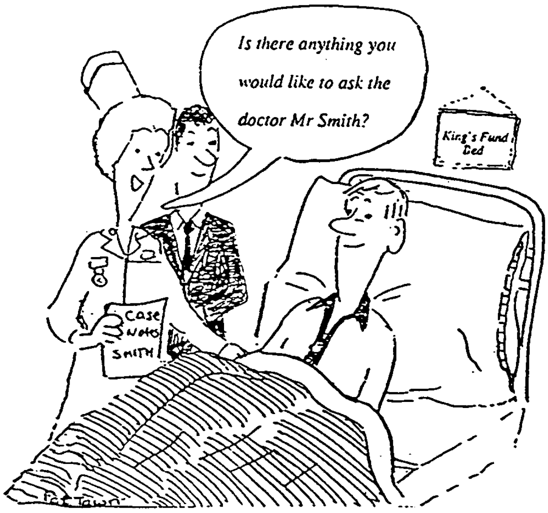
PATIENT EMPOWERMENT

A workshop held at

Scarman House, University of Warwick

5 and 6 April 1995

Report by Christine Farrell and Hilary Gilbert



Organised by the King's Fund Centre at the request of
The Patient Empowerment Focus Group of the NHS Executive

The KING'S FUND is an independent charity which seeks to stimulate good practice and innovation in all aspects of health care through service and organisational development, management education, policy analysis, audit, and direct grants.

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Introduction

Early in 1995 the Patient Empowerment Focus Group of the NHS Executive commissioned the King's Fund Centre to run a workshop on patient empowerment.

The terms of reference set out by the Executive are given below.

The seminar will aim to address the following issues:

What is meant by patient empowerment - both at a theoretical level and through practical examples of empowerment in practice. This might be informed by thinking and practice in both health and non-health settings.

How far are the building blocks already in place throughout the Patient's Charter, quality work, research and development links etc.

Does the NHS need a policy and strategy specifically for patient empowerment? What are the implications for health policy and practice?

If so, how far can patient empowerment be taken in current circumstances - what are the limitations operationally, politically, financially, sociologically?

How can patient empowerment be achieved - what would an implementation strategy contain; what work needs to be done and by whom; which relevant work is currently being done [in the NHS, the Department of Health and elsewhere]?

How will we know the strategy is successful - what measures or indicators or success are needed and/or available?

The seminar itself was designed to meet three objectives:

- to develop a working definition of what is meant by 'patient empowerment'
- to identify probable component parts of a strategy to achieve patient empowerment in the NHS and identify where responsibility for their achievement should lie
- to take a preliminary view of indicators of successful outcomes of the strategy.

The workshop took place on 5 and 6 April 1995. The participants came from a wide range of agencies working with patients and with expertise in a specific area of work related to empowerment. Several people were invited because of their own patient experiences. A list of participants is at Appendix I. Several organisations and individuals who were invited were unable to attend.

This report summarises the proceedings and presents the main recommendations which emerged. Most of the time was spent working on two themes:

- **the empowerment of individual patients receiving care and;**
- **the empowerment of user organisations and the public to represent their views to policy and decision-makers.**

There is much common ground between these two themes but also some important differences. The decision to separate the two was made on the basis of a survey of recent literature on the subject. This survey was sent to all participants before the seminar to inform the debate. Participants were asked to submit written replies to five key questions about the process of patient empowerment [listed at Appendix II]. The replies were analysed and presented at the seminar. The literature survey and the analysis of participants' views of key issues, revealed many different approaches to and perspectives on the subject of patient empowerment. The seminar itself discussed principles and mechanisms which had the support of many participants. However, the recommendations themselves cannot be said to have the support of all participants since there was insufficient time to discuss them collectively.

The three sets of recommendations presented in this report represent the outcomes of the two groups working separately. The third set has been produced subsequently, to demonstrate where there was common ground between the two.

The Seminar

Sir Cecil Clothier, Chairman of the two day event introduced the first session with the following remarks.

Whilst it is important to keep a critical eye on established traditions, the deferential attitude with which all professions were formally regarded has now been swept away. Respect for the sapiential authority of doctors - the 'Doctor knows best' approach - has been dealt a blow by mass communications. The media tend to demystify all authority; reverence disappears along with the sense of 'magic'. The pendulum swings between extremes of deference and its opposite. Most services are more client-centred nowadays, but medicine is slow to change. Sir Cecil's experience as Health Service Commissioner would suggest that young doctors may find change as hard to achieve as older consultants. Although professional attitudes can present problems, too much cynicism and questioning tends to inhibit development and innovation in medicine. Society has become greedy, and real problems have arisen as a result of the growth of litigation.

Both sides should talk to each other more. Sir Cecil recalled the words of a senior doctor: "Always encourage your patient to talk; sooner or later they will tell you what is the matter with them". Patients should be encouraged to speak out more; many fail to do so from timidity or a sense of gratitude. Sir Cecil referred to his own monograph: 'The Patient's Dilemma [1], and welcomed participants to the event.

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1. *Sir Cecil Clothier: 'The Patient's Dilemma'. Rock Carling Fellowship Monograph. London Nuffield Provincial Hospitals Trust, 1988.*

The Literature Review

Hilary Gilbert presented a summary of the main points of a literature review on patient empowerment carried out for the seminar.

The NHS Executives's original brief was to come up with a definition of patient empowerment; to look at both the theory and the practice of patient empowerment; and to consider whether a strategy and policy for patient empowerment were needed in the NHS. In looking at the literature the following questions were borne in mind: What is patient empowerment? What issues does it raise in theory and in practice? What structures are already in place to address it and are they working? And if not, what needs to be changed, and how should it be done?

Definitions

The definitions selected in the literature review aimed to fit the purpose of the seminar - to inform and clarify discussion. They were selected as a basis for common ground, since there is no consensus about the people referred to or the activities they are involved in.

The following definitions are a synthesis of those which appear in the literature review.

- **Patient empowerment is used to describe the process of redressing the balance of power between the professional and the individual receiving care in a provider context**

- **Patient is used as the preferred term for individuals receiving health care, in recognition of the passivity which traditional structures impose upon people in that setting**

- **User is chosen as the preferred collective terms for people currently using services, whether in provider or commissioner context**

- **Participation is used to define the fullest level of activity at which people can contribute to service planning and delivery**

- **Public engagement is the preferred term for the commissioner function of bringing the wider community of citizens, tax-payers and potential users into questions of public interest.**

The rest of the survey aimed to address the theory and practice of patient empowerment. The subject matter was divided into issues affecting individuals as they receive care in provider settings, and collective issues which are more the province of commissioners.

Policy Framework

The survey begins by noting the policy thrust of the NHS Reforms in establishing the patient in the role of consumer - someone who exercises choice and thereby drives the market. Several commentators have challenged this approach as it applies to the NHS, noting that consumers of healthcare do not have control of resources and cannot exercise real choice in the sense of someone purchasing other services or commodities. It has been seen as questionable to give patients consumer rights through the Patient's Charter in the way that service delivery to other consumers might be guaranteed.

The review also asks how far those rights are supported by the courts - either in terms of rights of access to services, or to redress in cases of alleged negligence or medical accident. It also notes that current practice supports traditional views of doctor-patient relationships.

It then goes on to look at policy and practice in three main areas: the doctor-patient relationship; service delivery at provider level; and wider issues that commissioners need to address.

In the doctor-patient relationship, it draws on an interesting body of work mostly done in the United States. In this country the amount of information a doctor gives is considered as much a matter of clinical judgment as the treatment prescribed. Doctors have traditionally not been good at giving patients as much information as they want. However, the American research shows that patients do want information, both about their condition and treatment, and that they may feel better if they are given more information and feel more in control. Some people also wish to take an active part in decision-making about their care, and those who do, may feel better faster than those who do not. What is more, doctors can encourage people to ask for information and play a more active part by their own manner and attitude. So doctors can affect the outcome of care by their manner as well as by the exercise of their professional judgment.

It appears then, that information is good for your health. One of the most important services doctors can provide for their patients is good, unbiased, evidence-based information about the risks and benefits of different treatment options, so that people can have enough information to decide what is best for them. Commissioners and providers too have an increasing role to play in developing services which get good quality information to patients, their relatives, and the wider public.

Service Delivery

At provider level there is less generally applicable evidence to refer to about what works and what does not work in service delivery: initiatives tend to be tailored to local needs. But the Health Service Commissioner's Epitomes provide a sobering account of shortfalls in the service, and instances of the way the NHS can totally disempower people. There is a range of books detailing the cultural and religious needs of people from different minority groups, and the requirements of people with differing special needs but the contrast with the service they actually receive is often all too striking.

At provider level the Patient's Charter is the main policy initiative, and that - coupled with quality strategies and other initiatives - is making a considerable impact. But how can providers be sure the Charter is addressing the right issues, and really works to make empowerment a reality? One way is by careful examination of complaints, and the introduction of responsive complaints procedures [Publication of Acting on Complaints post-dated the review].

Another way of helping services to meet people's needs is by asking users themselves to participate, both in monitoring non-clinical service delivery through surveys, focus groups etc, and in assessing the quality of clinical care. Patients can get involved in research -participating in clinical trials and even contributing to their design. They can take a more active role in clinical audit. Researchers can use patient-assessed outcome measures, and the more subjective approach of consumer audit can be adopted. Patients and user groups can also help shape professional attitude by involvement in training doctors, and by accepting doctors as honorary members of health-based self-help groups.

Finally there is the vexed question of how NHS users and funders - the wider public - can be empowered by having a greater say in decisions that affect the shape, quality and quantity of services available to them. Important lessons have been learned about what does and does not work operationally. There must be real commitment at the most senior level in any organization. Information must be shared openly and honestly from the start so public expectations are clear. Users must have a say in setting the agenda.

But the question of accountability is unresolved. There is no established good practice for anyone wanting to involve the public in prioritizing decisions, much less rationing. No one has yet come up with a practical way of empowering the citizens who fund the NHS.

Participants' Written Responses on Definitions and Mechanisms for Patient Empowerment

Christine Farrell presented an analysis of participants' written responses to five key questions [see Appendix II] related to definitions, factors which influence patient empowerment and mechanisms which work in practice to encourage and remove barriers to patient empowerment. The analysis is based on replies from 29 participants.

Almost everyone who submitted a written response agreed with the definition below which is a composite of the most commonly offered definitions. The two most frequently used phrases in the responses were: Informed decision/choice; and active partners.

Definition of Patient Empowerment

A process [or processes] of giving people the knowledge and skills to make it possible for them to become active partners, with professionals, in making informed decisions/choices about their own treatment and care: and of enabling communities to exert informed influence on NHS service planning, development and delivery.

Two important riders also emerged:

1. Not everyone wishes to be involved in this way and the process must recognise this.
2. Not everyone starts from the same place and the process should take account of different needs.

There was much more similarity between definitions offered by workshop participants than there was between the many definitions used in the literature. Participants agreed that the definition above could be used as a working definition to which most people in the field would subscribe.

Factors contributing to individual patient empowerment

The attitude of health professionals and good quality information for patients were the two most commonly identified factors in the empowerment of individuals. Support for patients was mentioned by about two thirds of the respondents. Resources were mentioned specifically by far fewer people but there are, of course, resource implications in the first three categories. The points mentioned within the categories represent all the points made but some were mentioned more frequently than others.

Attitudes of professionals

- respect for patients' rights/views
- equal partnership - recognition of the value of patient experience/views/expertise
- encouragement of expression of patient feelings, concerns
- listening - giving adequate time
- communication - willingness to share information/power/decisions

Information for patients

- about treatment outcomes, risks and benefits
- which is unbiased, relevant and consistent
- in clear, accessible language(s)
- available in verbal, written, taped or video format as appropriate

Support for patients

- education to develop confidence and skills to communicate with professionals
- education to develop knowledge of diseases
- training to participate in information production
- advocacy and self-help groups to support vulnerable patients and carers
- a culture and environment which respects patients' views/experience/opinions and encourages them to participate in decisions, if they wish

Resources

- time from professionals to listen and to encourage patient participation
- good management which sets standards and recognises patients' rights and the importance of a user friendly service

Factors Contributing to Collective Empowerment

The most commonly mentioned factors under this heading were structural mechanisms and professional attitudes. Resources were mentioned more frequently for collective empowerment than they were for individual empowerment. Alliances were mentioned much less frequently than the other three factors.

Structural

- a strategy which builds user involvement into the accountability framework and reviews progress annually
- clear terms of reference for user involvement in service planning and delivery
- legitimisation of the roles and rights of user involvement
- managements which listen to and respect the contribution of users at all stages of service planning and delivery
- managements which are responsive to local needs and give feedback to groups involved in service planning and delivery

Professional

- recognition and encouragement of patient groups and their contribution
- sharing information, knowledge and skills
- respect for views and rights of patient groups
- preparedness to work in partnership with patient groups

Resources

- information on research and outcomes in clear language(s) or other formats
- training to enhance and develop professional and patient skills
- support from professionals
- financial to pay costs of patient involvement and training

Alliances

- with other organisations to promote broader involvement and participation
- with professions to share knowledge and develop partnerships

Mechanisms to Promote Individual Empowerment in Treatment/Care

The main emphasis in this section was on structural [ie formal] mechanisms and mechanisms to support patients.

Structural

- policies committed to equal partnership concept
- audit, monitoring and review systems which involve patients and feed back outcomes to all users
- treatment protocols and service specifications based on partnership concept
- care contracts negotiated and agreed with patients
- effective complaints procedures
- effective Community Health Councils
- staff training to emphasise the importance of sharing and listening to patients

Support for Patients

- information provision:

  - helplines
  - community health information services
  - access to Internet
  - bulletins on rights and standards
  - staffed information centres
  - patient information booklets in Trusts, clinics etc
  - counsellors in GP practices
  - local resource centres

- patient forums/groups with professional/patient membership to be given resources and facilities and to be well publicised in GP practices and hospitals
- advocacy schemes for those who need help
- networks of groups within NHS
- resources to support mechanisms above

Mechanisms to Allow People to Contribute to the Design, Management and Review of Health Services

Structural mechanisms and resources for specific actions were listed by most respondents. Research as a mechanism for the idenfitication and monitoring of patient empowerment/involvement was mentioned by only a few respondents.

Structural

- a more democratic and open system within the limits of an accountable NHS. Openness emphasised with suggestions for more open meetings, published audits and public discussion of medical dilemmas. The Code of Openness to be implemented and monitored
- elected or more openly selected, lay non-executives on Trust Boards
- contracts and purchasing processes which involve patients and local people
- lay members of review bodies, audit and monitoring systems
- consultation processes which genuinely involve local people. Chief Executives/managers to meet local people annually or more often
- active equal opportunities policies
- accessible complaints procedures and policies, with local offices and publicised names and telephone numbers
- establish advocacy groups at all service levels

Resources

- to support lay involvement
- to produce good quality information and establish local databases to spread good practice
- to involve users always in the production of patient information
- to train users to develop relevant skills and knowledge
- to train professionals to value and use lay involvement

Research

- identify patients'/users' needs and views
- evaluate different methods of involving the public/patients in NHS decision-making, to discover which work best
- use different methods of collecting patient/public views - surveys, focus groups, interviews, suggestion boxes, to build a real picture
- encourage the commitment of senior managers to use the findings of good research on local/patient views

Methods that Work to Empower Individuals

The final questions invited participants to mention ways of empowering individuals and groups which they themselves had evidence of; and knew worked in local situations. The examples included information provision and services to support patients and patient groups as well as resources given to training and for services.

Information

- health information services: help-lines
- on-site access to good quality information
- nurse-led information clinics
- tape recordings of doctor consultations
- accessible literature - evidence based.

Services

- well-managed responsive services which take account of patient needs for time and information'
- independent advocates/patient representatives, self-help groups/support groups
- sympathetic environments and attitudes

Resources

- time to listen/build trust with professionals
- training of patients and professionals
- payment for user involvement [because it changes professional attitudes]

Commitment

- of managers and professionals to improve services in light of patient views

Methods that Work to Empower Groups

Structural

- locality forums/open forums/patient forums
- CHCs
- good, accessible complaints procedures
- representation of users on service committees
- equal opportunities policies

Research

- independent surveys of patients' needs, views
- combined qualitative and quantitative methods for deeper understanding of public values
- research in specific areas of patient needs which can be used as a model for other needs

Attitudes

- professional: sensitivity, openness, sharing with the user
- equal/shared responsibility for working together with patient groups

Alliances

- with professionals
- with other user groups, voluntary organisation

Patient Empowerment Focus Group of the NHS Executive

Barbara Stocking, Chair of the Patient Empowerment Focus Group of the NHS Executive offered a brief summary of the Forum's view of the work that needed to be done. She said that Patient Empowerment had been identified as one of several priorities for action by the NHS Board and that there would be no better time to influence policies in this area. What was needed was a clear policy with a realistic programme for action. This seminar was an opportunity for people working in the field to influence patient empowerment strategies for the next five years.

Seminar Outcomes

After these introductory presentations, participants worked in two groups on two key areas:

- **strategies to empower individual patients**
- **strategies for collective patient representation and empowerment.**

At the end of the first day, some common themes emerged from both groups. These were identified and commented on by the chairman at the beginning of the second day.

Cultural Change:

This is probably the most difficult thing to achieve. Training staff to see patients as people with rights must be an integral part of professional and other staff training. Traditional patterns of behaviour must be changed. The different approach of staff in private hospitals was noted, indicating that attitude change is possible. Sir Cecil suggested that coercion might need to replace persuasion! Nonetheless, he noted the difficulty of achieving change in practice. Lots of training bodies are setting standards independently; it will be a daunting task to ensure all of them build in attitude training. Patients should be involved in setting standards and training staff.

Policy:

Policies needs to be more stable. Staff need to feel more secure. We need to engender a sense of value in staff because they cannot empower patients if they feel devalued themselves. Patients also need training in the concept that their opinions matter.

Paid peer advocates could make an important contribution here, although the need for education would present difficulties, especially in acute care [where need cannot always be foreseen].

Information:

Information is a source of power: 'knowledge is power'. Patients do not have enough access to information: it must be in the right place at the right time, and be the right sort of information in the right language. There should be less jargon. Sir Cecil noted the rudeness of many professionals using jargon in conversation with lay people, suggesting good manners should also be on the training agenda! Patients should have full right of access to information.

A brief discussion followed with with one participant who suggested that in some cases carers should have legal access to patients' medical record in order to dispel any unfounded and prejudicial comments made in patients' notes. Sir Cecil suggested this would entail serious legal difficulties and would need new laws to detail specific conditions for special cases.

Communication:

A further item for the training agenda. Listening skills are vital as is the time to listen.

Maintenance of Standards:

Everyone agreed that standards are important and that patients should be involved in setting standards and training staff. Sir Cecil asked whose responsibility the maintenance of standards should be?

Representation:

Representation is patchy. Organisations show varying degrees of 'togetherness', organisational skills and levels of funding. They are therefore of variable effectiveness. Implementation of patient empowerment will depend on resourcing. New money is better than recycled money; but these are political decisions.

The two groups subsequently worked on the same themes, individual and collective empowerment - to produce practical elements of a strategy which could be implemented to achieve change.

The same strands emerged from this work as on the previous day and from the literature review and analysis of written answers - but with some flesh on the bones of the previous work and several practical suggestions.

Recommendations

The first two charts identify the main recommendations made by the two groups; the third chart was produced subsequently to indicate the common ground between the two groups.

Recommendations to Empower Individual Patients
(GROUP A)

OBJECTIVE	ACTIVITY	ACTION	OUTCOME MEASURE
<u>POLICY ISSUES</u> 1. Raise profile and priority of patient empowerment	• incorporate patient empowerment into national policy guidelines	NHS E	
	• strengthen Patients Charter by consulting users about new and existing standards and by implementing 'soft' standards with same force as hard standards	NHS E	• implemented through performance management, with more emphasis on soft standards
2. Formalise user representation at national and local decision-making levels	• strengthen role and resources of CHCs	NHS E	• measurably more consistent performance
	• create a Health Service Advisory Group elected/nominated from voluntary organisations and local groups	NHS E	• impact on decision-making and operations in key areas
	• create a database of voluntary organisations for consultation on relevant policy/implementation issues	NHS E	
	• produce guidelines on trained user representation on key committees	NHS E	
			• implementation built into performance management
3. Reform complaints procedures	• implement 'Acting on Complaints'	NHS E	• rise in complaints figures accepted centrally
	• Introduce "no fault compensation"	Commissioners & Providers	• monitoring built into performance management for managers and professional staff
		Government	• measurably faster - less destructive legal process

Recommendations to Empower Individual Patients
(GROUP A)

OBJECTIVE	ACTIVITY	ACTION	OUTCOME MEASURE
8. Improve patient support by ensuring every patient has access to appropriate level and type of advocate if desired	• Appoint Patient Representatives • Appoint clinical nurse specialist where appropriate • Support paid 'Peer Advocates' from user groups • Support Citizen advocacy	Providers Joint Planning Teams (or equivalent)	• measurable increase in user satisfaction • Funding bodies to evaluate impact
PROFESSIONAL ISSUES			
9. Promote partnership approach to care	• Build respect for patients' perspective into training • Build multi-professional elements into medical school curricula • Involve patients themselves in training/sharing their experience with professionals	Professional bodies Curriculum Committees	• measurable increase in patient satisfaction • measurable increase in professional awareness • (identified budget allocation for patient expenses)
10 Promote patient involvement in research and audit	• Produce guidance on successful methods of involving users • Produce guidance for researchers and audit staff on incorporation of patients'views (eg through involvement in research design, use of patient assessed outcome measures) • introduce further guidance on role and training needs of lay membership of key committees, eg Research Ethics, Clinical Audit	NHS-E	• Measurably more effective initiatives • Patient involvement an integral part of research and audit activity, implemented through performance management • Increase in lay membership. Increased confidence and satisfaction of members

Recommendations to Empower Individual Patients
(GROUP A)

OBJECTIVE	ACTIVITY	ACTION	OUTCOME MEASURE
4. Ensure adequate resources for patient empowerment work	• issue guidance to permit ring-fencing of local allocation/top-slicing of regional allocation for empowerment activities and initiatives listed above	NHS E	• identified new developments/initiatives growing from availability of pump priming cash
PATIENT ISSUES 5. Improve quality and quantity of patient information	• Introduce central co-ordination/evaluation of patient information resources (pilot six key conditions)	NHS E	• (Service to develop own outcome measures)
	• Build information provision into quality standards in contracts	Commissioners	• Standard contract monitoring to include user input
	• Ensure provision of good patient information in appropriate formats in all clinical settings	Providers	• Write information provision into consultants' annual performance management process • Commissioners to manage process in primary care (GP contract?)
6. Strengthen effectiveness of Regional Health Information Services	• Produce operational guidelines; introduce quality standards; market more effectively	NHS E	• Measurable increase in user satisfaction
	• Support piloting of wider distribution of materials in key outlets (eg to football grounds) in pilot areas	NHS E Regional Officer	• Measurable increase in awareness in target groups
7. Improve patients' access to own information notes	• Issue guidance to ensure records readily accessible in every case	NHS E	• Performance management at provider level; assess contribution of appropriate managers
	• Introduce patient held records where appropriate	Providers	• Audit acceptability of practice to patients and staff

(GROUP B)

Recommendations for Collective Empowerment

OBJECTIVE	ACTIVITY	ACTION	OUTCOME MEASURE
1. Develop a health service users council with a strong voice and role in policy development	• agreement to consultation • negotiations with local and voluntary organisations • resources identified	NHS E NHS E	• Establish by April 1996. Evaluation by April 1999.
2. Strengthen CHCs	• clarification of roles and functions • increase local representation and accountability to local groups	NHS E CHCs	• demonstrable impact on decision-making locally • a focus for enabling user involvement at local level
3. Develop pro-active Community Development, Liaison & Consultation	• A senior post with designated responsibility for at Trust, DHA & Executive Board level	NHS E Commissioners & Providers	• services will reflect local & project priorities
4. Increased accountability in Primary care and fundholding	• review existing initiatives for lay involvement in decision-making /standard setting/service delivery • piloting of a range of models	NHS-E Fundholders Commissioners	• pilot range of models by December 1996. • best models introduced by 1998 • increased lay involvement
5. Education and Training	• introduce principles of patient empowerment into professional education & training • develop training for professionals working with users • develop training for lay people to work with professionals	NHS-E GMC Fundholders	• evidence of systematic curricula & teaching • quality assessment by Higher Education Funding Council and purchasers
6. Improve access to good quality information	• establish an information /resource bank for user representatives • create a national information system /database	NHS-E Commissioners Providers	

Concluding Remarks

Sir Cecil explained that he had taken the role of an impartial observer so as not to be 'blinded by the dust of battle'.

He noted that we have ended up with a very detailed agenda, and asked how organisations could be motivated to put these principles into practice? A large list of mechanisms had been identified: we now need to identify the few most influential to proceed with. Information (or 'intelligence') comes from below at the coal face. Sir Cecil pursued his military metaphor by noting that good COs listen to their troops and explain their problems to them. They also concentrate the forces where they will do the most good. He asked what measure would induce the *political will* to bring about the profound cultural change needed. We need a strategy for this, and we will need to target the most influential agencies to address the most difficult parts of the agenda. The most influential organisation is the NHS Executive/Department of Health, working to the Secretary of State. It really has the ability to effect change.

Acknowledging the contribution of every participant, Sir Cecil drew the seminar to a close.

Summary and Conclusions

The seminar was successful in meeting its three primary objectives: to develop a working definition of patient empowerment: to identify components of a strategy for patient empowerment in the NHS: and to suggest indicators of successful outcomes of the strategy. This last objective was dealt with more superficially than the other two because time was limited and the participants less experienced in this kind of work.

The literature survey and the written responses from participants provided a variety of definitions of patient empowerment. It was then possible to construct a composite definition which appeared to be acceptable to all participants and one which they felt would be acceptable to most people working in the field. This is the definition which appears earlier [page 7].

During the seminar two groups worked separately, on the themes of empowerment for individual patients and empowerment for patients and their representatives working collectively, to produce a series of recommendations which could form part of a strategy for patient empowerment. These recommendations were analysed after the seminar and a single set of key recommendations produced to reflect the common ground between the two groups. Although the majority of participants

	guidance to purchasers & providers on methods of making patient records easily accessible to them; and by the introduction of patient held records	Providers	
3. To develop short and longer term strategies to introduce the principles of patient empowerment into professional and non-professional health care education and training	• introduce the principles of patient involvement and empowerment into all relevant curricula • develop people skills training aspects of curricula • develop ways of involving patients in relevant aspects of education and training of NHS staff: with training for this involvement	GMC Royal Colleges Curriculum designers in medical schools and other Higher Education Institutions Funding Council	• Quality assessment by peers. • Royal Colleges and Higher Education Funding Council to decide own outcome measure with advice from professionals and users
4. To develop effective measures for patient support and advocacy	• support and increase the number of paid patient representatives and advocates in provider units	Providers & Commissioners	• measurable increase in consumer satisfaction and local inolvement
5. To develop an effective strategy for community development, liaison and consultation	• designate a senior manager responsible for this work at NHS-E level, and in every Trust and Health Authority	NHS-E Providers and Commissioners	• local services will reflect local and specific project criteria and priorities
6. To develop effective research and audit mechanisms which involve users and monitor patient involvement	• evaluate methods of patient and public education and involvement to uncover 'best models'	NHS-E Commissioners and Providers	• research outcomes will reflect patient and user priorities as well as professional

KEY RECOMMENDATIONS

POLICY OBJECTIVES	ACTIVITIES	ACTION BY	OUTCOME MEASURE(S)
POLICY ISSUES			
1. To increase public representation and patient involvement in health care nationally and locally	• create a health service users council with a strong voice and role in health policy development; with members elected/nominated from local groups and voluntary organisations; and which has adequate resources to support it's effective working • strengthen CHCs role and function in relation to local representation and patient support • formalise local user involvement by election/nomination of trained user representatives to key local decision-making committees • reform complaints procedures in line with 'Action for Complaints' • create a national database of voluntary organisations and local groups for consultation as appropriate • strengthen the accountability of primary care/fundholding by reviewing existing initiatives for lay involvement in decision-making and standard setting and service delivery and recommend which models are best suited for the future eg school governing bodies	NHS E NHS E NHS E Commissioners & Providers	• establish by 1996 • evaluate by 1999 • evaluation of impact on decision-making locally and ... of user-involvement at local level • numbers of user-representatives on key committees • implementation and monitoring built into performance management for managers and professional staff
2. To implement an effective strategy for the production and dissemination of good quality information for patients and their representatives	• central co-ordination/evaluation of patient information resources [eg a patients' York Centre] • strengthen effectiveness of Regional Health Information Services with guidelines, marketing strategies and quality • improve patient access to information and their own records through central	NHS E NHS E NHS-E	• services and users to develop own outcome measures • Performance management at local level

would probably support these recommendations there was insufficient time to establish consensus. However, there is little in these recommendations to which many people could object and the Patient Empowerment Focus Group will hopefully be able to use them as the starting point for a development strategy. These recommendations meet the second objective of the seminar.

The indicators of successful outcomes of the strategy are listed alongside the key recommendations. Much less time was given to this third objective and the list reflects this. Nevertheless, some useful indicators were suggested and may form the basis for further work.

All the components of this work; the literature review; the analysis of written responses, and the recommendations from the seminar itself, reinforce each other in the identification of the areas where changes and improvements should be made to effect a higher profile for patient participation in their own care and in the planning and delivery of health care in the NHS. These areas are:

* information for patients which is relevant, unbiased, evidence based and provided in formats which are accessible to all communities and individuals:

* the attitudes of professional and other health care workers towards patients which do not always, but should, respect patients' rights and responsibilities, value their subjective experiences, and give time to the expression of their views and feelings;

* structural mechanisms for policy formulation, management and service delivery, audit, committee membership, complaints procedures and representation on patient organisations which are more democratic and open to the principles of patient involvement and representation.

Patient empowerment is a complex and difficult issue. It is inevitable that people will disagree about the rights of patients and the extent to which they should be involved in their own care and in the construction and delivery of health care services. The fact that this seminar took place and that senior policy makers recognise the importance of involving patients and their representatives in the process of policy formulation, means that when changes are introduced they are more likely to have the support of the people to whom they are directed. This is the principle behind all forms of empowerment; that the people for whom services are provided should have the opportunity to participate in their formulation and delivery.

APPENDIX I

PATIENT EMPOWERMENT SEMINAR

5 and 6 April 1995

Participants

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King's Fund Centre

Statement for the Patient Empowerment Seminar

5/6 April 1995

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1. What is your definition of 'Patient Empowerment'? [We recognise that this term is disliked by some but it is the one chosen by the NHS Executive].

2. What are the key factors which contribute most to the empowerment of: (i) individuals; and (ii) groups?

3. What mechanisms need to be in place to give individuals the information and confidence they need to be active participants in their own treatment and the management of their own and/or their relatives' conditions/illnesses?

4. What mechanisms need to be in place to allow people to contribute, as individuals or as groups to the design, management and review of health services?

5. In your experience what methods/activities work in practice to empower (i) individuals; and (ii) collective groups, to participate in their own health care and the design and management of health services?

APPENDIX III

Evaluation By Participants

Twenty participants returned evaluation sheets and the following comments are based on this number.

Almost all the participants who returned their evaluation forms agreed that the seminar had been a useful learning experience and that they had time to express their views. Three people had other views; two of them split their responses into two parts. One agreed that it had been a useful learning experience but had found it difficult to express views because the language and concepts being discussed were new. The other person had not found it a useful learning experience but felt that the time to express views was sufficient. A third person disagreed that the seminar had been a useful learning experience and that there had been sufficient time to express views.

Altogether 17 of the 20 respondents agreed with the statement that the organisation of the event had enabled all relevant issues to be discussed. Two people disagreed with this statement. One said "I question that all relevant issues were discussed as I question the qualification of those that were 'patient representatives' and the selection of delegates in attendance". The second person who disagreed added however that "the consensus of what was most important felt appropriate". The third person did not answer this question.

Eighteen participants agreed with the statement that the format of the event contributed to its effectiveness. Of the two people who disagreed with this statement, one questioned the knowledge that the seminar had been effective and the other wrote: "[the format] hindered the process of what was to emerge was national policy. Any one of a number of people could have written it before the seminar. Format did not contribute to ideas, stimulation, new thinking'.

Everyone agreed that the facilities at Scarman House met or exceeded their expectations. A popular venue obviously.

As always, the space offered for written comments provided the most useful feel for individual responses to the event. These comments appear below.

APPENDIX III

1. Would be very interested in developing the 'delivery' angle of empowerment, circa 'Primary Care/Fundholders' Governing Bodies.

2. As always, some very useful 'off the job' conversations too.

3. Please ensure that deprivation and the consequences of it are on the agenda. Poverty is more disempowering than people recognise, and poor people have no collective voice. As an advocate of people disadvantaged by unemployment, low pay, and benefits, I recognise their ability to get their voice heard is through people like me who have access to statutory bodies etc.

4. This was an extremely difficult subject to manage. The first day group sessions tended to lose focus, but with the range of the subject and individual views/experiences brought to bear on it this was inevitable. Much good material emerged, however, and I thought provided a very good basis for an excellent second day discussion.

5. No comment

6. No comment

7. A good experience which made me think hard, which is of course what much of this was about.

8. Where were mental health users who have done more on empowerment than any of us?

9. Very enjoyable and very constructive. I leave feeling optimistic.

10. Interesting being a token doctor.

11. A useful and enjoyable event, which the KF staff organised, professionally and effectively. Thank you.

12. It was very useful and exciting to meet other people who are interested in this issue - I'd really like to see more events on this subject.

13. I feel quite tired out but have been encouraged by the two days. It will be interesting to see what happens with the information and if/when the proposals become policy, practice - the norm.

14. Had some concern that some contributors did not understand what was expected of them. Considerable time wasted in irrelevant and long winded contributions about personal and or other experiences - not only patients did this!

15. Thank you!

16. A very useful seminar - on sharing the current state of thinking and drawing up many useful ideas, which I hope will be useful to the organisers. I would have liked to explore the concept of 'patient representation' further - there is some confusion round this.

17. A very useful workshop. If repeated in the future it may be useful to have consumer representation from a general rather than specific patient group who understandably like to promote their own cause. There needs to be more opportunities for health care professionals to hear what consumers have to say.

18. No comment.

19. Considering this is such an important issue, I am somewhat surprised that many groups/bodies were not approached and that participation was by invitation only. I also question how/what criteria was used in the selection/ invitation process of attendees. I would value a written document of the issues that were raised and would like to be kept abreast of where the issues/recommendations go from here.

20. The gross disparity in knowledge of participants was time wasting and counter productive - danger of ignorance being confused with wisdom. This was exacerbated by absence of good facilitation. More fundamentally, it raised serious issues which have to be addressed in a policy - the legitimation of representation; to whom are user representatives accountable? If I want to set up an organisation to offer services or represent people within a certain situation, who validates what I say? Who holds me to account? This echoes the arguments around vigilante movements. What are the responsibilities of user representatives and of the public servants to insist on safeguards? The selection of people for this event needs scrutinizing and lessons should be unpicked from it.

Evaluation By The King's Fund

We had mixed feelings about the 'success' of the event and list below the positives and negatives from our point of view.

Positives

1. The preliminary work on the literature review and written responses from participants was useful in identifying issues and providing background material for the seminar and a wider audience. Both features made it possible to consider the seminar outcomes in context. We are reasonably certain that the key recommendations will meet with extensive support amongst patients and their representatives.

2. The seminar involved users and their representatives as well as professionals in the formulation of the recommendations. This is consistent with the principles of patient empowerment.

3. The surprisingly broad agreement around central themes could give confidence to policy makers that the recommendations, if implemented, will meet with approval from users and their representatives.

Negatives

1. The short time scale involved in the lead time for the seminar limited the availability of some well-informed potential participants, who would have made good contributions. A number of important perspectives were lost due to last minute withdrawals and cancellations due to sickness. The remit to invite a maximum of 30 delegates necessarily limited representation.

2. Patient empowerment is a complex and difficult issue. It was inevitable that some participants would disagree with each other and that some would be more able to be succinct and creative than others. The participant evaluation indicates that the majority of participants felt they had both learned something and been able to make a contribution to the seminar. This will be a crucial element in gaining support in the field for any recommendations the NHSE Empowerment Group makes in the future. Nevertheless, we take seriously the comment from one person that the facilitators did not manage the intellectual process and are giving more thought to whether or not it is feasible to deliver an intellectual process in groups where participants have widely different experiences, agendas and skills and the time spent together is relatively short. Group dynamics can be managed but never fully controlled. This is part of the challenge and excitement of this kind of work.

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Please Note: At the end of July 1995, the King's Fund Centre moves to: 11-13 Cavendish Square, London W1M 0AN. Tel: 0171 307 2400.