



Patient Information Forum

For Professionals Working in Consumer Health Information

PiF response to the All Party Parliamentary Group on self-care call for evidence, October 2015

Inquiry into Delivering the Five Year Forward View: Behavioural change, information and signposting

Q1) Accelerating positive behavioural change and who is responsible

PiF strongly believes that significant behaviour change in the patterns of use and access of the healthcare system will only be achieved by increasing the provision of and access to high quality health information plus more active educational support.

In this submission we share evidence demonstrating that information and support empowers patients and service users to: better understand and self-manage their conditions; as well as better understand the range of health services that are available, and make appropriate choices about which services to access.

Being well-informed is an essential prerequisite for patient engagement but, generally, is not sufficient by itself. 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.

People 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.

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

For example:

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

- Self-management education and structured discharge planning can reduce unplanned hospitalisations, readmissions and subsequent length of stay.

The evidence to support these statements is clearly set out in the Patient Information Forum (PiF) report Making the Case for Information¹ (see pages 53-55).

Evidence in this report also demonstrates the link between the provision of high quality information and support and proactive patients (see pages 57, 63):

- Access to good quality health information empowers patients and can improve their confidence in care and in their relationships with health professionals.
- 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.
- 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.
- Increased self care for minor ailments has been linked to access to alternative format information and education resources

It is imperative that the provision of services, including information and support, be person centred – tailored to the needs and experiences of each patient and service user.

Building the system around the person is supported by political parties, think tanks and health system experts. But what does this mean in practise?

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.

This can't be achieved without a wider understanding and articulation of the benefits of person centred care. It can't just be a conversation about how to solve problems within the system, it needs to be talked about in terms of the benefits to patients and service users.

People want to be supported to be able to understand and use health information – for many it is not enough to just provide a leaflet or link to a website. While information is a key

¹ Patient Information Forum, Making the Case for Information, July 2013, <http://www.pifonline.org.uk/wp-content/uploads/2014/11/PiF-Case-for-Information-Report-Final-Full-Report.pdf> - see pages 53-55

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 alone.

For example in the PiF and MHP Communications poll² when asked what would be most helpful in making patients (with long term conditions) feel more in control of their own care and treatment, the most popular two options were around 'support' rather than just 'information' ('more opportunities to discuss your condition with people other than your doctor'; 'more opportunities to talk to people who also have your condition'). The third most popular option was 'more information'.

This highlights the importance not only to ensure that there is clear, reliable and relevant information available, that informs and educates, but that there is also support available that allows people to discuss the information and how it relates or might be applied to their specific circumstances: personalising the delivery of health information and support.

Professionals and the healthcare system can't just support or supply information at points it suits or benefits their service provision. The provision of information needs to be integrated into and throughout the delivery of healthcare.

Information needs to be recognised as a key intervention for improving outcomes as well as reducing or helping to better manage the use of services. This should be seen as a core part of a patient's care; it 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.

Recent PiF publications have identified three actions we believe to be key in driving this forwards:

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, and use commissioning and outcome measuring to ensure the plan is adopted and embedded.

Health information and its use should be integrated into appropriate healthcare education, alongside support for the development of listening and shared decision-making skills among healthcare professionals. For example, building on current guidance produced by the General Medical Council on partnership working between doctors and patients³.

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.

² PiF & MHP Communications, Is Knowledge Power?, March 2015, <http://www.pifonline.org.uk/wp-content/uploads/2015/03/Is-knowledge-power.-Using-information-and-support-to-empower-patients..pdf>

³ General Medical Council, Consent guidance: Partnership, http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_partnership.asp

Achieving these changes requires a culture change for health service decision makers, healthcare professionals, and for patients. Any successful initiatives to accelerate behaviour change in the use and access of services needs to work with and target all three 'groups'.

Q2 & 3) Health literacy and clearly communicating health messages

Health literacy concerns people's ability to read, understand and act upon health information.

Although anyone can be affected, some population groups have been identified as experiencing disproportionately low or inadequate health literacy. These are⁴: more disadvantaged socioeconomic groups, migrants and people from ethnic minorities, older people, people with long term health conditions, disabled people (including those who have long-term physical, mental, intellectual or sensory impairment).

Health literacy has very serious implications for health inequalities and outcomes as people with low literacy skills are less likely to adopt positive health behaviours, access screening services, understand their disease or disclose additional health problems. It also limits their capacity to prepare for follow-up appointments and self-care.

However, the desire to receive information and to participate in decision making is no different for those with low health literacy.

A systematic review by Morrison and colleagues found that low literacy interventions (such as an education booklet) targeted at parents in the US likely to have low health literacy can result in decreased use of accident and emergency (A&E) services.

The research team assessed eight studies investigating the impact of low literacy interventions, four of which were asthma-specific interventions, with the other four relating to general paediatric health. In three of the four general interventions, the distribution of a health education book (with low grade reading levels) led to significant decreases in emergency department utilisation over the following 6-12 months. Morrison and colleagues concluded that targeted health literacy related educational interventions have the potential to reduce repeat A&E visits and healthcare expenditures, and to narrow health disparities by empowering parents with low health literacy to obtain appropriate care for their children.

Addressing health literacy issues is a fundamental part of the consumer health information challenge, and will directly impact on national efforts to accelerate behaviour change and improve understanding amongst people about where and when to seek health advice.

⁴ Public Health England and UCL Institute of Health Equity, Improving health literacy to reduce health inequalities, September 2015
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/460709/4a_Health_Literacy-Full.pdf

Health information and support has the potential to significantly improve health literacy in this area, but in order to achieve this, resources and services must clearly communicate their messages and be developed with users.

The Making the Case for Information report (p65) found evidence that high quality information is most effective at achieving the benefits and impacts discussed above when:

- It is high quality – accurate, reliable, up to date and clearly communicated
- It is personalised: one size doesn't fit all. Consumer health information has the greatest effects when it is tailored to reflect an individual's particular needs and circumstances.
- Information must be converted into knowledge and understanding. How well information is communicated to patients is therefore critical.

In 2014 PiF conducted an evidence review on what makes health information 'work'⁵. This identified a systematic review (Nilson et al, reference 20) which found evidence that involving consumers in the development of patient information results in material that is more relevant, readable and understandable, and which can also improve knowledge without affecting anxiety.

Both the IPDAS (International Patient Decision Aid Standards Collaboration) guidelines and the Information Standard highlight the value and importance of information producers involving audience at key stages of the process: from deciding what is needed, through to content development, design, dissemination and evaluation.

Principle 3 of the Information Standard requires producers to demonstrate that they have a good understanding of who they are providing information for and why. Information products must be produced appropriately for that specific audience and their needs. They should also be user-tested with the intended audience and finalised in the light of user feedback. To ensure the necessary engagement with the intended audience, the IPDAS criteria advocate a systematic development process for involving patients, carers and health professionals in the co-design of health information materials.

As well as writing more accessible health information, the presentation and format of information materials is particularly important for people with low health literacy levels. Health information should be inviting and encourage people to apply it in practice.

Visual aids and simple diagrams can help improve accessibility, although sometimes it may be necessary to simplify written instructions. However, to fully respond to the needs of people with low health literacy, a range of accessible health information materials is required.

For many people, and particularly those with low health literacy, presenting health information in alternative formats may aid understanding. There is clear research evidence that interactive websites, short video clips, audio recordings of consultations, DVDs and

⁵ PiF, What does good health information look like?, October 2014, <http://www.pifonline.org.uk/wp-content/uploads/2015/03/What-does-good-health-information-look-like-October-2014.pdf>

other multimedia interventions can be effective in increasing knowledge, satisfaction and patients' ability to make informed decisions (references 35, 36, 37).

PiF has created a set of best practice and key steps to involving users in the creation of health information, and ensuring health information is clearly communicated. These can be viewed as a pdf or as part of our interactive [toolkit](#).

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