King's Fund

OUR NATION'S FUTURE HEALTH SERVICES

(A Second Better Chance)

A report on the deliberative Citizens' Groups on the future of the NHS prepared for the NHS 50th Anniversary Conference

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Foreword

This report documents the conclusions of a series of deliberative groups on the future of the NHS which were commissioned by the "All Our Tomorrows" Conference Steering Group.

A recurring theme throughout the work that led to this report is a clear commitment, by our fellow citizens, to the core values of the NHS. They continue to endorse the vision of a public service, largely funded from taxation, free at the point of delivery providing equality of access and equity of treatment across the UK. This was no "mantra", repeated for reassurance, but a statement of shared values that is integral to a modern civil society. While the NHS might not ever match this ideal, the notion that we can all continue to strive for such a public service says a great deal about the positive energy that this vision releases.

It has been inspiring to work with so many people who freely held these values and who, through processes of informed deliberation, sought to enhance our understanding of what could be achieved by 2020 and how we might journey there. Above all, it is an affirmation of active purposeful citizenship and the contribution "the extraordinary talents of ordinary people" can make to our Society's most important challenges.

Bob Sang
June 1998

Introduction and Overview

1.1 Developing the People's Perspective on the Future NHS

This report describes the planning, implementation and outcomes of a process for involving local citizens and users and their organisations in informing the NHS Confederation's major conference: "All Our Tomorrows" in July 1998, to celebrate 50 years of the NHS (cosponsored by IHSM and the International Hospitals Federation).

1.2 The Challenge

The King's Fund was invited to contribute to the design and planning of the above major conference by, inter alia, developing a deliberative process which helped to articulate the public's perspective on the NHS in the year 2020.

In preparing for this work we recognised that we were dealing with many publics living in increasingly diverse local contexts and that we would have to address the duality that all individuals face at some time in their lives, i.e. citizen-user/patient. Previous learning from piloting Citizens' Juries and long-term work on public participation helped in the design of these deliberative groups.

As citizens we all face wider responsibilities of stewardship and community interest as we address the future of the NHS. As users and/or potential patients we inevitably have a more immediate focus around particular needs. In order to take account of this duality and to provide conference participants with a rich source of material a three phase process was designed to elicit citizens' and users' views in relation to the Values, Purpose, Systems and Experience of the NHS now and in the future.

1.3 A Framework for Participation

A participatory approach was proposed which would link the work of the deliberative groups to the participation of conference delegates.

Phase I The Citizens' Perspective

We chose to work in collaboration with five Health Authorities (East London, Buckinghamshire, Sunderland, Mid-Wales and Lothian) because of their different socio-demographic profiles and their track records in public involvement. The King's Fund also produced a briefing relative to future thinking about the NHS to prepare the ground for the deliberation. Also, local senior staff agreed to act as witnesses to the process *(See Appendices I(a) and I(b))*. Colleagues in these authorities worked to recruit mixed groups of local people which as much as possible reflected the local population. (These were not representative samples. The participants were volunteers invited to come and speak for themselves as concerned citizens).

Phase II **The Users' Perspective**

Then, by working in collaboration with our growing network of advocacy and user organisations, we facilitated a set of groups consisting of a mix of users and workers who had complementary perspectives. In these groups it was important to share experiences and to acknowledge the "here and now" concerns that all users and carers face. (Again, participants were facilitated in speaking for themselves and to contribute freely and equally as peers).

The outputs of these groups were validated by participants as part of the final synthesis prior to the conference itself.

Phase III **The Conference Deliberation**

Conference participants working in their groups, will be invited to use the outputs from the two sets of groups to identify the implications for the NHS and its communities for the "modernising journey" from 1998 to 2020. In particular, they will be asked to focus on the likely changes and propose "Guiding Principles" drawing on the advice from fellow citizens and service users.

This will be linked to the outcomes of three other futures' projects:

An extensive Delphi study of staff views
A Scenario building exercise
An oversea's Comparative perspective

2.0 The Briefing

[Delegates are invited to read this for themselves as an aid to reflection.]

By working with two colleagues regarding the future of the NHS (Tony Harrison and Bill New) we produced the following briefing which was sent to all participants prior to the Groups:

"When we meet as a group our task will be to create a picture of the NHS as we see it in the year 2020... or not, as the case may be. Because we live in a diverse democratic society, we can each, in our own different ways, choose to influence the future. So, what we want for our health and health care in twenty years or so can be seen as a matter of personal responsibility and of citizenship.

The purpose of this document is to help you think about that personal responsibility by offering some ways of looking at the choices we all face in relation to our health and health services. There are no right or wrong answers. You may well think up some better ways of thinking about "Our Future NHS". The National Health Service is currently defined by the following core values:

- *Access to health care according to need - those who need health care will get it.*

- *Equity of access and treatment across the UK - people can get the same care, when they need it, wherever they live.*

So, the first choice facing us in the year 2020 AD is, "Are these what we still want as the defining values of the future NHS?"

However, when we think more about the future this apparently straightforward choice has complications.

Future Options

Can we envisage a future without an NHS? What might it be like? How would it be funded? What might we know that we don't know now? What will matter to us, our children and grandchildren?

When we think about such questions a lot of familiar hopes and fears run through our minds. Will the same hopes and fears be around in 2020, or will people be considering different issues? There is an optimistic and a pessimistic point of view to explore.

The optimists might say:

- Medical, scientific and technological advance will further help us overcome illness and disease, accident and injury.
- Increasing wealth will continue to fund our health and care needs.
- The healthcare systems and the people who work in them will be more efficient and effective.
- Public sector finance (money collected through taxes) will remain a secure and popular source of funds.

In other words, we will have a more accessible, quicker and safer system of healthcare available within our different communities.

The pessimists might say:

- The costs of scientific and technological advance will provide opportunities to improve people's health at a price the NHS cannot afford.
- Poorer people are even more unlikely to receive the same level of health care as wealthier people.
- An overstretched system will be breaking down as more and more people demand health care and good staff are leaving in increasing numbers.
- Most people will depend on private health insurance to cover their health needs.

In summary, an NHS as we now know it cannot continue.

Our experience of the NHS today - influences whether we take an optimistic or pessimistic view. One way to think differently is to put yourself in someone else's place in 2020 AD, and try to see what it might be like.

For example, imagine you are:

- *The parents of a sick child waiting for a GP to call in the middle of the night.*
- *An elderly patient with terminal cancer who also needs kidney dialysis.*
- *A community nurse on his/her rounds.*
- *A local politician preparing for the next election.*

What might you feel about the NHS in each of these situations in the year 2020.

In 2020, what assumptions are you making? How would you like it to be? How would you like it not to be? Remember, we all get caught up in different roles:

- *Those who need healthcare services.*
- *Those who provide them.*
- *Those who directly - or indirectly - pay for them.*

How might these different interests be resolved in 2020?

This is not a test and you do not need to write your thoughts down, although you might want to make a few notes on your thoughts before the workshop."

Readers of this report are invited to reflect on this Briefing too.

3.0 Findings from the Deliberative Groups

Group participants agreed that their work should be distilled into a statement addressed directly and personally to all conference delegates.

3.1 "Our Nation's Future Health and Health Services"

"This statement pulls together the findings from 8 "Deliberative Groups" held earlier this year to consider the future of the NHS and produce a "report" for your important Conference. It is written in the spirit of partnership because our vision of a healthier future, and indeed the journey there, is an exciting one entailing a great deal more participation of us all as fellow citizens - not just as "patients", "carers", "professionals", and "managers", and so on. Health and the health of future generations is a matter for all fellow citizens. This is about the kind of society we want for our future.*

Many of us came to our Groups with this view - we were willing volunteers after all. And, through a process which enabled us to share our experiences, thoughts and feelings as equally valued participants, we produced a strong consensus. We created dissent too. It is important that dissenting voices are heard.

Above all, we believe that if we all find ways to co-operate, deliberate and work together, the next fifty years offer a better second chance to continue to improve our nation's health and health care.

By working co-operatively we have tried to create a pluralist view that is not constrained by current structures and vested interests.

*(Facilitator's Footnote: This final synthesis has been improved and validated by participants. The methodology is deliberative drawing on a process model developed for Citizens' Juries. Essentially it entails a safe, equitable process which enables diverse groups to share, reflect and distil a consensus while ensuring dissenting voices are heard and valued too. The "extraordinary qualities of ordinary people" came shining through when volunteers were given a chance to work in this way. Their evaluation has been very positive. There is one ground rule: everyone speaks for themselves alone. This is about participation not representativeness, leaving conference delegates to choose for themselves how to respond. Bob Sang, King's Fund, May 1998)

There are four fundamentals to our vision of the future:

1. *The core values of the NHS will remain central: a free public service, largely funded from taxation, achieving equality of access and equity of treatment.*

2. *The context of the NHS will be very different:*

   a) *Care in our communities will be integral to health promotion, treatment and care. It will be seen as part of a preventive strategy, especially for elders. In this the role and work of informal carers will be highly valued.*

   b) *The workforce will be more highly valued, with health professionals working on a mutually respectful basis with patients and carers. Informed dialogue will be the essence of a more mature relationship between people and services.*

   c) *Also, a new, more balanced relationship will have been established with all commercial vested interests, entailing a major shift in emphasis from profitability towards social responsibility.*

   d) *Locally accessible networks of care and communications will enable users, carers and citizens to be much more fully engaged in the planning and monitoring of services - as well as in delivery. Joint development and use of new technologies will make this all the more possible. "Self Health" will have a much bigger part to play, as will the use of alternative therapies.*

3. *We shall all share a much more "whole life" perspective on health and well-being which will influence all aspects of policy-making and organisational assumptions.*

4. *Finally, health will be subject to a much more democratic system of accountability with public participation at all levels and in all processes... including research.*

We are reassured that on the best of our experiences the future is here in the present, if we are all prepared to listen and to learn on the journey to this vision. We want to share this responsibility and we recognise that the pace of change will be different for different groups. Remember, we already share responsibility for care to a massive, largely unrecognised extent.

This "journey" will be full of risks which we want to share with you through your Conference. Our meetings provoked important questions:

- ***How can we develop health and healthcare systems that are not dominated by particular interests and fragmented by organisational structures and hierarchies?***

- ***Can we achieve a rigorous review of the "contract" with doctors and other professions, and the impact of commercial interests on the health sector? We are divided on this, seeing a big tension between the underlying principles and necessary pragmatism, especially in relation to private healthcare and the profitability of the drug companies.***

- ***Can we learn to work together to build consensus on priorities, plans and performance standards that is genuinely grounded in reliable information and a people's perspective? We particularly want a role in the Research agenda.***

- *How do we work together to address the long-term challenge and overcome short-term political interference and private vested interest? In particular, we need to achieve better use of existing resources and wiser investment of new resources.*

- *As fellow citizens, how can we all share in the ethical debates that arise as our knowledge of what is possible grows?*

We have also identified significant risks to our working well together:

- *Fundamental social and economic inequalities are not being addressed.*

- *We worry that the NHS remains very discriminatory - especially if you are from an ethnic minority, or if you are getting old, if you have a communication disability, or if you are seen as disabled and not able, or even if you are a woman.*

- *From the bottom-up we see the system from the perspective of the whole person; from the top-down our lives and services get divided and fragmented.*

- *There is not much listening going on! It is a matter of training, education and attitude... on all sides. Openness, transparency and reliable information help too!*

- *We recognise that we want both a fast, reliable emergency system and a responsive long-term health system. Is this achievable?*

- *Finally, our colleagues in Scotland and Wales see enormous potential in their new democracies. Will Regionalisation in England help too?*

We are confident that these challenges can be addressed and that together we can move forward. All the best for your deliberations.

With good wishes,

Your Fellow Citizens"

In summary, the vision retains a strong sense of the core values of a public service NHS - one that becomes more integrated from a patient and community perspective and one that is more open and democratic in all its processes. The challenge for conference delegates is to visualise new forms of organisation, which will both facilitate a more preventive and flexible participatory system and achieve a more equitable balance between legitimate vested interests (personal and commercial) and the social impact of the NHS system for people and communities.

4.0 Reflections on the Deliberative Group Process

4.1 Overview

There were five local groups (East London, Buckinghamshire, Sunderland, Mid-Wales, Lothian) which were recruited through collaboration with the local health authorities (boards). 48 Local people attended these (range 8-12) and each group had the opportunity to deliberate on a witness session provided by the local Health Authority Chief Executive, with the exception of Lothian where the Director of Public Health took on the witness role.

The three "users' groups" were better attended (42 in all) and were drawn from a wide range of organisations (e.g. Carers' National Association, Association for Disabled Children, etc). Clearly, participants in the groups had a great deal of exposure to the current challenges of the NHS, and this had advantages and disadvantages for the group process. In particular, some individuals found letting go of their special interests quite hard. (The "representative model" of involvement is very limiting and leading members of voluntary organisations often find open, equal participation quite hard).

The quality of deliberation in all the groups was very high and the response to the time-limited task was extremely constructive, resulting in a focused set of outcomes *(Appendices II-IV)* with a great deal of common ground emerging (see previous section). In the remainder of this section I shall comment on the substantive differences between the groups and reflect on the implications for longer term work. As with the summary report I shall endeavour to pull out the distinctive learning points - the primary material is available in the appendices for those who want to develop their own interpretation *(see Appendices II-IV)*. This section concludes with a reflection on the process itself, based on the evaluation feedback.

4.2 The Local Groups

All five groups were concerned with three themes: the future funding of the NHS, fairness, and democracy and accountability. Indeed, the chance to work face-to-face with their local Chief Executive or Director of Public Health in a facilitated witness session was responded to very constructively on all sides. (We found this with the Citizens' Juries pilots too: an excellent lesson in democracy and accountability in practice).

In East London, where the group had the biggest age range, there was an over-riding concern with fairness. The group's vision was of a non-discriminatory service which was much more sensitive to personal and cultural difference and which was not so constrained by commercial vested interests. In common with all the other groups these local people wanted a greater degree of public involvement.

The Buckinghamshire group was slightly "managerial" in its view and was concerned to see the creation of a much less cumbersome and bureaucratic system. Their vision was of "A Second Better Chance" to create a public service that was much more transparent and organised around patient and carer needs not organisational and professional interests.

In Sunderland a vision emerged of a "People's NHS" which took much greater account of socio-economic, structural inequalities and which was based on a new "contract" with doctors and less political interference. They echoed a wider concern about the tensions and ambiguities created by private income earning and commercial vested interests.

This sense of a more open, democratic public service system gained even more impetus in Lothian. The energy for local participatory democracy has been opened up by the whole regionalisation process and the creation of a Scottish Parliament. The future of the NHS is about "the kind of society we want in Scotland". The group also recognised that local people would have a key role to play in the new ethical debates in health and in addressing the fundamental economic inequalities that potentially constrained a healthier future.

Finally, in Wales, where the group was facilitated by colleagues from the Welsh Institute for Health and Social Care, a more structured "ranking" approach was used *(see Appendix IV)* to assess priorities. This group struggled with the issue of funding and the need to grow a genuine partnership approach to address tough financial choices. In common with the other groups they affirmed the importance of recognising the role of unpaid carers.

4.3 The "User Groups": Emerging Themes

"Our Nation's Health Services"

These groups had been recruited through a network of independent and voluntary sector organisations drawn largely from the Patients' Association published database of user and carer organisations. The *Appendix III* includes the record of their emergent thinking and their conclusions. There are three key characteristics of the work of these groups.

- As they deliberated so they moved from a consumerist position, reflecting the particular interests of individuals, towards a more shared position of citizenship - reflecting a wider perspective on the future of the NHS.

- In each group there was a mix between paid staff (e.g. chief executives, policy officers) and voluntary participants, often current users of services (e.g. mental health, disability, long-term conditions, cancer). This mix enriched the process as they learned to work together as peers.

- The overall messages were the same as those from the local groups although the deliberation was often more intense with, at times, rather less listening going on! (On the other hand these groups did not have witness evidence. The participants brought so much that was rich with them).

Group 1 identified the problem of a top-down, bureaucratic set of structures which fragmented patients' lives. They began to visualise a much more holistic approach for the future where the individual became the integrator of the services. They saw the development of real - not rhetorical - partnerships as one way of underpinning a more integrated future. In particular, they envisaged a need for an open dialogue on the ethical implications of medical advances.

Group 2 affirmed the aspiration of a more integrated future, noting the common ground they all shared in terms of both their hopes and fears for the future. They felt strongly that the constant restructuring of services - "change for changes sake" - did not offer a helpful way forward and that a more developmental approach emphasising accessibility, information and education would enable a healthier future... including a healthier future for NHS staff.

Participants in **Group 3** echoed these concerns and visualised a much more democratic future whereby users and carers would be more actively involved as informed fellow citizens. For example, their vision of citizen involvement ranged from the design and use of information services, to the further development of the role of complementary therapies, to an active role in medical research (free of vested interest) and in the medical education curriculum.

[Footnote: I often hear NHS professionals and managers refer to active patients/users as "the usual suspects". This is marginalising and demeaning. Deliberative group work helps to take the anxiety and adversarialism out of the participatory process and, when it works well, prevents the institutionalisation of roles and the mindsets that go with this. Participants begin to share the 'bigger picture' by seeking mutual clarification as opposed to establishing and defending set positions. It is a rich process of adult learning. Bob Sang, King's Fund]

5.0 Learning From Deliberative Groups

5.1 Background

When I was invited to take part in this project the original 'brief' was to run a series of focus groups. However, as co-facilitator of some of the pilot Citizens' Juries in the NHS, I had learned that local people responded very well to the opportunity to work in an explicitly more reflective way than is usual in focus groups. *(See B. Sang and S. Davies "Perfect Strangers" in "Ordinary Wisdom" S. Elizabeth et al, King's Fund, forthcoming).* In this earlier work we had defined the group process as an adult learning process designed explicitly to enable individual participants to value and explore their differences while addressing a tough, sensitive question.

The role of the facilitator(s) is to ensure equitable participation and, where there is witness evidence, to support a process of mutual clarification as opposed to antagonistic question and answer. I firmly believe that Health is too personal and complex a subject to be left to didactic and adversarial processes of engagement. I also believe that as fellow citizens we all share a responsibility to learn how to participate in this field on the basis of a mutually respectful dialogue. I made these values clear at the outset of my work with the groups.

"It was refreshing to work with a group of people who had clear ideas and of course vested interests, but who could listen to each other and respect other opinions. If these groups could be a starting point for this type of dialogue we could have a very powerful force indeed" User Group participant.

5.2 Working Well Together

In *Appendix VI* we have tabulated the 'ground rules' developed by the various groups as part of the first phase of the deliberative process *(see Appendix I for a typical process outline)*. There are two important lessons to be learned from the way the groups addressed this stage of their work together. First, it establishes a sense of collective responsibility, expressed in their own words, for the quality of their working relationship. This enabled me as facilitator to conduct a quick process review in the morning session in order to keep the smaller groups grounded as they became more intensively immersed in the subject and the task. Second, these 'ground rules' are very human and sensible. One participant, a self advocate from "People First" the organisation run by and for people with learning disabilities, had much to contribute here as this way of working is fundamental to the participatory democracy that underpins many user-led organisations. A lesson for all.

5.3 The Evaluation Synthesis *(See Appendix V)*

The overall feedback, through letters and returned evaluation forms has been very encouraging and constructively critical. A "warts and all" synthesis is included in the appendices for readers to explore at their leisure. I would like to highlight just a few key learning points:

- The process is risky. Some of the critical feedback reflects what I would call a naturally "dependent" view of group process. Bringing strangers together on an important topic does raise levels of anxiety, so some structure and some prior briefing is needed. My view is the less the better, but for others that is an unwelcome imposition as they need a documented base from which to build their participation.

- Sustaining focus requires energy, and these days were very intensive. Creating a future orientation is even harder when energy sags and it is safer to dwell in the present. This is where a team of two facilitators really helps. My NHS colleagues from the localities provided invaluable support in this respect *(see "Acknowledgements")*.

- The design of the day did predispose the group towards one outcome - a co-created consensus - and this was deliberate and explicit. The point is that difference and dissent are the essence of consensus and this deliberative design supports a process of mutual clarification through which dissenting voices enrich the outcome. This left some of the more adversarial participants slightly frustrated... they still wanted to 'win' the 'debate'.

- Finally, a word on witnesses. The witness role fulfilled by the Chief Executives created the basis for a different relationship between these senior officers and their fellow citizens. The dialogue that evolved produced, inter alia, an underpinning sense of mutual respect and recognition. The essence of a sound accountable public service relationship! (Our witnesses did real credit to the current NHS in this respect).

5.4 Conclusion

"Co-operative, reflective deliberation" - Quite a mouthful... but it works! Readers of this report may wish to learn more about the process and the methodology... and this will be written up and disseminated soon. But, really this is all about WILL: developing the will to hear others and respond appropriately; to seek mutual clarification; to let go of the natural anxieties and fears that pervade the world of health policy and the NHS; to see beyond vested interest. It is also a matter of belief, belief that we can share in improving our society and its institutions as fellow citizens - *"We have it in our power to build the world anew" (Thomas Paine).*

This work has deep roots in participatory approaches to democracy and community development. These traditions are re-emerging and in a modern form, for example through Health Action Zones. Readers are invited to reflect and deliberate for themselves on how we might take this forward in creating a healthier future.

Bob Sang
June 1998

Appendices

Acknowledgements

Appendix I: Briefings:

a) Workshop Briefing

b) Witness Briefing

Appendix II: Local Group Outcomes

Appendix III: User Group Outcomes

Appendix IV: Welsh Group Outcomes

Appendix V: Guidelines and Evaluation:

a) The Evaluation Synthesis

b) An Evaluation of the Day

Appendix VI: Working Well Together

Acknowledgements

To all the individuals who participated in the groups.

To our co-workers in the field:

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Marcus Longley	(Wales)
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Julie Wells	(Buckinghamshire)

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Peter Stansbie	(Wales)
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Claire Dodgson	(Sunderland)
Jackie Haynes	(Buckinghamshire)

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Our Future NHS: Local Citizens' Perspective

Workshop Briefing

1. Purpose

From the attached document you will see that this event provides you with an opportunity to work with a group of your fellow citizens in providing your perspective on the future of the NHS.

2. Priorities

Throughout the day we will focus on the values that underpin a National Health Service, what this means in practice for "ordinary people", what we might aspire for in the future, and what threatens this vision.

3. Plan

0945	Arrive/Coffee
1000	Introductions and "How we will work well together".
1030	Sharing Experiences: What are our Values?
1115	Break
1130	Preparing for our Witness
1200	Expert Witness (a senior person from your local health services) Exploring the Evidence
1300	Lunch
1400	Review - What have we learned?
1430	Deliberation: Our Future NHS
1530	Pulling it Together: Our Consensus, Our Concerns
1600	Close and Tea

[NB: The basic approach will be to enable the group members to work together in different ways to produce the messages they most want their colleagues in the NHS to share.]

Appendix I(b)

"People's Perspective" Deliberative Groups

Witness Briefing Paper

Thank you for agreeing to act as a witness to the above process.

We attach the participants' briefing and outline programme for information.

Your role is to enrich the process through sharing your vision of the NHS and its informing values in 2020 AD. Of course, it would be helpful and necessary to illustrate this by referring to the implications locally. Please feel free to be as visionary (and informing) as you like and to help us get a sense of the journey between now and then.

Your process works like this:

5 mins	Step 1	Welcome & Introduction (Who you are; responsibilities, etc)
10 mins	Step 2	Presentation (please stick to the time)
10 mins	Step 3	Questions of fact and clarification (citizens' time)
15 mins	Step 4	Reflection and deliberation (you get a break)
20 mins	Step 5	Deep questioning (you are in the focus!)

I will chair this process assiduously! My experience is that it results in a very healthy adult dialogue.

I am looking forward to working with you.

With good wishes.

Bob Sang

Local Group Outcomes

(NB: This is presented from the Groups' own words)

East London

Buckinghamshire

Sunderland

Lothian

"Future NHS"

Notes from the Deliberative Group: East London & The City Health Authority 7 April 1998

Introductions:

- Me
- What I hope to gain from today
- What I hope to contribute

Our key questions:

- Finance
- Underpinning Health principles
- Public & Community participation
- Transparency at all levels (£'s)
- Staffing: Professional
  Volunteers
  Carers
- Discrimination
- Research priorities
- Commitment to prevention

What we have learned about what really matters:

- Waiting is not only about how long but also about how we are respected.
- Information about services is "pot-luck".
- Affirm NHS as free public service:
  Equality of access, equity of treatment, comprehensive, principle of altruism
- Poor communications - lack of care and follow-up and proper recording.
- Good health, promoting good health:
  early appointments prevent long-term problems
- An ageist service for elders and young alike
- Elitist: Services white middle class.
- Poor understanding of mental health - a low priority... crisis service only.
- Complaints procedure should be more accessible.
- Lack of adequate resources creates problems... dominated by hospital services, presents shift to community services.
- Doctors' power to strike off lists is unjust.
- Staffing: Level of care will deteriorate if dedicated staff replaced by volunteers.
- Inherent racism made worse by lack of democratic accountability.

Sharing experiences (in small groups)

Each Person:

"The NHS"

- Something positive
- Something not so positive

What I Learned

↓

What We Learned
About Our Values

"Future NHS"

Notes from the Deliberative Group:
East London & The City Health Authority
7 April 1998

POSITIVE PRIORITIES:

- Need for adequate funding for the NHS especially services for the elderly, mental health
- Need to reaffirm belief in the integrity of the NHS principles
- Need for collaborative teamwork between patients and their carers on the one hand and all health professionals and other agencies in health care planning and provision and setting of research priorities

- from Day 1 -

- Information Technology
  For patient benefit
- Prevention of illness - collaborative health checks - based on dialogue

- NHS Existence is positive
- Community health services
  child development and
  dental clinics (crucial)
- Free Primary Care Team
  emergency cover outside surgery hours

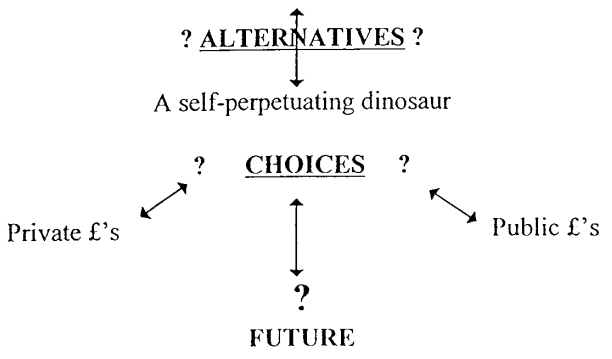
NEGATIVE BLOCKAGES:

- No law for euthanasia
- Personal choice or public debate
- No mixed sex wards
- No more prioritising expenditure on nuclear weapons and instead spend money on health
- No more charges for dental and eye services
- Rethink health services as comprising both environmental health and poverty aspects

SUBSTANCE NOT RHETORIC

- No place for private practice in NHS
- Equity of treatment:
  - Ethnocentric
  - Disability
  - Ageism
- Not "Client-Centred"
- Emphasis on disease not health
- Open up the no blame debates
- Where does personal responsibility begin and end?
- Cost of 'after' care and who cares for the carers? (exploitation?)

Affirm fundamental principles and values.... prevention/treatment



EAST LONDON

The Future:

- First and foremost we want to affirm the basic principles of the NHS as a free public service, affording equality of access and equity of treatment. These will be fundamental in the future.
- It will be a collaborative set of services based on teamwork between patients and carers on the one hand and professionals and managers from all the agencies involved on the other. This collaboration will extend to service improvement, planning, and setting research priorities.
- Adequate public funding will be sustained - especially in community services for disabled people, elders, and those of us with mental health needs.
- There will be a much broader, preventive view of health, taking account of issues like poverty, environment, transport, and so on.

Getting There:

In order to achieve this healthier future we believe a number of priorities must be addressed:

- Learning to develop services that are not discriminatory towards elders, women, disabled people and people who are not white and "middle class".
- Work with us to develop information services and health checks that help us to manage our own health.
- Continue to develop community services that are accessible during our daily lives; including emergency cover, child health and dental services.
- Share the big ethical debates with us as fellow citizens - they are too important, especially those concerned with the limits of personal responsibility.

Key Questions:

- How will <u>you</u> learn to be more client-centred, focusing on the <u>health</u> of the whole person <u>not</u> specific conditions?
- What are you going to do about private vested interests?
- How will we all address care and the needs of carers?
- Can you think of better, less bureaucratic ways of organising our services? - How can we help?

"Future NHS"

Notes from the Deliberative Group: Buckinghamshire Health Authority 8 April 1998

What matters most.... What concerns us most...	**Key Issues for our Witness...**
• Inappropriate use of facilities takes up time/clogs the system. • Really urgent need often not met. • Not enough care/d community/follow-up (fragmented - doesn't flow) • Staff committed but undervalued: Pay/Contribution/Turnover • Lack of time to care... lack of time for decision-making/reflection • Need to focus on whole person - their dignity/respect/humanity • Still a two-tier system (private/public) e.g. remedial care - inequitable	• If/When things breakdown... who will be accountable? • How will we get a more "streamlined" system? (treatment) • What will the logic be behind the ratio between patient treatments and "Beds"? • How will healthcare be funded? • How will all services interact to produce a "seamless"/holistic patient and carer experience? • What will we mean by "patient" and "carer" in 2020? • How/When will we assess the capacity for people to care? • Where will we fit in the health-disease continuum? • Where does health fit with: education, housing, environmental health, transport... • Choice (personal/public) who chooses? • Choice (treatment/care) who chooses? • Are the appropriate investment decisions made? (By the right people?) • Can we trust the information and the people who make the decisions using it? • Who is responsible/accountable? • Where can we get valid/reliable/impartial information?

So, what have we learned? ..... so far ....

- "Frightening" .... we will have to pay for anything above minimum.
- Two-tier society.
- Dramatic increase in IT-use (information is dangerous).
- Chaos in the systems.
- Risk of loss of human contact.
- Communications and interpersonal skills paramount.
- Decision-making authority devolved.
- Involving the "Primary Care Team" more.
- Access/Referral more complex.
- What kind of democracy?

"Future NHS"

Notes from the Deliberative Group: Buckinghamshire Health Authority 8 April 1998

A Second Chance

- A national care service community oriented with readily accessible facilities and aftercare
- Adequate funding - with appropriate contribution - paid on a medium to long term basis
- Attractive employment and career prospects for all staff with minimum building and equipment standards
- Greater integration of all social and economic aspects and wide coverage of all health (e.g. planning, transport, opportunities, housing)
- Costs/Loss of comprehensive NHS - parts of community not covered , facilities not available in local area, outbreak of epidemics
- Costs: of underfunding
  loss of service
  recession funding and catch up arrangements
- Inadequate and disgruntled staff -
  poor service
  unacceptable waiting lists and general hardship
- Community breakdown - costs

SO LET'S XXXX GET IT RIGHT

Group 2 (1)
AIM

1. All PC agencies to be working as one for the patient
   - Nobody should be excluded from PC services
   - Easy transition from primary care to secondary care and back to Primary Care
3. Better prevention
   Better health education to change attitudes and lifestyle
   Ratio of professional to patient should be greater

2. Equal access nationally to all health services to meet individuals' **needs**

Group 2 (2)

- Reliable/Economic/Free
- To have easy access to one telephone no. to get advice/help/guidance immediately with referral to named agency where necessary

POSITIVE:

1. Free access to medical care in the future - regardless of who you are
   Good care in the community (set up community care on the NHS)

2. NHS **not so** business orientated
   Increase in staff and training to ensure 'hands on care'

3. Set up an emergency clinic (in between doctor's surgery and A&E)
   Better education and awareness in community
   Increase in availability of beds
   increase in care of elderly

NEGATIVE:

1. (Free access to NHS): Overloading system - costs go up - waiting times. Open to abuse

2. Balance
   costs - very high
   resources wasted
   accountability lost

Transparency about information and effectiveness — Financial / Clinical

3. Cost
   Staff
   Could close local A&E dept
   Ensure correct use - education/awareness

A SERVICE WITH REAL ACCOUNTABILITY

RISKS

1. Difficult to get people to give up their little empires
   May become unwieldy

2. Will not be adequate funding, what there is - who makes decisions? Local or national or individual

3. Difficulty in changing people's attitudes — Personal Responsibility / ? / Political Accountability

BUCKINGHAMSHIRE

The Future:

- A national community-orientated care service based on public service (not business) values funded from a medium to long term contributions' strategy.
- An attractive service in which to work - a safe, stimulating environment offering good career development.
- An integrated system based on equality of access to and through primary care services which prioritise prevention and education.
- Greater investment in community care - especially staffing levels to support "hands on" care and carers.
- A network of community-based emergency services supported by single-access patient information services.

Getting There: "A Second Chance"

- Loss of staff commitment is a real, pressing risk.
- Underfunding because of economic pressures will lead to longer-term costs and costly disruption.

Questions:

- How can we get a better balance between personal responsibility and transparent political accountability?
- Will the "organisational empires" of the NHS still get in the way?
- How will we all learn to understand and address the financial and the clinical measures of change and improvement?

"Future NHS"

Notes from the Deliberative Group:
Sunderland Health Authority
9 April 1998

What matters most:	Key Issues/Questions for Our Witness
• Attitude to patients is human ("not talking down", "not conveyer belt") • Take time to look behind the problem... listen. • Trust in the professionals, based on openness. 'True' professionals are open, human, listen well. • Continuity of GP... through whole life. • Emergency response good but waiting lists are a big problem. • NHS is comprehensive: private care is selective. • Too many accountants. • Professionalism important (knows what they are doing and communication, humanity). • The Health Service is National for everyone, free at point of delivery. • Lack of choice for the individual. • Lack of resources - money - people • Illness is personal, so waiting for treatment is a personal problem - out patients as well as for treatment. • There is no effective alternative: Do we appreciate it? Will never be enough funding! Great NHS - "second to none". • Reasons for change (i.e. bed closures) - ? Political - ? Really get better at home - What's true? • Are prescription costs fair? Should those who can afford it pay for prescriptions, trips to GP. • Mixed messages - confusing people • ? Shouldn't be able to "buck the system" - shouldn't need to do it.	• Will there be an NHS? • If so, what will be the major changes? • What are the plans - if any - for the future? • Will there be enough money? • Will it be free or affluence-tested? • Should doctors make a choice (private/public)? • Will National/Private be integrated? • What choices will face individuals? • Will there be a cost on people's lives? • What will be the moral dilemmas? • What will be the emphasis on prevention?

"Future NHS"

Notes from the Deliberative Group:
Sunderland Health Authority
9 April 1998

GOALS:

- CHOICE for PATIENTS
- Immediate point of contact

↓

- Reduce waiting lists
- Preventative medicine

RISKS:

- Charges for services (mixed economy)
- Keep costs to poorer patients down
  i.e. prescription charges not per item
- Quality and Equality of service is maintained

↓

Reconsider the Doctors' Contract

NOW, what have we learned:

FUTURE	JOURNEY
• NHS will be here • There will be funding • A good, committed workforce • Largely free • Change is a matter of emphasis... ways means £'s • Impact of new technology • In the "wrong hands"	Political Effects Openness Accountability Truthfulness Flexibility → • A People's NHS • More say, more public involvement • Sharing responsibility

GOALS:	RISKS:
1. More efficient use of resources	1. Technology (im)personalising Confidentiality
2. Preventative healthcare: More education More clinics i.e. Well Person Clinics Which in turn may reduce WAITING LISTS	2. Amalgamation of health authorities and trusts (not being in touch with local needs) 3. Too much political intervention. 4. Politicians etc. Playing God Who decides ?
3. Consistency of policy and flexibility for local needs e.g. IVF and Hayfever treatments, openness of information also	
4. Raise money specifically for NHS use e.g. 1p to £1.00 extra tax	

SUNDERLAND

Future Goals:

- There will still be an NHS - largely free - with equality of access and fair treatment available wherever you live.
- The emphasis will shift towards preventive care and medical education, reducing waiting lists through early intervention and better use of technologies.
- Improved access and information will result in more resource efficient services enhanced by specific tax - income for health.

Risks to be Shared:

- Increasing charges for services - including to "private" doctors.
- Falling quality and equality in the short-term, leading to long-term costs.
- Lack of democracy - openness, accountability, truthfulness.
- Discrimination and lack of flexibility in poorer communities.
- Unwillingness of politicians and professions to share leading to political interference.

Questions:

- Will mergers result in out-of-touch health agencies.
- Will technology become impersonal and inaccessible?
- Will this really become a People's NHS?
- How can we help?

"Future NHS"

Notes from the Deliberative Group:
Lothian Health Board
1 May 1998

What matters most:

Fears

- There will be no NHS in 2020.
- Insurance based health care.
- Charity dependence?

Hopes

- Properly funded NHS.
- 'Free' health care maintained.
- Increase in local control and accountability.
- Proactive action on causes of ill health e.g. housing, poverty, etc. Structural not lifestyle.

What matters most:

- NHS for All - not just safety net for poor.
- Public service - not private.
- Democratic accountability and community influence.
- More preventative care.
- Recognition of relationship between health and housing/employment/poverty etc.
- Adequate resourcing.
- Rewards and conditions re: staff

What matters most:

1. Integrity of NHS maintained.
2. Adequate funding

Funds A Government }
B Industry } *Board of Governors Accountable*
C Lottery }
D EEC }
E BUPA etc }

3. Technology/Research
4. Preventative Medicine v Reactive (screening and health clinics)
5. Stress Management and Treatment
6. Health Education

What matters most: Key Questions:

Future:	Getting There:
Whole picture ←	NHS ↔ other Government policies
Science & Technology →	£'s implications
? NHS Democracy ←	Accountability & ? control
Informed participation →	Beyond quango's
(Experience & knowledge) ←	Role of people and groups and communities
New ethical challenges ←	Impact of technologies
Centralised/ Decentralised ←	Reg'l/Nat'l Govn't & EU (subsidiarity)
Choice & Priority ←	Funding

What kind of Society do we want in Scotland?

LOTHIAN

Vision:

- Confirm the principles of a free public service, funded largely* from taxation, equality of access and fairness of treatment for all.

  *There was dissent about the potential role of private health care also whether, pragmatically, it was part of the vision.

- A much more democratic NHS with public involvement extending to the ethical dimensions of prevention, the use of new technologies (Bio- and information/communication) with greater, demonstrable accountability of politicians, professionals and managers. (In Scotland this is seen as much more possible as devolution progresses).

- Supported "self health" in local communities in the context of national commitment to dealing with structural inequalities.

Journey:

- Learning to use a wide range of means - from hearing feedback on service quality, to better public information and education, to developing a whole range of means of participating in decision-making - to share responsibility for health.

- "Health" integrated as a theme in all government policies/structures.

- A referendum of the "Health £" and dedicated taxation.

- Return to free prescriptions.

- Stop "blaming the public for poor health - work together for better health".

- Create a new relationship with employers to promote healthier workplace.

- Control commercial drug prices and increase public funding for health R&D.

Work of the User Groups

(NB: This is presented from the Groups' own words)

User Group 1

User Group 2

User Group 3

(NB: The reports have all been validated by group members)

"Future NHS"

Emerging Themes

User Group 1

- Communication
- Holism
- Education
- Prevention
- Participation
- Resources - more and better

- Accountability
- National framework for health care:
  - encouraging consistency
  - including process

  Equity in access/care/information
- Partnerships:
  encourage/enable/engaging user involvement
  consultation in a 'real' way
  develop innovation/sharing good practice
  responding to local needs

<u>Hopes</u>

- Person involvement
  - → • appropriate info
  - → • shared control
  - → • shared understanding
  - → • advocacy
  - → • 'think small'
  - → • carers' needs
- Tax-based NHS
  - access
  - equity
- Awareness of discrimination
  - → education/training
- Redress
- Balance acute/chronic/expensive/rare
- Prevention

<u>Fears</u>

Huge
Inflexible
Bureaucracy
BUT FRAGMENTED

- NHS staff
  - } pay
  - *nurses* } hours
  - } training
- Vested interest
  - bureaucracy
  - industry
- Privatise/PFI/Insurance
- Stress

- <u>Remains a free service</u>
- More resources (both financial and human) for service provision and health promotion
- <u>Equal, accessible services</u>
- Patient partnership (empowerment;choice)
  Rights ? Responsibilities
- Seeing patient as a <u>person</u> not a disease/Holistic approach
- Considerations of ethics and values of medical advancements
- A seamless service

"USER GROUP 1"

The Future:

- A jointly "owned" NHS based on principles of public service, equality of access, equity of treatment and experience, largely funded from taxation.
- Practice - of users, carers, and professionals - grounded in a holistic approach to health of the individual and facilitated by reliable information/evidence in relation to prevention, treatment and care.
- A valued continuously developing workforce working in and with communities.
- Health as the key enabler of employment, welfare, well-being.
- Open, shared exploration of the ethics and values associated with sustaining a system in balance; promotion and cure; emergency and long-term care.
- A rigorous use of resources, expertise and information.

The Journey

- Continuous improvement of public involvement; including professionals' education.
- Focus on health and services... and outcomes for people.
- Shared information on policy, performance and good practice.
- Challenge vested interests; internal and external.
- Increase tax base.
- Tackle discrimination, at all levels.
- Health is inter-agency, multi-professional, cross-communities.

"Future NHS"

Emerging Themes

User Group 2

1. Common hopes and fears
2. Public health care is important for general well-being
3. There is a need to look for ways to improve general well-being through society rather than healthcare professionals
4. Social/community support mechanisms are important
5. Importance of public participation in deciding the priorities of healthcare spending and service provision
6. Improvement in education/training/selection of healthcare professionals
7. Great need to start early in public healthcare ed.

Fear of fragmentation Hope of integration

***

No change for the sake of change

***

Accessible information

Uniform standards

Access to Services

***

Education of Medical Professionals

***

Fear of Rationing

"USER GROUP 2"

The Future:

- A participatory system that works towards meeting individual user's needs and wider community needs on the basis of a realistic, informed dialogue.
- Equality of access, fair treatment based on shared evidence of what is affordable and effective.
- Mutual empowerment of staff, carers and users achieved through listening, feedback and a focus on improvement.
- Independent advocacy and complaints systems integral to assuring quality of performance and accountability.
- Local, integrated networks of service addressing well-being.

The Journey:

- Continuous investment in the development of people and resources, including the "users' voice", through patients' councils.
- Open, transparent processes of decision-making and accountability which connect people in communities with all agencies.
- Building a holistic, whole system, view of health.
- Learning to be honest and realistic about what is achievable... open about vested interests.
- Listening and learning all the way...

"Future NHS"

Emerging Themes

User Group 3

1. National guidelines - quality of care and access to treatment strategic planning - not local HAs 2. Recognition of interdependence social/medical care - not robbing one to pay other 3. Realistic consultation - partnership of users/providers accountability - not tokenistic independence of user groups - HA, DoH and drugs COs 4. Concern about reliance on charities/vol orgs for research funding, support and education 5. Recognition of carers' role 6. Prescription/consultation fees/charges 7. Role of EC standardising drug prices	1. Increase user involvement 2. Change in culture and attitudes of medical elite to become more inclusive 3. Access to (appropriate) information 4. Consistent national standardisation of services 5. Genuine partnership arrangement with other service providers 6. Identification of user needs leading to more effective use of resources
1. Guaranteed basic entitlements 2. Adequate resources 3. User control/Democratic Accountability 4. Accessible information: *for all *including preventative stages 5. Respect for long term care 6. Training and communication skills for <u>all</u> staff to respect <u>all service users</u> 7. Integrated care in partnership with all agencies/vol sector AND CARERS 8. User input into use of new technologies	**Priorities:** 1. NHS should be <u>accessible</u> (how?) 2. Priorities should be publicly discussed with user involvement 3. Service user involvement in a meaningful way in <u>all</u> key decision-making 4. More expenditure on <u>independent</u> research (not funded by drug companies) 5. Health not to be considered in isolation: more emphasis on environmental issues (pollution, pesticides, etc) 6. Medical education: more listening skills/more support staff 7. More one-stop self-referral shops for some conditions 8. Review role of GPs 9. Support for health professionals 10. Capital investment needed - ? Source 11. Review of management structure : more accountability and evaluation 12. Mechanism for <u>implementation</u> of national clinical guidelines 13. Integration of complementary therapies

"USER GROUP 3"

The Future:

- Our Nation's Health Service, involving citizens at all levels to ensure a free public service, equality of access, equity of treatment - wherever people live.
- A framework of common standards and accessible, reliable information services underpinning a working partnership between agencies and communities, and between users, carers and staff.
- A holistic philosophy for the whole health process: from causes to prevention; from treatment to care.

The Journey:

- Involve users and carers as fellow citizens throughout the journey... as equal, informed partners.
- Shift the culture from top-down (political) to bottom-up (societal) to gain a whole system perspective and approach.
- Open up the "funding debate" to wide public involvement free from distorting vested interests.
- Grow and nurture the workforce by responding to emerging needs, the growing evidence-base, and citizens' experiences.
- Enhance public participation through feedback, audits and independent monitoring.

Work of the Welsh Group

(NB: This is presented from the Group's own words)

Welsh Institute for Health and Social Care
University of Glamorgan

Brief Notes from Deliberative Meeting on the Future of the NHS
Landeilo, Dyfed, 29 May 1998

1. Attached are brief notes from this meeting, derived from the flip charts produced during the session.
2. There were nine participants, six drawn from established patient and other groups within Dyfed Powys, and three from elsewhere in Wales who had served as jurors during the Institute's Citizens' Jury on Genetic Testing, held in November 1997. There were five men and four women, with ages ranging from c. early 40s to 60s. Two senior health authority staff observed throughout.
3. The process was that developed by Bob Sang of Kings Fund, with plenary sessions on ground rules and key values, followed by preparation for, and discussion with expert witness, (Peter Stansbie, Chief Executive, Dyfed Powys Health Authority). In the afternoon, the group split into two for an hour to discuss their vision of the future, the issues to be faced along the way (the 'journey'), and the obstacles to their achievement.
4. There developed a good 'group feeling', which adhered closely to the ground rules proposed by the group at the start.
5. Purely from a personal perspective, I would highlight the following:
    - the participants were keen to preserve traditional NHS values such as equity and no cost at the point of use, but also wished to leverage in more money. They accepted that the latter could only be done by developing new, additional sources of non-taxation funding, but were determined that this should be done while preserving the core values. Interesting parallels with Labour's 'Stakeholder' concepts;
    - there was also a recognition that rationing of some sort was inevitable, and they had great difficulty in deciding whether this should be via throughput controls (e.g. waiting lists) or by limited the range of service available. I don't think they ever resolved this one;
    - there was much concern that the NHS was poor at PR, and the public generally were worried about/did not understand essentially reasonable changes in the nature of service provision. In other words, managers were usually taking the right decisions but failing to communicate the reasons for them to the public; (They may have been unduly influenced here by the very reasonable performance of Peter Stansbie!)
    - this is linked, I think, to the universal desire to 'take the politics out of the NHS' - a belief that there were (technocratically) 'right' decisions to be made, and therefore no need for political interference. This was especially surprising given that Dyfed Powys is trying to close several cottage hospitals (on 'rational' grounds) against bitter local opposition;
    - there was some nervousness that technology - and its commercial sponsors - may take over - 'because we can do it, therefore we must do it'. Examples quoted were genetic engineering, cosmetic surgery, heroic life saving. This echoes our own Citizens' Jury and focus groups on genetics;

- another strong theme was for 'power sharing' - the NHS to create 'partnerships' with other organisations (especially the voluntary sector) and with individual patients and carers;
- the list of questions put to Peter Stansbie should also perhaps be put to the Conference!

Marcus Longley
Associate Director and Senior Fellow

MJL/4.6.98 MARCUS\GENERAL\DELIBMTG.DOC

- *The following brief notes are based on the flip charts produced during the session*

Ground Rules

- Confidentiality
- Listen to everyone
- Good tempered
- Say what you think
- Plain English
- Brevity
- Think of both sides
- Work as a team

Values

- Free at the point of use BUT overuse
- Equality of treatment from first contact
- Access when needed - no undue delays, sufficient time allocated to each patient
- Responsive to individual patient's needs
- Citizen responsibilities
- Ensure suppliers do not exploit NHS
- NHS should spend its resources wisely
- Care/repair AND create/change - but uncertainty about genetic engineering, some cosmetic work
- Equality of opportunity for all
- Democratise decision making - decision not made on money grounds alone, nor led too much by high technology
- More emphasis on prevention - in schools
- More support and respect for carers
- Better communication and co-ordination between parts of NHS and other services
- Patient control over care received
- Full involvement of voluntary organisations

Questions for expert witness

1. What will be the optimal balance between local and centralised services?
2. What will be the consequences for the NHS of an aging population?
3. How will the NHS ensure that the proper balance is maintain between clinical services and management?
4. How can the NHS spend more on prevention?
5. What should be done about future shortages of nurses? How should the training of healthcare professions generally be changed in the future?
6. Is rationing inevitable? What alternative sources of additional funding should be sought?
7. How will carers be better supported in the future?

Group 1: Vision of the Future

In order to reduce the six suggested key values for the future to four, a votes was taken amongst the four participants, with each having four votes

	Rank	No. of votes (Max = 4)
More money for the NHS, and greater use of non-taxation sources of finance	1	4
Greater partnership between patient and the NHS	2=	3
De-politicisation of the NHS	2=	3
Comprehensive provision	2=	3
More emphasis on prevention	5	2
Free at the point of use	6	1

Group 1: The journey to the Future

- Avoid inequity along the way - especially as a consequence of increasing the share of non-taxation funding
- There may be a need to move from comprehensive services to core services as time goes by
- The voluntary sector should be much more closely integrated into service provision, as partners

Group 1: The obstacles

- Professional power and cultures may not accept *partnership* with patients
- Commercial interests are powerful
- Politicians will not accept de-politicisation of the NHS
- Patients may not accept responsibilities, and may lack interest in sharing power
- People may be unwilling to pay more for their health care
- People may not accept any degree of growing inequity (2-tier services)

Group 2: Vision of the Future

- NHS caring for an aging population and aware of their needs
- Centres of excellence in services; good back-up community services
- GPs should provide most care
- More patient/public participation, with more patient responsibility
- Nationally agreed eligibility criteria for services

Group 2: The journey to the Future

- Need more money!
- Public and patient consultation should lead to better PR for the NHS
- There should be less politics in the NHS
- Resources should be shifted - accept some hospital closures, move more money to primary and community care
- More preventative care - education in schools
- Encourage private enterprise, charities and other partners

Group 2: The obstacles

- Lack of money
- Public and professional resistance to change
- Too many negatives - overspending, rising waiting lists
- Failure to consult - hidden citizens, vested interests
- Biased information
- Technology - resistance, temptation to move away from basic services

Final vote (whole group)

Are you now generally optimistic about the prospects for the NHS in 2020?

Yes	5
No	2
Don't know	2

Our Future NHS: The Welsh Public

Carmarthen
29 May 1998

How we will work well together

The main criteria for working well together included:

- Confidentiality - *'don't reveal personal experiences to others outside the room'*
- Listening - *'everyone has an equal voice so respect what others say'*
- Tempers - *'keep them!'*
- Freedom of speech - *'can we be controversial?'*
- Putting things in simple English
- Brevity - *'not too many personal stories'*
- Roundedness - *'always think of the advantages and disadvantages of everything we come up with'*
- Try and work as a team

Shared values

Disappointment expressed because there was no younger point of view [no-one under 35 at the meeting]

Some of the issues that mattered most to participants are:

- *'that it is free at the point of delivery'*
- paying for a prescription *'is a tax on being ill'*
- *'but the money's got to come from somewhere'*
- *'if something is free there is a tendency to overuse'*
- *'human nature being what it is ... we take what we can'*
- *'but it is generally accepted that we pay for dental treatment now'*
- *'it is unfair on those in the middle incomes who have to pay'*
- *'uniformity of treatment'*

EQUITY

- *'access .. I think .. is the key*
- *'access to GPs these days is not as good as it used to be'*

Group consensus on too much time spent waiting for an appointment and the fact that there was limited time once you're in with the GP

Too much variation between practices

RESPONSIVENESS

- *'not being responsive to patients'*
- *'my value is that it should be responsive to patients .... and that you don't sit in a waiting room for 2-3 hours'*
- *'it's an educational thing to show that you don't just pop along to the doctor on a Monday morning'*

ACCOUNTABILITY

- *'most departments have a budget, but come January if you've got a surplus, you spend it on whatever you want'*
- *'accountability is important ... the NHS should spend it's money wisely' ....*

'but what is wisely .... how do you compare a childless couples need for fertility treatment and hip replacements for the elderly'

- *'we depend on the professional integrity of the GP ... we can't rely so much on that anymore'*
- *'you'll always have doctors who are not on the ball ..... you'll always have nurses who are not quite caring enough'*
- *'demanding a test could result in you being struck off the doctor's register ... patients can only go so far'*

SENSE OF DIRECTION

- *'we need dome rationales'*
- *'you've got 60 million people, and 60 million opinions, and 60 million requirements'*
- *'we've got to prioritise certain things'*
- *'patients are not used to their full capacity'*
- *'.. to what extent are we going to be Playing God?... '*
- *'what is health about..? .... are we going to tinker with DNA and create artificial human beings..? '*
- *'how far can we as a society allow medical science to go..? '*

Strong emphasis on the need for treatment plans

DECISION MAKING

- *'those who shout loudest get the most'*

'government departments always have equal opportunities in their mission statements, but they are all playing politics'

- *'citizens' bodies should decide'*
- *'not a committee'*
- *'I really believe the people must decide for theirselves'* [sic]
- *'.. the health agenda is pushed forward by the experts not the public'*
- *'... have to give it back to the people'*
- *'the driving force is money so we've got to go back to basics ... the people have to decide'*

'I disagree .... you can't stop the wagon rolling'

- *'there should be ground rules set at the point of entry'*

WRONG EMPHASIS IN THE NHS

Single mothers with young children - *'we're creating ill-health'*

Obesity - '*young people have no awareness of lifestyle'* (gave examples of lifestyles portrayed on soap operas' .....)

- '*15 pints and pot bellies ... we need more education'*
- '*Citizens have responsibilities, but we are conditioned into doing the wrong thing'*
- '*Anyway the government will decide what the issues will be'*

CARERS

- *'carers getting ill is a hidden cost on the NHS'*
- *'no centralisation or co-ordination for carers in Carmarthen'*
- *'my value is supporting carers'*
- *'communication is not happening'*
- *'this caring business has been a cop-out throughout the country ... it's saving the NHS money'*
- *'homecarers have no support'*
- *'carers don't have a legitimate voice as patients or professionals'*

Preparation for Witness

How best to configure services to ensure that they are delivered locally?
Where will the greatest need be in 2020? What plans are there to tackle it?
What is the ratio of money spent between professionals and managers?
What is the availability of the future workforce (nurses)?
How can we make effective use of information technology?
Will the NHS make explicit exact entitlements in the future?
Should we be looking for new ways to fund health care?

The Evaluation Synthesis

How we found this "Deliberative Group" process?

Ideas for Improvement:

- Might have helped if smaller groups had a facilitator as some people partly dominated the discussion in the small groups.
- More information required about the other invitees before i.e. who the day was for.
- Design of day was fine, a bit more background information would have helped me understand better the purpose of the day. I kept on having to refer back to other papers to ascertain why we were here, and what we were supposed to be doing.
- Maybe a 'vision brainstorm' would free up ideas. The solutions we arrived at were based on present state rather than stretching the Group to consider future possibilities.
- Shorter session in the morning or afternoon - brain death after lunch.
- More forward planning/more notice should be given for preparation.
- Longer period required for preparing 'Vision' and 'Journey' session.
- Include 'pairwork' in the design.
- We could have been asked to write down our thoughts in advance and have them circulated?
- We could possibly have re-visited the sheets we did at the beginning of the day in case the dynamics squeezed the issues out.
- Good facilitator. Food didn't account for the Jewish Passover. Application forms should use 'first name' not 'christian name'.
- Limit people's introductions to 2/3 minutes to enable people to focus on their contributions/gains instead of particular fields.
- I would prefer the question to be answered, to be specifically stated, and prominently displayed in the meeting room, as a reminder.
- Longer whole group discussions on specific topics. Allow group to explore one or more issues in depth.

Acknowledgement and Affirmation:

- I enjoyed the design of the day and thought it most productive.
- A well run day. Good day, well facilitated.
- Generally well constructed process of reflection and synthesis of knowledge and experience in the Group. We did not move away from these positions during the day.
- Time managed very effectively.
- I appreciated the diversity of the components of the group.
- Focus on 'goals' - although asking attendees to think "2020" worked.
- Structure enabled all participants a fair hearing and encouraged tolerance for alternative views. Well done.
- Fascinated by the structure of the day and how very clear cut headings could facilitate 'what really matters'.
- Good to see such a diverse group of people working together.
- Every opportunity was given to contribute views.
- Thank you for the opportunity to be involved in the debate about the future NHS.
- Layout of tables and circulating for groups seemed to work quite well and was refreshing change from line of chairs.
- Thank you for being accepting, encouraging and positive about contributions.
- Well done for being such an excellent catalyst in handling so many different personalities/views with respect, and in permitting us to reflect a united vision for a more caring 'second chance' for the future.

Doubts or Dissent:

- Might encourage the 'political' discussion to come up earlier or to give more time to debate it.
- Should have mixed i.e. local authority/health personnel.... maybe that would have produced a less consensual outcome?
- Not sure how our work will relate to the July Conference.
- I picked up some sort of atmosphere - a barrier more I guess - very much doctor/patient/territorial atmosphere. Interesting and an excellent opportunity for information exchange.
- I thought that the day was very well facilitated - I do have very slight suspicions that this day with these topics might have been designed to produce the conclusions - however, I very much enjoyed this opportunity to be consulted.
- How were 'we' selected, and why - the old 'representation' concept.
- Good mix of voluntary organisations: worth adding professionals and managers (possibly too confusing?). Do 'ordinary' people so strongly express the same values?

So, What Might Happen Next?

Extending the Emphasis:

- There is a need to emphasise and cater for long term care as well as acute care in the NHS.
- Someone directly in charge of Stoke Mandeville Hospital should have attended - as a lot of the talk was local not national.
- Politicians, Civil Servants & NHS workers are users too!
- Rich and variable day - maybe medical doctors/clinicians/dieticians/ complementary therapists, minister, children/YP, Civil Servant, representative from ethnic minority communities/disabled people should have attended our group.
- Professor Crick may be interested in the citizenship related observations.
- Ask delegates to bring with them information bout their organisations to be given to others attending.
- Possibility some members of the medical/hospital staff - such as staff nurses, receptionists - but realise they may feel threatened in such a situation if mixed with 'outsiders'. So many people work in a local 'mind-set' and are unaware of how citizens/users/patients feel or view the service they receive. It is good for people to come away from their workplace and hear how others in similar situations work. I'm always amazed at the reaction of health visitors/health promotion managers etc. who enjoy networking on training days and are refreshed by coming away and seeing their job through different eyes. This is addressing a different need, but will any consultation similar to the process we have had be offered to people in the NHS - not just doctors and consultants?!
- Providing an attendance list detailing contact no's. etc would be useful for networking.
- Would like to hear/learn more from other organisations attending.
- Frank Dobson should have attended - it would be beneficial for him to hear 'real' feelings instead of those generated by his advisers.
- I am especially pleased that a summary of our deliberations will go to the Secretary of State.
- Include 80+ people who are major users or at least have increasing need for health services.
- No mention was made of nurses - the workers who cement the whole system together. These people often work long hours with small financial reward. Single nurses often do 'bank' nursing on days off just to keep their heads above water - thus not functioning at their best. Highly-trained nurses are often discarded in favour of cheaper, less well-trained substitutes. I feel this is a subject which should be addressed.
- Need to make Health Commissioning, with respect to the African communities a key strategic focus and involving Africans with the rising infection rates participants in this.
- Health professions do not seem to recognise heart symptoms in women, all research is done for men.
- Front of house NHS staff (a doctor, nurse, physio, radiologist, cleaner, auxiliary staff etc) as part of the Witness involvement.
- Hope work done today will really be able to be taken on board by those able to attend the July conference. Fear is that little may change if other conferences are considered.

Extending the Emphasis: ...

- I would suggest that perhaps in future complementary/alternative therapies could be prescribed as an alternative to orthodox treatment just as in a few pilot areas GPs are able to issue prescriptions for exercise at local leisure centres. This would necessitate safeguards for appropriate professional qualifications and membership of relevant professional bodies.
- Importance of better public information/education about health issues to inform public participation in decisions re. health provision - not enough time to raise/discuss this point.
- Representative of another government department or local authority department which has health implications (e.g. transport, industry) should have attended.
- Very interesting and useful. Need to do this and other participatory exercises with many more people/groups. Interested in being involved in other groups.

Reflection and Renewal:

- Restate and re-affirm the value and values of NHS. Beware of over-generalisation and examine so-called 'pressures' on NHS and their causes: vested interests - demography? inefficiency? etc. Be clear about cause and effect on these pressures and recognise need for increased tax.
- Thanks - It was very demanding but a superb 'journey'.
- More groups of people would have generated more debate.
- 'Healthy Habits' are influenced by so many factors - we need more responsible media.
- I found the day uplifting - it gave me hope in the future.
- I don't think there is much you can do to improve what was a well structured, informative, thought provoking and personally satisfying day.
- The much needed Patient's Charter created more belligerent patients by promising unrealistic and unachievable timescales for NHS consultations/treatment. Suspicions of cosmetic manipulation of waiting time statistics were raised by delays in notifying patients of awaited appointments until an 'acceptable' time lay ahead. A more open policy of public apology for errors made also unlikely to reassure than have a negative effect in future - to be encouraged.
- I hope the King's Fund can help users realise some of the goals identified today.
- Reduce the consultants' private work to increase time spent with NHS patients and therefore reduce waiting lists. Nurses must be replaced when they leave.
- Good luck with the report. It is important to all of us for our future life standards.
- I would like to see a more 'freeer' NHS.

Appendix V(b)

An Evaluation of the Day

Is there anything unsaid that you want to record now?

The day had a particular design - how could we have helped your contribution further?

If we were to do this again, how could we improve?

Who was missing from the room that you would like to have been there?

Any messages for the facilitator (Bob Sang)?

Organisation:
(*optional completion*)

Please complete and return to:
Bob Sang, King's Fund, 11-13 Cavendish Square, London W1M 0AN
or by fax: 0171 307 2809

"Future NHS"

How will we work well together?

- Listen to each other
- Give every individual space
- Don't criticise the person
- Empathise
- Be open in outlook
- Let's relax... have fun
- Respect confidentiality
- It's OK to disagree/differ
- Seek clarification
- Be at ease with each other
- Respect and understanding others' views
- Try to bring in something new
- Non-judgmental
- Voice our views as honestly as possible
- Health and illness
- Focus on solutions
- Accept positive criticism
- Equal time
- Don't take things personally
- Future orientated (improving)
- Clear Communication
- Good use of time
- An agenda
- Focus on the issue
- Sense of humour
- Finding what's common from difference
- Seeking a focus through common language
- Working as a partnership - common goal
- Keep comments brief - distil
- Use synopses as foundation
- Focus on the future - think 2020
- Mutual exploration
- Fun and food!
- Recognising others' needs - supportively
- Value feelings
- Equal participation
- No cross-talking
- No Jargon
- Equality of contribution
- Focus on underlying principles
- Freedom to network