



COI, on behalf of Department of Health

How to be heard
Qualitative Research
Report of Findings

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CONTENTS

1.	BACKGROUND	3
2.	RESEARCH OBJECTIVES	4
3.	METHOD AND SAMPLE	5
4.	MANAGEMENT SUMMARY	7
5.	MAIN FINDINGS	11
5.1	Current context for <i>How to be heard</i> communications	
5.2	Awareness of channels	
5.3	Existing patient involvement channels	17
5.4	Encouraging potential future involvement	24
5.5	Contents	25
5.6	Tone and language	26
5.7	Delivery channels	33
5.8	Recommendations	34

APPENDIX: TOPIC GUIDE

1. BACKGROUND

The close of January 2009 saw the unveiling of a legally binding NHS Constitution – an innovatory measure that afforded patients legal rights in relation to healthcare for the first time. In celebration of this new benchmark initiative, the Health Secretary, Alan Johnson, commented:

“Since the NHS was founded in 1948, the public has never had such a clear, concise definition of their rights and responsibilities brought together in one place... I would be most surprised if this constitution does not become something people refer to over and over again.” (The Guardian, 21/01/09)

The constitution set out 25 separate rights for patients – from access to drugs approved by NICE to the right of parents not to vaccinate their children with certain immunisations. It represented a major shift in the dynamics of power between the National Health Service and its patients, with the latter now enjoying far more autonomy, but also a degree of responsibility.

Merely offering rights to patients is not, however, the extent of this new vision. The Constitution set out to engage with and respond to the nation’s needs and desires regarding healthcare, as David Pink, chief executive of National Voices, explained:

“It is no longer enough for the government to set funding, and for patients to be grateful for the care that they get from doctors and nurses. We need a service that listens and responds to the needs of the people it serves.” (The Guardian, 21/01/09).

The constitution is now in place and gives the public the right to be involved in the planning of NHS services, and for patients to be involved in decisions about their care.

The NHS is aware of its legal obligation to engage and consult with local populations. However, the public are largely unaware of the potential routes into engagement. The next step, however, is to ensure that, not only are patients clear about how to access these channels, but also that they are aware they are entitled to do so.

In order to address this issue the Department of Health have committed to producing a guide for the public, highlighting the various ways in which they can engage with the health and social care system. The purpose of the *How to be heard* guide is:

- To increase public awareness and understanding of the rights and how the NHS Constitution applies to all audiences
- To provide the public with accessible, engaging information on the ways that they can shape their own care and local health and social care services
- To empower all audiences to feel confident in how to use their rights

2. RESEARCH OBJECTIVES

The overarching objective was to explore the content and channels for the planned *How to be heard* guide. There were three main objectives:

- To gauge understanding and current awareness of existing information;
- To establish positioning and messaging: looking at three different levels of content and exploring reactions towards tone of voice;

- To consider all delivery channels: exploring as many channels as possible

3. METHOD AND SAMPLE

The approach was entirely qualitative and consisted of 10 extended focus group discussions (each of 2 hours duration, comprising 8 respondents).

The sample included members of the general public who were defined as 'well' and NHS patients. The sample is described in detail below.

- **extended focus groups (2 hours duration, 8 respondents) with 'well' members of the general public:**

- Mixed gender, 18-25, years old, no children, BC1
- Mixed gender, 26-39, family stagers – young children, BC1
- Mixed gender, 26-39, family stagers – young children, C2DE
- Mixed gender, 40-59, family stagers – older children, BC1
- Mixed gender, 40-59, family stagers – older children, C2DE
- Mixed gender, 60+, empty nesters/retired, C2DE

'Well' was defined as those who had all interacted with the NHS at least once in the past six months, but had not been seriously ill for a prolonged period in the recent past. Older respondents were all living independently.

- **2 extended focus groups (2 hours duration, 8 respondents) with patients with long-term conditions:**

- Mixed gender, 20-39, C2DE, mix of those with and without children
- Mixed gender, 40+, BC1, mix of those with and without children

The long-term conditions sample included those who were managing chronic conditions (for example, arthritis, diabetes, osteoporosis, COPD, psoriasis, epilepsy, inflammatory bowel disease, heart disease and asthma).

2 extended focus groups (2 hours duration, 8 respondents) with patients with recent experience of acute care:

- Mixed gender, 20-39, BC1, mix of those with and without children
- Mixed gender, 40+, C2DE, mix of those with and without children

The acute care sample included those who had recent experience of NHS acute care services, defined as at least a 24 hour stay in hospital within the last 3 months.

Respondents with very negative experiences of NHS services were excluded from the group sessions. Individuals with very negative experiences would be likely to dominate the sessions and bias the debate in an unproductive manner.

Ethnic representation was achieved across the general public and patient sample.

Our sample excluded those involved in patient groups or consultations.

Fieldwork was conducted between the 23rd and 26th November 2009 in Nottingham, Sutton, St Albans, Northampton and Birmingham.

4. MANAGEMENT SUMMARY

4.1 NHS Change

Patients are seemingly being encouraged to interact with the NHS because of the introduction of the NHS Constitution and greater patient choice in general. This change has made the public and patients more likely to want to voice their opinions. However, perceptions of the way in which decisions are still perceived to be made within the NHS – unchanging process, patriarchal relationships and the organization's questionable ability to listen and act – generates a spectrum of dissatisfaction, frustration and anger amongst patients.

The extent to which respondents wanted to become involved in decision-making was influenced by their level of experience of NHS services and their exposure to NHS change. Patients had more experience of NHS services and change and were, therefore, more willing to become involved in decision-making than 'well' respondents. Amongst the 'well', interest in becoming involved was influenced by attitude, with C2DE groups less interested in the NHS as a 'social concept' and therefore less altruistic in outlook than BC1 respondents.

In future, all were interested in having more involvement in their own care, with patients with long-term conditions the most motivated to become involved in decisions about care. Patients with experience of acute services were the most vocal because of their comparatively dramatic experiences and this segment was most actively interested in becoming involved in planning services.

4.2 Channels for involvement

Currently, patients typically give negative feedback (e.g. complaints) or informal positive feedback (thank you cards to NHS individuals or teams) but not official

positive feedback about NHS services. The 'well' segment does not give any feedback to the NHS, either positive or negative.

There was very little awareness of existing channels for interacting with the NHS. All believed that, if they wished to complain about – or comment upon – their NHS care, they would seek information about how to do this directly from local healthcare sources. Overall, it was apparent that respondents simply did not know *how* to start a dialogue with the NHS or find out how to do so – although there was an expectation that patient feedback options would be available if required.

As channels for interaction with the NHS, PALs, LINKs and NHS Choices were not familiar to a majority of respondents:

- PALs was seen as a channel for those with major issues and was seen as similar to an Ombudsman service. It was also perceived to be run on behalf of the NHS, not patients;
- LINKs was seen to be representing patients' views and lobbying in relation to local NHS issues. However, many were skeptical that LINKs could effect genuine change;
- NHS Choices was seen as a useful source of information about the quality of healthcare. However, online delivery alienated non-internet users (older and C2DE in particular).

Clearly there is a lack of knowledge about channels for feedback and involvement which needs to be addressed. However, this is not simply an 'information-only', awareness-raising exercise. The positioning needs to reflect a changing NHS. In order to encourage patients to interact with the NHS, *How to be heard* must:

- Communicate that the NHS welcomes patient involvement, both positive and negative feedback;
- Stress that all users of NHS services – regardless of background or experience – can contribute
- Encourage patients to participate in a process of improvement.

4.3 How to be heard content

All respondents felt that having their opinions and choices set out in a single document would be likely to encourage people to play a more active part in both decisions about local NHS services and their own care.

Reactions to the contents page were positive: it was seen as clear and easy to understand. Typically, respondents focused on sections that seemed relevant to their own life circumstances – so that *how to take control* and *how to have your say* were more interesting than *how to get involved*, as respondents could see themselves using this information in the future.

To encourage NHS users to participate in decisions about their own care and decisions about planning, the communication needs to preface the ‘how to’ information by explaining:

- *Why* patients involvement is important to the NHS;
- *What* can be contributed: i.e. both positive and negative;
- *How* their contribution will be actioned and valued by the NHS.

4.4 How to be heard tone and messaging

In relation to positioning and messaging, the persuasive tone had more impact and appeal amongst a majority of the sample. This approach, it was felt, was

friendly, engaging and relevant to a wide range of the public – giving the impression that the NHS is genuinely interested in soliciting the news of ordinary people. Conversely, the informative tone and language reflects an old-style NHS which is *informing* patients of their rights, but does not necessarily wish to *engage* them.

The paragraph was the most appropriate length of message and produced the most favourable response from a majority of respondents – giving enough detail to stimulate interest and action without offering unnecessary detail or off-putting, technical, language.

The paragraph in the persuasive tone has a strong conversational approach which combines a commonsense tone with some straightforward, directive, statements about the potential benefits of *How to be heard*. In future, avoid flippant colloquialisms (for example, 'right?')

4.5 Channels to promote and disseminate *How to be heard*

Patients had little doubt that they would be able to access *How to be heard* information during one of their visits to NHS services. However, promoting *How to be heard* through a broader set of channels was felt necessary for 'well' respondents, so that, in future, they are aware of the decisions they can make regarding their own care and how to become involved in decision-making.

It was felt that the *How to be heard* material should be made available through:

- Traditional NHS channels (such as GP surgeries and hospital waiting areas);
- But also more widely accessible via sources such as pharmacies, post offices, supermarkets and libraries.

When considering channels for promoting *How to be heard*, respondents typically supported a local, rather than national, approach, using local media such as radio and newspaper.

5. MAIN FINDINGS

5.1 Current context for *How to be heard* communications

Views about contributing to decisions about one's own care as well as decisions regarding local health and social care services were grounded in perceptions of how patients are currently expected to interact with NHS services.

5.1.1 NHS change

For all sample groups, the NHS remains an essentially 'local' phenomenon, represented by local structures such as GP practices, health centres, dentists and hospitals. Respondents were unable to articulate a coherent sense of the organisational development of the NHS. They tended to focus on service inconsistencies at a local level (e.g. differing appointment procedures at GP surgeries) rather than an overall vision of how the NHS has changed in recent years.

Analysis of responses to *How to be heard* demonstrates that there is a tension between the way in which patients are being encouraged to interact with the NHS and the way in which patients perceive that decisions are still being made within the NHS:

- On the one hand, the NHS is offering patients more choice and greater responsibility for decisions about care. This is encouraging patients (particularly younger patients with more recent experience of the NHS) to

adopt more of a 'consumer' mindset. They are therefore more likely to want to voice their opinions about NHS services.

- On the other hand, respondents perceived decision-making processes within the NHS to have remained largely autocratic. 'They' [the people who make decisions about NHS services] tell 'us' [service users] what services are available and how and when we can use them.

"You just accept what you get. How can we do anything about what the doctors say and do?" (General Public, C2DE, Family)

Overall, respondents described an essentially parent/child relationship, where the 'parent' figure [the NHS] was perceived to have questionable ability to listen to the 'child' figure [service users]. A spectrum of satisfaction with this status quo emerged, but included a number of resigned, frustrated and angry patients.

"It's being up against a hierarchy and not really knowing where you stand."
(General Public, BC1, Older Family)

5.1.2 Current involvement

Amongst the 'well', awareness of the right to be involved in decisions about care was limited to experience of patient choice (e.g. changing GPs and choosing hospitals).

Patients with long-term conditions were confident to shape their own care and challenge the views of health professionals where necessary.

Patients with experience of acute services had taken advantage of patient choice initiatives to select hospitals and prompt referrals.

At present, respondents had some difficulty envisaging what form 'patient involvement' might take. At present, perceptions of 'patient involvement' were narrow and polarised – either 'thanks' or complaints.

Thanks comprised 'thank you' cards, often given by patients to staff who had delivered care. Thus thanks tended to be offered informally to individuals or teams. Compliments were not offered to larger entities (e.g. services as a whole). Services were more likely to receive complaints from patients.

The source of feedback also tended to be biased. 'Well' people (i.e. those interacting with NHS services on a more ad hoc basis) did not tend to offer any feedback. However, many were keen to offer 'points', 'ideas' and 'thoughts':

"The repeat prescription process is crazy. I have to drive to the surgery to pick it up and hand it in. Why not have it sent direct or use text to alert me?" (Chronic patient, younger)

Overall, the language of 'patient involvement' was not familiar to respondents. *How to be heard* needs to communicate that the NHS values all types of feedback – both positive and negative – from all users of NHS services, regardless of experience or background.

5.1.3 Potential future involvement

The extent to which respondents wanted to become involved in decision-making was influenced by their level of experience of NHS services and their exposure to NHS change. 'Well' people had less experience of NHS services and NHS change – and were therefore less interested in becoming involved in decision-making. Patients had more experience of NHS services and NHS changes and were therefore more interested in becoming involved in decision-making.

When made aware of the rights and responsibilities established by the NHS

constitution, it was clear that most respondents focussed on potential involvement which might affect them personally (i.e. involvement in decisions about care, rather than involvement in planning health services):

"If I know I can make this or that choice then I'm going to. By knowing I have the choice and knowing the doctor knows it too then I'd be a bit more willing to suggest something else or challenge his treatment choice." (General Public, Pre-family, BC1)

Appetite for becoming involved in decisions about care was greatest amongst patients i.e. those who have most personal involvement with NHS services. Amongst the 'well', future interest in becoming involved in decisions about care was influenced by experience: older people were most interested since they had the most contact with NHS services. By comparison, there was relatively little interest in becoming involved in planning local health services. This type of involvement was perceived to be further removed from direct experience of NHS treatment – and therefore less personally relevant.

Amongst the 'well', potential interest in becoming involved in decisions about planning services was influenced by socio economic background. In general, C2DE groups were less interested in the NHS as a 'social concept' and were therefore less altruistic in outlook. By comparison, ABC1 respondents were more likely to evince interest in improving services for the benefit of all users:

"I wouldn't get in contact or involved in how they spend the money locally. I'm just not interested in that. Probably when I'm older, but not now. " (General Public, Pre-family, BC1)

Patients with long-term conditions were typically more motivated to become involved in decisions about their own care than become involved in planning services for the 'greater social good'. They tended to focus on their personal

circumstances rather than seeing themselves as part of a service user community.

Patients with experience of acute services were the most vocal amongst the sample in terms of offering ideas for service developments. Their appetite to voice their opinions stemmed from comparatively dramatic experiences of NHS services. It was this group that included individuals actively interested in becoming involved in planning services.

In summary:

- In future, 'well' respondents were interested in becoming involved in decisions about their care. There was very little interest in becoming involved in planning NHS services.
- In future, patients with 'chronic' conditions were also interested in becoming involved in decisions about their care. Although they lacked motivation to become actively involved in planning local NHS services on an individual basis, they expected that their views would be taken into consideration by those planning services.
- In future, patients with recent experience of acute services were most interested in becoming involved in planning NHS services, as well as becoming involved in decisions about their care.

5.2 Awareness of channels

There was very little awareness of specific channels for complaint or comment about NHS services. One respondent had been invited to become a trustee of his local hospital, while two others – both mothers of children with chronic conditions, and therefore familiar with the hospital environment – had heard of PALS. (However, neither could actually define the nature or purpose of PALS):

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“Can we telephone them? Is there a website?” (General Public, BC1, Older Family)

When asked, an assumption was made that there would be formal channels for complaints (e.g. ombudsman) or as in the ‘Katie’ case study when it was suggested she would need to contact her MP). A majority expected that patient feedback organisations would exist, but gave little or no consideration to the type of organisations that might exist:

“Yes it’s very important for a back up – if you can get the information to find out where and who they are.” (General Public, C2DE, Retired)

Help make the NHS a success

Kate has a young family and has used the local health centre for many years. She lives in a big town and likes the service because it is close by (she does not drive) and she knows and trusts the staff. Kate has heard from neighbours, who also use the centre, that it could be closed, along with several other local health centres, to be replaced by one big service in the centre of town. She feels quite strongly that this is wrong because it will be less convenient for her and her neighbours and they will not know the staff at the new centre.

All believed that, if they wished to complain about or comment upon their NHS care, they would seek information about how to do so directly from local healthcare sources such as GPs, hospitals or even NHS Direct! For example, discussion of the ‘Michael’ case study saw him asking for information from his GP surgery, simply because this was perceived as the ‘obvious’ place for patients to start their journey:

“That’s the first place I’d think to go.” (General Public, BC1, OlderFamily)

Taking control of your own care

Michael is 34. He has been feeling down for some time now and thinks he might be depressed so decides he needs to speak to someone. He has known people with depression who have been given anti-depressants and is concerned that he will be given them too. His GP surgery is busy and the doctors don't have much time with each patient, so Michael is worried he won't have enough time to properly discuss how he feels with his doctor.

Overall, it was apparent that respondents simply did not know *how* to start a dialogue with the NHS nor find out how to do so. A majority therefore believed that it will be important to promote the option to become involved in one's care and shape local NHS services, so that those with an inclination to do so can get involved more easily:

"Maybe older people would want to get involved. They have more time."

(General Public, Pre-family, BC1)

5.3 Existing patient involvement channels

The discussion of existing patient involvement channels was supported by written stimulus describing PALs, LINKs and NHS choices, as well as a range of materials publicising these channels. The stimulus is included in the text below.

5.3.1 PALs

PALs has been introduced to ensure that the NHS listens to patients, their relatives, carers and friends, and answers their questions and resolves their concerns as quickly as possible. Each PALS (local office) can provide you with accurate information about their Trust's services and other health related issues, using reliable sources. If you have a question about local health services or an enquiry about health matters, you can contact PALS.

Information it covers:

Provide you with information and help introduce you to agencies and support groups outside the NHS

Provide an early warning system for NHS Trusts and monitoring bodies by identifying problems or gaps in services and reporting them

Help resolve concerns or problems when you are using the NHS

Patient Advice and Liaison Services (PALs) were seen as a channel for those with a major issue or serious complaint and was likened to an ombudsman.

"You'd get involved when things are bad." (General Public, Pre-family, BC1)

Due to a lack of understanding of the service, PALs was perceived to be run 'on behalf' of the NHS – not for patients.

When shown the stimulus (please see box above), the key elements of communication were identified as:

- Provides you with information
- Provides an 'early warning system'
- Helps resolve concerns or problems

Respondents were also shown a leaflet publicising the PALS service from Salford Royal NHS Trust (please see electronic appendix file). First impressions were that the Salford Royal NHS Trust title overshadowed the PALS reference. As a result, the service was perceived to be a complaints service for patients at Salford Royal, rather than a larger network.

Although the language employed in the leaflet was generally considered clear, plain and informative, the *'voice your appreciation'* message was overlooked. As a result, the leaflet did not deliver the broader invitation to voice a full range of comments, whether positive, negative and/or suggestions for improvements.

5.3.2 Local Involvement Networks

Local Involvement Networks (LINKs) aim to give citizens a stronger voice in how their health and social care services are delivered. Run by local individuals and groups and independently supported - the role of LINKs is to find out what people want, monitor local services and to use their powers to hold them to account. To find out what is happening in your area, contact the department of your local council that has social services responsibility, or go online.

LINKs role is to:

- Ask what local people think about local healthcare services and provide a chance to suggest ideas to help improve services
- Investigate specific issues of concern to the community
- use its powers to hold services to account and get results
- Ask for information and get an answer in a specified amount of time

Local Involvement Networks (LINKs) were perceived to be representing patients' views and lobbying relevant organisations in relation to local NHS issues.

Although applauding these efforts in theory, many respondents were sceptical that LINKs would be able to effect genuine change. This scepticism was based on a feeling that there would be little patients could do to influence decision-

making within the NHS.

The key elements of the LINKs stimulus (please see box above) were identified as:

- Use their 'power'
- 'Local' people
- Get results
- Investigate

Overall, LINKs was of interest as an organisation that can deliver change. However, communications need to convince service users that LINKs organisations have been able to achieve service user inspired changes in the past:

"Have some of the improvements been as a result of patient feedback? Is there a history saying this is how it works? That would be a great selling point for the whole process?" (General Public, BC1, Older Family)

"The wording is very good, but it's whether they take any action over what people say is needed." (General Public, C2DE, Retired)

Respondents were also shown a sticker produced by LINKs, shown below:



The spontaneous reaction was that the sticker failed to communicate what LINKs is:

"Is it for the elderly?" (General Public, C2DE, Family)

It became apparent that, without prior knowledge of the organisation, the title failed to communicate a health focus. Respondents were not interested in the service since the sticker did not communicate any reason why they should.

Motivating elements of the LINKs leaflet material (please see electronic appendix file) included:

- To 'hear about your experience'
- To 'bring about changes'
- More about what LINKs achieves e.g. GP surgery changes, opening hours
- The four channels of involvement (pg8) are hidden, but are of interest
- 'Independent', 'run by the people' and key terms but are also hidden (pg 9)

Future suggestions for developing the content of a preferably shorter LINKs leaflet focussed on communicating a small number of key messages, namely:

- this is an independent organisation
- which provides everyone with an opportunity to 'have their say'
- remember, 'it's your NHS'

"I like the fact that it's independent and locally focused." (General Public, Pre-family, BC1)

Suggested channels for raising awareness of LINKs included: GP, surgeries, health centres, CAB offices, clubs and charities.

5.3.3 NHS Choices

NHS Choices is a comprehensive information service that helps to put you in control of your healthcare. NHS Choices provides a single 'front door' for the public to all NHS online services and information through the country's biggest health website.

Information it covers:

- Providing telephone numbers and full details for all the health services in your area
- Providing an unbiased and evidence-based daily analysis of the science behind health stories that make the news
- Comparing hospitals you might go to by various criteria covering such things as cleanliness, experience of a particular procedure and, in some cases, survival rates, through to car parking arrangements, general facilities, or availability of A&E departments

NHS Choices was perceived as a useful source of information about quality of healthcare services. Due to their lack of awareness of the different types of information available, some respondents were clearly disturbed by the presence of survival rates (which came as something of a surprise).

Whilst the content was broadly welcomed, as was the focus on key patient concerns, the lack of access to web-based information was a difficulty for a number of non-internet users amongst the sample (older and C2DE respondents specifically):

*"It looks like if you are not online, then you won't be able to make the choices!"
(General Public, C2DE, Retired)*

The key elements of the NHS Choices stimulus (please see box above) included:

- Information
- Comparing hospitals
- Cleanliness
- Survival rates
- Car park arrangements

5.3.4 Long-term conditions leaflets

Patients with long-term conditions had been living with their conditions for 5-10 Years. As a result, their condition had simply become 'part of life'. Typically, patients managed their conditions by maintaining treatment and check-up routines. Whilst none had an explicit 'care plan', all felt that they had clear guidelines and advice for managing their condition.

When asked about sources of information, patients focused on discussions with members of their healthcare team during regular monitoring sessions. Re-evaluation of their condition was more common amongst BC1 respondents, and tended to be prompted by changes e.g. new symptoms or new information.

The leaflets discussed (please see electronic appendix file) were felt to target newly diagnosed patients - '*Have you got a care plan*' in particular. '*Help and advice for living well*' was considered useful at the diagnosis stage. However, once past the diagnosis stage, the content was felt to be too general and not specific enough to particular conditions.

The channels suggested for disseminating the long-term conditions leaflets included specialist health professionals (e.g. diabetic nurse, consultants), condition specific charities and online.

5.4 Encouraging potential future involvement

Clearly, there is a lack of knowledge about the channels which patients can use to provide NHS services with feedback. This lack of awareness needs to be addressed. However, this is not simply an 'information-only', awareness-raising exercise.

The positioning of the campaign needs to reflect a changing NHS which patients expect should:

- welcome patient involvement;
- value patient feedback as part of an ongoing dialogue;
- encourage patients to participate in a process of improvement.

"It needs to capture our imagination." (General Public, BC1, Older Family)

In order to do so, there are a number of barriers which need to be addressed:

1. Firstly, service users need to be reassured that their participation will be worthwhile. Common questions included: *Will they [the NHS] listen? Is anything going to happen? Is it worthwhile?* To encourage involvement, the NHS needs to demonstrate that they are listening and fully appreciate the benefits of patient involvement in terms of improving services.
2. Secondly, service users need to be reassured that their views are valued. There are no qualifications or criteria which would make them a more or less useful participant. A common question was: *Surely we don't know enough in order to participate in decision-making?* To encourage feedback, people will need to understand *how* they are contributing i.e. that they are part of a process of informing decisions

"People are paid lots of money in order to make informed decisions." (General Public, ABC1, Older Family)

3. Thirdly, service users may be reticent to offer feedback, particularly if nervous about the feedback they wish to offer. In short, many lack willingness to feed back and some patients will be nervous about doing so. For example, some respondents (both patient and well) were uncomfortable confronting NHS staff with critical feedback. To encourage feedback, people will need access to support – an ‘intermediary’ with whom they feel comfortable. This support needs to be publicised as part of the communication.

5.5 Contents

All felt that having their options and choices set out in a single document would be likely to encourage people to play a more active part in decisions about local NHS services or their own care.

Overall, reactions to the contents page were positive – the section headings were clear and easy to understand:

“The headings make it easier to go to the section I want to go to.” (General Public, Pre-family, BC1

Typically, respondents focussed on sections that seemed relevant to their own life circumstances:

- For example, *‘how to take control’* and *‘how to have to have your say’* were more obviously interesting than *‘how to get involved’* (which most saw as an unlikely scenario);
- Sections such as *‘how to choose you GP’* and *‘how to choose which hospital you would like to be referred to’* were an obvious focus, since respondents

could see themselves actually using this information.

To encourage NHS users to participate in decisions about their own care and decisions about planning services, the communication needs to preface the 'how to' information by explaining the context for the invitation:

- Firstly, service users need to understand *why* patient involvement is important to the NHS. Patient involvement will improve decision making in terms of individual treatment and planning local services, which will benefit the whole NHS;
- Secondly, service users need to understand *what* to contribute (i.e. BOTH positive and negative comments on any issue, large or small);
- Thirdly, service users need to be convinced that their contribution *will* be valued by the NHS. The best way of doing so is to demonstrate some positive outcomes which have been informed by patient involvement.

5.6 Tone and language

The persuasive tone was consistently the most appealing. It was preferred by a majority for whom it was friendly, accessible, engaging, human and relevant. The 'commonsense' style strongly appealed to lower SEG respondents in particular.

"This one (persuasive) makes me think they actually want our opinion but this one (informative) just says the facts, like they've put it out there, done their bit but aren't really interesting in promoting it to us." (General Public, Pre-family, BC1)

The informative tone was more formal or distant, and was most suited to communicating legalities. Therefore it worked best in the short message setting

when it communicates quickly and simply. Generally however, this tone is likely to discourage reading, particularly amongst less literate sections of society:

*"You have the right....it's very dry and doesn't really make me want to read on."
(General Public, Pre-family, BC1)*

For some, the legal emphasis implied that *How to be heard* was about complaints:

"Reading between the lines, it seems as if this is for people who have a problem, an axe to grind." (General Public, BC1, Older Family)

5.6.1 Informative tone – short

*"Did you know that you have a **legal right** to be involved in discussions and decisions about your **own healthcare** - and to be involved in the planning of health and social care services for **your area**?"*

Overall, the 'informative' tone was perceived as sounding 'political'. By this respondents meant that they felt it sounded like a 'typical' piece of government communication regarding the NHS.

The brevity of the statement did not encourage respondents to engage with the communication; nor did the use of the term 'legal right' which conferred a sense of unfriendly formality.

More positively, the focus on the personal and local (as in 'your own healthcare' and 'services for your area') was well received.

5.6.2 Informative tone – paragraph

The new *NHS Constitution* sets out your rights in relation to healthcare including the *right to be heard*, whether it's about your own healthcare or local health and social care services. In particular:

- You have the right to be involved in discussions and decisions about *your healthcare* and to be given the information you need to support this
- You have the right to be involved in your *local health service* and *have a say* in how health and social care services are planned and delivered

Currently, the bullet points failed to clarify how the 'right to be heard' will work. Once again, the text focuses on informing us about our rights, but not how to do so (which proved frustrating for readers). This lack of clarity suggested to some that the NHS is not genuinely concerned about patient opinions.

However, the focus on 'speaking out' very much appealed, for example, your 'right to be heard' and to 'have a say'.

5.6.3 Informative tone – full page

These rights give you a voice in everything from consultations with your GP to major decisions about the future of health and social care services in your area. They can help you to **take control** of your own healthcare, **have your say** about how services are run, or make the NHS better by **getting involved**

A number of positive phrases were noted in the full page example, once again those which pursued the popular theme about 'speaking out'. Well received phrases included: 'take control', 'getting involved', 'give you a voice' and 'have your say'.

Take control of your healthcare

You have the right to be involved in decisions about *your treatment* and to receive the information to help you do this. By asking the right questions of your doctor, you will get more out of your GP and hospital consultations, so you can be happy that your treatment is right for you. *But if you aren't happy, remember you have the right to move your GP, or to choose a different hospital.*

Patients were focussed on 'having their say' and influencing outcomes in their favour. Therefore, some were annoyed about the sentence '*But if you're not happy, remember you have the right to move GP*'. This, they felt, implied that the NHS was ignoring patient concerns and simply recommending that they move GP rather than resolving their difficulties with a particular GP:

"Why don't they ask for our thoughts, ask us to let them know we're unhappy rather than just say go somewhere else?" (Chronic patient, BC1)

Have your say

You have a right to have a say about your own healthcare and about local and health and social care services. That includes the right to make a complaint about your treatment, rate your doctor or hospital, *suggest an improvement* or simply comment on the care you've received. You can find advice and support to help you make your voice heard on the NHS Choices website, from the NHS Patients Advice and Liaison Service (PALS), Patients' Opinion and the Independent Complaints Advisory Service (ICAS).

Although providing greater detail about how people can become involved in decision-making, the text does not appear to contain many references about feeding back positives (apart from '*suggest an improvement*').

"Surely this is all about improvement and moving forward." (General Public, BC1, Older Family)

5.6.4 Persuasive tone – short

“You wouldn’t have your hair cut without giving an opinion. So why not have a say in your healthcare? Whether it’s about your own treatment or your local health and social care services, you have a right to be heard.”

The short paragraph was very poorly received. Respondents described the style of this opening as ‘marketing’, and ‘spin’. The use of the rhetorical question, especially the use of the hair cut example was strongly felt to trivialise the issue:

“They’ve been paying someone not enough money to build this marketing campaign.” (General Public, BC1, Older Family)

5.6.5 Persuasive tone – paragraph

“Nothing’s more important than your health, right? So why keep quiet about it? Under the new NHS Constitution, you have a right to be heard, whether it’s about your own treatment or your local health and social care services.

This guide is full of information and contacts to help you do just that – for example, it will:

- help you ask the right questions of your GP or hospital doctor*
- tell you how to let us know when things go wrong, or if you have an idea to improve the service, and*
- enable you to get involved in shaping health or social care services in your area.”*

robably the most effective option overall. A strong, conversational approach (e.g. ‘Nothing is more important than your health’) combined a persuasive, commonsense tone with some straightforward, directive statements about the potential benefits of *How to be heard*.

Once again, any attempts to be casual or colloquial were rejected (e.g. ‘right?’). However, the paragraph offers clear ways of becoming involved, for example,

the guide is described as 'full of information and contacts' and it promises to 'help us ask the right questions'. This paragraph therefore suggests that the guide will be useful and therefore is most likely to prompt interest in finding out more about the *How to be heard* initiative.

5.6.6 Persuasive tone – full page

As discussed above, the tone of the opening paragraph was considered appropriately chatty and friendly. Respondents also appreciated the use of headings to break up the text and provide clear navigation.

Your right to be heard extends from the doctor's surgery to your Primary Care Trust (PCT). It gives you a voice in everything from GP visits to the big decisions about services in your area. It can help you take control of your own healthcare, have your say about how services are run, or make the NHS better by getting involved

The opening of the second paragraph reverts to a serious, formal tone by referring to 'rights' which was considered unnecessary. However, a number of phrases were noted for their positive contribution to this paragraph: there are a number of references to 'having one's say' which very much appealed.

Take control of your healthcare

Don't be afraid to ask questions about your healthcare or say how you feel about it. Not only will this give you more control, it will help your doctors to provide a better service. Remember, you have a right to make decisions about your treatment and to get the information you need to do this. And if you aren't happy, you have the right to move your GP, or to choose a different hospital.

This paragraph successfully introduced the idea of 'rights' in a more conversational manner: "remember, you have a right ... And if you aren't happy, you have the right ..."

The final two paragraphs ('Have your say' and 'Get involved') provided too much

detail for the less interested groups (general public respondents and particularly those from C2DE audiences).

Have your say

Don't keep it to yourself. You have a right to have your say whether you want to make a complaint about your treatment, rate your doctor or hospital, suggest an improvement, or simply say thank you for the care you've received. There's plenty of advice and support available to help you make your voice heard, from the NHS patient advice service PALS to the independent complaints service, ICAS.

Get involved

The NHS belongs to all of us. That means more than the right to free medical treatment. It means the right to be involved in the big decisions that shape your health and social care services. It's easy to get involved - for example, you can join your Local Involvement Network (LINK). These are groups of local people and organisations with the power to influence big NHS decisions and hold service providers to account. You can also apply to join the patient or service user group that advises your local Primary Care Trust or become a member of an NHS Foundation Trust – full details inside.

In future, consider a brief paragraph on each with contact information for LINKs, PALs and NHS Choices for those who are more interested to pursue.

5.6.7 Messaging: conclusions

The paragraph was the most effective option overall and was seen as likely to prompt interest in finding out more about the *How to be heard* initiative. The 'persuasive' tone and language reflects an NHS which welcomes and values patient feedback. The 'informative' tone and language reflects an old-style NHS which is informing patients, but does not really want to engage with them.

5.7 Delivery channels

Spontaneous views about how the materials should be disseminated focussed on traditional NHS-based channels (i.e. GP surgeries). Patients had little doubt that they would be able to access the leaflet during one of their visits to NHS services:

“They should just tell us when we’re in the hospitals or doctors because we’re in the right mindset for that type for thing.” (Acute Patient, Older, C2DE)

Since awareness of existing patient feedback channels is so low, LINKs and PALs were considered to offer limited opportunities for dissemination.

‘Well’ respondents were conscious that, for much of the time, they have little contact with the NHS. They realised that disseminating *How to be heard* material solely through GP surgeries and hospital waiting areas might not be effective. Promoting *How to be heard* information via non-NHS channels was therefore considered appropriate for ‘well’ respondents so that they too would know how to take control of their care and become involved in decision-making in future.

It was suggested that the leaflet could be made available through:

- pharmacies
- libraries
- supermarkets
- post offices
- as well as ‘traditional’ NHS channels

Both patients and 'well' felt that promotion via services would need to be supported by local media coverage to drive basic awareness. As a result, both patients and 'well' suggested using local radio and press to alert people that more info is available.

All believed that a leaflet format would be required in order to deliver the detail necessary for understanding and actioning the *How to be heard* principles.

There was an assumption that more info would be available via the internet.

Only a minority suggested national TV coverage or a national door-drop of the leaflet which was seen as less appropriate for encouraging involvement in local services.

5.8 Recommendations

- To reflect a changing NHS, the positioning of *How to be heard* should reflect an NHS which welcomes patient involvement, values patient feedback as part of an ongoing dialogue and encourages patients to participate in a process of improvement.

- The barriers that need to be addressed are not only to promote the channels for involvement which already exist, but also:
 - to explain why patient involvement is worthwhile;
 - to demonstrate that the NHS will listen and learn from patient involvement;
 - to support people to become involved (which will include independent sources of support to encourage people to voice complaints).

- In relation to positioning and messaging, the persuasive tone had more impact and appeal amongst a majority of the sample. This approach, it was felt, was friendly, engaging and relevant to a wide range of the public
 - giving the impression that the NHS is genuinely interested in soliciting the

views of ordinary people.

- The paragraph was the most appropriate length of message and produced the most favourable response from a majority of respondents – giving enough detail to stimulate interest and action without offering unnecessary detail or off-putting, technical, language.
- It was felt that the *How to be heard* material should be made available through traditional NHS channels (such as GP surgeries and hospital waiting areas) as well as more widely accessed sources such as pharmacies, post offices, supermarkets and libraries.
- When considering channels for promoting *How to be heard*, respondents typically supported a local, rather than national, approach – using local media such as radio and newspapers.

J. 1738 Department of Health: How to be heard

Topic guide (draft 2)

1. EXPLANATIONS (5 minutes)

- Introduce self and RWL, an independent research agency
- Explain that Research Works Limited has been commissioned on behalf of **Department of Health** to conduct research amongst the general public and patients
- The aim of the research is: *to ask the public about the idea of being involved in the planning of NHS services, and for patients to be involved in decisions about their care.*
- Ask permission to record the session, explaining that the recording will only be used for Market Research purposes only (Data Protection Act)

2. INTRODUCTIONS (10 minutes)

- Respondents to introduce themselves:
- Working/family status
- Current health status and involvement with NHS services. *Probe: which services have you used in the past 12 months? When? For whom – your or your children?*
- **FOR PATIENTS ONLY:**
- What types of NHS services do you use?
- Which services do you use relating to your specific health conditions?
- How often do you use these services?

3. CURRENT AWARENESS OF INFORMATION (10 minutes)

Introduce the idea that we are keen to learn how much you know about the NHS and the ways in which services are developing - and how you might wish to be involved in that process.

- What do you see the NHS comprising of?
- Could you describe the ways in which you would **approach the NHS locally**? (*PROBE: GPs, A&E, Health Centres, pharmacies, walk-in centres, polyclinics, minor injuries units etc*)
- In what ways has your interaction with the NHS developed over the past couple of years?
- Have you noticed much **change or development within your local NHS** services recently? If so what? (*PROBE: availability, ease of access, range of services*)
- What would you *like to see* change within your local NHS services?
- Overall, do you feel like the **NHS is a changing entity**?
- If so, in what ways do you feel it is changing? What's better, what's worse?

4. INFORMATION AUDIT (10 minutes)

Thinking specifically about how patients engage and become involved in the shaping of NHS services and how patients become involved in decisions about their care.

- What type of information would patients need to become more involved in the NHS? Why do you say that? Why would that be important?
- **Group to break into syndicates and spontaneously list possible sources for information.** *Probe: Google search, health websites,*

Research Works Limited 37

direct.gov, face-to-face, GP surgeries, libraries, CAB, charities, local radio, hospitals, other?

- **WRITE ON CARDS AND GET GROUP TO GROUP ANSWERS TOGETHER BASED ON CATEGORIES THEY DEEM TO BE IMPORTANT E.G. EASE OF ACCESS, CREDIBILITY?**
- Which sources do you believe would deliver what type of information? Why do you say that? *Probe factors such as: credibility, practicality, accessibility*
- When was the last time you picked up a leaflet/spoke to someone/searched the internet for information about health services (stress about services not care)? How effective was that channel?
- What organisations are you aware of that help patients engage with NHS services? *Probe: if known, which ones are known?*
- *If no organisations known:* Do you think organisations to help the public and patients become more involved in NHS services exist? How important is it to have organisation for patients to be able to comment and get involved in the development of their services and care? Why?

- ***Prompted understanding*** – introduce established channels and organisations PALs, LINKs, NHS Choices and local initiatives (**stimulus 1**):

Patient Advice and Liaison Services (PALs) has been introduced to ensure that the NHS listens to patients, their relatives, carers and friends, and answers their questions and resolves their concerns as quickly as possible.

Local Involvement Networks (LINKs) are organisations there to influence how health and social care services are planned and delivered by listening to patients and the public.

NHS Choices is a comprehensive information service that helps to put you in control of your healthcare. It is a NHS online service and information site that covers many areas of information.

Probing issues such as:

- have they heard of them?
- if so, what have they heard?
- what do they think they do?
- who is involved in this organisation?
- what is their purpose?
- would they be inclined to use these channels? Why/why not?
- what would encourage you to seek advice from these channels? *Probe: Knowing more about what they do? Who they are? How easy it is to get in contact with them?*

5. SCENARIOS – Stimulus 2 (15 minutes)

I would like to introduce 3 examples of patient situations and for each one I would like to discuss how the patient could ideally deal with their situation. Such as, where would they go for help, how would they go about getting their preferred outcome?

Ask for each scenario:

- What would you expect (scenario name) do in this situation?
- Ask group to tell the story of the person in the scenario – how would he/she deal with the situation?
- What would they do first?
- If nothing, why is that? What might prompt them to do something?

Research Works Limited 39

- Imagine they do take steps towards getting a favourable outcome, how would they approach it? *Probe: search the internet, speak to someone, read literature?*
- Where would they go? *Probe: local sources, google, family or friends?*
- After the first contact, what would they do next? What might put them off continuing to engage and get the outcome they wish?
- What might encourage them to take more control of decisions about their own care – both physical and mental health?
- What would help someone to become an equal partner in terms of their relationship with their GP? *Probe: Where would they search to find out more about talking more control? What would help them towards developing a more equal relationship?*
- What might encourage the person to become involved in shaping patient services? Refer to PALs, LINKs and NHS Choices
- Overall if you experienced a situation like these scenarios, what would you do:
 - Where would you go for information?
 - What would encourage you to become involved more consistently in shaping an equal relationship with your GP?
 - What would encourage you to become involved more consistently in shaping other NHS services?

6. POSITIONING AND MESSAGING (40 minutes)

The NHS Constitution gives the public the right to be involved in the planning of NHS services, and for patients to be involved in decisions about their care. The next section is to discuss how the NHS could best highlight the various ways the public could engage with NHS services. It is the first stage of developing this

communication called 'How to be heard' and we have some different examples of how they could publicise the various channels/ways of involvement

- How do you feel about the NHS providing patients with How to be Heard information? Would this be useful? If yes, why? If not, why not?

There are three messages, each more detailed than the last. There are two versions of each message with differing tones: informative vs. persuasive.

Stimulus 3: Informative tone messages (short 3A, paragraph 3B & page 3C)

Stimulus 4: Persuasive tone messages (short 4A, paragraph 4B, page 4C)

FORMAT A: Short Message

- What are your initial reactions to this approach? Why?
- Does this approach interest you? Why/not?
- What specific wording is appealing/unappealing here?
- **Get respondents to tick and cross words that are appealing and unappealing. Sort words in order of level of appeal.**
- Is this message credible – either regarding rights, services or involvement? Why/not?
- What elements are you already aware of? And what is new?
- Does this idea affect your perceptions of the NHS in anyway? If so, how? Does it change your relationship with the NHS? If so, how?
- Does it communicate to you that there are channels for greater involvement with the NHS?
- How would you change or alter the language within this message?

Research Works Limited 41

- If a person was speaking these words how would they sound? How would you describe the tone of voice? Is it appropriate? Why/not?
- What improvements would you suggest to strengthen this approach?
- How do you feel about the call to action? Would you be likely to follow this up? Why/why not?

FORMAT B: Single Paragraph

- What are your initial reactions to this approach? Why?
- Does this approach interest you? Why/not?
- What specific wording is appealing/unappealing here?
- **Get respondents to tick and cross words that are appealing and unappealing. Sort words in order of level of appeal.**
- Is this message credible – either regarding rights, services or involvement? Why/not?
- What elements are you already aware of? And what is new?
- Does this idea affect your perceptions of the NHS in anyway? If so, how? Does it change your relationship with the NHS? If so, how?
- Does it communicate to you that there are channels for greater involvement with the NHS?
- How would you change or alter the language within this message?
- What do you think about the length of the text – too much/too little? Why do you say that?
- If a person was speaking these works how would they sound? How would you describe the tone of voice? Is it appropriate? Why/not?
- What improvements would you suggest to strengthen this approach?

FORMAT C: Single side of A4

- What are your initial reactions to this approach? Why?

- Does this approach interest you? Why/not?
- What specific wording is appealing/unappealing here?
- **Get respondents to tick and cross words that are appealing and unappealing. Sort words in order of level of appeal.**
- Is this message credible – either regarding rights, services or involvement? Why/not?
- What elements are you already aware of? And what is new?
- Does this idea affect your perceptions of the NHS in anyway? If so, how? Does it change your relationship with the NHS? If so, how?
- Does it communicate to you that there are channels for greater involvement with the NHS?
- How would you change or alter the language within this message?
- What do you think about the length of the text – too much/too little? Why do you say that?
- How would you describe the tone of voice? Is it appropriate? Why/not?
- What improvements would you suggest to strengthen this approach?

Having seen all three communication approaches (with 2 different tones):

- We discussed three levels of information, which level is most appropriate and why?
- Which tone of voice do you prefer? Why do you prefer this tone of voice?
- Which is most likely to encourage you to become involved in planning and decision making NHS services? Why?

7. CONTENT (10 minutes)

Explain to respondents that the How to be Heard communication is not yet decided. This lists the areas How to be Heard would cover, like a table of contents or menu

Introduce the contents page (stimulus 5).

- Is covering all these areas appropriate?
- What are the most important ones to you? Why is that?
- What are the least important ones to you? Why is that?
- Why should it be included in a communication like this?
- What type of information would you expect to see included in this section title? Why is that type of information important?
- Should it be all covered in one format? *Probe: what type of format – leaflet, flyer, booklet, poster?*

8. COMMUNICATION DELIVERY (15 minutes)

Explain that we want to explore ideas for how the How to be Heard communication might be delivered, looking at the most relevant and suitable channels.

- Where would you place the How to be Heard information? *Probe: refer to our scenarios and prompt if necessary*
- Rank channels: which channel is most likely going to reach the most people? Why that channel?

Show respondents the DH patient communication channels (stimulus 6) to aid with discussion of suitable channels:

Which of these channels would be the most suitable for you to be informed about becoming more involved in your local NHS and your rights as a patient?

- What is the strength of the channel? What is the weakness?

- **Can we rank these channels into those most likely to be successful (credible, accessible, encouraging)?** Moderator: use cards with each channel written on it to rank the channels in order – include any additional channels suggested by respondents.
- If an information campaign were to go ahead – how should this communication idea be delivered? (*PROBE: door drop, radio, television, local press etc*)
- Would a national or local campaign be more appropriate for you? Why do you say that? *Probe: is it important for the information to be tailored to local initiatives?*

9. SUMMING UP (5 minutes)

Overall, we have discussed the idea of How to be Heard communication, which aims to highlight the various ways you can engage with NHS services:

- How important is it to raise awareness of the different ways of involvement?
- What has been the most interesting/useful and least interesting/useful elements of our discussion?
- Overall, what are we saying about the content of the draft material shown? What are the good and not so good elements?
- Overall, what are we saying about the language used?
- Overall, what are we saying about the tone of voice?
- Which style of message is preferred?
- What format should the information be presented in? Leaflet, guide, flyer, poster
- Finally, how should the communication be delivered? Probe: local health venues, on-line, call centres, local church groups, local patient organisations, CAB?