



Patient Information Forum

For everyone involved in health information and support

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Summary Report PIF Executive Circle Meeting

Integration: Perfect patient information journeys

Wednesday 13 June 2016; 2.00-5.00
kindly hosted at MHP Communications

Introduction

This summary report outlines discussions that took place at the Patient Information Forum Executive Circle meeting on Integration on 13 June 2016.

PIF has long calledⁱ for health information to be better integrated into the provision of care, and to be established as a 'therapy' in its own right. June 2016's Executive Circle meeting explored the potential levers that can drive this Integration agenda forwards, and considered some examples from current practice.

Short presentations saw overviews of PIF's research to date on the current landscape, and how tools such as the Patient Activation Measure or Shared Decision Making can be used to support integration along the whole system pathway.

A focused discussion followed where participants sought to identify the opportunities that exist to establish the provision of high quality health information within care pathways, what support is needed to achieve this, and the key influencers who can move this from rhetoric to reality.

Discussions from the meeting will feed into PIF's 'Perfect patient information journeys' project, the initial findings of which will be shared in a report later this year. This document contains a summary of the key discussions at the meeting.

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1. Barriers to ensuring access to information

The meeting discussed the question ‘within your organisation, or in the services around which you have experience, what do you see as the biggest barrier to ensuring access to information?’:

- Among the biggest barriers identified by one group was the **lack of consistency that exists across different services**, with even simple things like posting up information posters differing depending on the organisation’s individual processes. This can often hold up the systematic embedding of access to information and prevent the adoption of the kind of flexible, needs-responsive pathways that are required.
- **A lack of resources and capacity limitations** can often present barriers to ensuring information access, with one group noting that the case for investing in information has not been made strongly enough, and that initiatives like PAM, etc, which present opportunities are often only invested in for a short / limited amount of time before disappearing from the agenda.

Capacity-wise, where for example it can be useful to have systems in place such as a panel to review current information and identify any gaps / areas for improvement, many services will not have the capacity to put in place such a well-developed information infrastructure. Unlike the field of Diabetes care, where GPs are paid for meeting certain targets, many other long-term conditions also often do not have the same financial incentives in place to encourage improved information access.

- Participants in one group noted that there is often difficulty in getting the message across that **services need to take in the bigger picture, not ignoring any part of it and working in partnership in order to embed information access**. This same issue was raised by another group, which noted that existing NHS systems (across primary and secondary care, geographically and departmentally) often do not talk to each other, making it hard to gain a complete picture of the patient, and therefore of the type of targeted information and support that is appropriate.
- **Avoiding duplication of information is often a difficulty**; many services forget to look at the resources already available before developing their own new resources, or forget to check with key partners that may be able to signpost to relevant sources of existing information.
- **Particular barriers for GPs were discussed**, especially around GPs often not knowing how to access high quality information themselves so that they know what to pass on to patients; their often not having access to the same computer systems as other services (e.g. some have access to summary care records, some do not); and many having varying levels of knowledge or confidence in relation to particular conditions, impacting on how much information different patients receive.
- There are barriers for patients and professionals in understanding clearly which information is the most useful and authoritative and how to access this, and for

patients in particular there **are issues around recognising which information is the most reliable, and understanding where to go next if the information was not retained very well when first received.**

- **Specialist nurses, who are already pressured, may be relied upon to deliver too much of the crucial information.**
- **Establishing organisational accountability is often a challenge in successfully embedding information access;** currently it is often the case that no one is held accountable for the provision of information, with no recognition of where responsibility for providing information lies. This presents difficulties in tracking improvements and encouraging progress.

2. Levers for ensuring better access to information

The meeting discussed the question **‘based on your experiences or knowledge, can you identify any particular ‘levers’ for ensuring better access to information, on which PIF should focus its attention through this project?’**

- **Making the economic case to commissioners for investing in improved information access** was thought to be a particularly key lever in overcoming the barriers of resource and capacity constraints and to encourage the necessary changes in attitudes and organisational culture.
- Participants thought it to be **crucial for professionals to see every interaction with patients as an opportunity to transfer information,** and to think about how they could either direct patients on to others who can provide information, or to signpost on to other sources of information even if they cannot provide it themselves.
- **Effective internal communications channels, changing national legislation and encouraging national policy incentives around information access,** were highlighted as crucial levers.
- Ensuring that bodies such as the Care Quality Commission (CQC) **consider the quality of information access across pathways and that they inspect and report on the systems in place,** to encourage progress.
- **Feeding into existing technological platforms,** including electronic pathway tools like the Map of Medicine and systems such as EMIS and SystmOne, to try and ensure that information access points are included. A clear opportunity was identified to make better use of existing tailored information sources online.

- Making simple adjustments to services, such as **ensuring that information is stored somewhere that is swiftly accessible (either physically or digitally)**, was suggested in order to fit in with the time pressures often experienced by health professionals.
- Incorporating information access points and detailed advice on how to ensure high quality information, within all relevant **NICE guidance** for long-term conditions.
- **Ensuring that information access is seen as integral to the successful implementation of existing initiatives** (e.g. around shared decision making) or those under development, rather than starting from scratch with another information-focused initiative within a service.
- Participants agreed that it would be useful for the **fundamental principles of information access points to be articulated clearly**, with the key touch points at which information should be provided, identified.
- Identifying certain points in the pathway where information access should be paid special attention (where possible) was highlighted as important. For example, all of the groups noted that **giving information to people when first diagnosed is especially useful**, such as a pack given out in hard copy by Specialist Nurses for those with Crohn's and Colitis.
- Special care must be taken to **consider all relevant organisations along a patient pathway and the role they might play in delivering information**. For example, it was noted that everyone will visit a pharmacist and so there may be scope for pharmacies to play a greater role in signposting to information, and that information should be shared as much as possible across sectors.
- Participants agreed that **taking time to understand the patient's priorities and perspectives from an early stage, and involving them in the development of information, is extremely important**, as well as considering the different channels that might be necessary in order to distribute information effectively to different audiences.
- Any trial for the 'perfect information pathway' **should include a clinical perspective and incorporate views from clinicians and nurses, as well as patients**.
- Any attempt to implement a model 'perfect information pathway' within a service should **begin by examining closely how the current pathway operates, where the gaps might be and where they may already be achieving good quality information access**.
- **Training** was discussed as being vital, with potential for the training of many different professionals to include more around good communication and information provision, in order to achieve longer term, sustainable change.

- Possible **opportunities were identified with the emerging models of (increasingly collaborative) commissioning**, with many areas coming together and commissioning in large blocks; creating potential for more joined up work and systematic information provision.
- **Awareness-raising measures targeted at the public** must also be adopted alongside reforms to services, with a rights-based approach that educates the public about their rights as patients to be provided with high quality information, and which provides guidance around which questions to ask of their health professional. Options such as greater links with the education system and health messaging, were explored.
- Participants thought it crucial to **consider different key decision-making bodies influence on the quality of information provision in a service**, such as Health and Wellbeing Boards and the role that could be played by Patient Participation Groups within GP surgeries (these are becoming increasingly prominent and exist as a must-have within the GP contract). PIF could look into feeding into such groups, perhaps tying in with a national organisation supporting the local groups.

3. Key elements of PIF's 'Perfect patient information journeys' project

The meeting discussed the question 'what form could PIF's 'Perfect patient information journeys' project resources most usefully take, to ensure real change on the ground?':

Some key suggestions around the format of PIF's perfect information pathway resources included those that:

- Provide a step-by-step guide for commissioners
- Dynamic templates that make it as easy as possible for healthcare professionals to provide information
- Resources created that cut across therapy areas whilst overcoming the challenges presented by varying therapy areas and which recognise the different organisational processes according to service location
- Any resources must rest upon a concept which is clearly backed up by evidence and explained; that integrating and providing information consistently within care has a beneficial impact on patients' experience, outcomes of care, their ability to self-manage, and cost reductions.
- Public facing 'Questions to Ask' campaign aimed at patients

4. PIF strategic objectives for Integration 2016-2021

PIF's strategic aims for 2016-2021 are:

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

PIF's objectives for the Integration strategic aim are:

1. Establish the 'Perfect patient information journeys' project to identify the information and support needs of patients along the care pathway, which will consider shared decision making and personalisation.
2. Work with key stakeholders, throughout the UK, to develop clear access routes and signposting for patients to high-quality healthcare information and support, so it becomes embedded into care pathways.
3. Encourage and support healthcare providers to have a named senior level Champion for Healthcare Information, within all commissioning and provider organisations.

5. List of meeting attendees

Individuals attended the meeting from the following organisations:

- AbbVie
- Alzheimers Society
- British Heart Foundation
- Coalition for Collaborative Care
- Crohn's and Colitis
- Health literacy Group UK
- MHP Communications
- MND Association
- MSD
- My Clinical Coach; Totally Health Ltd
- Proprietary Association of Great Britain
- Principle Consulting
- Prostate Cancer UK
- Royal Pharmaceutical Society
- UCB Pharma

ⁱ PIF & MHP Communications, [Is Knowledge Power?](#), 2015; PIF, [Making the Case for Information](#), 2013