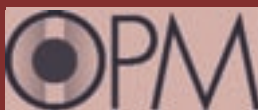


INVOLVING PEOPLE IN PUBLIC DISCLOSURE OF CLINICAL DATA

Report on research with user organisations and patients

Jane Steele



The Nuffield Trust
FOR RESEARCH AND POLICY
STUDIES IN HEALTH SERVICES

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Foreword by John Wyn Owen CB



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CONTENTS

Foreword	4
Summary	5
1. Introduction	7
2. The context for public reporting about the performance of healthcare providers	9
Readiness to be critical	9
National policy on patient choice	10
National policy on the publication of performance information	11
New structures for public involvement	11
3. Roles for the public in improving quality	13
Involvement in defining quality	14
Provision of data for the assessment of performance	14
Input into decisions about the presentation and delivery of information ...	15
Advocates and interpreters of information for individuals	15
Evaluating sources of data	16
Decision-making about own care	16
Raising awareness, educating providers and public	17
4. Motivation to act on quality issues	19
Moving from information to action	20
The pace of change	22
5. Barriers: a summary	27
6. Conclusions	29
7. Strategies for overcoming barriers to public involvement: a summary	31

FOREWORD

The Nuffield Trust has a long standing interest in quality in healthcare, and over the last five years has supported a programme, working with RAND Health, on achieving improvements in healthcare quality through the public release of information about performance. In the first phase of this programme, projects were carried out in the acute sector (on the public release of data on mortality in cardiac artery bypass graft (CABG) surgery)^A and in primary care (on data for clinical quality assessment in general practice)^B. Both these projects focused on the experience of health care professionals, and on developing and improving systems to support the publication of data on clinical performance which would be credible and useful to these professionals and at the same time contribute to the understanding of managers and policy makers.

Jane Steele's report complements these two projects. For it, she drew on the experience and support of RAND Health and the California Healthcare Foundation, and the Trust records its gratitude to these two organisations and to Robert H Brook, Beth McGlynn and Ann F Monroe, for their help. As with the cardiac and primary care projects, this study of involving the public in the public release of information about performance demonstrates the importance for the United Kingdom of learning from experience on the other side of the Atlantic.

It is not controversial today to suggest that improving the quality of healthcare is important. But it has only recently begun to be acknowledged that there is an important role for the public in determining what the priorities should be in this area, and that providers of healthcare should be more directly and publicly accountable for the quality of the services they provide. The difficulties encountered in developing and providing publicly satisfactory information about performance are paralleled by those of involving the public in this process. Jane Steele's report explores the issues involved in bringing user organisations and patients into the process of holding the healthcare system accountable for its performance and providing incentives for quality improvement. The Nuffield Trust is publishing her report as a contribution to the current debate of the place of people in the public disclosure of information about performance.

John Wyn Owen CB
Secretary

September 2003

For a general discussion of the concept that producing public information about the quality of care actually provided will complement the mechanisms designed to improve quality, see Marshall M, Shekelle P, Brook R, Leatherman S. *Dying to know. Public release of information about quality of health care*. Nuffield Trust, London, 2000.

^ASee Fine LG, Keogh BE et al. How to evaluate and improve the quality of an outcomes database: validation and feedback study on the UK Cardiac Surgery Experience. *British Medical Journal* vol 326, 4 January 2003; see also Fine LG, Keogh BE et al. *Improving the credibility of information on healthcare outcomes*. The Nuffield Trust, London, 2003.

^BSee Marshall M, Roland M et al. *Measuring general practice. A demonstration project to develop and test a set of primary care clinical indicators*. The Nuffield Trust, London, 2003.

SUMMARY

For some years, UK government has been placing increasing emphasis on the use of targets and monitoring as a means of improving performance of health service providers, and public involvement in health service provision. At the same time, the public is said to be more demanding and critical of health and other public services. This paper considers how public involvement in information about performance can be harnessed to improve the quality and public accountability of health services. It draws on discussions with eighteen user organisations and a small group of heart patients about the publication and use of performance data.

User organisations already play a number of roles in relation to information about performance. Individual and collective action by members of the public are both required at most stages of the information process, from defining information needs through to using information for individual decisions and public accountability. For many individuals, however, there is a reluctance to become involved in the process and to use information. Lack of choice means people may see information as irrelevant; they are reluctant to engage in an exercise they regard as criticising those who help them, and do not relate wider issues of quality variation to their own circumstances or the use of information. Small, local support groups often see their role as supporting other individuals, not lobbying for changes overall.

Organisations at a national level are much more enthusiastic about involvement, and believe that quality information can help individuals exercise some choice, and raise the quality of health care overall. But organisations also face difficulties regarding performance information. Although many see such information as a priority they do not have the resources to produce information of the necessary standard. Some also perceive the medical profession to be hostile to information use by patients and their organisations.

Individuals and organisations can both be motivated by beliefs that they (or those whom they represent) are at risk from variations in quality and that their failure to act will have a negative effect on the quality of service. Organisations readily acknowledge that variations exist, and hope to use quality information to help establish quality standards across the country. Individuals recognise quality variation in theory, but are fearful to acknowledge they may have had inferior treatment. The belief they have had the 'best' treatment together with a lack of choice means many individuals are currently uninterested in quality information.

For individuals to be motivated to become involved with quality information they must believe that information can address variations in quality, and that such variations may affect them. They must also see that this is a legitimate role for the public to play in the NHS. Organisations may need to be assured that involvement will result in a positive outcome for their particular group, and will be welcomed by medical professionals as an attempt to establish mutually acceptable standards in a supportive partnership.

1. Introduction

Appraisals of experience with the publication of information about the performance of healthcare providers in the US have shown that publication has only a small impact on the actions of health care consumers there. With that in mind, and because the National Health Service is increasing the range and types of performance data it puts into the public domain, this paper considers the involvement of the British public in information about the performance of health care providers.

It considers strategies to make sure that public involvement will serve the objectives of improving the quality of healthcare and public accountability, taking into account the reaction of user organisations and a small group of heart patients to the publication and use of performance data. We consider the roles that the public could play, and may be willing to play, both individually and collectively. We also discuss what may motivate people to take on these roles; to act on those motivations, and the real and perceived barriers to involvement.

Methods

We held discussions with nine user organisations during October/November 2000 and a further nine during May/June 2001, to explore their activities in the areas of quality and performance. User groups and voluntary sector health organisations vary enormously in size, resources and objectives. The eighteen organisations consulted for this paper illustrate this mixture of approaches and resources.

Some groups are concerned with a particular condition or disease; others with a particular group of people, such as children or minority ethnic groups. A few are concerned with issues of interest to all types of users of the health service. Different groups concentrate on different activities. Some carry out social and/or clinical research; some are active in policy development and campaigning; others concentrate on providing information and support to individuals in their particular user group.

It would be a mistake to think of these organisations as forming an homogeneous sector, or one in which it would be easy to reach agreements about priorities or policies. The people

we spoke to also emphasised the difficulties of creating consensus among hard-pressed organisations with limited resources and specific interests. However, the period between the two sets of interviews of the groups had seen a growing awareness across the sector of performance data and public involvement in the health service, following the publication of the NHS plan and other quality initiatives.

A second stage of the work involved discussing the issues with a number of service users, specifically people who had experience of heart disease. Two focus group meetings with the same group of people were held in June 2001. Those attending were drawn from support groups associated with the British Heart Foundation and the British Cardiac Patients Association. We chose to focus on heart disease because the Department of Health had recently made the results of the National Survey of Coronary Heart Disease available. We were interested in the focus group reactions to the information, both as individuals and as a support group.

At the first group meeting the general issues of information provision were discussed. At the end of that meeting the attendees were given performance information to take away and look at before the second meeting, where the information would be discussed. The information consisted of the National Survey of Coronary Heart Disease Patients 1999, web pages from Dr Foster's website about heart services (mostly drawn from the same National Survey) and extracts from the NHS Plan Clean Hospitals Programme. The information samples included coverage of hospitals that the patients had used themselves.

Each person in the group had gone through a serious, and in many cases, life-threatening illness. They were also a group of older patients. These points should be remembered when considering the response of the group as discussed in this paper.

2. The context for public reporting about the performance of healthcare providers

In the UK, the National Health Service has always had to manage conflicts between the different social goals that it is expected to deliver. Long-established public expectations of the NHS include, for example, a belief in universal and equal access to health care. Now, however, an increasing emphasis on patient choice as a policy objective has led some commentators to question how far it is possible to extend patient choice in the NHS, and to wonder if greater choice may obstruct the achievement of other desirable goals.¹

Readiness to be critical

There seems to be a widespread belief that NHS users and citizens are becoming more critical and demanding of the NHS. This is thought to have been encouraged by the development of consumer-oriented policies in public services as a whole which have, over the last 15 years or so, tried to change people's expectations about the 'customer' care they should be able to expect in the public sector.

However, this was not the case in discussions with the focus group for this research, where people were very reluctant to be critical of any aspects of their care, particularly their treatment by doctors and consultants. This was the case even where people had experiences that could be expected to provoke criticism.

"I had the experience of being on a trolley overnight, and, frankly, it didn't bother me in the slightest. Some people see it as something dreadful. I didn't, I was very happy to be there."

There may be a marked difference in attitudes between generations, with younger people much more likely to expect high standards of communication and easily accessible services, and to complain if they do not receive them. Our focus group mainly consisted of older people, which may account in part for their reluctance to be critical. Recent research carried out in Scotland has shown that younger people are more likely to make complaints about their treatment.²

1 King's Fund, *What is the real cost of patient choice*, 2003

2 The Scottish Executive *Public Attitudes to the NHS in Scotland*, June 2001

Some of the organisations also commented that only the more articulate and better educated patients were able, or felt able, to make their views heard. This often excluded groups of people, such as those from ethnic minorities and from more deprived communities.

Organisations often feel that medical professionals do not welcome them giving patients any type of performance data, even where patients seek it. Organisations are willing to be critical where they feel there is poor performance, but this information is usually only given 'off the record'. It is then up to individual patients to make use of the information, often without revealing the source. As many patients are so disempowered within the health system, this 'off the record' information may be of little help.

Many organisations would like a more formalised collection of data, to be available to those patients who want it. This, they feel, would raise standards and encourage treatment centres with a better performance to share their experience and knowledge with others.

A series of well-publicised incidents in which the quality of NHS treatment has failed disastrously is said to have further undermined public confidence. The organisations we visited often related these incidents to the necessity of having good quality information, and the incidents have probably been partly responsible for an increasing willingness of organisations to give priority to this area of work. However, the focus groups did not seem to make a connection between these incidents and an information need.

National policy on patient choice

In a speech on July 16 2003, John Reid, the Secretary of State for Health said, 'the main question is not whether [patients] can and should exercise choice, but whether we can ensure that choice can be exercised within the NHS'. He then went on to say 'if the Government really does believe in equity of access, and it does, then we need to equalise the access to knowledge about hospitals and consultants and ensure that everyone has the same rights to use that knowledge.'

Pilots of patient choice in elective surgery have offered the option of going to an alternative hospital to patients who have been waiting for more than six months for heart surgery and, subsequently, to patients with cataracts and with other conditions. These pilots have not, therefore, been concerned with choice of treatment or choice based on performance and quality, but only on waiting time.

It is clear that the further extension of patient choice will depend on much improved information provision, if choice is to be real and effective. A simulation exercise to explore the impact of plurality and choice highlighted the importance of information and advice for users, and noted that information needs were diverse and complex.³ Many patients would require personal advice and advocacy if they were to exercise effective choice. A recent

³ Strategy Unit, Department of Health *NHS 2005 Report on a simulation to explore the impact of plurality and choice* May 2003

report concluded that ‘Currently, the NHS provides little or no information about quality that patients can use.’⁴

National policy on the publication of performance information

More broadly, the publication of performance information is seen by Government as part of a strategy to improve quality and accountability. Professions and managers are no longer simply entrusted to use resources well. The Government is asking for evidence, in the name of the user and the taxpayer, that they are doing so.

Significant additional funding for the NHS is accompanied by Government demands that performance must improve and that variations in achievement must be reduced.

To make sure this happens, the Government monitors performance, will publish results and intervene where local management fails to deliver the required standards. The onus is firmly on professionals at the local level to improve their performance.

The downside of the current environment is the defensive reaction it can create in professionals, who may see the approach as one of ‘name and shame’ rather than one of support for improvement. They may resist these moves towards public accountability.

The majority of organisations that we spoke to as part of this research often commented on the reluctance of doctors to become involved in performance measurement, and noted that any moves to equip members of their organisations with such information was met with hostility.

In contrast, a small number of organisations had a very good working relationship with the doctors in their field, and performance measures existed and were welcomed, to raise quality and encourage the exchange of good practice. However, these organisations often worked in a relatively small and specialist field, with a small number of doctors, where the supportive relationship had developed over a number of years. Where groups did encounter hostility, all wanted to develop a mutually supportive relationship, they certainly thought there was no place for ‘naming and shaming’ of professionals. Likewise, the majority of the focus group would not want to identify individuals for criticism.

New structures for public involvement

Provision was made in the NHS Plan of June 2000 for the involvement of the public in health services in several capacities. Since then, many new structures have been introduced and others are under development. The overall aim is to give patients and the public a voice in national policy and local services. So, for example, the National Institute for Clinical Excellence has a Citizens’ Council and the proposals for Foundation trusts include engaging the public and patients as members to elect the board of governors.

Many organisations were sceptical of how these structures would work in practice, although everyone welcomed the principle of user involvement. In particular, many felt

4 King’s Fund, *What is the real cost of patient choice*, 2003

that their groups were not a priority for government. These organisations tended to be those whose members had longer-term medical conditions, affecting relatively few people. They feared that these conditions would never be allotted the resources to have any meaningful performance monitoring and therefore their voice in the user involvement arena would not be strengthened.

Most people in the focus group showed no knowledge of the plans for user involvement. For people who had been involved in the hospital system for relatively long periods of time, either as patients or support group members, there was also a surprising lack of knowledge regarding current ways to make their views heard. Most, for example, had no idea of what would happen to any complaint they made. The group were also sceptical about whether the hospital would share 'internal' performance information freely.

3. Roles for the public in improving quality

There are a number of roles that the public, collectively and individually, could play in the use of performance information to improve quality. Public involvement could be part of each stage of the information process: defining what information is to be collected; providing raw data; advising on how information should be presented; evaluating and disseminating information; using information for individual decisions and public accountability.

Collective and individual actions are both important. Some roles require a contribution from both organised groups and the ‘ordinary’ user. Others are for one type of actor.

Individuals are not only consumers or users of services, who can be helped to make informed choices in order to improve the quality of service they receive, but they are also the experts on their own experience and needs. They therefore have key roles to play in defining quality and designing services.

Roles for the public are summarised in the following table. Below the table we discuss the extent to which groups and individuals in the UK are engaged in these roles, drawing on our own research.

	Group or organisation	Individual user
Involvement in defining quality	*	*
Provision of data for the assessment of effectiveness		*
Input into the presentation and delivery of information	*	*
Advocates and interpreters of information for individuals	*	
Evaluation of sources of data	*	
Shared decision-making about own care		*
Raising awareness, educating providers and public	*	

Involvement in defining quality

If measures of performance are to be meaningful to users, they should incorporate users' views and experience about what constitutes quality. The current National Survey of NHS Patients uses a questionnaire that was drawn up after qualitative research into patients' criteria for assessing their experience. In the US, the National Breast Cancer Coalition has worked with the National Cancer Institute to define the essential components of quality breast cancer care and to identify ways of measuring it.

However, this is not a standard approach. A report on Patient-Defined Outcomes by the College of Health in the UK (a consumer organisation) concluded that 'the dimensions and measures used by clinicians and researchers to assess outcomes often do not reflect what patients would say or what they would recognise as relevant if given the opportunity.'⁵

The organisations interviewed also pointed to many non-medical issues that were of concern for their members. Often, these had been neglected in the past. One organisation described a very long process of persuasion, over a number of years, before medical professionals in the field thought quality of life issues important enough to discuss at their annual conference.

Whilst the organisations, therefore, welcomed the recent surveys that address these issues, they felt there was a limit to how transferable the data was from one patient group to another. Even, for example, the findings about non-medical aspects of care during a stay in hospital should not be assumed to be equally applicable to a different group. Organisations felt that each patient group would need their own study to even begin to relate to the information, and under current Government priorities this was very unlikely, and not feasible for organisations to do themselves, despite their desire for such information.

Provision of data for the assessment of performance

If measures of performance are to reflect users' and patients' concerns and experience, then patients have to be prepared to provide the data that will enable such patient-centred measures to be taken. Many people were surprised that the Survey of NHS Patients was able to secure a response rate as high as 60% or more to postal questionnaires.

Certainly, the people contacted to attend the focus group were all willing to attend and eager to help with a project they thought may help others, despite their having some difficulties in seeing how quality information could be helpful. Organisations believed that generally there were many people within their groups who would be willing to provide data. Many organisations already successfully involve people in their own projects. However, organisations did point out that their membership was on the whole drawn from a narrow section of society, often the white middle classes. Organisations are keen to make contact with a wider group, but recognise the difficulties in doing this. Possibly, involvement of patients in data provision will have the same problems.

⁵ Marcia Kelson *Patient-defined outcomes. A paper prepared on behalf of the Clinical Outcomes Group, patient subgroup* College of Health, 1999

Input into decisions about the presentation and delivery of information

Work on both sides of the Atlantic has shown that much of the information which is provided for the healthcare consumer or user is either difficult to use or does not tell them what they want to know, or both (for example, work by Judy Hibbard in the US and by the 'Information about Health Care Effectiveness' project at the King's Fund in London).

Language, layout and content make it difficult for people to interpret information about outcomes and quality. Yet there is experience in health and other sectors of involving users in designing and evaluating information materials and in discussing with them their preferred means of accessing information. This is the type of 'market research' that would be routine in some sectors but can be neglected by public services.

Most organisations have a range of information available for enquirers, and are often innovative in the formats they use. All have embraced new technology as a way of informing people, and have experience of the most appropriate way to present information to people who are often trying to cope with a stressful situation. Many have skills in adapting the more technical documents for lay people.

As discussed below, people in the focus groups found the information presented to them, particularly in the National Survey of Heart Patients very difficult to understand.

Advocates and interpreters of information for individuals

This is an important function for groups. It includes the production of information materials for the public, provision of helplines, websites and advice services. People have difficulty in using comparative data, particularly on issues that they find technically complex or with which they are unfamiliar. Interpretation of performance data for the layperson is an essential step to ensuring it is useful, and used well.

Most of the organisations have advice services that provide guidance on a one-to-one basis, outside the relationship with the healthcare provider. Users see this service as independent, trustworthy and confidential, and are often able to ask questions they don't feel they can ask their doctor or they forget to ask.

Organisations help the user to apply information to their own particular circumstances and preferences and to understand how they might use the information in their own situation. Many organisations reported increasing numbers of people using advice services, usually via a telephone help line, and see this as an essential part of the service they provide. They also see helplines and other advice services as a way of giving people performance information and explaining how they can use it.

The one to one discussion was seen by the focus group as the most appropriate way to give any information about treatment, as it was far more reassuring than written information, and also gave people the opportunity to ask questions. However, they did not see that it could be their own role to impart and discuss any performance information, seeing their role as reassurance to patients who were going through a similar experience to them.

“I feel that we can make a difference to the people who have actually had their operation by going to see them and explaining that there is a hereafter.”

Evaluating sources of data

For published data to be seen as useful, its source has to be seen as reliable and trustworthy. Users will be suspicious of information coming from those they see as having a vested interest in it, whether this is financial or otherwise. Aware of the current climate of anxiety in the NHS about performance measurement, consumer organisations may doubt the integrity of the data that services provide about themselves. The involvement of these groups in assuring the quality of data and in endorsing it could add to its value for the public.

Further, as more organisations become involved in the collection and publication of performance data, it is likely that different sources will appear to contradict each other. This is already happening in the US. These apparent contradictions can result from the types of data used, the methods of collection and interpretation. But these differences need to be explained and interpreted for the public by well-informed groups.

People are already dubious about the sources of available data. The focus group questioned the methodology behind the data and seemed more inclined to question its validity than to discuss the findings. This could have been a reaction to a lack of understanding of the data, but could also have been due to a feeling that something coming from the NHS about hospital performance is not to be trusted.

Some organisations believe that data should be collected by an independent source, rather than by the NHS. This could be a role for their own organisation, but not necessarily. Many said that users of their organisation felt they could trust them to be honest more than they could trust the NHS. Organisations did not seem to believe there is any reason to think that the NHS would not attempt to collect valid and accurate data, but did believe that some data already collected was inaccurate for other reasons.

Decision-making about own care

Users might make two broad types of decision about their own care, using information about performance. The first has to do with the choice of treatment, based on evidence-based information and the second has to do with the choice of a provider, based on information about outcomes and performance.

Choosing treatment

Individual patients are naturally concerned about their own situation: what is the best treatment or course of action for me, bearing in mind the outcomes that are important to me? As trends towards patient involvement in decision-making and evidence based care continue, there is increasing demand for evidence-based information that enables the patient to discuss, with clinicians, the approach they want to take. User groups are

concerned about improving the quality of this type of evidence-based information for patients, and with ensuring that clinical guidelines (which should themselves be informed by user views) are available in an accessible version for patients. The choice of treatment requires information about ‘what works’, and not primarily about ‘how well does this provider work’?

People are sometimes given a choice of treatment, but have so little information on which to base the decision that such ‘choices’ sometimes only confuse and upset people.

“My husband was asked what type of valve he'd like. How do we know what types of valve are available, and what the differences are between them?”

Organisations often spoke of the need to empower people, to give them the information, and the skills to use it, to make such decisions about their own healthcare. This is seen as one of their prime functions, as there appears to be a growing realisation that groups should help people to take control of their own care, rather than making decisions for them. This is done by giving people information, but also empowering them with the confidence to use the information.

Choosing a provider

Unless choice is a practical reality, people see performance information as at best irrelevant, and at worst very alarming. Most people in this research would simply not want to know if the system does not allow them to act on the information.

“This information would be all right if we could choose the hospital, but if you consider that you have one thrust on you, it doesn't really mean a whole lot”

Most organisations also commented on the lack of choice available. Some organisations are also concerned that the lack of choice means that the publication of comparative data will only frighten those patients who have to use a poorly performing provider. Nonetheless, all still thought that performance data in some form should be available.

Raising awareness, educating providers and public

Experience and opinion in both the UK and the US suggest that to rely on decision-making by the individual consumer, as the sole route to improving quality, would be too optimistic. While it should be possible to increase the number of individuals who seek and use quality information about healthcare, the impetus of individual decisions will not be sufficient to drive up standards.

Consumer organisations therefore have an important role to play, targeting different stakeholders as a means of influencing providers. They could work with providers to develop measures of performance and reward good performance. They could lobby politicians and policy makers to press for policy change. They could use the media to raise public awareness about variations in quality, with the intention of creating public concern, or an impression of concern, that will impel the system to improve itself. In fact, anecdotal accounts in newspapers may do more to shape public perceptions about quality than objective, comparative data.

The focus group of patients, who were already organised into self help and support groups were strongly opposed to becoming, as a group, involved in any type of lobbying to influence quality.

“It’s surely not for the public to see that the standard of the hospitals is brought up - that is for the National Health Service generally to say this hospital isn’t doing well enough”

They also felt that they may not be ‘allowed’ to address any such issues, and they may be prevented from doing their other work as a result.

“We’re already going into hospital to speak to the patients. If we were to speak to the management, they may take umbrage and not even give us the time of day.”

However, as the discussion developed the group did begin to see a role for the public in monitoring performance, but only regarding what they saw as ‘non-technical’ issues. Non-technical issues were very narrowly defined, for example, cleaning was non-technical but waiting times were not. They also only saw this role as being carried out at a local level, perhaps with a system similar to prison visitors.

“If we could do what we’re doing now [talking about performance data] in our local hospital, you’d be making it more parochial, and you might get something done in your local hospital.”

However, at no time did anyone suggest that their own particular group become involved in this type of role despite suggestions that other groups may already exist who may take this task on.

Whilst limited support for this type of action exists, people are still very reluctant to become involved in anything they believe is critical of those who are seen as having saved their lives. As the group discussion developed, people would share anecdotally some difficulties they had, such as communication problems with doctors, but were unwilling to do this outside of an informal discussion. They also did not seem to see that this type of criticism done in an organised way may help to raise standards overall. Perhaps if ‘officially’ sanctioned, people may feel they have been given ‘permission’ to be critical, and would be more willing to become involved. They may also be willing to move into ‘technical’ areas if they see improvements in ‘non-technical’ areas resulting from their efforts.

The organisations did see one of their primary roles as raising awareness in providers, the public and patients. Despite the reluctance of some medical professionals to become involved with user organisations, most saw themselves as providing a bridge between professionals and users, helping to set quality standards and patients charters which were acceptable to all, in a bid to raise standards. In some sectors this has already been successful. Other organisations are not as advanced. Some are confident that they will succeed, but for others it is still a struggle to work in partnership with medical professionals, and have their condition recognised as a priority.

4. Motivation to act on quality issues

Motivation can come from ‘fear or faith’ - fear that harm will result from not acting or faith that action will produce a beneficial result. Motivational messages can be expressed in terms of fear or faith and there is some evidence that messages with a negative spin (based on fear) are more effective in health education.

It seems that people have to believe four things simultaneously before they are moved to act on quality issues. Expressed as fears, these are the beliefs that:

- variation in quality exists, and I may not get the best quality;
- failure to act will have a negative effect on health;
- the harm that will result from failure to act is greater than any risk which is perceived to be associated with the action, and;
- the harm that will result from failure to act is greater than the burden of time and effort involved in taking action.

Those in the focus groups did not seem to have any of these fears, or if they did they were not willing to share them with the group. Although people recognised a variation in quality could exist in theory, they all felt they personally had had the best quality care available, and so did not believe there was any reason to act. They seemed to be fearful of recognising that, if variation in quality exists, then they may not have had the best treatment.

If they did have any complaints these were seen as very minor, compared to the seriousness of their medical condition and the difficulty of the doctors’ job. The one person in the focus group who had asked questions and tried to assess quality for herself was regarded by many others in the group as wasting the valuable time of doctors:

“I think it is very frivolous to ask people who are obviously overstressed ... I’m sorry I don’t go along with that at all”.

There was a feeling that as a patient it is necessary to be worthy of treatment. Therefore, taking any action may do more harm than good, you would be perceived as a ‘troublemaker’ and may not get the best treatment. Also, the NHS is seen as a large,

bureaucratic and unresponsive organisation. Making yourself heard takes so much time and effort, for very little result, and is simply not worth it.

Most, if not all, people attending the focus groups would have to go through a sea change in attitude before they would be willing to become involved in quality issues. This may not be impossible to achieve, but would take a long educative process and perhaps a clear signal by the medical profession to the public that they welcome quality information and public involvement in the information process would be a good idea.

Organisations recognise that variation in quality exists, and are very concerned that members of their group may receive varying qualities of treatment. However, many groups have only anecdotal evidence regarding quality, and feel unable to lobby for changes without firm performance data. They see, more than individuals, the consequences of a variation in quality and the failure to act. Some groups described instances of people only finding out by chance that their quality of care was far inferior to others with the same condition. For individuals to be aware of quality variations there may have to be a very obvious difference, such as 'post code prescribing'.

Moving from information to action

Motivation is not sufficient on its own to produce action. People also have to be enabled or equipped to translate these motivations into action. The impact of strategies to encourage public involvement with the publication of performance information will depend on the capacity of the strategies to convert motivation into new types of behaviour.

Here we have drawn on theoretical and empirical work across multiple domains by Everett Rogers, who outlines five steps in the process by which an innovation gets translated into a decision, by an individual or group, to implement the innovation⁶. In this case the innovation is the publication of information about performance. The five steps which strategies would have to facilitate are:

- Knowledge: learning about the innovation
- Persuasion: forming a favourable or unfavourable attitude towards the innovation
- Decision: activities that lead to choice of whether or not to use innovation
- Implementation: putting the innovation to use
- Confirmation: adoption or rejection of the innovation, based on the consequences of using it.

Knowledge

The knowledge stage involves creating a need and/or responding to a demand for information about quality. If people are unaware that variation in quality exists, then they

6 Everett M Rogers *Diffusion of Innovation* Free Press, 1995

will not realise they need information about it. If people are already dissatisfied with quality, they may demand information to help them resolve the problem.

Currently people appear to have no real need or demand for quality information. Whilst recognising that variation exists, they do not feel that they have had inferior treatment, do not see it as their place to use information to improve quality and do not connect the existence of information with a possible way to improve quality. For many, the fears surrounding their illness, coupled with having no choice in their place of treatment mean that they simply do not wish to know any information.

Organisations, however, appear to have an increasing awareness of the need for quality information and how it can be used. They are well aware that variations in quality exist, and that performance data can play an important role in contributing to debates about quality and ultimately raising standards. Despite the recognition of their needs for quality information, few were aware of information currently in existence. Only two of the organisations interviewed in the second round of interviews were aware of the Dr Foster's website, and most know little about the National Patients Surveys, apart from those groups who were directly involved.

Also of concern to organisations is the problem in distributing information, both about the work they do and the information they can give to people. The concerns are that most patients are not told that support groups are there to help them, if they wish to use the service. Medical professionals seem at times reluctant to refer patients to an appropriate organisation, and/or distribute information on their behalf. Many organisations see the distribution of information as one of their biggest challenges. This is likely to continue to be the case with performance information, unless some formal mechanism for distribution is set up.

Persuasion

In the persuasion stage people have to be convinced that the advantages of using the innovation will outweigh any disadvantages. The opinions and experiences of peers seem to be the most persuasive influence, but it may still be difficult to cross the gap between changing people's attitudes and persuading them to act.

The people in the focus groups did not see any advantage in even having the information, as they did not see how they could use it at all. People may see an advantage in the information if they believed they had a real choice, or if they see an overall raising of standards as a result of the information. However, it is likely to take a long time to convince them of the advantages.

Organisations do seem convinced that information use will bring advantages that outweigh disadvantages for them, such as time and resources needed to make use of the information. Those interviewed in the second round of interviews were more aware of quality information and seemed more likely to seek resources to act on it.

From the discussion with organisations and focus groups it is possible to predict how the first two steps of knowledge and persuasion can be achieved. The final three steps below

can only be discussed theoretically at this stage, as neither organisations nor individuals have reached this point in their thinking or actions.

Decision

A decision to act is more likely if the innovation can be tried on a limited basis rather than adopted in full.

Implementations

The implementation stage is the point at which behaviour change takes place. For example, an individual uses information about quality to choose treatments or providers.

Confirmation

At the confirmation stage the individual or group decides whether or not to continue using the innovation. This depends on whether it conferred the expected benefits, is acceptable to others and can be integrated into the relationship with the health care system.

The pace of change

The rate at which the innovation - public involvement in performance information - is adopted depends on several factors:

- relative advantage: how much better is it than the idea or approach it supersedes?
- compatibility: how compatible is it with existing values, past experiences and needs of the potential adopters?
- complexity: how difficult will it be to understand and to use?
- trialability: can it be experimented with on a limited basis?
- observability: how visible are the results to others?

Organisations have already accepted the benefits of performance information and, depending on time, resources and so on, they are likely to move towards using performance information. Individuals, for the reasons discussed in this paper seem to have very little awareness of such information, and seem on the surface to have little interest in its use. Therefore the pace of change for individuals, certainly for some groups of individuals, is likely to be much slower than for organisations.

Relative advantage

There is, as yet, insufficient evidence to demonstrate the relative advantage of information about performance in health care over an environment in which there is limited or no information. People in the focus group did not see performance information as advantageous, particularly as they did not believe the system allowed for choices to be made using the information.

Organisations also recognise that for individuals the information had limited value due to lack of choice, although they did feel it was more helpful than those in the focus group. It was difficult for organisations to gauge how advantageous the 'off the record' information had been as few people reported back. In the absence of feedback, it was often assumed that the information had been helpful and people had ultimately been happy with their treatment. Much seemed to depend on the ability of the individual to use the information to their advantage in the current system, which some people find very difficult to do.

Also, organisations saw the information as advantageous to their group as a whole, not only individual members. The present system gives little help to them to attempt to raise and unify standards, and the production of quality information would. They see public involvement in all aspects of information production as an essential part of this process.

Compatibility

Information about performance appears to be incompatible with several aspects of people's existing values and needs. The information may not match people's decision making processes, in which non-clinical factors such as ease of access, closeness to home, familiarity, communication, continuity of care may be seen as more important than clinical outcomes. People may not trust the sources of information or see them as relevant, preferring the subjective opinions of individuals they trust. The setting in which the information is to be used, such as a dialogue with a provider who does not expect the patient to express choices, may inhibit action.

The focus group members overall did not appear to identify with the overview of hospital services given in the statistics, despite one set of statistics being about a hospital that many of them had attended, and based on responses from patients with the same disease as themselves. The discussion inevitably turned back to anecdotes whenever performance information was being discussed, and people had great difficulty in relating to anything other than personal stories. Our research with heart patients show that, even where there has been consultation, a similar type of patient may not always relate the information to their own situation. The people in the focus groups did not relate the experiences of those who responded to the questionnaire to their own, although some of this difficulty could perhaps be alleviated by presenting the material in a more user friendly way.

On the surface it seemed that clinical outcomes were the only thing of importance to this group of people, they were simply glad to be alive and nothing else mattered. But as the discussion developed it was clear that non-clinical aspects of care, such as communication, cleanliness and mixed sex wards were very important to many of them.

"I think there is a certain contempt. I was asked if things should be discussed with my daughter, but I said, no! you discuss it with me!"

Organisations are actively engaged in quality issues, but can be more concerned with access, evidence-based care, shared decision making and so on than with performance information. They need the opportunity to continue to develop their thinking about how performance information fits into their other policy objectives, especially as some are

concerned that an emphasis on consumer choice as the route to quality will erode equity. On the whole, consumer organisations advocate partnership and engagement as the preferred forms of public involvement in the NHS, alongside an element of individual choice, and may be more interested in establishing minimum levels of performance for all providers to meet.

Organisations also question whether information that currently exists, or which they envisage may be collected, meets their needs and that of their users. They are concerned that information may be simplistic, inappropriate, arbitrary and unreliable. There is some concern about a risk of rushing into performance information without truly considering what is the most suitable information for the very diverse groups of service users in the National Health Service. They do see a place for performance information, but with reservations, which must be addressed before any information system is put into place.

Complexity

The language of performance and quality issues is technical and can seem excluding, to both individual members of the public and consumer organisations. The task of interpreting and using information about performance can be a complex one, which requires skill and support. The evidence on some issues may be unclear or ambiguous. For example, it may not cover all the user's interests or it may suggest that a provider performs well on some things, poorly on others.

As discussed above, users in the focus groups say now that they do not feel they can tackle 'technical' issues. If they already feel that many issues are too technical for them any information will have to be presented in a very user friendly way. The information that they were given at the group meeting was not seen as being particularly well presented, especially the bar charts in the National Heart Patients Survey. Most people agreed when one member of the group commented;

"I found it difficult to assimilate any of it. Far too much information for a brain like mine to absorb! I'm not trained in that way at all; if I had been, I might have been able to make sense of it ... it wasn't written for the layman; it was written for the experts in their field."

More popular were the more simple colour codings of the Clean Hospitals Programme (where hospitals are coded red, amber or green depending on their state of cleanliness). There is a difficult balance to strike between presenting information in a simple way, but giving people enough so that they are not simply left asking more questions. The Clean Hospitals list was easy to understand at a glance, but left people asking many questions about what lies behind the various codings.

Organisations will probably be less concerned for themselves regarding the understanding and interpretation of information. They normally have people within the organisation who have the skills to explain information for others in the organisation and for service users.

Trialability

Certain situations offer an opportunity to experiment with using performance information on a limited basis. People need time to consider the information and to experiment without a perception of undue risk. We can imagine this happening where people are living with long term conditions and have become experts in their own conditions and requirements, and where people are involved in routine care for which there is unambiguous information, rather than in emergencies.

Some organisations where people have long-term conditions are already using performance information in this way. For example, some use performance information for accreditation schemes or assessment schemes.

Observability

People are influenced by the experience of their peers or others they trust, whether these are friends, families, members of the same support or user group or organisations similar to one's own. Evidence of success, (for example, user satisfaction or the adoption of outcome measures devised through public involvement) will be a powerful tool. At present, many consumer organisations, which have put considerable efforts into partnership initiatives with the NHS, feel frustrated that the service is apparently unable to translate much of this learning into practice.

It may take more than someone else's success at using information to convince individuals they should follow. People who attempt to exercise choice are in a small minority, and others feel that individuals who 'complain' are wrong to do so.

5. Barriers: a summary

The following table summarises the barriers to public involvement in performance information and quality improvement:

Individuals	Organisations
Awareness Limited, but growing, awareness of the issue	Awareness Variable awareness of the issue
Resources Lack time and money to access information	Resources Numerous different demands on organisations with limited resources
Timing Very often, the time when people most need information is when they are least able to collect, absorb and act on it	Timing Organisations may have to focus on short-term priorities rather than on issues which require action over the longer term
Relevance Measures of performance may not seem relevant to the public, may not reflect their priorities	Relevance Measures of performance may not seem relevant, may not be based on public consultation
Credibility The providers of information may be suspected of vested interests which distort its collection and presentation	Credibility The providers of information may be suspected of vested interests which distort its collection and presentation
Other priorities In other aspects of their life prevent this getting attention	Other priorities Many other pressing issues, a climate of enormous change in all aspects of NHS.
Evidence What evidence do people have that taking action will really improve their situation?	Evidence If they get involved, how will they measure the success of their efforts?
Skills People need skills to find and use the information e.g. interpretation, assertiveness, knowledge of 'the system'	Skills Organisations need skills to interpret and act on information in several different ways
Relationships This approach may be experienced as a large, inappropriate and risky change in the patient's relationship to their doctor. If they try it, it may be rejected.	Relationships There may be nervousness about how activity in this sphere will change their relationships with both their users and the professions
Other motivations Other aspects of their healthcare e.g. closeness to home, familiar providers, may be more important	Other motivations Perverse incentives may be a factor e.g. sources of funding for the groups
Uncertainty About their role in relation to the NHS and what it is appropriate to expect and therefore what action may be appropriate.	Uncertainty Sometimes the evidence is ambiguous or not available
Intensity The effort required seems too demanding and intense	Intensity Long-term, intense and demanding effort may be required.

6. Conclusions

While there is still a way to go before user organisations become actively involved in performance information, there is evidence of their increasing interest in quality and greater readiness to engage with performance information as a tool for quality improvement. They need to develop a role for it that fits in with their organisations' objectives and ethos.

There are a number of possible roles for organisations to play. Many of these activities are already taking place, to some extent. They are particularly interested and active in defining quality, but have difficulty in collecting data and in seeing how this could be achieved. They are experienced in the presentation of information to users, and in providing advice and support, particularly on choices of treatment. They are well-placed to educate the public and create awareness.

Our findings from the work with heart patients are quite different. It is important to note that these are older people (the great majority were retired and some were quite elderly). We suspect that younger people may have different attitudes. They had also experienced very serious illness; many referred frequently to their good fortune in 'being alive to tell the tale'. This seemed to contribute to their deferential attitudes towards the NHS.

This group of people did not see it as their place, either as individuals or as an organised support group, to have a role in information about performance and quality. They felt that, given that they had no choice of provider, such information would be irrelevant and could even be distressing. Even were choice to be a possibility, they would need to be encouraged and helped to understand more about their own health situation and assisted to make appropriate choices.

There was a more deep-seated belief amongst the great majority that they did not, and could not, have the capacity to deal with such issues. Further it was not their role to get involved as this was an 'internal' matter for the NHS, in which the public had no part to play. Finally, their view of the NHS as a large and unresponsive bureaucracy that protected its own people meant that they could not hope to make a difference, and that any attempts to do so could even misfire on them as individuals or a group.

However, as discussions developed over our two meetings, people began to envisage a role for an independent body or individual who would monitor performance information, deal

with complaints and take up issues with healthcare providers. They saw this as a lay role, which should be confined to the non-technical issues that they had identified as important to them, such as cleanliness. The body should have an authority within the NHS. It was not a role that they saw for themselves as a self-help or support group.

The motivation to get involved in performance information is thus much greater amongst user organisations than it is amongst the types of individuals that we consulted.

Organisations are much more aware that variation in performance exists and show a growing interest in tackling this. The pace of change is picking up but is not fast. The availability of more resources and the sorts of strategies outlined below could have a significant impact.

We suggest that a strategy of working with organisations will have the most impact in the short and medium term, and that the process of informing the public and changing attitudes will be a slower process. However, we conclude with a caveat about the nature of our particular focus groups and a reminder that other groups may have rather different attitudes. Further work with different user and age groups will be important to understand these issues more widely.

7. Strategies for overcoming barriers to public involvement: a summary

Individuals	Groups
<p>Awareness Facilitate an informed debate in the media</p>	<p>Awareness Provide opportunities for organisations to come together to discuss</p>
<p>Resources Make information more readily accessible in different media</p>	<p>Resources Help groups to develop approaches that match other priorities. Facilitate funding for specific projects</p>
<p>Timing Identify and target situations where it is least difficult for people to adopt new approaches</p>	<p>Timing Identify some short-term or staged projects which show early results</p>
<p>Relevance Provide opportunities for people to take part in developing measures</p>	<p>Relevance Work with groups to provide influential opportunities for public involvement</p>
<p>Credibility Provide independent advice on the reliability of data. Ensure the same data sources are available from different places e.g. government, user groups</p>	<p>Credibility Seek their involvement in quality assurance and endorsement of the data</p>
<p>Other priorities Raise awareness of the issue through media</p>	<p>Other priorities Bring groups together to discuss the importance of the issue and its relationship to their other objectives</p>
<p>Evidence Generate examples of 'making a difference' and publicise them</p>	<p>Evidence Evaluate efforts and experiments, demonstrations of impact</p>
<p>Skills Improve the presentation of information. Encourage media coverage of its uses and meanings. Provide supportive and independent advice services</p>	<p>Skills Provide opportunities for organisations to learn from each other about how to use the information</p>
<p>Relationships Encourage and publicise examples of action. Suggest techniques.</p>	<p>Relationships Suggest different options and approaches. Provide ongoing opportunities for groups to share experiences and build coalitions</p>
<p>Other motivations Put performance information in context. Discuss the relative importance of different factors.</p>	<p>Other motivations Provide opportunities for involvement which appears less risky</p>
<p>Uncertainty Facilitate a public and media debate about public values and expectations of the NHS</p>	<p>Uncertainty Start with areas where the evidence is clear</p>
<p>Intensity Provide support for actions which require less effort</p>	<p>Intensity Suggest short-term, manageable efforts at first</p>

