



Local healthcare commissioning: *grassroots involvement?*

A national survey of health advocacy groups

A report prepared for

The Royal College of Nursing and National Voices
by PatientView



February 2009

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Preface

Why this survey?

This nationwide survey was jointly conducted by National Voices (an umbrella organisation established in September 2008 by and for the voluntary sector) and the Royal College of Nursing. The survey is one of the first efforts to discover whether patients and the public are truly involved in the government's local commissioning initiatives. The study explores the attitudes of patient groups (and other relevant voluntary organisations) to local commissioning in primary care. The intention is to look at current practice, and identify mechanisms by which commissioning processes can be improved (from the patients' perspective).

Some definitions

The Department of Health (DoH), intends local healthcare commissioning to become the main mechanism by which NHS treatment and care is purchased¹. For the purposes of this study, local commissioning is considered to occur at three levels:

- 1] Practice-based commissioning (PBC), run at so-called 'practice'-level by groups of local GPs, nurses, and other healthcare professionals.
- 2] Commissioning at primary-care-trust (PCT) level (sometimes described as 'world-class' commissioning).
- 3] Specialist-based commissioning, run by groups of PCTs at strategic-health-authority (SHA) level.

The government wants all of these commissioning activities to take into account the views of patients and the public. Stakeholder engagement is considered a key means of ensuring that local healthcare addresses the requirements of patients and the public in every local community.

¹<http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/index.htm>

About the survey

The survey was conducted (primarily) online between 20th October and 15th December 2008. In all, 226 groups completed the survey's questionnaire (of which 200 are local groups based across different parts of England). Taken together, the participating groups represent a broad range of patients and their families and carers, and concerned members of the public.

Every effort was made to include the views of groups that represent the interests of minorities, including people with a disability, with a rare disease, from different ethnic backgrounds, or those caught in a poverty trap. Also participating in the survey were a number of the new LINKs (Local Involvement Networks), which bring together individuals and voluntary groups whose duty is to find out what local people want from their healthcare services.

The main geographic focus of the survey was England (the regional remit of National Voices).

To allow the respondents maximum freedom of expression, the survey's questions were open-ended. The Appendix to this report contains as many of the comments received as possible, as well as a list of the organisations that wished to be named as respondents and their profiles.

Both National Voices and the Royal College of Nursing plan to communicate the survey findings to government. The main message contained in this report is that local healthcare commissioning has, thus far, shown limited ability to engage patients and the public in health policymaking, and pays too little attention to many disease-specific issues.

National Voices and the Royal College of Nursing would like to extend their thanks to everyone who volunteered their valuable opinions to this study, and to PatientView, the research and publishing organisation that designed and administered the study, and which drafted the findings.

Yours faithfully,
Howard Catton,
Head of Policy Development and Implementation, Royal College of Nursing
and

Mark Platt,
Director of Policy and Public Affairs, National Voices.

Backgrounder

According to the Department of Health¹, "Commissioning is the process by which we ensure that the health and care services provided most effectively meet the needs of the population". The process is complex because it involves assessing the needs of populations, designing and implementing care pathways around those needs, and then policing the whole system, to ensure that it works.

Following concerns raised about the quality and standards of traditional PCT commissioning processes, the government introduced in July 2007 its world-class commissioning (WCC)² programme for delivering "outstanding performance in the way we commission health and care services". At the time, the public were promised better care, health, and well-being as a result of the radical changes implemented. Words like "fair", "personalised", "effective" and "safe" were used by government to describe the new WCC processes.

A key element of the newly-launched WCC programme is the inclusion of local partners. (In addition to PCTs, local authorities, and health professionals,) patients and the public are meant to assist in deciding on local priorities and how best to deliver them. [The duty for the NHS to involve the public comes from Section 11 of the Health and Social Care Act 2001, which later became Section 242 of the National Health Service Act 2006.]

To catalyse communication between Commissioners and patients and public, the government has launched a separate but parallel initiative to "give citizens a stronger voice in how their health and social care services are delivered" through a vehicle called LINKs³ (Local Involvement Networks). LINKs are individuals and voluntary groups that come together and whose duty is to find out what people want. LINKs monitor local services and use their policing powers to hold healthcare providers to account.

Today, Commissioners are expected to base their decision-making on evidence of what really matters to patients, public, and staff. Hence the need to develop close ties with the local community. In the case of clinical input, the hope has been that practice-based commissioning (run at GP practice level) will provide a vital link to the WCC process.

Commissioners are also charged to deploy "outstanding negotiating, contracting, financial, and performance-management skills to shape local services, and to drive continuous improvement in quality, safety and choice."

¹ <http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/index.htm>

² http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080956

³ http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/dh_076366

Executive summary

Key recommendations for improving local healthcare commissioning (LHC)

1. *Involve service users more, and raise the public's awareness of LHC.*
2. *Deploy, and make greater use of, specialist nurses to articulate patients' needs, and to commission services that address those needs.*
3. *Encourage more joined up thinking by reducing the complexity that currently characterises the commissioning process, eg., by making clear the lines of responsibility.*
4. *Provide greater support for LINKs and raise public awareness of their existence.*

The results

The government intends local healthcare commissioning (LHC) to be the main means by which healthcare services are purchased—with the aim of suiting local need. Commissioning bodies include practice-based commissioning (PBC), run at GP practice level; primary care trust (PCT) commissioning, also known as 'world-class'; and specialist-based commissioning, run by groups of PCTs at strategic-health-authority (SHA) level. To be effective, LHC was meant to engage patients and the public (including their representative patient and voluntary groups). This survey, completed in early December 2008, finds, however, the following alarming results:

- Less than half of the respondent groups indicate any involvement with LHC. Of these, only a few estimate that they have made a meaningful contribution to the process [page 39].
- Overall, local healthcare commissioning has not brought about beneficial change in many of the areas singled out by the Department of Health as important—particularly the scale of services provided at home; seamless care between providers; and complex care met by the right professionals [pages 12-15].

About this survey:

The survey was conducted (primarily) online between 20th October and 15th December 2008. In all, 226 groups completed the survey's questionnaire. Taken together, the participating groups represent a broad range of patients and their families and carers, and concerned members of the public. The profiles of the respondents groups are to be found in the Appendix. The majority of groups (200, or 77%) are local and small, with membership between 10-499; they represent patients with some 50 different types of medical condition (none of which predominate in the survey, though 16.5% of the respondent groups represent people with multiple sclerosis, and 10.2%, people with a mental health problem). The respondent groups come from across England—the highest percentage (20%) being from the south east; the lowest (6%), from southern England.

- Even when a majority of the respondent groups perceive improvements in access—such as to NHS staff; to correct treatment and care; to alternatives to hospital admission; and to patient choice—they also point out that these gains are unevenly spread across the country [pages 12-15].
- Nearly a quarter of respondents report having had no help to encourage their involvement in LHC. Many of the respondents believe that the scale of patient/public involvement in LHC is not sufficient, and that—in any case—users' views can be disregarded by commissioners who favour a more traditionally clinical approach [page 42].
- Categories of individuals most overlooked by local healthcare commissioning include minority groups, people with a disability (especially people who are deaf, visually impaired, or both), and the poor [page 16].
- Conditions sidelined by local healthcare commissioning include autism, coeliac disease, diabetes, fibromyalgia, multiple sclerosis, rheumatoid arthritis, rarer neurological conditions, and various mental health problems [page 16].
- Some respondents insist that health services which are locally-commissioned and -run could leave the NHS fragmented and inflexible, with its administrators micro-managing the minutiae of their local healthcare area, rather than keeping sights on the bigger picture—the necessity to help a population stay healthy [pages 16-23].
- Respondents rate GPs poorly in most aspects to do with the designing and implementing care pathways. But they blame doctors' heavy workload and their need to focus on their careers as the main reasons for this result. A few respondents point to the perpetuation of paternalistic doctor-patient relationships as the reason for the poor performance. [pages 24-33].
- Respondents declare commissioning processes inefficient and opaque. The fragmentation of the process, they suggest, can discourage joined-up care. Indeed as many as 70% of the respondent groups report no improvement, as a result of the implementation of LHC, in the 'joining up' of health services to enable provision in a seamless way. Respondents describe some of the managers of LHC as inexperienced and untrained [pages 16-23].

Good practices identified by the respondent patient and voluntary groups

- Respondents rank specialist nurses as best (compared with other healthcare professionals) in all aspects of the commissioning process: understanding patients' needs, designing and implementing care pathways, collecting patient feedback, and being transparent. A plausible reason (as judged by respondents' comments) might be that specialist nurses, unlike GPs, are more familiar with the personal circumstances and challenges that are faced by people with specific medical conditions in daily life. As a result, these nurses are better able to communicate and form close relationships with patients, and to understand their needs [pages 24-33].

Section I: Patient and public views on local healthcare commissioning

1.1. Patient and public definitions of local healthcare commissioning

In theory, at least, local healthcare commissioning could be defined as the informed purchasing of healthcare services to suit local needs. The information required to drive the commissioning process is gathered from various people involved in the healthcare system at local level (including patients and the public). One NHS commissioning organisation responding to the survey described the procedure as:

“Practice-based commissioners working with their local communities to commission health services appropriate to the needs of the local population, but within a framework of national standards of care.”

But, although stakeholder consultation is a key part of local commissioning, remarkably few of the English groups responding to the survey include this element in their definition of the term. Instead, the vast majority of respondents prefer to emphasise that local healthcare commissioning means healthcare services purchased locally (and/or a system that provides for local healthcare needs). [Respondents' comments on the subject can be found in Appendix 1: 'Patient and public views of local healthcare commissioning'.]

Of the 226 participants completing the survey questionnaire, as many as 28 say that they have never heard of the term 'local healthcare commissioning' before. Reasons for not being familiar with the phrase include the following:

“Cannot answer this, as our organisation has never been exposed to such a procedure in Newham, London.”

—Anonymous organisation specialising in the healthcare problems of families with a child aged under 5.

“This is the first time I have heard of it, but have an idea what it is. I took this group over in July 2008, and have a lot to learn.”

—Sheffield Fibromyalgia Help Group.

Outside England

A few of the respondent groups are based outside England. These offer similar definitions of local healthcare commissioning to those put forward by English respondents. A minority of the non-English respondents refer to local consultation, the inclusion of user groups, or listening to patients' views. The majority, though, point to the decentralisation of purchasing power within their regional NHS, and/or the role of local healthcare commissioning at meeting local needs.

Drawing ire

A number of respondent groups use their opportunity of defining the term 'local healthcare commissioning' to criticise the process itself. These groups identify the following problems with local healthcare commissioning:

In certain parts of the country, local healthcare commissioning is an excuse to deny funds for care or treatment.

"Another word for postcode lottery."
—Local group; southern England.

"Someone else saying what services will be provided, regardless of consultation—and usually in accordance with what they intended to do before the consultation took place."

—Organisation representing the interests of people with a disability; Greater London.

It is a back-door means of cutting costs.

"Contracting-out of services to local groups. We are a charity providing rehab services and therapy for people with MS, but we cannot get the local PCT to recognise this. Our local newspaper recently reported that the NHS is failing to meet NICE guidelines."

—Local multiple sclerosis group; West Midlands.

It reinforces the existing medical hierarchy in healthcare.

"The mechanism by which services are delivered to patients/service users via the medical hierarchy."

—A personal response (respondent represents the interests of people with diabetes).

It has the right intentions, but defective mechanisms of implementation.

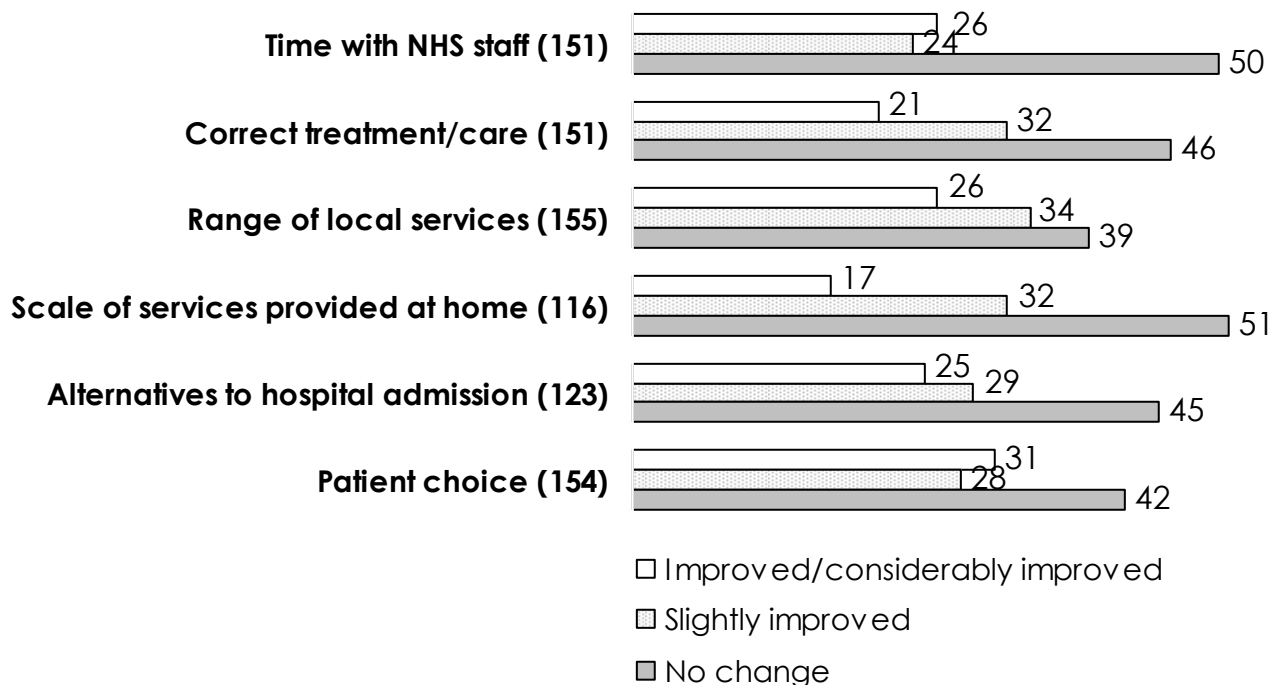
"PCTs commission healthcare to speed up care, and cut long-term waiting for all healthcare, but it's not always happened this way."

—Local organisation with an interest in chronic disease; south-east England.

1.2. The perceived impact of local health commissioning: good and bad

Access to healthcare services, treatment and care:

% of responses from local groups based in England (excluding "don't knows").
Number in brackets denotes number of groups able to answer the question.



Local healthcare commissioning began to make an appearance in England in April 2005. The Department of Health (DoH) laid out a list of desirable changes expected to result from the transformation in the purchasing of NHS services—most relating to improvements in patient access to healthcare services, treatment and care, as well as better co-ordination of the delivery of care.

Local patient groups and other health voluntary organisations taking part in this study were asked whether local commissioning has generated any noticeable enhancements to the areas of the health service singled out as important by the DoH.

On access

The following percentages of the survey's respondent groups report improvements in:

One or two of the respondent groups comment on the difficulty of estimating whether local health commissioning affects the quality of services in a particular geographic area. Headway East London, for example, observes:

"It is hard to infer a causal relationship between local commissioning and any changes we might see from the patient perspective. I have worked for this organisation for five years (since January 2003), during which time I have seen little change in the way that our members are treated by the NHS."

- access to (or time with) NHS staff (50%);
- access to correct treatment/care (53%);
- the range of local services provided (60%);
- alternatives to hospital admission (54%);
- patient choice (59%);
- and the scale of services provided in the home (49%).

Respondents' comments, however, suggest that improvements in service as a result of local health commissioning are patchy. In neurological services, for instance, a geographic bias exists, notes a group from southern England:

"This varies geographically for neurological services. Our group covers a wide area from Berkshire to Taunton. Services vary for individual health authorities."

Another respondent reporting geographic variation in the quality of services says:

"I think we in Central London are better off than anyone else. My recent knowledge of what happens in Bedford appalled me, and, I think, led to the untimely death of a patient."

A local group specialising in poverty-linked issues of health and social care in Yorkshire and North Humber states that people from minorities do not appear to have benefited greatly from local health commissioning:

"All of the above depends upon who is able to access information, who speaks English as a first language, and who understands the style of information shared. Many minority groups, and (poorer) uneducated white communities do not gain better access, or even understand their choices. Often, they will judge a 'good' service according to kindness levels, how well they were welcomed and/or spoken to, rather than recognising they received as good a service as others. This also links to how many services are 'personality led' rather than 'policy led'."

Patients who do not, or cannot, articulate their demands lose out, insists a representative of a mental health group from south-west England:

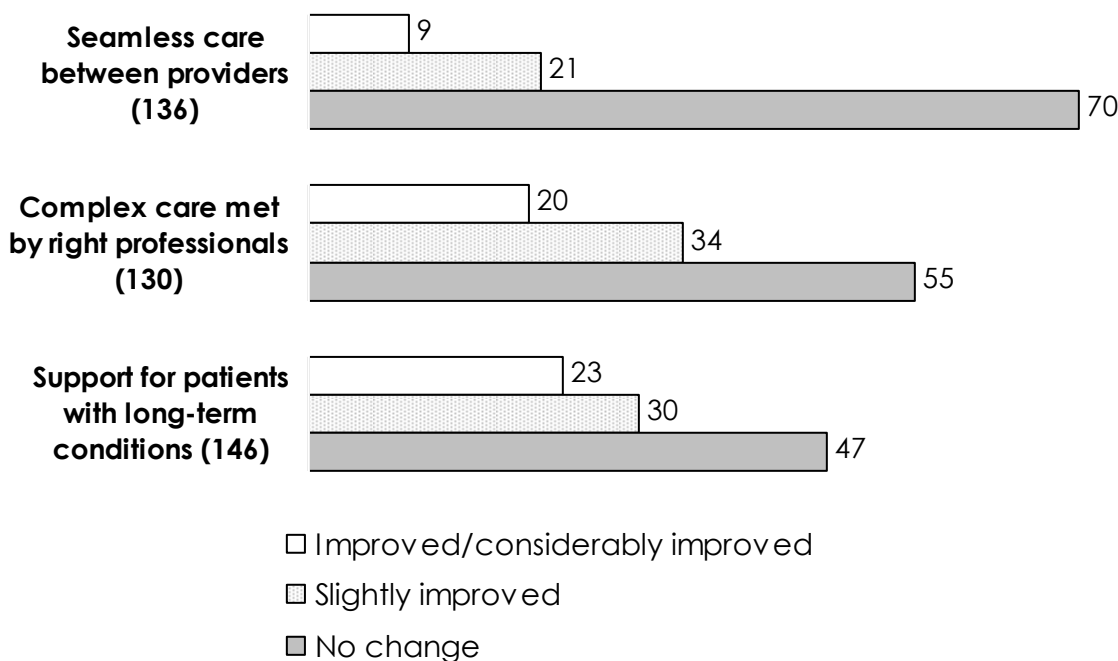
"It may sometimes look that there is more available to people, but the selection process is so complex and so exclusive that a lot of people never get a look in. Only the more acute and the more vocal stand half a chance."

Moving towards seamless care?

Respondents seem to agree that the fragmented delivery of NHS services (which can lead to a lack of continuity in

Other improvements to health services

% of responses from local groups based in England (excluding "don't know").
Number in brackets denotes number of groups able to answer the question.



care) remains a major failing. Some 70% of the respondent groups report no improvement in the 'joining up' of health services towards provision in a seamless way. Comments on the subject include the following:

"Consultants do not communicate between one hospital and another, leading to conflicting treatments and opinions, which are against patients' best interests/wellbeing/outcomes."
—Representative of a group that supports cancer services in a local hospital; West Midlands.

"The provision for autism is fragmented or ignored. People do not receive a seamless service, but mostly fall down the cracks until a crisis occurs. Then, expensive and time-consuming remedies are required for situations in which cheaper, early intervention would have sufficed."
—Group; Hertfordshire.

Long-term care?

Government is keen to enhance the support for the rising numbers of people with chronic conditions. Yet only a small majority of the groups participating in the survey (53%) mention any improvement here. Indeed, a London-based group specialising in eating disorders considers that the situation has worsened because of the failure of

hospitals to provide care to the long-term ill:

"Long-term care has got worse where secondary-care providers are less keen to support long term."

appointed as part of complex-care teams in early 2009.

A local group from London that specialises in myalgic encephalomyelitis (ME) says:

"We have had no experience of locally-commissioned services, and our members are very aware that there is no support for long-term conditions, such as ME. There are no specialist ME services of any description in either of the PCTs we cover. Our members have to travel to Sutton for an ME clinic. This is difficult and tiring for all, but impossible for the 25% of our members who are bedbound or housebound."

Provision of complex care by the right professionals

Some 55% of the respondent groups think that local health commissioning has not had any impact on the provision of care for complex conditions. As one patient replying in a personal capacity explains:

"I have coeliac disease, and also type-1 diabetes. I have developed a subsequent eating disorder, yet cannot receive help, due to lack of professionals/services. I have also been receiving homeopathic treatment until June 2007, when the treatment was abruptly stopped owing to a change in policy at PCT level. I feel really let down and frustrated. Does the government want me on sick leave and anti-depressants over it all?"

On a positive note, the Exeter branch of the Parkinson's Disease Society (PDS) reports that the establishment of a local PD working group may lead to improvements once specialist nurses are

The different forms of local healthcare commissioning

As mentioned by National Voices and the RCN in the preface to this report, the study tries to explore the impact of various types of local healthcare commissioning. Respondent groups were asked to comment, if able, on any improvements that they could attribute solely to the different types of local commissioning.

Respondents accordingly cite instances of both good and bad practice in local commissioning. Many of them describe innovative local health bodies working in tandem with patients to enrich people's experiences of the NHS, as well as improve clinical outcomes. An equal number cite inefficient, sometimes opaque, management of the commissioning processes. Some provide examples in which the care of people with complex or chronic diseases appears to be placed in the hands of the inexperienced, or note cases of care being handled inconsistently. Finally, a handful of groups decry a loss of services, mostly following the amalgamation of PCTs and the deployment of tools to set healthcare priorities. [Further case studies of the positive and negative impacts of local healthcare commissioning (of all types) can be found in Appendix 1.2.]

Feedback from respondents underscores the survey's finding that the various types of local health commissioning can have a selective impact on the experiences of patients, depending on who the latter are. Minority groups, people with a disability (especially those who are deaf or visually impaired, or both), and the poor, all seem worst assisted by NHS services.

Services for specific medical conditions also do not seem to benefit much from the local reforms. Noteworthy are complex disorders such as autism (reclassified as a mental illness), coeliac disease, diabetes (in some parts of the country), fibromyalgia, certain mental health problems (such as attention-deficit hyperactivity syndrome, ADHD), multiple sclerosis, rheumatoid arthritis (RA), and rarer neurological conditions (such as progressive supranuclear palsy, PSP). Cancer patients living at home can find out-of-hours urgent care difficult to obtain, or they may have to travel further to get hospital treatment. In the case of RA, patient representatives worry that GP commissioning could have a detrimental effect on access to specialist services.

With some exceptions, PCT commissioning appears to have been largely unsuccessful in improving dental health. And a 'postcode-lottery' effect remains present in the provision of the more expensive treatments and care (such as physiotherapy).

A few of the participating groups emphasise that it may be too early to make any judgements on the effect of local healthcare commissioning.

Practice-based commissioning (PBC) is health commissioning run at so-called 'practice level' by groups of local GPs, nurses, and other healthcare professionals. The 51 respondent English groups that express opinions on PBC attribute the following general country-wide improvements to this type of commissioning process:

- *Greater involvement of patients in GP-practice affairs.*
A personal response from a member of the North Norfolk Older People's Forum gives the example of patients' views being represented among GP staff meetings. A group from north-west England specialising in motor neurone disease refers to local briefings with GP practices.
- *Doctors allocating more time to patients.*
A representative from a group in north-west England that specialises in Sjogren's syndrome mentions longer surgery hours. A patient representative from an east Midlands organisation that specialises in public health at acute and general-practice level remarks:
"Pro-active care. Patients at risk of emergency admission to acute care are monitored, and their home care adjusted to prevent avoidable acute admissions."
- *A closer and more effective relationship between GPs, practice nurses, community matrons, pharmacists, and hospitals.*
This can benefit the chronically ill, and lead to shorter referral times for operations. The Chair of a central

London GP practice's patient participation group states:

"Our doctors being able to make hospital appointments for us with the specialist of our choice, and to provide all the paperwork (normally posted from the hospital) right there during our visit."

- *Greater near-the-home availability of a whole range of healthcare services, including counselling, diabetic and heart failure clinics, minor operations, mobile diagnostic facilities (such as retinal photography), nurses trained in asthma/COPD care, and pharmacists located within GP practices.*
- *The emergence of specialist GPs (quoted by a group from south-east England specialising in patient participation).*
- *Patients involved in supporting more effective commissioning.*
An example given by a representative from a patient involvement group in Essex:
"The Brentwood Cluster established their model for the services to be provided at the new Brentwood Community Hospital. Then, with the PCT, GPs, and myself as PPI rep, carried out over 50 interviews of NHS and private organisations, before issuing contracts to four NHS organisations to cover the 12 specialisations covered. The unit will include a primary-care assessment unit."
- *Patients involved in supporting local NHS services.*
A mental health group from Greater London offers a pair of examples:
"1.) Mental health guides, to which our group plans to be a feeder. 2.) The Local Mind Association is to co-host a broad

'reaching-people' participation programme for the Foundation Trust"

- *A greater interest in alternative therapies* (quoted by a group from south-west England that specialises in aging, disabilities, learning difficulties, and mental health problems).
- *New services.*
A group from Cornwall and the Scilly Isles lists the facilities recently achieved through PBC in that part of England:

"Investment to ensure equitable access to physiotherapy services. Nurse practitioner roles in the community. Additional outpatient and minor-surgery services in the community. Access to locally-held diagnostic clinics (such as ultrasound and echocardiography). Exercise programmes targeted at particular groups of patients. Acute GP scheme in secondary care, to reduce emergency admissions. Development of community services (both nursing and community hospitals). Piloting of improvements to dementia care and to end-of-life care."

Another respondent applauds a new home-visiting scheme established in an NHS Primary Care Trust in north-west England:

"One of our PBC consortia has developed an acute home-visiting scheme which has had a dramatic impact upon the health and wellbeing of some of our more vulnerable patients, and has led to greater independence and the avoidance of hospital admission."

But, despite the accolades, as many as 20 of the 51 groups offering views on PBC believe that improvements resulting from the application of this commissioning

system have been erratic. PBC appears to be let down, in part, by varying knowledge levels among GP practices and the willingness of GP practices to embrace change. A respondent group from Tunbridge Wells that specialises in brain injury explains:

"Very dependent on individual GPs understanding our particular group's needs."

The Suffolk-based Hypermobility Syndrome Association (HMSA) adds:

"The new ways of choosing consultant appointments, etc, online using passwords is very good. My local GP is incredibly good at learning about HMS and providing the best care possible. However, I am hearing stories from other members who are having huge difficulties obtaining a decent level of care, as their GPs are not in the least sympathetic to their problems and needs. I believe that it is practice-based commissioning that needs to be dealt with urgently, to bring these practices up to date with modern conditions, and to get more sympathetic care than is currently available."

A local diabetes group in north-west England endorses these opinions:

"Diabetes is being managed more by GPs, with vast differences between surgeries."

And a former participant at a Patient and Public Involvement Forum (PPIF) in Oxfordshire observes:

"There are signs that the GPs want to provide more diagnostic services. Several business cases have been put forward to the governance committee. Big differences between six consortia."

Commissioning at primary-care-trust (PCT) level (sometimes described as '**world-class' commissioning**). The 75 respondent English groups that express opinions on this type of commissioning process attribute the following improvements to it:

- *Improvements in dedicated health services.*
Respondents cite improvements to a large range of services, including alcohol and drug services; cancer chemotherapy services (for example, being made available closer to patients' homes); children's services (for example, for children with asperger's syndrome or autism); complex care (in the community); crisis and home-treatment teams; diabetes care (for example, the delivery of type-1 diabetes 'carb-counting' education locally to a high standard, plus retinal screening); eye clinics in hospitals; local community maternity care (for example, increased staff numbers); minor injuries units; pain clinics; physiotherapy clinics in hospitals; psychological therapies (for example, the Improving Access to Psychological Therapies Programme, IAPT); and pulmonary rehabilitation (for example, COPD specialist nurses).
- *Improvements to health services across the board.*
Other respondents comment on more community care (for example, community matrons to reduce the load on A&E departments, and 'home-from-hospital' teams); on quicker appointment times; on the better

performance of out-of-hours services; on quicker access to diagnostics tests (for example, MRI scanning); on shorter waits, and more choice of places for elective surgery; on increased numbers of specialist clinics at local community hospitals; and on co-ordination of care with social services.

- *An improved supply of individual treatments.*
An MS group from Exeter mentions beta-interferon.
- *A greater interest in the well-being aspect of patient care, and the searching out of ways to improve this.*
Examples submitted by respondents include public health interventions aimed at supporting people with chronic disease. A national group explains:
"Improvement in health development (for instance, the use of leisure centres in exercise on prescription, and in the rehabilitation of heart and stroke patients). The Expert Patient initiative. Some integrated work with health and social care."
• *The development of the LINKs (Local Involvement Networks), through which people are invited to be involved in the review and commissioning of services.* A local group in north-east England believes that ...
"Voluntary-sector provision is also starting to become a reality."
A mental health group, Headway South Bedfordshire, offers itself as an example of PCT-generated local involvement:

"Luton PCT commissioning Headway South Bedfordshire to provide specialised community support for people with long-term neurological conditions (acquired brain injury) has improved the well-being of over 150 patients, their families and/or carers every year within Luton."

Local groups supply the following examples of improvements in their own areas:

- *Respite care:*
"I have been able to take part in discussions with the PCT on the maintenance of respite care for Parkinson's disease."
—PD group; Greater London.
- *Speedier referral procedures:*
"Pressure from patients and GPs re diagnostic scans led to a contract with a local private provider, with tremendous improvements, enabling speedy, more accurate, referral by GPs, if necessary."
—Patient involvement group; south-west Essex.
- *Better out-of-hours services:*
"The recent re-tendering of opted-out-of-hours contract involved PPI, and allowed more flexibility to introduce improvements, especially relating to reducing A&E attendance."
—Ditto.
- *Financial support to services for people with aphasia:*
"Continued provision of a long-term aphasia centre."
—Aphasia support group; north-west England.
- *The testing of innovative technologies:*
"Whole-systems demonstrator pilot project." [Editor: aimed at testing the potential that new systems such as Telecare and Telehealth have in supporting care for

people with complex health and social needs.]
—Local group; Cornwall and the Scilly Isles.

- *Greater user consultation:*
"Involvement in discussions re CSS (personal budgets)-joint meeting with reps from PD, MS, and MND groups—with the promise that this will become continued involvement!"
—Local motor neurone disease group; north-west England.
"Southwark's commissioners (to alcohol and drug treatment/mental health) have had direct contact with service users for about eight years now. They use information gathered by service users to guide their commissioning"
—Alcohol Services Independent Forum (AS IF); Greater London.

As one local group from south-east England summarises:

"There have been big strides made here: improved public health services for exercise, obesity, and for education in dealing with diabetes. Improved clinics like Falls, and Heart Failure. And additional planning for a range of concerns, including end of life, maternity, and breast feeding."

However, against these many positive comments stand a great number of negative ones, including: the withdrawal of certain PCT services for patients with multiple sclerosis (MS) or mental health problems; the vested interests of the PCT dominating the commissioning process; a lack of transparency about PCT commissioning; infighting between departments about which picks up the tab; ineptitude at managing the tendering and contracting procedures among some PCTs; and the tardiness of some PCTs in involving end-users.

Of the 75 respondent groups that answered the survey's questions on PCT commissioning, 30 complained about the system. These reported no improvements from PCT commissioning, and deemed the situation unsatisfactory. Their comments included the following:

"This has been a disgrace. Poor practice, nepotistic relationships, lack of transparency, and person led, rather than a fair process. Short-term feedback processes are used to meet the PCT agenda, with no respect for our time-frames or agenda. No written evidence of process is produced, no copies of what we fed back, nor any knowledge of what is actually being used to review and assess our sector and individual organisations."

—Group that specialises in general health and social issues related to poverty; Yorkshire and North Humber.

"Commissioning at PCT level is extremely lazy and of poor practice. They often put bids out without proper descriptions of what they want, and expect people to agree with this. Plus, there is less and less money on offer to do more and more work. This creates intolerable difficulties for a lot of people trying to do a good job, and involving local service users. Those blind bids are extremely common. You would not ask someone to apply for a job without giving them a full job description and person specification, would you? Yet that's what they are doing with those bids."

—Individual representing the interests of people with mental health difficulties; south-west England.

"Disappointment that commissioning and decommissioning decisions seem to ignore Section 242 (Duty to Involve) legislation. They have given £15,000 to set up a Parent Carers Council, but this is only one third of costs needed to make it viable. Meanwhile, major commissioning decisions occur unchallenged."

—Group; Brighton and Hove.

"A bun fight for the different departments to apply for funding. Priorities become prioritised (necessary), leading to departments not getting the staff and funding they need to maintain a high standard of care and treatment."

—Group that wishes to remain anonymous.

"Nurses are grossly under rated, under paid, and over worked (what's new?). It is about time the NHS in general acknowledged nurses, and valued them and their skills. Without them, where would patients be?"

—Individual representing the interests of people with cancer; Wales and the West Midlands.

Specialist-based commissioning, run by groups of PCTs at strategic health authority (SHA) level. The 40 respondent English groups that express opinions on this type of commissioning process attribute the following improvements to it:

- *Greater availability of certain examinations and treatment (for example, insulin pumps; hip and knee operations).*
- *An increase in the number of consultant neurologists.*
- *Improved patient care (especially for patients with cancer) as a result of innovative training.*
- *More housing support for people with mental health needs (mentioned by a group that specialises in addiction problems).*
- *The needs of rural and homebound patients are better met (for example, a Greater London-based group praises the funding of a community-outreach nurse for people who cannot attend GP practices).*
- *Improved access to specialist nurses, notably nurses specialising in epilepsy, multiple sclerosis, neuro-rehabilitation, and Parkinson's disease (for example, an MS group in the Isle of Man believes that patient power and lobbying have bolstered the provision of, and access to, specialist nursing in the island's stand-alone health service).*
- *Reviews of maternity and neonatal services (noted by a group from Essex).*
- *A new centralised service for specialist cancer surgery, leading to improvements in outcomes for patients (reported by the Dorset Oesophagectomy and Gastrectomy Support Group, DOGSG).*
- *Implementation of Improving Outcomes Guidance for various cancers (mentioned by a local cancer group with a Cornwall and Scilly Isles remit).*
- *The development of local personality disorder services (noted by a group from East Anglia).*
- *Funding for a dental health project, as well as a PCT-level co-ordinator for Health Action Planning (HAPs)—the latter being an integral part of person-centred healthcare. (Both reported by a group from Greater London.)*
- *More effective mental health commissioning (mentioned by a group from north-east England that attributes the changes to one PCT taking the lead on behalf of others, resulting in "better joined-up service across the area").*
- *A Local Multi-Disciplinary Team (LMDT) to help adults and children manage chronic fatigue syndrome and myalgic encephalomyelitis (ME) (noted by an ME/CFS group from Sheffield).*

But, like the other types of local healthcare commissioning, specialist-based commissioning also attracts criticism for either having no effect, or for damaging the delivery of healthcare services. Amaze, for example (a Brighton and Hove-based group that specialises in supporting the parents of children with complex health needs, or learning or physical disabilities), argues that SHAs are too remote and aloof from service users, and do not keep stakeholders informed:

“Staff groups and families are the last to know of changes. There is a lack of accountability and engagement over planning services. SHAs are too distant.”

A south-east England group specialising in autism thinks that in-fighting between providers hampers progress:

“There have been no improvements to service. Eligibility criteria are the first hurdles at which most cases fail. The in-fighting between different service providers not to deliver prevents any meaningful progress. Autism does not fit easily into learning disability nor health, and this is a barrier to holistic services.”

A group from southern England that specialises in neurological conditions regards specialist-based commissioning as unlikely to involve patients and the public:

“Specialist-based commissioners identified some time ago the need to involve patients in their work, but report in writing that they cannot identify a way to do so!”

Section II: The staff in local healthcare commissioning —patient and public views

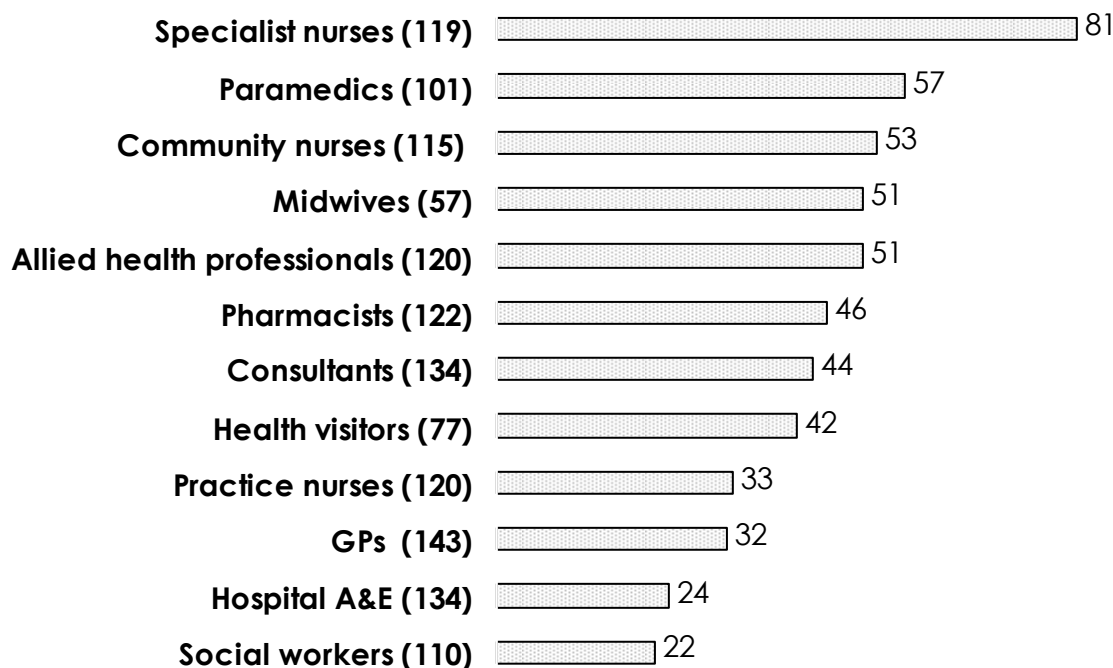
2.1 Understanding patients' needs

If patients' needs are to be met by local commissioning, the professionals involved must be able to understand those needs in the first place. This survey therefore asked its respondent patient and voluntary groups to indicate how good different healthcare professionals are at comprehending the needs of patients.

Who is good at understanding patients' needs?

% of responses from local groups based in England that stated "good " or "very good" (excluding "don't know").

Number in brackets denotes number of groups able to answer the question.



It would probably be fair to say that the patient organisations (and similar health-oriented advocacy groups) responding to the survey are well equipped to understand patients' perspectives. As such, far more respondents (81%) vote nurses that specialise in a single disease area (for instance, arthritis, cancer or diabetes) as "good" or "very good" at understanding patients' needs than any other category of health professional.

Paramedics, community nurses, midwives, and allied health professionals achieve a middling number of respondents' votes. Most other health professionals are deemed, at best, "adequate", or, at worst, "having no understanding" of the patient agenda. GPs, for instance—healthcare's primary gatekeepers—are regarded as "good" or "very good" at understanding patients' needs by only one third of the respondent groups.

"We only have limited anecdotal information on our members' experience of local health provision. It is apparent, however, that many local health professionals (including GPs) have little or no understanding of the needs of a person with ME. There are no specialist ME staff in our area."

—ME group; Greater London.

One senior executive of a Yorkshire and North Humber-based group specialising in poverty and health believes that health professionals do not devote enough time getting to know their patients:

"Over 20 years in the NHS, I worked directly with health visitors, midwives, and dieticians, before working in the voluntary sector. I have seen how little many of them relate to the people they serve. They don't spend time helping people to make informed choices, or acknowledge diversity, other than via

negative stereotypes."

Some respondents insist that even professionals familiar with the patient perspective may know little about the full ramifications of living with a particular medical condition. A speech disorder group from north-west England notes:

"Ambulance staff (and police and fire service) are not always aware of the needs of people with a laryngectomy—of their need to breathe through their neck, and that no water is to go down the stoma in neck. Don't throw water at them."

The Greater Midlands Cancer Network User Partnership considers that even specialist cancer nurses do not know "what is going on in the service".

Even when professionals do try to understand the patient view, they can be thwarted by bureaucratic considerations, argues a neurological group from southern England:

"The local MS professional team tried to introduce an excellent new care pathway, but were instructed to standardise with a generic system. We have a Local Implementation Team for Neurology (it includes a consultant), but the administrator keeps cancelling meetings, so there is no progress."

A patient representative from south-east England concludes:

"No—and this is the point! If healthcare professionals want to improve the patient experience, they have to engage with patients, and find out what their preferences and requirements are. The only example I know of is the Local Implementation Team. But this still has a long way to go."

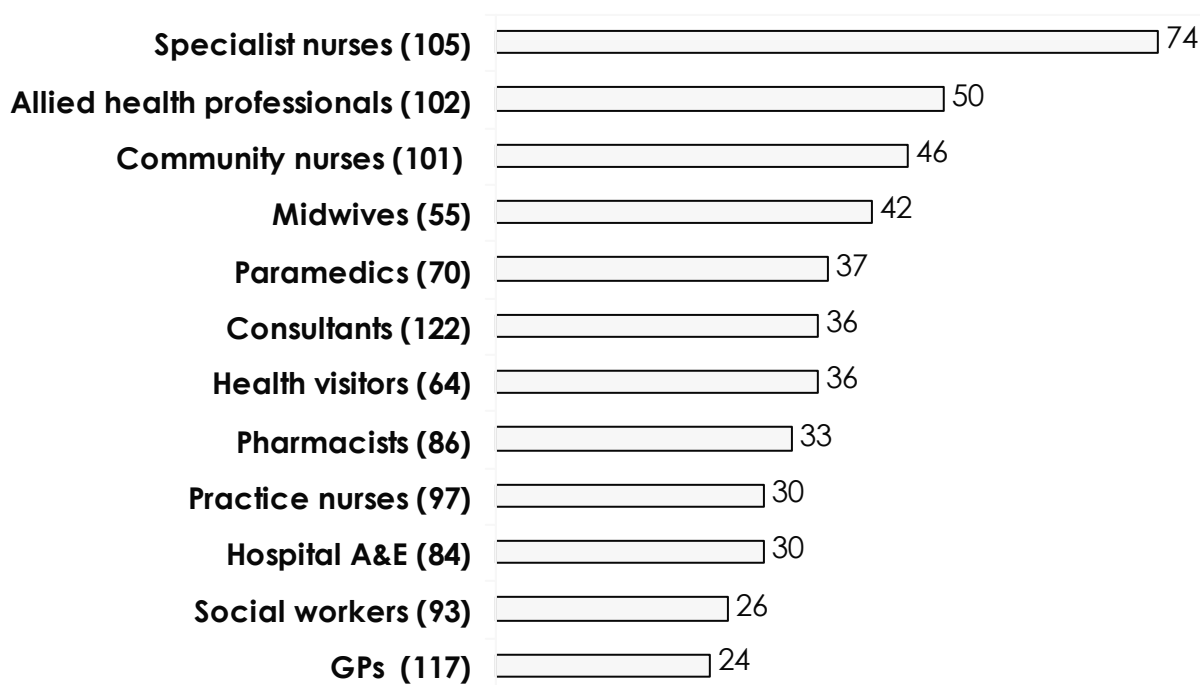
2.2. Designing care pathways

Another next key requirement for professionals operating in local healthcare commissioning is having the ability to design care pathways that match patients' requirements and needs.

Who is good at designing care pathways?

% of responses from local groups based in England that stated "good " or "very good" (excluding "don't know").

Number in brackets denotes number of groups able to answer the question.



In being able to design care pathways to match patients' needs, specialist nurses are once again judged as excelling over colleague health professionals. Nearly three quarters of the respondent groups believe that specialist nurses are either "good" or "very good" at such tasks. Some respondents single out for specific praise nurses with expertise in cancer, or heart disease, multiple sclerosis, orthopaedic services, palliative care, or rheumatology.

Only 36% of the respondent groups think that consultants are well equipped to design care pathways to suit patients' needs. The percentage of respondents saying the same about GPs is, at 24%, even lower.

Headway East London indicates that care pathways are not always a suitable tool in the care of people with complex conditions (such as brain injury)

"Many professionals are notionally engaged in the design of care pathways (though I can't comment on how many of them do this knowingly). Of those that are actively engaged in the process, none are able to pursue it meaningfully, because the concept itself is irrelevant. Unfortunately, the concept of the 'care pathway' is unhelpful in the context of profound irreversible injury, because it implies both a linear quality to the process of recovery, and a final destination—both of which are misleading."

"People with severe brain injury, for example, typically need support for the rest of their lives. The nature of these needs changes with time, and corresponds to life events, as well as to changes in health and function. To be useful, support services need to be responsive and non-linear in structure, and they also need to be open ended. Reliance on 'care pathways' delivered by health services will always lead to a situation in which people with brain injury are offered only pointless, cyclical readmissions to meaningless 'treatment'—processes that fail to address the underlying social systemic problems faced by these people."

While acknowledging the complexity of the task of designing care pathways, respondent groups also pinpoint several types of healthcare (or related) professional that they estimate could do better at incorporating patients' needs into the delivery of healthcare services. Thus:

"I know of midwives who do this, and they constantly undermine projects where ethnic minority work is working effectively (but they are not in charge of it) in order to give less profile to good work they don't personally deliver on. Institutional racism still plays a big part in how they work, and allows services to (not) develop".

—Group specialising in health and social issues linked to poverty; Yorkshire and North Humber.

"Physios do not always understand the whole issue, or the holistic approach required with fibromyalgia"

—Local group; south-east England.

"Social services commonly block access in order to keep their own costs down by the denial of any need"

—London Development Centre User Survivor Reference Group (an organisation specialising in mental health problems).

Although specialist nurses do gain many plaudits from respondents, a number of the groups make the additional observation that the design of care pathways could be improved if patients and patient groups were more directly involved in the exercise. These groups call

for greater inclusion within the designing and commissioning process.

"Designing care pathways to patients' needs is a complex process. Unless patients are actively involved in the process, it might not be efficient or effective. Collaborative pattern of work has proved to be both more efficient and more effective."

—Group specialising in health promotion and preventive care; Greater London.

"The voluntary sector should be at the forefront of this, along with carers, consultants, GPs, pharmacies, social services, LAs, LINKs, etc. Whatever pathway is set for one condition will not suit another. For instance, epilepsy will not suit motor neurone disease, will not suit MS, Parkinson's, Huntingdon's, cerebral palsy, etc. They will link in parts, but then split after. Huntingdon's does not involve medication, whereas epilepsy is controlled by finding the right drug and dose for the right person. One solution does not fit all."

—Epilepsy group; West Midlands.

One example of the active engagement of patients and patient groups in designing care pathways is provided by the MS Society:

"The MS Forum (a joint venture between health professionals and the Multiple Sclerosis Society) has designed, and is implementing, care pathways (following NICE guidelines) for the newly diagnosed, and for those with progressive MS. This is an ongoing project. The Forum won an award from the MS Society in the UK in 2006 for its work."

2.3. Implementing care pathways

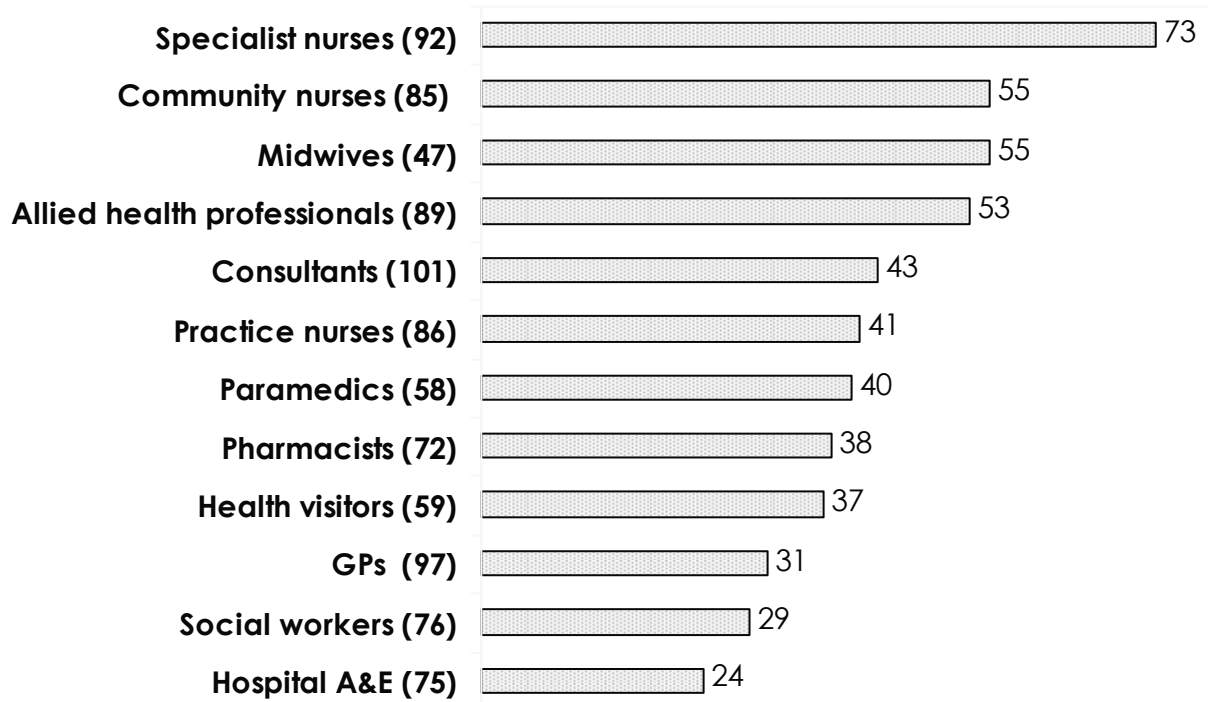
Once care pathways are designed, they have to be implemented. As a Greater London-based group specialising in myalgic encephalomyelitis (ME) emphasises, the most rigorously-designed care pathway is irrelevant if the appropriate healthcare professionals do not participate in its application:

“The ME clinic at Sutton produces adequate care pathways for its patients. But, when the patients are discharged, they are left to their GPs for treatment, with varying degrees of understanding.”

Who is good at implementing care pathways?

% of responses from local groups based in England that stated “good “ or “very good” (excluding “don’t know”).

Number in brackets denotes number of groups able to answer the question.



Again, almost three quarters (73%) of respondents view specialist nurses as best able to implement care pathways. Only 43% think the same of consultants, and 31% of GPs. A West Midlands group specialising in epilepsy explains why it believes that specialist nurses are better in this regard than doctors or other health professionals:

“GPs know nothing. Consultants do not have the time. Specialist nurses are crucial, and, in many cases, voluntary-sector charities can assist these. A newly-diagnosed patient will want to go away from the clinic thinking: ‘That was good. I got this information.’ At the moment, there is no information to hand in hospitals on a lot of these conditions.”

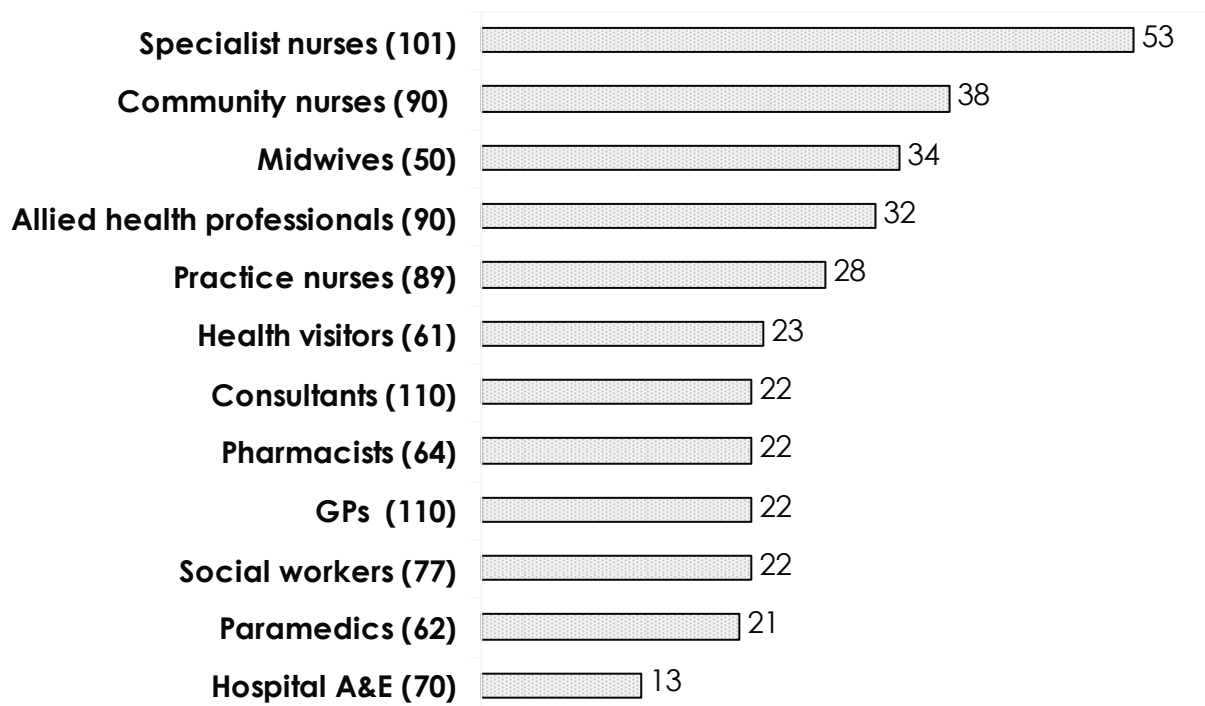
2.4. Obtaining patient feedback

Patient feedback is vital in discovering whether newly-implemented care pathways successfully meet the needs of patients.

Who is good at obtaining patient feedback?

% of responses from local groups based in England that stated "good " or "very good" (excluding "don't know").

Number in brackets denotes number of groups able to answer the question.



Over half of the respondent group see specialist nurses as "good" or "very good" at obtaining feedback from patients. Respondents offer two main reasons for the better performance of specialist nurses: 1.) They maintain excellent patient communications:

"Our nurse specialists, OTs, and physios are particularly good at verbal feedback."
—York Rheumatoid Arthritis Support Group (YORKRA).

And 2.), specialist nurses are thorough at managing data:

"Specialist nurses are very good at putting information onto the database, where it is retrieved by those able to interpret the information."
—Anonymous group.

Survey respondents provide several case studies of successful patient feedback:

“At the recent Diabetes UK patient conference in Portsmouth, a serious attempt was made to gain patient feedback about diabetes consultations with healthcare professionals.”

—Local group specialising in diabetes; southern England.

“Surrey and Borders Partnership NHS Foundation Trust has a commitment to ‘placing people at the heart of the way we do things’. There have been various initiatives including FoCUS [Forum of Carers and people who use Services] and the Standards for Involving People, which I developed. As a result, there is now far greater emphasis on services getting feedback from service users and carers. Some practitioners have taken this on board on an individual basis, but we are still fighting for more open evaluation of appointments with consultants and other doctors. It is these people who have most resistance to people being proper partners in their own care.”

—Patient representative; south-east England.

“The PCT supports local GPs in conducting patient experience surveys, as well as providing a robust Customer Care Unit to handle complaints, comments and compliments. The PCT also recently conducted a major listening exercise, under the umbrella of ‘Ambition for Health’, to listen to local people and other partner organisations’ opinions on local health services, and the priority areas for the local community.”

—NHS Trust; north-west England.

“Our local child-and-family unit sends out questionnaires annually to ask families who have used their services over the last year about the kind of experience they had. This year, they have involved us in designing the questionnaire as well.”

—Group specialising in ADHD; north-east England.

Respondent groups argue that the following factors need to be taken into account during any discussions on the subject of patient feedback:

- Many medical professionals (nurses perhaps least of all) are prevented from gathering patient feedback by lack of time.

“Medical practitioners have, in general, little chance to obtain the feedback from their patients, other than repeated prescription or other treatment.”

—Group specialising in health promotion educational programmes; Greater London.

- Feedback is ineffective unless gathered in a way that is meaningful to patients and/or their carers. More vocal patients can influence the agenda, while passive patients do not get their views aired. Feedback also needs to be obtained in the patient’s own language.

“Real feedback can be collated through the involvement of neutral agents outwith the system (such as following discharge, or by a voluntary-sector source).”

—Group representing the needs of older people; Norfolk.

- On occasions, feedback is biased by any relationship built between the person collecting the information and the patient.
- Failure to involve carers fully, notes one mental health group, or to realise that the patient may not understand what is being asked, will hinder any meaningful dialogue.
- A number of respondent organisations are concerned about being unaware that patient feedback is collected by

the healthcare system. These groups wonder how widespread such a practice might be.

- Finally, feedback can sometimes be ignored. An East Midlands respondent with expertise in public health and acute general practice warns that GPs and consultants can, even today, remain over-protective of their position and setting, and refuse to be influenced by feedback from local patients.

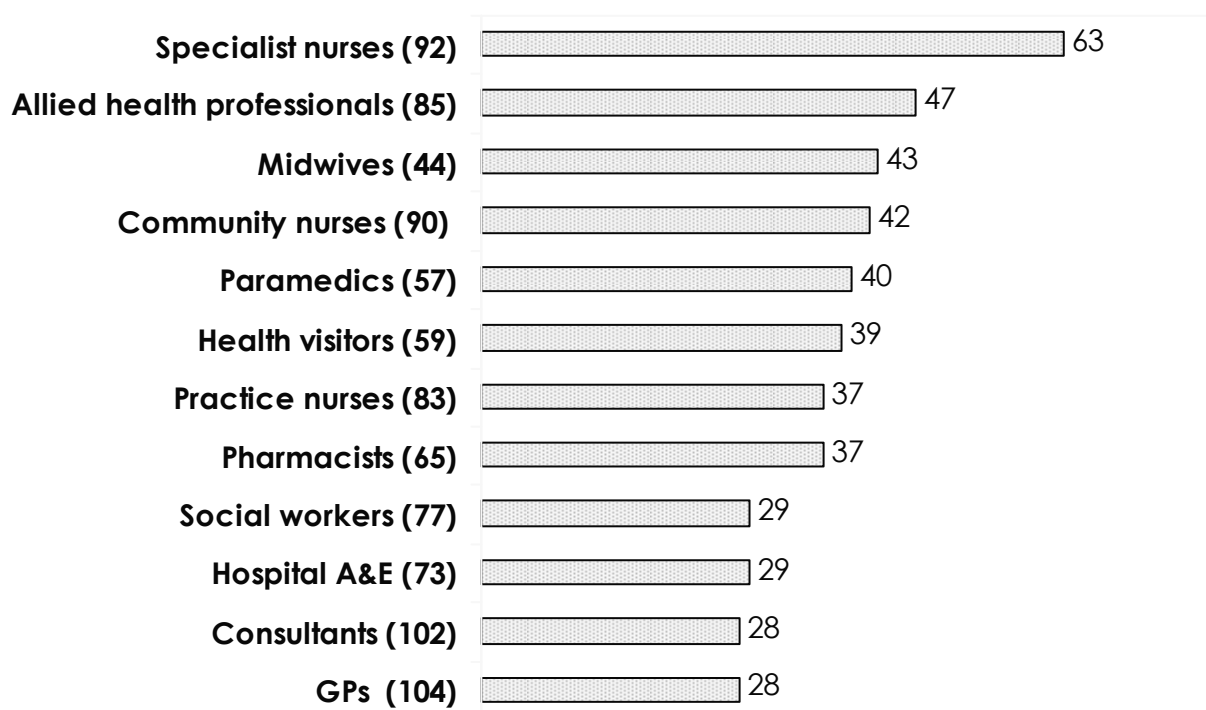
2.5. On transparency

For local healthcare commissioning to work, decisions need to be taken in an open, transparent, and non-prejudicial way. How good are health professionals at meeting those requirements? Patient groups answering this survey were asked to comment.

Who is good at being transparent and honest?

% of responses from local groups based in England that stated "good " or "very good" (excluding "don't know").

Number in brackets denotes number of groups able to answer the question.



Once again, specialist nurses emerge as the health professionals best at being open and honest (63% of the respondents think as much). Respondent groups regard consultants and GPs as the least transparent of the health professionals (only 28% believe that these two latter categories conduct themselves in an open and honest way). Some respondent groups, however, refer to a great deal of variety among the behaviour of professionals. Winchester District Advocacy Project also cautions:

“ ‘Poor’ scores are not generally a criticism of the profession concerned. They are a reflection of the overloaded and under-resourced way in which people are obliged to work.”

Respondents supply the following reasons why some healthcare professionals are perceived as more open than others:

- *Doctors seem to prioritise career motives over patient care.*
According to a Leeds-based group specialising in poverty-related health and social issues, a healthcare system overly focused on financial considerations has eroded the medical profession's interest in caring for patients:

"Obviously, there are good and hard-working, non-prejudicial professionals, but my experience in Leeds over the last 20 years has only shown me how this is manipulated, and how fewer people are joining the professions because they 'care' about others. Rather, these career paths are influenced by financial gain, and we have lost the understanding that spending public funds should serve people, and that we are not here doing 'favours'. But the inflexible and harsh business structures will not encourage positive changes to be a reality, despite policy 'development'."

- *Patients' faith in the medical system appears to be reduced by the sight of infighting among professionals.*
Lambeth Mental Health and District People's Action Group offers an example:

"Social workers and psychiatrists are often at loggerheads with each, as their agendas vary."

- *Nurses do not consult sufficiently with colleague professionals, to the detriment of patients.*
A group from north-west England that specialises in speech disorders elaborates:

"Clinic nurses, in my opinion, err on the side of safety. They don't always look at the

wider picture, and the individual needs of every different patient. Some patients have other medical problems, so nurses tend to go the safe route, instead of getting more senior advice, and having discussion with doctors. One glove does not fit all hands."

- *PCTs fail to feed enough guidance into the system.*

A respondent attached to a patient involvement group in Essex specifies:

"This area is one where the PCT needs to provide the right framework, including (at the planning stage) the criteria to be monitored. These criteria should also be the ones openly tabled, discussed, and agreed at any consultation regarding changes to service provision. The 'we-know-best' attitude needs to be tempered, even between health professionals and managers."

Perhaps the biggest barrier of all to openness among health professionals remains the paternalistic doctor-patient relationship that continues to pervade many parts of the NHS. Headway East London explains further:

"We deal primarily with the health services for adult mental health and physical disability, and my comments do not apply to other disciplines. In these areas, opacity is built into the health professions. In the area of brain injury, the idea of involving people in rehabilitation goal planning (for example) is a relatively new idea. The primary models for rehabilitation (such as inpatient rehabilitation wards) perpetuate practices and settings that are largely inappropriate, in which people often make gains—despite, rather than because, of the help on offer."

2.6. Some final notes on patient and public perceptions of healthcare professionals.

Survey results on patients' perceptions of health professionals' performance in relation to local health commissioning should be treated with some caution—for the following reasons.

Firstly, as noted by a group from north-east England that specialises in obsessive-compulsive disorder (OCD), professionals vary in the level to which they possess the skills necessary for local healthcare commissioning.

And, with many professionals typically involved in the drafting and implementation of care pathways within the local healthcare commissioning process, attributing virtues or faults to different health professionals may be difficult.

In some cases, problems are caused not so much by ineptitude, but by the vested interests of professionals getting in the way of the implementation of care pathways. Many of the professionals resist change, and “do not understand the new personalised systems”, says the London Development Centre User Survivor Reference Group.

A patient representative from south-east England poses a question:

“How do you define a care pathway? Something that is dictated by NICE, or something that has been properly negotiated between the healthcare practitioner and the patient? I'm sure that

certain healthcare practitioners may have attempted to apply NICE care pathways to me—but, in the main, without success. The care pathways that have worked for me have been the ones where I have been an equal partner in making decisions, and NICE guidelines have not come into it!”

Nonetheless, as an older people's group from East Anglia tells the survey, one clear message stands out: greater understanding between patients and health professionals leads to mutual respect and, almost inevitably, to improvements in care.

“Once people are engaged, respected as owning decisions, and have an input into resolving the major issues, and professionals respond innovatively to the needs of their communities, the challenges we face will diminish, with a decrease in the gulf between professionals, the voluntary sector, and the community.”

Section III: Involving the public, patients and their representatives

3.1. Patient and public involvement (PPI) mechanisms

Survey respondents were asked to comment on the mechanisms that exist to enable patient participation in the healthcare commissioning process. While a number of respondents did not know enough about such mechanisms to offer any opinions, the rest describe several systems of patient engagement, including:

- PCT mechanisms.
- Local Involvement Networks (LINKs).
- Overview and Scrutiny Committees (OSCs).
- Patient partnerships/forums.
- Other mechanisms.

A number of groups are dissatisfied with the mechanisms that allow patients and the public to engage with NHS policymakers and providers. A few think the mechanisms ineffective.

[For all of the respondents' comments to this section, see Appendix 3.1.]

3.1.1. What groups say about PCTs' PPI mechanisms

Primary Care Trusts (PCTs) have several means of engaging patients and the public. PCTs can, for instance, appoint patients as representatives to sit on their commissioning boards. Or, patients may participate in the Local Implementation Teams (LITs) that oversee the functioning of care pathways. A few PCTs, such as Cornwall and the Isles of Scilly, maintain an openly-declared PPI strategy in the commissioning process.

Since taking office in May 1997, the present Labour government has tried various methods of promoting PPI. The aim has been to encourage greater grassroots involvement in local healthcare decision-making (as well as to channel bottom-up information to policymakers in Whitehall). The latest such initiative is LINKs (Local

Involvement Networks), which replaced Patient and Public Involvement Forums (PPIFs) in 2008.

Comments listed in Appendix 3.1. reveal that former members of PPIFs feel aggrieved at disbandment. Meanwhile, a few respondents declare that “the jury is still out on the merits of LINKs”. Even so, the signs for LINKs seem good. PCTs are at least showing willingness to work with these new structures.

Aside from LINKs, PCTs also provide funds for the statutory Patient Advice Liaison Services (PALS). Although PALS do not represent patients as such, they are usually aware of local patients' concerns, and act as a valuable bridge between users and providers.

PCTs also run dedicated panels of patients or members of the public that sit on commissioning boards, or which examine specific aspects of health services.

Patient and other health advocacy groups may be invited to commissioning meetings or workshops arranged by PCTs. They can act as consultants or advisers to various parts of the NHS, functioning under the management of a PCT. They can also be actively involved in the design and provision of health services. The mental health group, Amaze, for example, reports that it helped in the setting up of a Parents' Carers Council, which is to feed directly into the PCT. Other groups refer to sitting on local National Service Framework Committees (such as for long-term conditions).

PCTs can encourage voluntary organisations to assume responsibility for administering local consultation processes with patients and the public.

One NHS administrative body from north-west England sums up its PPI initiatives:

“We provide a variety of opportunities for local people to have their say. We work closely with the local Councils for Voluntary Services (CVSs), patient groups, and other partner organisations, and we recruit patient representatives and other stakeholders to be part of the design and implementation of new services.”

The variety of the disparate public-involvement activities currently available are illustrated by the busy PPI agenda of one neurological group in southern England:

“1.) Attendance at PCT/Trust Board meetings. 2.) Membership of patient panels, PPI, etc. 3.) Membership of Acute Trust governing bodies. 4.) Focus groups run by the PCT. 5.) Direct access to NHS directors and commissioners. 6.) Membership of Local Implementation Teams. 7.) Membership of Clinical Network. 8.) Use of ad-hoc commissioning advisory groups.”

However, a long-standing patient advocate who has worked with the NHS for decades notes [see full quote in Appendix 3.1.] that no one has attempted to merge the diversity of PPI strands offered by PCTs (nor, indeed, does any hard and fast policy exist on how PPI should be effected):

“There is, at the moment, no organisation to pull things together, and consult with a wider public. And I consider this to be a serious disaster.”

3.1.2. What groups say about Local Involvement Networks (LINKs)

LINKs are a collection of local voluntary groups that have the ear of some PCTs in England. According to a patient representative in south-east England:

“The individual members of Local Involvement Networks (LINKs) are invited to attend all commissioning meetings.”

Bradford's LINK explains that it negotiates with the PCT via another network, called HealthNet Bradford.

Being a new phenomenon, LINKs are unsurprisingly referred to by only 10 of the survey's respondent groups.

3.1.3. What groups say about working alongside Overview and Scrutiny Committees (OSCs)

The Department of Health website states that every local authority with social services' responsibilities (150 in all) has had the power to scrutinise local health services since January 2003. OSCs take on the role of scrutiny of the NHS—looking not just at the ongoing operation and planning of services, but at the potential for major changes. Hopefully, they bring democratic accountability into healthcare decisions, and may make the NHS more responsive to local communities.

Only one of the survey's respondents, a cancer group from north-east England, mentions OSCs. It talks about how the local voluntary and community sector takes an active role in PPI and OSC work.

3.1.4 What groups say about patient partnerships/forums

Patient partnerships are alliances of users and service providers. One such among the respondents is the Shropshire and Mid-Wales Cancer Forum. The Forum describes taking part in an October 2008 regional conference that examined the challenge of raising public awareness of bowel cancer. Another regionally-organised body is the Mental Health Partnership Board, which frequently discusses care pathways. Yet another is the MS Forum.

3.1.5. Why some groups are disgruntled with PPI

Despite the apparent presence of extensive PPI facilities in England, 12 of the respondent groups outline why they believe the whole process of patient-public involvement smacks of “tokenism”. Asperger's Syndrome Access to Provision (ASAP), for instance, which is based in south-east England, says on the subject:

“Primary-Care Trust Partnership Boards that work only as long as you agree with their decisions. Communication between PCT and local stakeholders is virtually non-existent.”

Workshops and meetings can be announced at short notice, “to help commissioners with what they should already know”, cautions a group from Yorkshire and North Humber.

A coeliac group in south-east England feels that existing PPI procedures merely prevent public representatives from expressing their views:

"I was invited to the first meeting before signing it off. But I was not allowed to voice opinion or concerns. A very prominent GP overruled two gastric consultants."

A mental health group from the West Midlands reports a similar experience:

"We are invited to attend meetings that discuss strategies. But our input is often overruled or ignored, and we are merely a box ticked that service users have been involved—with no opportunity to genuinely and meaningfully involve service users, or to ensure the feedback and information imparted by us on behalf of service users."

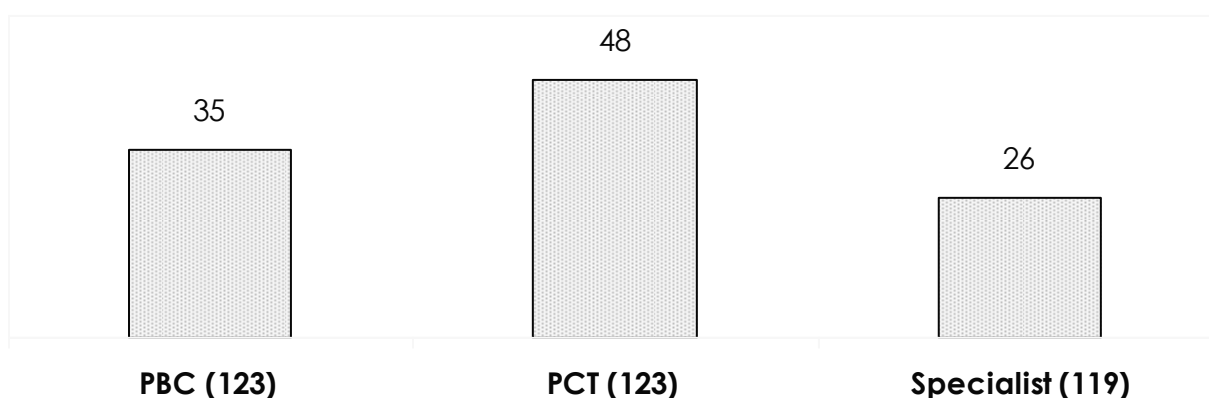
One anonymous group calls PPI a "cumbersome process". A group in Devon believes that PPI has been seriously compromised by the appearance of LINKs.

3.2. Experience with the different types of health commissioning

3.2.1. Has your organisation any experience with the three types of local healthcare commissioning?

% of responses from local groups based in England that stated "good" or "very good" (excluding "don't know").

Number in brackets denotes number of groups able to answer the question.



PBC = Practice-based commissioning, run at so-called 'practice'-level by groups of local GPs, nurses, and other healthcare professionals.

PCT = Commissioning at primary-care-trust level (sometimes described as 'world-class' commissioning).

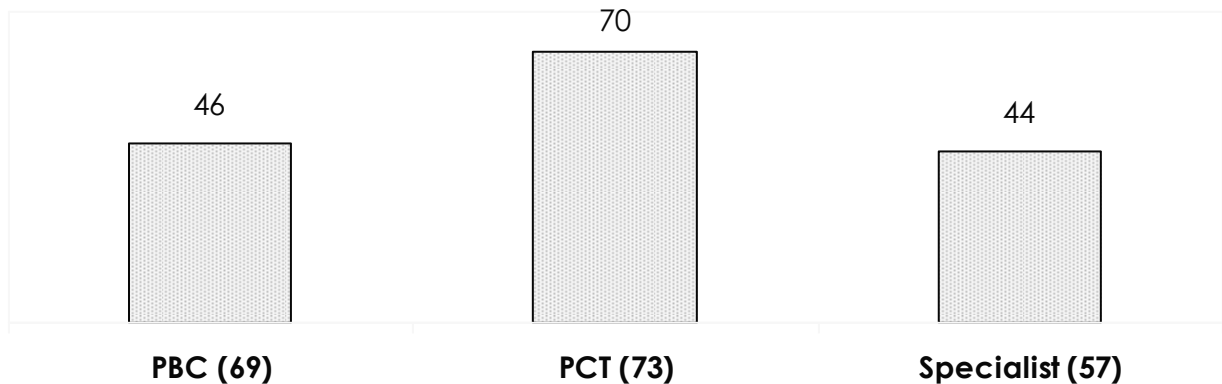
Specialist = Commissioning run by groups of PCTs at strategic-health-authority (SHA) level.

Respondents' involvement with commissioning ranges from mere attendance at meetings to more active participation (including decision-making on the commissioning of local NHS services). Although practice-based commissioning was originally intended by government to be the main driver of PPI, responses to the survey suggest that PCTs have primarily assumed that role.

3.2.2. Whether the three types of local healthcare commissioning have had an impact (good or bad) on NHS services

% of responses from local groups based in England that stated "good " or "very good" (excluding "don't know").

Number in brackets denotes number of groups able to answer the question.



PBC = Practice-based commissioning, run at so-called 'practice'-level by groups of local GPs, nurses, and other healthcare professionals.

PCT = Commissioning at primary-care-trust level (sometimes described as 'world-class' commissioning).

Specialist = Commissioning run by groups of PCTs at strategic-health-authority (SHA) level.

Taken together, 70% of the survey's respondent groups from England believe that PCT commissioning has had some impact (though, as one respondent points out, this could be for the good or the bad). The equivalent figures for practice-based commissioning and specialist-based commissioning are 46% and 44% respectively.

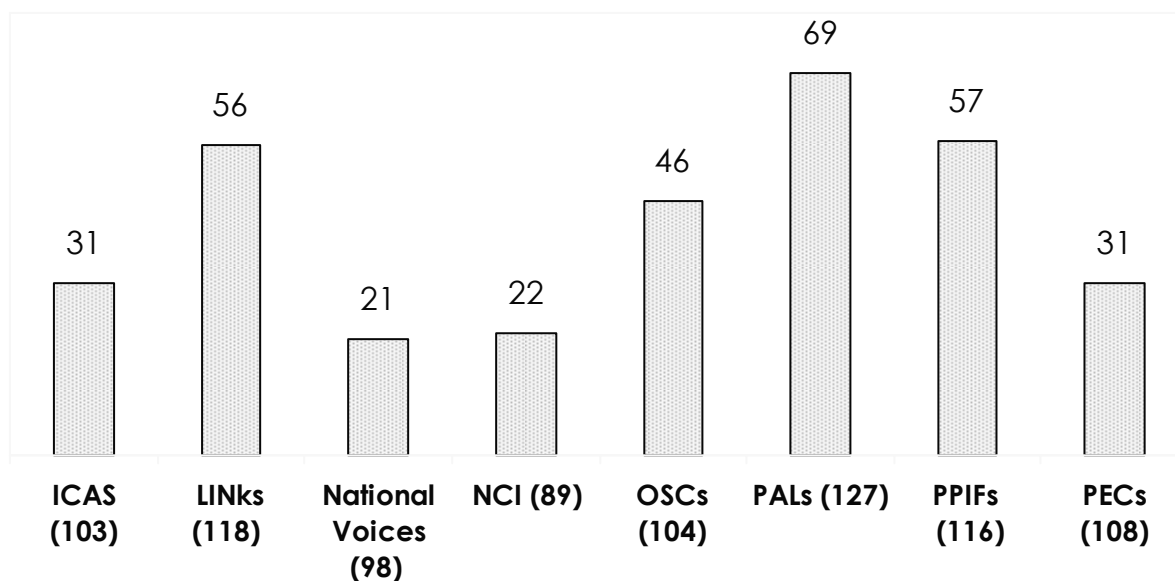
Extensive lobbying may sometimes be required to get results. Asperger's Syndrome Access to Provision (ASAP) of south-east England recounts being obliged to use the courts to ensure that the patients it represents had their needs addressed. Other respondents, such as the Grief Centre—Manchester Bereavement Forum, perceive commissioning bodies as more accepting, and better able to accommodate patients' views.

3.3. Experience with NHS agencies that have an interest in PPI

3.3.1. Has your organisation been involved with any of the following agencies?

% of responses from local groups based in England that stated "good" or "very good" (excluding "don't know").

Number in brackets denotes number of groups able to answer the question.



ICAS = Independent Complaints Advocacy Service.

LINKs = Local Involvement Networks.

NCI = NHS Centre for Involvement.

OSCs = Oversight and Scrutiny Committees.

PALs = Patient Advice and Liaison Services.

PPIFs = Patient and Public Involvement Forums [disbanded in 2008].

PECs = Professional Executive Committees.

The above-mentioned bodies have been created to enable patients to achieve some leverage over the NHS. But a number of respondents comment that patients and the public have only a limited opportunity to interact with these agencies. Other respondents draw attention to the abundance of agencies involved, and wonder why they cannot all work together. Amaze, a learning disability group based in Brighton and Hove, emphasises that, as with other aspects of PPI, the benefits wrought by the agencies can be geographically patchy:

"Some individual managers and healthcare professionals are genuinely trying to involve service users and carers. But major barriers exist which are not addressed—such as key people who cannot change their 'traditional' attitude to their work, and who continue to regard service-user involvement as a token gesture, a nuisance, or an irritation."

3.4. The types of support available to aid involvement in local healthcare commissioning

Respondents report that the support offered to patients and voluntary groups to promote their involvement in commissioning seems to be limited to the provision of small sums of money, inclusion at meetings (assuming the existence of infrastructure accessible to anyone with a disability), the supply of information, and—occasionally—some training. Health professionals (such as specialist nurses) or national umbrella patient organisations may help out with any of these.

Almost 50 respondents mention receiving no help. Other groups complain about never being given feedback to their input into the commissioning processes.

3.4.1. Support at practice-based level

One group refers to receiving training on PBC software, and being given expenses for attending PBC meetings.

3.4.2. PCT support

Eight patient and voluntary groups note receiving seed-corn funds from various local-government-supported initiatives and/or the local council. According to a member of the North Norfolk Older People's Forum, these small sums have been enough to "provide a newsletter, open meetings, and build a membership to represent the views of older people living in North Norfolk". A respondent who works with the London-based Alcohol Services Independent Forum references one PCT that runs Patient Experience Teams to support

voluntary groups interested in PPI. Patient and voluntary groups are then invited to meet the PCT at the launch of its commissioning strategies.

3.4.3. Support at specialist (SHA) level

Only three groups confirm receiving involvement support from SHAs—whether through an association with SHAs at monthly meetings, or through their contact with Local Implementation Teams.

3.4.4. Support by Patient Advice Liaison Services (PALs)

Respondents report that this occurs through the provision of information.

3.4.5. Support by Local Involvement Networks (LINKs)

Groups interested in getting involved in LINKs mention the receipt of training.

3.4.6. Support by Oversight and Scrutiny Committees (OSCs)

OSCs can mediate the commissioning activities of patients and the public to ensure that voluntary groups which make a contribution do not replicate activities occurring elsewhere in the local NHS.

3.4.7. Support by disease-specific bodies (such as the Cancer Forum)

Such partnerships can provide effective infrastructure and high-profile spokespeople to represent the interests of people with cancer in the commissioning structures.

Section IV: The way forward

Respondents to the survey were asked to propose ways in which local healthcare commissioning (LHC) could be improved to enhance the patient experience. Three aspects are considered by respondents:

1. The mechanisms by which the process of LHC can be improved.
2. Improving engagement of LHC among patients and the public.
3. The ideal outcomes of LHC (from the patient and public perspective).

[Comments relating to this section of the survey can be found in Appendix 4.]

4.1. Mechanisms by which LHC can be improved

The respondents propose several ways in which the process of local healthcare commissioning might be improved.

4.1.1. Commissioners need to be experienced at their job

Two of the respondents (both from the south of England) observe that commissioners are often inexperienced, and lack the ability to do the job effectively.

4.1.2. LHC needs to involve patients more

Large numbers of the respondents concentrate on a failure to consult the views of patients and the public in the commissioning, implementation, and feedback processes. A respondent representing the interests of patients within NHS services delivered in south-east England points out that ...

"If commissioning is going to enhance the patient experience, it is vital that patients and their carers are involved in the commissioning process."

Respondents argue that the tools used to bring about patient and public involvement (PPI) do not seem to be well thought out, consistent across the country, or integrated in their approach. These failings need to be overcome if PPI is to help frame the LHC

process [for more on ways to improve PPI, see section 4.2.). Some respondents add that when patients' views are collected, they can often be ignored or muted by the opinions of healthcare professionals (especially doctors).

4.1.3. Greater involvement of voluntary groups

A similarly large number of groups stress how important it is that the expertise of the voluntary sector be embraced by the commissioning process. A local voluntary-sector umbrella group that functions in the area of health, social care, and wellbeing advises commissioning bodies to ...

"Link with local patient groups/voluntary-sector forums, to engage and involve in the planning process those who receive the service."

Although patient groups and other voluntary organisations have been invited to take part in local commissioning, the approach appears not to have been comprehensive. Groups specialising in specific diseases can feel particularly sidelined.

A few groups stipulate that the so-called third sector is capable, in some instances, of occupying more than just advisory and oversight roles in local commissioning—voluntary groups can also plug obvious disparities in provision by supplying real healthcare services themselves. Comments on the subject include:

"The commissioning of voluntary services which fill the gap where health services are not currently provided (such as in cognitive rehabilitation)."
—Brain injury group; south-west England.

"Yes, we should be commissioned to provide services for people with MS!"
—Multiple sclerosis group; West Midlands.

4.1.4. Greater involvement of health professionals

Two of the respondents argue that the views of health professionals should be given more credence when local needs and priorities are assessed:

"Much greater analysis of local needs and local priorities—especially in relation to the most vulnerable groups. More responsive to gaps identified by frontline services, rather than relying on out-of-date statistical information."
—Mental health group; West Midlands.

4.1.5. Greater involvement of statutory agencies

One citizens' advocacy group believes that the untapped capabilities of statutory agencies—such as Patient Advice Liaison Services (PALs), or Local Involvement Networks (LINKs)—should be exploited in the commissioning process.

4.1.6. Commissioning must be more localised than it is now

Three groups—one representing the interests of people with a rare disease (Sjogren's syndrome); another a national pan-disability group; and a multiple sclerosis (MS) organisation from south-east England—call for an even more finely-tuned focus on the local level during the commissioning process. People's needs, insist these groups, vary according to where they live.

4.1.7. Commissioning must be more centralised than it is now

Two groups, on the other hand, press for more centralisation of purchasing services—especially for the rare conditions that affect only a few members of the public. Centralised commissioners can base their decisions on a larger selection of patients, thereby addressing needs more efficiently, and preventing endless duplication of effort across the country. One respondent argues that services for deaf people is such an example:

“The issues for very small minority groups (profoundly deaf people who use British Sign Language are 0.1% of the population) are specialist areas, and the incidence of patients in these categories is very rare in an individual practice. Providers of services for these patients, or organisations advocating for these patients, now have to go through the same educative process in every practice or PCT. Previously, we dealt with higher-level authorities who could commission services more intelligently, and purchase more effectively, because of the scale they were working on.”

—The Royal Association for Deaf People.

4.1.8. Commissioning must be speeded up

Two groups request that commissioning processes be accelerated, to enable patients with life-threatening or severely-debilitating conditions to access innovative treatments more quickly.

4.1.9. Commissioning must be less bureaucratic

The Local Involvement Network (LINK) based in Bradford describes the tendering process as unnecessarily complex, and

contends that groups like itself cannot always find the time required to assemble documents for tendering.

4.1.10. Commissioning must be more transparent

Eight groups call for greater transparency in local commissioning. The organisations would like language and procedures to be simplified, and commissioners to be more open about what the public can expect from the processes. A group from Yorkshire and North Humber specifies:

“Ensure that language support is used. Train PCT staff in how to communicate with people who don't work at their heels. Get them out of their ivory towers to meet real people, and see the actual impact of their decisions (they only come into our neighbourhoods when they want examples for positive publicity). Employ local people, and train them to gather the relevant information. Be honest and realistic with local people on what can, and what can't, be delivered. Help people make sense of red tape, and justify decisions with evidence of what has to be done. We get fed up being told that commissioners are transparent, when we know they are not. Third-sector staff aren't naive about the politics—we just want the commissioners to stop moving the goalposts.”

4.1.11. More investment—and clarify LHC's financial obligations

Seven groups raise different issues on the subject of financing. Some appeal for further investment; others wish money to be spent more wisely. However, all seem in accordance with denouncing a key LHC requirement—the necessity for costs to be cut—which, for two reasons, they regard as self-defeatist:

- Firstly, because any remit that concentrates on financial retrenchment sparks infighting between stakeholders who do not want to be the ones to have to spend the money. Once a commissioning pathway is designed, factional battles within the NHS as to who should shoulder the financial responsibility of those services lead to a negative effect on the patient experience.
- Secondly, a pursuit of savings prevents expenditure on services that may elicit better outcomes for patients.

One of the seven organisations advises:

"Remove the requirement for any practice-based commissioning initiative to save money. Equal cost with better outcome should be encouraged. Greater cost with significantly better outcome should be allowed."

4.1.12. A need for greater flexibility?

The survey generates no single solution to the numerous faults with the local commissioning process identified by respondents.

One fairly consistent theme that does seem to emerge from respondents' comments, however, is that the fragmentation of the local commissioning system appears to encourage little of the flexibility needed to exploit resources that would otherwise lie redundant (and which could be directed at purposes other than those for which they were originally commissioned). Headway East, the London-based mental health group, refers to this mindset when it indicates that local-

level commissioners are reluctant to send money out of a borough (even if doing so would allow patients to access facilities not available elsewhere). Many groups emphasise the system's lack of will to improve access through simple measures, such as GP home visits, or through recruiting voluntary groups to provide healthcare services [as mentioned in 4.1.3.].

Many aspects of local healthcare commissioning need to be tackled if the procedure is to improve. The previously-quoted member of the North Norfolk Older People's Forum summarises the situation as ...

"We need to build cohesive teams of professional and community activists. We need to maximise resources, consider new, innovative ways to deliver services, and to involve our community. Patients need strong representation, with an understanding of the issues, including: increases in the elderly population, decreased income, and the costs of drugs and new developments. We also need to provide opportunities to facilitate innovation, and to encourage teams to tap into resources (such as building flexible jobs to employ the experienced retired members within our communities)."

4.2. Improving patient and public involvement in LHC

Respondents suggest many means of improving the involvement of patients and the public (PPI) in LHC. [For the full set of comments, see Appendix 4.2., and some comments in Appendix 4.1./2. and 4.1./3.]

4.2.1. Less bureaucracy and complexity

A respondent who is attached to a diabetes group, and who replied to the survey in a personal capacity, deplors the innate bureaucracy of the NHS, which, she considers, can lead to prevarication during decision-making—to the detriment of patients.

If the commissioning process were simplified, patients might be more eager to get involved, stresses a cancer group from the West Midlands:

“The current healthcare provision is very complicated, and so it puts people off getting involved and giving their views.”

4.2.2. Greater involvement of patient and other voluntary groups

The groups responding to the survey clearly see themselves as specialists in understanding the patient/public perspective, and a facility that could be better utilised by the commissioning process. As an ADHD group in north-west England notes:

“Don't be afraid to talk to small local charities that specialise in one area (for instance, a particular disability). They can be a great source of help.”

Many respondents want to see patients' representatives appointed at every stage of commissioning. Says a mental health group from East Anglia:

“Commissioners should be seeking to have patient and public involvement in the entire commissioning cycle. Until this is achieved, commissioned services will always struggle to satisfy patient expectations.”

Respondents believe that such practice is relatively uncommon. Patient representatives only tend to be appointed to some (but not all) PCT commissioning boards, or to regional forums (partnerships) that look at specific diseases. Patients may be also be asked to contribute to Local Implementation Teams, which are charged with realising the blueprints drawn up by the local commissioners. To increase the chances of patients' views being taken seriously within commissioning circles, commissioning boards need to maintain a reasonable ratio of patients to managers.

As well as expertise and representative abilities, patient groups and similar voluntary bodies can bring another significant advantage to commissioning activities—superb infrastructure and networks for obtaining patient feedback. The Transverse Myelitis Society, for instance, explains that patients with this condition can be approached through its group leaders based in Poole/ Bournemouth, and seven other locations in the UK. The Society, which has 500 members with neurological disorders, also runs a national main committee.

4.2.3. Greater involvement of patients

The respondent groups argue for an active approach to the task of embracing patients in the local commissioning processes. A health advocate from the West Midlands who represents patients with cancer proposes:

"I do appreciate that everything has a cost, but I do think that a positive step would be for a follow-up letter to be sent to patients, carers, and even relatives of the deceased, asking their views on the treatment process. At the very least, this is a point of contact. It may well attract adverse comments, but they may well be valid, and may encourage that person to become more involved in the actual process of commissioning."

An organisation representing deaf-blind people in Greater London emphasises that people with a disability may be willing to help develop service priorities:

"Talk to us, and work with us (understand, too, that people with multiple and profound learning difficulties, challenging behaviour, and deaf-blindness have communication needs and a right to good healthcare)."

One local disability group believes that the public needs incentives to become involved in local healthcare commissioning. A group representing patients' interests in East Anglia states:

"Practice-based commissioning is key to many services now being commissioned. Some GP clusters lack input from patients at the strategy stage. One way to avoid pitfalls would be to ensure that the patients' model/pathway/objectives are agreed. The commissioning to meet those should then be much simpler, and not lead to patient dissatisfaction when the contracts are let. In our area, patient participation groups need to be developed, and would provide a patient focus."

4.2.4. Conduct more research among patients

Other respondents see the problem as not so much reaching out to patients, but for patients' opinions to be taken seriously during commissioning.

One way to achieve this might be for more use to be made of patient surveys as a platform to inform implementation processes. A group specialising in palliative care in south-west England provides an example:

"Carry out more surveys with groups of patients. One of our local PCTs has just done this with patients who have a neurological disease. The results are about to be discussed at appropriate levels in the PCT, in order for decisions to be made to improve services for these patients."

Another organisation in south-west England refers to the need to monitor patient experiences following the introduction of any new services:

"Routinely monitor patient experience of new services, and act on any issues that may need addressing."

A respondent associated with a group specialising in the neurological condition, progressive supranuclear palsy, thinks that a case can in fact be made for building a large databank of patient experiences.

4.2.5. More sensible strategies for the promotion of LINKs (and methods for ensuring their accountability)

Five groups recommend the following ways of putting LINKs on a firmer footing: prevent local authorities from overly

interfering in the introduction of LINKs; ensure that their creation is open and transparent; get health provider buy-in from the outset; track progress and bringing laggards to account; and invest more money into current networks of service users and carers (which form the bedrock of LINKs).

4.2.6. Alternatives for PPI

Not all respondents expect LINKs to have any effect on patient and public involvement in local commissioning. A group from south-east England that specialises in ADHD advises utilising simple market research tactics instead: chatting at street level “to the people who count”.

4.2.7. Greater powers for OCSs

Some respondents favour the involvement of agencies, such as Oversight and Scrutiny Committees (OSCs), at the beginning of any LHC exercise, and not after matters have gone wrong.

4.2.8. Greater support for PCTs, and for NGO interaction with them

One group urges PCTs to increase communications with the voluntary sector by appointing staff whose remit is liaison with NGOs:

“From a voluntary organisation point of view, it would be good to have a contact officer within the local PCT, to arrange monitoring and contracts between us.”

4.2.9. Enhanced public awareness of PPI

Many members of the public remain unaware that healthcare commissioning occurs at local level, and that it wishes to engage them. A respondent group specialising in diabetes asks that it be invited to commissioning activities, so that, in turn, it can promote the local commissioning cause to the parents and carers of children with diabetes. A group specialising in patient participation in south-east England recommends using advertising to encourage the public to become involved.

4.2.10. Remove barriers that prevent public involvement

Respondents identify all sorts of factors inhibiting patients and the public from becoming involved with local healthcare commissioning. Firstly, many people do not have the time to participate. A representative from a mental health group in south-west England notes that the same faces attend commissioning events because these are the people who have the time and means to do so. PPI should therefore strive to be conducted at the convenience of those who the NHS seeks to engage: the patients and the public. A representative from a disability group asserts:

“The Commissioners MUST shed the comfortable culture of expecting service users to go to them, at their convenience. They MUST replace that by reaching out to service users and carers—going out to where service users are (local libraries, pubs, cafes, schools, WI meetings, village halls, sports locations, music venues, etc). They need to do something about engaging younger people and those existing on benefits.”

'Shaping Our Lives', for instance, hosted a major project on benefit barriers to involvement, and the findings are available. Commissioners MUST pay heed to such projects."

4.2.11. Change the attitudes and practices of NHS staff

Twelve of the respondent groups submit that the concept of PPI should become accepted as part of the very fabric of the NHS, and not be thought of by NHS staff as merely a legal obligation or an onerous duty. Thus, a representative from Alcohol Services Independent Forum (AS IF) urges:

"By treating service-user involvement as a required 'mind-set', rather than an irksome legal obligation."

A mental health group from East Anglia warns:

"Until commissioners understand that their ways of working will need to radically change, so that the voices of service users and carers can be clearly heard and understood, patient and public involvement groups like ours will continue to fight an uphill battle."

4.2.12. Communicate in a more open and understandable manner

"Think-tank terminology"—the jargon employed by the NHS—forms a barrier in its own right to patient and public involvement, thinks an arthritis group from south-west England. Especially disadvantaged by the arcane parlance of the NHS are people with a communication disability (such as the deaf or blind). A national ADHD group proposes:

"Start some kind of outreach programme to let people know about local healthcare commissioning—but be sure to include a definition. We do want to commend you for sending our organisation this survey form, because that is, at least, a start. We're very sorry that we could not provide more helpful answers, but our lack of knowledge (and many of us are university graduates) is a very good indicator of the non-involvement of the public in local healthcare commissioning. Patient/public involvement is currently not very effective, because it is very difficult to access by the people who need to be involved."

4.2.13. Exploit local resources

One group counsels that commissioning should focus most heavily on what local providers are doing, rather than "build fancy PPI schemes on the backs of conglomerates of stakeholders".

4.2.14. Still a role for national commissioning

Last, but not least, three groups believe that certain disabilities (such as deafness), some medical conditions (such as rare diseases), and particular services (such as GPs communicating with their patients) might all be better commissioned at a national, rather than a local, level [see also 4.1.7.]. The respondents worry that the absence of a national approach may deny these latter areas the opportunity for improvement. Nationally-organised approaches, they say, would take advantage of economies of scale.

4.3. Ideal outcomes for LHC (from the patient and public perspective)

[For appropriate comments, see Appendix 4.3.]

As mentioned earlier in this report, the Department of Health has described the types of outcomes it hopes may be generated by local healthcare commissioning (LHC)—ranging from generally improved access to services, to attaining a system that delivers care around the patient effortlessly.

The patient groups and allied voluntary organisations that responded to this survey have outlined their own agenda for local healthcare commissioning. Their viewpoint emphasises how important specialisation is in the treatment of complex diseases:

- Easier access to services that are dedicated to specific medical conditions.
- A more holistic approach to medicine.
- Promoting patient information—especially if it can encourage choice and access to alternative methods of support.
- Better communications across the NHS (including email communication between GPs and patients).
- Dedicated centres to address the needs of people with a disability.
- Greater specialisation among health professionals, and—in particular—more specialist nurses.
- Deployment of non-medical professionals when relevant.
- Integration of carers into healthcare systems.
- Putting patients—rather than budgets—first.

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