How much of this impact was due to the King's Fund?
11. Would the project have taken place without the support of the King's Fund?
12. What was the real cost to your organisation, in terms of time and resources?
13. How much press coverage did your project receive? Did this help with:
  - dissemination to potential users?
  - influencing others within or outside your organisation?
14. What do you think we can learn from this project that might help other, similar projects?
15. What are your plans for the project now?



