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MEDICINES
FOR HEALTH

Coming of Age
Grown-up Stakeholder Involvement
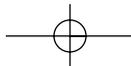
Meeting Report
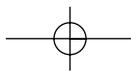
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The Association of the
British Pharmaceutical Industry

LMCA
alliance for health

Long-term Medical
Conditions Alliance

ABPI/LMCA Health Forum 2004

OBJECTIVES

Establish the guiding principles of grown-up patient and
public involvement

The views expressed in *Coming of Age – Grown-Up Stakeholder Involvement* are the opinions of those concerned and do not necessarily represent the views of the ABPI or the LMCA.

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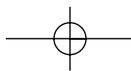Website: www.abpi.org.uk

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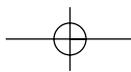Unit 212, 16 Baldwins Gardens,
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Coming of Age
Grown-up
Stakeholder Involvement

A meeting held at the Royal College of Physicians in London on
25 November 2004 to discuss the involvement of health service users
and carers in the way that health policies are developed,
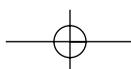and to create and consider practical steps that could be taken.

Meeting Objectives

Not long ago, stakeholder involvement in healthcare was a novel concept. Now it is accepted as essential in the development of public policy and the delivery of high-quality health services. Things have certainly improved. But making worthwhile changes on an *ad hoc* basis is different from having clear objectives for stakeholder involvement and developing a strategy for moving patient-centred care forward in timely way.

The meeting aimed to

- establish the guiding principles of grown-up patient and public involvement

- consider a realistic future that embraces these principles

- look at the barriers to achieving this future

- outline practical steps that could/should be taken to get there

Contents

Recommendations

- All healthcare organisations should analyse their current approach to stakeholder involvement and develop a strategy to encourage, enable and resource effective engagement of stakeholders.

- Stakeholders should have a role in deciding the objectives and parameters of their involvement, and should not simply be invited to respond to consultations.

- Stakeholders should be fully informed about the remit and scope of opportunities for involvement, the use to which their contribution will be put, and realistic time-frames for responses.

- Healthcare organisations should promote partnership between individual patients and health professionals, encourage patients to become as involved as they wish to be in decisions about their own healthcare and ensure they have access to the information they need to make that possible.

- The impact of stakeholder involvement should be monitored and evaluated to ensure that it leads to a more patient-centred health service.

Key Points

- 'Stakeholder involvement' is an integral part of a patient-centred NHS and a central theme of national and local policy. It can be defined as the formal integration of health service users – and potential users, which is virtually everyone – into the process of planning and delivering services.

- However, meaningful stakeholder involvement is more than simply a series of techniques and tools, regardless of how effective they might be. It also requires a significant cultural change within organisations.

- Stakeholder involvement offers benefits both to individuals and organisations. But the real test of benefit lies in the implementation of change, not in the activity of 'consultation' or the involvement of individuals on committees.

- Public consultation is not the same thing as stakeholder involvement. Neither is the development of consumerism in healthcare, the rise in the number of health-related campaigns and the popularity of self-help groups. All of these have a role to play in influencing the development of policy and the delivery of services – consumerism, by encouraging service users to exercise choice; campaigns, by applying external pressure; and self-help, by promoting services provided by users and carers themselves.

- Effective stakeholder involvement, on the other hand, drives service change by ensuring that stakeholders are not simply invited to express an opinion but to participate actively in decision-making. Surveys of service users' experiences and views may have an important role to play in improving services, but they are not a substitute for engaging stakeholders fully.

- Developing effective mechanisms for stakeholder involvement is crucial, and should not be done in isolation from stakeholders themselves.

- Stakeholders have a role to play in identifying goals and priorities, setting parameters and evaluating the effectiveness of the approach adopted and the outcomes achieved.

- Stakeholders' time is valuable and should be respected. Stakeholders need full information about the remit and scope of their involvement, the use to which their contribution will be put, and realistic time-frames to make their contribution.

- If stakeholder involvement is to be taken seriously as a significant way of influencing policy and practice in healthcare, it must become a mainstream activity rather than an 'add-on'.

- Making this a reality will require substantial resources and a commitment from senior decision-makers within an organisation.

Chairmen

Elizabeth Wincott,
Chair of the Long-term Medical Conditions Alliance (LMCA)

Elizabeth Wincott has worked in the health and social care field for many years, including being a trustee of various charities, chairing many national working groups, and being a consultant in social healthcare and governance. Elizabeth was Chair of Oxfordshire Mental Healthcare T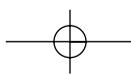rust until 2001, and more recently has been working to get the healthcare needs of refugees and asylum seekers addressed as part of restoring their dignity and autonomy in very difficult conditions in detention. Her executive positions have included being CEO of the Homeopathic Trust and Faculty of Homeopathy, and the British Deaf Association. Elizabeth was elected Chair of the LMCA in June 2004.

Dr Richard Barker, ABPI Director General

Dr Richard Barker is Director General of the Association of the British Pharmaceutical Industry, which represents companies researching, developing and marketing medicines in the UK. In this capacity he is also a board member of EFPIA (the European industry association) and Council member of IFPMA (the international equivalent). Prior to joining the ABPI, Richard was president of New Medicine Partners, a firm focused on consulting and entrepreneurship in pharmaceuticals, biotechnology, molecular diagnostics, and biodefence. His past operating roles include CEO of iKnowMed, a clinical decision support and pharmaceutical services business in oncology, Chief Executive of Chiron Diagnostics, a global diagnostics company, and General Manager of IBM's Worldwide Healthcare Solutions business. He also led McKinsey's European pharmaceuticals and healthcare practice.

Introduction

The past ten years have seen significant changes in the involvement of the public, patients and carers in healthcare. Stakeholder involvement is a much-used phrase, but it should mean ensuring that people who are affected by particular policies or who use public services have an opportunity to be involved in the way those services are developed. This is a broad constituency, and includes patients and those associated with them, including their families and carers, and the professionals who work alongside them.

A key dimension to stakeholder involvement is that all service users and carers should be involved in the way that health policies are developed at an early stage. This needs to be genuine engagement, not just token representation. Stakeholder involvement is an essential part of policy-making – we won't be able to meet the needs of high-quality patient-centred care without it. In his reports to the Government on the future of healthcare in this country, Derek Wanless describes it as a 'fully engaged scenario'.

This is a crucial time for stakeholder involvement. The main political parties subscribe to stakeholder involvement, but now need to make it happen. Public services need to be more accountable and stakeholders should be able to use their involvement as a lever for change.

In short, the conference theme of 'Coming of Age' is appropriate. Stakeholder involvement is still in its infancy and now is the time to push it forward.

The potential for influence of a major stakeholder group

Peter Cardy, Chief Executive, Macmillan Cancer Relief

Peter Cardy has worked in charities and voluntary organisations for over 30 years. Following periods as Chief Executive at the Motor Neurone Disease Association and the MS Society, he moved to Macmillan Cancer Relief at the end of 2001. Macmillan is a pioneering organisation, one of the ten largest charities in the UK, which develops new and better ways of caring for people affected by cancer from the time of diagnosis to the end of life. He is on the NCRI Board, the NHS Modernisation Board, the Department of Health Patient Experience Board, Chair of the NCRI Lung Cancer Strategic Planning Group and an adviser to the HTA Pharmaceuticals Panel and the Taskforce on Medicines Partnership.

Macmillan Cancer Relief is a development organisation, working with a number of partners to create improvement in cancer care that would not take place without it. Although it contributes its tax-free contributions into the tax-funded system, it doesn't finance services that would properly be funded from taxation. Macmillan doesn't employ the professionals that it funds and doesn't develop services without willing partners. It doesn't fund biomedical research.
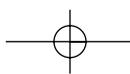
Macmillan is undergoing a radical change from an organisation where priorities were shaped by **people who help people affected by cancer** to one where the priorities are shaped by **people who are themselves affected by cancer**, which includes carers. It was more than ten years ago that the Calman-Hine Report gave a mention to user involvement. In 2000, the Cancer plan formed the basis of the National Service Framework for cancer, setting targets for user involvement in cancer services, co-funded with Macmillan.

Macmillan's research priorities have been selected by patients and carers and include:

- Choices for people affected by cancer
- Best practice in service delivery
- Long-term survival
- End of life matters
- Self-management
- Involving people affected by cancer in research.

Involving cancer patients is quite new in the NHS. The Cancer Partnership Project set out in the Cancer Plan is co-funded by the Department of Health and Macmillan. It brings patients and carers into formal decision-making roles and has produced a measurable change. Although it is currently a three-year project, it has to be seen as long-term and needs adequate staffing and funding to support users. The goal of user involvement is that better treatments bring an improved quality of life, not just quantity.

User involvement has come late in cancer, because of the dominance of the medical approach, which is itself dominated by technology. Technology is dominated by the pharmaceutical industry. People with cancer depend heavily on their doctors. No single voice is representative in supporting people with cancer and it is important to listen to other organisations in the same field, to callers, to health and social care professionals and the like. It is important to remain independent, but Macmillan doesn't want to seen as the single voice of people with cancer.
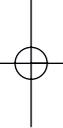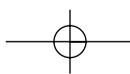
Some of the current challenges to user involvement are:

- Weaving user involvement into the fabric of health care is still new
- The role of patient groups as external consultees
- Democracy can disenfranchise some groups of people
- Elderly people can be excluded
- Death or relapse can cause an attrition of participants
- Long-term activism, where the process of user involvement becomes more important than the outcome.

Challenges for the future include:

- Avoiding doctrinaire positions that disregard some stakeholders and discount their views – no single model is perfect
- Recognising that central dirigisme doesn't work
- An ageing population, often with several concurrent medical conditions
- The tyranny of the random clinical trial as the gold standard for evidence of efficacy and the effect on funding – there are other routes to the same goals in healthcare
- Including quality of life issues in the authorisation of medicines and devices
- Maintaining a realistic view of what services look like to users.

Pharmacy's role in creating change

Beth Taylor, Specialist Principal Pharmacist, Community Health, London South/Southwark PCT

Beth Taylor has worked with community health and social care services for many years, both locally in Lambeth, Southwark and Lewisham, and across London. She has wide experience of developing innovative pharmacy services – hospital at home, emergency contraception through community pharmacies, NHS Direct and new ways of prescribing for nurses and pharmacists. She has been a member of the national NHS Modernisation Board since its establishment in 2000, and was awarded an OBE in 2002. Beth participated in the autumn 2003 Choice consultation process through her membership of the Primary Care Task Group.

Medicines matter to all of us as consumers and to the Government, since medicines are the most frequent clinical service provided to patients, with around 750 million prescriptions handed out at a cost to the NHS of £9.3 billion in 2003.

The question is whether we provide medicines to people in a way they can easily use. Many medicines are returned unused. Do we assess patients' medicines needs correctly? Are their medicine containers user-friendly? Can patients read the labels? Are they in the right language? There hasn't been enough emphasis on these aspects of pharmacy services.
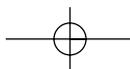
Patients tell us that for the millions of patients with long-term conditions, the existing arrangements for getting a repeat prescription, requiring the GP's signature on each occasion, frustrate patients and GPs alike. In the modern world, they are absurd. Healthcare professionals do not have the time to devote to concordant consultations, but with the evidence showing that many medicines are taken by fewer than half the patients to whom they are prescribed, the waste alone should make them think again.
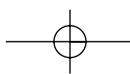
Outdated NHS structures have led to these frustrations, but major changes are on the way. Since 2000, policy developments in pharmacy have advocated:

- Pharmacy as an integral part of the NHS
- Planning and delivering local services
- Supporting self-care
- Responding to the diverse needs of patients and communities
- Innovating in the delivery of services
- Helping deliver the aims of NSFs
- Helping to tackle health inequalities.

Some of the policy announcements in the Department of Health's 2003 strategy paper, *Building on the Best – Choice, responsiveness and equity in the NHS*, chime in well with the pharmacy strategy. It proposes an 'increased choice of access to a wider range of services in primary care… and an increased choice of where, when and how to get medicines'.

The aim is to introduce a more sensible system for people to be able to access medicines in ways which suit them, rather than just the NHS. Pharmacy services should be included in choices for patients in primary care, such as in monitoring long-term conditions at the local pharmacy, or direct access to treatments for minor ailments. And pharmacists are a prime source of information about medicines. We need to focus on self-care and self-management, as they are very important aspects of

healthcare and often undervalued and overlooked. Improving access to medicines can be approached by improved repeat dispensing systems, electronic transfer of prescriptions (email), nurse and pharmacist prescribing, on-line pharmacies and the availability of more prescription medicines over the counter. What patients say they want is more information about their medicines, tailored to their particular needs, covering their condition and broad range of treatments in a variety of formats.

In the future, pharmacy wants to:

- Focus on health inequalities, health improvement and harm reduction
- Develop pharmacists and their staff as public health practitioners
- Use the pharmacy as a community resource
- Support long-term care
- Introduce levers for change, such as the new community pharmacy contract, working with GPs and develop pharmacist prescribing.

Pharmacy is undergoing a long overdue revolution. There are risks – will there still be a local pharmacy when you need one? The pharmacy sector is more familiar with the consumer culture than then NHS. In the end, if they are dissatisfied, patients and the public can always vote with their feet and support only the services they value.

Working with patients

**Margaret Goose, Chair,
Royal College of Physicians Patient and Carer
Involvement Steering Group**

Margaret Goose spent 30 years in NHS Senior Management, including eight years as Chief Executive of North Bedfordshire Health Authority and at the Nuffield Institute for Health in Leeds. She was Chief Executive of The Stroke Association from 1997 to her retirement in March 2004 and was a member of the Stroke Task Group for the English National Service Framework for Older People and chaired a similar subgroup in Wales. She worked with the Clinical Governance Development team of the NHS Modernisation Agency to run the stroke specific programmes. She is now a lay member of the Council of The Royal College of Physicians of London and chairs their new Patient and Carer Involvement Steering Group. A Past President of the Institute of Health Services Management, Margaret was a member of the NHS Executive working party implementing the first Patient's Charter in 1992. Margaret was awarded an OBE for services to healthcare in 2004.

The Royal College of Physicians has made the issue of patient, carer and public involvement in the College's work a key theme. The previous Patient and Carer Liaison Committee was not effective, so a small working group was established and a completely different approach was decided upon.

The RCP set up a Patient Involvement Unit in September 2003, with a Fellow of the College and a salaried staff member to lead the initiative. A Patient and Carer Involvement Steering Group operates at a strategic level and has six College representatives and six lay representatives. Its aim is to assist with the development of overall College policy in respect of improving clinical standards for the benefit of patients, carers and the public.

The Group has selected a project on individual doctor/patient information and communication, starting with the explanation of risk and shared decision-making. Doctors tend to think in numbers, while patients may not. The aim is to ensure an appropriate dialogue between the doctor and patient or carer, to enable an informed choice about treatment to be made, including prescribing. The move from compliance to concordance signals a shift in thinking.

In parallel, there is a College Patient and Carer Network. Recruitment was through open advertisement, including local hospitals and The Big Issue, and 74 Network members were appointed for a period of three years, drawn from a variety of ages, backgrounds, experiences and skills. It is still early days; three induction days have been held; protocols for working with the Network have been drawn up with a private internet forum for members and a Patient and Carer section on the RCP web site. Network and Steering Group members sit on six college boards, and there are network members on 30 College committees and working parties. They have provided comments on 32 consultation documents and a Patient and Carer Handbook has been produced.

There are a number of initiatives for the future. Network members are now going out to hospitals as a member of the professional team doing general professional training visits. Workshops are planned on various specific issues, and there is joint working with the NHS University on training needs. Network representation on College committees is increasing and there will be an RCP open day in 2005 for the first time, led by the Patient and Carer Network.

A regular column in the College Commentary means that College members and staff now expect a patient and carer perspective; an evaluation of the contribution of the Network members will take place. The Network exists to help the College do better in the interests of improving patient care.

Campaigning alliances, cascades and consultations

David Pink, Chief Executive, Long-term Medical Conditions Alliance

Almost all of David Pink's career to date has been dedicated to developing and shaping a first-class health service. Early in his career, he worked in the Department of Health as policy advisor to various Health Ministers. One of David's last jobs in Government was working on 'A First Class Service'. This was a White Paper which outlined the Government's new approach to quality in the NHS throughout England. Directly before coming to LMCA, David held various senior posts with the National Institute for Clinical Excellence (NICE), including Head of Guidelines and Audit, and Audit Programme Director. His career at NICE culminated with the success of Best Practice in Clinical Audit, a text book and evidence review published last year, which David co-authored in partnership with leading academics and healthcare professionals. David took up the reins of the LMCA as Chief Executive in July 2002.

In some ways, patient organisation networking is what the LMCA is all about, rather than simple stakeholder involvement, but some LMCA stakeholders may see it as being the essence of the LMCA and over the past few years, facilitating 'stakeholder involvement' has taken up a greater proportion of its work.

Patient organisations in the UK are increasingly becoming national and local advocacy organisations, changing from organisations **for** people with a disease to organisations **of** people with a disease. They are influenced by the rise of consumerism, human rights and equal opportunities, but keeping a distinct healthcare identity. These changes have meant a very different message comes from patient organisations today, no longer speaking out as well-meaning people who want to do good, but as representative organisations with a feeling of entitlement to claim that representation.

Consumerism has shaped the way patient organisations approach involvement in healthcare. Consumerism is different from stakeholder involvement and is more likely to be characterised by a lack of involvement – different stakeholders do communicate, but they do not necessarily engage with each other.

People may see LMCA as a large umbrella organisation with wide-ranging activities, but in practice, it is a small organisation, despite the fact that it works for the interests of 17 million people in the UK.

One advantage of LMCA is that it monitors all national and international policy and links into its members. It supports small patient organisations and give them collective strength. It can build alliances of large patient organisations on major campaigns. It can speak out for a large group, rather than a narrow interest group, identifying issues and trends of interest to patient groups. It can develop work that is not disease specific and therefore enable even wider stakeholder involvement. Not all of this is genuine stakeholder involvement, however.

The LMCA does do campaigning work, and patient organisations are generally quite effective campaigning organisations. Campaigning is not so oppositional as it used to be and nowadays it is used for lobbying and engaging with those it wishes to influence. But campaigning still isn't grown-up stakeholder involvement.

LMCA receives up to 12 invitations every week to contribute to involvement and consultations. Because of the wide scope of the LMCA, it is a natural target for people who would like our input, but the sheer volume and timescales of the demands are overwhelming. Consultation exercises have their value, but they have to be thought through and their methods are not always appropriate. Consultation exercises aren't necessarily grown-up stakeholder involvement either, although they might be part of it.

How do we move towards grown-up stakeholder involvement? The ground rules for partnership and engagement are to:

- Involve stakeholders from the outset
- Agree the objectives of engagement
- Agree the methods to be used
- Secure resources for everyone
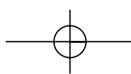- Use a variety of methods at different stages.

The exact methods used are becoming less of an issue. More important is to consider who the stakeholders are and what the issues are, and how much those issues matter to each party. Timescale and resources issues are a constant theme and then finally, there is the overarching question of what is genuinely possible. These questions are so important that they may need to be revisited more than once, in discussion with stakeholders, before final plans can be agreed.

Overall, stakeholder involvement is agreed to be a good thing and lots of people are trying to do it. Techniques and methods are spreading and the engagement with the issue is mostly genuine. All of these developments are good. But there is still an air of 'ticking the box' – paying lip

service to the idea of stakeholder involvement. There is wholly inadequate time and poor planning put into the idea. There are inadequate resources for the people seeking to do stakeholder involvement and the people who they are seeking to engage. These resources involve people, expertise, staff, volunteer time, methods, technologies, etc.

Stakeholder involvement has to be taken on as a mainstream activity, for all public services, industry, government services and voluntary sector organisations. We're all judged by our performance in the media, so it's fundamental to get it right. At present, very few organisations are capable of getting it entirely right.

Stakeholder involvement can seem to be easy if you see it as just a series of techniques and tools, because the information exists on how to practise it. Stakeholder involvement is actually much more difficult, because it's a serious business, and it requires resources and careful planning. None of the methods and techniques are magic bullets and the selection of appropriate ones is tough. But we all have to be involved, because we all have constituencies which we are answerable to and stakeholder involvement is the way we're going to do it.

Patient and public involvement: learning for the future

David Gilbert, Senior Advisor, Patient and Community Engagement, NHS University

David Gilbert is Senior Advisor for Patient and Community Engagement (PACE) at the NHS University, where he is leading work on developing learning opportunities in the field of patient and public involvement. He was formerly Head of Patient and Public Involvement at the Commission for Health Improvement (CHI). He has worked at the Consumers' Association, King's Fund, Office for Public Management (OPM), Consumers in Europe Group and with Health Action International, an international network of groups campaigning on health and pharmaceutical issues. He led the public consultation on the NHS Plan in England and the development of the Wales Assembly Government public and patient involvement strategy. He was a Community Health Council member, Chair of MIND in Barnet and user of mental health services. He is a member of the Royal College of Physicians Patient and Public Involvement Steering Group and on the Steering Group for the British Red Cross User Engagement Programme.

I'm going to talk about learning in two different ways – what have we learnt about patient and public involvement so far and people's individual learning in order to enable their voices to be heard or, from a staff point of view, to enable them to listen and respond.

The law says there is a duty on health and social care providers to consult people early on in planning and decision-making. As a psychiatric patient, I didn't know which medicines or treatment I wanted. I had no training in how to cope. I had no learning or information about how to understand information or how to access services. During the time when I was getting better, I had no opportunity to find out how to get my voice heard, or how to help other people in similar situations. I had to find out for myself.

I stumbled into a community health council office and found out that there was a consultation on reconfiguration of services. I attended a lot of meetings without knowing what I was talking about, got invited to be a trustee of a MIND group, but I had no learning, no training, no accreditation, no payment, no incentive, no support, no computer to help me take part in any of the decisions.
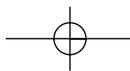
But being on committees meant being asked for advice and opinions. My role was unclear – was I a patient representative, or was I representing only myself? It became a journey from the individual level of involvement to a broader view, from being a representative to a patient and public involvement adviser. Involvement is not representation, and the links between the two are quite tricky. Representation is a catalyst.

Towards the end of my time at the Commission for Health Improvement, after around 300 inspections, we asked each and every trust what they had been doing about involvement. The key question was "what changed?" The answer was: not a lot. The NHS is getting better at providing information, both to patients and the public, and also at obtaining feedback from people, but leaves much of the information obtained it on the shelf. Involvement is not yet leading to improvement.

One of the reasons for this is that the staff doing PPI are very enthusiastic, but often don't have the strategic clout to make things change. It's almost a case of marginalised staff talking to marginalised patients in the community – an exact reflection of my own experiences during psychiatric care. Now things are a little better, but we don't really need an entire technical industry devoted to running focus groups. It would be better to revisit the work done and find out why it's still on the shelf. Staff want to do it, but don't know how. They don't lack the techniques, they lack the empowerment, support, learning training and development. And so do the directors.
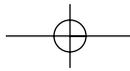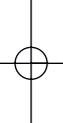
At the NHSU, we're trying to develop learning opportunities for the individual patient, through to having their voice heard, through to being a community leader, through to developing a generic national programme for the effective community representative. With regard to the last of these, the essence is to identify and develop the core role of the lay representative. Are they there just to produce the patient perspective and nothing else, or be some sort of link to their communities? Or do they turn themselves into some sort of catalyst and aim to bring patients and public into the equation? Then they would be

Trojan horses for bringing the next set of people in to have their voices heard.

We're also working with staff, running 10 regional learning events with Strategic Health Authorities in 2005 for staff and non-staff, working at both service and strategic levels to see why the reports are not being implemented, and what training everyone needs in taking the report off the shelf. We want to identify the learning and support needs for staff and non-staff so that they can influence change. We can't afford to miss the chance to do it now.

Developing the pharmaceutical industry's role

Kate Tillett, Chair, ABPI Involved Patient Initiative Task Force

Kate Tillett is a member of the Association of the British Pharmaceutical Industry (ABPI) Board of Management and Chair of the ABPI Involved Patient Initiative Task Force. This group works on behalf of the pharmaceutical industry to understand changes in today's healthcare environment relating to patient choice and involvement, involving patients in a dialogue with the industry about a range of issues from the discovery and development of pharmaceuticals through to the use of medicines. Kate has a long standing interest in the principles of patient and public involvement in healthcare. She was a founder member of the Concordance Working Group at the Royal Pharmaceutical Society of Great Britain on which she served for five years; she is a member of the Ask About Medicines Week Advisory Board and a previous member of the Future Patient Advisory Group at the Institute for Public Policy Research. Kate has been Director of External Affairs for Merck Sharp & Dohme (MSD) since 1992.

This is an exciting time for the future of patient care, and the ABPI supports the development of patient involvement and user-centred care work. Individuals are making ever more complicated decisions about their lives, their healthcare and that of their immediate families. In each decision, we balance risk and benefit with varying degrees of confidence, in most cases taking the guidance of experts and intermediaries.

The debate within the industry has moved on from the earlier discussions about direct-to-the-consumer advertising and direct-to-the-consumer information. Now the agenda is much broader, and is no longer two-way, but a multi-dimensional one.
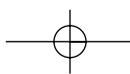
There are guiding principles for the involved patient. The involved patient is both a consumer and a citizen, and should be equipped and encouraged to be active in the maintenance and management of their health, with the right to choose and expect the best outcome. The involved patient has the right to feel at the centre of their care, relying on a broad set of relationships with the key stakeholders.

There are guiding principles for the industry too. Our focus must always be safety, quality and efficacy. Our business is the discovery, development, manufacture and marketing of medicines. It's only been in the past ten years that we have started to talk about issues of information and getting involved in the use of medicines as a good thing to do. Mature companies will be guided by the need to build partnerships that go beyond their shareholders to a much wider range of stakeholders.

We need to maintain the traditional strengths of the industry: The industry has unique expertise in:

- Innovation
- Knowledge transfer from academia to commerce
- Research and development
- Our own medicines
- Pharmacovigilance
- Risk assessment and safety management.

These are critical success factors in our business. Better medicines have brought huge improvement in health outcomes over the past 40 years.

But there are challenges for the industry as well:

- Knowing where we are not yet experts
  - Combining medicines with lifestyle choices
  - Understanding real-life experience
  - Cost-effectiveness of medicines
  - How political decisions are made about access to medicines
- Information provision and transparency
- Communicating the balance of risk and benefit of medicines use
- Minimising errors and learning from mistakes
- Engaging across the life cycle of a medicine
- Building confidence and trust.

'No change' is not an option. If we can't achieve change, the NHS will carry on as an illness service. Regulators will increasingly face crisis management as a modus operandi. Professionals may not return to full confidence, patients will have an inadequate sense of control over their healthcare

destiny. For the industry, innovation will be undermined, leaving it with a mediocre business model and a poor public image. The stakes are high for everyone taking part.

Some suggestions for practical steps forward, at the right pace and at the right time, include

- a review of the ABPI Code of Practice, with a specific focus on the patient agenda and including consultation with patient organisations
- Increased stakeholder consultation
- Focus groups conducted with patient groups
- New model of patient focus in the ABPI underpinned by a more 'joined-up' approach
- Identification of best practice models

In conclusion, the ABPI and its members are committed to making patient involvement work and to working with all stakeholders to help develop a user-centred healthcare system.

An agenda for the future

Niall Dickson,
Chief Executive, King's Fund

Niall taught for two years at a comprehensive school in Edinburgh before joining the policy and research body, the National Corporation for the Care of Old People (now the Centre for Policy on Ageing). From there he went to Age Concern England, first as a Press Officer and later as Head of Publishing. In 1981 he took over as editor of Therapy, a weekly newspaper for the remedial professions, and in 1983 was appointed editor of Nursing Times. In 1988 Niall moved to the BBC as Health Correspondent and went on to become Chief Social Affairs Correspondent. He became Social Affairs Editor in 1995 , and headed a team of more than 80 journalists covering all aspects of social policy. Niall joined the King's Fund, the independent health think tank, training and development organisation, at the beginning of 2004. He is a member of the NHS Modernisation Board and chair of the Department of Health's Direct Payments Steering Group. He sits on the University of Warwick Faculty of Medicine Advisory Board and is a member of the Royal College of Physicians working party on medical professionalism.

The landscape of stakeholder involvement is changing. Expectations have risen and will continue to do so. The drive and professionalism of user groups has increased, as has the ability to form alliances, whether they are with industry or professionals or challenging them. The speed of social change is rapid. In a tax-funded and necessarily cash-limited system, there will be new groupings and demands for new ways of working. And the area of debate is changing too.

There is a new emphasis on long-term conditions and public health. The politicians may have succeeded in reducing waiting lists and times for now, but they know all too well the other challenges ahead. The recognition of long-term conditions is a belated acknowledgement of the scale of the problem – and the same is true in public health, where many of the key indicators are going the wrong way. So while some issues may have been addressed, others are on the horizon and all unless patients are engaged in their own care and in their own health, the cost of the system will be unsustainable.

Some of these issues take a very long time to turn around, and politicians don't often think long-term. There are real questions too about professional attitudes. We need to build a new set of relationships between patients and professionals which are not based on confrontation, but which are fundamentally different from the paternalism of the past.

The information revolution means that industry and professionals will have to be much more transparent. The impact of this revolution is poorly understood, what we can say is that it will be powerful and that it's unstoppable. The truth is we yet don't understand how people will behave when they are given real choices. That encompasses choices between different providers, choices between therapies, conventional or alternative medicine, or even about whether to be treated at all. And of course there are risks of undermining equity: if we are to develop choice, people will need help navigating through the system. Some will need access to advocacy, others additional help. We need to ensure the system promotes equal opportunity for choice.

While there has been real progress in advancing how users interact with the system individually, the taxpayer's role is a shambles by contrast. The government has constructed a complex and opaque structure with little or no coherence. We need public involvement as well as patient engagement. These are centrally and publicly funded services – some form of accountability and democratic involvement is essential. We don't have it yet.

The final uncertainty is about funding. Although health has received increased funding in the recent years and more than other public services, all the signs are that the rapid growth of recent years will not be sustained beyond 2008. So there is only a brief window of opportunity. There is a limited time to engage patients in new ways, to develop new forms of service and to demonstrate that our free at the point of delivery system can actually deliver and maintain the social glue that is the NHS. We have to use the time well.
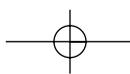
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Discussion sessions

How should service users be selected? Do we need to include representative patient groups, or just individual patients?

We need both: the role of patient representatives is changing. Stakeholders have an important role to play in identifying goals and priorities, setting parameters and evaluating approaches and outcomes. There are inherent difficulties about representation which are linked to the idea that involvement needs to be active involvement by people directly affected by a particular condition. We still need groups to apply pressure in a system where patients are less powerful and may be marginalised, but it is important to recognise that representation is not always representative – it's obviously not possible to represent every point of view. Patients don't always ask for the world, they often just want changes that make their lives easier, and health professionals often agree with them. Once patients have been successful in bringing about change, they may become champions for the changes that the professionals wanted in the first place. There is no single right way of involving stakeholders. Both industry and the voluntary sector organisations are putting time and resources into equipping people adequately to become involved in decisions about their own health and care and about the way that services are developed and delivered.

There won't be empowerment among patients with long-term conditions until there is reciprocal empowerment among professionals.

The medical profession is undergoing a profound change in terms of motivation. It used to be driven by the feeling of doing good, of being in control, of being respected. Some of this has been undermined. Now we rightly challenge the variations in standards that exist. In addition, professionals may be constrained in the extent to which they can exercise professional judgement – for example, in how they prescribe. The answer may lie in a new relationship with patients that is based on partnership, ultimately moving on to a new world where the patient has a different role. Even though the power relationship may be asymmetrical, patients increasingly expect to take part in decision-making. Forward-looking GPs won't find this threatening, and involved patients may save them time as well, since they come to the consultation better prepared. Furthermore, patient involvement tends to lead to better health outcomes. Health professionals may find it hard to change attitudes, and altering the power structure with patients is a sort of deliberate self-disempowerment which can be very hard to do. If stakeholder involvement is taken seriously as a significant way of influencing policy and practice, it will become a mainstream activity and not just an 'add-on'.

Pharmaceutical companies should work with patient groups to conduct disease awareness campaigns

Companies can and do work with patient groups and other voluntary sector health organisations to provide the public with important information about medical conditions. There are many good examples of such campaigns. But in the process of developing and running a disease awareness campaign, a company (or anyone working with or funded by them on the campaign) cannot provide any promotional information about a prescription medicine. The MHRA has guidance on the conduct of disease awareness campaigns and the ABPI Code of Practice would also apply. The difficulty is that the interpretation of promotion is much broader than most people would tend to understand the term, so anyone involved needs to look at the detail of such campaigns very closely in advance.
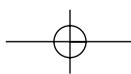
Shouldn't the media be active in encouraging patient involvement?

Because it's the nature of news to be negative, media coverage of health issues is sometimes depressing. There is a split between the rather negative coverage in the national media and more positive local news coverage. The White Paper on public health suggests a National Health Media Centre, independent of Government, similar to the Science Media Centre, which has been very successful.

Consultation often ends up as a discussion about service cuts

Service users should always have the opportunity to comment on proposed service changes. But people will be discouraged from participating in the future if they don't see the results of their contribution taken into account. But even if change is not immediately possible, the views of stakeholders can still be important. They need to be aware of this difference so that they can decide if they want to participate.
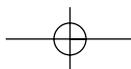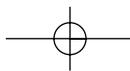
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The Expert Patient Programme was initially a generic initiative. Now it seems to be moving towards a focus on specific disease areas

The EPP is basically generic, but specific disease modules have now been added, which may have advantages over a generic course. It isn't always easy to persuade doctors to refer patients to expert patient courses, but they may be more likely to do so if courses came with the name of a condition attached. By 2008, these courses will be routinely offered to doctors interested in long-term conditions and should be available to all patients who want to participate. There will be the potential for voluntary organisations to develop disease-specific modules.

Should the role of complementary healthcare be integrated into conventional healthcare, supporting self care and self management?
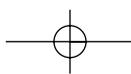
Complementary and alternative medicine is a key area of patient choice and should be an integral part of total healthcare. If we are considering stakeholder involvement in the NHS and looking for its support, we have to recognise the importance many people attach to complementary therapies. But a note of caution is necessary, since complementary and alternative medicine comprises a huge range of therapies. These must come with proper professional accreditation if they are to be recognised. The NHS often doesn't engage in the question of complementary medicine, because it is dominated by professionals who don't subscribe to its value. But it's important to remember that the NHS doesn't just belong to the people who work in it. People increasingly want information about complementary and alternative medicine and may well even decide to opt out of effective treatment with conventional medicines. An informed decision, after careful consideration, should be regarded as an acceptable outcome. We shouldn't be squeamish about complementary therapies, but should also be prepared to withdraw them if evidence suggests that they are unsafe. It is possible to research complementary and alternative medicine, but it will be costly. What the debate about complementary medicine reveals is what patients want from their relationships between their therapies and their therapists, and that they want to work more closely with the people caring for them and to make decisions about their treatment and care – a wider lesson for all healthcare providers.
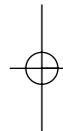
More should be done for people with disadvantages or other limitations in their access to information

Self-management courses within the Expert Patient Programme seek to help people develop the skills to live their lives to the full, which means recognising their limitations, or working round them. For example, although many web sites are not yet fully user-friendly, many organisations are making a real attempt to catch up. Many Government web sites are still poor. Being user-friendly goes far beyond access to the internet, though, and rather than try to provide a single sort of service, organisations could train their staff to help people to use existing services. These are early days, and things are on course to improve in the future.

Useful information

www.abpi.org.uk	ABPI's main web site, links to other related sites
www.lmca.org.uk	Long-term Medical Conditions Alliance
www.healthcarecommission.org.uk	Healthcare Commission
www.nice.org.uk	National Institute for Clinical Excellence
www.dh.gov.uk	Department of Health's main website
www.macmillan.org.uk	Macmillan Cancer Relief

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