

## Patient Information Forum Conference: The Power of Partnership – 25<sup>th</sup> May 2016

#pifconf2016

The annual Patient Information Forum (PIF) Conference took place at the Royal College of Physicians in May. I had signed up to represent the Health Care Libraries Unit North, initially with some reluctance. The topic of health information for the patient and public lay well outside my comfort zone – something which I imagine many NHS LKS colleagues will relate to. Public and Patient Information, however, had been identified as one of the new Knowledge for Healthcare priorities so there was an incentive to find out more about how our services might tackle this vast area.

The day was filled from the start with interesting facts and snippets of useful information which sparked ideas for possible engagement at local level. One of the first talks was by Kate Betteridge who has lived most of her life with Rheumatoid Arthritis, being diagnosed in her teens. Kate provided a perspective of how someone living with a long-term condition might seek health information. Themes from Kate's discussions included:

- 1) There is a need for both pro-active and responsive information. If patients ask they expect a response – however they sometimes fail to ask for information because they don't know it is there – hence proactive services are vital.
- 2) Patients, particularly those with long-term conditions are rarely physically in a healthcare setting for the overall duration of their condition. Rather they will be working or at home getting on with their lives. This has a number of implications for healthcare information in that it needs to be online - accessible outside an NHS location. It also reinforces the need to make "every contact count" in terms of making sure patients can be signposted to good healthcare information by trusted professionals on the few occasions they do come into contact with the system.
- 3) The point of diagnosis has been shown to be by far the most useful point at which patients value healthcare information. This is usually a point at which patients are in touch with the healthcare system. Is this an opportunity for NHS LKS to help ensure patients are provided/signposted to good information at the point of diagnosis?
- 4) Patients like personalised not generic information. I am not "patients" or "the public" I am me. How do we respond to these specific needs within the limited resources available.

Later in the day Jane Fox from NHS England gave an overview of the *Information Standard* and the new *Accessible Information Standard*. The former provides a kite-mark of good quality for any organisations willing to abide by the principles of the standard. The latter is a new obligatory standard which requires certain governmental and other bodies to ensure that any information they provide is accessible to those with particular needs. Several aspects of the presentation stood out in terms of applicability to NHS LKS:

- I. One of the principles of the Information Standard is that information is only used from up-to-date, relevant, and trust-worthy evidence sources. Surely NHS LKS staff are in a great position to assist colleagues within organisations to achieve this?
- II. CCGs have a responsibility to ensure that any organisations they commission services from (including NHS Trusts of course) conform to the requirements of the information standards. Is this something that NHS LKS can assist with?

During the keynote conversations in the afternoon Casper Thomson (Executive Director of NAM – a HIV information provider) spoke candidly about his experience of partnership working. He described the dangers that can come about if partnerships are reduced to little more than “lunch, a launch, and a logo” with nothing in the way of longer term outcomes. Efforts need to be made to ensure worthwhile partnerships are established that are more than this.

I attended a workshop led by Claire Cohen who spoke about engaging BME groups in a short video about Cervical Smear Testing. Melanie Thomas and Kimberley Littlemore then spoke about using films to provide patient information for Lymphoedema patients in Wales. An emerging theme was the use of multimedia – particularly films – in patient information provision.

All in all the event was a clear eye opener for me to the vast range of activity taking place in the area of healthcare information provision to patients and the public. The large number of credible organisations present on the day reinforced the message for me that there is already a great deal of useful information out there for patients. NHS LKS are in a somewhat unique and privileged role in that many are physically based on a site where healthcare is delivered and as such are in a great position to help to signpost and deliver these vast realms of information to the patients that need it. Many of us also have a presence on the websites of these healthcare organisations and have a chance – working with other Trust departments as appropriate – to signpost patients to useful and authoritative sources of healthcare information using these websites.

You can use the hash-tag **#pifconf2016** to retrieve tweets from the event.



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