



**Patient Information Forum**

*For Professionals Working in Consumer Health Information*

# Executive Summary

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

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## **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.

This is a short summary of key points.

You can read the full report on PiF's website at **[www.pifonline.org.uk](http://www.pifonline.org.uk)**.

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 'infomedary' 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.**

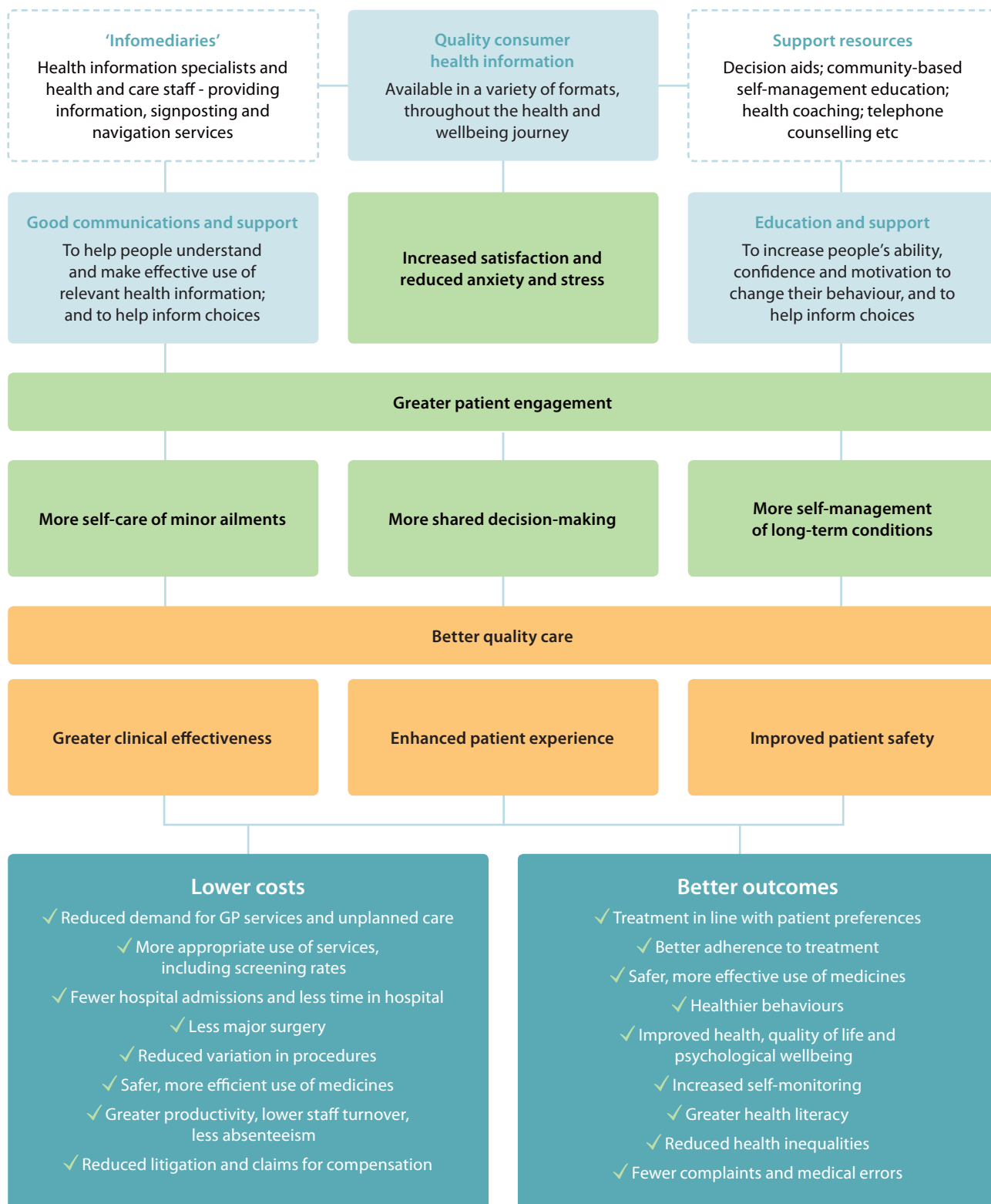
It presents the business case for investing in consumer health information and support, and reviews the detailed evidence regarding the beneficial impacts this can have on:

- 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.



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## 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.

## 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](mailto: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](mailto:chair@pifonline.org.uk)

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