



Patient Information Forum

For everyone involved in health information and support

www.pifonline.org.uk

Summary Report PIF Executive Circle Meeting

Ensuring quality: Quality standards in healthcare information and support

Wednesday 16 March 2016; 1.00-5.00

kindly hosted by MHP Communications

Introduction

This summary report outlines discussions which took place at the Patient Information Forum Executive Circle meeting on Quality on 16 March 2016.

The meeting asked attendees to consider their own approach to quality, and reflect on effectiveness of the wider policy and standards framework for ensuring quality within the provision health information and support across the UK.

The meeting established a key theme in PIF's 5-year strategic aim to raise the quality of health information for patients and the public. Discussions were wide-ranging and identified key challenges and questions that will be explored and addressed as part of PIF's ongoing programme of work.

The report covers the following:

1.0 Setting the scene

2.0 The current environment

- The Accessible Information Standard
- The Information Standard

3.0 Quality challenges and possible solutions

- Improving understanding
- Professionalising the workforce
- Avoiding duplication of effort
- Recognising the value of information
- Anticipating the future and dealing with a rapid pace of change
- Adjusting to cultural shifts

4.0 PIF strategic objectives for quality 2016-2021

5.0 Further information

6.0 List of attendees

1.0 **Setting the scene**

1.1 Useful resources from PIF

- [Judging and assuring quality in health information](#) (March 2016)
- [PIF Guide to Appraising Health Information](#) (2010)

1.2 Quality is a key PIF strategic aim for 2016-2021

Quality We raise standards and highlight good practice in the production and provision of healthcare information and support.

Integration We campaign for high-quality healthcare information and support to be an integral part of the patient journey.

Expertise We champion and enhance the expertise of people working in the field of healthcare information and support.

Impact We promote the importance of measuring high-quality healthcare information and support.

1.3 Identifying the perfect patient information journey

PIF is establishing a 'Perfect Patient Information Journey' project to identify the information and support needs of patients along the care pathway, which will consider shared decision making and personalisation.

AbbVie is kindly providing funding for this work via an unrestricted educational grant.

1.4 Working together to improve quality

Attendees' reasons for joining the meeting revealed a common desire to improve quality by sharing experience and insights, learning from each other and working together.

What are the key issues attendees wish to explore?

- Involving patients – what does this mean and how to approach this.

- Using digital well.
- Exploring possible links between standards and qualifications.
- Ensuring people can understand information, make sense of it and act upon it.
- Evaluating effectiveness of information and getting meaningful feedback.
- The place of high-quality information within integrated care pathways; ensuring information reaches people and that they know where to find it.
- The role high-quality information has in facilitating self-care, particularly for people with multiple, long-term conditions.
- The relationship between quality and regulations, particularly with respect to the information people need to enable them to self-treat, e.g. patient information leaflets that come with medicines, which are subject to very particular regulations.
- How the Information Standard is working in the real world.
- The impact of 'Googling it'.
- The gap between the rhetoric and people's own experiences of accessing information as a patient or carer within the NHS.
- A lack of recognition by the NHS of 'information as a therapy'.

2.0 The current environment

2.1. Which quality standards are attendees aware of, or using?

- The Information Standard
- The Accessible Information Standard (mandatory from 1 August 2016)
- Organisation's own standards
- Health on the Net (HON) code
- Easy Read
- Plain English Campaign marks
- Association of the British Pharmaceutical Industry (ABPI) code and European equivalents.

- Regulations governing patient information leaflets that come with medicines involve user testing.
- Translation
 - Back translation is one way to ensure quality – information is translated from one language to another by one person/team, and then back to the original language again by another person/team.

2.2 Which awards have attendees applied for?

- British Medical Association Patient Information Awards
- Plain English Campaign Awards
- Health Service Journal Awards

2.3 Attendees are generally in favour of quality marks

Key reasons to have quality marks:

- There is a wide variety in the quality of information online and quality marks help people to tell the good from the bad.
- Even if members of the public do not recognise quality marks, they can help health and care professionals to know which information they can trust and which information to recommend to patients.
- Quality marks can help raise the standard of information produced by organisations that use them.

Considerations:

- How can we raise awareness of quality marks?
- How can we meet the needs of people with low health literacy, who may not know about quality marks, and who include some of the people who struggle the most with things like self-care and adherence?

2.4 The Accessible Information Standard (AIS)

- The Accessible Information Standard (AIS) is mandatory from 31 July 2016. <https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/>
- The AIS is a narrowly defined standard that follows on from the Equality Act. It directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and

parents, where those needs relate to a disability, impairment or sensory loss.

- The AIS is of particular relevance to individuals who are blind, deaf, deafblind and / or who have a learning disability, although it will support anyone with information or communication needs relating to a disability, impairment or sensory loss, for example people who have aphasia or a mental health condition which affects their ability to communicate.
- The AIS applies to service providers across the NHS and adult social care system, including those who are commissioned to do so, and it specifically aims to improve the quality and safety of care received by individuals with information and communication needs, and their ability to be involved in autonomous decision-making about their health, care and wellbeing.

2.5 The Information Standard (TIS)

The Information Standard (TIS) is an NHS England certification programme for organisations that produce evidence-based health and care information for the public. Organisations or departments that adopt TIS are demonstrating their commitment to trustworthy health and care information as well as providing assurances of the quality of their internal processes.

<https://www.england.nhs.uk/tis/>

Update from the TIS team:

- TIS is shifting away from a focus on helping organisations to gain accreditation, towards a focus on helping people raise standards more generally. The TIS team is working more closely with organisations to review how they do things and identify changes they could make to improve their processes and their products, such as good ways for them to involve people in the development of resources and to evaluate impact.
- Organisations can benefit from the support of the TIS team to help them raise standards even if it takes them a long time to gain accreditation.
- NHS England is researching why there is less take-up of TIS by NHS organisations than voluntary organisations. A report is due in June 2016 and the TIS team will use its findings to drive take-up of TIS.
- TIS covers digital resources and TIS clients include organisations that produce apps.
- If you are producing information on a rare disease, then it may be necessary to involve users who live abroad.

Discussion and comment from other attendees:

- TIS has many benefits for accredited organisations:
 - *“TIS has totally transformed the way we work. It’s given us a structure, a framework, a process. It gives us authority and credibility. It helps with fundraising bids. The benefits are huge.”*
- TIS is not recognised by the public as widely as many would like.
 - People trust the NHS logo. Perhaps we should be using the NHS logo as a quality mark instead of the TIS logo?
 - It does not necessarily matter if the public does not recognise TIS if TIS is raising the standard of the health information that’s being produced by those organisations that are accredited or seeking accreditation. People do not necessarily know about other things that affect their care, such as their rights within the NHS Constitution, but it’s still good to have the Constitution.
- Perhaps TIS should be mandatory within the NHS? Perhaps NHS organisations that do not use TIS should be marked as ‘in need of improvement’?
 - When you walk into a hospital, the leaflets that are available are not necessarily all TIS registered.
 - If TIS suddenly became mandatory within the NHS, the TIS team would not have the capacity to cope with the sudden upsurge in demand, and who would police things?
 - Organisations might opt out of providing information altogether if TIS became mandatory. Then there might be less information of any kind available.
- Could TIS be a system lever for improving things like health literacy, shared decision making and self-care?
- What is the impact of applying the Accessible Information Standard to documentation or materials that do not meet TIS criteria, how can the two programmes link together to drive up quality more widely?

3.0 Quality challenges and possible solutions

3.1. Improving understanding

The problem

- It is well established that health information is not always understood by service users and patients. Information that cannot be understood, cannot be considered high quality.

Possible solutions:

- Improve communication within health information by using everyday language.
 - Consider using both jargon and everyday terms – this might help in situations where jargon is used.
 - See PIF [best practice on clear communication](#) in health information here: pifonline.org.uk/toolkit
- Adopt a person-centred approach, recognising the range of needs that different people have.
- Involve patients and service users in developing and testing health information materials.
 - See PIF [best practice on involving users](#) here: pifonline.org.uk/toolkit
- Draw on and continue research into health literacy.
- Recognise that some information can be standalone while other information may be best used during consultations with professionals, who can help people to understand it.
- Broaden understanding of ‘quality’ to ensure creating resources that can be understood by target users is embedded.
- Consider putting information through the same rigorous quality assurance procedures as medicines.
 - Information is one of many things that are competing for limited resources.

3.2 Professionalising the workforce

The problem:

- The professionalism and expertise of people who work in health information and support, and the skills that are required to deliver a high quality service, can go unrecognised.

Possible solutions:

- Develop accredited training programmes and qualifications.

- Improve understanding and awareness of the skills and expertise needed.

3.3 Avoiding duplication of effort

The problem:

- It seems like there is too much duplication of effort in information production, particularly between NHS Trusts.

Possible solutions:

- There is no need to reinvent content that is already available, for example on NHS Choices. Syndication has a role to play, as does sharing.
- The Patient Information Bank was an attempt to create master templates that could be adapted to suit local needs. Perhaps we could reinvigorate efforts here and create something more successful?

3.4 Recognising the value of information

The problem:

- Information is not valued as an intervention that forms part of a quality care package.

Possible solutions:

- Define what health information is and the role of different types of information – from more complex information (about the benefits and risks of treatments, for example), to more straightforward, local information (such as where to find support groups or services).
 - PIF developed a definition of information in May 2015 following stakeholder feedback, and further discussion at a focus group held in May 2015.

What is healthcare information?

Healthcare information (content) is a factual tool. When it is of high-quality, unbiased, accurate, clearly communicated, evidence based and developed with users it increases a person's knowledge and understanding about their health, wellbeing, treatment and care. Information is the foundation upon which people can engage in and make informed decisions about their health and care.

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Healthcare information has a role to play in person-centred care, shared-decision making, patient empowerment, self-management and many other patient engagement strategies.

You can read the full definition on the PIF website [here](http://pifonline.org.uk/about-us/):

- Investigate and add to the evidence base around benefits of information, for example:
 - Health economics – does information save money?
 - Patient-reported outcomes – does information help people to understand their condition and does it help to promote self-care?
 - New models of care – what role does information have and what is the role of devices that enable self-monitoring?
 - Policy aspirations – what is the role of information in self-care, shared decision making, medicines optimisation and making every contact count, for example?
 - Does the Friends and Family Test or the Care Quality Commission's (CQC's) Inpatient Survey provide insight?
 - Can studies of decision regret or behaviour change help?
 - Can we draw on evidence regarding the Patient Activation Measure (PAM), which includes information on cost savings?
- Educate healthcare professionals about the issues generally.
- Some simple things help demonstrate the need for information:
 - The demand for information demonstrates need, e.g. orders for leaflets.
 - Evaluating gaps in information provision.

3.5. Anticipating the future and dealing with a rapid pace of change

The challenge:

- Things are changing quickly: needs are changing rapidly as more and more people in our ageing society are living with multiple long-term conditions, and the capabilities of mobile digital technology/media are advancing apace.

Possible solutions:

- Understand how the ways people receive and demand information is changing: learn from other sectors and share with health sector.
- Explore the potential of the interactive nature of possible future self-management tools, such as apps.

- Draw on the strengths of people from more creative industries that have not been involved with health information before.
- Take advantage of opportunities presented by personal health and care records.
 - They have the potential to ensure people can access all of the information they need in one place.
- Explore how the more established, reputable sources of information fit in a world where people are increasingly producing their own information.

3.6. Adjusting to cultural shifts

The challenge:

- Patients and professionals are adjusting to a cultural shift away from patriarchal care to shared decision making, which is affecting their roles and their relationship.

Possible solutions

- Ensure patients and professionals can work together in partnership.
 - Enable a two-way dialogue between patients and health and care professionals.
 - Help patients to make the cultural shift towards being more involved in decision making about their care and managing their own care – some patients may become more consumer-like in behaviour.
 - Support professionals who are moving towards more of a coaching role.
 - Explore the benefits of multi-disciplinary teams providing coordinated care, with grouped appointments and sharing of information.
 - Give patients, who want it, access to their personal health and care records (PHCRs).
 - NHS England and NICE are conducting research on Patient Decision Aids, which should be reported in May 2016. Patient Decision Aids have an important role to play in realising ambitions around shared decision making. An organisation working in this area is the International Patient Decision Aids Standards (IPDAS) collaboration.
- Identify all the different people (e.g. patients, carers, GPs, pharmacists, nurses) who are involved in health information and support, and define how their roles are changing.

- Identify the most effective channels of communication:
 - Consider what information to target directly at the patient – the end user.
 - Consider what information to target at professionals who then signpost to patients.
 - Enhance professionals’ abilities to find high-quality patient information, and to signpost to it and to patient groups.
- Recognise the obligation of professionals to ‘First, do no harm’ (nonmaleficence), and how this affects their confidence in signposting to information, if they feel unsure whether that information is reliable.
- Encourage commissioners to view information as a therapy.
- Educate undergraduates appropriately – medics, pharmacists, nurses and other professionals.
- Ensure standards operate in a ‘joined up’ way – e.g. TIS, ongoing work by NHS England on patient decision aids, and the work by the National Information Board on apps.
- Consider boosting the role of patient information teams within NHS Trusts, primary care, health and wellbeing boards, etc. and enabling them to work together towards common goals.

4.0 PIF strategic objectives for Quality 2016-2021

1. Build and share a knowledge base of the key components of high-quality healthcare information including templates of key resources.
2. Undertake research to highlight how ‘support’ contributes to healthcare information being understood and acted upon.
3. Increase professional, patient and public awareness of what high-quality health information is and where to find it.
4. Share knowledge about current and emerging technologies with the PIF network.

5.0 Further information

PIF recently updated guidance on Quality

<http://www.pifonline.org.uk/pif-resources/topics-index/evaluating/quality-assurance/>

PIF Case for Information report

<http://www.pifonline.org.uk/wp-content/uploads/2014/11/PiF-Case-for-Information-Report-Final-Full-Report.pdf>

6.0 List of attendees

Individuals attended the meeting from the following organisations:

- AbbVie
- British Heart Foundation
- Bupa
- GSK
- Health Education England
- Information Standard
- Louise Coghlin
- Macmillan Cancer Support
- MHP Communications
- MND Association
- NHS England
- NICE
- PAGB
- Prostate Cancer UK
- Public Health England
- Royal College of Physicians