

## Making the Case for Information:

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



**Patient Information Forum**

For Professionals Working in Consumer Health Information

## A summary briefing for Health Information Specialists

**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.**

The advantages of improving access to good quality information 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.

Health information specialists have a vital role to play in championing high quality health information and in campaigning for significant and consistent investment in the provision of high quality services and resources.

### The Case for Information is compelling

The provision of health information to patients and the public is now firmly embedded in health policy across the UK.

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 reduce financial pressure on the health service.

Yet information for patients, in most places, remains a 'nice to have' instead of a 'must do'. Whether someone 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.

The *Case for Information* provides clear evidence about the benefits:

- High quality health information has a positive impact on service utilisation and health costs, patients' experience of healthcare and patients' health behaviour and status.
- There are good business reasons to justify the investment of more time, money and training in health information provision and support. These include positive impacts on service use and costs, capacity savings, and 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. It also helps achieve the other two quality domains - clinical effectiveness and patient safety. This 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.

### What works?

Our research identified the most effective ways of providing consumer health information and maximising its impact:

- **One size does not fit all** - Consumer health information has the greatest effect when it is tailored to an individual's particular needs and circumstances.
- **Quality is paramount** - High-quality information that is accurate, evidence-based and developed with users is essential.
- **Information must be converted into knowledge and understanding** - Effective communication with patients is vital to add value to information and encourage behaviour change.
- **Written information aids recall and understanding** - Verbal communication backed up with 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.**
- **Web-based solutions are not the only answer** - Lack of access to the internet and preferences for printed material mean that health information must continue to be provided on paper and in accessible formats.
- **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 means patients need to draw on support to enable them to get more involved in their healthcare.



- **Information is part of a broader process of communication** with health professionals, to supplement their clinical judgment. It needs to be embedded within care pathways and become an integral part of consultations.
- **Significant behaviour change will only be achieved by information plus more active educational support** - People need more than just information to be actively involved in decisions. Information needs to be provided alongside active encouragement, education and support. This is especially vital for those with low levels of health literacy and engagement.

### An essential service

Information is a key service which, delivered well, can be as important to health as any medicine, test or surgery. It is an essential service in its own right and its provision cannot be left to chance.

Information services must be properly planned and resourced. This means dedicated budgets and clear lines of accountability and responsibility.

Information production is a highly skilled activity and those who do it need training, learning and development opportunities.

Future research and learning should identify and evaluate the characteristics of quality information services, the roles and status of specialist staff and best practice in running information services and producing resources.

### The Information Specialist role

- 1 Analyse and quantify the value that information provides to your users, supporters, organisation and communities.
- 2 Share the *Case for Information Executive Summary* or briefings with the decision makers - your line manager, Director, Chief Executive, trustees or Board.
- 3 Use the *Case for Information* to produce a business case for investment in your organisation - for more money, staff, training and resources.



**The Patient Information Forum (PiF)** is the organisation for people working in consumer health information. PiF is a UK wide, not-for-profit, independent organisation with members in all healthcare sectors.

We commissioned Grant Riches Communication Consultants ([www.grantriches.co.uk](http://www.grantriches.co.uk)) to identify evidence on the benefits of providing, and the harms of not providing, high quality consumer health information.

The research was funded by the Department of Health's Innovation, Excellence and Strategic Development Fund and Macmillan Cancer Support ([www.macmillan.org.uk](http://www.macmillan.org.uk)).

This briefing is aimed at information specialists. You can read a more detailed executive summary and the full research report at [www.pifonline.org.uk](http://www.pifonline.org.uk).

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