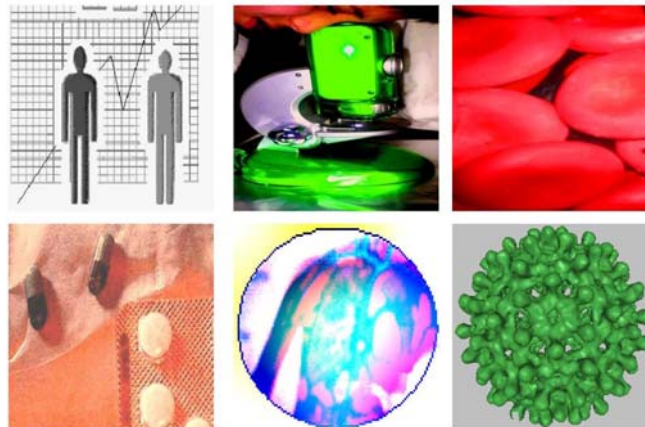


Should the NHS Take More Account of Patients' Rights?

A survey of health campaigners in England and Wales
by the Patients Association

Survey and analyses conducted by PatientView

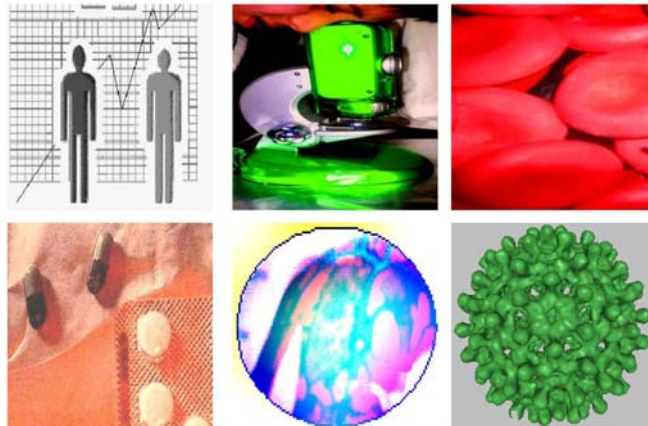
The administrative costs of this survey were funded by an educational grant from
Merck Sharp & Dohme



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When the views of mental health groups differ	<i>Slides 30-33</i>
Geographic diversity of views	<i>Slides 34-40</i>

Methodologies and significance of survey: *slides 3-7*



E-mail survey, end-July to Mid-September 2006

- Survey of patient/health advocacy groups in England and Wales.
- Specific focus on regionally-based and locally-based organisations.
- Two email shots only, no follow-up.

The survey aimed to learn about respondents' views on:

- The quality and state of NHS services—from a patient perspective.
- The ability of patients to exercise their legal rights within the NHS.
- The need for universal access to healthcare.
- Future rights for patients within the NHS, plus achievable goals.
- How a patients'-rights-based system should be managed and enforced (if at all).
- The personal responsibilities of patients.

- **188 patient/health advocates respond to the survey.**
 - Two thirds have a local geographic remit, and one third national. Some have more than one geographic remit.
 - One fifth are based in the south east / London/ or the East Midlands.
- **The majority respond on a personal basis. Most respondents are senior executives or trustees.**
- **Almost one third are happy to be attributed.**
- **Respondents are drawn from a wide range of specialities.**
 - 22% represent people with mental health problems (including learning disabilities).
 - 16% work with Patient and Public Involvement Health Forums (PPIFs/PPIHs)*.
 - 10% represent patients with neurological conditions.
 - 7% are with organisations representing the interests of carers.

* Based in each local NHS area, and staffed by local volunteers, Patient and Public Involvement Health Forums (PPIFs/PPIHs) provide input from patients on the running of local NHS services, and concentrate on how these services can be improved.

About the survey

III - The feedback

Patient/health advocacy groups happy to be named in this report

Most answered on a personal basis

Adrenomyeloneuropathy (AMN)-Easier
Age Concern Bexley
Agoraphobics United
Aid for Children with Tracheostomies.
Andover Service User Involvement Project
Androgen Insensitivity Support (AIS) Group
Angioma Alliance UK
Assert (Brighton and Hove)
Bassetlaw Cardiac Support Group
Bracken Trust, The
British False Memory Society (BFMS)
Birmingham Lifestyles
Caerphilly People First
Cancer Counselling Trust
Charcot-Marie-Tooth Disease (CMT)UK
Child and Adolescent Mental Health (CAMH)
Chronic Granulomatous Disorder Research Trust
(CGDRT)
Denbighshire Disability Forum
Ekbom Support Group
Elfrida Society
Family Rights Group (FRG)
Fibromyalgia Association (FMA) UK
Crossroads Caring for Carers, Gateshead
Gender Trust

Hafal Bridgend
Halton PPI
Harrow PCT, PPIF
Herpes Viruses Association
Hillingdon Carers
Hull & East Yorkshire Stammerers' Self-Help
Group
Hypermobility East Anglia Group
Leukaemia CARE
LifeSIGNS
Melton, Rutland & Harborough PPIF
Merseyside & Wirral Fibromyalgia Group
Mid Sussex PCT, PPIF
Mind Allerdale
North East Derbyshire PPIF
Newark & Sherwood PPIF
Nuffield Orthopaedic Centre (NOC) PPIF
Nottinghamshire Healthcare PPIF
One Click Group
Optua
People First
PXE Support Group (PiXiE)
Princess Alexandra Hospital, Harlow PPIF
Reading Fibromyalgia Support Group
Resources for Cross Cultural Health Care

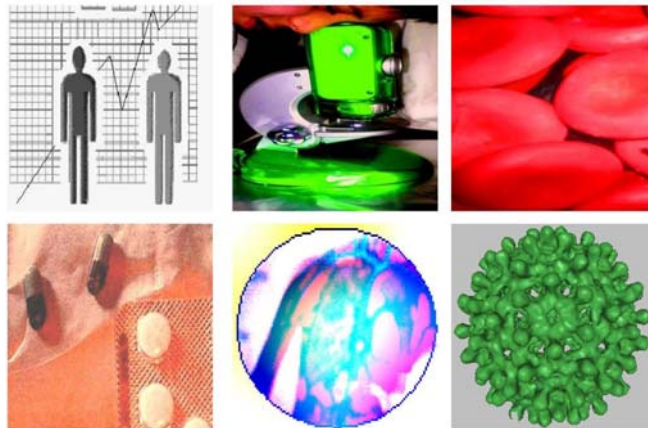
Scoliosis Association (UK)
Sherwood Forest Hospitals NHS Acute Trust, PPIF
South Bucks Fibromyalgia Support Group
South Leicestershire PPIF
Speakability
UK Coalition of People Living with HIV and AIDS
Uveitis Information Group
Wrexham Fibromyalgia Support Group

About the survey

IV - Significance

- The survey was designed to build on the results of a public-opinion poll published in December 2005 by the Patients Association. The 2005 poll showed that patients are often unaware of their rights within the NHS [http://www.patients-association.org.uk/publications_level2.asp?level2_ID=251].
- The current 2006 survey is the first extensive analysis undertaken on the subject of patients' rights among patient/health advocacy groups from across all disease areas in England and Wales.
- The survey has generated one of the best response rates ever attained from a poll of patient/health advocacy groups in the UK—suggesting that the topic of patients' rights is regarded as important by the patient advocacy community in England and Wales.
- The survey results give the Patients Association a solid basis for any campaign on patients' rights that it may choose to undertake. Some specific issues (such as implementation, policing, and enforcement) still need further exploration, however.

Executive summary: *slides 8-12*



Executive summary of survey results 1

- **On the quality and state of NHS services—from a patient perspective.**
 - Half of participants say that the NHS is not doing a good job for their constituency.
 - The equivalent figure for representatives from mental health groups is 68%.
 - Respondents from PPIFs/PPIHs are more positive about the NHS. Only 20% believe that the NHS is not doing a good job.
 - Groups based in London are more dissatisfied with the NHS than those located in the South East or the East Midlands.

- **On the ability of patients to exercise their legal rights within the NHS.**
 - The majority of respondents think that their constituents are unable to exercise all potential patients' rights within the NHS.
 - Noteworthy is the failure of patients to be offered a choice of hospital. 60% of respondents from mental health groups and from London-based groups say that their constituency cannot obtain a choice of hospital.
 - Over half of PPIFs/PPIHs point out that patients have difficulty obtaining information about the NHS under the FoI Act.

Executive summary of survey results II

- **On the need for universal access to healthcare.**
 - Over half of the survey participants believe that the NHS should not vary access to treatments and services to suit local patient needs.
 - The equivalent figure for respondents from the South East (where cash-strapped PCTs are particularly active at rationing treatments and services) is 67%.
 - Many respondents, however, acknowledge the need for some agreed minimum standards of care across the country.

- **Future rights for patients within the NHS and achievable goals.**
 - Three quarters or more of the respondents consider that patients need more information on medical conditions, treatments, and treatment choices; appropriate treatment before medical conditions worsen; guaranteed standards of care; access to second opinions; and equitable treatment throughout the NHS.
 - The same amount of respondents indicate that a patients'-rights-based NHS should aim to enable patients to take informed decisions and attain better outcomes.

Executive summary of survey results III

- **Future rights for patients within the NHS: mechanisms for enforcement.**

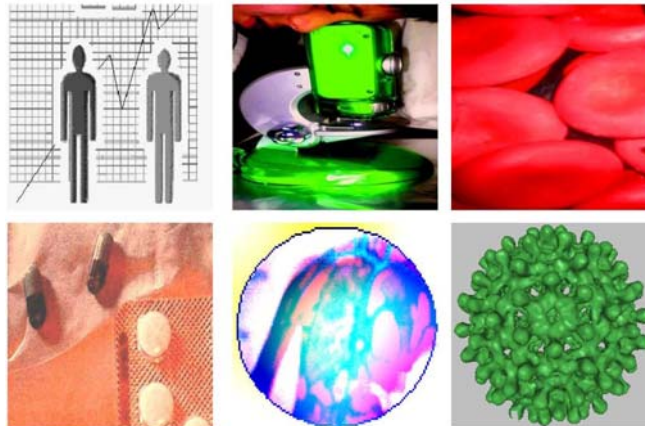
- Respondents favour no single method of enforcing patients' rights over another, though one third do stress that certain services should be basic entitlements.
- No individual agency is thought appropriate to be a patients' rights 'enforcer', but nearly half of the respondent groups from the East Midlands argue for any such body to be independent of government, the NHS, or patient representatives. A minority of respondents declare a willingness to take on the responsibilities themselves.
- Participants identify a combination of factors that they think would encourage the establishment of a patients'-rights-oriented NHS, including: campaigns to raise the public's awareness of their rights as patients; input from the General Medical Council; and formal training in patients' rights for healthcare professionals (backed up by financial penalties for the uncooperative).
- Nearly half of the respondents feel that patients would (under certain circumstances, and if they could afford to do so) be willing to pay administrative fees to exert their rights in the NHS.

Executive summary of survey results IV

- **Future rights for patients within the NHS: drawbacks and dangers.**
 - Only one third of the participants judge that a patients'-rights-based NHS will bring benefits and no disadvantages to both the nation's healthcare system and to patients.
 - The majority of respondents foresee various drawbacks if a patients'-rights orientation is imposed within the NHS.
 - Over half of PPIFs/PPIHs are concerned that such an arrangement would increase the number and cost of demands made on the NHS by patients.
- **The personal responsibilities of patients in a rights-based NHS.**
 - While participants are sure that patients will have to shoulder more responsibilities in a rights-based NHS, they remain unclear how patients could be encouraged to do so.

Analysis of pooled responses (all participants):

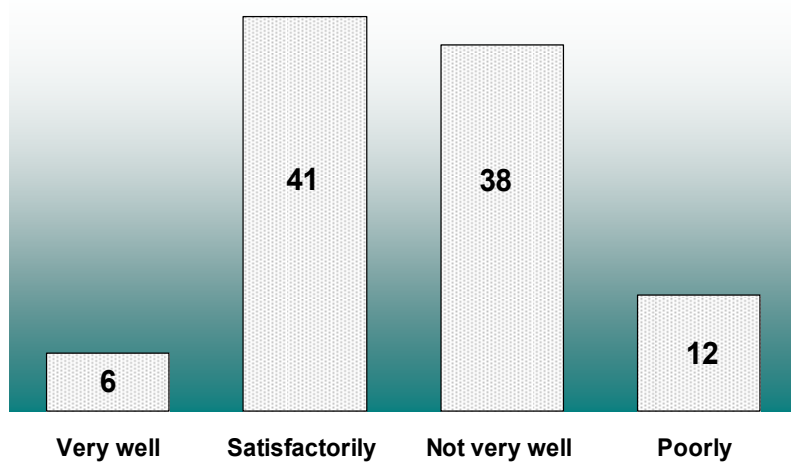
slides 13-24



Patients' rights within the NHS: all participants

The quality and state of NHS services

How well would you say the NHS serves your group's constituency?



% of responses (total = 188)

- 50% of the survey's participants believe that the NHS is not doing a good job for their constituency.
- Just 6% believe that the NHS is doing a very good job.

Patients' rights within the NHS: all participants

On the ability of patients to exercise their legal rights

Do you believe that the people your organisation represents have difficulty exercising any of these rights?

Being offered a choice of hospital — 51

Accessing personal medical records — 50

Getting info about the NHS under the FoI Act — 47

Refusing treatment/giving informed consent — 42

Registering with a GP — 36

Obtaining information on prescription medicines via patient-package inserts (PPIs) — 27

% of responses (total = 188)

Over half of the respondents estimate, in their experience, that patients are unable to exert some of the rights afforded them by the NHS (notably, obtaining a choice of hospital).

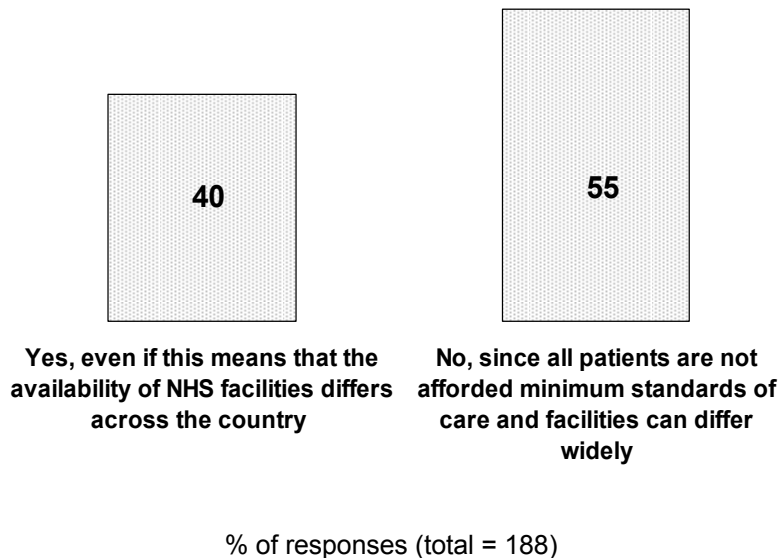
Respondents' comments include:

- "Generally, patients do not know their rights."
- "Choice of hospital is often not available."
- "In practice, patients are coerced into giving consent to doctor-supported procedures by inaccurate information."

Patients' rights within the NHS: all participants

On the need for universal care

Do you believe that local health providers should be entitled to vary access to NHS treatments and services so that they suit local people's needs?



Over half of all participants believe that the NHS should not vary services to suit local needs. Though many respondents acknowledge the need for some agreed minimum standards of care across the country.

Respondents' comments include:

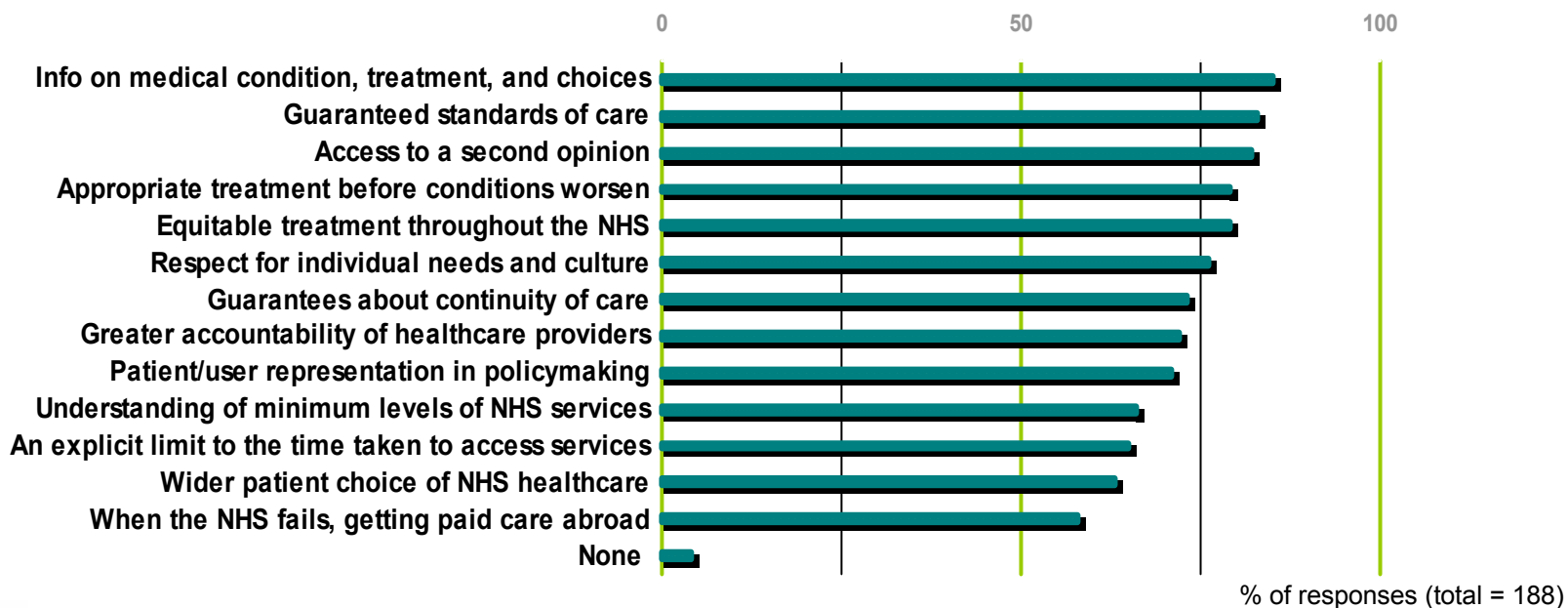
- "There should be centres of excellence, but the standard of healthcare should be the same across all regions."
- "Access depends on geographic variables. It is impossible to provide the same density of services everywhere, so healthcare provision must be defined before this issue can be discussed."

Patients' rights within the NHS: all participants

Future rights for patients within the NHS

None of the services listed below are provided for patients as a right within the NHS in England and Wales. Should any of them be?

- Over 60% of respondents believe that patients should be afforded more rights.
- 75%-plus believe that patients need more information on medical conditions, treatments, and treatment choices; appropriate treatment before medical conditions worsen; guaranteed standards of care; access to second opinions; and equitable treatment throughout the NHS.



Patients' rights within the NHS: all participants

Future rights for patients within the NHS

If NHS patients in England and Wales are afforded more protection through a rights-based system, what should be the goals of such an approach?

Informed patient involvement in decisions about their own healthcare and treatment	60
Better outcomes for patients	53
Reduction in healthcare inequities	45
Empowerment of patient/public	22
Greater patient/public satisfaction with NHS	22
Reduction in the number of medical errors	21
Improvement in doctor-patient relationships	21
Increase in patient safety	18
Reduction in patient stigma	10

% of responses (total = 188)

Around 60% of respondents believe the main goal of any rights-based system should be to enable patients to make informed decisions-over and above issues of patient safety or satisfaction.

Respondents' comments include:

- *"Incentive to develop a sense of self-worth and self-sufficiency."*
- *"More information on why PCTs, etc, choose their commissioning."*
- *"GPs and consultants trained to be 'people people.' "*

Patients' rights within the NHS: all participants

Future rights for patients within the NHS: mechanisms for enforcement

If NHS patients in England and Wales are afforded more protection through a rights-based system, what do you believe would be the best mechanism for implementation?

A basic set of entitlements for all NHS patients	35
A Bill of Patients' Rights, written into law	28
A guarantee on registration with GP	11
Part of health professionals' contract with NHS	8
A code of conduct to suit community needs	7
Patient access to the private sector	4
Stepwise legal action at grassroots level	2
A charter that is aspirational in nature	2

% of responses (total = 188)

Respondents favour no particular mechanism by which patients' rights should be effected in the NHS. One third of participants, though, do believe that certain NHS services should be basic patient entitlements.

Respondents' comments include:

- "Use of a voucher system [as an alternative mechanism]."
- "More contact with health-service minorities. We find many of them living in different world, and unable to answer constructively."
- "I honestly don't know. Just get it right—it's surely not rocket science."

Patients' rights within the NHS: all participants

Future rights for patients within the NHS: mechanisms for enforcement

What would be the best choice for policing and enforcing patients' rights within the NHS?

Independent body (of government, NHS and patient representatives)	32
Local patient organisations	20
National patient organisations	11
The Healthcare Commission	9
A national ombudsman [or Parliament]	8
Primary Care Trusts (as payers)	6
Local government-appointed bodies representing patients' interests	5
Medical professionals	2
Local government	1
Other healthcare professionals	1

% of responses (total = 188)

Respondents favour no particular 'enforcer'. Some patient groups show an inclination take up the responsibilities themselves.

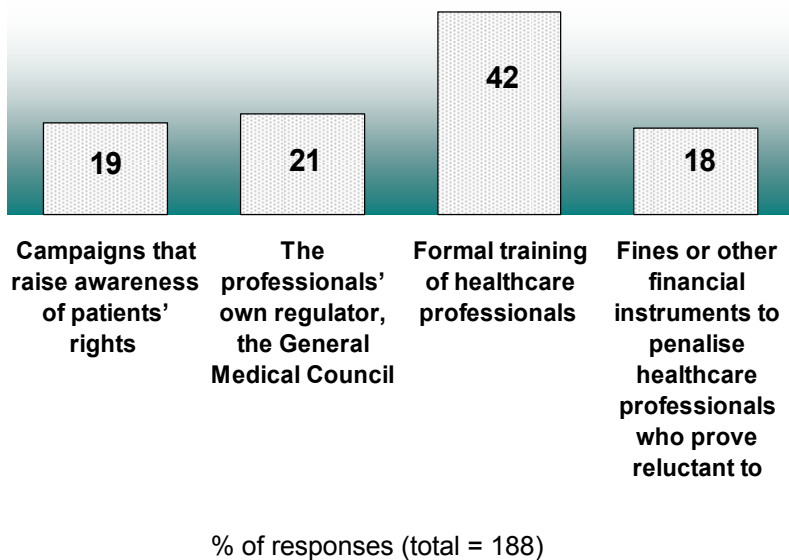
Respondents' comments include:

- *"A body that represents patients, and works within a legal framework that is robust, and has real power."*
- *"Local ombudsman [as an alternative]."*
- *"Not sure any of these by themselves would be sufficient. You'd need a board or committee made up of local and national patient bodies and an ombudsman, and a few doctors and nurses, plus the power to appeal to the courts if bad decisions are made."*

Patients' rights within the NHS: all participants

Future rights for patients within the NHS: mechanisms for enforcement

What do you think would be the best mechanism for encouraging healthcare professionals to embrace a rights-based system?



A combination of campaigns to raise awareness of patients' rights, formal training of healthcare professionals, input from the General Medical Council, as well as financial penalties are presumed the best way to effect a patients'-rights-based NHS.

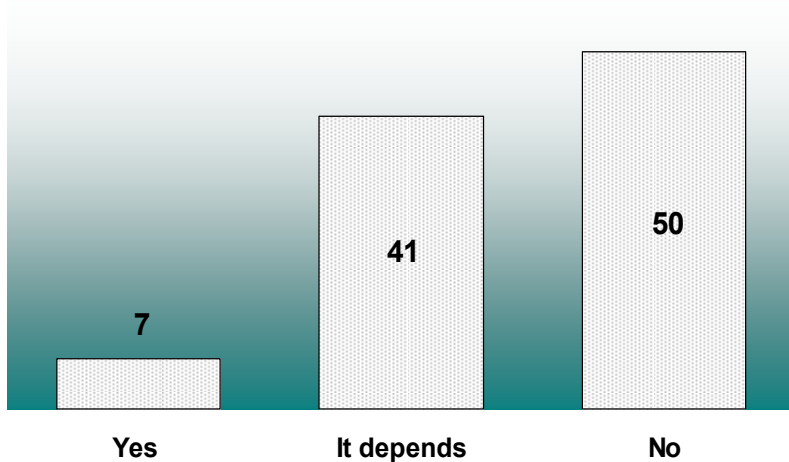
Respondents' comments include:

- "A mix of awareness for patients, and training for professionals."
- "Registers of patients' assessments of quality, and short-term and long-term outcomes of treatment."
- "Some sort of organisation to help patients get their rights."

Patients' rights within the NHS: all participants

Future rights for patients within the NHS: mechanisms for enforcement

Should patients be charged a monetary fee for exerting their rights? (This can happen today—patients who choose to access or copy their medical records may be asked to pay NHS administrative costs)



% of responses (total = 188)

Only 7% of respondents believe that patients should be charged fees to exert their rights. 40%, however, acknowledge that fees could be levied under certain circumstances.

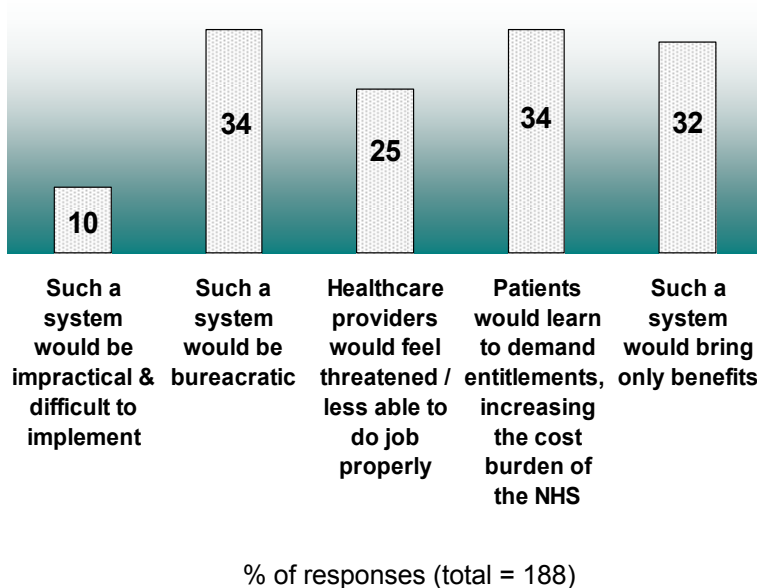
Respondents' comments include:

- *"Some patients would be happy to contribute to the cost of travel to a suitable specialist or centre if one did not exist locally. However, this option must be available to those who cannot afford to travel."*
- *"Don't think they should pay if part of a complaints process."*
- *"It would be pointless to have a system of rights which applies only to those who can afford to pay. But it might be reasonable to apply some ADMINISTRATIVE costs to those who could afford to pay."*

Patients' rights within the NHS: all participants

Future rights for patients within the NHS: drawbacks and dangers

What drawbacks or dangers do you envisage if a patients' rights-based system is introduced in the NHS in England and Wales?



Various drawbacks to a patients' rights-based system are envisaged by respondents. Only one third of participants believe that such a system can bring only benefits.

Respondents' comments include:

- "Without legislation, any attempt to change would be thwarted by bureaucracy."
- "More secrecy and misinformation, so patients cannot exercise their rights."

Patients' rights' within the NHS: all participants

On patients' personal responsibilities

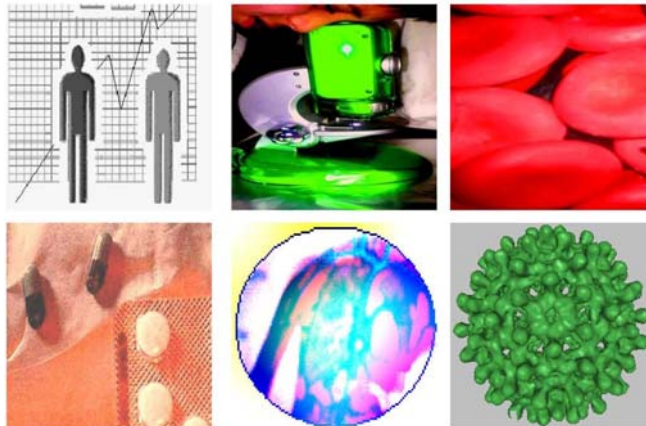
Within any rights-based system, patients will be expected to take more responsibility for the management of their health and care. Who should decide what those responsibilities should be, and how they should be enforced?

Respondents emphasise that patients will have to take more responsibility for their care within a rights'-based system. But their views on how to effect such change vary.



% of responses (total = 188)

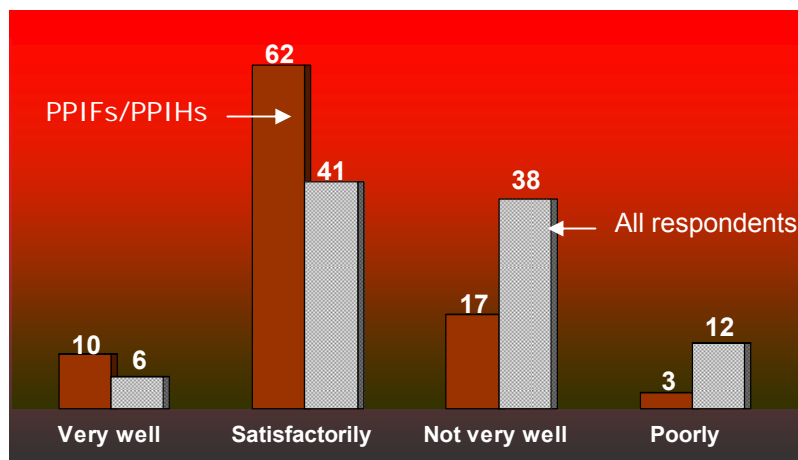
When PPIFs /PPIHs' views differ: *slides 25-29*



Patients' rights within the NHS: PPIFs and PPIHs

The quality and state of NHS services

How well would you say the NHS serves your group's constituency?



% of responses (PPIFs/PPIHs = 29; total = 188)

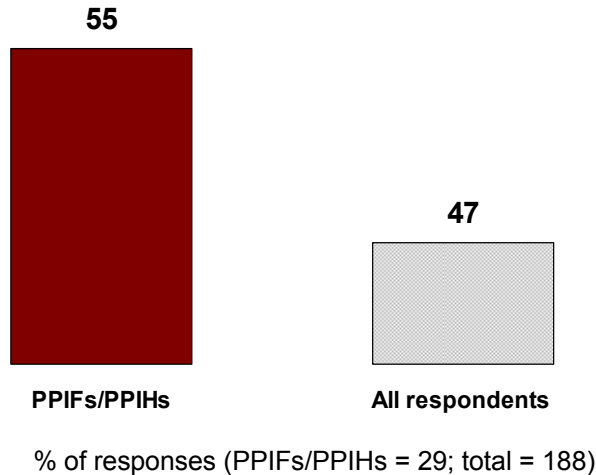
Patient and Public Involvement in Health Forums (PPIFs/PPIHs) appear to have more confidence in NHS services than all respondents. 72% of PPIHs/PPIFs believe that services provided are at least satisfactory; 47% of all respondents agree.

Patients' rights within the NHS: PPIFs and PPIHs

On the ability of patients to exercise their rights

Exercising patients' rights within the NHS

Percentage of PPIFs/PPIHs respondents who state that patients experience difficulty getting information about the NHS under the Freedom of Information Act, versus all respondents



PPIFs/ PPIHs are slightly more sceptical than the rest of survey respondents about whether patients can easily obtain NHS information under the FOI Act.

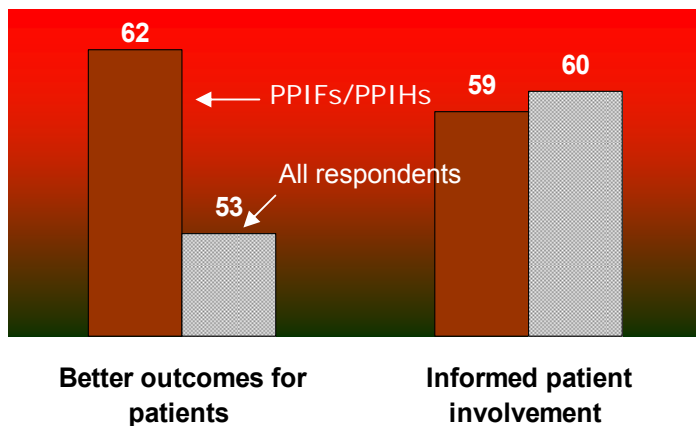
Comments from PPIFs/PPIHs respondents include:

- *"Much of this has to do with knowledge, education, and language."*
- *"Information is rarely offered. You have to know that it is available, and then demand it—often several times."*
- *"I have highlighted (the word "difficulty") to point out that I believe the NHS is too secretive, and is always unwilling to give out the information needed."*

Patients' rights within the NHS: PPIFs and PPIHs

Future rights for patients within the NHS

Goals of a patients'-rights-based NHS



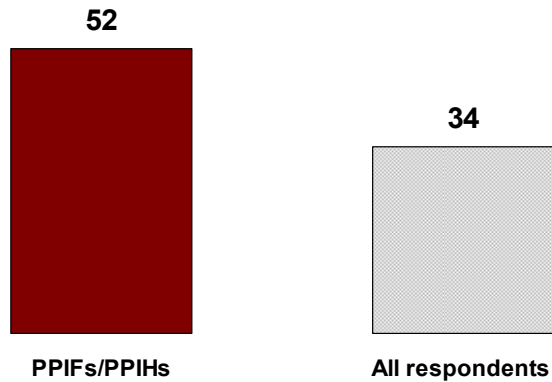
% of responses (PPIFs/PPIHs = 29; total = 188)

PPIFs/PPIHs appear to hold slightly different priorities for a future patients'-rights-based NHS than all survey respondents. They place better outcomes for patients as a higher priority than informed patient involvement in decisions about healthcare and treatment.

Patient rights' within the NHS: PPIFs and PPIHs

On the ability of patients to exercise their rights-drawbacks and dangers

Percentage of PPIFs/PPIHs that state patients would quickly learn to demand their entitlements and increase the cost burden of the NHS



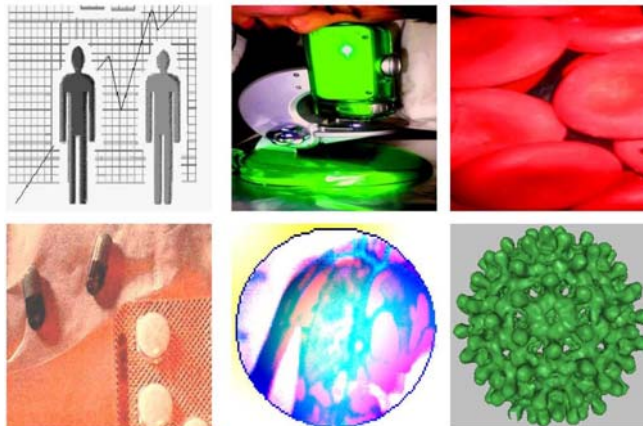
% of responses (PPIFs/PPIHs = 29; total = 188)

The majority of PPIFs/ PPIHs are concerned that a patients'-rights-based system would burden the NHS and prove excessively costly. Only one third of all respondents agree.

Comments from PPIFs/PPIHs respondents include:

- *"An overall independent organisation is required to balance the various needs of patients between the large number of medical conditions."*

When mental health groups' views differ : *slides 30-33*



Patients' rights within the NHS: mental health

The quality and state of NHS services

How well would you say the NHS serves your group's constituency?



% of responses (mental health = 41; total = 188)

Over two thirds of respondents from mental health patient organisations estimate that their constituency is poorly served by the NHS. The equivalent figure for all respondents is 50%.

Patients' rights within the NHS: mental health

On the ability of patients to exercise their legal rights

Do you believe that the people your organisation represents have difficulty exercising any of these rights?

Being offered a choice of hospital — 61

Accessing personal medical records — 54

Refusing treatment/giving informed consent — 51

Getting info about the NHS under the FoI Act — 46

Registering with a GP — 44

Obtaining information on prescription medicines via patient-package inserts (PPIs) — 24

% of responses from mental health groups (total = 41)

Compared with other patients, those with a mental health problem appear to have greater difficulty exercising their right to a choice of hospital, to access personal medical records, to refuse treatment or give informed consent, and to register with a GP.

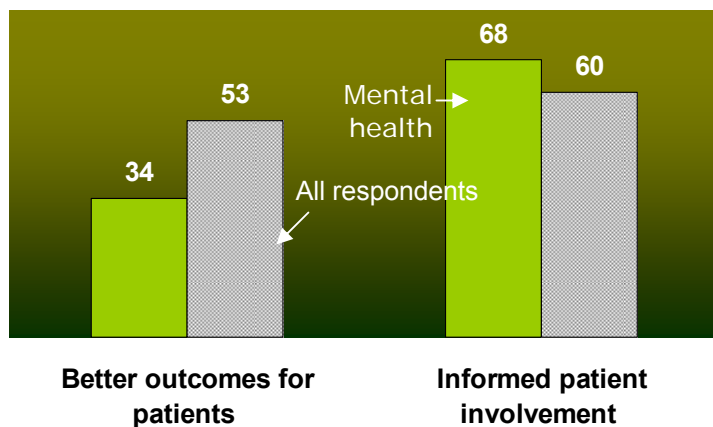
Respondents' comments include:

- *"Patients need to be able to choose which psychiatrist they see, irrespective of being in that psychiatrist's catchment area. 'Choose and Book' is not working, as I am not able to see the psychiatrist of my choice, due to being out of that Care Service's catchment area."*
- *"We are often asked to advocate for people who wish to access records. Patients who often come to us cannot find a GP, or are not happy with their limited choice of GP."*

Patients' rights within the NHS: mental health

Future rights for patients within the NHS

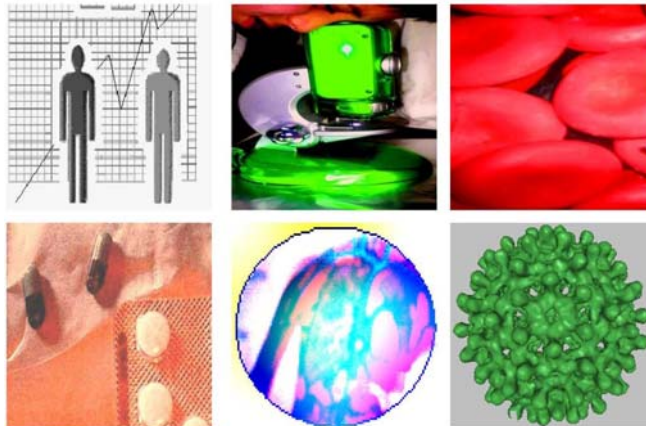
Goals of a patients'-rights-based NHS system



% of responses (mental health = 41; total = 188)

Nearly 70% of respondents from mental health patient organisations regard the main goal of any patients'-rights-based NHS to be informed patient involvement in decisions about personal healthcare and treatment.

Geographic diversity: *slides 34-40*



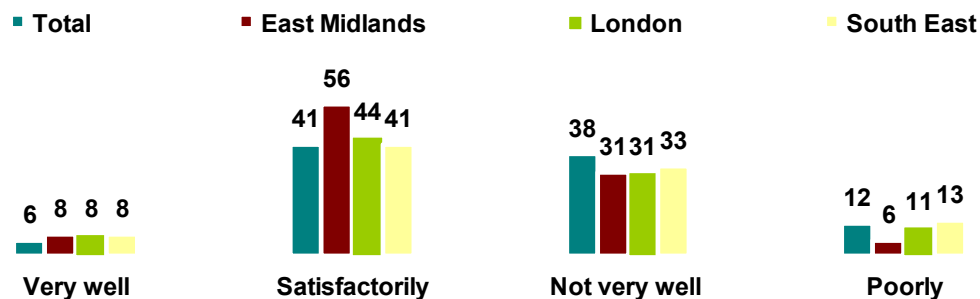
Patients' rights within the NHS: across the nation

The quality and state of NHS services

How well would you say the NHS serves your group's constituency?

No major regional differences are observed among participant on standards of NHS services (with the exception that services in the East Midlands seem to be marginally better than those in the south of the country).

% of responses (total = 188; East Midlands = 36; London = 36; South East = 39)



Patients' rights within the NHS: across the nation

On the ability of patients to exercise their legal rights

Do you believe that the people your organisation represents have difficulty exercising any of these rights?

According to respondents, patients in London have the greatest difficulty exercising rights (especially obtaining information about NHS services under the FoI Act). Patients in the East Midlands have the least difficulties.

% of responses (total = 188; East Midlands = 36; London = 36; South East = 39)



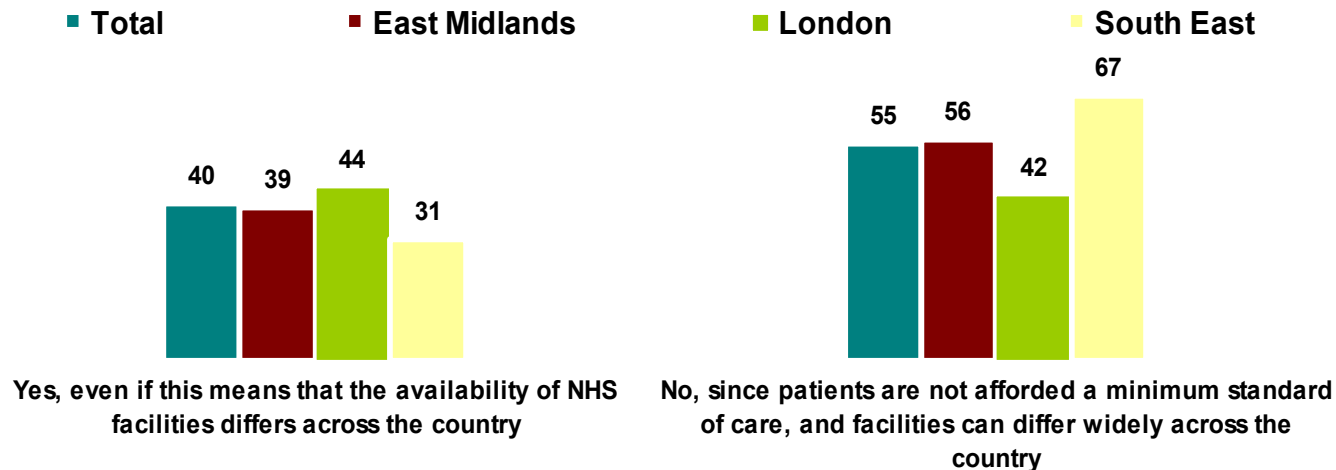
Patients' rights within the NHS: across the nation

On the need for universal care

Do you believe that local healthcare providers should be entitled to vary access to NHS treatments and services, so that they suit local people's needs?

Of all respondents, those from the South East are most adamant that patients should receive universal standards of care (presumably as rationing by PCTs is especially common in that region).

% of responses (total = 188; East Midlands = 36; London = 36; South East = 39)



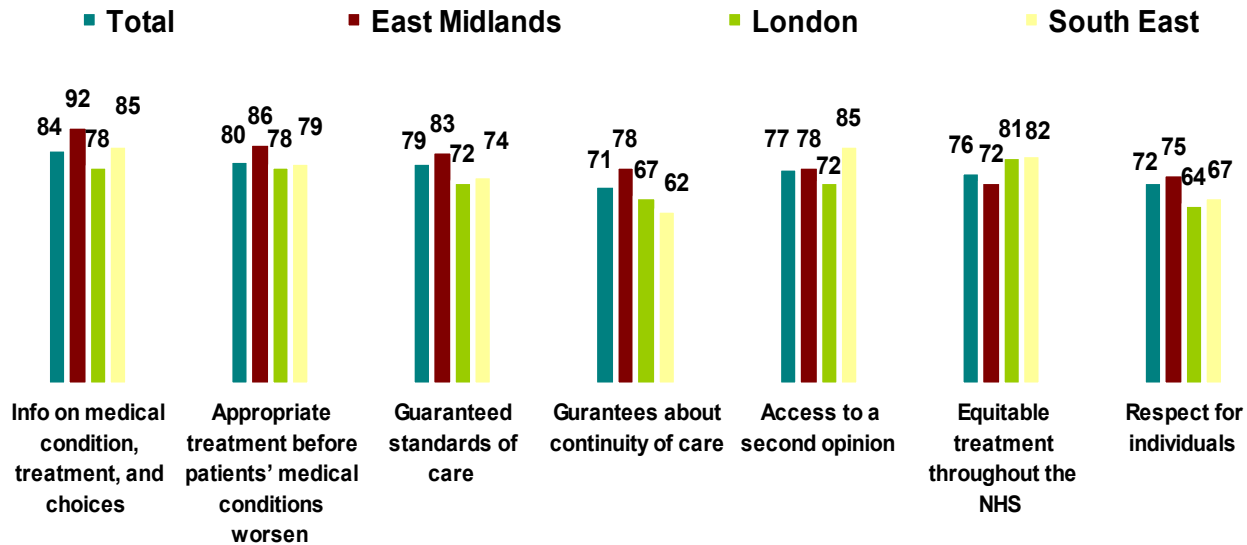
Patients' rights within the NHS: across the nation

Future rights for patients within the NHS

None of the services listed below are provided for patients as a right within the NHS in England and Wales. Should any of them be?

The vast majority of respondents support the introduction of more rights for NHS patients.

% of responses (total = 188; East Midlands = 36; London = 36; South East = 39)



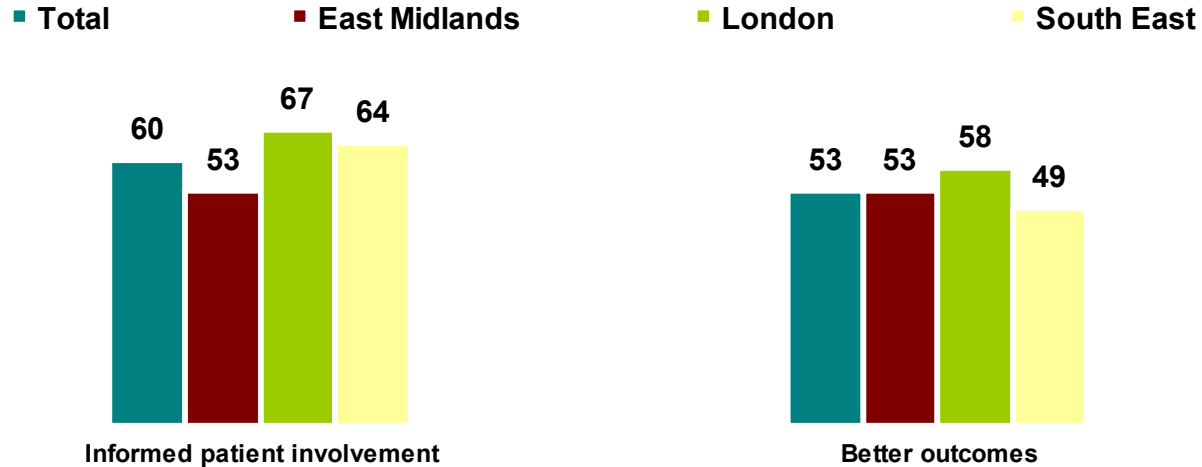
Patients' rights' within the NHS: across the nation

Future rights for patients within the NHS

Goals of a patients'-rights-based NHS

Respondents from across the country believe that the two main goals of any patients' -rights-based NHS should be more informed patient involvement in decisions about their own healthcare and treatment, and better outcomes for patients.

% of responses (total = 188; East Midlands = 36; London = 36; South East = 39)



Patients' rights within the NHS: across the nation

Future rights for patients within the NHS: mechanisms for enforcement

Who would be the best choice for policing and enforcing patients' rights within the NHS?

Respondents from across the country differ as to the best techniques of policing and enforcing a patients' -rights-based approach within the NHS. Overall, no preferred method can be identified.

Percentage of respondents from different geographic regions who thought that a body independent of government, the NHS, and patient representatives would be the best way of enforcing and policing patients' rights within the NHS

% of responses (total = 188; East Midlands = 36; London = 36; South East = 39)

