

IS KNOWLEDGE POWER?

**USING INFORMATION
AND SUPPORT TO
EMPOWER PATIENTS**

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INTRODUCTION

A person's right to information in order to inform their care is enshrined in the NHS Constitution.

“You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this.”¹

NHS Constitution

According to recent polling from Lord Ashcroft this is one of the most important needs for people when it comes to their health care – ahead of clean and comfortable surroundings².

A person's right to be involved in decisions about their own care is also enshrined within legislation.

“The NHS Act 2006 places a clear duty on the NHS Commissioning Board, and the clinical commissioning groups to: ‘...promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to—

(a) the prevention or diagnosis of illness in the patients, or

(b) their care or treatment”³

Empowering patients is widely recognised as essential to the future of the NHS, not only as people have the right to define their own care, but also as it unlocks untapped resource to ensure the sustainability of the service. Currently 70% of the NHS's budget is spent on those with long-term conditions, however such individuals are likely to spend only around 1% of their time with health care professionals⁴. As such, giving people the ability to be proactive partners in their care will play a major role in the NHS's ability to sustainably meet the needs of an aging population, which will increasingly have multiple long-term conditions⁵.

A patient's ability to be a proactive partner depends on them having the right kind of information and the appropriate support in order to use it effectively, which was clearly set out in the Patient Information Forum (PiF) report *Making the Case for Information*⁶. Beyond 'patients', this is true for all people whether we call them patients or whether they regard themselves as patients/carers or not. MHP Health and PiF have collaborated on this report to focus on those with long-term conditions, as a population where the need and benefit is particularly clear, for the reasons mentioned above. It takes a snapshot of their experiences and perceptions of information and priorities for the future.

With this snapshot we ask whether current approaches are enough to support people to truly be equal partners in their own care, and whether information provision, and its use through, for example, constructive, supportive patient-'professional' dialogue, needs to evolve in order to deliver the aspirational ideals to empower patients. As users of and payers for one of the leading health systems in the world, we should expect nothing less.

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ALL ABOUT THE PATIENT

Patient information, 'person-centred care' and patient empowerment

The term 'person-centred' has received much attention in debate about the future of the NHS, and its ability to meet our expectations and aspirations, or at least our needs.

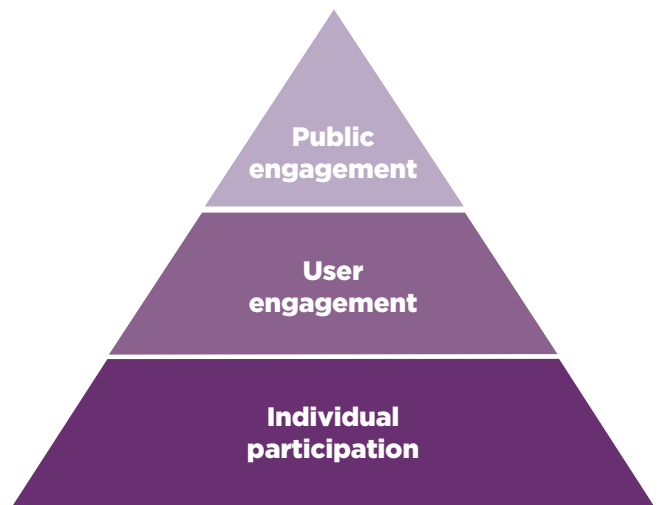
The increasing number of people with long-term conditions, fuelled by changes in lifestyle and an aging population, means the system must change. Structures built around acute and episodic care are struggling under the pressures of those with long-term, and often, deteriorating conditions. Building the system around the person is fundamentally appealing and is supported by political parties, think tanks, experts and commentators; but what does it mean?

'Person-centred' is used widely, and there is a danger that it is used within different contexts to encompass multiple meanings.

For a person to be in the centre they need to be:

- **Heard at the very top of the system**, sought out and understood by those making far-reaching structural decisions. Person-centred care therefore sees patients as advisers and political change agents expressing opinions and articulating priorities
- **Directly involved in decisions about how care is delivered in their area**, they need to be decision-makers, sat at the table as plans are made
- **Activist consumers**, providing feedback and exercising choice to encourage good care and drive up quality where care is less good
- **The central consideration in individual treatment decisions**, with healthcare professionals and patients engaging as partners to secure positive outcomes, going beyond management of symptoms and test readings

The three levels of participation



Core to all of these roles, in order for a person to be at the centre of their care, is this last definition, whereby a patient is empowered as a 'manager' of their own treatment, to the degree where they are willing and comfortable. This goes beyond being informed to touch on issues regarding self-referral and, access to reliable information of outcomes of different providers, but empowerment to take part in decisions about treatment.

Such an empowered patient will have *sufficient health literacy** (or support from a trusted person) to be able to engage with information materials, be able to understand the implications of their condition and treatment options, feel supported to use their information and understanding to engage proactively in their care, be trained/educated to use their knowledge to support positive outcomes and feel confident and respected as they work side by side with healthcare professionals in setting their treatment course. Accessible, trustworthy information and the encouragement to use it are the key.

It is this concept of patient empowerment through information which formed the centre point for the Government's vision for the NHS in 2012, setting out an aspirational ideal within *Liberating the NHS: No Decision about me without me*:

“Central to the vision of patient-centred care, is the principle of providing a wide range of appropriate, accessible and timely information enabling people to make informed decisions”⁷

It is also clearly set out in the Government's Mandate for NHS England which requires it to:

“Ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment”⁸

Mechanisms within the NHS to implement such ideals are evident in the publications of the *Transforming participation in Health and Care*⁹, the *NHS Choices Framework*¹⁰, as well as the launch of the shared-decision making¹¹ and expert patient programmes¹². Recognising information as part of, not just an addition to treatment was firmly established through the announcement of 'information prescriptions'. These were a commitment contained in the 2006 Government White Paper *Our health, our care, our say*¹³ where it was stated that all people with long-term health and social care needs would receive information prescriptions by 2008.

'Information prescriptions' are offered to an individual by a medical, health care, social care, or information and support professional and are a source of personalised information that clearly and simply lays out the most important points about an individual's information needs, during their consultation with a healthcare professional. Nine years on from the 2006 commitment we have just (January 2015) seen GPs being advised to use information prescriptions with any person with diabetes who does not have their condition under control (emphasis added)¹⁴. This is a welcome recognition of the power of information, but is an interesting restriction to impose, only using them where treatment 'isn't working'.

There is much evidence in policy of ambition to make patient empowerment a reality. However it is unclear whether this has made a real impact in empowering patients or is merely rhetoric – most recent statistics show that only 5.4% of people with a long-term condition report that they have an agreed care plan¹⁵.

The continuing refreshment of commitment stresses that, far from a passing policy idea, aspirations for patient empowerment and patient information have only strengthened in recent years within plans for the future of the NHS.

* “Health Literacy has been defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health Literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment”.¹⁶

Aspirations for future patient information: *Five Year Forward View and beyond*

Simon Stevens, Chief Executive of NHS England, recognises the empowerment of patients as one of the key ways in which the NHS could meet the needs of the changing population. In the Five Year Forward View (5YFV)¹⁷ he, alongside all organisations responsible for health, sets out that the first step in order to achieve this is improving the information to which people have access and supporting people to make informed decisions about treatment and managing their own health – focusing mostly on how to harness new technologies to increase accessibility to information.

*The Long Term Conditions (LTC) 'Year of Care' Commissioning Programme*¹⁸, which gives support to commissioners and providers to implement tailored individual funding models and its implementation, is also dependent upon “engaged, informed individuals and carers” as set out in the *House of Care model*¹⁹. However, despite its promise, challenges remain in delivering the programme within current commissioning processes²⁰. Early pilots of the model still saw information and data as one of the key challenges in the programme’s practical implementation²¹.

Personal health budgets, introduced initially in 2009, put real meaning behind empowerment, increasing emphasis on tailoring health budgets to individual need; this is now augmented through the proposed implementation of Integrated Personal Commissioning (IPC)²². This aims to give those with long-term and complex needs direct control over how a limited amount of money (relative to their condition) is spent on their health and social care – truly empowering patients to have choice within their care.

Whilst voluntary and third sector organisations will be commissioned locally to support personal care planning in such programmes, it is essential that people eligible for the programme have access to appropriate and adequate information and have support which enables them to use it. This is to ensure they are comfortable making such decisions about their own care – a point which leaders from the UK charity sector made clear in an open letter to *The Times* in September 2014²³.

The future ambitions for empowerment are clear: a future NHS where people are proactive partners in their own care, who are able to make informed choices and decisions about what that care should look like. All of this is built upon the availability of good information and support for patients (and carers).

What does 'good' information look like?

In terms of existing national best practice and guidance, the Department of Health produced the NHS Information Standard in 2004, to ensure consistent standards of information across the health service. This responsibility was formally transferred to NHS England in October 2014. The Information Standard certification programme acts as a quality mark for information and ensures that information is clear, accurate, balanced, evidence-based and up-to-date.

NHS England are looking to build on this by creating the Accessible Information Standard²⁴, which acts as a guide to health and social care organisations to ensure that everyone understands the information they receive and that it enables them to make their own choices.

In addition to standards and guidance from NHS England, best practice models for patient information have been produced by the former *Institute for Innovation and Improvement*, have been included in guidelines and quality standards from the National Institute for Health and Care Excellence²⁵, and a multitude of third sector and charity organisations (including the PiF - <http://www.pifonline.org.uk/pif-guidesreports/>) have produced information models in order to contribute towards defining standards.

National standards and guidance for patient information are important to assure accuracy and accessibility of information. They, however, support the inputs that patients receive rather than measuring the output of such information. For this we need to examine patients' satisfaction with information they receive, and their views of its value in supporting them to be in control of their own care.

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POLL RESULTS

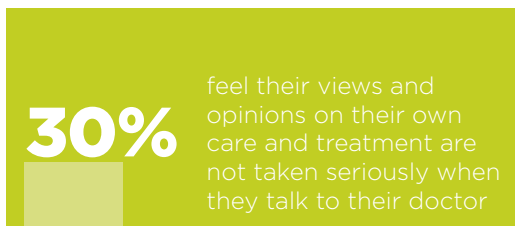
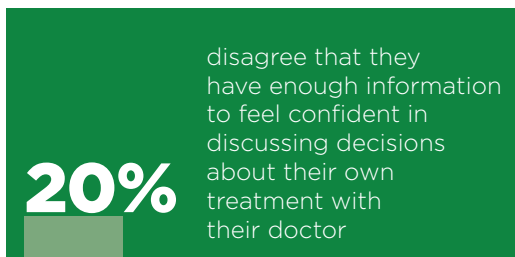
A poll to examine whether existing patient information empowers patients with long-term conditions

Ensuring that people have access to the right kind of information in order to make decisions about their own care, and are also supported to be able to use it, will be crucial to empower patients in line with current ambitions and the future visions for the NHS.

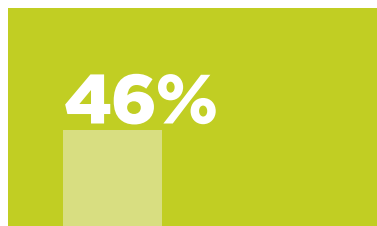
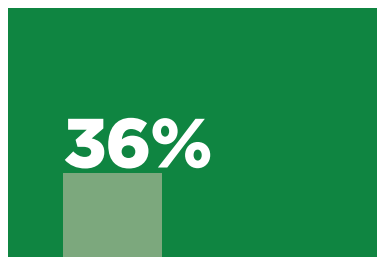
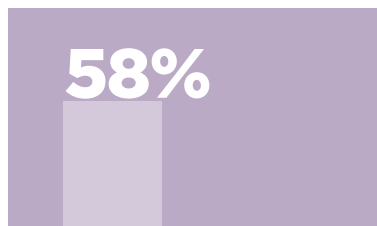
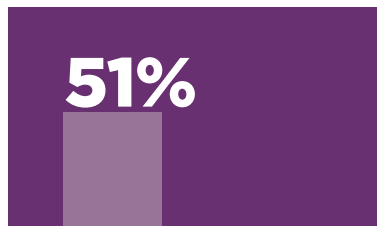
ComRes interviewed 1,567 GB adults with a long term condition online between the 18th and 27th February 2015. Data were weighted to be representative of all GB adults aged 18+. ComRes is a member of the British Polling Council and abides by its rules. Full data tables can be found at www.comres.co.uk.

In order to delve deeper into whether current information is able to deliver this, PiF and MHP Health commissioned a poll with ComRes.

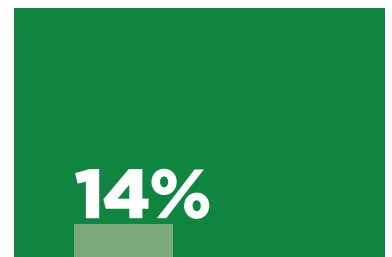
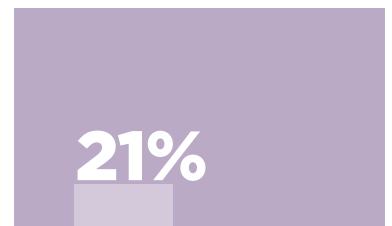
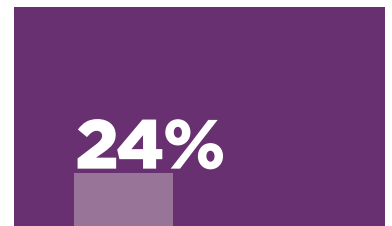
For people of all ages:



For those aged 18-24



For those aged 65+

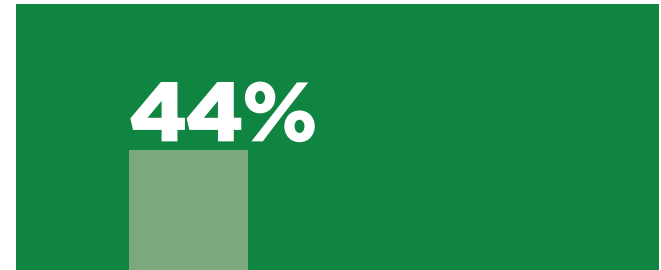


43% of people feel they would have enough information to make decisions on how money was spent in managing their condition, if they had more direct control over how a limited amount of money is spent:

For those aged 18-24

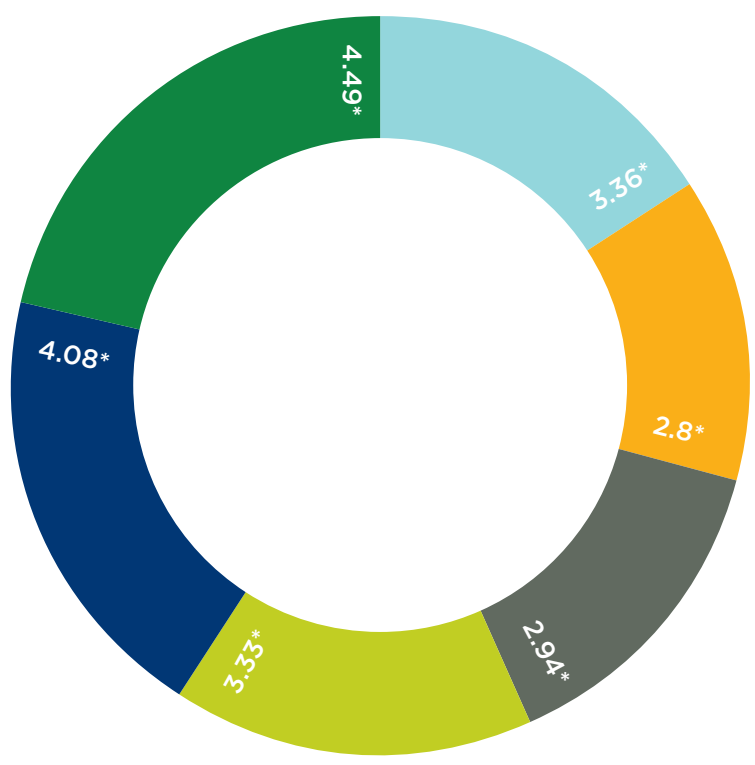


For those aged 65+



What would be most helpful in making you feel more in control of your own care and treatment

- Longer appointments with your doctor
- More information on how to manage your condition
- More opportunities to discuss your options with your doctor
- More information on your condition
- More opportunities to discuss your condition with people other than your doctor
- More opportunities to talk to people who also have your condition



*Mean score

Quotes from respondents:

“When I was diagnosed with cancer, my care plan had already been set up without any consultation with me and I was told this was what was going to happen. I would have preferred that I be told my diagnosis, given information about my various treatment options, and allowed to consult with the [Doctors] over which option would be best for me and my family.”

Poll respondent

“They [doctors] are not interested at all in your insight into your condition and if you challenge your treatment protocol or want pertinent information they are at a loss as to how to deal with you.”

Poll respondent

“Whilst being pregnant, my back problems caused issues in regards to pain management during labour. The consultant examined me in a thorough way and gave me as many options as were available explaining them all as necessary, he also even said I could go to another hospital as they offered different pain medication. Overall the consultant said it was my choice and I feel I had enough information to make an informed choice.”

Poll respondent

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ANALYSIS OF FINDINGS

While such a poll cannot provide a complete picture on current patient information provision within the NHS; it raises important questions concerning current approaches to patient information and highlights how consumer health information might need to evolve to meet the ambitions for the future NHS.

Satisfaction with information – room for improvement

Responses to the poll suggest a relatively high level of satisfaction among people with long-term conditions, both with regards to the information they receive, and how they can use it effectively when talking to their doctor.

While this is a relatively good report of satisfaction two issues clearly need to be addressed. First, there remains a large proportion where this isn't the case; second, further probing should be conducted regarding the expectations against which this satisfaction is being reported.

Room for improvement

Regarding the population among whom there is low satisfaction reported, based on these findings it is estimated that of the people with long-term conditions in England:

- **Over 5.5 million disagree that they were given helpful information when they were first diagnosed**
- **Over 3.2 million disagree that they have enough information to feel confident in discussing decisions about their care with their doctor**
- **Over 4.4 million feel that their views are not taken seriously by their doctor**

These numbers have been calculated based on the estimate of 15.4 million people in England living with a long-term condition²⁶

Do we know what we don't know?

Further probing of patients' expectations should be carried out to investigate whether people generally tend to expect less in terms of health information than they perhaps would from other sectors. Equally they may not actively expect to play a leading role in managing their health and reaching shared decisions with health care professionals²⁷. Despite statistics suggesting that people are as involved as they would like, and feel satisfied with information, there may be a case that they are not fully aware of the opportunities which could be available. For example, The Care Quality Commission *inpatient 2013 poll* found that 56%²⁸ of people were as involved as they wanted to be in the decisions about their care and treatment in the NHS, yet only 5.4% of people are reported to have agreed care plans²⁹.

Are both doctor and patient ready for a collaborative relationship?

Findings regarding whether people feel they have a collaborative relationship with their doctor when making decisions about their care are also important. For a relationship between a doctor and a patient to be effective, it should be a "partnership based on openness, trust and good communication, as each person has a role to play in making decisions about treatment or care"³⁰. However, almost a third of people feel their views are not taken seriously by their doctor.

In order for person-centred care to truly be achieved, health and care professionals must also be committed to partnership working as set out in the *House of Care model*³¹, supporting patients to discuss and use the information they have and listening actively, with some studies suggesting that patients speak un-interrupted for an average of 12 seconds during a consultation³².

Analysis of pilots of the *House of Care model* by the King's Fund found that the sharing of information in the 'two-stage' consultation was highly valued. This starts, however, from both "parties being better informed"³³.

“When I was diagnosed with ARVC [Arrhythmogenic Right Ventricular Cardiomyopathy – a heart condition], I was given the choice over whether to start speculative drug treatment (which may or may not help). While I was happy to be given the choice, I did not feel that I had enough information to decide in a thorough way.”

Poll respondent

“I have complicated conditions and my doctor has been very good in helping me to manage my conditions not only with medication but with very useful information”

Poll respondent

“I have only found useful information about my condition from a national charity and other people who have the condition. Doctors and nurses seem a bit off-hand when I have spoken to them [and are] only interested in checking I take the medication not how I manage the condition myself.”

Poll respondent

Patient information - the generation game

Of particular significance within these findings is the divergence in how useful and accessible younger and older people find current information. Those aged 18-24 are overall far more dissatisfied with the information they receive and how it informs their care, compared to those over the age of 65. The most significant gap can be seen when each age group was asked whether they find it difficult to access trustworthy information:

- **For those aged 18-24, 58% find it difficult to access trustworthy information on their condition**
- **For those aged 65 and over, 21% find it difficult to access trustworthy information on their condition**

What is driving this difference?

There will certainly be differences in the balance of long-term conditions for the respondents in these age groups, differences that our methodology does not enable us to address through weighting. But with this acknowledged, we must ask whether those over the age of 65 with a long-term condition feel they need less, expect less, or indeed receive more information than those of a younger age. Those who are 18-24, children of an age of consumerism and readily available information, are perhaps more critical of the information they receive.

Further investigation is needed, but consideration must certainly be given to whether current systems of information need to evolve so that they are appropriate, useful and accessible to those of a younger age, where gaining the skills to self-manage in the early stages of their condition can play a crucial role in how they manage their condition in what should be a long future.

Information materials alone are not enough

When asked what people would find most useful in order to feel most in control of their own care and treatment we find that, out of six options given, 'more information on your condition' received the third highest proportion of respondents selecting it as the most helpful.

This is behind the options of 'more opportunities to discuss your condition with people other than your doctor' and 'those who also have your condition'.

What this highlights is the importance not only to ensure that there is enough information available for people to make sure they feel in control of their own care, but also that people are able to discuss information and receive inputs from different sources. While information is a key enabler of patient empowerment, information materials alone are not enough. There is huge value in other factors such as peer support, hearing views from others in similar situations and knowing you are not alone³⁴.

People are not ready to make decisions on how money is spent on their care

Arguably the most striking finding in our poll is that the majority of respondents, regardless of age, do not feel they have enough information to feel confident about making decisions about how money is spent on their care.

Only 43% of people feel they would have enough information to make decisions on how money was spent in managing their condition, if they had more direct control over how a limited amount of money is spent.

Given ambitions to give people increasing power to make such decisions, attention is clearly needed on the support that people receive to exercise such power. Regardless of the merits of the policy, we must be cautious that transfer of budgets truly enables the patient to make decisions and does not simply insert a new level of 'commissioners'.

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CONCLUSIONS AND RECOMMENDATIONS

Despite an overall majority reporting satisfaction with the information and their ability to use it to inform decisions about care, the results of our poll suggest significant gaps remain. These gaps may also be larger than they appear; we are concerned that this level of satisfaction may be over reported due to low expectations.

Of particular note is the divergence in satisfaction levels between older and younger generations, with those aged 18-24 being substantially more dissatisfied with current information and how they can use it compared to those over 65.

Equally clear from the findings is that, regardless of age, information materials alone are not enough for individuals to feel confident in making decisions on how to spend money on their own care.

In order to ensure that the right kind of information and support is available so that patients are truly empowered, in line with future visions for the NHS, it is essential that ambitions for patient information, as set out within the Five Year Forward View, are realised.

For this to happen we believe that four conditions need to be met to assure the provision, delivery, quality and impact of information. We set these out as recommendations to the Government, NHS England and the Royal Colleges in order that they may deliver on the promise of a sustainable NHS, serving truly empowered patients:

Provision

1. Ensure provision: Integrating information within the care pathway

Information needs to be recognised as a key intervention for improving outcomes. This should be seen as a core part of a patient's care, should be personalised and delivered as a standard part of engagement. Information should be accompanied by appropriate support structures to ensure it can be used effectively. 'Information prescriptions' should be trialled and evaluated as a key lever to empower people through information.

Leadership

2. Ensure local leadership: Driving the provision of information locally

With information recognised as a key intervention, there should be a dedicated lead for patient information within all clinical commissioning groups and trusts. Such leads should have an appropriate mandate to ensure consistent and effective delivery and pursuit of commitments and aspirations for empowerment through information.

Quality

3. Ensure quality: Creating a national plan for information

NHS England should work with partners to develop a shared plan on how to deliver high quality information which has a meaningful impact in helping people to feel empowered within their own care.

Impact

4. Ensure impact: Embedding information within professional education such as communication skills training and dialogue/partnership working

Health information and its use should be integrated into appropriate education, alongside support for the development of listening and shared decision-making skills among healthcare professionals. This should build on current guidance produced by the General Medical Council on partnership working between doctors and patients.³⁵

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Is Knowledge Power?

ABOUT US

MHP Health

MHP Health is the award winning health and social care policy and public affairs consultancy within MHP Communications. Our clients – from multinational corporations to world class hospitals, professional bodies and healthcare charities – are all looking to shape the health and social care environment.

We help them to develop policy and to communicate, delivering business-critical results and health outcomes which transform lives. Core capabilities of the 180-strong MHP team span the disciplines of public affairs, public relations, corporate and brand communications, digital engagement, and crisis communications.



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Patient Information Forum

The Patient Information Forum (PiF) is an independent, not-for-profit organisation and is the UK's largest membership organisation for people working in health information, from across the voluntary, commercial, and public sector.

Together with our members, we believe that high quality health information and support should be available to everyone, to support informed decision making about their health and wellbeing.

PiF provides members with opportunities to access training, education and guidance; to share expertise and promote best practice and to be part of a strong collective, independent voice.



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