



**National Voices**

People shaping health  
and social care

# National Voices

## **NATIONAL VOICES' RESPONSE TO THE CONSULTATIONS:**

**'Liberating the NHS: An Information Revolution', and**

**'Liberating the NHS: Greater Choice and Control'**

### **About National Voices**

National Voices believes in people shaping health and social care. It is a coalition of health and social care charities and speaks on behalf of its members and of the millions of patients, carers and social services users they represent. It works to ensure that patient voices are heard and that they influence decisions at national level.

National Voices has responded to previous consultations in the 'Liberating the NHS' series.

### **About this submission**

At the suggestion of its members, and bearing in mind the interrelationship of the subject matter in these two consultations, National Voices has chosen to respond via a single submission which will be sent to both consultation teams.

This submission is informed by extensive consultation with National Voices' membership. All members have been offered the opportunities to:

- comment on the strategy for the response
- see an initial discussion paper suggesting areas of focus
- join an ad-hoc policy working group on the consultations
- comment on and contribute to the submission.

A priority-setting workshop was held with National Voices' Advisory Group and the Department of Health.

A live online consultation was held with individual members of our Service User Panel.



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The ad-hoc policy working group established among the members enabled policy specialists to comment in detail on drafts, and to share their own emerging submissions.

Among the organisations which have directly contributed to this submission are:

Asthma UK, AvMA, Polycystic Kidney Disease charity, British Heart Foundation, Stroke Association, the National Rheumatoid Arthritis Society, Mind, Macmillan Cancer Support, Breakthrough Breast Cancer, Motor Neurone Disease Association, Terence Higgins Trust, Epilepsy Action, Cancer Research UK, and the Patient Information Forum.

We have drawn quotes from some of these contributions, which are used throughout this submission, indented in italics.

**Note:** All views in this submission are the consolidated position of the National Voices coalition as a whole and should not be attributed to specific member charities (except where directly quoted). Many of our members will be submitting their own responses to the consultations.

## OVERVIEW

### Principal Focus of this submission: integrating information with supportive care and treatment

'Information', 'choice' and 'control' cover a very wide canvas, and have generated 88 consultation questions, of which many are in turn wide-ranging.

#### Clear priorities required

National Voices would urge the government to **set clear priorities** within these fields, to enable its information, choice and control strategies to have real impact. In our view, these priorities should be in line with the Vision of 'putting patients first' set out in the White Paper, 'Liberating the NHS'.

Thus the focus of these strategies should very clearly be on the choices -- and the information to inform choices and decisions -- that patients and service users, their carers and families say are *most important to them*.

#### Welcoming provider choice, and data publication

There are many different kinds of choice in health and social care, and many points along the patient's journey where decisions must be made. Indeed, patients with long term conditions are making choices every day, with or without their healthcare professionals.

Most of these choices have *some* importance to patients and service users.

We commend the choice 'offerings' set out in the 'Greater Choice and Control' consultation (including choice of provider, choice of consultant-led team, and choice in maternity, mental health, end of life care and long term conditions). Patients and service users, their carers and families will value such choices and take them seriously, and we look forward to their further development.

Likewise we welcome the government's commitment to the publication of all available relevant quality data. However, we welcome this because of the potential effect it can have on the behaviour of *commissioners and providers*, rather than of patients and service users. So far, most evidence suggests the effect on the latter is marginal.

#### But these are second order priority

Choices of provider or location – and the data to support these -- are a *second order priority* for patients and service users. The choice and control which is *most important* to people is in relation to living with their health status and conditions, and deciding on the course of care and treatment in which to participate.

This conclusion is supported both by published evidence and by the experience of our member charities as providers of support and information to millions of people.

#### 'No decisions about us' is top priority

Therefore when we asked our members and advisors where to focus this response they agreed that it should focus on the information required for achieving:

- participative, personalised care planning for long term conditions
- shared treatment decisions
- supported choice along patient pathways.

Summarising this, our Advisory Group, asked to prioritise among the 88 consultation questions, voted in the largest numbers for a *new* question which is not found in the documents:

**Q: How do we ensure information provision is integrated into care delivery?**

*“We believe it is vitally important that there be a focus on providing information within the delivery of care and treatment. This includes appropriate and accessible advice and information at initial diagnosis, referral and treatment. The provision of information should be something built in to the standard medical consultation, and into the care-pathway of all conditions.”*

Epilepsy Action

Implications

This focus on integrating information with choice and control in ‘every day’ care carries the following implications:

- the government should beware of placing undue emphasis on data systems and the information sets required for making choices of providers – these are *not* the highest priority for patients and service users
- the key location for effective information exchange, and participation in decisions, is in the *consultation* – the communication between patients and service users and their health and care professionals
- intensive efforts should be directed to:
  - a) changing the professional behaviours of clinicians and care givers towards partnership with, and the participation of, the people in their care; and,
  - b) helping, supporting and educating patients, service users, and their families and carers to understand and *make active use* of information in their day to day health and social care decisions – the ‘sheer provision’ of information is not effective or adequate
- decisions about care and treatment, and the information to support them, should be integrated around the patient.

In short, while ‘information, choice and control’ may appear initially to require new, bespoke strategies, the experience of patients, service users, their families and carers with whom our member charities are in contact leads us back to our recurrent concerns with:

- health literacy
- patient activation
- integrating health and social care, and

- ending paternalism.

### Additional issues

*Transparency:* in addition to publishing quality data, the NHS must further ensure transparency through its organisations holding board meetings in public, making information publicly available, and being publicly accountable. We further reiterate our support for a duty of candour to ensure mistakes are publicly known.

*Patient access to records:* we strongly welcome the government's policy here and look forward to rapid roll-out, on two conditions: a) that there are safeguards to protect the privacy of vulnerable people, and b) that patients can change their records as their preferences change; to correct inaccuracies; and to remedy omissions. There needs to be a dispute resolution procedure in the event, for example, of a disputed diagnosis.

*Standards for patient records:* if the patient record is to be the basic unit of data from which data sets are drawn upwards, it is vital that they are designed clearly to record patient needs, values and preferences (such as their attitudes to treatment risks), and to hold their personalised care plans.

*NHS Choices and the Information Standard:* NHS Choices continues to have the potential to be a one-stop signposted information service for patients and service users. The Information Standard has the potential to reassure patients and the public about the trustworthiness of information providers. There is strong support from our members for the government to recognise the potential of these interventions and to build them explicitly into its information strategy.

*Signposting:* patients, service users, carers and their organisations are exasperated by the persistent failure of the NHS to signpost people to other relevant sources of support, care and advice. Their frustration is especially focused on GPs as gatekeepers. While integrated care and personalised care planning may develop in the longer term, they want the government to consider as a matter of urgency what can be done to remedy this deficit.

## RESPONSES TO THE CONSULTATION QUESTIONS

### From 'An Information Revolution'

**Q1: What currently works well in terms of information for health and adult social care and what needs to change?**

*and*

**Q2: What do you think are the most important uses of information, and who are the most important users of it?**

National Voices argues that, on the basis of published evidence, and of the experience of patients, service users, their families and carers with whom our members have contact, the government should focus most attention on integrating information with the delivery of care and treatment, with particular emphasis on information:

- along patient pathways
- for shared treatment decisions
- for participative, personalised care planning

To support this case, we will use this Question 1 to establish the evidence with particular reference to these areas.

### EVIDENCE

#### *Current situation: general*

A large majority of patients (80%) actively search for information on health and social care. Three quarters cite their doctor as the most important source of health information, but many other sources are also used. For example, a third go to the internet, and a quarter look for information in leaflets and books. A wide variety of other sources are also used, including other professionals, family and friends, the media and patient organisations<sup>1</sup>.

There is already very widespread provision of 'patient information' in England. The market consists of public sector, private sector and Third Sector organisations totalling tens of thousands: a 2006 study suggested around 60,000 at that time<sup>2</sup>.

However, there are significant gaps in the available information at the point of care. The majority of the information is clinical or medical in nature, providing factual information about specific illnesses or conditions and the available treatments. This is necessary, but needs explaining to patients.

Clinicians tend to over-estimate the amount of medical information patients require, and may over-provide it, but are often less aware of their other information requirements.

<sup>1</sup> *Assessing the quality of information to support people in making decisions about their health and healthcare*, Coulter A, Ellins J et al, Picker Institute Europe, 2006

<sup>2</sup> *ibid*

Clinicians and policy makers usually think patients need mainstream medical information, such as the facts about a disease, but patients may be more interested in treatment options and their probabilities of success, or prognosis, or how to get support to manage their condition<sup>3</sup>.

Notably, the 2006 study concluded that while patients may be over-supplied with medical information, this was rarely presented in a way that enabled them to assess and participate in treatment choices:

“Few materials included a clear presentation of the likely outcomes of treatment, few mentioned clinical controversies or uncertainties, and many failed to acknowledge the patient’s decision-making role.”<sup>4</sup>

Patients from various condition groups report that there are often gaps or deficiencies in the following types of information:

- the financial effects of illness, and sources of benefits or help
- the social effects of illness, and sources of support
- the emotional effects of living with a condition, and how to cope with them<sup>5</sup>.

*“In our experience, the area in most demand (and also often most neglected) is the social and lifestyle impacts of a condition.”*

#### Epilepsy Action

Furthermore, there may be significant failures by both the NHS and local authority services to provide people with comprehensive information about *all* the services and sources of support that might be available locally.

Professionals and care givers – including, importantly, GPs – tend not to be aware of, or to refer people to, services that are outside their own ‘silos’. This leaves people who are often vulnerable or in physical or emotional discomfort to search out support services, social care and other information such as financial and employment information, for themselves<sup>6</sup>.

*“What patients and carers want to know about stroke is usually not the same as what health professionals think they should know.”*

#### Stroke Association

[Note: The above points are true for the generality of patients. However, those with rare or orphaned conditions often find it much more difficult to get accurate information from their

<sup>3</sup> *Why people don’t learn from diabetes literature*, Reid JC et al, Patient Education and Counseling, 25 (1), 1995

<sup>4</sup> Coulter C, Ellins J et al, *ibid*

<sup>5</sup> See for example, *Information for People Living with Conditions that Affect their Appearance*, Magee H, Heron P et al, The Healing Foundation and Picker Institute Europe, 2007

<sup>6</sup> *At a crossroads without signposts*, Picker Institute Europe, 2007

GPs and other local services – either about the nature of the condition itself or about the specialised services that may exist at some geographical distance.]

*Current situation: along patient pathways*

There are many points along patient pathways at which new information is required. National patient surveys indicate that, while some of these needs may be well met, others may not – which points to the need for commissioners to address information deficits along pathways.

For example, among hospital inpatients in 2009, 21% of the intake said they were not given enough information about their condition or treatment<sup>7</sup>. Information then improved for those (67% of the total) who subsequently had an operation or procedure -- 96% said the risks and benefits were explained completely or to some extent, and 95% said the same about explanations of what would be done during the operation or procedure.

Information then decreases – only 64% of this group said the results of the operation or procedure had been explained ‘completely’. And information gets worse at the discharge stage.

Indeed, **consistently the worst** area of information provision in the NHS is in relation to giving patients information, explanations and contingency plans when they are leaving hospital.

Among inpatients:

- only 63% said they were given any written or printed information about what they should or should not do after leaving hospital
- a mere 36% said they were told ‘completely’ about medication side effects to watch for when they went home
- 40% said they were not told about danger signals to watch for (and another 21% said only ‘to some extent’)

Among outpatients<sup>8</sup>:

- 55% of those taking home new medicines said they did not have a complete explanation of side effects
- 33% were not told about danger signals to watch out for
- 34% said they were not told who to contact if they were subsequently worried about their condition or treatment

Among women who used maternity services<sup>9</sup>:

- 11% left hospital without the information they needed about the birth and care of their baby

<sup>7</sup> *National survey of adult inpatients*, 2009, Care Quality Commission

<sup>8</sup> *National survey of adult outpatients*, 2009, Care Quality Commission

<sup>9</sup> *National maternity survey*, 2010, Care Quality Commission

- 13% didn't get help and advice from professionals about feeding after leaving hospital
- 18% said they didn't get enough information about their own recovery.

Although discharge from hospital is the outstanding area of failure in information provision, information gaps are not only found in hospital care.

In **primary care**, a 2008 survey<sup>10</sup> found that around one quarter of patients did not feel that they received explanations regarding treatment or action in a way that they could completely understand (23%); or were not given answers to questions in a way they could completely understand (25%). More than half (41%) of those prescribed new medicines said they were not fully told about side effects.

There is evidence within the national patient surveys that people in the **oldest age group**, over 75, have a worse experience of information and communication than those below them in age.

For example, among people who were admitted to Accident and Emergency in 2008, fewer over-75s than people under 75 said they had enough time to discuss their health problem, or that their condition, test results and treatment were fully explained in terms they could understand.

More than half reported not being told when they could resume normal activities. More than a third were not told about any danger signals to watch for. Around a third were not told who to contact if they were worried about their condition or treatment after leaving A&E<sup>11</sup>.

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<sup>10</sup> *National survey of local health services*, 2008, Care Quality Commission

<sup>11</sup> *Older people want more talk in A&E*, Redding D and Howell E, *Health Service Journal*, 22 January 2009

## Case Study: the benefits of collating information within the pathway

In 2001 Liverpool Alder Hey Hospital discovered that many children were not attending the GP surgery, as recommended to do so, for a thorough review following an acute asthma event. As a result, many were returning prematurely and inappropriately to A&E. Parents and carers felt that the treatment given for management of the acute attack had resolved the symptoms and so did not consider the review necessary.

### **What was done?**

Children aged 2-16 years who presented to A&E due to an exacerbation of asthma, but who did not require admission, were randomised to be followed up and reviewed by a Respiratory Nurse Clinician within 8 days. During this review diagnosis was confirmed, medication assessed and an asthma management **education programme** was implemented, together with a **self management plan** (if appropriate) or to have standard follow up by their family practitioner.

### **What was achieved?**

331 children were randomised, with 173 being allocated to the Nurse Clinician Group. In the Nurse Clinician Group only 19% re-attended, compared to 32% in the standard follow up group.

In addition, those children with more severe/problematic asthma were appropriately referred to a consultant respiratory paediatrician, either because of high dose inhaled steroid use, parental anxiety, associated co-morbidities, or for further investigation.

*Case Study supplied by Asthma UK*

### *Current situation: communication with professionals*

Although the majority of patients and service users will actively seek out information, they retain a strong preference for information that is delivered and discussed face to face with a health professional, allowing them to ask questions and examine their options.

This is because health professionals still generate extraordinarily high levels of trust and confidence – in patient surveys, typically between 85% and 95% of patients say they trust their health professionals ‘completely’.

This is a very significant preference, since the evidence of what is most *effective* in providing information and education to patients shows that the involvement of their health professional is crucial to success (see Table 1, below).

National patient surveys show that communication from and with health professionals is generally good, and in places has been improving over the last decade<sup>12</sup>. These questions cover such aspects of communication as: whether health professionals listen to what the patient says; whether explanations are given, and whether questions are answered in a way that patients can understand. It is likely that the increased emphasis on ‘communication skills’ in professional education is having some effect.

For example, among hospital outpatients, surveyed after a five year interval<sup>13</sup>:

- 81% said doctors definitely listened to them, compared with 79% in 2004

<sup>12</sup> *Is the NHS becoming more patient-centred?*, Richards N and Coulter A, Picker Institute Europe, 2007

<sup>13</sup> National survey of adult outpatients, 2009, Care Quality Commission

- 77% said they received good explanations, up from 76% in 2004
- 71% said they were given answers they could understand to important questions, compared with 69% in 2004

However, improved communication has not had any effect on the proportion of patients who feel they are as involved as they wish to be in decisions about their care and treatment. The proportion of patients who definitely feel as involved as they want to be in decisions about their care, measured by national patient surveys, has not changed significantly since 2002.

This highlights the limitations of the 'sheer provision' of information. More and better communication improves patient knowledge and satisfaction, and may help to increase adherence to treatments. **But more and better communication does not in itself drive greater patient participation.**

In order to improve participation, it is likely that two sets of issues need to be addressed:

- professionals need a wider set of skills than 'communication skills'**. The fact that a professional explains things better does not change the balance of power in the consultation, nor does it guarantee that the patient's views, values and preferences are being brought to bear on decisions. A wider skill set needs to be built into professional education and training, including: the awareness of the importance of patient views, values and preferences in affecting treatment choice; the ability to *elicit* patient views; the ability to check and identify at each stage how much the patient has understood, and is willing to participate; the ability to enable participation and to share decisions. The General Medical Council is beginning to recognise the importance of some of these skills<sup>14</sup>.
- patients need further help, support and advice to understand and make active use of information.** This is the agenda addressed under the terms 'health literacy', 'patient activation' and 'patient enablement'.

#### *Current situation: information for shared decisions*

As noted above, despite a plethora of medical information about illnesses and conditions, few materials are well designed to help patients to participate in care and treatment decisions.

There is only a very small number of patient decision aids in use in the UK, and these are either imported US materials, or are UK-specific materials but still at the pilot stage.

As we note under other answers in this submission, shared decision making is desired by most patients but is far from the norm. Depending on the setting, between one third and one half of patients do not feel they are as involved as they wish to be.

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<sup>14</sup> *Tomorrow's Doctors*, General Medical Council, 2009

*Current situation: information for participative, personalised care planning*

It is extremely difficult to assess the extent to which patients and service users are being provided with sufficient information of the right kind to plan their care over time.

In part this is because national patient surveys are location-specific, but there are many locations in which care planning could or should be taking place. In part, it may relate to a factor behind that surface, which is the lack of joined-up services in health and social care. And in part, it may be due to the fact that there is no reliable 'audit' of the extent to which good care planning is taking place across health and social care services.

The White Paper, 'Liberating the NHS' and its related consultation, 'Greater Choice and Control' both say that of the quarter of the population that have at least one long term condition, 70% already have a care plan.

**This statistic is dubious and potentially misleading and we urge ministers and the Department of Health not to rely on it or cite it again.**

The 70% statistic is built on patient responses to questions in the General Practice Patient Survey. Since 'care planning' is not a formal responsibility of general practice, it is not clear that these questions are addressing the right patients in the right location. Further, since there is no recognised formal framework, the questions have to refer instead to 'discussions' the patient may have held with the doctor or other health professional. But all primary care patients have 'discussions' – that is what we go to the doctor for! Whether these 'discussions' amount to true care planning is very dubious.

National Voices' member charities say the experiences of their beneficiaries cause them severely to doubt the statistic:

*"At least from the polycystic kidney patient perspective, I know of no-one who has such a [care plan] document or has even gone through a care planning process – other than when about to go on dialysis where it is excellent."*

Polycystic Kidney Disease charity

*"At present, only 10% of people with asthma in England have a written personal asthma action plan."<sup>15</sup>*

Asthma UK

*"An Epilepsy Action survey carried out in 2008 for our Time for Change report found that only 13% of the people with epilepsy who were questioned had a care plan."<sup>16</sup>*

Epilepsy Action

<sup>15</sup> Asthma UK/Ipsos-Mori survey 2010

<sup>16</sup> *Time for change*, Epilepsy Action, 2009

*“The simple fact of the matter is that despite universal recognition of their value, care plans are often absent or rudimentary.”*

Specialised Healthcare Alliance

We want patients, especially those with long term conditions, to be able to report that they:

- have participated in drawing up a care plan – and recognise it as such
- have been as involved as they wanted to be in deciding which care and support services to use
- know who is their keyworker and how to contact them
- know what to do if things change.

We note that within the national Cancer Strategy, people surviving cancer are now recognised as living with a long term condition, and they should accordingly have access to participative care planning.

Participative, personalised care planning depends on both seamless services and seamless information. We have described above the discontinuities that are caused, for example, when people leave hospital. We have noted also that there are commonly gaps in the information that patients would need for care planning – financial, social, and emotional issues, and comprehensive information on the wider services available. It therefore seems unlikely that good provision of information for care planning is widespread.

Both the published evidence, and our members’ experience, shows that what patients most want is to have ready access to ‘one-stop’ information ‘brokers’ – usually a trusted health professional who knows about them and their medical history and life circumstances, and who can direct them on to all relevant sources of help<sup>17</sup>. This would accord to some degree with the idea of the ‘case worker’ or ‘keyworker’ approach to care planning. Quite often this person will not be their GP.

For example, cancer survivors and their carers, interviewed to inform the national survivorship initiative, generally preferred to keep going back to the hospital for their follow-up care, because that was where they found the best blend of clinical specialist knowledge with continuity of care for the patient<sup>18</sup>. Likewise, many people with various long term conditions place high value on access to specialist nurses.

*“The clinical specialist who develops a good rapport with the patient and carer is more likely to inspire them to use the information and be proactive in their own health care.”*

Stroke Association

<sup>17</sup> *At a Crossroads Without Signposts*, Picker Institute Europe, 2007

<sup>18</sup> *Cancer follow-up care*, Sheldon S, Davis A and Parsons S, Picker Institute Europe, 2008

*“It is essential that people have access to healthcare professionals who have accredited training in asthma management (for example asthma nurse specialists) and who are best placed to give the right information.”*

Asthma UK

*“Patients find Clinical Nurse Specialists an accessible and well informed source of support and information and view access to a nurse as an essential part of their care. In the 2010 National Cancer Patient Experience Survey, 91% of patients said they got understandable answers to important questions all or most of the time from their Clinical Nurse Specialist.”*

Cancer Research UK

However, as the following case study demonstrates, this keyworker function could equally be found in community health, local authority care, an integrated service or a locally commissioned service.

### **Case Study: co-ordination of care in multidisciplinary working – British Heart Foundation heart failure nurses**

The British Heart Foundation’s 122 funded and 490 supported health professionals cover a wide range of specialities, including heart failure, acute coronary syndrome, paediatrics, arrhythmia, adults with congenital disease, genetics and palliative care. They monitor patients’ conditions, provide expert clinical and emotional support and advice, and are a vital interface between primary, secondary and tertiary care.

Heart failure specialist nurses have become the linchpin of a co-ordinated multidisciplinary community service to patients with heart failure. They see patients in their own home and in clinics to monitor their conditions, adjust their medication doses and provide information and support.

In 2009-10, British Heart Foundation specialist nurses saw a total of 111,645 patients, made 171,449 telephone calls to patients, delivered 9,658 teaching sessions and contributed to 8,438 hospital avoidances through nurse-led interventions.

A comprehensive evaluation by the University of York demonstrated that heart failure nurses reduce all-cause admissions by an average of **35 per cent**, and an average **saving of £1,826** per patient is gained after the costs of the nurse have been deducted (Pattenden et al 2008).

One heart failure patient described the support as an “absolute lifeline for us both, providing support, advice and practical assistance on many occasions. I am sure she helped us far above and beyond what you would expect of her.”

*Edited from ‘How to deliver high-quality, patient-centred, cost-effective care:  
Consensus solutions from the voluntary sector’*

*What needs to be changed: using what works*

The **highest priorities** for patients, service users, their families and carers are:

- information to live with and manage their condition, and to self-care
- information for participative, personalised care planning

- information with which to participate in making decisions about their care and treatment along pathways.

The **system reforms** that would most improve these kinds of information provision are:

- the integration of care to create seamless pathways
- health professionals skilled in partnership working, and trained to understand patient activation, health literacy and supporting self care
- the training and support of patients, service users, their families and carers to become literate, confident, activated and engaged in decision making
- widespread adoption of participative care planning approaches for people with long term conditions.

The government has, in 'Liberating the NHS', recognised the need for most of these approaches. The **exception** appears to be in health literacy and patient activation.

If the government wants patients and service users to achieve success in using information for choice, control and shared decisions, then it must take more account of the need to support them to do so, including making use of 'experts by experience' and trained peer group supporters. (These groups can also be used to help educate and train health professionals.)

Thus National Voices considers that the government is potentially moving in the right direction. Our concern would be that in these consultations the emphasis is disproportionately on system reforms that would provide more information for 'choice' – as opposed to 'control', a distinction we tackle under the responses to 'Choice and Control' consultation questions later in this submission.

If the government were to prioritise what *patients* prioritise, then the emphasis would be greater on the system reforms listed above. As the government has also recognised, there is a significant and growing evidence base for the effectiveness of interventions that can help to achieve these reforms.

The Department of Health funded Picker Institute Europe to produce the 'Invest in Engagement' website, published in 2010 ([www.pickereurope.org/investinengagement](http://www.pickereurope.org/investinengagement)). This identified and analysed 280 systematic and high level research reviews of patient-focused interventions.

Those which had the strongest evidence base for effectiveness were recommended to commissioners as 'best buys'. A selection of the most relevant is listed in Table 1 below. We suggest these are the interventions the government should prioritise.

The full tables can be accessed at

<http://www.investinengagement.info/Filestore/Downloads/BestBuys.pdf>

**Table 1: Evidence based information interventions to support patient engagement**

Intervention	Outcomes
<b>Communications training for health professionals</b>	<ul style="list-style-type: none"> <li>• Better interactions between clinicians and patients</li> <li>• Greater patient satisfaction</li> <li>• May improve patients' knowledge and understanding of their condition</li> <li>• May lead to improvements in treatment adherence and health outcomes</li> </ul>
<b>Patient-centred consulting styles and longer consultations</b>	<ul style="list-style-type: none"> <li>• Patients value this approach</li> <li>• May encourage better self-care</li> </ul>
<b>Personalised patient information (paper and electronic) reinforced by professional or lay support</b>	<ul style="list-style-type: none"> <li>• Improvements in patients' knowledge and understanding of their condition</li> <li>• Increased sense of empowerment</li> <li>• Greater ability to cope with the effects of illness</li> <li>• Improved patient satisfaction</li> <li>• May lead to improvements in health behaviour and better health outcomes</li> </ul>
<b>Pre-operative and pre-discharge information materials</b>	<ul style="list-style-type: none"> <li>• May lead to shorter length of stay and fewer follow-up visits</li> </ul>
<b>Telephone counselling and helplines, tele-care, tele-health, tele-monitoring</b>	<ul style="list-style-type: none"> <li>• Less social isolation</li> <li>• Improved self-efficacy and satisfaction</li> <li>• May improve diagnostic accuracy</li> <li>• May lead to fewer consultations and shorter waiting times</li> <li>• May lead to improved health status and better quality of life</li> </ul>
<b>Question prompts and coaching for patients</b>	<ul style="list-style-type: none"> <li>• Increased question-asking in consultations</li> <li>• May increase patients' knowledge and understanding</li> <li>• May empower patients and improve satisfaction</li> <li>• Does not necessarily increase length of consultations</li> </ul>
<b>Patient decision aids</b>	<ul style="list-style-type: none"> <li>• Increased patient involvement in decisions</li> <li>• Better understanding of treatment options</li> <li>• More accurate perception of risks</li> <li>• Improved quality of decision-making</li> <li>• Appropriate impact on uptake of screening</li> <li>• Does not increase patients' anxiety</li> <li>• May reduce intervention rates</li> <li>• May be cost-effective</li> </ul>

<b>Patient access to records</b>	<ul style="list-style-type: none"> <li>• Improved knowledge and recall</li> <li>• Greater sense of empowerment</li> <li>• May help to reduce incidence of lost records</li> </ul>
<b>Self-management education and support for patients with specific conditions, integrated into routine healthcare with active involvement of health professionals</b>	<ul style="list-style-type: none"> <li>• Improved patient knowledge and understanding</li> <li>• Improved confidence and coping ability</li> <li>• Improved health behaviours</li> <li>• May improve adherence to treatment</li> <li>• May improve health outcomes</li> <li>• May reduce hospital admission rates</li> <li>• May be cost-effective</li> </ul>
<b>Interactive web-based self-management programmes</b>	<ul style="list-style-type: none"> <li>• Improved patient knowledge and understanding</li> <li>• Improved social support</li> <li>• Improved health outcomes</li> <li>• Improved health behaviours</li> </ul>
<b>Proactive telephone counselling using motivational techniques</b>	<ul style="list-style-type: none"> <li>• Increased uptake of screening, immunisation and other preventive procedures</li> <li>• May reduce risk factors among disadvantaged groups</li> </ul>
<b>Parenting programmes and home visits</b>	<ul style="list-style-type: none"> <li>• Reduced health risks among children</li> <li>• Reduced substance misuse among adolescents</li> </ul>
<b>Patient involvement in the development of information materials</b>	<ul style="list-style-type: none"> <li>• Improved information quality</li> <li>• May improve people's knowledge and understanding</li> </ul>
<b>Lay health workers</b>	<ul style="list-style-type: none"> <li>• May reduce health risks among peers</li> </ul>

**Q3: Does the description of the information revolution capture all the important elements of the information system?**

No.

The consultation question does not adequately address the need for patients and service users to receive help, advice and support to become skilled and confident at using information for decisions about their health, care and treatment.

Merely providing information does not in itself ensure that it is used. This is a well known phenomenon in public health, where people may be aware of health promotion messages but do not change unhealthy behaviours. That has led to the investigation of 'health literacy', for which Nutbeam<sup>19</sup> defined three levels:

- functional: basic skills in reading and writing for understanding health information
- interactive: more advanced skills to enable active participation in health care choices
- critical: the ability to critically analyse information about health and health care and make effective use of it.

People with low health literacy:

- have poorer health status
- undergo more hospital admissions
- are less likely to adhere to treatment recommendations
- experience more drug and treatment errors, and
- make less use of preventive services.<sup>20</sup>

In fact, the American Medical Association concluded that health literacy is a stronger predictor of health status than age, income, employment status, education level, race or ethnic group<sup>21</sup>.

If people's health literacy can be developed, then it makes sense to target those with the lower levels, both because they have the worst health status and because they make greater use of healthcare resources.

For this purpose, researchers developed the Patient Activation Measure<sup>22</sup>, which can assess the level of a patient's confidence in understanding and using health information for decisions – and can track changes in this.

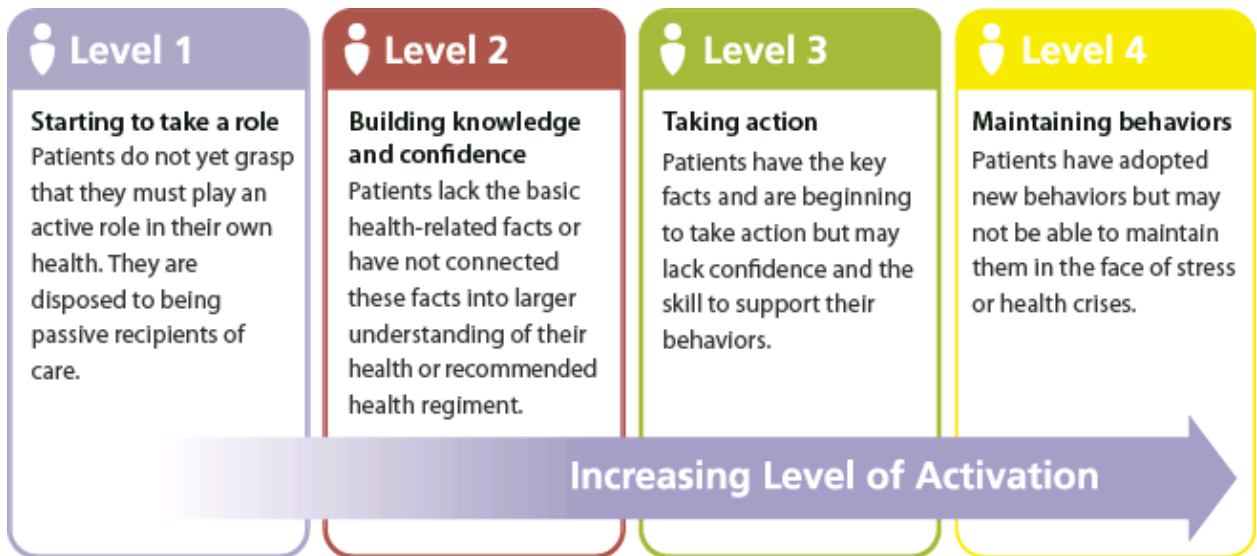
<sup>19</sup> *Health literacy as a public health goal*, Nutbeam D, Health Promotion International 2000;15:259-67

<sup>20</sup> *Health Literacy: a prescription to end confusion*, US Institute of Medicine, 2004

<sup>21</sup> *Health literacy: report of the Council on Scientific Affairs*, American Medical Association. JAMA 1999;281:552-7.

<sup>22</sup> <http://www.insigniahealth.com/ha/measure.html>

Co-developer Judith Hibberd of the University of Oregon, who particularly researches patient activation in relation to self-management, describes four levels of patient activation and estimates that around one quarter of the population is at Level 1<sup>23</sup>:



As we move up these levels, patients are increasingly engaged in more preventive behaviours, more healthy behaviours, more disease specific self-management, and more active searches for health information.

At the lower levels, however, patients neither seek, nor seek to *use*, the available health information to any great degree.

Having researched the close correlation between measured levels of activation, and the extent to which patients adopted evidence-based self-management techniques, Hibbard drew the following insights:

- “Use the activation level to determine what are realistic “next steps” for individuals to take
- Many of the behaviours we are asking of people are only done by those in highest level of activation
- When we focus on the more complex and difficult behaviours– we discourage the least activated
- Start with behaviours more feasible for patients to take on, increases individual’s opportunity to experience success”<sup>24</sup>

Hibberd has concluded that three types of tailored interventions have been shown to increase activation, and thereby to increase adherence, improve symptoms and reduce hospitalisation:

<sup>23</sup> Presentation to the European Public Health pre-conference, Amsterdam, November 2010

<sup>24</sup> *ibid*

- peer support and problem solving (self management education)
- support from clinicians, and
- tailored coaching in self-management.<sup>25</sup>

These are three streams of activity to support patients and service users in making use of health information which we recommend that the government should invest in.

**Q6: As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?**

Patients and service users have a strong interest in accessing their medical records.

The advantages are balanced by some concerns about the extent to which other people may be able to get access: for example, where a parent might access confidential information about a child's sexual health; or a carer might access without permission the records of a vulnerable person in their care.

So long as it can be demonstrated to patients that they can protect their privacy and confidentiality, and so long as patients are also given the opportunity to *change* their records where these are inaccurate or misleading, or where there are omissions, or there is a disagreement about diagnosis (eg in mental health<sup>26</sup>), then National Voices will strongly support the government's proposals to develop further the access to and control over their records that will benefit patients and service users.

As noted in Table 1, access to records is shown to help patients improve their knowledge and recall of information about their condition, discussions with their health professionals, and decisions about care and treatment options.

Access to records also increases patients' sense of 'empowerment' and therefore is a useful stepping stone in developing health literacy and patient activation.

Finally, access to records is shown to improve patient safety in that, if patients can correct the accuracy of the record, they are more likely to receive appropriate advice and treatment.

The company Paers, which helps to spread the practice of patients' access to records, notes that from its own and other studies the following benefits to patients accrue<sup>27</sup>:

- They trust the clinician and the practice more

<sup>25</sup> *Improving the Outcomes of Disease Management by Tailoring Care to the Patient's Level of Activation*, Hibbard J, Green J, Tusler M, The American Journal of Managed Care, V.15, 6. June 2009

<sup>26</sup> Mental health charities note that there needs to be a resolution process where the content of a patient care record – such as diagnosis – is disputed.

<sup>27</sup> <http://www.paers.net/patient-record-access-history.shtml>

- They feel more able to self-manage their illnesses
- They feel more confident in the clinical encounter
- They can correct the record and thus improve safety
- There is some evidence that record access improves health outcomes, improving medication compliance in heart failure and improving smoking quit rates

Again, however, National Voices emphasises that this kind of intervention should come with a support package for patients – particularly those with lower health literacy and lower activation levels.

At Haughton and Thornley Medical Centres, a primary care practice in the North West, patients and carers are educated in how to use the electronic portal, understand their records, and build up their own electronic framework for managing their condition.

Likewise Paers is developing a 'Web 2.0' version of its access system to create greater personalisation.

Thus online access to records can bring multiple benefits through joining up information offers at the time transactions are taking place. For example, if a patient is going online to book an appointment, having information on their condition available on the GP portal may increase the access and use of that information; patients might take up the option of pre-informing their doctor of symptoms by asking a pre-consultation questionnaire; and this might lead them to further condition or treatment-specific information prior to their appointment.

**Q7: As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?**

Evidence from systematic reviews and from patient surveys shows that patients value face to face contact above all, and that such contact significantly increases the effectiveness of information provision.

But as an addition, it is the view of National Voices and its members, online access to records, control of records, and the capacity to construct personal health areas and to communicate online with health professionals are all potentially valuable to patients and service users and should be rolled out as quickly as possible.

**Q10: As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?**

The answer to this question depends on the type of 'choice' that is being discussed.

With regard to the choice of provider, there is very little evidence to support the assumption that patients are increasingly acting as 'informed consumers' who 'shop around' for their provider.

The Kings Fund study for the Department of Health<sup>28</sup>, in common with other research, found that while patients say they value this choice, very few make active use of it.

*“Information, per se, is not enough. People do not behave like consumers when it comes to health information and choices.”<sup>29</sup>*

#### Stroke Association

Consultations with patients during the NHS Next Stage Review again reaffirmed that patients want, and generally expect, to find an equal ‘NHS standard’ of care at their local provider.

Research studies point to two circumstances in which patients may be more actively motivated to seek an alternative provider.

One is where waiting lists for procedures are long, and treatment could be accessed more quickly elsewhere<sup>30</sup>. This is not currently a general problem in the English NHS (but may recur).

However, Mind notes that there is a waiting problem for mental health – its We Need to Talk Survey<sup>31</sup> (527 responses) found one in five people has been waiting over a year to receive treatment and one in 10 people has been waiting over two years to receive treatment, with only around a third of people receiving treatment under six months. The availability of data on wait-times for services is therefore essential here.

The second circumstance in which patients may ‘switch’ provider is where the patient (or perhaps someone close to them) has had a poor previous experience with their local provider<sup>32</sup>.

Patients may look for published sources of quality information, but whether they do so or not, they rely on three other principal sources that they ‘trust’:

- the advice of their GP or other health professional;
- the opinions of family and friends; and
- their own experience<sup>33</sup>.

The second and third of these information sources are difficult for the government to influence. The first is clearly a barrier to extending choice if – as the Kings Fund study showed is frequently the case -- the GP or health professional is antagonistic to the policy or its implementation, or is convinced of their own ability to get the patient the best referral locally.

<sup>28</sup> *Patient choice: how patients choose and how providers respond*, Dixon A, Robertson R, et al, King’s Fund, 2010.

<sup>29</sup> *How do patients use information on health providers?* Marshall, M, McLoughlin, V. BMJ 2010; 341:c5272

<sup>30</sup> *Patients’ experience of choosing where to undergo surgical treatment: evaluation of the London Patient Choice scheme*, Coulter A, Le Maistre N, Henderson L, Picker Institute Europe, 2005

<sup>31</sup> *We Need to Talk: Getting the right therapy at the right time*, Mind, October 2010

<sup>32</sup> Kings Fund, *ibid*

<sup>33</sup> Kings Fund, *ibid*

In a review of the research literature on provider choice and its effects, which looked at Europe and the United States as well as the UK, the authors concluded that:

- “Choosing between hospitals or primary care providers is not currently a high priority for the public, except where local services are poor”
- “patients may themselves make limited use of choices... Patients do, however, want to be more involved in individual decisions about their own treatment, and generally participate much less in these decisions than they would wish.”<sup>34</sup>

This conclusion is supported by Dr Angela Coulter in a review article for the British Medical Journal:

“Most place greater value on involvement in choosing their treatment or care package.”<sup>35</sup>

#### **Q16: How can the benefits of seamless and joined up information be realised across the many different organisations (NHS and non-NHS) a service user may encounter?**

Seamless and joined up information is much more likely to develop where *services* are joined up. Hence the integration of primary, community, social care and Third Sector provision is the real underlying agenda here.

Pending further integration of services we make the following additional suggestions.

**i] widening the practice of participatory care planning for people with long term conditions.**

This would provide a regular opportunity for both the patient/service user and their professionals to bring together and consider all available information on their current health status, values and preferences; and to make decisions about future care and treatment. Good care planning needs someone to coordinate – a key worker of some kind who advocates on behalf of the patient. The nearest to this that some patients find is the Clinical Nurse Specialist.

**ii] developing patient-centred standards for the patient record.**

We support the government’s ambition to develop patient records as the basic unit of information in the NHS. However, it is very important to patients, service users, their families and carers that these should not just be *medical* records. There must be clear provision of areas for the recording of patient needs, values and preferences, so that these remain available both to the service users themselves and to professionals with whom they may wish to share them. Where a full participatory care plan has been agreed, this should form part of the same record (not a separate document). The benefits will be:

- ensuring that decisions are tailored to these preferences whilst avoiding the need for the service user repeatedly to argue these with different professionals
- assisting service users with their recall of key decisions and agreements already made

<sup>34</sup> *What benefits will choice bring to patients? Literature review and assessment of implications,*

Fotaki M , Roland M et al, *Journal of Health Services Research and Policy*, 2008;13:178-184

<sup>35</sup> *Do patients want a choice and does it work?*, Coulter A, *BMJ* 2010;341:c4989

- ensuring that a personalised care plan is understood by all who come into contact with the service user
- making the aggregation of people's care plan preferences available to commissioners.

iii] **developing NICE standards and NHS Commissioning guidelines that explicitly integrate information provision along care pathways.** This will encourage all commissioners to look across care pathways and to examine where and when relevant information should be provided – and by whom. (The maternity pathway is a good example of where this has already been done.) This should include identifying key decision points where information needs collating for the patient. Patient experience questions can then be used to monitor the degree to which the right information is being provided.

iv] **developing NICE standards and NHS Commissioning guidelines that explicitly identify points within care pathways where patient decision aids should be used.** Together with a related drive to develop and produce UK-specific decision aids, this would ensure that commissioners demand that service providers make use of these aids, thereby giving the patient a clear opportunity to consider the harms and benefits of all available treatment options and to share in the decision about which option to choose.

v] **use national clinical strategies to drive better tailoring and provision of information.** This would build on the successes of the 2007 Cancer Reform Strategy (CRS), for example, where clinicians were advised by a patient experience group. Alongside treatment standards were integrated approaches for improving information flows along pathways. As a result, in national inpatient surveys, patients who have been through cancer departments give higher scores than average on most information questions. As detailed in the CRS, models are currently being piloted and rolled out for providing better information and support to cancer survivors.

Cancer charities who are members of National Voices are strongly in favour of the information approaches developed under the strategy:

*“The Cancer Reform Strategy and earlier cancer policies introduced a range of initiatives to provide patients with access to high quality information to enable them to participate in decision making about their care and to reduce fear of cancer. In particular, this includes:*

- a) National information pathways by tumour type to provide high quality information products that healthcare professionals can offer to patients at key points in the cancer journey*
- b) Information prescriptions to enable healthcare professionals to generate tailored or personalised written information at any point in the cancer pathway*
- c) A support structure to ensure improvements in patient information delivery including the creation of patient information manager posts in each of the Networks along with patient information leads in each Trust at network level.”*

Cancer Research UK

Likewise Macmillan Cancer Support is calling for Information Prescriptions to be recognised as an integral part of the government's Information Strategy, as they provide personalised, high-quality information to patients at key points on their care pathway, and they are designed to be offered within structure of supportive information giving from professionals.

It is fair to say that charities representing other conditions are less positive about the relevant national strategies, as well as about Information Prescriptions. This reflects their experience that other national strategies have sometimes been less influenced by patient and service user groups, and the standards and approaches they defined may not have been implemented on the ground.

The demonstrable success of the CRS initiatives on information and support, however, could be used as a best practice model to inform the commissioning guidelines set by the NHS Commissioning Board, both in cancer and in other disease areas.

Likewise, we want to see detailed measures on information and support for all those with long-term conditions feature in the Commissioning Outcomes Framework, to encourage local commissioners to take up these initiatives and provide high-quality information and support to all patients.

**Q29: What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?**

and

**Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and ‘intermediaries’? Would factors such as cost and bureaucracy outweigh any benefits?**

Patients, service users, their carers and families are already active seekers of information. In this they face various challenges, two of which are: knowing which sources to trust and rely on; and dealing with a multiplicity of information sources, with little help from the NHS in terms of signposting.

The Department of Health has developed two interventions to try to help people with these challenges: NHS Choices and the Information Standard. While neither is perfect, both continue to have high potential.

NHS Choices has the potential to be a one-stop signposted information service for patients and service users. The Information Standard has the potential to reassure patients and the public about the trustworthiness of information providers. It needs to be more widely promoted, and the benefits of membership for voluntary sector organisations need to be kept under review.

We wish the government to note that, in contributing to this submission, National Voices’ members have expressed very strong support for both these interventions to continue.

*“Regarding NHS Choices, Asthma UK supports a single patient-facing information site which contains accredited information and signposts to other reliable sources. We advocate that NHS Choices integrates its information more effectively with that from the voluntary sector by working more collaboratively with accredited patient groups.”*

Asthma UK

*“The unavailability and or inappropriateness of health and patient information is a critical driver of poor use of health services and poorer health outcomes. It is important that an accreditation system, such as the Information Standard endorses information which is accurate, relevant and up to date.”*

Cancer Research UK

*“Accredited information provision is important as more choice becomes available in the new NHS architecture and through the ‘any willing provider’ policy for NHS-funded care. King’s Fund research into the information people use to make choices about where they would be treated states as a key lesson that ‘information providers shape preferences, they do not just elicit them’.”<sup>36</sup>*

Asthma UK

National Voices understands the government’s desire to see a ‘market’ in information develop. Information accreditation can be an important contribution to the functioning of such a market in ways that benefit the consumers of information. NHS Choices can play a role within the market in providing a single, comprehensive ‘official’ service that helps correct market failure (in a rough analogy with public service broadcasting).

National Voices and its members would therefore like to see the government recognise the potential continuing value of these interventions and integrate them into its information strategy.

*“Some organisations, such as Epilepsy Action, have invested considerable time and expense in earning the Information Standard, set up by the Department of Health, on the basis that this system would be the standard of health information in the UK. It would be unacceptable for this scheme to be abolished at such an early stage, before benefits can be assessed, and before those participating organisations can recoup the rewards of their involvement.”*

Epilepsy Action

**Q34: Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?**

**A) Transparency**

As part of its commitment to transparency, and to providing information for accountability, the government must ensure that *all* board business of NHS organisations, both commissioners and providers, and including Foundation Trusts, should be carried out in public; that boards make information publicly available; and that there are mechanisms to hold them accountable.

We also reiterate our support (as stated in our combined response to the White paper consultations) for a duty of candour to ensure that mistakes are publicly known.

**B) Signposting**

In contributing to this submission, many member charities have raised the persistent failure of GPs and others in both primary and secondary care to direct, or refer, patients and service users to relevant sources of support, advice and care. We highlight some aspects of this in our section on ‘Evidence – the current situation’.

*“People with long term conditions need to be signposted at an early stage in their diagnosis to relevant voluntary sector organisations and support groups who can help.”*

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<sup>36</sup> *Choosing a High-Quality Hospital*, The King’s Fund, London, 2010

National Rheumatoid Arthritis Society

*“We find that many of the people who need our specialist advice and support have struggled to find out about us even though they have been in contact with various agencies who should have told them.”*

AvMA

*“GPs just don't know enough about some conditions either to signpost to a charity or even to make the correct referral.”*

Individual National Voices Service User Panel Member

Member charities strongly wish to see this addressed. Ideally, progress on the integration of care, and the use of participative, personalised care planning, will in future greatly reduce this problem, we urge the government to consider what can be done **more urgently** to mitigate these failures.

### **C) Role of voluntary sector organisations**

The vast majority of voluntary organisations for parents, service users, their families and carers are information providers. National Voices members are engaged in a very wide and demanding range of information, education and support activities.

These include:

- explaining and interpreting medical information for patients
- advising people on treatment and support options
- filling gaps in information provision, for example by providing information on the social, emotional and financial effects of disease, and on how to manage these
- providing education for self-management and self-care
- signposting people to further sources of information, support and care that they may otherwise not have known about

In contributing to this submission many members have made the strongly felt point that this voluntary sector contribution is often unrecognised by mainstream services.

Lack of recognition and integration of voluntary sector organisations means, among other things:

- failure to signpost people to voluntary organisations
- failure to refer people to voluntary sector services
- failure to include voluntary sector services in the integration of local care economies
- failure to consider voluntary organisations as willing providers of services, and to make commissioning inclusive

*“We are currently doing a job which should really be done by government which is to translate health policy into meaningful information for the constituency we represent. We also have to help and guide them through the process of accessing good quality care. We also have to train patients to participate meaningfully in local service design consultations/meetings. All of this is done at our cost using precious, limited resources.”*

National Rheumatoid Arthritis Society

*“I would like to see an explicit commitment to giving ‘support’ to charities to help patients more. How about starting with the relevant Best Buy priorities? Support could be in the form of money and useful resources, such as NHS-funded conferences to enable charities and medical professionals to share and learn. At present, most conferences on ‘patient information’ are too expensive for small charities to attend.”*

Polycystic Kidney Disease charity

In the new architecture of health and social care presaged by the government’s White Paper – and particularly in the information strategy -- it is vital that:

- there is explicit recognition of the voluntary sector’s current and potential contributions
- the process of integrating care locally should explicitly include voluntary organisations as well as those from health and social care – and that this is explicitly promoted by the NHS Commissioning Board
- much better signposting arrangements to voluntary sector support and advice are put in place by local commissioners and providers
- voluntary organisations are enabled to become willing providers of information and support services on an equal footing with those from other sectors

[We now move to answer questions from the Choice and Control consultation.]

## RESPONSES TO SPECIFIC CONSULTATION QUESTIONS -- CONTINUED

### From 'Choice and Control'

#### **Q12. What else needs to happen so that personalised care planning can best help people living with long term conditions have more choice and control over their healthcare?**

As noted earlier in this submission, the government should not place reliance on the DH statistic that 70% of people with long term conditions have a care plan.

That statistic is based on questions about whether patients have had 'discussions' with their primary healthcare professionals. But if we look at the largest single long term conditions group – people with diabetes – a survey discovered that while 95% had regular checks, less than half had discussed with professionals the best way to manage the condition, and fewer still had set goals or agreed a care plan. The experience of our member organisations and their beneficiaries, likewise suggests very few patients and service users with long term conditions have anything that is recognisable as a true care plan.

A recent study for the National Institute of Health Research's Service and Delivery Organisation<sup>37</sup> provides a more realistic picture. It looked at self-care support across England, and found it only patchily available. It was rarely an active, integrated strategy on behalf of health and social care professionals. Rather, it was much more likely to be a 'bought-in' activity, such as generic self-management education – although both service users and systematic evidence reviews concur that condition-specific education is much more valuable -- or a stand-alone advice service.

The study found that a *minority* of self-care support is provided through case management, usually by nurses. They tend to operate from either a health service *or* a local authority base, rarely as a joined-up service. Although they may be providing many elements of care planning for this minority of patients, the nurses did not have control either of referrals or of budgets to back up the care plan decisions.

A significant source of learning here has been the Year of Care in diabetes, where a key aim of the pilots was to establish explicit care planning approaches – using diabetes as a pathfinder for other long term conditions. Drawing conclusions from these pilots, Year of Care stated that:

“while having a written care plan is important for many people, it is the process of collaborative care and joint working rather than the end product which is helpful. It is the action, 'care planning', which is important rather than the product, the 'care plan'.”

In other words, the formal arrangements – a care planning system, a written plan, a keyworker – are important, but are not the whole answer. It is the engagement of the service user within the process of care planning which is critical.

For this reason National Voices wants to see a change in terminology to **participative care planning**. This implies a system in which the engagement of the user (and their family and carers) is paramount.

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<sup>37</sup> 'Self-care and Case Management in Long-term Conditions: The Effective Management of Critical Interfaces', Challis D et al, SDO, 2010

Year of Care project concluded that the elements needed to ensure success for care planning are very closely linked to, and overlap with, those that are necessary to support people to manage their lives and conditions, namely:

- Healthcare professionals who are committed to working ‘in partnership’ with patients, and willing to change their consultation styles to do so
- Informed and engaged patients
- Organisational processes that are carefully thought out and quality assured – such as the experience of visiting the clinic; the flexibility and responsiveness of the service; and good processes for registration, recall and review.

National Voices rejects all approaches to ‘care planning’ that encourage a tick-box culture. We do not want people to be ‘given’ care plans. We want patients, especially those with long term conditions, to be able to report that, for example, they:

- Have participated in drawing up a care plan
- Have been as involved as they wanted to be in deciding which care and support services to use
- Have been able to access these services without long wait times
- Know who is their keyworker and how to contact them if things change

Indicators like these must be integrated into both the long term conditions and the patient experience domains of the National Outcomes Framework.

Participative care planning approaches would be best embedded in an NHS with an aggressive approach to implementing Chronic Care Models for long term conditions. Learning from the United States has led Kaizer Permanente to conclude that four themes are involved:

- breaking down the barriers between primary and secondary care;
- integrating care pathways to stop inappropriate referrals;
- making sure doctors are in leadership roles, working with managers; and
- focusing strongly on information and education for self care throughout the pathway.

This informed the Department of Health’s own model, published in 2005 but still not widely implemented in England<sup>38</sup>.

National Voices encourages the government and NHS commissioners to **return to this model** and examine its implications for the new architecture outlined in ‘Liberating the NHS’. The NHS Commissioning Board, in particular, should champion this model in its guidance on commissioning integrated services and long term conditions pathways.

The US experience suggests that **at the system level**, the following elements are crucial:

- Strong and integrated primary and community care systems
- Integration between primary and secondary care
- Clinical leadership
- Early identification of the local case mix

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<sup>38</sup> *Supporting people with long term conditions: An NHS and social care model to support local innovation and integration*, DH, London, 2005

- Targeted efforts to extend active care planning to the 10-20% of people most likely to be admitted to hospital
- Case management approach extended to at least the next 30% of the case mix
- Efficient information transfer with the patient from one service/setting to another

The Department of Health's QIPP (quality, innovation, productivity and prevention) team on long term conditions likewise emphasises four features of successful practice here:

- risk profiling
- neighbourhood teams providing integrated care
- systematic mechanisms to maximise self management, and
- clinical leadership and professional development.

Moving to this emphasis will require:

- embedding evidence and best practice in national commissioning standards and guidance
- a significant hearts and minds campaign to encourage clinicians, a) to commission the right services, and b) to take leadership roles in those services
- establishing proactive support to patients and service users as a *core purpose* of services, not an add-on or stand-alone facility.

**National Voices makes the following calls for rapid progress on participative care planning to support people to manage their lives and conditions:**

- a. The government should make clear the **outcomes** it requires from the devolved NHS in relation to supporting self care and self management. As the National Outcomes Framework develops through consultation it should include an outcome that clearly captures 'patients being supported to manage their own condition'. Potential indicators would include: 'patients with co-morbidities identified and participating in case management'; 'patients participating in care planning'; 'patients in receipt of condition-specific self-management education', including both group and individual provision; and 'patients being supported to be independent through patient-centred tele-health'.
- b. The government should consider how to mount a 'hearts and minds' campaign to encourage clinical leadership of self-care support and participative care planning.
- c. The DH and subsequently the NHS Commissioning Board should develop and issue commissioning guidelines for each long term condition, and these should include: service user participation in designing services; high standards of personalised patient information; provision of self-management education, both group and individual – but emphasising condition-specific education; identification of key points in patient pathways where information, education and decision support are required; standards for identification of patients most at risk of hospitalisation, and for case management of these; standards for care planning approaches, emphasising that care planning is a participative process (not just issuing a 'care plan').
- d. Best practice models for the integration of primary, community, Third Sector and secondary care to support people to manage their lives and conditions should be developed and disseminated to commissioners and local authorities

### **Q17. How can we encourage people to take more responsibility for their health and treatment choices?**

“Genuine patient choice is dependent on access to accurate, understandable and meaningful information at a time and place that suits patients, as well as patients having the confidence, skills and personalised support to make choices.”

British Heart Foundation

Most patients recognise the need for them to play a part in their healthcare and treatment. Although some patients prefer health professionals to take decisions on their behalf, 75% of patients want either to take decisions themselves or share the decisions with their health professionals<sup>39</sup>.

Most patients with long term conditions (ltcs) take some responsibility for their health status, behaviours and treatment choices. However, their ability to do so is limited by health literacy, skills and confidence. Use of the Patient Activation Measure shows that, for example, many people with ltcs can manage to maintain more or less complicated medication regimes, but that they are much less confident about what to do if their circumstances or symptoms change<sup>40</sup>.

They key issues to address, therefore, are health literacy and patient activation. Interventions which have demonstrable benefits to patients and service users include:

- question prompts and coaching aids to help people make use of consultations
- recording people’s consultations and agreements made (eg on their patient record; in a care plan) and enabling people to have access to these records
- self-management education (condition-specific and tied into their health consultations)
- proactive tele-coaching and tele-health to make regular contact with people and make sure they are continuing to be able to adhere to treatment plans.

These interventions are most effectively led by people’s health professionals. More health professionals need to be educated and trained to work in this way.

They are also most effective within a case management approach where people with particular vulnerability to their coping strategies breaking down are identified and proactively managed to prevent unnecessary emergencies and hospital admissions.

Voluntary organisations are often skilled at providing the additional support, information and advice that enables them to take on greater responsibility. National Voices strongly believes that local commissioners – both in the NHS and local authorities – must make sustainable Third Sector partnerships a key part of fulfilling their duties to integrate health and social care.

Finally, peer group supporters and experts by experience can play an important part in sustaining people’s confidence to manage their health status and conditions.

### **Q21. How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?**

<sup>39</sup> *The European Patient of the Future*, Coulter A and Magee H, McGraw Hill, London, 2003

<sup>40</sup> ‘Self management support amongst older adults: the availability, impact and potential of locally available Resources’, Parsons S. et al, SDO, 2010

Many of the policy, legislative and regulatory requirements that are necessary to support a culture of patient partnership are already in place in England. The 'Liberating the NHS' suite of documents, with their Vision of 'putting patients first' are a welcome further addition.

Medical education has improved in beginning to prepare doctors to work in partnership with patients. The next stage should be to build in the development of other skills for empowering patients and sharing decisions, beyond communication skills.

More important now is to address continuing professional development. Patient partnership forms a minority of the course content for doctors in education; and is often overruled by the 'hidden curriculum', through which trainee doctors absorb paternalistic values and approaches from their peers and seniors.

There needs to be greater provision of post-education professional training in specific approaches to patient partnership, including the principles and practice of shared decision making and participative care planning. GP commissioning consortia can play a role here in demanding that sufficient numbers of professionals in key integrated service locations have received such training as part of the quality thresholds required from service providers.

Among the trainers should be cohorts of lay people/experts by experience who can raise professionals' awareness of patient perspectives and preferences, and of health literacy and patient activation agendas. These cohorts will themselves need to be trained and supported to play this role.

The biggest remaining obstacle to changing these relationships, however, remains the resistance of the medical profession to changing their culture and practice. The lessons from social marketing in other contexts are relevant here.

In National Voices' view the most effective contribution that the government and the centre of the NHS could now make would be to fund and support a sustained 'hearts and minds' campaign, working with leaders and champions from within the medical profession, to convince their peers of the need for a radical change in culture.

**Q22. What needs to be done to ensure that shared decision making becomes the norm? What should we do first?**

In the United States, president Obama's health reforms have explicitly recognised the role shared decision-making can play in improving the quality of healthcare and improving the efficient use of healthcare resources. There is now a national programme to support the implementation of shared decision making, and to fund the development of patient decision aids.

Similarly in Scotland, shared decision making has been fully integrated into the latest health strategy of the government.

The first thing the English Department of Health should do is to examine the approaches being taken in the US and Scotland, monitor their success, and examine the lessons for the NHS in England.

The second thing the English DH should do is to establish a **national strategy for shared decision making**, drawing on the existing work of the QIPP 'Right Care' team. This should include

- A hearts and minds campaign to raise awareness of, and commitment to, shared decision making among key professional groups; and to make patients and service users aware of the relevant rights under the Constitution
- Identification of decision points in all main patient pathways at which shared decision making is relevant and valuable
- Identification of the best *service locations* for these decisions to be made (eg whether in primary care, acute providers, or in a specialist referral service such as the National Refractory Angina Centre)
- Building the recommendation for shared decision making and use of patient decision aids at those points and locations into **NICE standards and NHS commissioning guidance**
- Significant and rapid investment to research and develop a suite of UK-tailored patient decision aids for each of those pathway points, based on internationally recognised standards for patient decision aids (e.g. IPDAS)
- Commissioners to use incentives to get providers to institute shared decision making – justified on the basis of better outcomes both for patients and for the use of resources – and to monitor their use by patient experience questions
- A programme of Continuing Professional Education for doctors and nurses, on the principles and practice of shared decision making, which actively uses patients, service users and other lay trainers as providers