

# Community Action on Health

**“My body, my life”**

**Choice and Control:  
views of patients, carers and the public in Newcastle upon Tyne**

**March 2012**

**A report for the Policy and Representation Partnership**

**Policy&Representation  
Partnership**



Community Action on Health is a charity working within Newcastle to tackle health inequalities through patient, carer and public involvement.

We are experts in innovative and practical involvement, working with patients, communities and harder to reach groups to gain the insight needed to design the best, most responsive and cost-effective services.

We have vast experience and expertise in gathering the views and opinions of patients, carers and the general public in relation to health services. For example:

- locating new GP surgeries
- services to include in new community health facilities
- visibility of existing health services
- changes to care pathways

We employ various quantitative and qualitative data collection techniques:

- Questionnaires – paper-based and online
- Participatory appraisals
- Drop-in events
- Face-to-face interviews
- Focus groups
- Informal group discussions

We also provide guidance on:

- how services can engage with patients, carers and the public
- developing patient-friendly services
- a patient-focussed approach to delivering health services

For more information about the services we can provide please contact Kieran Conaty on 0191 2263450 or email [kieran@caoh.org.uk](mailto:kieran@caoh.org.uk). Visit our website at: [www.caoh.org.uk](http://www.caoh.org.uk)

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# Section 1 - Introduction

## 1.0 Introduction

Community Action on Health (CAOH) is an independent charity set up to tackle health inequalities through patient, carer and public involvement.

We work primarily with patients, communities and harder to reach groups to help service planners and providers gain the insight needed to design the best, most responsive and cost-effective solutions to local and regional health challenges.

## 1.1 The project and its aims

This report analyses the findings of one of three pieces of research carried out as part of the wider project NHS Reform: Winners and Losers in the Voluntary and Community Sector.

The project as a whole is funded by the Policy and Representation Partnership hosted by Voluntary Organisations Network North East (VONNE). It aims to examine the current relationship between the statutory and voluntary healthcare sectors in Newcastle, and to identify ways to strengthen that relationship.

Our primary aims are to provide intelligence about commissioning groups' priorities and behaviour that Voluntary and Community Organisations (VCOs) throughout Newcastle can use to develop productive relationships with statutory health professionals across the city; and to help raise awareness among clinicians of the effective interventions that the Voluntary and Community Sector (VCS) can offer.

Our report into GPs' perceptions of the Voluntary and Community Sector is available online at <http://www.resourcebank.org.uk/resource.asp?resource=189>; and we are currently working with Newcastle Council for Voluntary Service (NCVS) to examine VCS experience and expectations of working with the statutory health sector.

However, it is also important to capture the views of the people at the heart of any health service reform – the patients.

The White Paper Equity in Excellence: Liberating the NHS introduced the principle of 'No decision about me without me' and described a vision of healthcare where the patient is, if not an equal partner, then certainly an active participant in treatment decisions.

With this in mind, we designed the third part of this project to capture patients' hopes and expectations of a service in which they could have a significant input into choosing both the kind of treatment they received, and who might provide that treatment.

We were keen to establish levels of enthusiasm for, and potential engagement in, shared decision-making with clinicians at all stages of healthcare. We were particularly keen to gauge levels of acceptance for referral to non-medical treatments and providers.

This report sets out and analyses the views of a wide range of patients and healthcare service users across Newcastle upon Tyne.

# Section 2 - Methodology

## 2.0 Methodology

In order to collect a range of views from a diverse cohort of health service users, Community Action on Health developed a questionnaire that could be completed online via SurveyMonkey, or as part of facilitated focus group discussions. We conducted our research between September and December 2011.

## 2.1 Questionnaire

The questionnaire was designed to collect quantitative and qualitative information, to help us understand the reasoning behind a range of opinions and preferences.

The questionnaire is included in this report as Appendix 2.

Questionnaire responses are set out in Appendix 3.

## 2.2 Participants

In all, we received information from 220 people. We attended 11 events arranged by and for a number of different age, interest and ethnic groups, including people with mental health needs, learning disabilities, long term conditions and degenerative illnesses. Thirty-nine people completed our online questionnaire.

The full participant profile is included in this report as Appendix 1.



# Section 3 - Findings

## 3.0 Findings

This section provides a summary of the findings of the Patient, Carer and Public research undertaken for this project.

### 3.1 Awareness of change

Our first question asked whether people knew that the Government planned to make significant changes to the way the NHS is run. The majority of people (155, or 70.5% of the cohort) said 'Yes'.

Awareness was slightly higher among men: 78% of the men who responded said they knew changes were in the pipeline, compared to 66% of female respondents. Levels of awareness rose according to age, from 59% of 18-30 year-olds to 78% of over 60s.

For the purposes of this research, we did not investigate the nature or extent of respondents' knowledge; but it was clear that most respondents were at least aware that changes were taking place.

### 3.2 Access to health records

When we asked if people would like to have easier access to their own medical records, a comfortable majority (166, or 75.5%) said they would. Men and women were more or less equally in favour at 74% and 76% respectively. Support for greater access was highest among people aged 18-30 at 84% and lowest among people aged 60 or more (62%).

All of the 52 people who said they would not want access to their records were from white British or other white backgrounds. This group represented 26.8% of all the respondents from white backgrounds.

Reasons for wanting access generally centred on the importance of knowing and understanding one's own health and feeling more in control.

Some respondents suggested that open access might actually improve the quality of record-keeping and even of care.

#### 3.2.1 Patients who said they would not like access to their records generally felt this was unnecessary and some feared it might affect what was recorded:

'I'm concerned that if I had total freedom to look at them the GP would not be able to be as honest in them.'

Overall, however, people in the 'No' group clearly trusted their GPs – which meant they felt no great need to access their own records.

Interestingly, respondents in the 'Yes' and 'No' categories both referred to potential security problems arising from greater access:

'If there is no security built in, it could fall into the wrong hands.'

'I am concerned, though, about the security of my details and other personal information, particularly if someone else handles it.'

3.2.2 We asked respondents who supported greater access to choose their preferred method of accessing their records. Most people (85 in total) opted for some form of virtual access, either via a secure website or email. However, 69 people opted for paper copies.

### **3.3 Freedom to change GP practices**

Of the 220 people who completed the survey, 120 people (54.5%) said they would welcome the freedom to choose a GP practice irrespective of local boundaries. This represented a fairly even split, and in practice many people, regardless of their initial answer, were more worried about having to leave their current GP if they moved house than in making any radical changes based on satisfaction or perceived quality.

Enthusiasm for the freedom to move practices was greatest among the 18-30 age group. While 54% of all white respondents said they would welcome total freedom of choice, 80% of Chinese and 75% of Pakistani participants said yes to this question.

3.3.1 Some patients said that they would appreciate the opportunity to choose a practice near their place of work rather than their home.

Others, however, said they felt that walk-in centres now provided good alternative healthcare options, which in effect had reduced the usefulness of freedom to choose.

3.3.2 Some worried about the practical implications of registering with a practice that was not close to home:

From someone who broadly supported the freedom to choose: 'I would like the choice, but the problem is house visits. How can a doctor get from one place to another? Waste of GP time.'

And from someone who did not: 'It's silly. Your GP can only cover a certain area in emergencies and couldn't get around.'

3.3.3 Asked what they would look for in a GP practice if they had a completely free choice, (and given a list of options from which to choose as many factors as necessary), the majority of patients who supported choice focused on booking systems (83) and opening hours (80). Reputation, location and communication skills also featured.

3.3.4 We asked respondents if they would move away from their current practice if they were able to register with any GP anywhere. A clear majority of the 120 people who answered this question (96 people, or 80%) said no. There was no significant difference between genders or ethnic backgrounds in the replies to this question – but 25% of the 18-30 year olds who replied to this question said they would change, compared to just 9% of over-60s and 12% of people aged 31-59.

### 3.4 Choosing a hospital

While 54.5% of patients would welcome the opportunity to change GP practices, a much higher proportion (71.4%) said they would like to be able to choose which hospital to go to for further treatment.

Enthusiasm for the right to choose a hospital was evenly spread among age groups. It was slightly higher among women (77%) than men (65%), and among white British people (74%) than people of black, Asian or mixed descent (65%).

3.4.1 One respondent summed up most of the reasons given:

‘For the convenience, the easy visiting, the reputation, the specialisms – I want to stay where these meet my needs.’

Location was the single most popular consideration, closely followed by length of waiting lists.

### 3.5 Choosing a consultant

Having demonstrated considerable enthusiasm for the right to choose hospitals, respondents who answered this question were much more evenly split on the question of choosing a consultant: 107 said they would welcome this, while 108 replied that they would not. Responses were consistent across genders and ethnic backgrounds, although a significantly higher proportion of 31-59 year olds (64%) said yes than those in the over 60 or 18-30 age groups (36% and 45% respectively).

3.5.1 Of those who said ‘Yes’, reputation and the desire for the ‘best possible treatment’ figured prominently, alongside the need to build up a good rapport:

‘Some consultants do take their time and explain at length about your condition . . . seems they are more caring and have the right approach.’

3.5.2 People who did not want to choose their consultant said they were happy to trust their GP to make the choice for them, and did not feel that they knew enough themselves to make an informed choice.

### 3.6 Choosing types of treatment

We asked patients if they would like to be able to choose the type of treatment (for example, surgery, medication or therapy) they would receive if they were diagnosed with an illness.

A clear majority (139) said 'Yes', while 75 said 'No' and six did not answer.

#### 3.6.1 Eighty-two people answered along the lines of 'It's my body and my life', but they and others also referred to the need for good information to help them make the right choice:

'Any treatment should be discussed so pros and cons can be investigated with doctor and patient.'

Existing experience of shared decision-making varied: some respondents said they already felt able to participate in choosing their treatment, while others referred to disputes and difficulties they had experienced in this respect:

'Sometimes I feel you get passed from pillar to post then back again'

'I have been trying to get a choice. Trying to tell doctors I have an undiagnosed problem. They didn't think I was telling the truth'

#### 3.6.2 Several respondents acknowledged that the best treatment pathways may not always be the most conventional:

'Because the medical model is not always the way and you should be able to choose what medication you want to take, and whether psychological intervention may be a better option'

'Experience is that pills are the first approach. I would want to explore all other options, then choose which fits with my personal ideology'

'Medical only decisions don't always reflect personal circumstances or quality of life issues'

#### 3.6.3 Of the factors that would influence treatment choices, (using a list of options from which to choose as many factors as necessary), 110 said they would be influenced by the success rates of different treatments, while waiting lists (82 people) and GP recommendations (79) were also significant considerations.

#### 3.6.4 Everyone who said they had no wish to choose said they did not know enough to make informed choices, and that they trusted the doctor or other professional responsible for their care.

### **3.7 Support to make the right choice**

We asked whether people felt they needed support to help them choose GPs, hospitals, consultants and treatments.

- 3.7.1 In most cases, the majority of respondents (between 73% and 56.2% depending on the choice in question) said they would not need any support to make their decision.

Of those who said they would need support, the most popular source was the option to have a face-to-face discussion with a health professional.

In each case, a significant minority pointed out that their particular needs would necessitate some form of specialist support, ranging from alternative formats (Braille, large print, audio, pictures etc.) to interpreters or translated text.

- 3.7.2 When it came to choosing a course of treatment, only 43.5% said they would not need any support – reflecting a willingness to be guided or informed by experts. The most popular source of support was again a face-to-face discussion.

### **3.8 Referrals to Voluntary Sector providers**

Bearing in mind that this report forms part of a wider project to assess the likely impact of the proposed NHS reforms on the Voluntary and Community Sector (VCS), we asked two questions designed (particularly in the light of the current Government's commitment to 'No Decision About Me Without Me' to test patients' receptiveness to services provided by voluntary and community organisations (VCOs).

We asked how patients would feel if their GP referred them to a service provided by a charity. This open question elicited a very mixed response.

- 3.8.1 Sixty-five respondents were unequivocally positive, while 49 were cautiously receptive. Twenty-five people declared themselves to be apprehensive or anxious, and 21 were opposed to the idea.

Those who supported the idea tended to do so emphatically:

'Delighted. Good to see doctors using local groups and charities.'

'Would be good for the community.'

'If it was best for me, why not, and if it was quicker than a NHS service, all the better.'

'Great, as opposed to the private sector – mixed economy is better.'

‘As long as I was confident that it was the best option available I would not mind. I would welcome the opportunity to be able to research all the options and select the best one for me whether that be NHS, private or charity.’

3.8.2 Many of the more cautious responses centred on concerns that the service on offer would be appropriate and of an acceptable standard:

‘Depends on the illness. Minor, no problem. Major – concerned.’

‘I would rather have something that is NHS. A charity wouldn’t be trained the same.’

3.8.3 Other concerns included the financial implications:

‘Great as long as they were not expecting the charity to do it for free.’

‘I would hope they got adequate funding from the NHS to provide the service.’

3.8.4 There were also some doubts about charities being expected to ‘do the work of the NHS’:

‘Don’t agree with it – the NHS should provide it. Charities are there to support, not provide treatment. The NHS shouldn’t pile responsibility on to volunteers’ – a comment that illustrates the ongoing confusion about the distinction between ‘the voluntary sector’ and ‘volunteers’.

### **3.9 Referrals to non-medical treatments**

The final question asked patients if they would use non-medical treatments (for example exercise classes or talking therapies) if their GP prescribed them. We did not specify that these might be provided by VCS rather than NHS providers, although in practice this could often be the case.

3.9.1 Some respondents had already spontaneously stated their support for non-medical interventions (see 3.6.2 above); and when asked this specific question, a significant majority of respondents (195, representing 88.6% of the cohort) said they would be likely to use these services if prescribed.

3.9.2 Of the 19 people who said they would not, some focused on the examples given and said they were not able to take exercise or did not need talking therapy.

Others said they would not have time and one person said they preferred medication.

Interestingly, one person said: ‘Talking therapies may be relevant but exercise classes do not fall under healthcare *even though they may help my present illness*’ (our italics).

### 3.10 Summary

This research into the views of a very varied cohort of 220 people illustrates that most people do indeed value the opportunity to exercise a degree of choice and control over their own healthcare.

In most cases, people feel happy to make their choices without further support, although there is a broad welcome for opportunities to discuss options with health professionals.

However, in each case a significant minority said they would need support. The types of support they identified (information in different formats and languages; 'someone to sit down and explain it all'; 'paper and picture format') highlighted the importance of taking patients' special needs into account to ensure every patient can exercise their preferred level of choice and control.

3.10.1 There remains a firm commitment to the NHS as the provider of choice, and overall there is a strong sense of trust in GPs and hospital staff.

3.10.2 However, more than half of the respondents were either strongly or moderately comfortable with the idea that GPs might at some stage refer them to a charity or other voluntary organisation (against 46 who expressed clear discomfort).

The faith many people place in the medical profession also suggests that, if GPs and other health professionals were to move closer to a social prescribing model where patients' needs were addressed through non-medical interventions, most patients would be prepared to accept this approach in the right circumstances.

3.10.3 This has significant implications for voluntary sector providers, suggesting that, if a GP or other health professional sees the value in non-medical support of the kind provided by many VCOs, then most patients would be likely to follow their lead and at least accept referral to a voluntary sector service in appropriate circumstances. Many, in fact, would welcome this alternative approach.

The next section of this report contains some recommendations for supporting patients to take more control of their own healthcare, thereby making it possible for 'No Decision About Me Without Me' to become a practical reality.



# Section 4 - Recommendations

## 4.0 Recommendations

This section contains recommendations, based on the findings of our research, that health professionals and other healthcare providers could consider to ensure that patients, carers and the public have the means to assume greater control over their own healthcare.

### 4.1 Appropriate support

- 4.1.1. While most of the 220 people we consulted clearly valued the opportunity to exercise a degree of choice and control over their own healthcare, it will be important for health professionals to **take into account patients' needs** for, and right to, varying levels and types of support to help them exercise that control.

This will in some cases include **providing very specific and personalised help** to meet special needs that could include learning difficulties, language problems and sensory impairments.

### 4.2 Voluntary sector providers

- 4.2.1 Almost 85% of the GPs we interviewed for our report into the [relationship between GPs and the Voluntary Sector](#) felt that non-medical interventions by voluntary sector providers could in some cases be more effective than medication.

- 4.2.2 This was endorsed by many of the patients we interviewed for this report – but GPs and voluntary sector providers alike must **find ways to address the doubts** of the significant minority of people who expressed concern at the prospect of being 'treated' by non-medical providers.

The crucial factor here may be the faith, demonstrated in our research, that most patients place in the medical profession (or, more specifically, their own GPs). If GPs and other health professionals were to prescribe non-medical interventions where they felt them to be most appropriate, most patients would be prepared to accept this approach given **clear explanations and endorsement from health professionals**.

- 4.2.3 The second influential factor in developing appropriate and effective non-medical interventions will be the VCS's willingness and ability to **promote itself and its services clearly** – to commissioners and patients alike.

The next report in this series will look more closely at the specific steps the sector can take to make itself more clearly understood in this respect.



# Appendices



# Appendix 1 – Participant Profile

## Gender

	Number of respondents	% of respondents
Female	137	62.3
Male	78	35.5
Transgender	0	0.0
Not answered	5	2.3
<b>Total</b>	<b>220</b>	<b>100.0</b>

## Age

	Number of respondents	% of respondents
18-30	51	23.2
31-59	86	39.1
60+	77	35.0
Not answered	6	2.7
<b>Total</b>	<b>220</b>	<b>100.0</b>

## Location

	Number of respondents	% of respondents
Newcastle	47	21.4
Westerhope	17	7.7
Gateshead	12	5.5
Benwell	11	5.0
Fenham	11	5.0
Gosforth	10	4.5
Blakelaw	9	4.1
Chapel Park	5	2.3
Heaton	5	2.3
North Tyneside	5	2.3
Denton Burn	4	1.8
Scotswood	4	1.8
Walker	4	1.8
Wallsend	4	1.8
North Shields	3	1.4
West End	3	1.4
Whitley Bay	3	1.4
Arthurs Hill	2	0.9
Byker	2	0.9
Cramlington	2	0.9
Northumberland	2	0.9
Prudhoe	2	0.9
Whickham	2	0.9
Blyth	1	0.5
Alnwick	1	0.5
Blaydon	1	0.5
Brunton Park	1	0.5
Byker	1	0.5

	<b>Number of respondents</b>	<b>% of respondents</b>
Cowgate	1	0.5
Coxlodge	1	0.5
Cullercoats	1	0.5
Darlington	1	0.5
Dumpling Hall Estate	1	0.5
Edinburgh	1	0.5
Elswick	1	0.5
Felling	1	0.5
Gosforth	1	0.5
Hebburn	1	0.5
Inner West Newcastle	1	0.5
Jarrow	1	0.5
Kenton	1	0.5
Kenton Bar	1	0.5
Lemington	1	0.5
East Boldon	1	0.5
London	1	0.5
Middlesbrough	1	0.5
Newburn	1	0.5
Newton Aycliffe	1	0.5
North East	1	0.5
Otterburn	1	0.5
Pendower	1	0.5
Ponteland	1	0.5
Sandyford	1	0.5
Spittal Tongues	1	0.5
Stanley	1	0.5
Stockton-on-Tees	1	0.5
Gateshead	1	0.5
Swalwell	1	0.5
Throckley	1	0.5
Tow Law	1	0.5
Washington	1	0.5
Whitburn	1	0.5
Wingrove	1	0.5
No response	11	5.0
<b>Total</b>	<b>220</b>	<b>100.0</b>

### **Ethnicity**

	<b>Number of respondents</b>	<b>% of respondents</b>
White British	185	84.1
White Irish	3	1.4
Any other White background	6	2.7
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0

Mixed White and Asian	1	0.5
Any other Mixed background	0	0.0
Chinese	5	2.3
Asian or Asian British – Indian	1	0.5
Asian or Asian British – Pakistani	12	5.5
Asian or Asian British – Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British - Caribbean	0	0.0
Black or Black British - African	0	0.0
Any other Black background	1	0.5
Any other ethnic group	0	0.0
No response	6	2.7
<b>Total</b>	<b>220</b>	<b>100.0</b>



# The NHS reforms – what do you think?

There are plans to give you as a patient more of a say in the healthcare you receive and more choice in health services you can use and the treatment you are offered. We would like to know what you think of these planned changes.

We would really appreciate it if you could take a few minutes to complete this questionnaire and post it in the box provided.

**1. Before you had read the information above, did you know that there were changes planned to the way the NHS is run?**

Yes  No

**2. Would you like to have easier access to your own medical record?**

Yes  No

**2a. Why is this?**

.....  
.....  
.....

**If you ticked 'no' for question 2 above, please now go to question 3 overleaf →**

**2b. How would you prefer to access your medical record? (tick ✓ one box only)**

By being given a paper copy by your GP

By receiving an electronic copy by email

By logging in to a secure website

Other (please state).....

**2c. What support would you need to access your medical record?**

(tick ✓ all that apply)

Nothing

A face-to-face discussion with a health professional

Access to an interpreter

My medical record translated into another language

In another format e.g. audio, braille, large font

Other (please state).....

**Please turn over →**

**3. At the moment you can only be a patient at a GP practice if you live close to it. Would you like to be able to register with any GP practice?**

Yes  No

**3a. Why is this?**

.....  
.....  
.....

**If you ticked 'no' for question 3 above, please now go to question 4 overleaf →**

**3b. What information would you need to choose a GP practice? (tick ✓ all that apply)**

- |                               |                          |                        |                          |
|-------------------------------|--------------------------|------------------------|--------------------------|
| Number of GPs                 | <input type="checkbox"/> | Parking facilities     | <input type="checkbox"/> |
| Gender of GPs                 | <input type="checkbox"/> | Public transport links | <input type="checkbox"/> |
| Opening hours                 | <input type="checkbox"/> | Pharmacy on site       | <input type="checkbox"/> |
| Simple booking system         | <input type="checkbox"/> | Other services on site | <input type="checkbox"/> |
| Accessibility of the building | <input type="checkbox"/> |                        |                          |
| Other (please state).....     |                          |                        |                          |

**3c. What support would you need to choose a GP practice? (tick ✓ all that apply)**

- |   |                          |
|---|--------------------------|
| Nothing   | <input type="checkbox"/> |
| A face-to-face discussion with staff at the practice          | <input type="checkbox"/> |
| Access to an interpreter                                      | <input type="checkbox"/> |
| Information translated into another language                  | <input type="checkbox"/> |
| Information in another format e.g. audio, braille, large font | <input type="checkbox"/> |
| Other (please state).....                                     |                          |

**3d. Do you think you would change practices now if you were able to register anywhere?**

Yes  No

**4. Currently, if your GP refers you to see a consultant you can choose which hospital you go to for your first appointment. Would you like to be able to choose which hospital to go to for any further hospital care related to that illness?**

Yes  No

**4a. Why is this?**

.....  
.....  
.....

**If you ticked 'no' for question 4 above, please now go to question 5 overleaf →**

**4b. What information would you need to choose a hospital? (tick ✓ all that apply)**

- |   |                          |                                  |                          |
|---|--------------------------|----------------------------------|--------------------------|
| Location                                | <input type="checkbox"/> | Rates of MRSA and C.Diff         | <input type="checkbox"/> |
| Public transport links                  | <input type="checkbox"/> | Cleanliness                      | <input type="checkbox"/> |
| Parking facilities                      | <input type="checkbox"/> | Quality of food                  | <input type="checkbox"/> |
| Length of waiting list for appointments | <input type="checkbox"/> | Personal experiences of patients | <input type="checkbox"/> |
| Consultants available                   | <input type="checkbox"/> | Recommendation from my GP        | <input type="checkbox"/> |
| Success rates of operations             | <input type="checkbox"/> |                                  |                          |
| Other (please state).....               |                          |                                  |                          |

**4c. What support would you need to choose a hospital? (tick ✓ all that apply)**

- |   |                          |
|---|--------------------------|
| Nothing   | <input type="checkbox"/> |
| A face-to-face discussion with staff at the hospital          | <input type="checkbox"/> |
| Access to an interpreter                                      | <input type="checkbox"/> |
| Information translated into another language                  | <input type="checkbox"/> |
| Information in another format e.g. audio, braille, large font | <input type="checkbox"/> |
| Other (please state).....                                     |                          |

**5. Would you like to be able to choose to see a specific consultant if you are referred to hospital?**

- Yes  No

**5a. Why is this?**

.....

.....

.....

**If you ticked 'no' for question 5 above, please now go to question 6 overleaf →**

**5b. What information would you need to choose a consultant? (tick ✓ all that apply)**

- |   |                          |   |                          |
|---|--------------------------|---|--------------------------|
| Location of consultant                  | <input type="checkbox"/> | Success rate of operations              | <input type="checkbox"/> |
| Length of waiting list for appointments | <input type="checkbox"/> | Personal experiences of former patients | <input type="checkbox"/> |
| Recommendation from my GP               | <input type="checkbox"/> |   |                          |
| Other (please state).....               |                          |   |                          |

**5c. What support would you need to choose a consultant? (tick ✓ all that apply)**

- |   |                          |
|---|--------------------------|
| Nothing   | <input type="checkbox"/> |
| A face-to-face discussion with each consultant available      | <input type="checkbox"/> |
| Access to an interpreter                                      | <input type="checkbox"/> |
| Information translated into another language                  | <input type="checkbox"/> |
| Information in another format e.g. audio, braille, large font | <input type="checkbox"/> |
| Other (please state).....                                     |                          |

**6. Would you like to be able to choose the type of treatment (E.g. surgery/ medication/therapy) you receive if you are diagnosed with an illness?**

Yes  No

**6a. Why is this?**

.....  
.....  
.....

**If you ticked 'no' for question 6 above, please now go to question 7 below ↓**

**6b. What information would you need to choose the type of treatment you receive? (tick ✓ all that apply)**

Location of treatment  Length of waiting list for treatment   
Success rate of treatment  Recommendation from my GP   
Personal experiences of patients who have had the treatment   
Other (please state).....

**6c. What support would you need to choose the type of treatment you receive? (tick ✓ all that apply)**

Nothing   
A face-to-face discussion with people providing each treatment   
Access to an interpreter   
Information translated into another language   
Information in another format e.g. audio, braille, large font   
Other (please state).....

**7. Some services for patients are provided by the NHS and some are provided by charities. How would you feel if your GP referred you to a service provided by a charity?**

.....  
.....  
.....

**8. If your GP prescribed, for example, exercise classes or talking therapies, do you think you would use those services?**

Yes  **If 'yes', please move on to question 9 overleaf →**  
No

**8a. If 'no', why is this?**

.....  
.....  
.....

## About you

9. Gender      Female            Male            Transgender     

10. Age      18 – 30            31 – 59            60+     

11. Where do you live? .....

12. Please indicate your ethnic background

<b>White</b>		✓	<b>Asian or Asian British</b>		✓
British			Indian		
Irish			Pakistani		
Any other White background			Bangladeshi		
<b>Mixed</b>			Any other Asian background		
White and Black Caribbean			<b>Black or Black British</b>		
White and Black African			Caribbean		
White and Asian			African		
Any other Mixed background			Any other Black background		
<b>Other ethnic groups</b>					
Chinese					
Any other ethnic group (please state)					
.....					

Thank you for taking the time to complete this questionnaire. Please return it in the FREEPOST envelope provided by (date).



## Appendix 4 – Questionnaire responses

Before you had read the information above, did you know that there were changes planned to the way the NHS is run?

	Number of respondents	% of respondents
Yes	155	70.5
No	65	29.5
<b>Total</b>	<b>220</b>	<b>100.0</b>

Would you like to have easier access to your own medical records?

	Number of respondents	% of respondents
Yes	166	75.5
No	54	24.5
<b>Total</b>	<b>220</b>	<b>100.0</b>

If you ticked 'Yes', why is this?

- To help me remember my past history / treatment I have had over the years x 25
- It's my personal information, so it should be available to me x 22
- Because it is good to know what has been said about me x 20
- For my own information x 20
- To understand my condition better/ be more aware of my health x 18
- To save time x 7
- Just in case I need it x 4
- To have better control over my own health x 3
- As people are often asked to fill in questionnaires about their health (plus I am part of a lifelong national study so need to answer questions on health) it would be useful to be able to access records
- At the moment you are pushed from pillar to post
- Because although I request to be copied into letters from my consultants I very rarely get them.
- Because at the moment it is very difficult
- Because of my Parkinson's disease, the history of my symptoms could help in research
- Ensure receiving appropriate care/service
- Generally be helpful to have it when I move around
- I am concerned though about the security of my details and other personal information, particularly if someone else handles it
- I do anyway, mainly because my sister has accessed hers and told me about it
- I might like to look at it in the future
- I recently had cancer, the information I received was bit clouded, would have liked more information about the way I feel. My medical records could have helped me find that out
- I thought about it but I didn't know if I would like it. Only get access to what they think we should. What good is half a look? I heard a doctor say they will only show you what the medical profession thinks is appropriate
- If they knew people had access to them they might keep better quality records and staff would be more accountable

- If you are anywhere in the country and you have an accident the A & E staff can bring up your record immediately
- If you were trying to explain to someone what was wrong with you, you could just show them
- I'm not sure information is accurately shared between NHS organisations
- It helps you find out what is going on, help work out your illness. Plus, you never get to see the same doctor so it would be good to use it to explain to the doctor what is wrong with you in more detail. It needs to be in plain English though
- Just to be prepared in case of any eventuality
- More transparent
- Not really bothered either way
- Often been curious as to what it actually says but unable to access it. Took me about a year to access my own diagnosis
- Point of reference - have asthma problems
- Proof of vaccinations. Overview of previous health complaints
- So you can see how you have been diagnosed. You often don't take in what you have been told at appointments
- Sometimes GPs can make mistakes. You can look through your records and identify treatments that have and have not worked, so if your GP prescribes one that doesn't you can tell them
- Sometimes request letters which are done about you but do not receive them sometimes
- To be able to make an informed choice
- To get access to past treatments and see what was done and judge a past poor treatment/op
- To make sure information is accurate, and to check medications etc. I've been prescribed in the past
- To make sure that my information is up to date and that copies of latest version of my advance medical directive are on file. Also, my husband is diabetic and other than his hospital check-up letters it would be useful for him to monitor his own progress by being able to view his own file and see how his blood glucose levels are changing etc.
- You might be able to improve your treatment - you can share information better with other services
- **Not answered x 4**

#### **If you ticked 'No', why is this?**

- No need x 14
- Not bothered / interested x 11
- You get the information you need at your appointments x 3
- Never thought about it x 2
- I already can, if I need to x 2
- It will still be controlled by our GP
- Because I have not required so much as a glance of my medical records in 18 years and I do not believe it would help me to have the aforementioned 'easier access'
- Nothing to check on the records - if I had a lot of illnesses I might want to check. I got a letter about 'summary records'
- I'm concerned that if I had total freedom to look at them the GP would not be able to be as honest in them. Also I think too much information can be too much of a good

thing. For example, if people had known about my diagnosis I wouldn't have been eligible for my pension

- My memory is quite good and I'm pretty aware of what my records should be
- I trust the doctor. It's also a security worry, if there is no security built in it could fall into the wrong hands
- I would not know what to do, I would just get confused
- It is not necessary; GP etc. should be honest and explain everything properly. Medical records are written in medical language for health professionals so therefore will not always make sense to the lay person
- If you're not happy with your doctor it might be a good thing but mine is fine so I don't need it
- Because I have good health, I haven't tried to access my records. On the odd occasions where I have asked about past treatments, my GP has been sufficiently communicative. I am not aware that there is a problem with accessing medical information. If this is a problem for people, I would support the right to easier access
- It's another added expense - could be used for other things
- **Not answered x 2**

### How would you prefer to access your medical record (tick one box only)

	Number of respondents	% of respondents
By being given a paper copy by your GP	69	41.6
By logging in to a secure website	60	36.1
By receiving an electronic copy by email	25	15.1
Other	8	4.8
Not answered	4	2.4
<b>Total</b>	<b>166</b>	<b>100.0</b>

### Other:

- All of these
- I would like to use the internet but I don't have a computer
- I would need support x 3
- I'd need support with the email
- Paper and picture format
- Not answered

### What support would you need to access your medical record? (tick all that apply)

	No of responses	% of responses	% of respondents*
Nothing	104	60.5	64.2
A face-to-face discussion with a health professional	47	27.3	29.0
In another format (braille, large font etc.)	4	2.3	2.5
Access to an interpreter	3	1.7	1.9
My medical record translated into another language	3	1.7	1.9
Other	11	6.4	6.8
<b>Total</b>	<b>172</b>	<b>100.0</b>	

**Other:**

- Help to log on to the computer, and written in large font
- Help to access the computer
- An audio CD
- An advocate
- Help to access the website
- Someone to sit with me and explain it x 6

**At the moment you can only be a patient at a GP practice if you live close to it. Would you like to be able to register with any GP practice?**

	<b>Number of respondents</b>	<b>% of respondents</b>
Yes	120	54.5
No	95	43.2
Not answered	5	2.3
<b>Total</b>	<b>220</b>	<b>100.0</b>

**If you answered 'Yes', why is this?**

- I like my doctor, so if I moved I would like to stay with him/her x 31
- So I can choose a doctor that is best for me x 19
- Convenience x 16
- I would like to see a GP near my work x 10
- Ease of access x 7
- Greater personal choice x 6
- Useful if you move around a lot x 5
- A lot of people would not want to go further afield. But I suppose if my doctor relocated I might like to move with her but only if she wasn't going too far.
- Because we can check our health easily (access)
- Because when I was registered at a GP in Newcastle (Heaton Road) I felt the standard of treatment we received was excellent, however since moving to Northumberland my current 'local' GP surgery isn't the same standard . . . I would definitely chose to move back to Newcastle GP if I could and I personally use the walk in centre at Molineux centre rather than my own GP.
- Emergencies - there is one open later than my GP
- Students have to register as temporary patients. The doctor doesn't have as much background knowledge or access to everything. Medical records are not in the right place
- I live in Prudhoe and the doctors are not interested in mental health.
- I would like the choice. But the problem is house visits. How can a doctor get from one place to another? Waste of GP time
- In case you move away for a little bit for instance long holidays
- In case I was away from home
- It gives the opportunity to register somewhere which might be less busy than your current practice.
- Probably I would not use it but it may benefit others (close to work etc.)
- So I could choose to access a GP Practice which had specialist services if I needed them and I would like an independent body to inspect and rate the service provided

- So I could have a GP close to work for ease of access or be able to move to one that has a better quality of care or provides services or clinics that I would find useful
- Some GPs have better reputations than others. Some surgeries may have different opening/closing hours
- Sometimes your surgery is busy - could move to a less busy surgery
- To get better access to appointments
- Within reason - home visits could be a problem
- Not sure
- **Not answered x 1**

### **If you answered 'No', why is this?**

- It's not necessary x 20
- Happy with my GP x 13
- I would not want to travel x 13
- I believe there is already a choice of local GP practices. More choice could make it harder and more expensive to run GP practices
- I live in Whickham and people from Dunston think that everything is better in Whickham so they might come over and join the practices there and the practices might get inundated with patients. But if there was an MS specialist GP practice I might go there but only if it was close
- I think there are lots of other options such as walk-in centres so there is no need to look around for other GPs
- I work in a GP practice in Gateshead and visits out of area are a nightmare
- If people need services that their GP can't offer there are lots of other options such as walk-in centres, so why would you have to move practice?
- If people needed other services not provided by their GP there are plenty of other services such as walk-in centres
- If you were ill you would not wish to travel and if doctors had to call to your home have to be within a distance of surgery or less people would be seen
- If you have a good doctor then everyone may move there, resulting in long waiting lists
- If you needed to see a doctor at home you'd be dragging him all over the country
- If your surgery doesn't offer certain services then there are lots of other options such as walk-in centres - so there is no need to move practices
- It may not be convenient for a GP to be called out from that practice to your home - it may involve large travel times which would be difficult for me to get to the surgery and the doctor to get to me. And if GPs can let anyone go to their practice the popular ones will get very busy and you may find it difficult to see a doctor
- It's a silly idea; I'd never want to travel. If you're elderly you wouldn't want to travel. You need to go somewhere local, somewhere no more than a bus ride away
- It's silly. Your GP can only cover a certain area in emergencies and couldn't get around
- Majority are good at what they do after 7 years training and experience!
- There are lots of urgent care centres for out of hours or emergencies
- My own GP knows me best. It's only a short distance to travel and if other people from other areas join, it may reduce my chances of seeing my desired GP
- No GP is better than any other. There is usually a range to choose from close to home
- Not at my age

- There are usually several GP practices in populated areas so the element of choice is not an issue. It is also important to be registered to a nearby practice for ease of use
- Too much emphasis on ease of access, rather than the service provided
- What if they have a house call for someone who lives miles away, how are they going to get there?
- **Not answered x 7**

**What information would you need to choose a GP practice? (tick all that apply)**

	<b>No. of responses</b>	<b>% of responses</b>	<b>% of respondents*</b>
Simple booking system	83	19.6	69.2
Opening hours	80	18.9	66.7
Number of GPs	44	10.4	36.7
Public transport links	44	10.4	36.7
Gender of GPs	38	9.0	31.7
Pharmacy on site	34	8.0	28.3
Parking facilities	30	7.1	25.0
Accessibility of the building	27	6.4	22.5
Other services on site	20	4.7	16.7
Other	24	5.7	20.0
<b>Total</b>	<b>424</b>	<b>100.0</b>	

\*Number of respondents answering this question - 120

**Other:**

**Reputation and word of mouth**

- Reputation
- Recommendation of family
- Reputation of practice
- Patient recommendations

**Convenience**

- Location
- Out of hours services
- Online appointment booking system
- Availability of GPs (especially out of my work hours)

**Specialist knowledge and skills**

- It they had a specific interest in MS
- What they specialise in i.e. Mental health
- Knowledge of GP's record in regard to patient care
- How involved with the community it was
- Specialist information i.e. diabetes clinics etc

**Communication and relationships**

- Someone with good communication skills and English as a first language x 4
- Somewhere that offers phone consultants x 4
- Nice reception staff x 3
- Finding a GP that you can have a rapport with x 2

- Would stay with my GP so wouldn't need any information

- No answer

**What support would you need to choose a GP practice? (tick all that apply)**

	<b>No. of responses</b>	<b>% of responses</b>	<b>% of respondents*</b>
Nothing	76	61.8	65.0
A face-to-face discussion with staff at the practice	34	27.6	29.1
In another format (braille, large font etc.)	5	4.1	4.3
Information translated into another language	4	3.3	3.4
Access to an interpreter	3	2.4	2.6
Other	1	0.8	0.9
<b>Total</b>	<b>123</b>	<b>100.0</b>	

\*Number of respondents answering this question - 120

**Other:**

- Details on the background knowledge, record and patient care of the said person

**Do you think you would change practices now if you were able to register anywhere?**

	<b>Number of respondents</b>	<b>% of respondents</b>
Yes	24	20.0
No	96	80.0
<b>Total</b>	<b>120</b>	<b>100.0</b>

**Would you like to be able to choose which hospital to go to for any further hospital care related to that illness?**

	<b>Number of respondents</b>	<b>% of respondents</b>
Yes	157	71.4
No	55	25.0
Not answered	8	3.6
<b>Total</b>	<b>220</b>	<b>100.0</b>

**If you answered 'Yes', why is this?**

#### **Specialisms**

- It is essential as hospitals specialise in different things x 3
- So I could ensure I could be treated by a specialist and highly rated professional
- Potentially more specialist hospital for certain diseases or less waiting time
- I have a condition where there are specific treatment centres that specialise in that condition

### **Convenience and access**

- To make it more convenient x 15
- Ease of access x 9
- Good public transport links x 5
- Convenience and rapport with staff built up x 2
- To help me to choose the hospital that is most convenient for me. For example, this may not necessarily be the closest to my home, but may be the one that is closest to my work or that offers clinics at the most appropriate times
- So I could move if I did not like that location or stay in a location that is more convenient
- So I can stay at a hospital that is close to home or easy to get to for my family
- Rather come to one in Newcastle. Prefer NHS in cities
- Wansbeck is not close enough to me and yet I am often referred there instead of NTH
- I only want to go to a local hospital - RVI or Freeman

### **Quality of care**

- Like to know I'm getting the best care x 9
- It makes the hospital staff work harder to be the best. Competition
- To get the best hospital and to be treated quickly
- Because a hospital might have a bad reputation
- Some hospitals are viewed as better than others in Newcastle/North Shields
- Because the element of choice is introduced and I would be able to continue my hospital care where I thought best
- A nearer hospital to home or better reputation of consultant
- Personal preference and reputation of hospitals. Some have better reputations than others and I would like to go to the one that provides the best care
- I would want to know performance data of the best at the process I would be undertaking and then make a reasoned choice about where to go.
- It would be good to be able to go somewhere which I have been told has a good service.
- So I can choose what I think has the best facilities/ specialist staff

### **Consistency**

- Would like to stay where I first choose x 18
- I am used to my consultant and I like to see the same people x 7
- So I can go to my normal hospital and they have access to all my records and I can speak to specialists
- I would like to be able to stay at that hospital, unless I am unhappy
- Being at the same hospital may improve the information I receive
- I would prefer to stay/go back to my hospital of choice - would like to stay with the same team, particularly if it was an operation
- I prefer certain hospitals, so would want to choose and stay there

### **Speed of treatment**

- To be able to choose the quickest appointment x 4
- Because of waiting lists - I would choose a hospital with the shortest, would then not want to be transferred
- So I can choose ones that are better suited to me. I have transport so would be happy to travel further afield if I was to be seen quicker

### **Other responses**

- Location/reputation
- Convenience, Recommendation. Health record of that hospital. Freedom of choice
- Good - it's what they do now
- Ease and familiarity
- If it was necessary for my health concerns at the time
- It's a good idea but I don't think anyone in Newcastle would go past the RVI - we have good hospitals here!
- If you don't have a good experience. But would be happy at first to go wherever they said
- I like the Freeman
- I have received no choice before but hospitals are reducing e.g. Newcastle General
- To be able to get a second opinion
- Because of the different prognoses given by two top Parkinson's consultants - so would like to stay within a certain hospital
- For the convenience, for the easy visiting, the reputation, the specialisms - want to stay where these meet my needs
- Access and hospital results
- I would chose to be treated in a Newcastle hospital (Freeman, RVI) rather than in the Wansbeck
- Might get seen quicker but would prefer to be seen locally
- Personal choice x 4
- Good idea – good system x 2
- Not sure x 2

### **If you answered 'No', why is this?**

- Happy to go where I am told x 13
- I don't care where I go as long as I get the best quality treatment x 5
- My GP knows more about the best care for me than I do x 4
- I don't think I could make an informed choice x 3
- Would like to have good health service no matter where
- Not unless there was an actually problem with treatment received at the first hospital. Otherwise it would be more complicated and expensive to run all hospitals if there was a greater choice
- The more you complicate the NHS, the more things can go wrong
- I have always been happy with the service the NHS has provided me
- No issues - would take advice of Dr only. Do not want to choose
- I feel the hospitals in Newcastle are good enough
- RVI is suitable and close
- Unnecessary
- No reason
- I'm not that bothered. It would depend on the illness.
- Not worried about that

## What information would you need to choose a hospital?

	No. of responses	% of responses	% of respondents*
Location	113	12.9	72.0
Length of waiting list for appointments	110	12.6	70.1
Cleanliness	89	10.2	56.7
Recommendation from my GP	88	10.0	56.1
Success rates of operations	84	9.6	53.5
Public transport links	73	8.3	46.5
Consultants available	69	7.9	43.9
Rates of MRSA and C.Diff	67	7.6	42.7
Personal experiences of patients	67	7.6	42.7
Parking facilities	53	6.1	33.8
Quality of food	49	5.6	31.2
Other	14	1.6	8.9
<b>Total</b>	<b>876</b>	<b>100.0</b>	

\*Number of respondents answering this question - 157

### Other:

- Friendly staff are important x 4
- Specialisms x 3
- Previous experiences x 2
- Teaching Hospital, regional centres, outcomes
- Specialist equipment and facilities
- All of the named information, plus details of the doctors

## 4c. What support would you need to choose a hospital? (tick all that apply)

	No. of responses	% of responses	% of respondents*
Nothing	114	68.7	73.1
A face-to-face discussion with staff at the hospital	35	21.1	22.4
In another format (braille, large font etc.)	5	3.0	3.2
Access to an interpreter	3	1.8	1.9
Information translated into another language	1	0.6	0.6
Other	8	4.8	5.1
<b>Total</b>	<b>166</b>	<b>100.0</b>	

\*Number of respondents answering this question - 156

### Other:

- All of this information plus information on the care practice of

the medical staff and how this relates to the care of the patient.

- A write-up about it
- Internet
- An audio CD or video
- Information provided by GP on different hospitals or willingness to discuss with patient

**Would you like to be able to choose to see a specific consultant if you are referred to hospital?**

	<b>Number of respondents</b>	<b>% of respondents</b>
Yes	107	48.6
No	108	49.1
Not answered	5	2.3
<b>Total</b>	<b>220</b>	<b>100.0</b>

**If you answered 'Yes', why is this?**

**Reputation and quality**

- Reputation of consultant x 23
- I want the best possible treatment x 6
- So I could choose a consultant who was eminent in their field – similar to the choice private patients have always enjoyed
- To avoid being treated by a consultant with a poor record - but accurate information would be needed to make an informed decision

**Relationships and consistency**

- I prefer to see people who know me and my circumstances x 17
- Some are more understanding and have a different bedside manner
- Some consultants don't listen and are obnoxious. There are some really good ones
- Predominantly rapport - confidence in the practitioner improves wellbeing. I am assuming I have been able to check the performance and patient feedback which would help me identify my preference
- So I can choose an experienced consultant - one that knows how best to communicate with you
- Personal reasons very important Specialisms and interests vary
- Some consultants do take their time and explain in length about your condition which seems that they are more caring and have right approach
- Because I've had experiences of different consultants for different tasks and they have generally been very good and I would like to be able to choose these people again
- Due to the different prognoses the two top Parkinson's consultants give I would choose the one that has been most involved in my care

**Importance of choice**

- Choice should be a right x 13
- To see a specialist associated with my problem x 7
- It would be nice, but how do you decide between consultants? x 3
- Good to have choice of gender for some conditions
- If a certain consultant has been recommended to me and another recommended against then I would prefer to be able to choose between the two

- I would feel more secure
- Confidentiality and confidence when talking about personal issues
- I would hope my GP could advise me as to the better consultants
- I had a bad experience with a ENT consultant and I would never wish to go to him again
- Because sometimes it takes too long between visits to see my current consultant so I would like to choose another one
- I feel specialists can be set in their ways. Also clients often have multiple diseases and treatments my conflict. Liaising with other areas can be slow. Also I would like to be able to change consultants mid treatment. I know many people who have expressed this wish... if only to get second opinions
- Not sure x 2

**If you answered ‘No’, why is this?**

- I trust my doctor to make a recommendation x 18
- I don't know enough to make an informed choice x 16
- Quite happy that I would see the right person x 14
- You would only get league table information which is crap and inaccurate
- Could be expensive and you might end up waiting longer
- But what happens if everyone chooses the same one?
- If they are qualified and working there is no difference. But I would like to see a consultant who can explain my treatments in good, plain English
- If I don't like the consultant I would like to ask for another otherwise what's the problem?
- You usually see a registrar rather than the consultant anyway
- I don't mind x 6

**What information would you need to choose a consultant? (tick all that apply)**

	<b>No. of responses</b>	<b>% of responses</b>	<b>% of respondents*</b>
Success rates of operations	64	20.8	64.0
Personal experiences of patients	64	20.8	64.0
Recommendation from my GP	60	19.5	60.0
Length of waiting list for appointments	57	18.6	57.0
Location of consultant	42	13.7	42.0
Other	20	6.5	20.0
<b>Total</b>	<b>307</b>	<b>100.0</b>	

\*Number of respondents answering this question - 100

**Other:**

- Any teaching they do, how much time devoted to NHS v private practice
- Their expertise and reputation
- All of the above plus information on medical expertise and

- practice and attitudes
- Attitude of consultant – I need to feel comfortable
- Specialism of consultant x 2

**What support would you need to choose a consultant? (tick all that apply)**

	<b>No. of responses</b>	<b>% of responses</b>	<b>% of respondents*</b>
Nothing	59	52.7	56.2
A face-to-face discussion with each consultant available	34	30.4	32.4
In another format (braille, large font etc.)	4	3.6	3.8
Access to an interpreter	2	1.8	1.9
Information translated into another language	2	1.8	1.9
Other	11	9.8	10.5
<b>Total</b>	<b>112</b>	<b>100.0</b>	

\*Number of respondents answering this question - 105

**Other:**

- Details of background of ideas on medical care practice.
- Availability of online success rates, experience etc.
- Face-to-face discussion with my GP
- Advice and support to my level of understanding
- Someone to talk about it with

**Would you like to be able to choose the type of treatment (E.g. surgery/medication/therapy) you receive if you are diagnosed with an illness?**

	<b>Number of respondents</b>	<b>% of respondents</b>
Yes	139	63.2
No	75	34.1
Not answered	6	2.7
<b>Total</b>	<b>220</b>	<b>100.0</b>

**If you answered 'Yes', why is this?**

- My body, my life. Want an informed choice x 82
- Thorough information in newspapers about new treatments available in your own area but would still like information and choice
- You are able to anyway – I have joint discussions with my GP. I've just had an operation and had a joint discussion and made a choice myself
- I value complementary medicines. The emotional side of ill health is important
- I have been trying to get a choice. Trying to tell doctors I have an undiagnosed problem. They didn't think I was telling the truth.
- I have argued with my surgery about my medication so would like to choose
- As long as it was consistent with the best medical advice

- There are problems because there aren't alternative therapies offered. GPs try to protect their own profession - pill based from doctors.
- Have had a knee replacement and would like another - would like choice of type of prosthetic
- Nowadays by having the internet available is more convenient to research different approaches to treatment, different practices, operations, drugs so one can make up one's mind and suggest the best course of action
- Knowledge (as a nurse)
- I thought that was the norm - I have a good doctor
- Sometimes I feel you get passed from pillar to post then back again.
- Some of the options may be difficult with lifestyle
- But only if there are multiple choices of treatment available and I would need guidance as to which type of treatment would be most effective from the hospital staff
- I would like to receive all the relevant treatment to cure the illness of course
- It would depend on the circumstances
- Any treatment should be discussed so pros and cons can be investigated with doctor and patient
- I have MS and there are two types of medicine the GP said I could take. One which might not help me very much and one which will help me but the side effects are brain damage or early death - I chose the second medicine and two years later I'm still here and have had no ill effects!
- I would like to discuss with the doctor what we thought the best course of action was and come to a consensus of opinion about what would be best for me
- I would want the best for myself - no cost cutting
- It would be good to see what suits you best
- Otherwise treatment could be imposed on you that you know would impact negatively on other parts of your life. Your priorities might be different to the medical professional's (e.g. quality of life over quantity).
- I don't believe in popping pills all the time so I would like an alternative
- Would want to choose something to suit my lifestyle
- I could match it to my lifestyle
- I would take on board the advice from the doctor but I would like to choose something that would suit my lifestyle
- To be confident that I was getting the best treatment available
- I don't like some treatments, or needles
- So I could choose a treatment that would work the quickest
- I don't believe in pills much
- I would take my GPs recommendation into account but I know how I feel and the pain I feel on a daily basis so would like to be able to choose
- So I can choose the one that has the best success rate and is most suited to my lifestyle
- Would like to be able to make Informed choice which can only be made with full discussion with consultant/GP/medical practitioner
- To ensure that it's most suitable for my (and my family's) needs
- It's my choice which way my illness would be treated. I would listen to recommendations but ultimately I should decide.
- Because the medical model is not always the way and you should be able to choose what medication you want to take and if psychological intervention may be a better option

- I would expect a range of options or to be told there is no option but this one.
- Experience is that pills are the first approach. I would want to explore all other options, then choose which fits with my personal ideology.
- Medical only decisions don't always reflect personal circumstances or quality of life issues
- I would want the best possible treatment I could get for myself and for my family
- People don't want to always take medication

**If you answered 'No', why is this?**

- I don't know enough / I trust the professionals x 54

**What information would you need to choose the type of treatment you receive? (tick all that apply)**

	<b>No. of responses</b>	<b>% of responses</b>	<b>% of respondents*</b>
Success rate of treatment	110	27.2	79.1
Length of waiting list for treatment	82	20.3	59.0
Recommendation from my GP	79	19.6	56.8
Location of treatment	59	14.6	42.4
Personal experiences of patients who have had the treatment	58	14.4	41.7
Other	16	4.0	11.5
<b>Total</b>	<b>404</b>	<b>100.0</b>	

\*Number of respondents answering this question - 139

**Other:**

- Recognition of emotional aspects from health professional
- Personal knowledge through work
- Nothing. I am an expert patient so have done research
- Reliable information on the internet
- Phone line offering impartial information
- All of the above plus details of all available treatments.
- List of alternatives
- As long as it's a proven treatment, it would be chosen on how it would match/ not impact on my lifestyle
- Anything that helped me to stay at home
- Information from a consultant
- Side effects, long and short term, method of administration and availability of appropriate up to date equipment
- Research evidence for the range of possible treatments

**What support would you need to choose the type of treatment you receive?(tick all that apply)**

	<b>No. of responses</b>	<b>% of responses</b>	<b>% of respondents*</b>
A face-to-face discussion with people providing each treatment	65	43.9	47.1
Nothing	60	40.5	43.5
Other	15	10.1	10.9
In another format (braille, large font etc.)	4	2.7	2.9
Access to an interpreter	2	1.4	1.4
Information translated into another language	2	1.4	1.4
<b>Total</b>	<b>148</b>	<b>100.0</b>	

\*Number of respondents answering this question - 138

**Other:**

- Face-to-face if it was a major illness, nothing if it was minor
- Someone to ask questions of
- Some of the above plus up to date information on treatments.
- Web based information
- A face-to-face discussion with my GP
- Someone to support me through the process /help from family/carers x 6
- A video of the treatment
- Written material
- Evidence about each possible treatment

**How would you feel if your GP referred you to a service provided by a charity?**

- Fine / no problem x 65
- Fine as long as they are qualified / the same standard 49
- Apprehensive x 25
- Not happy. I would prefer the NHS x 21

**Positive reactions**

- Delighted. Good to see doctors using local groups and charities. They must be good quality though.
- Great, as opposed to private sector – mixed economy is better
- I would be fine, I have experienced charities before and they have been excellent
- If it was best for me, why not, and if it was quicker than a NHS service, all the better
- It would be fine, sometimes they have more time. There are more charities so there is a lot more scope for providing services and charities tend to have a one-stop-shop. Happy with the expertise of charities
- I've used them before for acupuncture and massages at Walkergate Hospital. I am happy with it
- Quite happy, MacMillan do a tremendous job in the region as do St Oswald's Hospice, I think there should be more support for charities who are involved in

healthcare from local authorities

- Would be happy with a charity, I have used charities in the past and they have been very good (MacMillan)
- Would be good for the community
- You might get a quicker appointment with them and if the NHS are supporting it they've got to have looked at who they are, so I'd definitely go

### **Funding concerns**

- Great as long as they were not expecting the charity to do it for free
- Happy if the service was the most appropriate and it was being properly funded
- All services should be free at point of use. Charities shouldn't have to fill in the gaps
- I would hope they got adequate funding from the NHS to provide the service
- I would not like this decision, how will my treatment be funded?
- I would want to know how good they are, success rates etc. and how they are funded
- Relaxed – as long as I felt I wasn't being referred for cost reasons
- This will only work for some services and needs to be regulated also it should not be the cheaper option

### **Other reactions**

- As long as I was confident that it was the best option available I would not mind. I would welcome the opportunity to research all the options and be able to select the best one for me whether that be NHS, private or charity
- Depends on the illness - minor, no problem, major - concerned
- Disgusted because why should charities do the work of the NHS?!
- Don't agree with it - the NHS should provide it. Charities are there to support, not provide treatment. The NHS shouldn't pile responsibility on to volunteers.
- Fine - they probably care more and have more experience - would need to be sure of the quality though
- Fine if it's non-medical
- I have no experience but would try it before I made a decision
- I would feel obligated to donate to that charity in future. I would also wonder why the NHS was not providing it. I would also worry about standards of the services and how they would be ensured.
- I would not let anyone other than myself decide on my care and would make a decision on the facts.
- I would rather have something that is NHS. A charity wouldn't be trained the same. I would possibly go if it was NHS approved
- I would want more information about the charity and what they offer - waiting lists, protocols use, diversity of the group, location
- I would want them to send me to the NHS except when the NHS doesn't offer the service e.g. Brook and BAPS
- I'd want the NHS due to past reputation. If the NHS is not available then charity would be OK
- If I needed it and it was quicker it would be okay
- It all depends how good they are - I wouldn't know anything about them. But I suppose anything is worth a try and you might get an appointment quicker
- It would depend on services and reason why
- It would depend on what the service was and who the charity was
- No bother if the doctor recommended them. The NHS should be getting more

money

- No different. If I need help it doesn't matter where I'm getting it from but it should be the NHS as we pay our taxes. But if unavailable on NHS, happy with charity.
- Would need to check it out
- Would prefer the NHS but would consider if there was a full explanation as to why the NHS couldn't provide it, or the charity could do it better

**If your GP prescribed, for example, exercise classes or talking therapies, do you think you would use those services?**

	<b>Number of respondents</b>	<b>% of respondents</b>
Yes	195	88.6
No	19	8.6
Not answered	6	2.7
<b>Total</b>	<b>220</b>	<b>100.0</b>

**If you answered 'No', why is this?**

- Too much time
- I can't do exercises as I have osteoarthritis
- I wouldn't have time to do my job (nurse in GP practice)
- Personal preference
- Not happy as this is privatisation of the NHS
- I would use my own
- Not a problem for me
- Cannot answer this question. Talking therapies may be relevant but exercise classes do not fall under healthcare even though they may help my present illness
- Because I can do all of this for myself.
- I have people I can talk to, have a good community so talking therapies wouldn't be needed
- I don't like them
- I prefer medication
- I might be scared at first, if it was different people
- I have taken part in these before and found them a waste of time