

Patient **Insight**

**Harnessing the power
of public opinion**



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A handwritten signature in black ink that reads "Harry Cayton".

Harry Cayton
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The argument about why patients should be more actively engaged in their healthcare has been won. However, we know that many healthcare providers remain uncertain about how they can bring active involvement and participation about and how to use information from and about patients to improve their services.

Research from the Picker Institute, The Health Foundation and others shows how far away we are in England from healthcare that really meets the priorities and preferences of patients; cleanliness and safety, good communication, respect, accessibility and choice. Public services are not serving public need.

This report, *Patient Insight*, suggests how healthcare providers might systematically incorporate the experiences, views and preferences of their service users into their organisations' planning and performance measurement.

Patients and their families and friends, both individually and collectively, know a great deal about health services from the most important end – service delivery. We need to utilise this intelligence, these experiences, to guide and inform and make it part of the power of change.

The NHS may not have to depend on its patients for its income but it does depend on them for its social and political validity. In any service-providing organisation, learning from and about its customers should be core business.

Services should be designed with input from users, using the 'wisdom of crowds' and drawing on delivery-end experiences to inform providers about the usefulness of the services they provide. This approach is hardly innovative, but it may prove to be a new way of doing things within healthcare that will lead to improved services which are designed using the most honest and reliable information about the service – user satisfaction.

Services designed in such a way possess intimate knowledge of those they serve, they will have endurance and can adapt to their users' changing needs.

I should like to thank all the members of the *Patient Insight* working group for their time and thoughtful contributions to our discussions and also Helen Rowntree of Dr Foster, who has acted as our committee secretary, report writer, researcher and guide.

Introduction

In February 2006, Dr Foster Intelligence published *The Intelligent Board*. The report addressed the information challenge faced by NHS Boards. All too often board members were deluged by papers and reports, undermining their key role in focusing on strategic rather than operational matters.

To help boards be more strategic, *The Intelligent Board* identified a number of key domains or areas of performance, which boards should review regularly, including information about patients or customers. But beyond mandated national surveys and complaints data, the report found that many trusts were not collecting patient feedback systematically or using it intelligently.

A survey of board directors of acute trusts a year after the publication of *The Intelligent Board* found that customer insight was the area of information where board directors wanted to see most improvement.

This new report picks up on this deficit. It seeks to equip decision makers in organisations providing healthcare with techniques to improve how they engage with and listen to their patients so that they can ensure their services are centred on the needs of those using them, rather than those delivering them.

The report is aimed at those leading healthcare organisations providing patient care, whether primary, secondary or tertiary care in both the public and independent sectors. The report focuses on board members, but many of the principles it sets out are equally applicable to others, including senior managers or partners within a GP practice. It should also be accessible to anyone reading it: clinicians, managers, other non-clinical staff, patient and public involvement leads and patients.

Our approach is not intended to be prescriptive. Clearly the level of information that the board of a large acute trust will wish to review will be very different from how a GP practice might review data or feedback from its patients. Board members should adapt the information framework and principles set out in the report to meet their local circumstances.

The steering group focused on provider organisations given that commissioners will face a very different set of legal requirements, challenges and audiences in their engagement with patients and wider communities. Nevertheless we hope that commissioners may find the report helpful in suggesting some of the questions about patient intelligence they should be asking their providers.

The steering group

The report was developed by a steering group with broad experience of healthcare and patient involvement:

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Research and secretariat support for the group was provided by Dr Foster Intelligence.

The information deficit

In preparing this report, we were keen to understand how organisations are currently using information about and from their patients. We wanted to test assumptions and to guide the recommendations made later in this report. Our review looked at 12 NHS provider organisations covering a range of acute, specialist and mental health trusts and reviewed board papers and minutes of meetings covering a six-month period. It was a snapshot of current practice and was by no means comprehensive. However, a number of key findings emerged.



Data collection

There were considerable variations between organisations and often a lack of consistency between board meetings in terms of the types of patient experience information reviewed.

Trust board papers showed a high level of awareness of mandated annual patient surveys, but made little use of other data, particularly compared with information about clinical quality and performance.

Little use has been made of sources beyond the national surveys and complaints, in particular, Patient Advice and Liaison Service (PALS) data was rarely reviewed by boards.

Good practice: *Homerton University Hospitals NHS Foundation Trust receives instant feedback from patients to identify potential improvements and review progress. Results from standard patient surveys had proved to be too slow and the trust now uses electronic handsets to gather information from patients in ten areas, including inpatient wards, A&E and surgical centres. Clinicians and managers help to identify key issues to focus on and the questions can be adapted accordingly, including translation and Braille versions. The teams involved in the project receive feedback reports twice a week. Results and improvement plans are displayed on posters throughout the trust. This shows visitors how the trust is performing and what it is doing to improve. It also helps staff reassure patients where an issue has been raised, as they can show that the problem has been recognised and is being addressed. Jenny Negus, deputy director of nursing, leads the project. “Improvements can be difficult to measure and this project goes a long way in providing that information,” says Negus. “Trust departments knew what they wanted to look at and, while I provide support and ongoing development, it is the clinical areas that own the project. It is data about their area and their practice that we are analysing. It is a partnership and I help them look at ways they could improve their work.”*

Analysis and presentation

Many boards did not seem to have a systematic approach to the presentation and/or use of patient experience information in board meetings. Some trusts produced regular patient experience reports, which are presented and discussed at board meetings. Others reviewed data on a more ad hoc basis.

Some trusts incorporated patient experience indicators into their general KPI reports. However, these indicators were rarely the focus for board discussion.

Interpretation

Board items dedicated specifically to the experience of patients formed a relatively small proportion of the total items discussed by the board. Based on their own itemising systems, each trust discussed upwards of 100 items over the six-month period. The number of distinct discussions relating to patient experience data was low for all trusts, ranging from two items to 15.

Follow-up

Follow-up of information and discussion was varied. In many cases, patient information was noted by the board and neither discussed nor followed up. However, there were exceptions: organisations regularly reviewed complaints information and followed up serious issues. Some boards adopted a systematic approach to following up patient experience information, devising action points and tracking these in future meetings.

Mechanisms for involving patients in board decisions relied on lay members, often members of the PPI forum. However, their attendance was not always regular.

Patients' views seemed to be well reflected in discussions around service planning and redesign.

Good practice: Gloucestershire Partnership Foundation NHS Trust produces a quarterly Service Experience report that covers five different areas of public and Service User and Carer involvement and experience. The report is produced by Jennifer Berry, the Mental Health Development Manager, and is presented first to the Practice Standards Committee and then to the Trust Board. The report suggests follow-up actions for the various issues and themes that emerged from the quarter. The Practice Standards Committee discusses the suggestions and approves an implementation plan that is then included in the summary report sent on to the Board.

“One of the best things about pulling together this report is the insight it gives us into the broader concerns people are having with the Trust and their care. It helps us identify themes and ongoing concerns rather than just single incidents,” said Berry.

Groups that provide information for the report include:

- Strategic Service Units for Service User and Carer involvement
- Speak Out, a service user consultation group
- The Patient and Public Involvement Forum.

All PALS activity is covered by the report, as are complaints. Tables at the end of the report detail the numbers of complaints and divide them by topic and directorate. Every other report also includes a review of the Freedom of Information requests that shows the number and nature of requests received. Survey results, both interim and final, are also provided.

Good practice: York Hospitals NHS Foundation Trust produces a quarterly patient experience report, which is presented to, and discussed by, both the executive board and the board of directors.

The four-page reports are compiled by the patient experience team and cover complaints, PALS queries and PPI initiatives. The reports aim to cover everything from the specific to the general in a clear, concise format that is informative and useful. Marilyn Thirlway, the Trust's Patient and Public Involvement Coordinator, believes they accomplish this.

“Each report includes a patient case study,” she said. “This helps give everyone a better sense of how Trust policy and senior-level decisions translate into patient care and experience.”

The report contains information by directorate and compares the last two quarters as well as examines the yearly trend. Where necessary, action points are agreed by the boards for follow-up at a future meeting.

“In future,” said Thirlway, “I'd like to correlate the numbers more closely with the strategic work of the Trust and get more people involved. I think that following through and consistently looking at ways to improve our processes is one of the hardest things for anyone in healthcare to achieve. Time, money and other pressures often take priority.”

Reasons to do better

Healthcare organisations are by their very nature complex. Managers and clinicians need to balance a number of pressures and priorities from sound financial management to developing an engaged, enthused workforce. There are many well-rehearsed and well-evidenced reasons for why providers should focus on what their customers tell them and act on that information. System reform over the past two years has put in place a set of rigorous levers and incentives.

There are a number of reasons why organisations should ensure that systems are in place for customers to have the information they need to make decisions about their health and care.

Because information from and about patients directs improvement. Listening to patients identifies areas of strength and weakness for organisations, as well as potential solutions in relation to non clinical care in particular, leading to an improved experience for both patients and staff.

Because providers need to stay in business. This commercial imperative for organisations to listen to and act on customer feedback is entrenched in private sector service organisations. For healthcare providers, the introduction of payment by results, linking activity and outcome, choice and contestability means providing high-quality healthcare, responsive to patients' needs is essential for financial survival.

Because the regulatory framework demands satisfied and engaged patients. Providers need to demonstrate that they meet national targets and standards as regulated by the Healthcare Commission. While national targets and local systems of involvement are under review, it is unlikely that the emphasis on listening to, involving and engaging those using services will change.

Because information promotes more effective use of resources: equipping patients with more information about the clinical and cost-effectiveness of treatments will help them, or their purchasing agent, make more informed purchasing decisions.^{†1}

Because informed patients have better clinical outcomes: greater patient participation leads to better health outcomes by improving treatment compliance and self-management^{2,3,4} for patients.

Because informed patients are more satisfied: patients' perceptions of both the quality of care and their quality of life are associated with clinicians' ability to transfer key information to patients.⁴

Success story: *first direct has been rated the most recommended bank by an independent survey for the past 16 years. The bank has established a set of customer guarantees relating to the quality and responsiveness of its service and has successfully blended up-to-the-minute technology with a human touch. More than one in three of first direct's customers join because of personal recommendation. According to Peter Simpson, the bank's former commercial director, its success is down to working from the customer backwards – from the outside in. As Simpson says: "Today it's customers who choose how they wish to interface with your organisation, not you."*



AT A GLANCE: KEY DRIVERS OF SYSTEM REFORM

- 1 More choice and a stronger voice for patients. Patients are receiving more information to support choices about their healthcare.
- 2 Plurality of provision, with freedom to innovate and improve. More trusts have attained foundation trust status; more services are contracted to the independent or the third sector.
- 3 Money following the patient. Providers are now paid according to the activity they undertake in order to ensure there is an incentive to improve quality and efficiency.
- 4 Regulation and an accountability framework. To ensure patients receive the best quality, equity, access and value for money.

Source: The Intelligent Commissioning Board

[†]This is particularly powerful in the US model. As Kemper notes, "An information benefit is key to creating the health plan design that will attract employers looking for cost containing consumer-choice models of coverage"

Overcoming the information deficit

The NHS Plan set out the vision of a ‘health service designed around the patient.’ Seven years on from its publication, organisations are meeting this aspiration with varying success. There are a number of immediate steps which an ‘Intelligent Board’ might take in order to develop better relationships and a better service.

Develop your capacity and capability to collect, interpret and interrogate information.

Patient information is available from a wide range of sources and using a number of techniques and technologies. Ensure that you understand potential limitations of the data. Consider outsourcing the collection of data where you lack the internal capacity to do so.

Ask the right questions.

Challenge and discussion is the sign of a healthy organisation. Relying on a single source of information is never enough.

Be proactive in your relationships with involvement structures.

One current challenge for boards is operating within a period of institutional instability in relation to involvement structures. Local Involvement Networks (LINKs) are replacing forums. Organisations need to continue to engage with Overview and Scrutiny Committees (OSCs) and, if they are Foundation Trusts, their membership and governors. The challenge is to create a dynamic relationship with engagement and involvement groups and to facilitate an intelligent discussion.

Drive the spread of innovation and best practice throughout your organisation.

Healthcare providers are often aware of pockets of best practice, but less sure about how this can be embedded across a potentially complex system. Review systems for internal learning and take a clear leadership role in communicating innovation and encouraging improvement.

Be open in your relationships with staff and patients.

In the era of choice, being transparent is not necessarily perceived to be in the provider’s interest. However, organisations claiming commercial interest as a justification for a lack of transparency will not win the trust of their local communities and patients.

Success story: *The John Lewis Partnership (JLP) was voted Britain’s favourite retailer in February 2007 for the second year running, and in March, JLP was voted Retailer of the Year at the annual Retail Week awards. All permanent staff are partners in the business that includes 26 John Lewis department stores, 183 Waitrose supermarkets and a turnover of nearly £6 billion last year. Each of the 68,000 partners shares in the benefits and profits of the business, which last year was the equivalent of nine weeks’ pay. In the words of Sir Stuart Hampson, chairman of the group until recently, “(It’s) clear that co-ownership is the starting point, but its power only clicks in when combined with the full engagement of employees in ‘co-creation’ of value”.*

Support the relationship between the professional and the patient.

An individual’s healthcare experience is often defined by their interaction with the professional. Boards should ensure that systems are in place to develop an informed relationship where decision-making is shared, but recognise that impact on this very personal sphere will be restricted by a number of complex factors.

Encourage an ethos of customer care.

Hundreds of thousands of interactions take place in the health service each day. As a board, review whether you have standards in place in relation to customer care that are understood by all staff as comprehensive, ongoing initiatives and that adherence to the standards will be consistently evaluated. Ad hoc intelligence-gathering projects are useful for specific answers or to solve specific issues, but should be used only as a supplement to sustainable programmes of customer care.

Follow-up issues and ensure that decisions are acted upon.

Identify clear action points as a result of discussions and make sure that you act on the information you have collected.

Incorporate patient-defined quality standards into SLAs.

Use national and local data to identify key standards from the patients’ point of view

(respect, transparency, good information, response to questions, privacy during examination, access to their own data). Include these in all commissioned SLAs both by PCT and by PBC.

Use patients as teachers.

This process helps to define good practice from the patients’ points of view and teaches that to professionals. In addition, good-practice patient-derived guidelines are written as part of the process.

Boards to look at one clinical area in depth per meeting from the patients’ viewpoint.

Gather information from PALS reports, national data, local Discovery interviews or other satisfaction reports. If they don’t exist, then they should and the clinical leaders should be encouraged to get simple data on which to base change.

Primary care commissioners can include patients in key data processes such as identifying priorities for change, monitoring quality and discussing the application of any savings that have been made.

Information framework

The table below is divided into two sections – information about and from patients and information for patients. It looks at the key questions boards might ask, the type of information that might be reviewed and potential sources. Where national data are available, organisations should benchmark

INFORMATION ABOUT AND FROM PATIENTS		
Question	Type of information	
<p>Who are we providing services for? What are their health needs?</p>	<p>Population and demographic make-up, current and projected:</p> <ul style="list-style-type: none"> breakdown of local population by age, gender, deprivation and ethnicity public health indicators, for example mortality rates (overall mortality rates and cause, e.g. CHD), morbidity rates, risk factors, hospital admissions (acute and mental health), birth rate current and projected hospital admissions by source of referral information about health behaviours – such as marketing information 	
<p>What do patients say about our services?</p>	<p>Patient feedback on services/providers (themes of staff attitude and responsiveness, whether patients are treated with dignity and respect, complaints, cleanliness, communication etc)</p>	
<p>What sort of service do our customers want? What are their preferences?</p>	<p>Feedback from commissioners, public, patients and key stakeholders</p>	
<p>What impact do we have on patients' health?</p>	<p>Patient-reported outcome measures Clinical outcomes/efficiency measures, such as outlying readmissions or long lengths of stay DNA rates</p>	

their performance wherever possible with their peers according to either case mix or local population make-up. Trends should also be reviewed over time, so variations in performance and improvement can be monitored.

Sources	Comments
Office of National Statistics Compendium of Clinical and Health Indicators Patient Administration Systems (PAS) Secondary Uses Services (SUS) Health survey for England Public health common data set National and local public health observatories Joint Strategic Needs Assessment (JSNA)	Information for: <ul style="list-style-type: none"> • Primary care trusts • Strategic health authorities • Foundation trusts • Acute trusts • Local and national public health observatories Gathered and reviewed: <ul style="list-style-type: none"> • Annually – mortality, morbidity and population health inequality information for strategic planning • Monthly – activity updates and outcome measures by the SHA, acute trusts and primary care trusts to keep plans relevant and up-to-date
National patient and GP surveys Complaints and compliments PALS data Service-specific feedback NHS Choices website Spot-checking and local patient questionnaires Expert Patients Programme (EPP)	Information for: <ul style="list-style-type: none"> • Primary care trusts • Strategic health authorities • Foundation trusts • Acute trusts • General practices Gathered and reviewed: <ul style="list-style-type: none"> • Annually – national surveys for a broad overview of care provided; this is a national requirement • Quarterly – progress reports to PCTs and SHAs • Real-time – responses implemented at a local level (GP practice, trust ward, clinic)
Overview and Scrutiny Committees Local Involvement Networks (LINKs) Commissioners EPP National patient organisations Marketing/behavioural data JSNA Targeted focus groups and other commissioned stakeholder research	Information for: <ul style="list-style-type: none"> • Primary care trusts • Local authorities • Strategic health authorities • Foundation trusts • Acute trusts Gathered and reviewed: <ul style="list-style-type: none"> • Annually – health needs assessment review through public consultation • Quarterly – feedback from local partnerships working with patient and public groups
Local reporting using validated outcome methods, eg SF-36 and EQ5D PAS SUS Patient Reported Outcome Measures (PROMs)	Information for: <ul style="list-style-type: none"> • Foundation trusts • Acute trusts • Primary care trusts • General practices • Strategic health authorities Gathered and reviewed: <ul style="list-style-type: none"> • Annually – Department of Health, SHA and PCT surveys • Monthly – review of outcome data by hospitals, PCTs and GPs

Information framework

INFORMATION ABOUT AND FROM PATIENTS CONTINUED		
Question	Type of information	
Are staff supported and able to provide the best patient care?	Feedback from staff and patients	
INFORMATION FOR PATIENTS		
Do patients have access to the information they need to make decisions about their care?	Targeted feedback on whether patients have adequate access, for example, to decision aids, information signposting, etc	
Do patients have access to their health information?	Targeted feedback on whether patients have adequate access to their health records, e.g. Healthspace, referral/follow-up letters	
Do patients get high-quality customer service?	Assurance that customer service standards exist and that staff receive necessary training	

Sources	Comments
National patient, GP and staff surveys, plus locally collected information	<p>Information for all organisations</p> <p>Gathered and reviewed:</p> <ul style="list-style-type: none"> • Annually – national surveys • Potential for local surveys to be carried out more often with local implementation and change policies
National patient and GP surveys Complaints and compliments PALS Service-specific feedback Spot-checking and mystery shopping NHS Choices website Healthcare Commission website	<p>Information from:</p> <ul style="list-style-type: none"> • Acute trusts • Foundation trusts • Private healthcare organisations • Primary care trusts • Local public health observatories • General practices <p>Information should continually be gathered and reviewed. Websites can offer insight into local and national services, and there is potential for PCTs to provide more evidence-based recommendations for patients on quality and choice in line with local and national data.</p>
Complaints and compliments PALS Service-specific feedback Spot-checking and mystery shopping EPP Freedom of Information	<p>Information from:</p> <ul style="list-style-type: none"> • General practices • Acute trusts • Primary care trusts <p>Patients currently have to request in writing and provide payment to receive access to their personal medical records. Choose and Book provides access to the booking process and with the development of the Electronic Patient Record (EPR), the future may provide patients with direct access to their own records.</p>
Trust policy and standardised approaches to staff appraisal Healthcare Commission	<p>The annual health check of providers and commissioners published by the Healthcare Commission gives an overview of services. There is the potential for more dedicated customer-service initiatives at hospital, PCT and GP levels.</p> <p>Additionally, the NHS Operating Framework and world-class commissioning policies include plans to review PCT performance, something that could help patients and the public gauge the quality of customer service.</p>

Appendix: Checklist for boards

The list below is compiled from the suggestions outlined in this report. As a board, you may wish to consider whether you need to change your practice or behaviours.

Do you make information publicly available wherever possible?	
Do you base decisions on multiple sources of information?	
Do you combine types of information? In particular, experiential and demographic information	
Do you review systems rather than monitoring feedback from every service?	
Do you review systems for sharing good practice?	
Are you aware of areas of good practice within your own organisation? Locally? Nationally?	
Do you challenge information and ask questions of others?	
Do you identify clear action points as a result of discussions?	
Are these action points followed up and monitored?	
Are customer-care standards in place?	
Are relationships with local engagement structures constructive?	
Do you have a regular board agenda item reviewing the difference PPI has made to patients?	
Do you gather feedback from your staff about patients' needs and preferences?	
Do you assess the impact on patients of new policies and service changes?	
Do you build patient focus into your appraisal process?	
Do you and your board set aside time to make regular site visits across the organisation and talk to clinical and non clinical staff?	

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Case Studies

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York Hospitals NHS Foundation Trust

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first direct

The John Lewis Partnership

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