



Patient Information Forum

For Professionals Working in Consumer Health Information

Full Report

Making the Case for Information

The evidence for investing in high quality
health information for patients and the public

Credits and acknowledgments

Credits


The Patient Information Forum (PiF) is the organisation for people working in consumer health information. PiF campaigns to ensure that consumer health information is central to high quality, patient-centred care and helps providers develop high quality information for their patients and the public.





PiF (www.pifonline.org.uk) is a not-for-profit, independent organisation with members in all healthcare sectors and in every country in the UK.

This report is possible thanks to funding from the Department of Health's Innovation, Excellence and Strategic Development Fund and from Macmillan Cancer Support (www.macmillan.org.uk).

It has been researched and written by Paul Treadgold and Carol Grant from Grant Riches Communication Consultants (www.grantriches.co.uk).

Acknowledgements

This report has benefited greatly by inputs from many people who have kindly contributed their time, ideas, comments and material. PiF and the authors would like to express their thanks to everyone involved for their help and support with this project, and especially to our expert interviewees and reviewers (as indicated by ):

- **Ruth Carlyle**, Acting Head of Information, Financial and Work Support and Information and Support Policy Lead, Macmillan Cancer Support
- **Jocelyn Cornwell**, Director, The Point of Care programme, The King's Fund
- **Angela Coulter**, Director of Global Initiatives, Informed Medical Decisions Foundation 
- **Mark Davies**, Executive Medical Director, NHS Health and Social Care Information Centre
- **Kim Diprose**, Information and Support Programme Manager, Macmillan Cancer Support
- **Colin Douglas**, Director of Communications, NHS Commissioning Board
- **Jo Ellins**, Principal Consultant, GHK Consulting (formerly Lecturer at the Health Services Management Centre, University of Birmingham) 
- **Bob Gann**, Director of Partnerships and Strategy, NHS Choices
- **David Halsall**, Principal Operational Research Analyst, Clinical Quality and Efficiency Analytical Team, NHS Commissioning Board
- **Amir Hannan**, General Practitioner, Haughton Thornley Medical Centres (Hyde) and CCG member, NHS Tameside and Glossop
- **David Land**, Intelligence and Research Team, Macmillan Cancer Support 
- **Anna Liebowitz**, Head of Cancer Information Development, Macmillan Cancer Support
- **Colin MacKenzie**, Contract Director, The Information Standard
- **Mike Pyrah**, Founder of the Social Value Foundation and former NHS Chief Executive and Board Member of NHS Employers.
- **Helen Rowntree**, Director of Strategy and Digital Media, NHS Choices
- **Adrian Sieff**, Assistant Director, The Health Foundation 

Contents

Executive summary	4
1 The brief	19
2 Our approach	20
Methodology.....	20
Academic literature review.....	20
Grey literature review.....	20
Limitations of the research.....	20
Structure of the report and framework for analysis.....	21
3 Context	22
Healthcare in the UK is changing.....	22
Finances are tighter than ever.....	22
Patients are at the centre of health policy-making.....	23
A push for patients to engage in their own healthcare.....	24
Patients need information in order to engage.....	25
Information is the key to improving patient experience.....	26
Improving patient experience has wider benefits.....	27
Section 3 - References.....	28
4 The Information landscape	30
Patient information is now on the agenda.....	30
The main levers for making the Case for Information.....	31
Yet there is still some way to go.....	34
Patient satisfaction with information and communication.....	35
What information do patients want?.....	35
Sources of health information.....	36
Information provided by health professionals.....	36
Health information online.....	37
Supporting patient choice.....	38
A perfect information journey?.....	40
Ensuring informed consent.....	41
Improving health literacy.....	41
Investing in health information.....	43
The harms of not investing in health information and support.....	43
Section 4 - References.....	45
A simplified model of the Case for Information.....	48
5 The business case for investing in consumer health information	49
Section 5 - References.....	52
6 Patient engagement, service utilisation and health costs	53
Section 6 - References.....	55
7 Enhancing patient experience	56
Section 7 - References.....	60
8 Patient engagement, health behaviour and status	62
Section 8 - References.....	64
9 Providing health information – what works	65
Section 9 - References.....	68
10 The Patient Information Forum’s view	69
11 Quality standards	70
12 Recommendations for further work	71
Section 12 - References.....	72
Appendix - Main levers to support the Case for Information	73
Moral and ethical levers.....	74
Policy and legislative levers.....	75
Service priorities.....	78
Financial levers.....	81
Going forward	82

What is the evidence for investing in high quality health information for patients and the public?

The provision of health information to patients and the public is now firmly embedded in health policy across the UK. There are powerful legal, moral, ethical and financial incentives for providing quality information to enable people to better manage their health and wellbeing and make fully informed decisions about their treatment and care. Providing access to good quality health information, and the support to use it, is the key to unlocking much sought after and much needed patient and public engagement.

Yet information for patients, in most places, remains a 'nice to' instead of a 'must have'. Investment in the development and delivery of health information is often uncoordinated and in many cases absent. Whether an individual receives information to support their care is currently a lottery. Despite the rhetoric, we are a long way away from truly informed decision making for all.

Health information for patients and the public needs investment and a coordinated and systematic approach to delivery. Policy makers, clinicians and commissioners must understand why providing high quality information is so important, and what failure to do so means. This Case for Information does just that. It identifies and sets out the evidence about the benefits of providing, and the harms of not providing, high quality health information for patients and the public.

The case is compelling:

- The evidence shows that providing high quality health information is beneficial. It has a positive impact on service utilisation and health costs, patients' experience of healthcare and patients' health behaviour and status.
- Providing access to quality health information and support is crucial to unlocking what has been termed the 'blockbuster drug' of patient engagement. Patient engagement is vital to help people manage their health, make informed decisions about their healthcare, and mitigate financial pressure on the health service.
- There are good business reasons to justify the need for commissioners and providers to invest more resource (time, money and training) in health information provision and support. These reasons include positive impacts on service use and costs, substantial capacity savings, significant returns on investment by increasing the self-management of long-term conditions and attracting customers.
- Providing consumers with high quality and accessible health information helps to enhance patients' experience of care, which is core business for the NHS and an important motivator for staff. It forms part of the statutory duty of quality for board members - both a 'must do' and the right thing to do.

- Evidence from this review points to the most effective ways of providing consumer health information and maximising its impacts, including information tailored to the individual which addresses health literacy needs and which is supported by health or information professionals.
- The advantages of improving access to good quality information (and the equally clear drawbacks of not doing so) are so great that consumer health information services

must be properly planned and appropriately resourced. This requires dedicated budgets and clear lines of responsibility and accountability. To do any less will continue to diminish patients' experiences of healthcare, compromise their safety, health status and wellbeing, and waste increasingly scarce public resources. Given the weight of the evidence contained herein, to not support patients and the public with better information, is bordering on negligence.

PiF calls on commissioners, clinicians and providers, and the broader health and care system, to commit to investment in information and support services and to recognise that:

- Information is **an intervention** that impacts health and wellbeing and it contributes to all three aspects of quality: clinical effectiveness, safety and patient experience.
- Information must adhere to **quality standards**. It should be user tested, co-designed and co-produced where possible. Information must also be designed to meet different levels of health literacy.
- Information production is a **highly skilled** activity and those who do it need an infrastructure and learning and development opportunities.
- Information provision must be **integrated** into health and care delivery. Healthcare providers should have a Board Director responsible for the provision and monitoring of information and support, with dedicated personnel and resources to deliver it.
- Health and care professionals should offer information as part of a **shared decision making** process. The most helpful information and support is personalised to the person receiving it: one size does not fit all.
- The **impact** of information provision must be measured. The information given to an individual should be recorded in their care record. It is not enough to measure the volume of information provided: behaviour change and financial impact should be measured too.



The report

This report aims to identify evidence on the benefits of providing, and the harms of not providing, high quality consumer health information.

Consumer health information (CHI) is defined as information and support provided to help patients and carers understand, manage and/or make decisions about their health, condition or treatment.

High quality means effective information, which meets the needs of users and empowers them to make choices and take control of their health and wellbeing.

The full report sets out the detailed findings based on an extensive review of the academic and grey literature, and interviews with a broad range of experts in this area.

The principles and concepts contained in this report are intended to be broadly applicable across the UK health and care system(s), even when the narrative is focused on a particular country.

Patient engagement is vital to help people manage their health, make informed decisions about their healthcare, and mitigate financial pressure on the health service. Providing access to good quality health information and support is key to unlocking what has been termed the 'blockbuster drug' of patient engagement.

Healthcare in the UK is changing, with major structural change in England implemented in April 2013. The challenge across all UK nations is to provide high quality, patient-centred care in the face of rising demand, tightening financial constraints and demographic changes.

Patients are at the centre of health policy-making. For example, in England, the intention is that shared decision-making should be the norm - 'no decision about me, without me'. In Scotland, this is expressed as the concept of a 'mutual' health service.

Achieving patients' active engagement and involvement in their healthcare has become a key goal for policy-makers and is central to government plans for the NHS. This includes ideas of shared decision-making, self-care/self-management and personalised care planning.

Financial and service pressures mean that patient engagement is now seen as a necessary part of a more modern and efficient health service rather than as a 'nice to have' extra.

Research shows that engagement improves patients' knowledge, experience and satisfaction, reduces costs through greater self-care/self-management and more appropriate use of services, and leads to improved health behaviours and adherence to treatment.

Patients' ability to engage depends on finding and using health information to increase their understanding, and being supported to develop the motivation, confidence and care skills needed to actively manage and improve their own health. There is clear evidence that more active patients enjoy better health outcomes and incur lower costs.

Investing in high quality consumer health information and support, therefore, is not only the right thing to do from an ethical standpoint as a crucial element of patient-centred care; it is also a financial and clinical imperative.

More needs to be done to encourage patient involvement. In England, the Care Quality Commission has concerns about people not being properly involved in decisions about their care.

Delivering a positive experience of care for patients is as important as the treatments they receive. Information is central to this and is one of the eight areas that the National Quality Board's NHS Patient Framework sets out for measuring patient experience in England.

Achieving better patient experience is not just important on moral grounds. It also brings wider benefits in terms of improved outcomes and reduced service costs. Research also shows that health services which score well on patient experience also perform well on clinical quality.

Such findings endorse the view that access to good quality health information, education and support is key to unlocking what has been termed the 'blockbuster drug' of patient engagement.

The information landscape

The advantages of improving access to good quality information (and the equally clear drawbacks of not doing so) are so great that consumer health information services must be properly planned and appropriately resourced. This requires dedicated budgets, clear lines of responsibility, accountability and governance. To do any less will continue to diminish patients' experiences of healthcare, compromise their safety, health status and wellbeing, and waste increasingly scarce public resources.

Policy framework

Information, and access to it, is now firmly embedded in health policy across the UK - including in the NHS Constitution and the Health and Social Care Act 2012 (in England), the Patient Rights (Scotland) Act 2011, Together for Health (in Wales), Quality 2020 (Northern Ireland) and in professional codes of conduct.

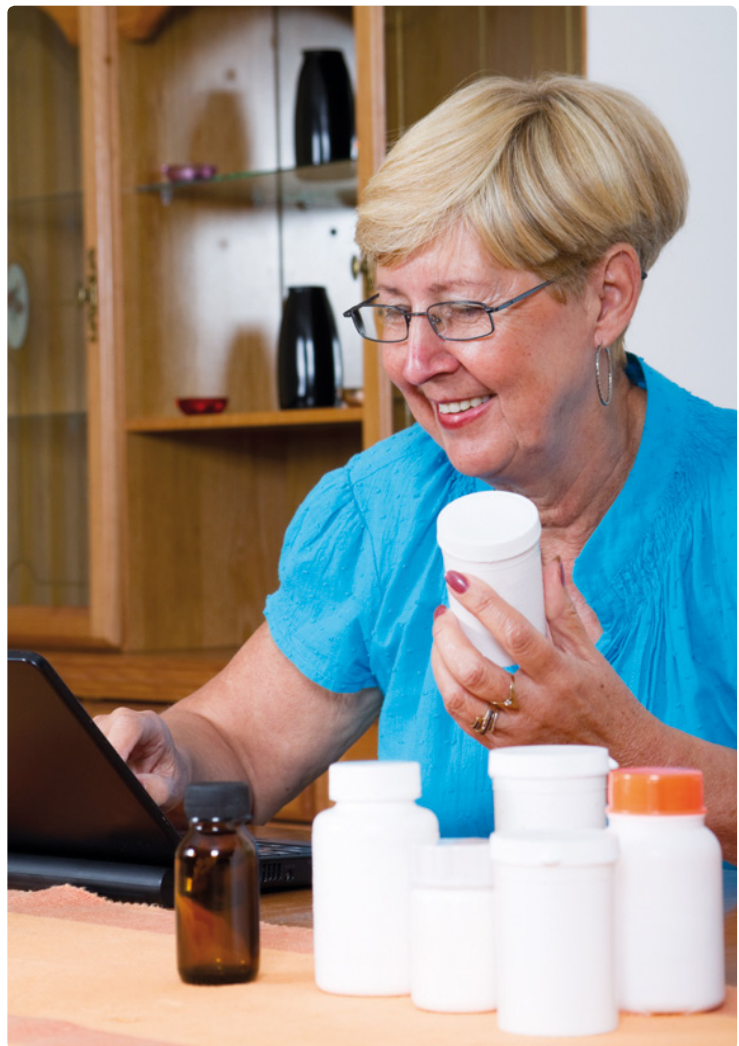
There is a greater focus on quality through schemes such as the Information Standard, and delivery channels for information via Information Prescriptions, NHS Direct, NHS Choices and its future integrated customer services platform. These are echoed via NHS inform in Scotland and NHS Direct Wales.

The Power of Information, the ten-year information strategy from the Department of Health, published in May 2012, sets out a framework for transforming information within the NHS and establishing it in England as a service in its own right.

Current practice

PiF's survey work shows that two-thirds of those working within NHS trusts report that patient information is rising in importance in their organisation.

Yet, despite this, investment in the development and delivery of health information is often uncoordinated and in many cases absent. Many trusts have no central budget for patient information, and one quarter have no organisational standards for information provision.



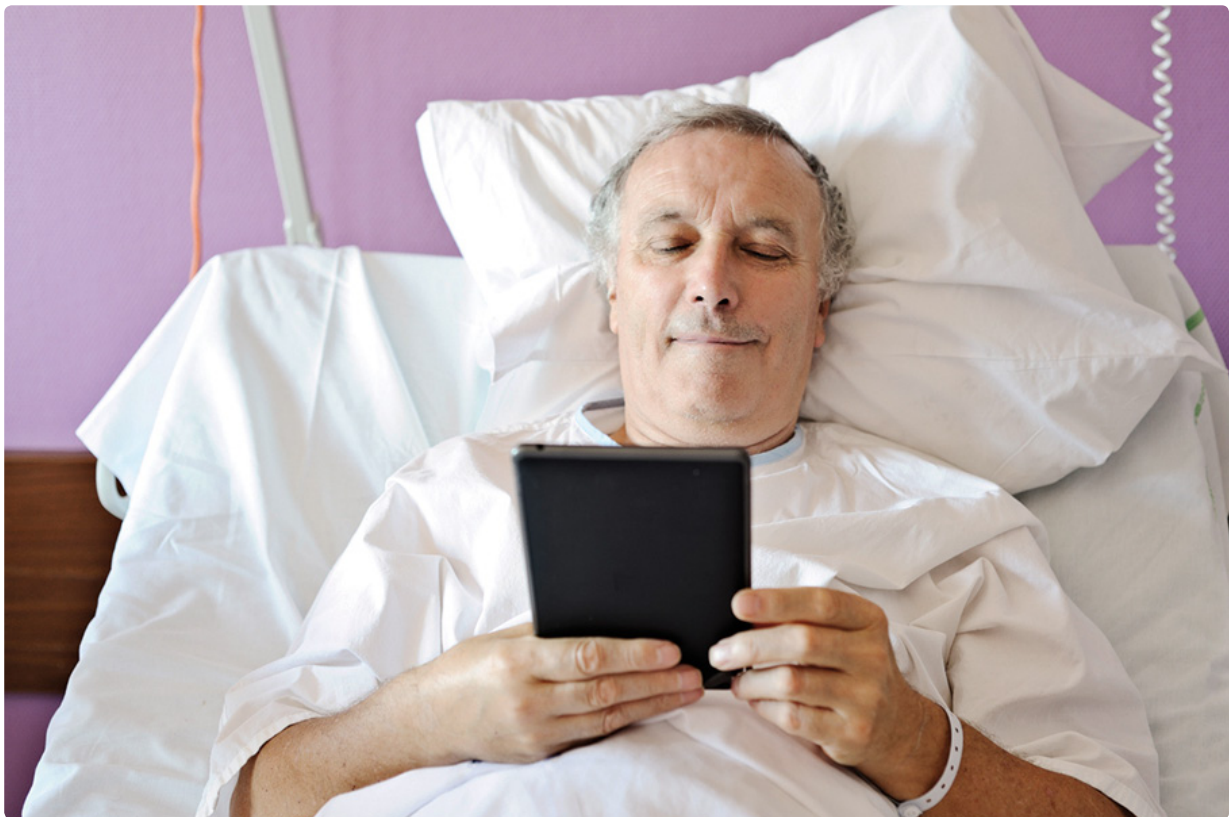
Patients want and need effective communication so that they are able to make informed choices about their healthcare. The Department of Health says that **high quality information empowers people** to make effective choices.

Yet a fifth of patients say they were not given enough information about their condition or treatment while in hospital and only half felt they were definitely involved as much as they wanted to be in decisions about their care.

Family doctors are the preferred source of health information for most people. Yet one-in-six people (17%) do not feel that their GP is good at explaining tests and treatments, and one-in-four (24%) do not feel their GP is good at involving them in decisions about their care.

Increasingly, people are looking to websites, digital sources and apps for information. The main benefits are convenience, coverage and anonymity. However there are concerns about the quality, readability, reliability, relevance and currency of some web-based health information and the ability of some people to access it - the so-called 'digital divide'.

Research highlights the importance of clinicians and specialist support staff acting as an 'infomediary' for their patients/clients - signposting them towards, and helping them to acquire, the high quality health information and support they need. Without appropriate guidance and support, there are concerns that information will not only fail to have the desired impacts, it could also serve to widen existing health inequalities.



Low health literacy is a significant problem and is closely associated with significant health inequalities. Access to appropriate and meaningful information is particularly difficult for those who need it most. This challenge is now even more important with the increased emphasis on self-management for long-term conditions and personal responsibility for maintaining good health.

To have substantial effects, information first has to be successfully communicated - so that it translates to greater patient knowledge and understanding which is crucial to achieving patients' more active engagement and behaviour change. The benefits are so powerful that some researchers have developed the concept of 'information therapy' and argue that information is as important to health as any drug, medical test or surgery.

By failing to provide patients with all the information and support they need to maintain their own health and to actively participate in decisions about their healthcare, the health service is compromising all three key dimensions of quality care - patient experience, patient safety and clinical effectiveness.

For the taxpayer and service users generally, such information failings carry high costs in terms of reduced efficiency, effectiveness and economy. There is also substantial evidence that failures in patient-doctor communications result in higher levels of complaint and increased claims of negligence and expensive legal challenge.

Clinicians' failure to fully inform and involve patients in decisions about their care has been described by the Kings Fund as 'a silent misdiagnosis', every bit as dangerous as failing to diagnose disease correctly. Addressing this could save the NHS billions of pounds.

Quality matters

PiF wants everyone to be able to access relevant, high-quality information and support to help them understand their care and make confident, informed decisions about their health and wellbeing.

High quality means effective information, which meets the needs of users and which empowers them to make choices and take control of their health and wellbeing. High quality information is accurate, evidence-based and developed with users.

The better the quality, the more useful, relevant and accessible the information is, and the more effective it will be in encouraging self care, effective long-term condition management and healthy lifestyle choices.

Information needs to be embedded within care pathways and become an integral part of consultations between patients and their health and social care professionals. It must be supported in its delivery by people who are properly trained to source and give information based on accurate assessments of health literacy. Its impact must be properly evaluated.

The Case for Information

This project considers the benefits of providing quality information to improve consumers' knowledge and understanding, facilitate patients' active engagement in maintaining and improving their own health, and informed participation in key decisions about their healthcare.

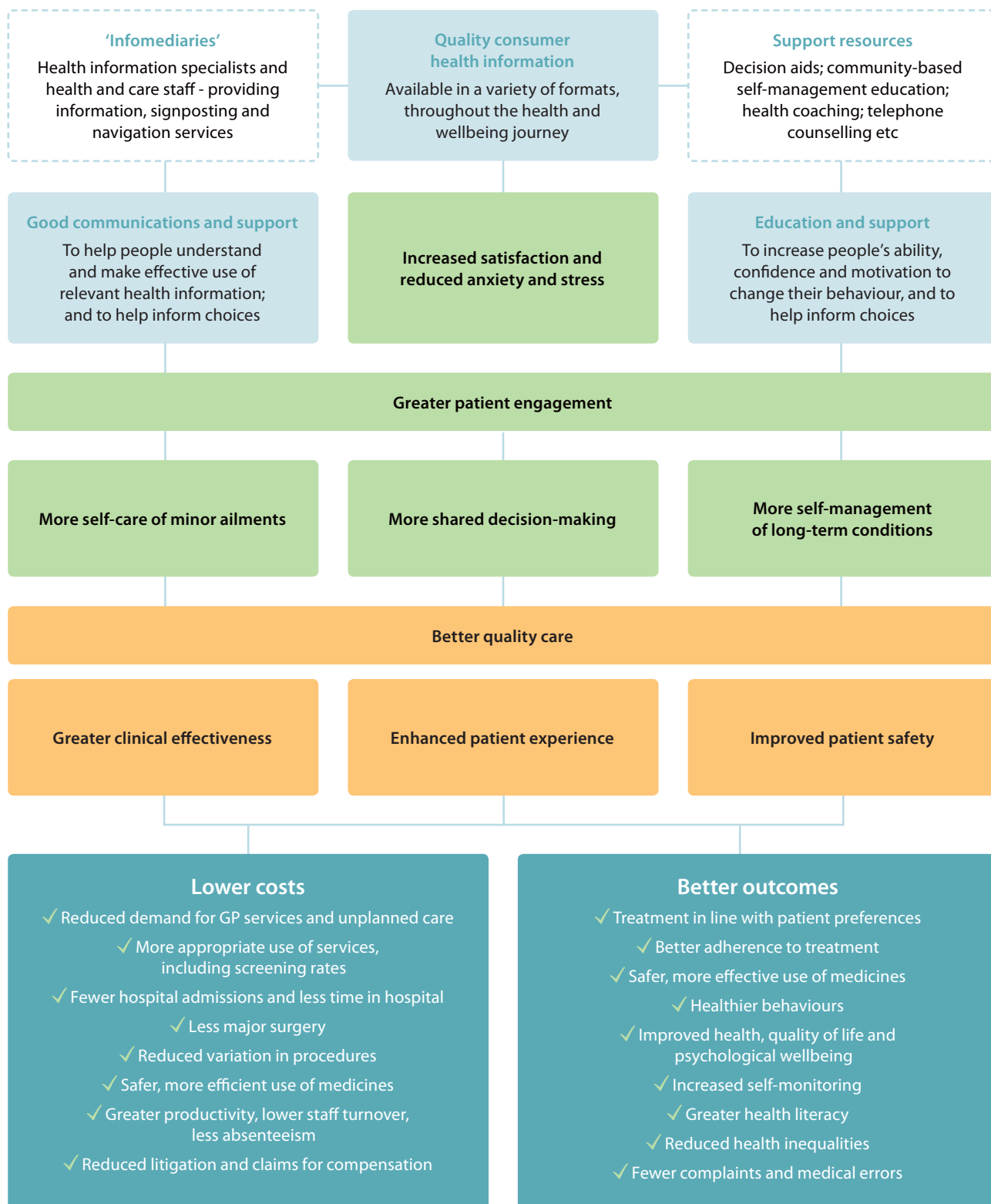
It presents the business case for investing in consumer health information and support, and reviews the detailed evidence regarding the beneficial impacts this can have on:

- service utilisation and health costs
- patients' experience of healthcare
- patients' health behaviour and status.

Additional evidence is presented as to what works best in improving consumers' access to and effective use of health information, together with recommendations for further work.



A simplified model of the Case for Information




The business case for investing in consumer health information

There are good business reasons to justify health commissioners and provider bodies investing more money in consumer health information and support.

- ***Improving health information raises quality and is key to unlocking patient engagement*** - The 2002 Treasury report by Sir Derek Wanless estimated that maximising patient engagement could generate potential annual savings of £30 billion by 2022.
- ***Better health information can have significant impacts on service use and reduce costs*** - This includes reducing the numbers electing for major surgery, wasted medications, demand for GP consultations, A&E attendances, emergency admissions, re-admissions and the amount of time spent in hospital, as well as reducing compensation and litigation costs. Emergency admissions among people with long-term conditions that could be effectively managed in primary care cost the NHS £1.4 billion annually; and more than £1 billion is currently wasted through low adherence to, and the misuse of, prescribed medicines.
- ***Ending the 'silent misdiagnosis' could save the NHS billions of pounds*** - Correctly diagnosing patients' preferences could save the NHS billions of pounds because well-informed patients choose fewer treatments, and involving people in decisions about their healthcare helps to reduce unwarranted variations in treatment.
- ***Making greater use of e-communication channels could deliver very substantial capacity savings in primary care*** - One analysis suggests that if 10% of GP attendances for minor ailments could be avoided through online self-care advice, annual savings would be around £830m.
- ***Increasing the self-management of long-term conditions can yield significant returns on investment*** - The management of long-term conditions accounts for 70% of total health spending. In giving rise to the greatest pressure on health resources, it also presents the greatest scope for reducing costs. Evidence from the Expert Patients Programme found that 50% of participants reported having subsequently made fewer GP visits, while 35% reported having reduced their medications. Overall, for an investment cost of £400 per attendee, the research estimated an average net saving of £1,800 per chronically ill patient per year.
- ***Actively engaged patients incur lower costs*** - Evidence from the United States shows that more active participants in treatment decisions and self-management incur significant lower costs, overall and for different long-term conditions. More actively engaged patients are also less likely to experience a medical error or be readmitted within 30 days of discharge. A study for the Commonwealth Fund found the cost of health care to be 21% higher for the least activated patients than for the most activated.

- **Increasing active participation among patients with low health literacy will generate the greatest returns** - In the UK, patients with low health literacy have poorer health status and incur higher health costs than other patients. Improving engagement among patients with low health literacy would not only deliver much greater savings than for any other group, it would also help reduce health inequalities.
- **Current payment schemes provide little incentive to enhance patient experience, including through improved information and support** - Yet research shows that information provision increases patients' satisfaction and their positive experiences of healthcare. This will be far more important in the reformed health service.
- **There are clear links between patient experience, quality and financial health** - Evidence from the United States clearly demonstrates a positive association between excellent patient experience and the market performance and financial health of providers, as well as a positive association between quality and financial performance.
- **Positive patient experience and feedback will attract customers and reassure commissioners** - With the introduction of greater competition, choice and transparency into the UK health system, providers are more likely to focus on improving their patients' experience. From a business perspective, this is both a major risk-management issue and a significant opportunity.



In the UK, patients with low health literacy have poorer health status and incur higher health costs than other patients. Improving engagement among patients with low health literacy would not only deliver much greater savings than for any other group, it would also help reduce health inequalities.

Patient engagement, service utilisation and health costs

Providing consumers with high quality, accessible health information and support not only enhances their experience of healthcare, it also helps to facilitate greater patient engagement in managing and improving their health. This reduces costs and improves the utilisation of appropriate services and treatments.

- **More appropriate screening rates** - Targeted health information, reminder letters and decision aids can help to increase or reduce the uptake of screening tests, as appropriate.
- **Reductions in major surgery** - People who are sufficiently well-informed and motivated to get involved in decision-making are often more risk averse than clinicians and less likely to choose major surgery.
- **Reduced variation in procedures** - Shared decision-making assists in reducing unwarranted variation in clinical practice and procedures of limited clinical value.
- **Reduced demand for primary care** - Patients who assume more active responsibility for managing and maintaining their health help to reduce the demand for GP consultations.
- **More appropriate use of services** - Effective health information and support helps to facilitate better adherence to treatment and medication regimens, and to reduce A&E attendances and unplanned hospital admissions.
- **Reduced medical errors, malpractice claims and litigation costs** - Poor doctor-patient communications and poor survey results for patient experience are associated with increased numbers of complaints and higher litigation costs.
- **Fewer hospital admissions** - Emergency admissions among people with long-term conditions that could be effectively managed in primary care cost the NHS £1.4bn annually. Self-management education and structured discharge planning can reduce unplanned hospitalisations, re-admissions and subsequent length of stay.



Enhancing patient experience

Providing consumers with high quality and accessible health information helps to enhance patients' experience of care. Understanding and acting to improve patients' experiences of care is core business for the NHS and an important motivator for staff. It forms part of the statutory duty of quality for board members - both a 'must do' and the right thing to do.

- **Improved knowledge, understanding and recall** - Patients are unable to act to help maintain or improve their health unless they understand and can remember important information about their condition.
- **Increased shared decision-making** - Information is a pre-requisite for patients to be able to participate in shared decision-making.
- **Greater self-management and self-care** - Information, alongside education and support, enables patients to take on greater personal responsibility for managing and maintaining their health.
- **More realistic expectations about potential health outcomes** - Information helps to engender more realistic expectations about the likely outcomes of treatment. This can also help to increase satisfaction.
- **Improved confidence in the doctor-patient relationship** - Information empowers patients and can improve their confidence in care and in their relationships with health professionals.
- **Improved psychological wellbeing** - Feeling well-informed can help reduce patients' fear and anxiety levels and increase feelings of being in control.
- **Reduced stress and improved relationships** - Information and support that also addresses broader issues such as financial worries can help to reduce stress, improve relationships and aid recovery.
- **Better quality of life** - Information provision can make a significant difference to patients' overall wellbeing by helping to improve physical and mental health and their ability to look after themselves.
- **Increased patient engagement** - Knowledge and understanding is an essential pre-requisite for patients becoming more actively engaged in their healthcare. Well-informed patients are also better equipped and prepared with questions to make the most of consultations with health professionals.
- **Increased patient satisfaction** - Providing high quality accessible information helps to increase patients' satisfaction with care, while lack of information can lead to misconceptions, anxiety and fear. Feeling well-informed correlates strongly with patients' overall rating of their experience.

Patient engagement, health behaviour and status

By enhancing patient experience and facilitating greater patient engagement in healthcare, high quality and accessible health information also helps to improve patients' health behaviour and status.

- **Reduced health inequalities** - Successful initiatives to increase active participation in their own healthcare among patients with low health literacy will improve health behaviours and help to reduce inequalities.
- **Increased self-care for minor ailments** - Increased self-care for minor ailments would generate substantial capacity savings in primary care and allow GPs to spend more time assisting patients with more complex health needs.
- **Increased self-management of long-term conditions** - Care for the chronically ill accounts for 70p out of every £1 spent in the NHS. Increasing self-management through patient information, education and support is therefore a key objective of UK health policy. This can improve people's quality of

life and health outcomes, at the same time as reducing or constraining costs through more appropriate patterns of service use.

- **Improved adherence to treatment and medications** - Poor understanding of doctors' instructions and concerns over side-effects cost the NHS about £500m per year, with this problem being greatest among ethnic minorities and deprived communities. Information and self-management education programmes provide important support for tackling these problems and reducing their cost.
- **Increased patient safety** - Well-informed, actively involved patients are in a much better position to give or withhold their informed consent to any treatment or procedure, and to protect their own personal safety.
- **Protection against harmful treatments** - Well-informed, engaged patients are less likely to seek out potentially dangerous alternative therapies.



Increased self-care for minor ailments would generate substantial capacity savings in primary care and allow GPs to spend more time assisting patients with more complex health needs.

Providing health information - what works

Information is best understood as part of a broader process of communication with health professionals, to supplement their clinical judgment and advice. Evidence from this review points to the most effective ways of providing consumer health information and maximising its impacts.

- ***One size does not fit all and no one method suits everyone*** - Consumer health information has the greatest effects when it is tailored to reflect an individual's particular needs and circumstances.
- ***Quality is paramount*** - High-quality information that accords with PiF's guidelines or the Information Standard is essential to empowering users to make choices and take control of their health and wellbeing.
- ***Information must be converted into knowledge and understanding*** - Effective communication with patients is vital to adding value to information and facilitating behaviour change.
- ***Written information aids recall and understanding*** - Supplementing verbal communication with some form of written information is most effective in improving patients' knowledge and recall.
- ***Information needs change over time*** - Patients need access to the right amount of health information and support, at the right time, at all stages of their 'patient journey'.
- ***Simpler materials, visual aids and alternative formats are needed to address health literacy*** - The accessibility and presentation of materials can aid understanding and application of health information.
- ***Web-based solutions are not the only answer*** - The digital divide and many people's preferences for hard copy mean that health information must continue to be provided on paper and in other formats too.
- ***Patients need specialist support to help them access, understand and act upon reliable health information*** - The bewildering volume, complexity and poor quality of much health information highlights the importance of patients being able to draw on expert support. A collaborative, partnership-based approach works best.
- ***Information alone will only have a limited effect*** - To be truly effective, information needs to be provided in a context of more active encouragement, education and support. Such support is especially vital to those with low levels of health literacy and engagement - without it, there is a danger of widening health inequalities.
- ***Significant behaviour change will only be achieved by information plus more active educational support*** - People need more than just information to be motivated to become more actively involved in decisions about their healthcare and to assume - and sustain - greater personal responsibility for maintaining and improving their own health.

1 The project brief

This report aims to:

- identify, collate and document evidence on the benefits of providing, and the harms of not providing, high quality consumer health information and support to patients and their families, healthcare professionals and the wider healthcare system;
- look at the business case for information provision, including any cost-benefit analyses; and
- identify any gaps in evidence and areas where more work is needed.

Consumer health information (CHI) is defined, in this research, as information and support provided to help patients, families and carers understand, manage and/or make decisions about their health, condition or treatment.

High quality means effective information, which meets the needs of users and which empowers them to make choices and take control of their health and wellbeing. The better the quality, the more useful, relevant and accessible the information is, and the more effective it will be in encouraging self care, effective long-term condition management and healthy lifestyle choices. High quality information is accurate, evidence based and developed with users.

It includes information produced in print, online and as audio and visual material which is accessed by patients (via websites or mobile apps for example) or given to them as part of their care. It also includes information provided through health information services such as helplines and hospital information centres, NHS 111 and NHS Choices.

For the purposes of this research we have not included other forms of information provided under the Government's transparency agenda, for example performance data, information to enable patients to choose a healthcare provider or gain access to their records. We have also not included consumer information relating to public health or social care.

2 Our approach

Methodology

Our research methodology included an extensive review of the academic and grey literature relating to consumer health information. This was supplemented by a series of in-depth, individual telephone interviews with health policy-makers, researchers, information specialists, commissioners and providers. The interviewees were selected for their knowledge, experience and interest in the subject, and to provide views from a reasonably representative range of bodies across the new health service.

Academic literature review

The academic literature search was performed using the PubMed database to identify relevant articles from peer-reviewed journals. A first search for “consumer health information” (in the title or abstract) identified 199 articles, 24 of which were selected for more detailed study. This search was expanded using the ‘Related Articles’ function in PubMed to retrieve nine more articles of interest.

This initial search was supplemented by two further searches, both filtered to only include “reviews”. The first of these additional searches for “patient information” identified 394 reviews, with 16 being identified as relevant to this review; the second search for “consumer health info*” returned 34 reviews, 21 of which were selected for further study. Of the 37 review articles generated by these additional searches, eight were duplicates of studies previously identified.

The overall total of 72 studies identified for closer review by these original searches was further expanded in the course of the work through cross-references in the articles and additional citations in the grey literature.

Grey literature review

Grey literature can be broadly understood to include all published information except peer-reviewed books and journals. It comprises a wide range of material including government documents, strategy consultations and proposals, research and technical reports, statistical bulletins, conference proceedings and websites.

Details of relevant sources attached to the ‘Invitation to Tender’ document and additional ‘evidence’ provided by the Patient Information Forum formed the starting point for our grey literature review. Extensive additional sources were identified through related citations, individual commendations, key websites and the news media.

This aspect of the work also entailed a thorough review of all the legal, policy and financial ‘levers’ that have an important bearing on patients’ access to high quality health information (the results of which are summarised in an appendix).

Limitations of the research

An exhaustive review of all the evidence pertaining to consumer health information, and further searches of additional databases, were beyond the scope of this project. Nonetheless, a very extensive and up-to-date range of evidence has been considered, including over 170 academic research articles and more than 200 documents from the grey literature. This is in addition to a wealth of detailed information provided by members of the Patient Information Forum, and the expert knowledge and insights provided by each of the interviewees.

Yet despite collating, reviewing and summarising such a vast array of materials, it must also be acknowledged that some of the research around the impacts of consumer health information is of variable quality. Research studies rarely include any details about the costs of different initiatives so it can sometimes be difficult to assess their wider applicability to more general settings.

The nature of the information materials employed is similarly varied, and it is often difficult to separate out any particular impacts of the information elements within multi-faceted interventions. The 'default' position regarding the extent and nature of information routinely provided to any control group is frequently not described, and nor is any definition of quality made explicit.

That said, this review has drawn on the highest quality evidence available, including from systematic and major reviews of the literature wherever possible. In so doing, it has amassed a wealth of evidence to suggest that investing in high quality consumer health information and support is not only the right thing to do from an ethical standpoint as a crucial element of patient-centred care, it is also a financial and clinical imperative.

Structure of the report and framework for analysis

This review first considers the changing organisational and policy context for consumer health information. It highlights both the growing emphasis on patient experience as a key aspect of improving quality, and the increasing pressures on scarce health resources that require patients to become more actively engaged in managing their health.

It goes on to review the current information landscape across the UK. Despite the growing importance of consumer health information, this section reveals a number of shortcomings in the organisation and delivery of current information services and identifies some particular challenges for the future.

The third main section of the report considers the case for information in far greater detail. As a framework for analysis, this section first details the business case for investment. It subsequently reviews the detailed evidence regarding the beneficial impacts consumer health information and support can have on:

- service utilisation and health costs
- patients' experience of healthcare
- patients' health behaviour and status.

The last part of the report presents an overview of what works best to increase the effectiveness and impacts of consumer health information. This includes details of key levers for making the case for information, PiF's vision for the future, and of the key quality standards that information and support must attain to be fully effective.

Finally, recommendations are made for further work and research.

3 Context

Healthcare in the UK is changing

This report is published as the NHS in England adjusts to another round of large-scale reorganisation. From April 2013, over 160 organisations, including primary care groups, were abolished and replaced by 211 clinical commissioning groups and a host of new regional and national organisations. Public health responsibilities have been devolved to local government.

The way in which resources and financial incentives operate across the NHS in England has changed fundamentally. These changes are as a result of a policy framework, set out three years ago in the White Paper, *Equity and Excellence: Liberating the NHS*,¹ to improve the quality and efficiency of services through increased competition, choice and personalisation.

Information, combined with the right support, is the key to better care, better outcomes and reduced costs.

Equity and Excellence: Liberating the NHS – 2010 White Paper

In Scotland, responsibility for the protection and improvement of the population's health and for delivering the high quality, patient-centred care rests with 14 regional NHS Boards, seven Special NHS Boards and one public health body. One of the three main 'quality ambitions' set out in the *Healthcare Quality Strategy for Scotland*² is to develop mutually beneficial partnerships which respect individual patients' needs and values and also recognize the importance of clear communication and shared decision-making.

Following the reorganisation of NHS Wales in October 2009, *Together for Health*³ was published in 2011 and outlines a five-year vision based around community services. This places prevention, quality and transparency at the heart of healthcare to make health better for everyone, enhance access and patient experience, and improve health outcomes through better service safety and quality.

Since April 2009, responsibility for arranging and commissioning services in Northern Ireland rests with the Health and Social Care Board. Consultation on major reforms to the province's health and social care system – as set out in *Transforming Your Care: Vision to Action*⁴ – ended in March 2013. Key proposals in the document include a shift from hospital care to more primary and community-based services, a network of hospitals working more closely together, and the establishment of 17 new integrated care partnerships to improve patient experience locally.

Finances are tighter than ever

Financial pressures resulting from increased demand as a result of demographic change, the rise in patients with long-term conditions and higher patient expectations of treatment options such as new drug therapies are all contributing to the squeeze on spending in the NHS.

Alongside the major structural changes, NHS organisations in England are tasked with delivering £20bn of efficiency savings by 2015 through the transformational programme of QIPP - Quality, Innovation, Productivity and Prevention. Although the structures for delivery of health services in Scotland, Wales and Northern Ireland are different, many of the key drivers are the same. The challenge for all those working in health services is to provide high quality, patient-centred care in the face of rising demand and tightening financial constraints.

Getting information and communication better will be crucial for driving quality and reducing waste and duplication in the current financial squeeze – a critical underpinning of health promotion, self-care, self-management, quality improvement and integrated care.

Information: A report from the NHS Future Forum, 2012

Demand from patients is set to increase. The House of Lords Select Committee on Public Service and Demographic Change reports that half of those born after 2007 can expect to live to over 100.⁵ In evidence to the Committee, Professor Carol Jagger of Newcastle University forecast that unless treatment and cures were improved, the incidence of the five most common chronic conditions among the over 65s – arthritis, heart disease, stroke, diabetes and dementia – will increase by 25% by 2020, and by more than 50% by 2030.⁶

Patients are at the centre of health policy-making

All UK nations share one overarching stated principle in delivering healthcare – to put the patient first.

In England, the intention is that shared decision-making should be the norm – ‘no decision about me, without me’. This golden thread of a patient-centred experience runs through everything from the original 2009 NHS Constitution to the 2010 White Paper Equity and Excellence, Liberating the NHS, the 2012 Health and Social Care Act and in all operational guidance on health service commissioning and delivery for the NHS.

It was re-emphasised in the findings of the final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry in 2013, which contained 290 recommendations to create a *common patient-centred culture across the NHS*.⁷

People must always come before numbers. Individual patients and their treatment are what really matters. Statistics, benchmarks and action plans are tools not ends in themselves. They should not come before patients and their experiences. This is what must be remembered by all those who design and implement policy for the NHS.

Final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, February 2013 – Chair, Robert Francis QC

In Scotland, the watchword is ‘mutuality’, with the Healthcare Quality Strategy aiming to create *a mutual NHS in Scotland where staff, patients and carers fully understand their rights and responsibilities, and what they should expect from their NHS. A mutual NHS is an underpinning requirement of person-centred healthcare in Scotland*.⁸ These principles are enshrined in The Patient Rights (Scotland) Act 2011.

The healthcare patients receive should...

consider their needs, consider what would be of optimum benefit to them, encourage them to take part in decisions about their health and wellbeing, and provide information and support for them to do so.

The Patient Rights (Scotland) Act 2011

Similar themes of improving quality and the patient experience are also found in Together for Health, the Welsh Government’s vision for the NHS, and in the strategic priorities of the Northern Ireland Executive’s Department of Health, Social Services and Public Safety.

A push for patients to engage in their own healthcare

Alongside the drive for patient-centred care, and the enshrinement of patients' rights in legislation and policy guidance, comes a focus on patient engagement and the responsibility everyone has for their wellbeing. The NHS Constitution asks of patients that they should recognise *that you can make a significant contribution to your own, and your family's, good health and wellbeing and take personal responsibility for it.*⁹

The Patient Rights (Scotland) Act 2011 and its accompanying Charter of Patient Rights and Responsibilities requires that patients take some responsibility for their own health and take an active part in discussions and decisions about their healthcare and treatment.¹⁰

This is also echoed in Wales where Together for Health includes a commitment to forge a new partnership with the public to increase patient engagement while, in Northern Ireland, Quality 2020 aims to empower people to take greater responsibility for their own health and wellbeing.

Patient engagement is an umbrella term that encompasses a number of closely related concepts that provide a practical framework for supporting and empowering people to become more actively involved in decisions and actions about health and healthcare.¹¹

Patient engagement includes:

- Shared decision-making – which involves patients (and their carers) becoming active partners with clinicians in considering treatment options, with the aim of reaching mutual agreement on the best course of action;¹²
- Self-care / self-management – where patients are encouraged and supported to take greater personal responsibility for maintaining and improving their health;
- Personalised care planning – which sees patients jointly agreeing a care plan for managing their long-term condition (including advanced planning for terminal care).

A consensus has emerged that, as far as possible, patients should become active partners in their health and healthcare. Research evidence for the Health Foundation shows that such engagement improves patients' knowledge, experience and satisfaction, reduces costs through greater self-care and more appropriate utilisation of services, and leads to improved health outcomes with improved health behaviours and treatment adherence.¹³

If once this kind of patient engagement was seen as a 'nice to have', financial and service pressures dictate that it is now seen as a necessary part of a more modern and efficient health service. Achieving patient engagement has therefore become a key goal for policy-makers and is central to the government's plans for the NHS.¹⁴

The wider quality and economic case for good information is often insufficiently appreciated. Good information and communication promote health literacy, treatment adherence, self-management, shared decision-making, confidence and realistic expectations.

Information: A report from the NHS Future Forum, 2012

In particular, there is a strong emphasis on increasing self-management in the reform of care for the chronically ill. This is unsurprising given that 20 million people in the UK with a long-term condition¹⁵ currently account for 70% of all health and social care expenditure¹⁶, with their number also being projected to increase by 50% over the next twenty years.¹⁷

Self-management support can be viewed in two ways: as a portfolio of techniques and tools to help patients choose healthy behaviours; and, as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership.¹⁸

The Patient Activation Measure (PAM) – developed by Judith Hibbard and colleagues at the University of Oregon – can be used to assess people’s knowledge, confidence and skills for self-management.¹⁹ It is built on a four-stage model of patient activation:

Stage 1 – believing that the patient role is important

Stage 2 – having the confidence and knowledge necessary to take action

Stage 3 – actually taking action to maintain and improve one’s health

Stage 4 – staying the course, even under stress.

A national survey by the Picker Institute Europe found that activation levels are generally lower among people who are elderly, from deprived areas and/or who left school at 16. The capacity for self-management was also least evident amongst those with poorest health, and fewer people with long-term conditions had progressed to more advanced stages of self-management.²⁰ Subsequent research evidence has demonstrated that patients with low activation scores incur higher health costs,²¹ are more likely to be readmitted to hospital within 30 days of discharge, experience more medical errors, experience poorer co-ordination of care, and are more likely to suffer an adverse health consequence because of poor communication among providers.²²

Patients need information in order to engage

Angela Coulter (2012) identifies a number of distinct roles that engaged patients can play as active ‘co-producers’ of health by:

- understanding the causes of disease and the factors that influence health
- self-diagnosing and treating minor conditions
- knowing when to seek advice and professional help
- choosing appropriate healthcare providers
- selecting appropriate tests and treatments

- monitoring symptoms and treatment effects
- being aware of safety issues and preventing errors
- coping with the effects of chronic illness and self-managing their care
- adopting healthy behaviours to prevent occurrence or recurrence of disease.²³

Patients’ ability, motivation and confidence to enact these roles depends on acquiring crucial health information to increase their knowledge and understanding of their condition and, also, to encourage and support them to develop the confidence and self-care skills needed to actively manage their health.

Information can bring enormous benefits. It is the lifeblood of good health and wellbeing, and is pivotal to good quality care.

The Power of Information, Department of Health, 2012

Most patients now expect to be given good quality information about their condition and treatment options, and the potential risks and benefits of different procedures. They want clinicians to take account of their preferences and some expect to be actively engaged in the decision-making process, or to take decisions themselves²⁴. Although not everyone wants or is necessarily able to play an active role in their healthcare, most surveys suggest that the majority of patients do want to participate in decisions about their care and many people express disappointment about the lack of such opportunities.²⁵

An NHS that gives patients and the public more information and choice, works in partnership and has quality of care at its heart.

Lord Darzi – High Quality Care for All: NHS Next Stage Review, 2008

However, despite the well-documented benefits, patient involvement is another area where significant progress still needs to be made, along with the provision of essential information.²⁶ Concerns about people not being properly involved in decisions about their care were highlighted in the Care Quality Commission's most recent report on the state of health and social care in England.²⁷

Information is the key to improving patient experience

In introducing his final report of the NHS Next Stage Review, Lord Darzi stated that:

*High quality care should be as safe and effective as possible, with patients treated with compassion, dignity and respect. As well as clinical quality and safety, quality means care that is personal to each individual.*²⁸

This definition of quality as consisting of the three (inter-related) domains of patient safety, clinical effectiveness and patient experience has subsequently been enshrined in the Health and Social Care Act 2012. Improving patients' experience of healthcare is not just important from an ethical perspective, it can also bring very practical benefits in terms of improved outcomes and reduced service costs.²⁹ Delivering a positive experience of care for patients is just as important as the treatments they receive.³⁰

We believe good information is vital to good health.

Together for Health Public Information

Improving access to, and understanding of, good quality health information is integral to delivering high quality, person-centred healthcare that places a premium on enhancing patient experience. The crucial importance of health information is reflected in the Picker Institute Europe's Principles of Patient-Centred Care³¹ which have formed the basis for the National Quality Board's NHS Patient Framework.³²

One of the eight areas that this new NHS framework sets out for measuring patient experience is:

Information, communication and education on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion.

The value of information to patient experience is not, however, confined to this particular aspect of experience. It is also intrinsic to a number of other key areas highlighted by the framework, including:

- respecting patient autonomy and facilitating shared decision-making
- helping to ensure the co-ordination and integration of care services
- underpinning emotional support and the alleviation of fear and anxiety
- involving family and friends in decision-making
- promoting successful transitions in care away from the clinical setting.

In defining nine criteria for a high-performing health system, the King's Fund also emphasises patient experience and the key role consumer health information plays in this, stating that:

*A high-performing health system delivers a positive patient experience. This includes giving patients choices and involving them in decisions about their care, providing the information they need, and treating them with dignity and respect.*³³

Again, the critical role of information is not just confined here to enhancing patient experience but is equally relevant to ensuring high performance in all the eight other areas of the model – in:

- improving access to services
- enhancing patient safety
- promoting health
- supporting self-management of long-term conditions
- increasing clinical effectiveness
- underlining equity
- ensuring efficiency
- delivering accountability.

The key characteristics of high quality, patient-centred care services that are identified in all such frameworks accord closely with research evidence of what is most important to patients in their experiences of healthcare. Based on an extensive review of the literature, existing studies provide a consistent picture of what matters most to patients and reflect the high value individuals place on being well informed - by:

- getting clear explanations of what will happen during an operation or procedure
- being told the risks and benefits of any treatment in a way they can understand
- getting clear explanations of their condition or treatment
- being told how an operation or procedure has gone in a way they can understand
- being treated as an individual with dignity and respect.³⁴

Voluntary organisations providing advice and support to people with a very wide range of different medical conditions also emphasise the importance patients attach to being treated as a person, feeling well-informed and being involved in decisions about their care.³⁵ These findings highlight the importance of recognising the particular importance patients attach to the 'nature of care' and to the more 'relational' aspects of their experience, alongside the functional aspects and content of their treatment.³⁶

Improving patient experience has wider benefits

The importance of attending to the 'how' as well as the 'what' of health and social care has been a cornerstone of UK health policy since the late 1990s, and care, compassion and respect for patients are enshrined in the value statements of the health professions.³⁷

Although the inclusion of patient experience is most often justified on moral and ethical grounds for its intrinsic value, there is also a strong justification on more utilitarian grounds as a means of improving both patient safety and clinical effectiveness.

A systematic review by Doyle and colleagues of evidence from over 500 studies demonstrates consistent positive associations between patient experience and patient safety, clinical effectiveness and resource use for a wide range of outcomes measures, settings and conditions.³⁸

Out of 378 studies which presented sufficient information for categorisation, 312 (83%) showed positive associations (where a better patient experience is associated with safer or more effective care) for the following outcomes:

- objectively measured health status
- self-reported health and wellbeing
- adherence to treatment (including medication)
- preventative care
- healthcare resource use
- adverse events
- technical quality of care.

Further evidence of the positive association between patient experience and the clinical quality of services in general practice is provided by Raleigh and Frosini's analysis of Quality Outcomes Framework and GP Patient Survey data for 2010/11 for all general practices in England.

In general, they found that practices that scored well on patient experience also performed well on clinical quality. Similarly, patients' responses to questions about their satisfaction with information received also consistently showed a clear positive link with all process and outcome measures of the quality of clinical care.³⁹

A focus on patient satisfaction and experience can also deliver business benefits for health providers, enabling them to increase value by delivering higher quality services at the same or reduced cost – including through:

- higher employee morale, lower staff turnover and reduced absenteeism
- improved productivity, reduced waste and greater efficiency
- avoided costs (e.g. enhanced recovery reducing lengths of stay)
- more timely responses/actions to minimise the escalation of issues
- enhanced organisational reputation.⁴⁰

Doyle and colleagues believe that clear health information and empathetic, two-way communication that respects patients' beliefs and concerns are essential to realising these very significant and much wider benefits of enhancing patients' experience – suggesting that this:

...could lead to patients being more informed and involved in decision-making and create an environment where patients are more willing to disclose information. Patients could have more 'ownership' of clinical decisions, entering a 'therapeutic alliance' with clinicians. This could support improved and more timely diagnosis, clinical decisions and advice and lead to fewer unnecessary referrals or diagnostic tests. Increased patient agency can encourage greater participation in personal care, compliance with medication, adherence to recommended treatment and monitoring of prescriptions and dose.⁴¹

Therefore, as well as contributing to patient experience, providing access to good quality health information and support is also key to unlocking (what some have termed) the 'blockbuster drug' of patient engagement in healthcare.⁴²

Section 3 References

¹ Department of Health (2010) Equity and Excellence: Liberating the NHS

² Scottish Government (2010) The Healthcare Quality Strategy for NHS Scotland

³ Welsh Government (2011) Together for Health: A Five Year Vision for the NHS in Wales

⁴ Northern Ireland Executive (2012) Transforming Your Care: Vision to Action

⁵ Select Committee on Public Service and Demographic Change (2013) Report of Session 2012–13, Ready for Ageing? House of Lords

⁶ *ibid.*

⁷ Robert Francis QC (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry

⁸ Scottish Government (2010) The Healthcare Quality Strategy for NHS Scotland

⁹ Department of Health (2013) The NHS Constitution: the NHS belongs to us all

¹⁰ Scottish Government (2012) Your health, your rights: The Charter of Patient Rights and Responsibilities

¹¹ Capita (2013) Draft guidance on the statutory duty to promote the involvement of patients in decisions about their care and treatment (unpublished)

¹² Coulter A & Collins A (2011) Making shared decision-making a reality: No decision about me, without me, King's Fund

¹³ Ellins J and Coulter A (2005) *How engaged are people in their healthcare?* Health Foundation

¹⁴ Picker Institute Europe, *Invest in Engagement* website, www.investinengagement.info

¹⁵ House of Commons Health Committee (2013) *Management of long-term conditions – Terms of Reference and Call for Evidence*

¹⁶ Department of Health (2012) *Long Term Conditions Compendium of Information, Third Edition*

¹⁷ The Guardian (2013) *Britain's old-age time bomb: peers warn of crisis as population of over-65s soars*, 25 February 2013, p3

¹⁸ de Silva (2011) *Helping People Help Themselves*, Health Foundation

¹⁹ Hibbard J, Stockard J, Mahoney E & Tusler M (2004) Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers, *Health Services Research*, 39(4, Part 1) pp1005-1026

²⁰ Ellins J and Coulter A (2005) *How engaged are people in their healthcare?* Health Foundation

²¹ Hibbard J, Greene J & Overton V (2013) Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores', *Health Affairs*, 32(2) pp216-22

²² AARP Public Policy Institute (2009) *Beyond 50.09 – Chronic Care: A Call to Action for Health Reform*

²³ Coulter A (2012) Patient engagement – what works? *Journal of Ambulatory Care Management*, Vol. 35 No. 2, pp 80-89

²⁴ Coulter A & Ellins J (2006) *Patient-focused interventions: a review of the evidence*, Picker Institute Europe

²⁵ Flynn K, Smith M & Vanness D (2006) A typology of preferences for participation in healthcare decision-making, *Social Science and Medicine*, vol 63, no 5, pp 1158–1169

²⁶ Foot C and Cornwell J (2010) *Improving patients' experiences: an analysis of the evidence to inform future policy*, King's Fund

²⁷ Care Quality Commission (2012) *The state of healthcare and adult social care in England: An overview of key themes in care in 2011/12*

²⁸ Lord Darzi (2008) *High Quality Care for All: NHS Next Stage Review Final Report*, Department of Health

²⁹ Foot C and Cornwell J (2010) *Improving patients' experiences: an analysis of the evidence to inform future policy*, King's Fund

³⁰ Picker Institute Europe, *Invest in Engagement* website, www.investinengagement.info

³¹ Picker Institute Europe, *Principles of Patient-Centred Care*, www.pickereurope.org/our-mission-and-values.html [accessed 5 February 2013]

³² National Quality Board (2012) *NHS Patient Experience Framework*

³³ Gregory S, Dixon A & Ham C (2012) *Health policy under the coalition government: A mid-term assessment*, King's Fund

³⁴ Robert G & Cornwell J (2011) *'What matters to patients?' Developing the evidence base for measuring and improving patient experience*, King's College London & King's Fund

³⁵ *ibid.*

³⁶ Iles V (2011) *Why reforming the NHS doesn't work*

³⁷ Goodrich J & Cornwell J (2008) *Seeing the person in the patient: the Point of Care review paper*, King's Fund

³⁸ Doyle C, Lennox L & Bell D (2013) A systematic review of evidence on the links between patient experience and clinical safety and effectiveness, *BMJ Open*, Jan 3; 3(1)

³⁹ Raleigh V & Frosinin F (2012) *Improving GP services in England: exploring the relationship between quality of care and the experience of patients*, King's Fund

⁴⁰ Wilson T & Devlin J (Undated) *Costs and Benefits of Implementing a Patient Experience Strategy: Or Why Every Director of Finance Should be Investing in Patient Experience*, <http://patientexperienceportal.org/article/costs-and-benefits-of-implementing-a-patient-experience-strategy-or-why-every-director-of-finance-should-be-investing-in-patient-experience> [accessed 29 Jan 2013]

⁴¹ Doyle C, Lennox L & Bell D (2013) A systematic review of evidence on the links between patient experience and clinical safety and effectiveness, *BMJ Open*, Jan 3; 3(1)

⁴² Kish L (2013) *The blockbuster drug of the century: an engaged patient* www.hl7standards.com/blog/2012/08/28/drug-of-the-century/ [accessed 7 March 2013]

4 The information landscape

Patient information is now on the agenda

Information, and access to it, is now firmly embedded in health policy across the UK. The NHS Constitution includes a commitment to shared decision making as one of its seven overarching principles. The Health and Social Care Act 2012 enshrined the legal foundation for the Constitution and placed new duties on the NHS Commissioning Board and clinical commissioning groups to promote it.

The rights of patients set out in the NHS Constitution are vital. They must be delivered.

Everyone counts: Planning for Patients 2013/14, NHS Commissioning Board

A new, strengthened constitution to reflect more clearly that the NHS supports individuals to manage their own health and involves them, their families and carers in decisions that affect them was launched very recently, in March 2013.⁴³ Under the constitution, patients have the rights:

- to be given information about the test and treatment options available to them, what they involve, and their risks and benefits
- to be involved in discussions and decisions about their health and care, including end of life care, and to be given information to enable them to do this.

The constitution also commits the NHS:

- to inform patients about the healthcare services available, locally and nationally
- to offer patients easily accessible and relevant information in a form they can understand – to enable patients to participate fully in healthcare decisions and to support them in making choices
- to involve patients in discussions about planning their care, and to providing a written record of the agreed care plan if requested.

It also reminds staff of their own responsibilities to involve patients fully in decisions about prevention, diagnosis, and their individual care and treatment.

In Scotland, the Patient Rights (Scotland) Act 2011 includes the right that the healthcare patients receive should consider their needs, consider what would be of optimum benefit to them, encourage them to take part in decisions about their health and wellbeing, and provide information and support for them to do so.⁴⁴

In 2006, the Northern Ireland Executive's Department of Health, Social Services and Public Safety published Quality Standards for Health and Social Care - Supporting Good Governance and Best Practice. These set out the standards that people can expect from Health and Personal Social Services in Northern Ireland.

The standards are presented in relation to five key quality themes, one of which is Effective Information and Communication. This includes providing:

a range of published up-to-date information about services, conditions, treatment, care and support options available, and how to access them both in and out of service hours, which are subject to regular audit and review.

The Welsh Assembly Government launched a revised set of standards for health services in Wales in 2010, Doing Well, Doing Better: Standards for Health Services in Wales. These require health services in all healthcare settings to ensure they comply with the standards to make improvements to their services. Standard 9 relates specifically to information, stating that organisations and carers must:

...recognise and address the needs of patients, service users and their carers by:

- *providing timely and accessible information on their condition, care, medication, treatment and support arrangements;*
- *providing opportunities to discuss and agree options.*

Professional codes of conduct now mandate information provision as a key part of ethical behaviour and to seek informed consent from patients. For example, the General Medical Council guidance on Good Medical Practice states that clinicians *must give patients the information they want or need in a way they can understand*. It also obliges doctors to *work in partnership with patients, sharing with them the information they will need to make decisions about their care, including their condition, its likely progression and the options for treatment, including associated risks and uncertainties*.⁴⁵

The General Pharmaceutical Council's Standards of Conduct, Ethics and Performance requires pharmacy professionals to *explain the options available to patients and the public, including the risks and benefits, to help them make informed decisions* and requires them to make sure the information given is impartial, relevant and up to date.⁴⁶

In setting standards for the conduct and behaviour of nurses and midwives, the Nursing and Midwifery Council's guidance places a similar emphasis on nursing staff acting *as an advocate for those in your care, helping them to access relevant health and social care, information and support*.⁴⁷

It also highlights the importance of sharing information in a way that patients can understand and of upholding people's rights to be fully informed in decisions about their care.

There is now, in most areas, a greater focus on quality and delivery channels for information.

The Information Standard voluntary quality mark scheme, set up by the Department of Health, has supported enhanced organisational credibility and reputation, greater clarity around information production costs, cost savings due to improved internal processes leading to more efficient ways of working, and reduced risk of litigation due to a clearly defined information audit trail.⁴⁸

NHS Choices, and its proposed integrated customer services platform is based on the principle of producing information once and using it repeatedly across different platforms.

The Power of Information, the ten-year information strategy from the Department of Health, published in May 2012, sets out a framework for transforming information for the NHS, public health and social care in England.⁴⁹

PiF's own NHS Trusts in England Survey (2010) shows that two thirds of those working within the NHS report that patient information is rising in importance in their organisation.⁵⁰

However, in highlighting that good information, well used, is a crucial component of improving health, wellbeing and the quality of care, the NHS Future Forum also emphasises that *it is both increasingly feasible and necessary to turn the vision in the Government's 'information revolution' into a reality*.⁵¹

The main levers for making the Case for Information

The appendix to this report contains a list of the main levers which can be used by anyone seeking to make the case for the provision of high quality consumer health information. It is not an exhaustive list and policy and legal requirements change over time. Web references are given where appropriate and it is important to check for relevant updates. The table on the next page summarises the information at a glance.

Lever	Key points
Moral and ethical levers	
The Report of the Mid Staffordshire Foundation Trust Public Inquiry (the 'Francis Inquiry'), 2013	The main thrust of the 290 recommendations of the Inquiry was to create a common, patient-centred culture across the NHS. The provision of the right information to patients is a vital part of this.
Informed consent: guidance from health departments and professional bodies	The principle of consent is an important part of medical ethics, human rights law and specific legislation on issues like Human Tissue and Mental Capacity.
Policy and legislative levers	
NHS Constitution (England), 2009, updated 2013	A commitment to the principle of shared decision-making. Rights for patients and pledges from the NHS on provision of accessible, reliable and relevant information to support consent, informed choice and involvement in healthcare.
White Paper: Equity and Excellence: Liberating the NHS, (England) 2010	Commits to shared decision-making as the norm – 'no decision about me without me'. Says that information, combined with the right support, is key to better care and outcomes and reduced costs.
Quality 2020 (Northern Ireland), 2010	Ten-year strategy for healthcare, including a requirement that all patients should be fully involved in decisions affecting their treatment, care and support.
Together for Health (Wales), 2011	Five-year vision placing prevention, quality and transparency at the heart of healthcare.
20:20 Vision for Healthcare (Scotland) 2010	Strategic narrative underpinning healthcare policy, placing the person at the centre of all decisions.
Health and Social Care (Reform) Act (Northern Ireland) 2009	Introduced a new statutory Duty of Involvement.
Patient Rights (Scotland) Act 2011	With associated Charter of Patient Rights and Responsibilities 2012, aims to support people to become more involved in their health and healthcare.
Health and Social Care Act 2012 (England)	Strengthens the legal foundation of the NHS Constitution and creates a new duty on commissioners to promote involvement in healthcare by patients and carers.
NHS Mandate (2012) and Outcomes Framework (2013 – 2014)	Set out the outcomes and indicators to hold NHS England to account, based round five domains of high quality care, including patient experience.
Care Quality Commission guidance on compliance (England)	Three of CQC's essential standards are relevant to patient information, and CQC guidance includes a section on involvement and information.
NHS Litigation Authority Risk Management Standards	Of the six standards, two relate to patient information.

Service priorities	
The Power of Information, 2012 (England)	Ten-year information strategy that states that 'information is an essential service in its own right'. A key element is the new NHS web portal due to go live during 2013.
Together for Health Public Information Delivery Plan, 2012 (Wales)	Aims to make substantial improvements in the way people can access health information.
Everyone Counts: Planning for Patients 2013/14 (England)	The planning framework under which Clinical Commissioning Groups are expected to operate, which emphasises that the rights of patients set out in the NHS Constitution must be delivered.
The Healthcare Quality Strategy, 2010 (Scotland)	Builds on the proposal in an earlier policy document to create a 'mutual' NHS Scotland and emphasises the importance of clear communication and explanation about healthcare.
Achieving Excellence: the Quality Delivery Plan for the NHS in Wales, 2012-2016	Details how quality assurance and improvement arrangements will operate and raises the importance of good quality health information.
National Institute of Health and Clinical Excellence (NICE) Guidelines	NICE produces three sets of guidance relevant to the provision of information (clinical, commissioning and quality standards). There is a specific quality standard on patient experience which includes a strong focus on information.
Information Standard (England)	Voluntary quality mark scheme set up by the Department of Health to help the public identify sources of evidence-based health and social care information.
National Service Framework for Long-term Conditions, 2005 (England)	Sets out quality requirements, many of which focus on the importance of information provision.
Designed to Improve the Management of Chronic Conditions in Wales, 2007	States that effective communication and information systems form the basis of good service delivery and patient care in managing chronic conditions in the community.
Financial levers	
Quality and Outcomes Framework (QOF), (UK)	Part of the General Medical Services Contract, a voluntary incentive scheme for GP practices in the UK. Some clinical domains include references to the importance of information provision.
Commissioning for Quality and Innovation (CQUIN) Framework (England)	Links a proportion of providers' income to local quality improvement goals. Patient experience is one of three areas of focus.
Quality, Innovation, Productivity and Prevention (QIPP) (England)	Coming to an end, a national programme to improve the quality of care delivered in the NHS while making up to £20bn of efficiency savings to be reinvested in frontline care. Some programmes have focused on issues such as shared decision-making.

Yet there is still some way to go

Despite all the positive statements and policy about the importance of having well informed patients, substantial progress still needs to be made in many parts of the UK where investment in the development and delivery of health information is uncoordinated and in many cases absent. Results from PiF's survey reveal that many trusts in England do not have a centrally held budget for patient information and, where there is one, this often represents a very small percentage of the trust's overall budget. One quarter of trusts have no trust-wide standards that directorates and clinical teams must conform to. The lack of any real 'place' for health information to sit, plus the part-time, wide-ranging and lone nature of many information roles highlight its low priority.⁵²

In the current financial climate, cutting information provision is seen as an easy win for NHS organisations faced with hard budget choices. This is exacerbated by the fact that investment may be necessary in one area but return on that investment may not be evident until further along the patient journey. In today's cost-focused NHS, shared benefits are not necessarily front of mind.

As a result, information is still seen as a nice to have rather than an essential component of a quality health service. Many health organisations have no strategy for health information, no quality assurance standards or processes, and no dedicated budgets or staff. Information often has no home within NHS organisations (including within primary care and clinical commissioning groups as well as in hospitals) and it is often an 'add on' to the work of clinical governance, communications or patient and public involvement teams. Provision is patchy across different types of healthcare organisations, geographical regions and conditions.

Despite the work of the Patient Information Forum and others, there is no shared definition of consumer health information. Talk about 'information' is often really about the transparency agenda - access to records and performance data for example. While these aspects are very important, they sometimes

take precedence over more basic health information needs from patients.

The Power of Information strategy was an important statement of intent from the Department of Health and asserted the benefits of information as *the lifeblood of good health and wellbeing*.⁵³ Yet it was a high level strategy and did not include the detail of how and what should be delivered in the way of good quality consumer health information.

While charities and other third sector organisations have embraced the quality assurance process of the Information Standard, NHS organisations have been slower to accredit information provision, and there has also been low commercial sector use of the Standard. As a result, money is often wasted through inefficient production of poor quality information and unnecessary duplication.

There is also no audit trail to show what information is provided to which patients in which context. Substitute the word 'medicine' for 'information' and this would be seen as negligent. Yet information continues to be regarded as relatively unimportant.

There has been a huge range of innovation in the production and provision of online health information, yet there is still insufficient recognition of the continuing need for face-to-face support to help people access, navigate and understand the information available.

There are issues of inequality relating to access to and understanding of technology (the 'digital divide'), issues of 'health literacy' (understanding and using the health information provided), as well as problems of basic literacy. For example, Professor Gill Rowlands, Professor of Health Disparities at London South Bank University, has highlighted that a standard of NVQ level 2 literacy and numeracy (i.e. that of a 14-16 year-old) is required to understand a BMI (body mass index) chart. Yet the National Literacy Trust reports that one in six people in the UK have a literacy level below that expected of an 11 year-old.

The Health Foundation, in its work on Helping People Help Themselves makes the point that information is a necessary but not sufficient

ingredient of self-care and that information without support could even widen existing health inequalities.⁵⁴ Information plus support is seen as the key to achieving the necessary behaviour change.

Patient satisfaction with information and communication

Despite a significant fall in the past year, overall public satisfaction with the way the NHS runs remains at a historically high level.⁵⁵ However, although patient ratings of care for hospital, primary care and community mental health services are also positive, there has been no discernible improvement in these measures over time.⁵⁶

This is likely, in part, to reflect patients' continuing concerns over not receiving sufficient information about their healthcare.⁵⁷ Recent results from the National Patient Survey Programme showed that 21% of patients stated that they were not given enough information about their condition or treatment while in hospital; and only 52% felt that they were definitely involved as much as they wanted to be in decisions about their care.⁵⁸ Similarly, in primary care, only half of patients were satisfied with the information they received from their GP practice.⁵⁹

Research has revealed that nearly six out of ten cancer patients would like to receive more information than they are given.⁶⁰ A lack of information, explanation and support has also been cited as the greatest cause of anxiety and stress in cancer patients.⁶¹ Recent studies have also highlighted similar information and communication deficits in the care of people with multiple sclerosis.⁶²

Patients attach great priority to good communications so that they are able to make informed choices about their healthcare.

High quality information empowers people. With poor information they cannot make effective choices; and without information they have no real choices at all.

Better information, better choices, better health: Putting information at the centre of health, Department of Health, 2004

Patients have to make many decisions about their healthcare, and it is self-evident that they cannot express informed preferences unless they have been provided with sufficient and appropriate information.⁶³ Reliable information is also essential to help patients understand their health problems and to know how to deal with them.⁶⁴ Yet problems relating to poor communications and inadequate information are still one of the most common causes of (rising) formal complaints in the health service⁶⁵ and remain the greatest source of patient dissatisfaction.⁶⁶

What information do patients want?

High quality information is essential for improving access to healthcare – increasing consumers' awareness and understanding of available services and, also, their ability to successfully navigate the system.⁶⁷

A focus group study identified a wide range of more specific reasons why people need good information.⁶⁸ Most of these reasons are directly related to their condition and treatment options, reflecting patients' desire to be involved in decisions and to:

- understand what is wrong with them
- gain a realistic idea of their prognosis
- know when to seek professional help
- be able to make the most of consultations with clinicians
- understand the processes and likely outcomes of possible tests and treatments
- assist in their own self-care
- seek reassurance and help to cope
- help others (e.g. family, friends and/or employers) to understand what is wrong
- legitimise help-seeking and concerns
- identify the 'best' healthcare providers.

In addition to such 'medical' concerns, the same research also revealed patients' wider interests in accessing information that helps them to:

- learn about available services and sources of help
- identify further information and self-help groups.

Evidence for these further requirements is provided by a review by Macmillan Cancer Support which highlights particular gaps in the provision of information about cancer, regarding patients' broader emotional, financial and social concerns.⁶⁹ People are concerned with the impacts of their illness on their everyday life, and many patients with serious long-term conditions experience substantial stress around relationship and financial issues.⁷⁰ Once these pressures are eased, patients are more able to deal with their illness and treatment.

Sources of health information

In addition to verbal communication during consultations, patient information is made available in a wide variety of formats using different media – from simple photocopies and printed leaflets to more complex websites and interactive multimedia.

Information provided by health professionals

Consumers vary enormously in what they need to know at any time about their health.⁷¹ This is affected by a number of factors including their personal characteristics, circumstances and beliefs, their health condition and whatever stage they may have reached in their 'patient journey'.

Family doctors are consistently identified as being the preferred source of health information for most people.⁷² This reflects the high trust and regard in which they are generally held – as confirmed by the latest Oxford Internet Survey which showed that doctors are still the most trusted individuals people have contact with.⁷³

Information needs therefore change, and not always in a predictable way, with different kinds of information being more important at different times. When it comes to information, one size does not fit all. Consequently, the timing and amount of information provided is as important as its quality and content.⁷⁴ A key task for health professionals therefore is continually re-assessing their patients' needs for information and support so that they can offer this in timely stages or layers in accordance with individual patient's changing requirements.⁷⁵ This requires sensitivity to patients' emotional state, and an understanding of their levels of health literacy and engagement, and where they are on their health journey.

While the vast majority of people have trust and confidence in their family doctor, around one-in-six (17%) do not feel that their GP is good at explaining tests and treatments, and one-in-four (24%) do not feel that their GP is good at involving them in decisions regarding their care.⁷⁶

Evidence from two major research studies conducted for the Department of Health also points to significant failings in information provision at all stages of the patient experience in both hospital and community settings⁷⁷, including inadequate information being provided about treatment options and on the availability of local services and support.⁷⁸ This leads Smith and Duman (2009) to highlight an apparent mismatch between the high levels of trust generally placed in doctors and cultural flaws in the medical profession that result in unmet patient needs for information.⁷⁹

The 'baby boomer' generation, when they get older, are going to be more demanding, health literate and potentially litigious if they don't get what they need. The message to clinicians and organisations is 'get with the programme now, as your patients will demand this stuff anyway.'

Jo Ellins, Principal Consultant, GHK Consulting, and former Lecturer at the Health Services Management Centre, University of Birmingham

The Future Forum also highlights a highly consistent message from patients and voluntary organizations that many health professionals do not always display the behaviours, skills and attitudes that are conducive to good communication, information sharing and shared decision-making.⁸⁰ In its recommendations to Government, the Forum consequently highlights the importance of education and training for healthcare professionals being far more geared towards excellence in communication and health coaching skills.⁸¹

In response to such requirements and to help develop mutuality, NHS Scotland has established 'The Knowledge Network'. This is an online knowledge management platform that provides high quality information and learning resources for health and social care staff. This includes a training module on 'information partnership' and a dedicated 'information literacy' portal.⁸²

Health information online

Increasingly, people are looking to specialist health websites and apps for information. Digital health – or 'e-health' – is a rapidly growing market and, in September 2011, some 9,000 health-related apps were available to consumers⁸³.

Very recently, the NHS launched its own Health Apps Library of validated tools to help consumers manage their health, and the NHS Choices website currently gets around 24 million unique visits per year.⁸⁴

Data from the 2011 Oxford Internet Survey reveal that nearly three-quarters (73%) of the British adult population (and exactly the same proportion of households) now has internet access. Almost all adults (97%) now own a mobile phone, with around half (49%) using a smart phone for email and to access the internet.

Information seeking has become a common activity for all internet users, and the proportion of users searching for health information on the net nearly doubled from 37% in 2005 to 71% by 2011 – with younger, more affluent and better

educated people being the most active online.⁸⁵ The survey provides further evidence of a continuing 'digital divide' and highlights the danger that increasing reliance on web-based health information resources could reinforce or even further exacerbate existing health inequalities.

Research by Powell and colleagues (2011) established four main reasons why people seek health information online:

- the desire for reassurance
- the desire for greater understanding to supplement other information
- the desire for a second opinion to confirm or challenge other information
- perceived external barriers to accessing information from traditional sources.

The main benefits of obtaining web-based information clustered around three themes – convenience, coverage and anonymity.⁸⁶ A literature review by McMullan (2006) found that the majority of internet searches relate to specific medical conditions and are carried out by patients either before a consultation, to help them manage their own health or to decide whether they might need professional help or, after a consultation, for reassurance or because they are dissatisfied with the information provided by their clinician.⁸⁷

Any view as to the many benefits of online consumer health information must be balanced with an awareness of some of the drawbacks. First – and aside from issues regarding access – as with much printed media, there are concerns about the quality, readability, reliability, relevance and currency of a lot of web-based health information.

A number of evaluation studies have reported that both written and web-based consumer health information materials are of variable and often poor quality⁸⁸ – frequently omitting relevant data, failing to give a balanced view, and ignoring uncertainties.⁸⁹ A systematic review of research evaluating the quality of online health information resources found that around one-third contained inaccurate information.⁹⁰

While the internet now affords consumers unprecedented access to health information this does not automatically enhance patient choice as, for many, the sheer volume can be overwhelming, conflicting and, ultimately, very confusing.⁹¹

There is also a danger that policies and initiatives which emphasise the provision of online information to support 'independent' choice-making by patients run the risk of overlooking the continuing importance of both personal support and professional-patient interactions. This could lead to a deterioration in both decision quality and patient experience.⁹²

With the development of more interactive applications, many people increasingly value and benefit from direct online communication with their peers. This may involve the use of social media or participation in dedicated forums where patients can share their own questions, thoughts and feelings about their illness, and learn from the experiences of others in a similar position. Healthtalkonline (www.healthtalkonline.org) is one example of a charity-run website where people can watch video, listen to audio clips or read about people's experiences of a wide range of conditions, treatment choices and support.

A major research study conducted for the National Institute for Health Research highlighted the increased significance of 'personal experiences' information to people's decision-making.⁹³ While the researchers found a strong consensus among participants that 'general facts' should underpin informed decisions, it was also evident that 'personal experiences' information can also help support decision-making in a number of ways. This includes by helping people to:

- recognise decisions that need to be thought about
- identify possible options
- appraise options and make a selection (for example by helping to: think 'what it might be like'; identify possible sources of decision support; and identify and consider different ways of reasoning about issues)

- support coping – including living with decisions made.

Although participants were able to exercise some discrimination in accessing and 'using' personal experiences information, the authors emphasise the need for care when it is used in resources for patients.

Supporting patient choice

In order to become actively engaged in their healthcare and to participate fully in decisions concerning their care, patients require access to good quality health information and any additional support that may be required to increase their knowledge and understanding. Unfortunately, the tight time constraint on clinical consultations substantially inhibits the amount of information health professionals are able to share with their patients in any encounter.

This dilemma has led some commentators to recommend clinicians adopting a more collaborative, participatory style which would see them acting as more of an 'infomediary' for their patients – signposting them towards and helping them acquire the high quality health information and support they need, and also helping them to relate it to their own situation.

For many health professionals, including doctors, the emphasis may be 'less on trying to know all the answers and more on knowing how to help the patient find them out'. Never before have good communication skills been so vital, or involving patients in their own care and treatment so important.

The State of Medical Education and Practice in the UK, General Medical Council 2011

This need to provide timely, personalised assistance to help patients and their carers access high quality health information that addresses their needs has led the Picker Institute to recommend the establishment of a new information signposting and navigation service in each local area, and specialist training to help health professionals assess, understand and respond effectively consumers' health information needs.⁹⁴ McMullan has also emphasised the importance of clinicians responding positively to patients' desire and search for greater knowledge and understanding, including by guiding them to reliable, high quality sources of consumer health information.⁹⁵

As an example of how good quality health information and support might be experienced by a patient, we have reproduced here an illustrative example of a 'perfect' patient information journey. This was originally created by PiF with assistance from Macmillan Cancer Support for inclusion in the NHS Future Forum's report to the Secretary of State for Health on information.⁹⁶

A perfect patient information journey?

Maria is 34 years old. She has been encouraged throughout her life to take responsibility for her health. She attended an enlightened school that encouraged physical exercise, regardless of sporting prowess, and incorporated health literacy into the curriculum. She is therefore aware of what is normal for her body and of where to access information if she needs it.

Recently, she has noticed that unexpected things have been happening: she has been dropping pencils or tripping over things that are not there. Maria looks at a symptom-checker on the internet, but decides that the things she has been experiencing are too infrequent to be a concern just at the moment. One morning, Maria wakes up with blurred vision. She is shocked and scared by this, but manages to get an emergency appointment to see her optician. Her optician tells Maria that it is likely to be a temporary blurring due to optic neuritis, but suggests that she visits her GP in case it is a sign of something more serious.

Maria rings her GP practice and gets an appointment to visit her GP. By now, her vision is getting better. She makes a note of 'optic neuritis' in her personal health record. Her GP listens to her story and proposes a referral to a neurologist. The GP explains to Maria that she has a choice of a consultant-led team and that there is an information advisor in the GP practice who can help her to choose a consultant. The GP also suggests information sources that she may find helpful. Maria spends some time with the information advisor, reviews options on an online information intermediary tool and makes an appointment with a consultant-led team.

Whilst waiting for her appointment with the neurologist, Maria decides to do some research of her own. The GP mentioned that the optic neuritis may be a sign of multiple sclerosis, so Maria rings the MS Society helpline one evening after work.

At Maria's appointment with the neurologist, she shares the notes on her personal health record, so that the consultant can see details of when she dropped things unexpectedly as well as the date when she had the optic neuritis and how long the blurred vision lasted. The neurologist advises Maria that tests will be needed to establish a diagnosis; the neurologist suggests that Maria watches a YouTube video about having an MRI scan.

The diagnosis of multiple sclerosis takes some time, but Maria is supported through it by her Clinical Nurse Specialist. Once she has a diagnosis, she is given an information prescription which contains short pieces of information from charities that has been compiled for her, with details about information centres, support groups, voluntary sector organisations and online forums. As well as including health information, information is also provided on social issues such as employment and finances. The information prescription has been emailed to her, so she forwards it to her brother in Australia, so that he knows what is happening. She also uses the information prescription to help her to work out the questions she wants to ask at her information centre.

Maria is keen to stay in control of her life. She asks at a self-help group and through online forums about other people's experiences of living with multiple sclerosis and about the treatment options. She uses experience gathered from the forum and self-help group to help her to ask questions about treatment options and to support her choices.

She chooses to take a treatment that she needs to inject herself. She agrees with her Clinical Nurse Specialist that she will keep in touch mostly by email, but she also has the option of speaking on the telephone or making an appointment. Maria uses a treatment diary on her mobile phone to help her to monitor her treatment. She also sets up a personal health diary so that she can track her mood and her fatigue over time.

Above all, Maria continues to ask questions, to access and share information, and to make her own decisions about living with multiple sclerosis.

Ensuring informed consent

Failure to provide full and balanced information to patients about the risks and uncertainties of any proposed treatment can give rise to unrealistic expectations. In some cases, this can also lead to costly legal action.⁹⁷ It is also not possible for patients to give their informed consent to treatment unless they have been fully informed about the potential risks and outcomes of the options available to them in a way that they can understand.

Obtaining informed consent protects the patient for whom treatment is planned by ensuring that the correct treatment decision is made for that individual. The well-informed patient may also be better equipped to guard against medical error, thereby enhancing their personal safety.⁹⁸ The importance of patients giving their valid consent is enshrined as a right in the NHS Constitution.⁹⁹ However, the consent process is often approached by medical teams as a bureaucratic hurdle to be overcome, and frequently in a manner that leaves the patient feeling disempowered – by signing a form that they may not have even read, and often not understanding the procedure for which they have just consented.¹⁰⁰

Failure to obtain consent that is truly informed increases the risk of expensive litigation for health providers. There is currently some £4bn of related outstanding NHS liabilities.¹⁰¹ Assisting patients with informed decision-making is also a professional obligation for surgeons but their appreciation of patients' information needs appears to be poor.¹⁰² However, successfully communicating risk and obtaining truly informed consent requires good communication skills and effective educational resources for patients with different levels of health literacy.¹⁰³

Clinicians therefore need to develop and use effective communication techniques and appropriate decision aids to ensure that their patient achieves true autonomy in making decisions.¹⁰⁴ By ensuring truly informed consent in this way, health providers will not only enjoy fewer claims of malpractice, they

will also increase patients' satisfaction with their treatment choices and their overall experience of care.¹⁰⁵

Improving health literacy

Health literacy is not just about individuals' ability to read and make sense of health information. According to the definition adopted by the World Health Organisation, addressing health literacy is an empowerment strategy. Ensuring that people are able to access, understand, appraise and utilise health information effectively is the cornerstone for their active and informed engagement in healthcare and in decisions relating to this.¹⁰⁶

Although functional health literacy is closely related to general literacy and numeracy skills, it is context specific. This means that:

...an individual may be capable of understanding everyday sources of information, but struggle to make sense of health-related materials which routinely contain unfamiliar vocabulary or concepts. Basic literacy strategies will need to be supplemented by specific initiatives to identify and target those with communication difficulties arising from low health literacy.¹⁰⁷

Health literacy describes people's ability to make sound health decisions in the context of everyday life.¹⁰⁸ Low health literacy compromises people's ability to understand their own health needs and to navigate complex healthcare systems, with profound consequences for their health and finances.

Low health literacy represents a very significant problem and challenge in the UK. Around 7 million adults (20%) cannot read or understand simple instructions or labels such as those found on medicine bottles, while around half the population would be unlikely to understand cancer information brochures routinely used in hospital settings.¹⁰⁹ More recent research regarding women with breast cancer established that 19% of those in the study would have been unable to understand and consequently act on the written information that they were given.¹¹⁰

Patients with low health literacy:

- have poorer health status
- experience higher rates of hospitalisation and emergency admissions, and have longer stays
- are less likely to adhere to treatments and self-care plans
- have more medication and treatment errors
- make less use of preventative services and more use of unplanned services
- have less knowledge of disease-management and healthy living behaviours
- have decreased ability to communicate with health professionals and participate in decision-making
- are less able to make appropriate health decisions
- incur substantially higher health costs.

Those most affected by low health literacy include people who are: older, from ethnic minority backgrounds, with a low level of educational attainment and/or who suffer socio-economically deprivation.¹¹¹ Low health literacy is therefore closely associated with significant health inequalities between different groups in the UK; and one key objective for health literacy interventions is to help reduce such inequalities in health and access to healthcare services by targeting consumer health information and education at low literacy, hard-to-reach and disadvantaged groups.¹¹²

Successfully addressing health literacy issues is of crucial importance to, and a fundamental part of, the consumer health information challenge – to help turnaround the ‘reverse information law’ whereby access to appropriate and meaningful information is particularly difficult for those who need it most.¹¹³ In a second report of its Primary Care Review, the Patients Association recently issued an urgent ‘call to action’ to tackle this very serious problem – by demanding *greater coherence and resourcing of public education and awareness campaigns / initiatives with the aim of improving health literacy.*¹¹⁴

We are not going to be able to meet the challenge of saving £20bn unless we stop seeing patients simply as passive consumers of healthcare. We have to see them as a resource and help them become mature consumers by helping to drive up their health literacy and ability to seek the right sort of help when they need it.

Mark Davies, Executive Medical Director,
NHS Health and Social Care Information
Centre

This challenge is now taking on even greater importance with the increased emphasis in health policy on self-management for long-term conditions and personal responsibility for maintaining good health.¹¹⁵

A successful response to this critical challenge must include having consumer health information materials available that have been specifically written and designed to be accessible to people with low health literacy levels. Providing user-friendly information in other formats including through DVDs, digital television and websites can also improve accessibility for many people with low literacy,¹¹⁶ although there is inevitably a concern that those with the greatest need for such health information and education are the least likely to have access to such technologies.¹¹⁷

However, the information consumers need to make choices about their healthcare can be quite complex, and information without good communication is of little or no value. In addition to the help that they may receive from their doctors, some patients will therefore need further guidance and support to understand and make effective use of it. Different approaches to providing this include face-to-face advice, telephone support by trained advisors, translation and interpretation services, patient decision aids, and community-based self-management education programmes.¹¹⁸

Investing in health information

The preceding discussion has highlighted the vital role that health information plays in the delivery of high quality, patient-centred care by helping to enhance patient experience, patient safety and clinical effectiveness. In underpinning a positive experience of healthcare, the provision of consumer health information is also a major factor in facilitating the active engagement of people in their healthcare and treatment in order to:

- increase patient satisfaction and staff morale
- increase health literacy
- facilitate shared decision-making
- promote greater self-management and self-care
- encourage more appropriate service use
- increase productivity and efficiency, and reduce overall costs
- enhance patient safety
- improve health behaviours and outcomes
- reduce health inequalities.

To have such substantial and far-reaching effects, however, information has to be successfully communicated so that it translates to greater patient knowledge and understanding.

The immediate impacts and associated benefits of this are so powerful that Don Kemper and Molly Mettler of Healthwise developed the concept of 'information therapy' as a strategy for enhancing consumer access to health information. In asserting that *information is as important to patient's health as any drug, medical test or surgery* they argue that patients should be prescribed accessible, accurate, evidence-based information as an important part of their treatment.¹¹⁹ Rather than patients being given information about their care, this approach posits consumer health information as itself a key component of the treatment process.¹²⁰

Information is an essential service in its own right, allowing us to understand our own health, choose healthier lifestyles, and choose the treatment and support that is right for us.

The Power of Information, Department of Health. 2012

Quality health information for, from and about patients and the support to understand it is certainly the lifeblood of modern, patient-centred services. Information is so intrinsic to the delivery and improvement of high quality care that it is now recognised, in policy terms at least, as an essential service in its own right.¹²¹ However, despite previous policy exhortations, strategies, action plans and statements of principle, patients are still dissatisfied with the amount of information they receive, and also want greater involvement in decisions about their healthcare and treatment.

The significant advantages of improving access to good quality information (and the equally clear drawbacks of not doing so) are so great that consumer health information services must now be properly planned and appropriately resourced. At a minimum, this requires dedicated budgets and clear lines of responsibility and accountability. Given our current state of knowledge, to do any less would be to continue to diminish patients' experiences of healthcare, to compromise their safety, health status and wellbeing, and to waste increasingly scarce public resources.

The harms of not investing in health information and support

With information being the lifeblood of good health and wellbeing,¹²² and the key to providing better quality care, better outcomes and reduced costs,¹²³ then the consequences of failing to provide patients with high quality information and support may be extremely serious. According to the NHS Future Forum:

Information for patients and service users is an integral part of care. Like medicine, good information can heal but poor information or poor handling of information can harm. We need to regard poor information as poor quality care and as such a potential breach of the minimum standards that the NHS Constitution is intended to safeguard.¹²⁴

Having insufficient information is likely to increase any patient's fear, anxiety and stress levels. However, for someone who is chronically ill, a lack of information and support about how best to manage their condition could very well lead to poorer health, increased pain and discomfort and greater adverse effects on their daily life; and, for someone with an acute complaint, inadequate information may lead them to receive more expensive and invasive treatment that they might well not have chosen had they had better information about care options, outcomes and evidence¹²⁵.

For the health service, the existing information failures can only result in increased, unplanned demand and higher costs. By failing to provide patients with all the information and support they need to maintain their own health and to actively participate in decisions about their healthcare, the health service is also compromising all three key dimensions of quality care – patient experience, patient safety and clinical effectiveness. For individual patients, the impact of not being properly informed and involved can, potentially, be devastating. For the taxpayer and service users generally, such information failings also carry very high costs in terms of reduced efficiency, effectiveness and economy.

A recent report from the King's Fund presents a comprehensive analysis of why patients' preferences matter so much. The authors describe how clinicians' failure to fully inform and involve patients in decisions about their care amounts to 'a silent misdiagnosis'.¹²⁶ This failure to diagnose patients' treatment preferences can be every bit as dangerous as failing to diagnose disease correctly. They argue that ending the silent misdiagnosis would not only ensure that patients will get the medicine they would choose if they were properly informed, it could also save the NHS billions of pounds - because well-informed patients choose fewer treatments, and involving people in decisions about their healthcare helps to reduce unwarranted variations in treatment.

... the NHS must recognise the need for new, dedicated teams focused on gathering and disseminating information. It must also aid commissioners in shifting their focus, from trying to calculate need to trying to eliminate preference misdiagnoses, so that patients receive the care they need (and no less), and the care they want (and no more).

Patients' Preferences Matter, Al Mulley & colleagues, King's Fund, 2012

Pointing to examples of 'breathtaking gaps' between what patients actually want and what doctors think they want, Mulley and colleagues call for a coordinated effort across the NHS to tackle this serious defect in clinical decision-making.¹²⁷

Any failure to invest in providing appropriate support to aid patients' knowledge and understanding, and to assist them in developing the confidence, ability and motivation to assume greater responsibility for their own health, could also have serious implications for health inequalities. In identifying information as a health and care service in its own right, The Power of Information strategy also underlines the crucial importance of *appropriate support in using information [being] available for those who need it, so that information benefits everyone and helps reduce inequalities*.¹²⁸ Given the digital divide and the generally lower levels of health literacy and patient engagement among disadvantaged people and those with the poorest health, there is a danger that information minus support could actually exacerbate existing health inequalities.

There is also substantial evidence that failures in patient-doctor communications result in higher levels of complaint and increased claims of negligence. The Citizens Advice Bureau estimate that communication or information failures account for at least one-in-five of all patients' complaints. Overall, the number and cost of negligence claims paid by the NHS Litigation Authority has risen from £0.6 billion in 2006/7 to £1.3 billion in 2011/12¹²⁹ and,

at the end of March 2012, there were just over 22,500 'live' claims¹³⁰, with total outstanding liabilities of £18.9 billion.¹³¹

Not having access to quality information and the support to understand it also means that patients will be more likely to seek information elsewhere from less trustworthy sources. Unreliable information can lead to incorrect self-diagnosis and/or increased feelings of anxiety and stress.¹³²

Section 4 - References

⁴³ Department of Health (2013) *The NHS Constitution*

⁴⁴ Scottish Government (2011) *The Patient Rights (Scotland) Act 2011*

⁴⁵ General Medical Council (2013) *Good Medical Practice*

⁴⁶ General Pharmaceutical Council (2010) *Standards of Conduct, Ethics and Performance*

⁴⁷ Nursing and Midwifery Council (2008) *The code: Standards of conduct, performance and ethics for nurses and midwives*

⁴⁸ Capita Group Research (2010) *Research Now Survey 2010*

⁴⁹ Department of Health (2012) *The Power of Information: putting all of us in control of the health and care information we need*

⁵⁰ Smith S (2010) *NHS Trusts in England Survey: summary of results*, Patient Information Forum

⁵¹ NHS Future Forum (2012) *Information: A report from the NHS Future Forum*

⁵² *ibid.*

⁵³ Department of Health (2012) *The Power of Information: putting all of us in control of the health and care information we need*

⁵⁴ de Silva D (2011) *Helping people help themselves*, Health Foundation

⁵⁵ Appleby J (2012) *Public satisfaction with the NHS and its services: Headline results from the British Social Attitudes Survey*, King's Fund

⁵⁶ Thorlby R & Maybin J (2010) *A high-performing NHS? A review of progress 1997-2010*, King's Fund

⁵⁷ *ibid.*

⁵⁸ Care Quality Commission (Undated) *National summary of the results for the 2011 Inpatients Survey*

⁵⁹ Raleigh V & Frosinin F (2012) *Improving GP services in England: exploring the relationship between quality of care and the experience of patients*, King's Fund

⁶⁰ Sheldon H & Sizmur S (2009) *An Evaluation of the National Cancer Survivorship initiative test community projects*, Picker Institute Europe

⁶¹ Evans B D (1995) *The experiences and needs of patients attending a cancer support group*. *International Journal of Palliative Nursing*, 1: 189-194

⁶² Heesen C, Kasper J, Köpke S, Richter T, Segal J & Mühlhauser I (2007) *Informed shared decision making in multiple sclerosis – inevitable or impossible?* *Journal of Neurological Sciences*, 2007 Aug 15;259(1-2):109-117

⁶³ Coulter A, Entwistle V, Gilbert D. (1999) *Sharing decisions with patients: is the information good enough?* *British Medical Journal*. 1999; 318–322

⁶⁴ Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, Magee H & Sheldon H (2006) *Assessing the quality of information to support people in making decisions about their health and healthcare*, Picker Institute Europe and Public Health Resource Unit, Oxford

⁶⁵ Leatherman S & Sutherland K (2008) *The quest for quality: Refining the NHS reforms. A policy analysis and chartbook*, Nuffield Trust

⁶⁶ Coulter A (2005) *What do patients and the public want from primary care?* *British Medical Journal*. 2005 Nov 19; 331(7526):1199-1201

⁶⁷ Ellins J & McIver S (2009) *Public information about quality of primary care services*, Health Services Management Centre, University of Birmingham

⁶⁸ Coulter A, Entwistle V & Gilbert D (1998) *Informing patients: an assessment of the quality of patient information materials*, King's Fund

⁶⁹ Macmillan Cancer Support (2010) *Local information and support services: An evidence review*

⁷⁰ Chapple A, Ziebland S, McPherson A & Summerton N (2004) *Lung cancer patients' perceptions of access to financial benefits: a qualitative study*. *British Journal of General Practice*, 2004 Aug;54(505):589-594

⁷¹ Detmer D, Singleton P, MacLeod A, Wait S, Taylor M & Ridgwell J (2003) *The informed patient: study report*, Cambridge University Health

⁷² Ellins J and Coulter A (2005) *How engaged are people in their healthcare?* Health Foundation

⁷³ Dutton W & Blank G (Undated) *Next Generation Users: the Internet in Britain 2011 report*, Oxford Internet Institute, University of Oxford

-
- ⁷⁴ Hand A, Greenwell K, Corbett S, Walker R & Kirrane H (2008) Developing an information prescription service, *Nursing Times*, 2008 Sep 30-Oct 6;104(39):34-7
- ⁷⁵ Levenson R, Jeyasingham M and Smith S (2012) The information needs and preferences of people newly diagnosed with MS, MS Trust
- ⁷⁶ Care Quality Commission (2012) The GP Patient Survey: January – September 2012, summary report
- ⁷⁷ Robert G & Cornwell J (2011) 'What matters to patients?' Developing the evidence base for measuring and improving patient experience, King's College London and King's Fund
- ⁷⁸ Swain D, Ellins J, Coulter A, Heron P, Howell E, Magee H, Cairncross E, Chisholm A & Rasul F (2007) Accessing information about health and social care services, Picker Institute Europe
- ⁷⁹ Smith S & Duman M (2009) The state of consumer health information: an overview, *Health Information and Libraries Journal*, 2009 Dec;26(4):260-78
- ⁸⁰ NHS Future Forum (2012) Information: A report from the NHS Future Forum
- ⁸¹ *ibid.*
- ⁸² NHS Education for Scotland (undated) The Knowledge Network website - www.knowledge.scot.nhs.uk
- ⁸³ Gann R (2012) Single portal workstream 2: evidence base, Presentation to the NHS Commissioning Board, Aug 2012 (unpublished)
- ⁸⁴ Murray J, Majeed A, Khan M, Lee J & Nelson P (2011) Use of the NHS Choices website for primary care consultations: results from online and general practice surveys. *JRSM Short Reports*, 2011 Jul;2(7):56
- ⁸⁵ Dutton W & Blank G (Undated) Next Generation Users: the Internet in Britain 2011 report, Oxford Internet Institute, University of Oxford
- ⁸⁶ Powell J, Inglis N, Ronnie J & Large S (2011) The characteristics and motivations of online health information seekers: cross-sectional survey and qualitative interview study, *Journal of Medical Internet Research*, 2011 Feb 23;13(1):e2012
- ⁸⁷ McMullan M (2006) Patients using the Internet to obtain health information: how this affects the patient-health professional relationship, *Patient Education and Counselling*, 2006 Oct;63(1-2):24-8. Epub 2006 Jan 6
- ⁸⁸ Coulter A & Ellins J (2006) Patient-focused interventions: a review of the evidence, Picker Institute Europe
- ⁸⁹ Coulter A, Entwistle V & Gilbert D (1999) Sharing decisions with patients: Is the information good enough? *British Medical Journal*, 1999;318: 318–22
- ⁹⁰ Eysenbach G, Powell J, Kuss O & Eun-Ryoung S (2002) Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review, *JAMA*, 287 (20): 2691-2700
- ⁹¹ McMullan M (2006) Patients using the Internet to obtain health information: how this affects the patient-health professional relationship, *Patient Education and Counselling*, 2006 Oct;63(1-2):24-8. Epub 2006 Jan 6
- ⁹² Wyke S, Entwistle V, France E, Hunt K, Jepson R, Thompson A & Ziebland S (2011) Information for choice: what people need, prefer and use, Report for the National Institute for Health Research Service Delivery and Organisation programme
- ⁹³ Entwistle V, France E, Wyke S, Jepson R & Hunt K (2011) How information about other people's personal experiences can help with healthcare decision-making: A qualitative study, *Patient Education and Counseling*, 85 (2011) e291–e298 Sue Ziebland b,e, Andrew Thompson
- ⁹⁴ Swain D, Ellins J, Coulter A, Heron P, Howell E, Magee H, Cairncross L, Chisholm A & Rasul F (2007) Accessing information about health and social care services, Picker Institute Europe
- ⁹⁵ McMullan M (2006) Patients using the Internet to obtain health information: how this affects the patient-health professional relationship, *Patient Education and Counselling*, 2006 Oct;63(1-2):24-8. Epub 2006 Jan 6
- ⁹⁶ NHS Future Forum (2012) Information: A report by the Future Forum
- ⁹⁷ Coulter A (2002) The Autonomous Patient, Nuffield Trust
- ⁹⁸ Benjamin D (2003) Reducing medication errors and increasing patient safety: case studies in clinical pharmacology, *Journal of Clinical Pharmacology*, 2003 Jul;43(7): pp768-783
- ⁹⁹ Department of Health (2013) The NHS Constitution
- ¹⁰⁰ Mulsow J, Feeley T & Tierney S (2012) Beyond consent - improving understanding in surgical patients, *American Journal of Surgery*, 2012 Jan; 203(1): pp112-120
- ¹⁰¹ EIDO Healthcare website, www.eidohealthcare.com/patient-information/procedures/ [accessed 14 February 2013]
- ¹⁰² Mulsow J, Feeley T & Tierney S (2012) Beyond consent - improving understanding in surgical patients, *American Journal of Surgery*, 2012 Jan; 203(1): pp112-120
- ¹⁰³ Coulter A & Ellins J (2006) Patient-focused interventions: a review of the evidence, Picker Institute Europe
- ¹⁰⁴ Pape T (1997) Legal and ethical considerations of informed consent, *AORN Journal*, 1997 Jun;65(6): pp1122-1127

¹⁰⁵ Keating N, Guadagnoli E & Landrum M et al (2002) Treatment decision-making in early-stage breast cancer: should surgeons match patients' desired level of involvement? *Journal of Clinical Oncology*, 2002;20: pp1473–1479

¹⁰⁶ Coulter A & Ellins J (2006) Patient-focused interventions: a review of the evidence, Picker Institute Europe

¹⁰⁷ *ibid.*

¹⁰⁸ Harry Cayton OBE (undated)

¹⁰⁹ Manning D & Dickens C (2006) Health literacy: more choice, but do cancer patients have the skills to decide? *European Journal of Cancer Care (English edition)*, 2006 Dec;15(5):448-52

¹¹⁰ Cox N, Bowmer C & Ring A (2011) Health literacy and the provision of information to women with breast cancer, *Clinical oncology : a journal of the Royal College of Radiologists*, 2011 Apr;23(3):223-7

¹¹¹ Ellins J & Mclver S (2008) Systematic provision of information on quality of primary care services, Health Services Management Centre, University of Birmingham

¹¹² Coulter A & Ellins J (2006) Patient-focused interventions: a review of the evidence, Picker Institute Europe

¹¹³ Eysenbach G & Diepgen T (2001) The role of e-health and consumer health informatics for evidence-based patient choice in the 21st century, *Clinics in Dermatology*, 2001 Jan- Feb;19(1):11-7

¹¹⁴ Patients Association (2013) Primary Care: Access Denied?

¹¹⁵ Smith S & Duman M (2009) The state of consumer health information: an overview, *Health Information and Libraries Journal*, 2009 Dec;26(4):260-78

¹¹⁶ Ellins J & Mclver S (2009) Public information about quality of primary care services, Health Services Management Centre, University of Birmingham

¹¹⁷ Eysenbach G & Diepgen T (2001) The role of e-health and consumer health informatics for evidence-based patient choice in the 21st century, *Clinics in Dermatology*, 2001 Jan- Feb;19(1):11-7

¹¹⁸ Ellins J & Mclver S (2009) Supporting people to make informed choices in primary care: what works? Policy Paper no. 4, Health Services Management Centre, University of Birmingham

¹¹⁹ Mettler M & Kemper D (2006) Information therapy: The strategic role of prescribed information in disease self-management. *Studies in Health Technology and Informatics*. 2006;121:373-83.

¹²⁰ Coulter A & Ellins J (2006) Patient-focused interventions: a review of the evidence, Picker Institute Europe

¹²¹ Department of Health (2012) The power of information: Putting all of us in control of the health and care information we need

¹²² Department of Health (2010) Equity and Excellence: Liberating the NHS

¹²³ Department of Health (2012) The power of information: Putting all of us in control of the health and care information we need

¹²⁴ NHS Future Forum (2012) Information: A report by the Future Forum

¹²⁵ Mulley A, Trimble C & Elwyn G (2012) Patients' Preferences Matter: Stop the silent misdiagnosis, King's Fund

¹²⁶ *ibid.*

¹²⁷ Coulter A blog, Please stop muddling shared decision-making and provider choice, www.kingsfund.org.uk/blog/2012/06/please-stop-muddling-shared-decision-making-and-provider-choice [Accessed 7 Feb 2013]

¹²⁸ Department of Health (2012) The Power of Information: putting all of us in control of the health and care information we need

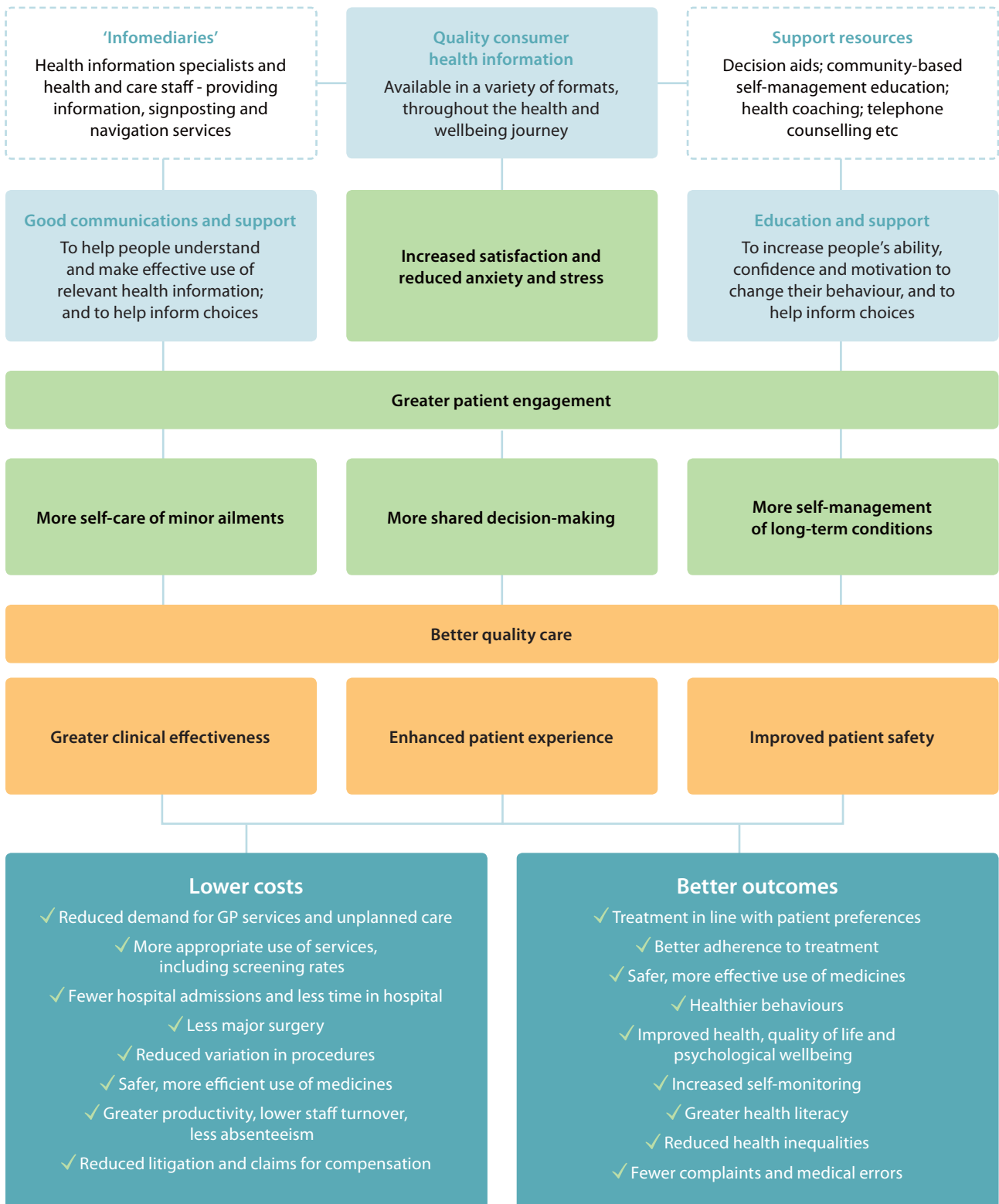
¹²⁹ The NHS Litigation Authority (2012) Factsheet 2: financial information

¹³⁰ The NHS Litigation Authority (2012) *Factsheet 3: information on claims*

¹³¹ The NHS Litigation Authority (2012) *Factsheet 2: financial information*

¹³² Macmillan Cancer Support (2010) *Local information and support services: An evidence review*

A simplified model of the Case for Information



5 The business case for investing in consumer health information

This report outlines a compelling case for investing a greater amount of dedicated resources in improving access to high quality consumer health information and support. While it may not be possible to quantify the overall return on investment that this could generate, the savings potential of actively engaging informed patients in their healthcare is clearly enormous.

This conclusion accords with the 2002 Treasury report by Sir Derek Wanless which argued that the only sustainable option for the longer-term future of the NHS lay in his 'fully engaged scenario'. Wanless estimated that maximising patient engagement could generate potential annual savings of £30 billion (16% of the total budget) by 2022.¹³³ However optimistic that figure may be, the dividend created by an NHS that addresses health literacy and promotes self-care, self-management and shared decision-making, and which integrates services around patients certainly amounts to billions of pounds.¹³⁴ As Al Mulley and colleagues comment:

Health care may be the only industry in which giving customers what they really want would save money. Well-informed patients consume less medicine – and not just a little bit less, but much less. When doctors accurately diagnose patient preferences, an enormous source of waste – the delivery of unwanted services – is eliminated... [When] doctors accurately diagnose the preferences of patients struggling with long-term conditions, those patients are far more likely to keep their conditions under control, leading to fewer hospitalisations and emergency department visits.¹³⁵

There are therefore incontrovertible business reasons to justify health commissioners and provider bodies investing more money in consumer health information and support. These are summarised below:

Improving health information raises quality and is key to unlocking patient engagement

- Improving access to health information increases patients' knowledge and understanding and enhances their experience of care. Combined with appropriate education and support, it is also key to unlocking patient engagement – facilitating patients more active involvement in their healthcare and contributing to associated improvements in patient safety and clinical effectiveness, the other two pillars of quality. Investing in information must therefore be seen as core business for health organisations – both a 'must do' and the right thing to do.¹³⁶

Better health information can have significant impacts on service use and reduce costs

- The preceding analyses have highlighted the positive impacts that quality health information and support can have on service utilisation and costs, including through:
 - reductions in unwarranted treatment and the numbers electing for major surgery
 - lower demand for GP consultations from people with minor ailments
 - reduced compensation and litigation costs
 - possible reductions in A&E attendances, emergency admissions, re-admissions and time spent in hospital
 - reduced wastage of prescribed medicines (which currently costs the NHS over £1 billion annually).¹³⁷

The relative cost of different health services (to the taxpayer)¹³⁸

Nil	Self-care
46p	Accessing NHS Choices
£16	Calling NHS Direct
£32	Stepping into a GP surgery
£111	Stepping into A&E
£455	Calling an ambulance

Ending the 'silent misdiagnosis' could save the NHS billions of pounds

- Correctly diagnosing patients' preferences could save billions of pounds because well-informed patients choose fewer treatments, including less major surgery.
- Involving people in decisions about their healthcare – ensuring that they only get treatment that they need and the care that they want – helps to reduce unwarranted variations in treatment.

Making greater use of e-communication channels could deliver very substantial capacity savings in primary care

- Although it is not possible to quantify the effects at a local level, the scale of the potential capacity savings in relation to GP consultations for minor ailments is considerable. One analysis suggests that if 10% of GP attendances for minor ailments could be avoided through online self-care advice, savings could be around £830m; if a similar proportion were transferred to NHS111, the cost could be around £570m less.¹³⁹
- The potential for such channel shift, especially among younger, healthier people should not be under-estimated. A recent survey of NHS Choices users found that one third of respondents said that using the site decreased their number of GP visits.¹⁴⁰

Increasing the self-management of long-term conditions can yield significant returns on investment

- It is in the self-management of long-term conditions that the greatest pressure on health resources arises and, consequently, where there is the greatest scope for reducing costs. As highlighted in the previous section, the weight of research evidence points to the need for multi-faceted information and education strategies to increase patients' understanding, motivation, skills and confidence to assume more responsibility for maintaining their own health.
- The chronically ill already account for two-thirds of overall health costs, including around 80% of GP consultations and 60% of hospital bed days.¹⁴¹ With their numbers projected to rise by more than 50% over the next 20 years¹⁴², the need for investing more resources in enabling and supporting self-management could not be more urgent. According to the Wanless report, every £100 spent on promoting the full engagement of patients in their own healthcare should generate a 50% return on investment.¹⁴³
- Evidence of the clear economic benefits of investing in community-based self-management education comes from the Expert Patients Programme (EPP). Research into the impacts of the EPP on 1,000 people who had participated in the programme during the previous two years found, for example, that 50% of participants reported having subsequently made less GP visits, while 35% reported having reduced their medications. Overall, for an investment cost of £400 per attendee, the research estimated an average net saving of £1,800 per chronically ill patient per year.¹⁴⁴

- It is also clear from the research that attending a lay-led, self-management education course can trigger a cycle of positive re-enforcement that produces long-term changes in behaviour and confidence and reverses previous cycles of dependency and helplessness. In addition to the key economic benefits of reduced service demands/costs, the EPP was also found to generate a broader social return on investment – the key universal benefits being:
 - improved and new relationships with family and friends
 - increased engagement in volunteering
 - positive employment-related outcomes.¹⁴⁵

Actively engaged patients incur lower costs

- An additional incentive for investing more resources in promoting patient engagement comes from research evidence from the United States which shows that more ‘activated’ participants in treatment decisions and self-management incur lower costs. This was true overall and for different long-term conditions. Patients with the lowest activation levels had 21% higher costs than those with the highest levels.¹⁴⁶ Less engaged patients are around twice as likely to be readmitted to hospital within 30 days of discharge, and to experience a medical error, than the more engaged.¹⁴⁷

Increasing active participation among patients with low health literacy will generate the greatest returns

- In the UK, patients with low health literacy have poorer health status and incur higher health costs than other patients. They are less engaged in their health, less likely to adhere to treatment and self-care plans, less able to participate in decision-making and less able to maintain their own health. However, improving engagement among patients with low health literacy would not only deliver much greater savings than for any other group, it would also assist in reducing health inequalities.

- There is evidence that patient engagement can be increased among those with low levels of involvement, and that ‘patient activation scores’ could be used to target information and education initiatives where the benefits and return would be greatest.¹⁴⁸

Current payment schemes provide little incentive to enhance patient experience, including through improved information and support

- Patients want more information about their health and treatment options and, as already noted several times, meeting this demand increases satisfaction and contributes to patients enjoying a more positive experience of care. Although current payment schemes provide very little financial incentive for health providers to improve patient experience, such considerations will take on far greater importance in the reformed health service.

There are clear links between patient experience, quality and financial health

- In the United States, there is evidence of a positive association between excellent patient experience and the market performance and financial health of providers.¹⁴⁹ Similarly, there is also increasing evidence of a positive association between quality and financial performance.¹⁵⁰

Positive patient experience and feedback will attract customers and reassure commissioners

- With the introduction of greater competition, choice and transparency into the UK health system, health providers will need to become much more concerned for their reputation. With greater encouragement and the increased willingness of people to comment on and rate their experiences of healthcare online, providers are now likely to focus far more sharply on improving their patients’ experience.

- From a business perspective, this is both a major risk-management issue and a significant opportunity. Good feedback from consumers is an excellent marketing tool but any shortcomings in any aspect of the quality of care provided – but particularly in patient experience – may lose a provider custom and also damage its standing with local commissioners.¹⁵¹

Section 5 - References

¹³³ Wanless D (2002) *Securing Our Future Health: Taking a Long-Term View*, HM Treasury

¹³⁴ Department of Health (2009) *NHS 2010-2015: from good to great*

¹³⁵ Mulley A, Trimble C & Elwyn G (2012) *Patients' Preferences Matter: Stop the silent misdiagnosis*, King's Fund

¹³⁶ Dr Foster (2010) *The intelligent board 2010: patient experience*

¹³⁷ Patient Information Forum website (2012) *Faculty of Pharmaceutical Medicine Annual Symposium: Life or livelihood: Does adherence to medicines matter?* www.pifonline.org.uk/faculty-of-pharmaceutical-medicine-annual-symposium-life-or-livelihood-does-adherence-to-medicines-matter/ [accessed 10 April 2013]

¹³⁸ Gann R (2012) *Single portal workstream – Evidence Base*, NHS Choices

¹³⁹ Capita Health (2011) *Channel shift in the NHS: transforming the relationship between citizen and service*

¹⁴⁰ Murray J, Majeed A, Khan M, Lee J & Nelson P (2011) *Use of the NHS Choices website for primary care consultations: results from online and general practice surveys*, *JRSM Short Reports*, 2011 Jul;2(7):56

¹⁴¹ Coulter A & Ellins J (2006) *Patient-focused interventions: a review of the evidence*, Picker Institute Europe

¹⁴² The Guardian (2013) *Britain's old-age time bomb: peers warn of crisis as population of over-65s soars*, 25 February 2013, p3

¹⁴³ Wanless D (2002) *Securing Our Future Health: Taking a Long-Term View*, HM Treasury

¹⁴⁴ Expert Patients Programme (undated) *Self Care Reduces Costs And Improves Health – The Evidence*

¹⁴⁵ Expert Patients Programme (undated) *Healthy lives equal healthy communities – the social impact of self-management*

¹⁴⁶ Hibbard J, Greene J & Overton V (2013) *Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'*, *Health Affairs*, 2013 Feb;32(2):216-22

¹⁴⁷ AARP Public Policy Institute (2009) *Beyond 50.09 – Chronic Care: A Call to Action for Health Reform*

¹⁴⁸ *ibid.*

¹⁴⁹ Foot C & Cornwell J (2010) *Improving patients' experiences: an analysis of the evidence to inform future policy development*, King's Fund

¹⁵⁰ Dr Foster (2010) *The intelligent board 2010: patient experience*

¹⁵¹ *ibid.*

6 Patient engagement, service utilisation and health costs

Providing consumers with high quality and accessible health information not only enhances patient experience, it also helps to facilitate greater patient engagement in healthcare.

This section summarises the key benefits to service utilisation and health costs that are associated with increasing patients' active engagement in their healthcare. Detailed references to supporting research evidence are given in a table at the end of the section.

More appropriate screening rates

- Targeted health information, reminder letters and decision aids can help to increase or reduce the uptake of screening tests, as appropriate.

Reductions in major surgery

- People are sufficiently well-informed and motivated to get involved in decision-making are often more risk averse than clinicians and less likely to choose major surgery.

Reduced variation in procedures

- By ensuring that patients only get the care they want and need, shared decision-making assists in reducing unwarranted variation in clinical practice and procedures of limited clinical value.

Reduced demand for primary care

- Patients who assume more active responsibility for managing and maintaining their health help to reduce the demand for GP consultations.

More appropriate use of services

- Better adherence to treatment and medication regimens helps to reduce A&E attendances and unplanned hospital admissions which are both costly and disruptive to elective care. Increased self-management and self-care will alter the pattern of resource use.

Reduced medical errors, malpractice claims and litigation costs

- Poor doctor-patient communications and poor survey results for patient experience are associated with higher complaints and litigation costs. Issues relating to informed consent are less likely to arise among patients who are more engaged in their healthcare, or when clinicians have checked that their patients fully comprehend the proposed treatment and any associated risks.

Fewer hospital admissions

- Emergency admissions among people with long-term conditions that could be effectively managed in primary care cost the NHS £1.4bn annually. Self-management education and structured discharge planning can reduce unplanned hospitalisations, readmissions and subsequent length of stay.

Key benefits	Detailed evidence	Source
More appropriate screening rates	Invitation letters were most effective in improving screening rates for cervical cancer	Forbes et al, 2002 ¹⁵²
	Information that is tailored to specific risk groups generally increases the uptake of screening, however it is presented	Edwards et al, 2013 ¹⁵³
	The use of a decision aid results in significantly fewer men deciding to be screened for prostate cancer	Whelan et al, 2002 ¹⁵⁴
	Decision aids reduced the number of men having a PSA test after one year	Evans et al, 2005 ¹⁵⁵
	The use of more detailed decision aids reduced the number of women choosing menopausal hormones	Stacey et al, 2011 ¹⁵⁶
Reductions in major surgery	Patients involved in decision making are less likely to choose major surgery	Stacey et al, 2008 ¹⁵⁷
	The use of decision aids reduces the number of patients electing for major surgery, without any adverse effect on health outcomes	Stacey et al, 2011 ¹⁵⁸
Reduced demand for primary care	The use of NHS Choices results in reduced demand for primary care, especially among younger, healthier users – leading to estimated annual capacity savings of £94m pa	Murray et al, 2011 ¹⁵⁹
	The use of digital TV may reduce the number of GP visits	Nicholas et al, 2002 ¹⁶⁰
More appropriate service use	Short video clips about living with advanced dementia can help older people to decide whether to opt for life-prolonging treatment or comfort care only	Volandes et al, 2011 ¹⁶¹
Reduced medical errors, malpractice claims and litigation	Patient experience is positively associated with lower risk of malpractice claims in primary care	Browne et al, 2010 ¹⁶²
	Better communication with patients reduces litigation costs	Eastaugh, 2004 ¹⁶³
	Honest disclosure of medical errors has been found to increase patient satisfaction and trust, and to reduce the likelihood of litigation	Mazor et al, 2004 ¹⁶⁴
Reduced medical errors, malpractice claims and litigation	Some evidence than an emphasis on improved communication, patient engagement and family involvement can reduce adverse events and malpractice claims	Charmel & Frampton, 2008 ¹⁶⁵
Fewer hospital admissions	Some evidence that giving patients verbal plus written information at discharge can reduce the rate of return visits to hospital	Johnson et al, 2003 ¹⁶⁶
	Personalised information booklets improved self-management and reduced hospital admissions for patients with asthma	Osman et al, 1994 ¹⁶⁷
	A mailed health promotion programme with individualised education letters reduced the amount of time spent in hospital by patients with Parkinson's disease	Montgomery et al, 1994 ¹⁶⁸
	A patient-centred approach combined with guidebooks and self-written management plans resulted in fewer hospital admissions among patients with ulcerative colitis and Crohn's disease	Kennedy & Robinson et al, 2003 ¹⁶⁹
	Structured, individualised discharge planning is effective in reducing unplanned re-admissions	Shepperd et al, 2010 ¹⁷⁰

Section 6 – References

- ¹⁵² Forbes C, Jepson R & Martin-Hirsch P (2002) Interventions targeted at women to encourage the uptake of cervical screening, *Cochrane Database of Systematic Reviews*, 2002;(3) CD002834
- ¹⁵³ Edwards A, Naik G, Ahmed H, Elwyn G, Pickles T, Hood K & Playle R (2013) Personalised risk communication for informed decision making about taking screening tests, *Cochrane Database of Systematic Reviews*, 2013;(2) CD001865
- ¹⁵⁴ Whelan T, O'Brien M, Villasis-Keever M, Robinson P, Skye A, Gafni A, Brouwers M, Charles C, Baldassarre F & Gauld M (2002) Impact of Cancer-Related Decision Aids: Summary, *AHRQ Evidence Report Summaries*, Agency for Healthcare Research and Quality (US)
- ¹⁵⁵ Evans R, Edwards A, Brett J, Bradburn M, Watson E, Austoker J & Elwyn G (2005) Reduction in uptake of PSA tests following decision aids: systematic review of current aids and their evaluations, *Patient Education and Counselling*, 58(1) pp13-26
- ¹⁵⁶ Stacey D, Bennett C, Barry M, Col N, Eden K, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F & Thomson R (2011) Decision aids for people facing health treatment or screening decisions, *Cochrane Database of Systematic Reviews*, 2011;(10) CD001431
- ¹⁵⁷ Stacey D, Samant R & Bennett C (2008) Decision making in oncology: a review of patient decision aids to support patient participation. *CA: A Cancer Journal for Clinicians*, 58(5) pp293-304
- ¹⁵⁸ Stacey D, Bennett C, Barry M, Col N, Eden K, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F & Thomson R (2011) Decision aids for people facing health treatment or screening decisions, *Cochrane Database of Systematic Reviews*, 2011;(10) CD001431
- ¹⁵⁹ Murray J, Majeed A, Khan MS, Lee J & Nelson P (2011) Use of the NHS Choices website for primary care consultations: results from online and general practice surveys, *JRSM Short Reports*, (2)56 pp1-25
- ¹⁶⁰ Nicholas D, Huntington P, Williams P & Gunter B (2002) First steps towards providing the nation with health care information and advice via their television sets, City University London
- ¹⁶¹ Volandes A, Ferguson L, Davis A, Hull N, Green M, Chang Y, Deep K & Paasche-Orlow M (2011) Assessing end-of-life preferences for advanced dementia in rural patients using an educational video: a randomized controlled trial, *Journal of Palliative Medicine*, 14(2) pp169-177
- ¹⁶² Browne K, Roseman D, Shaller D & Edgman-Levitan S (2010) Analysis & commentary: Measuring patient experience as a strategy for improving primary care, *Health Affairs*, 29(5) pp921-925
- ¹⁶³ Eastaugh S (2004) Reducing litigation costs through better patient communication, *Physician Executive*, 30(3) pp36-38
- ¹⁶⁴ Mazor K, Simon S & Gurwitz J (2004) Communicating with patients about medical errors: a review of the literature, *Archives of Internal Medicine*, 164(15) pp1690-1697
- ¹⁶⁵ Charmel P & Frampton S (2008) Building the business case for patient-centered care, *Healthcare Financial Management*, 62(3) pp80-85
- ¹⁶⁶ Johnson A, Sandford J & Tyndall J (2003) Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home, *Cochrane Database of Systematic Reviews*, 2003;(4) CD003716
- ¹⁶⁷ Osman L, Abdalla M, Beattie J, Ross S, Russell I, Friend J, Legge J & Douglas J (1994) Reducing hospital admission through computer supported education for asthma patients. Grampian Asthma Study of Integrated Care, *British Medical Journal*, 308(6928) pp568-571
- ¹⁶⁸ Montgomery E Jr, Lieberman A, Singh G & Fries J (1994) Patient education and health promotion can be effective in Parkinson's disease: a randomized controlled trial, *American Journal of Medicine*, 97(5) pp429-435
- ¹⁶⁹ Kennedy A, Robinson A, Hann M, Thompson D & Wilkin D (2003) A cluster-randomised controlled trial of a patient-centred guidebook for patients with ulcerative colitis: effect on knowledge, anxiety and quality of life, *Health and Social Care in the Community*, 11(1) pp64-72
- ¹⁷⁰ Shepperd S, McClaran J, Phillips C, Lannin N, Clemson L, McCluskey A, Cameron I & Barras S (2010) Discharge planning from hospital to home, *Cochrane Database of Systematic Reviews*, 2010;(1) CD000313

7 Enhancing patient experience

Providing consumers with high quality and accessible health information helps to enhance patients' experience of care. Understanding and acting to improve patients' experiences of care is core business for the NHS and an important motivator for staff. It forms part of the statutory duty of quality for board members – both a 'must do' and the right thing to do.¹⁷¹

This section summarises the key benefits to health processes that are associated with enhancing patient experience. Detailed references to supporting research evidence are presented in a table at the end of the section.

Improved knowledge, understanding and recall

- This is the most fundamental reason for providing consumer health information and support. Patients are unable to act to help maintain or improve their health unless they understand and can remember important information about their condition.

Increased shared decision-making

- Ensuring patients are well-informed is a prerequisite for them becoming more actively involved in their healthcare and their ability to participate in shared decision-making.

Greater self-management and self-care

- Patient information, education and support can give people the knowledge, skills and confidence they require to take on greater personal responsibility for managing and maintaining their own health.

More realistic expectations about potential health outcomes

- Providing full and balanced information to patients about the potential benefits and risks of different procedures helps to engender more realistic expectations about the likely outcomes of treatment. This can also help to increase satisfaction.

Improved confidence in the doctor-patient relationship

- Access to good quality health information empowers patients and can improve their confidence in care and in their relationships with health professionals

Improved psychological wellbeing

- Increased knowledge and feeling well-informed can help to reduce patients' fear and anxiety levels (which can delay healing) and increase feelings of being in control.

Reduced stress and improved relationships

- Serious diseases can place enormous pressure on relationships, while financial worries can affect people's ability to cope with their illness. Information and support that also addresses these broader issues can help to reduce stress, improve relationships and aid recovery.

Better quality of life

- Information provision can make a significant difference to patients' overall wellbeing by helping to improve their physical and mental health and their ability to look after themselves.

Increased patient engagement

- Improving patients' knowledge and understanding and their experience of care supports their becoming more actively engaged in maintaining their health. Well-informed patients are better equipped and prepared with questions to make the most of consultations with health professionals.

Increased patient satisfaction

- Improving communications and providing high quality accessible information helps to increase patient satisfaction with care, while lack of information can lead to misconceptions, anxiety and fear. Feeling well-informed correlates strongly with patients' overall rating of their experience.

Key benefits	Detailed evidence	Source
Improved knowledge, understanding and recall	Written information (as an adjunct to professional consultation and advice) improves health knowledge and recall – especially when it is personalised to the individual	McPherson et al, 2001 ¹⁷²
	Patients offered personalised materials are more likely to use them, find them relevant, show them to others and feel that they have learnt something new	Jones et al, 2006 ¹⁷³
	Combination of verbal and written information has greater impact on knowledge outcomes and satisfaction than verbal information alone. It is more than just a ‘nice thing to do’.	Johnson et al, 2003 ¹⁷⁴
	Decision aids perform better than ‘usual care’ interventions by increasing people’s knowledge	Stacey et al, 2011 ¹⁷⁵
	Users felt better informed about their health condition after using a DiTV service. They also obtained information on conditions they would not ask their GP about.	Nicholas et al, 2002 ¹⁷⁶
	Users of health websites report better understanding of health problems, and gain access to information not provided by their GP	Nicholas et al, 2004 ¹⁷⁷
Improved knowledge, understanding and recall	Audiotapes of consultations have a small but significant effect on patient knowledge and satisfaction. Summary letters can also be effective but patients prefer audiotapes.	Gaston & Mitchell, 2005 ¹⁷⁸
	Audiotapes or written summaries of (key points in) consultations improved recall and satisfaction with information received.	Scott et al, 2003 ¹⁷⁹
Increased shared decision-making	Decision aids improve patients’ perception of risk, increase their involvement in decision-making, lower decisional conflict and reduce the proportions of people remaining undecided	Stacey et al, 2011 ¹⁸⁰
Greater self-management and self-care	Personalised information booklets increase patient’s confidence to self-care	Little et al, 2001 ¹⁸¹
	Internet information can have positive effects on self-efficacy and task behaviour	Eysenbach, 2003 ¹⁸²
	Access to information in alternative formats can have beneficial impacts on self-efficacy and health behaviour	Bessell et al, 2002 ¹⁸³
	Self-management education for arthritis patients increased self-efficacy, enhanced control, helped to reduce symptoms of pain and fatigue, and improved psychological wellbeing	Barlow et al, 1998 ¹⁸⁴

Key benefits	Detailed evidence	Source
More realistic patient expectations	Interventions designed to assist decision-making can improve knowledge, increase patient involvement, and help patients to develop more realistic expectations of the potential benefits and harms of different procedures and treatments	O'Connor et al, 2003 ¹⁸⁵
	Failure to provide full and balanced information about the risks and uncertainties of procedures can give rise to unrealistic expectations and lead to costly legal action	Coulter, 2002 ¹⁸⁶
Improved confidence in the doctor-patient relationship	Internet information empowers patients to make health-related decisions and improves confidence in the doctor-patient encounter	Eysenbach, 2003 ¹⁸⁷
	Decision aids can have a positive effect on patient-practitioner communication	Stacey et al, 2011 ¹⁸⁸
Improved psychological wellbeing	Cancer patients who are well-informed are better able to understand and participate in their care plan, experience less anxiety, and are more likely to cope with their illness	Manning & Dickens, 2006 ¹⁸⁹
	Information provision led to enhanced control and decreased anxiety	Ream & Richardson, 1996 ¹⁹⁰
	Some evidence that patients' sense of control can be improved and their anxiety levels reduced by pre-operative information and education	McDonald et al, 2004 ¹⁹¹
	Some evidence that written information can reduce anxiety levels for patients with advanced cancer	Gaston & Mitchell, 2005 ¹⁹²
	Provision of technical information can reduced fear and uncertainty, and potential harmful self-management	Couldridge et al, 2001 ¹⁹³
	Patient decision aids can reduce decisional conflict around choices without increasing anxiety levels	Garrud et al, 2001 ¹⁹⁴
Reduced stress and improved relationships	Take home information materials can be shared with friends and family at home, thereby increasing levels of practical and emotional support	Gaston & Mitchell, 2005 ¹⁹⁵
	Combined information and education may improve family functioning	Forster et al, 2012 ¹⁹⁶
Better quality of life	With the right information and support, patients are better equipped to look after themselves and their quality of life is much improved	Jones et al, 2006 ¹⁹⁷
	Cancer survivors who received sufficient information reported a better quality of life	Husson et al, 2011 ¹⁹⁸
	From a psychological point of view, there is evidence that information and understanding is related to wellbeing, quality of life, coping, control and self-efficacy	Couldridge et al, 2001 ¹⁹⁹
	Radiation therapy patients most frequently perceived that better information and communication, including for family and friends, would have improved their wellbeing	Mackenzie et al, 2013 ²⁰⁰

Key benefits	Detailed evidence	Source
Increased patient engagement	Internet information can empower people to make health-related decisions and improves confidence in the doctor-patient encounter	Eysenbach, 2003 ²⁰¹
Increased patient engagement	Interactive web-based interventions have a beneficial impact on empowerment for patients with chronic conditions	Kuijpers et al, 2013 ²⁰²
Increased patient satisfaction	Patients value good inter-personal communications with health service personnel	Leatherman and Sutherland, 2007 ²⁰³
	Reinforcing verbal communication with written information at discharge increases satisfaction	Johnson et al, 2003 ²⁰⁴
	Providing access to information in alternative formats has demonstrated high user satisfaction	Nguyen et al, 2004 ²⁰⁵
	Audio recordings of health information were consistently reported to increase patient satisfaction (and have positive impacts on self-care measures)	Santo et al, 2005 ²⁰⁶
	Audio recordings of consultations have a small but significant effect on patient knowledge and satisfaction	Gaston & Mitchell, 2005 ²⁰⁷

Section 7 - References

- ¹⁷¹ Dr Foster (2010) The intelligent board 2010: patient experience
- ¹⁷² McPherson C, Higginson I & Hearn J (2001) Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials, *Journal of Public Health Medicine*, 23(3) pp227-234
- ¹⁷³ Jones R, Pearson J, Cawsey A, Bental D, Barrett A, White J, White C & Gilmour W (2006) Effect of different forms of information produced for cancer patients on their use of the information, social support, and anxiety: randomised trial, *British Medical Journal*, 332(7547) pp942-948
- ¹⁷⁴ Johnson A, Sandford J & Tyndall J (2003) Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home, *Cochrane Database of Systematic Reviews*, 2003;(4) CD003716
- ¹⁷⁵ Stacey D, Bennett C, Barry M, Col N, Eden K, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F & Thomson R (2011) Decision aids for people facing health treatment or screening decisions, *Cochrane Database of Systematic Reviews*, 2011;(10) CD001431
- ¹⁷⁶ Nicholas D, Huntington P, Williams P & Gunter B (2002) *First steps towards providing the nation with health care information and advice via their television sets*, City University London
- ¹⁷⁷ Nicholas D, Huntington P & Williams P (2004) *Digital consumer health information and advisory services in the UK: a user evaluation and sourcebook*, City University London
- ¹⁷⁸ Gaston C & Mitchell G (2005) Information giving and decision-making in patients with advanced cancer: a systematic review, *Social Science and Medicine*, 61(10) pp2252-2264
- ¹⁷⁹ Scott J, Harmsen M, Prictor M, Entwistle V, Sowden A & Watt I (2003) Recordings or summaries of consultations for people with cancer, *Cochrane Database of Systematic Reviews*, 2003;(2) CD001539
- ¹⁸⁰ Stacey D, Bennett C, Barry M, Col N, Eden K, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F & Thomson R (2011) Decision aids for people facing health treatment or screening decisions, *Cochrane Database of Systematic Reviews*, 2011;(10) CD001431
- ¹⁸¹ Little P, Somerville J, Williamson I, Warner G, Moore M, Wiles R, George S, Smith A & Peveler R (2001) Randomised controlled trial of self management leaflets and booklets for minor illness provided by post, *British Medical Journal*, 322(7296) pp1214-1217
- ¹⁸² Eysenbach G (2003) The impact of the Internet on cancer outcomes, *CA: A Cancer Journal for Clinicians*, 53(6) pp356-371
- ¹⁸³ Bessell T, McDonald S, Silagy C, Anderson J, Hiller J & Sansom L (2002) Do Internet interventions for consumers cause more harm than good? A systematic review, *Health Expectations*, 5(1) pp28-37
- ¹⁸⁴ Barlow J, Wright C, Sheasby J, Turner A & Hainsworth J (2002) Self-management approaches for people with chronic conditions: a review, *Patient Education and Counselling*, 48(2) pp177-187
- ¹⁸⁵ O'Connor A, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M & Jones J. Decision aids for people facing health treatment or screening decisions, *Cochrane Database of Systematic Reviews*, 2003;(2) CD001431
- ¹⁸⁶ Coulter A (2002) *The Autonomous Patient*, Nuffield Trust
- ¹⁸⁷ Eysenbach G (2003) The impact of the Internet on cancer outcomes, *CA: A Cancer Journal for Clinicians*, 53(6) pp356-371
- ¹⁸⁸ Stacey D, Bennett C, Barry M, Col N, Eden K, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F & Thomson R (2011) Decision aids for people facing health treatment or screening decisions, *Cochrane Database of Systematic Reviews*, 2011;(10) CD001431
- ¹⁸⁹ Manning D & Dickens C (2006) Health literacy: more choice, but do cancer patients have the skills to decide? *European Journal of Cancer Care*, 15(5) pp448-452
- ¹⁹⁰ Ream E & Richardson A (1996) The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature, *European Journal of Cancer Care*, 5(3) pp132-138
- ¹⁹¹ McDonald S, Hetrick S & Green S (2004) Pre-operative education for hip or knee replacement, *Cochrane Database of Systematic Reviews*, 2004;(1) CD003526
- ¹⁹² Gaston C & Mitchell G (2005) Information giving and decision-making in patients with advanced cancer: a systematic review, *Social Science and Medicine*, 61(10) pp2252-2264
- ¹⁹³ Couldridge L, Kendall S & March A (2001) A systematic overview - a decade of research. The information and counselling needs of people with epilepsy, *Seizure - European Journal of Epilepsy*, 10(8) pp605-614
- ¹⁹⁴ Garrud P, Wood M & Stainsby L (2001) Impact of risk information in a patient education leaflet, *Patient Education and Counselling*, 43(3) pp301-304
- ¹⁹⁵ Gaston C & Mitchell G (2005) Information giving and decision-making in patients with advanced cancer: a systematic review, *Social Science and Medicine*, 61(10) pp2252-2264
- ¹⁹⁶ Forster A, Brown L, Smith J, House A, Knapp P, Wright J & Young J (2012) Information provision for stroke patients and their caregivers, *Cochrane Database of Systematic Reviews*, 2012;(11) CD001919

-
- ¹⁹⁷ Jones R, Pearson J, Cawsey A, Bental D, Barrett A, White J, White C & Gilmour W (2006) Effect of different forms of information produced for cancer patients on their use of the information, social support, and anxiety: randomised trial, *British Medical Journal*, 332(7547) pp942-948
- ¹⁹⁸ Husson O, Mols F & van de Poll-Franse L (2011) The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review, *Annals of Oncology*, 22(4) pp761–772
- ¹⁹⁹ Couldridge L, Kendall S & March A (2001) A systematic overview - a decade of research. The information and counselling needs of people with epilepsy, *Seizure – European Journal of Epilepsy*, 10(8) pp605-614
- ²⁰⁰ Mackenzie L, Sanson-Fisher R, Carey M & D'Este C (2013) Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey, *BMJ Open*, 2013;2:e001265
- ²⁰¹ Eysenbach G (2003) The impact of the Internet on cancer outcomes, *CA: A Cancer Journal for Clinicians*, 53(6) pp356-371
- ²⁰² Kujipers W, Groen W, Aaronson N & van Harten W (2013) A Systematic Review of Web-Based Interventions for Patient Empowerment and Physical Activity in Chronic Diseases: Relevance for Cancer Survivors, *Journal of Medical Internet Research*, 15(2): e37
- ²⁰³ Leatherman S & Sutherland K (2007) *Patient and public experience in the NHS: a quality chartbook*, Health Foundation
- ²⁰⁴ Johnson A, Sandford J & Tyndall J (2003) Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home, *Cochrane Database of Systematic Reviews*, 2003;(4) CD003716
- ²⁰⁵ Nguyen H, Carrieri-Kohlman V, Rankin S, Slaughter R & Stulbarg M (2004) Internet-based patient education and support interventions: a review of evaluation studies and directions for future research, *Computers in Biology and Medicine*, 34(2) pp95-112
- ²⁰⁶ Santo A, Laizner A & Shohet L (2005) Exploring the value of audiotapes for health literacy: a systematic review, *Patient Education and Counselling*, 58(3) pp235-243
- ²⁰⁷ Gaston C & Mitchell G (2005) Information giving and decision-making in patients with advanced cancer: a systematic review, *Social Science and Medicine*, 61(10) pp2252-2264

8 Patient engagement, health behaviour and status

By enhancing patient experience and facilitating greater patient engagement in healthcare, high quality and accessible health information also helps to improve patients' health behaviour and status.

This section summarises the key benefits to health behaviour and status that may be associated with increasing patients' active involvement in healthcare. Detailed references to supporting research evidence are given in a table at the end of the section.

Reduced health inequalities

- Patients from ethnic minorities, deprived areas or with only a basic education are most likely to have low health literacy, low levels of engagement, poorer health, and an increased risk of hospitalisation. Successful initiatives to increase active participation in their own healthcare among patients with low health literacy will improve health behaviours and help reduce inequalities.

Increased self-care for minor ailments

- It is estimated that the total cost of GP consultations and associated prescriptions for minor ailments (like coughs, colds, sore throats and indigestion) is £2bn. Increased self-care for such minor ailments would generate substantial capacity savings and allow GPs to spend more time assisting patients with more complex health needs.

Increased self-management of long-term conditions

- Even though the great majority of care for long-term conditions is undertaken by patients themselves and their families, care for the chronically ill accounts for £2 out of £3 spent in the NHS. Increasing self-management is therefore a key objective of UK health policy, with evidence also suggesting that it can improve people's quality of life as well as their health outcomes and service use.

Improved adherence to treatment and medications

- Improving adherence to treatment and medications is crucial to achieving better health outcomes, especially for those with the poorest health. Information and self-management education programmes provide important support for this. Poor understanding of doctors' instructions and concerns over side-effects cost the NHS about £500m pa, with this problem being greatest among ethnic minorities and deprived communities

Increased patient safety

- Well-informed and actively involved patients are in a much better position to give or withhold their informed consent to any treatment or procedure, and to protect their own personal safety. Patients with low health literacy are more at risk unless deliberate measures are taken to ensure adequate comprehension of treatment options and regimes.

Protection against harmful treatments

- Active, well-informed patients are less likely to seek out potentially dangerous alternative therapies.

Key benefits	Detailed evidence	Source
Reduced health inequalities	The health benefits can be greater for disadvantaged groups when access barriers are overcome because they have most to gain from health information and education	Gustafson et al, 2002 ²⁰⁸
Increased self-care for minor ailments	Access to alternative format information and education resources can have beneficial impacts on self-efficacy and health behaviour	Bessell et al, 2002 ²⁰⁹
Increased self-management of long-term conditions	Audio recordings of consultations were consistently reported to have positive impacts on self-care measures	Santo et al, 2005 ²¹⁰
	Participants in self-management education experienced small to moderate positive effects on their health	Warsi et al, 2004 ²¹¹
Adherence to treatment and medications	Patient experience is positively associated with better adherence to treatment and improved health outcomes	Browne et al, 2010 ²¹²
	Pre-operative information and education for orthopaedic patients can improve knowledge and performance of exercises	Johansson et al, 2005 ²¹³
	Older people with diabetes who had attended self-management education were more likely to self-monitor blood glucose levels, take appropriate medications and go for regular eye tests	Millar et al, 2010 ²¹⁴
	Short-term adherence to medication can be improved by written information, personal phone calls and counselling	Haynes et al, 2008 ²¹⁵
	A combination of strategies incorporating information, reminders and patient reinforcement are likely to be more effective in improving adherence to medication	Schedlbauer et al, 2010 ²¹⁶
Increased patient safety	Providing detailed information about medicines, and especially easier to read materials, can lead to significant improvements in medical errors	Ioannidis & Lau, 2001 ²¹⁷
Increased patient safety	Involving patients in hospital in decisions about their healthcare can help to improve patient safety, as well as their experience of care	Weingart et al, 2011 ²¹⁸
	Well-informed patients may be better equipped to guard against medical error – thus enhancing their own safety	Benjamin, 2003 ²¹⁹

Section 8 - References

²⁰⁸ Gustafson D, Hawkins R, Boberg E, McTavish F, Owens B, Wise M, Berhe H & Pingree S (2002) CHES: 10 years of research and development in consumer health informatics for broad populations, including the underserved, *International Journal of Medical Informatics*, 65(3) pp169-177

²⁰⁹ Bessell T, McDonald S, Silagy C, Anderson J, Hiller J & Sansom L (2002) Do Internet interventions for consumers cause more harm than good? A systematic review, *Health Expectations*, 5(1) pp28-37

²¹⁰ Santo A, Laizner A & Shohet L (2005) Exploring the value of audiotapes for health literacy: a systematic review, *Patient Education and Counselling*, 58(3) pp235-243

²¹¹ Warsi A, Wang P, LaValley M, Avorn J & Solomon D (2004) Self-management education programs in chronic disease: a systematic review and methodological critique of the literature, *Archives of Internal Medicine*, 164(15) pp1641-1649

²¹² Browne K, Roseman D, Shaller D & Edgman-Levitan S (2010) Analysis & commentary: Measuring patient experience as a strategy for improving primary care, *Health Affairs*, 29(5) pp921-925

²¹³ Johansson K, Nuutila L, Virtanen H, Katajisto J & Salanterä S (2005) Preoperative education for orthopaedic patients: systematic review, *Journal of Advanced Nursing*, 50(2) pp212-223

²¹⁴ Millar A, Cauch-Dudek K & Shah B (2010) The impact of diabetes education on blood glucose self-monitoring among older adults, *Journal of Evaluation in Clinical Practice*, 16(4) pp790-793

²¹⁵ Haynes R, Ackloo E, Sahota N, McDonald H & Yao X (2008) Interventions for enhancing medication adherence, *Cochrane Database of Systematic Reviews*, 2008;(2) CD000011

²¹⁶ Schedlbauer A, Davies P & Fahey T (2010) Interventions to improve adherence to lipid lowering medication, *Cochrane Database of Systematic Reviews*, 2010;(3) CD004371

²¹⁷ Ioannidis J & Lau J (2001) Evidence on interventions to reduce medical errors: an overview and recommendations for future research, *Journal of General Internal Medicine*, 16(5) pp325-334

²¹⁸ Weingart S, Zhu J, Chiappetta L, Stuver S, Schneider E, Epstein A, David-Kasdan J, Annas C, Fowler F Jr & Weissman J (2011) Hospitalized patients' participation and its impact on quality of care and patient safety, *International Journal for Quality in Health Care*, 23(3) pp269-277

²¹⁹ Benjamin D (2003) Reducing medication errors and increasing patient safety: case studies in clinical pharmacology, *Journal of Clinical Pharmacology*, 43(7) pp768-783

9 Providing health information - what works

It is important to be aware of the context for health information provision or information-seeking behaviour. It may be best understood as part of a broader process of communication with health professionals to supplement their clinical judgment and advice. Based on an overview of the evidence, this section highlights some key messages about the most effective ways of enhancing the impacts of consumer health information.

One size does not fit all and no one method suits everyone – personalisation increases impact

- There is a wide variety of ways that consumer health information can be made available through print and electronic media. Patients also vary widely in their individual characteristics, circumstances, preferences and beliefs, so no one method of providing information could ever suit everyone or be equally effective in different situations. Consumer health information has the greatest effects when it is tailored to reflect an individual's particular needs and circumstances.²²⁰

Quality is paramount

- It is obvious that for consumer health information to have any beneficial impact, however it is provided, it needs to conform with the highest quality standards – for example, in accordance with the PiF guidelines detailed earlier in this report or the new Information Standard.

Information must be converted into knowledge and understanding

- Information by itself carries little benefit. To make a difference and have any effect on behaviour, it must be first translated into knowledge and understanding. How well information is communicated to patients is therefore critical to realising this added value.

Written information aids recall and understanding

- Research evidence suggests that supplementing verbal communication with some form of written information is not just 'a nice thing to do' but is most effective in improving patients' knowledge, understanding and recall, as well as their satisfaction with information received.²²¹

Information needs change over time

- When it comes to consumer health information, one size very clearly does not fit all. Just as information preferences may vary substantially between people, so too can any one person's requirements for information change over time. A key task for health professionals therefore lies in assessing and addressing their patients' varied requirements for health information. This will help ensure that patients have access to the right amount of quality health information, at the right time, at all stages of their 'patient journey'.
- An exemplar of a 'perfect information journey' created by the Patient Information Forum was included in the NHS Future Forum's recent report setting out recommendations and advice to Government on its new information strategy.²²²

Simpler materials, visual aids and alternative formats are needed to address health literacy

- To respond to and help address the problems of low health literacy, a range of accessible health information materials is required – suitable for people with different levels of functional health literacy. Presentation is also important – health information should be inviting and encourage people to apply it in practice. Visual aids and simple diagrams can also help improve accessibility, and sometimes it may be necessary to simplify written instructions.²²³

- For many people, and particularly those with low health literacy, presenting health information in alternative formats may also aid understanding. There is clear research evidence that interactive websites, short video clips, audio recordings of consultations and other multimedia interventions can be effective in increasing knowledge, satisfaction and patients' ability to make informed decisions.^{224, 225}
- One good example of the benefits of utilising alternative formats is provided by a free, multilingual audiovisual resource that was created by the Roy Castle Lung Cancer Foundation. Lung cancer patients who viewed the DVD reported dramatic improvements in every outcome measured, including: their understanding of the role of the multidisciplinary team, their optimism about diagnosis, and their understanding and acceptance of the proposed treatment plan.²²⁶

Web-based solutions are not the only answer – people need paper and other formats too

- Despite strong evidence of the many advantages offered by electronic communications, it is important not to become over-reliant on web-based solutions to the health information challenge. Printed information may still be the preferred medium for some, including many of the e-literate, and there is a continuing digital divide in the UK – with over one quarter of adults and households not having internet access.²²⁷ Even among those with access, a lot of consumers will continue to need guidance to identify the most useful and reliable internet resources and, possibly, closer support to make effective use of the information they access.
- The continuing importance of printed resources is further highlighted by a recent evaluation by Macmillan Cancer Support of their own information materials. This found, across all age groups, that the self-assessed outcome scores were significantly higher for patients who read the information in booklets than they were for those who accessed the same information online.²²⁸

Patients need specialist support to help them access, understand and act upon reliable health information

The vast amount of health information on the internet and its variable quality also means that it can be overwhelming, confusing and, at worst, potentially harmful. This underlines the potential value to patients of expert assistance from health information specialists, as well as from clinicians, nurses and other healthcare staff who are able to take on an 'infomediary' role as part of a more collaborative, partnership-based approach to care.²²⁹

Information alone will only have a limited effect

- It is important to be realistic about how much difference information the passive provision of information alone can make. Providing accessible information can help to improve people's health literacy, including their ability to navigate the complex health system and access relevant services. As well as improving knowledge, understanding and recall, better health information also helps to improve patients' experience of care and their satisfaction with services – but, to be truly effective, it needs to be provided in a context of more active encouragement, education and support.²³⁰

Significant behaviour change will only be achieved by information plus more active educational support

- Being well-informed is an essential pre-requisite for patient engagement but, generally, is not sufficient by itself. People also need to be motivated to become more actively involved in decisions about their healthcare and to assume greater personal responsibility for maintaining their own health. Greater self-efficacy and confidence is also required for patients to take on the mantle of increased self-care for minor ailments and, for those with long-term conditions, increased self-management.²³¹

- Information provision alone is unlikely to be sufficient to motivate the behaviour change needed to make a significant difference to health outcomes.²³² A more effective approach could be characterised as ‘information plus’. This would see information being supplied or accessed in the context of more active educational support with an emphasis on encouraging behaviour change. Such support might be provided, for example, through prescribing a decision aid, individual coaching support, or by referring patients to some form of self-management education programme. Evidence suggests that multifaceted information and education strategies that focus on self-efficacy and behaviour change are likely, with regular refreshers, to be more effective in motivating and sustaining patient’s active engagement in their healthcare and treatment.²³³

Section 9 - References

- ²²⁰ Coulter A & Ellins J (2007) Effectiveness of strategies for informing, educating, and involving patients, *British Medical Journal*, 2007 Jul 7;335(7609):24-7
- ²²¹ Johnson A, Sandford J & Tyndall J (2003) Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home, *Cochrane Database Systematic Review*, 2003;(4):CD003716
- ²²² NHS Future Forum (2012) *Information: A report by the Future Forum*
- ²²³ Hibbard J & Peters E (2003) Supporting informed consumer healthcare decisions: data presentation approaches that facilitate the use of information in choice, *Annual Review of Public Health*, 2003;24:413-33
- ²²⁴ Gysels M & Higginson I (2007) Interactive technologies and videotapes for patient education in cancer care: systematic review and meta-analysis of randomised trials, *Supportive Care in Cancer*, 2007 Jan;15(1):7-20
- ²²⁵ Volandes A, Ferguson L, Davis A, Hull N, Green M, Chang Y, Deep K & Paasche-Orlow M (2011) Assessing end-of-life preferences for advanced dementia in rural patients using an educational video: a randomized controlled trial, *Journal of Palliative Medicine*, 2011 Feb;14(2):169-77
- ²²⁶ Dickson J (2010) *Using multimedia information to improve outcomes for lung cancer patients and carers*, Roy Castle Lung Cancer Foundation
- ²²⁷ Dutton W & Blank G (Undated) *Next Generation Users: the Internet in Britain 2011 report*, Oxford Internet Institute, University of Oxford
- ²²⁸ Shared Intelligence (2013) *Information Resources Evaluation – Headline interim results*, for Macmillan Cancer Support
- ²²⁹ Detmer D, Singleton P, MacLeod A, Wait S, Taylor M & Ridgwell J (2003) *The informed patient: study report*, Cambridge University Health
- ²³⁰ Ellins J & McIver S (2009) Public information about quality of primary care services, Health Services Management Centre, University of Birmingham
- ²³¹ de Silva D (2011) *Helping people help themselves*, Health Foundation
- ²³² Gibson P, Powell H, Coughlan J, Wilson A, Hensley M, Abramson M, Bauman A & Walters E (2002) Limited (information only) patient education programs for adults with asthma, *Cochrane Database Systematic Review*, 2002;(2):CD001005
- ²³³ Health Foundation (2012) *Helping people share decision-making*

10 The Patient Information Forum's view

PiF wants everyone to be able to access relevant, high-quality information and support to help them understand their care and make confident, informed decisions about their health and wellbeing.

To do this, information needs to be planned, developed and disseminated well; it needs to be embedded within care pathways and become an integral part of consultations between patients and their health and social care professionals; it must be supported in its delivery by people who are properly trained to source and give information based on accurate assessments of health literacy; its impact must be properly evaluated.

More specifically:

- Information is **an intervention** that impacts health & wellbeing and it contributes to all three aspects of quality: clinical effectiveness, safety and patient experience.
- Information must adhere to **quality standards**. It should be user tested, co-designed and co-produced where possible. Information must also be designed to meet different levels of health literacy.
- Information production is a **highly skilled** activity and those who do it need an infrastructure and learning and development opportunities.
- Information provision must be **integrated** into health & care delivery. Healthcare providers should have a Board Director responsible for the provision and monitoring of information and support for people, with dedicated personnel and resources to deliver it.
- Health and care professionals should offer information as part of a **shared decision making** process. The most helpful information and support is personalised to the person receiving it: one size does not fit all.

- The **impact** of information provision must be measured. The information given to an individual should be recorded in their care record. It is not enough to measure the volume of information provided: behaviour change and financial impact should be measured too.

11 Quality standards

PiF believes that the provision of high quality health information and support is one of the most important aspects of an effective, ethical and empowering healthcare service. The better the quality, the more useful, relevant and accessible the information is, and the more effective it will be in encouraging self care, effective long-term condition management, and healthy lifestyle choices.

Although there isn't one set of golden rules that can be applied to every resource and development process there are some key factors on which consensus has been reached. The main ones are that information should be:

- evidence based, accurate and reliable – factually correct and consistent, produced by an individual or organisation with appropriate qualifications
- comprehensive – covers all aspects of the condition, service, etc
- balanced and non-judgmental – not favouring any particular option(s)
- peer reviewed - by relevant health and other professionals and by patients and the public, a robust review process
- current – up to date with stated publication and review dates
- clear – understandable and straightforward, developed with a specific audience in mind
- relevant – targeted to its audience and users are involved in development and production
- accessible – a range of formats, effectively disseminated, pitched at the right level(s)
- readable – easy to read, informal, active
- transparent – in terms of authorship and sponsorship
- complementary – supports the decision making process and the health professionals/patient relationship
- delivered, supported and evaluated by health, care and other professionals.

12 Recommendations for further work

This report has presented a wealth of compelling evidence in support of health organisations investing more resources in ensuring that quality health information and the support to use it effectively is available for everyone. Yet, as major reforms of the health service come into effect and despite repeated policy commitments, health information is still far from being properly established as a key service in its own right.

Nationally, the ‘information revolution’ is largely focused on providing shared access to patient records, increasing online transactions, and promoting greater data transparency to enhance accountability and help drive patient choice (of provider). By the end of 2013, the new national online portal (to ‘replace’ NHS Choices) should be up and running, bringing together quality-assured information on health and social care.

Patients, however, will need far more information and support than will be available through these national initiatives if they are to take on more responsibility for managing their own health and become fully involved in key decisions about their healthcare. There is an urgent requirement, therefore, to transform the current patchwork of poorly supported and largely uncoordinated information provision into coherent, properly planned and adequately resourced local services capable of making a crucial contribution to maintaining and improving the quality of patient-centred care in the face of unprecedented demand and financial pressures.

Consequently, future research and learning should focus on identifying and evaluating the detailed characteristics of quality information services. Providing quality information and support will be a new area for many organisations and very little guidance and few tools currently exist which would help them address this challenge with any confidence of success.²³⁴

Such future work may wish to look at a broader definition of ‘consumer health information’ – taking in, for example, any additional needs arising from providing patients with online access to their own health records and the increasing amounts of data that will be made available to enhance provider choice. It should also have a clearer focus on assessing the costs and benefits of health information and education initiatives to assist with making an even stronger economic and business case. In particular, it may be helpful to focus on:

- identifying successful information and support strategies for improving health literacy and patient engagement – especially among those with low measures of patient activation
- the benefits of continuing to provide health information in a variety of formats and through a range of channels including direct, face-to-face support for those who need it
- the roles and status of specialist information staff in:
 - producing and disseminating health information
 - supporting the information activities of other healthcare professionals
 - liaising with other organisations, including the voluntary sector, to increase the quality and range of available services and reduce any unnecessary duplication or wasted effort
 - providing direct support to individual patients to help them access and make effective use of health information and support most relevant to their situation
 - successful approaches to overcoming any organisational, professional and/or cultural barriers to establishing well-managed, properly resourced information services, and to achieving high-level support.

Future work should also consider the requirements of new clinical commissioning groups for guidance and advice on how best to secure the provision of quality health information and support locally. This might explore how commissioning can ensure how appropriate health information and support is built into care pathways – especially at key decision points. Another possibility would be to consider how a requirement to meet certain quality standards for health information and support – perhaps linked to the NICE measures for patient experience²³⁵ – could be built into local contract and payment processes. Finally, CCGs will also need to consider the pivotal roles that primary care, carers and the voluntary sector can play as providers of health information, guidance, support and advocacy.²³⁶

Section 13 - References

²³⁴ Patient Information Forum (2012) Information provision: Challenges, barriers and good models of delivery

²³⁵ NICE (2012) Quality standard for patient experience in adult NHS services: NICE quality standard 15

²³⁶ NHS Future Forum (2012) Information: A report by the Future Forum

Appendix Main levers to support the Case for Information

This appendix lists a selection of the main levers which can be used by anyone seeking to make the case for the provision of high quality consumer health information. It is not an exhaustive list and policy and legal requirements change over time. Web references are given where appropriate and it is important to check for relevant updates.

We are very grateful to PiF members Greta Hughson (NAM), Rachel Iredale (Tenovus) and Leona O'Reilly (NDR-UK) for their help in drawing up this list.

Moral and ethical levers

- The Report of the Mid Staffordshire Foundation Trust Public Inquiry (the 'Francis Inquiry'), 2013
- Guidance on informed consent from the Department of Health (2009)

Policy and legislative levers

- The NHS Constitution (England)
- 2010 White Paper Equity and Excellence: Liberating the NHS (England)
- Quality 2020 (Northern Ireland)
- Together For Health (Wales)
- 20:20 Vision for Healthcare (Scotland)
- Health and Social Care (Reform) Act (Northern Ireland) 2009
- The Patient Rights (Scotland) Act 2011
- The Health and Social Care Act 2012 (England)
- The NHS Mandate and Outcomes Framework (England)
- Care Quality Commission (CQC) Guidance about compliance (England)
- NHS Litigation Authority (NHSLA) Risk Management Standards 2012-13

Service priorities

- The Power of Information, 2012 (England)
- Together for Health Public Information Delivery Plan, 2012 (Wales)
- Everyone counts: Planning for Patients 2013/14 (England)
- The Healthcare Quality Strategy for NHS Scotland, 2010
- Achieving excellence - The quality delivery plan for the NHS in Wales 2012 – 2016
- National Institute of Health and Clinical Excellence (NICE) Guidelines
- Information Standard (England)
- The National Service Framework for Long-term Conditions, 2005 (England)
- Designed to Improve the Management of Chronic Conditions in Wales, 2007

Financial levers

- Quality and Outcomes Framework (QOF)
- Commissioning for Quality and Innovation (CQUIN) Framework (England)
- Quality, Innovation, Productivity and Prevention (QIPP) (England)

Moral and ethical levers

The Francis Inquiry

The Report of the Mid Staffordshire Foundation Trust Public Inquiry (the 'Francis Inquiry') in 2013 heard specific problems about communication including lack of information about patients' care or condition, lack of involvement in decisions, reluctance to give information or the provision of wrong information. The main thrust of the 290 recommendations of the Inquiry was to create a common, patient-centred culture across the NHS. The conclusions of the Inquiry included the observation that:

The provision of the right information to patients and their families at the right time is vital. This requires staff to possess it, and pass it on to colleagues to ensure continuity and consistency. Information needs to be delivered with sensitivity and due regard for the patients as valued individuals.

www.midstaffpublicinquiry.com

Informed consent

Consent is required from a patient regardless of the treatment, from blood test to organ donation. The principle of consent is an important part of medical ethics and the international human rights law. This principle reflects people's right to determine what happens to their own bodies, and is a fundamental part of good practice. A healthcare professional (or other healthcare staff) who does not respect this principle may be liable both to legal action by the patient and to action by their professional body. Employing bodies may also be liable for the actions of their staff.

For consent to be valid, it must be given voluntarily and freely, without pressure or undue influence being exerted on the person either to accept or refuse treatment. The consent must be given by an appropriately informed person who has the capacity to consent to the intervention in question.

The Department of Health (2009) and professional bodies have produced comprehensive guidance about consent.

The GMC provides guidance on the type of information that patients may need to know before making a decision, and recommends that doctors should do their best to find out about patients' individual needs and priorities when providing information about treatment options. It advises that discussions should focus on the patient's *individual situation and risk to them* and sets out the importance of providing the information about the procedure and associated risks in a balanced way and checking that patients have understood the information given.

Compliance with the Human Rights Act is largely reflected in existing good ethical practice, but all health practitioners should be aware of the Human Rights Act and ensure that they act in compliance with it. The British Medical Association (BMA) has a handbook of ethics and law that gives advice on how the Human Rights Act relates to a range of relevant issues.

Other relevant legislation relating to consent includes The Human Tissue Act 2004 and The Mental Capacity Act 2005.

www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition

Policy and legislative levers

The NHS Constitution

The NHS Constitution, first published in 2009, includes a commitment to shared decision making as one of its seven overarching principles.

There are also rights for patients, and pledges from the NHS, in the Constitution around information issues in the sections on respect, consent and confidentiality, informed choice, and involvement in your healthcare and in the NHS.

The Constitution was strengthened and re-issued in early 2013 to reflect feedback from consultation, advice from the NHS Future Forum, and the recommendations of the Francis Inquiry. The Constitution states that *the overriding value should be that patients are put first, and everything done by the NHS and everyone associated with it should be informed by this ethos.*

A key pledge, in Section 3 of the Constitution, is that the NHS commits:

to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices. This will include information on the range and quality of clinical services where there is robust and accurate information available.

www.gov.uk/government/publications/the-nhs-constitution-for-england

2010 White Paper – Equity and Excellence: Liberating the NHS

The White Paper explicitly states: *We will put patients at the heart of the NHS, through an information revolution and greater choice and control.*

It commits to shared decision-making becoming the norm – ‘no decision about me without me.’

The White Paper also says that:

International evidence shows that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment. It can also bring significant reductions in cost, as highlighted in the Wanless Report, and in evidence from various programmes to improve the management of long-term conditions...

It goes on to state that: *Information, combined with the right support, is the key to better care, better outcomes and reduced costs.*

www.gov.uk/government/publications/liberating-the-nhs-white-paper

Quality 2020

This is the 10 year strategy for healthcare in Northern Ireland. It includes a requirement that *all patients and clients are entitled to be treated with dignity and respect and should be fully involved in decisions affecting their treatment, care and support. It goes on to say that there is abundant evidence that such an approach delivers improved health and wellbeing...*

www.dhsspsni.gov.uk/quality_2020_-_a_10-year_quality_strategy_for_health_and_social_care_in_northern_ireland.pdf

20:20 Vision for Healthcare

In Scotland, the 2020 strategic narrative underpinning health policy focuses on prevention, anticipation and supported self-management. It places the person at the centre of all decisions. It provides a context for the implementation of the associated Quality Strategy.

www.scotland.gov.uk/Topics/Health/Policy/2020-Vision

Together for Health

Together for Health, published in 2011 by the Welsh Government, outlines a new, five-year vision for the NHS to 2016, based around community services and placing prevention, quality and transparency at the heart of healthcare.

<http://wales.gov.uk/topics/health/publications/health/reports/together/?lang=en>

Health and Social Care (Reform) Act (Northern Ireland) 2009

The HSC Reform Act introduced a new statutory Duty of Involvement for all the main health and social care bodies in Northern Ireland. This required them to involve people at a personal and public level in making decisions about service design and delivery.

www.legislation.gov.uk/nia/2009/1/contents

The Patient Rights (Scotland) Act 2011

In Scotland, the Patient Rights (Scotland) Act 2011 and the associated Charter of Patient Rights and Responsibilities 2012 aim to improve patients' experiences of using health services and to support people to become more involved in their health and healthcare. The Act includes the right that the healthcare patients receive should *consider their needs, consider what would be of optimum benefit to them, encourage them to take part in decisions about their health and wellbeing, and provide information and support for them to do so.*

www.legislation.gov.uk/asp/2011/5/contents

www.scotland.gov.uk/Topics/Health/Policy/Patients-Rights/Patients-Rights-Charter

The Health and Social Care Act 2012

The Health and Social Care Act 2012 strengthens the legal foundation of the NHS Constitution and places new duties on the NHS Commissioning Board and clinical commissioning groups to promote it. Section 23 creates a new duty on commissioners to promote the involvement of individuals, their carers and representatives in decisions about their own care and treatment.

www.legislation.gov.uk/ukpga/2012/7/contents/enacted

The NHS Mandate and Outcomes Framework

The NHS Mandate (published in November 2012) is the first mandate between the government and NHS England and sets out the ambitions for the health service from April 2013 to March 2015. It is essentially a more public-facing version of the NHS Outcomes Framework 2013 to 2014 (also published in November 2012).

This sets out the outcomes and indicators used to hold NHS England to account for improvements in health outcomes, as part of the Government's mandate.

Indicators are grouped around five domains, derived from the definition of high quality care first set out by Lord Darzi – clinical effectiveness, patient experience and patient safety. The second indicator on long-term conditions includes ensuring that people feel supported to manage their condition.

www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf

www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014

Care Quality Commission (CQC) Guidance about compliance

The CQC is the independent regulator of health and social care services in England. It checks that services meet the standards set by the government.

Three of the sixteen essential standards checked by the CQC are of particular relevance to patient information. These are:

- Outcome 1: Respecting and involving people who use services
- Outcome 2: Consent to care and treatment
- Outcome 9: Management of medicine

The CQC has produced a guide for service providers, which summarises guidance on compliance. It includes a section on Involvement and information.

www.cqc.org.uk/organisations-we-regulate/registered-services/guidance-meeting-standards

NHS Litigation Authority (NHSLA) Risk Management Standards 2012-13

The NHSLA sets out risk management standards, reviewed annually, against which healthcare services are assessed. Of the six standards, two relate to patient information.

Standard 5 (Acute, community and non-NHS providers) includes a provision that providers *must have an approved documented process for obtaining consent*. The NHSLA's Annual Report states that: *Analysis of the NHSLA claims database shows a significant number of claims where consent is an issue. The majority of these are in relation to surgical procedures or treatments. A major factor is the apparent lack of adequate, clear information for patients, due to issues with verbal or written communication, or competence contributing to these failures.*

Standard 6 (Mental health & learning disability) includes a provision that organisations providing mental health and learning disability services *must have an approved documented process for managing the risks associated with patient information.*

The rationale behind this standard is stated as:

Communicating clear and accessible information to all groups of patients is crucial to facilitating choice and working in partnership to achieve the best outcome. Among the core principles for promoting choice is acknowledging that people have the right to choose their treatment, and that choice applies across the spectrum of care.

www.nhsla.com/Safety/Standards/Pages/Home.aspx

Service priorities

The Power of Information: putting all of us in control of the health and care information we need

The ten-year information strategy from the Department of Health was published in May 2012 and sets out a *framework for transforming information for the NHS, public health and social care*.

It states, in the Executive Summary, that:

Information can bring enormous benefits. It is the lifeblood of good health and wellbeing, and is pivotal to good quality care. It allows us to understand how to improve our own and our family's health, to know what our care and treatment choices are and to assess for ourselves the quality of services and support available.

In Chapter 1, it asserts that:

Information is an essential service in its own right, allowing us to understand our own health, choose healthier lifestyles, and choose the treatment and support that is right for us.

As of April 2013, work is underway to develop a new NHS web portal, a key element of the Power of Information strategy. This is planned to go live by the end of the year.

This new customer service platform will include the migration to NHS Choices of certain content from other NHS websites, and integration with web services from other NHS organisations, such as NHS 111. A new 'app store' of NHS-accredited smartphone and tablet apps has been launched and the whole project will go hand in hand with future plans for the Information Standard itself.

www.gov.uk/government/publications/giving-people-control-of-the-health-and-care-information-they-need

Together for Health Public Information Delivery Plan, May 2012

In Wales, the Together for Health Public Information Delivery Plan aims to make substantial improvements in the way people can access health information, making it easier to find more, reliable, and up-to-date information and, also, to understand it quickly, by seeing it presented in a more user-friendly way.

<http://wales.gov.uk/docs/dhss/publications/120525planen.pdf>

Everyone counts: Planning for Patients 2013/14 – NHS England

This is the planning framework under which Clinical Commissioning Groups are expected to operate, based on the NHS Outcomes Framework and the NHS Constitution. The first point made in the document, under the heading Listening To Patients, is that: 'The rights of patients set out in the NHS Constitution are vital. They must be delivered.'

www.commissioningboard.nhs.uk/everyonecounts/

The Healthcare Quality Strategy for NHS Scotland

This builds on an earlier policy document (Better Health, Better Care) which set out the proposal to create a mutual NHS in Scotland where staff, patients and carers fully understand their rights and responsibilities, and what they should expect from their NHS. The Quality Strategy builds on this and emphasises the importance of Clear communication and explanation about conditions and treatment.

www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf

Achieving excellence - The quality delivery plan for the NHS in Wales 2012 – 2016

The plan details how new quality assurance and improvement arrangements will operate to 2016 and raises the importance of good quality health information.

<http://wales.gov.uk/topics/health/publications/health/strategies/excellence/?lang=en>

National Institute of Health and Clinical Excellence (NICE) Guidelines

NICE produces three sets of guidance relevant to the provision of information.

Clinical guidelines: NICE produces clinical guidelines for specific health conditions, which include the importance of giving information to patients. There is also a specific clinical guideline, CG138, on Patient experience in adult NHS services: improving the experience of care for people using adult NHS services, published February 2012. This reflects good practice in giving patients information about their treatment and care on issues like personalised information, participating in care, shared decision making and patient education.

<http://publications.nice.org.uk/patient-experience-in-adult-nhs-services-improving-the-experience-of-care-for-people-using-adult-cg138>

Commissioning: On a topic-specific basis, NICE commissioning guides provide support for the local implementation of NICE guidance, support commissioners with QIPP priorities and signpost to case examples, NICE Quality Standards and other relevant supporting information. Many of these reference provision of personalised information and education.

www.nice.org.uk/usingguidance/commissioningguides/bytopic.jsp

Quality Standards: The Health and Social Care Act 2012 includes new duties on quality. As part of this duty, the NHS Commissioning Board will have to have regard to NICE quality standards. Those published to date emphasise the importance of patient information and shared decision-making.

Related to CG138, Quality Standard 15 for Patient experience in adult NHS services sets out 14 quality statements to provide commissioners and providers with clear guidance on the components of a good patient experience. Although all are relevant, the following statements relate directly to the provision of health information and support:

- Statement 2 - Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.
- Statement 4 - Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.
- Statement 5 - Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.
- Statement 6 - Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.
- Statement 13 - Patients' preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.
- Statement 14 - Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.

<http://publications.nice.org.uk/quality-standard-for-patient-experience-in-adult-nhs-services-qs15/introduction-and-overview>

Quality Standard 15 provides similar guidance for Service user experience in adult mental health.

<http://publications.nice.org.uk/quality-standard-for-service-user-experience-in-adult-mental-health-qs14/introduction-and-overview>

Information Standard

The Information Standard is a voluntary quality mark scheme, set up by the Department of Health in England, to help the public identify sources of evidence-based health and social care information. The scheme evaluates the systems used by information producers (including NHS bodies, local authorities, businesses and charities) and accredits organisations with robust systems – rather than evaluating individual resources. Stated benefits include enhanced organisational credibility and reputation, greater clarity around information production costs, costs savings due to improved internal processes leading to more efficient ways of working, and reduced risk of litigation due to a clearly defined information audit trail.

www.theinformationstandard.org

The National Service Framework for Long-term Conditions

Published in 2005 by the Department of Health in England, the framework document sets out requirements to support people with long-term neurological conditions to live as independently as possible. In presenting the guidance the DH suggests it can be applied to anyone living with a long-term condition, and commissioners are encouraged to use the framework in planning services for people with other long-term conditions.

The document sets out 'quality requirements', and the first of these, described as underpinning all the others, is focused on patient-centred care. The importance of information provision is highlighted in several of the quality requirements (QR), but this QR sets out that people with long-term

neurological conditions should have *the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.*

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4106042

Design to Improve The Management of Chronic Conditions in Wales

This 2007 document states that effective communication and information systems form the basis of good service delivery and patient care in managing chronic conditions in the community – noting that identifying information needs, accessing and analysing relevant data and using this to plan and commission services will need to be strengthened.

www.wales.nhs.uk/documents/Chronic_Conditions_English.pdf

Financial levers

Quality and Outcomes Framework (QOF)

Introduced in 2004 as part of the General Medical Services Contract, the QOF is a voluntary incentive scheme for GP practices in the UK, rewarding them for how well they care for patients. Some clinical domains, such as on epilepsy and mental health, and an organisational domain on smoking cessation, include references to the importance of information provision.

www.nhsemployers.org/Aboutus/Publications/Documents/qof-2013-14.pdf

Commissioning for Quality and Innovation (CQUIN) Framework

The CQUIN payment framework in England links a proportion of providers' income to local quality improvement goals. Indicators are set in local areas, but the schemes are advised to address three areas: safety, effectiveness and patient experience.

The CQUIN for 2013/14 is set at a 2.5 per cent value for all healthcare services commissioned through the NHS Standard Contract. One fifth of this is to be linked to the national CQUIN goals.

National goals with some relevance to CHI are:

- Set a trajectory for 2013/14 for increasing planned use of telehealth/telecare technologies.
- Establish a 2012/13 baseline and a trajectory for improvement to reduce inappropriate face-to-face contact.
- Demonstrate that plans have been put in place to ensure that for every person who is admitted to hospital where there is a diagnosis of dementia, their carer is sign-posted to relevant advice and receives relevant information to help and support them.

www.england.nhs.uk/wp-content/uploads/2013/02/cquin-guidance.pdf

Quality, Innovation, Productivity and Prevention (QIPP)

QIPP is a national programme to improve the quality of care the NHS delivers while making up to £20 billion of efficiency savings by 2014-15, which will be reinvested in frontline care.

There are 12 workstreams, 5 of which relate to commissioning care. One of these is on long-term health conditions and part of its focus is on supporting people to understand and manage their own conditions. Another is about 'Right Care', developing work around shared decision-making.

www.evidence.nhs.uk/qipp

Going forward

Recommendations for further work

Health information is still far from being properly established as a key service in its own right. Nationally, the 'information revolution' is largely focused on providing shared access to patient records, increasing online transactions, and promoting greater data transparency to enhance accountability and help drive patient choice.

Patients will need far more information and support than will be available through these national initiatives if they are to take on more responsibility for managing their own health, and become fully involved in key decisions about their healthcare.

Future research and learning should focus on identifying and evaluating the detailed characteristics of quality information services, the roles and status of specialist information staff and successful approaches to establishing well-managed, properly resourced information services.

It should also consider the requirements of new clinical commissioning groups for guidance and advice on how best to secure the provision of quality health information and support locally.

Support, feedback and updating the report

We, and our members, are here to help. Please contact us at admin@pifonline.org.uk to discuss further.

PiF are intending to produce regular updates of this report - to review and present the most up-to-date evidence on the Case for Information.

PiF would also welcome any comments on this report, and would ask anyone with any relevant information or research to contact Mark Duman, Chair of PiF, by sending an email to chair@pifonline.org.uk

Contact details

Patient Information Forum

Mark Duman

Executive Chair and Director,
Patient Information Forum

Tel: 07824 605352

Email: chair@pifonline.org.uk

www.pifonline.org.uk

Sarah Smith

Operations Director,
Patient Information Forum

Tel: 07740 867297

Email: operations@pifonline.org.uk

www.pifonline.org.uk

Patient Information Forum

500 Chiswick High Road
London W4 5RG

Email: admin@pifonline.org.uk

www.pifonline.org.uk

 twitter.com/PiFonline

 facebook.com/patientinformationforum

 linkedin.com/in/patientinformationforum

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ

Tel: 0207 840 7829

Email: infomanager@macmillan.org.uk

www.macmillan.org.uk

Carol Grant

Grant Riches Communication Consultants

4 Borough Street
Brighton BN1 3BG

Tel: 0870 770 5258

Email: carol@grantriches.co.uk

www.grantriches.co.uk

Paul Treadgold

Policy Research Consultant

12 Semley Road
Brighton BN1 6EP

Tel: 07775 506045

Email: paul.treadgold@ntlworld.com



Patient Information Forum

For Professionals Working in Consumer Health Information

**WE ARE
MACMILLAN.
CANCER SUPPORT**