

## Note of the oral evidence session with Claire Murray during the '*Methods of evaluating evidence*' Working Group meeting on 5 November 2015

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**Academy of Medical Sciences, 41 Portland Place, London W1B 1QH  
Tuesday 5 November 2015, 10.30-11.00**

### **Claire Murray – Joint Head of Operations, Patient Information Forum**

The Patient Information Forum (PIF) focuses on health information for patients and the public and investigates best practice for creating and providing information resources. The key points covered in the presentation and discussion were:

The PIF 'Communicating Risk'<sup>1</sup> project identified **best practice for communicating risk to patients**, guidelines include:

- To be cautious of labels such as 'rare' and 'common', particularly in verbal descriptions.
- Where possible, report absolute risk rather than relative risk.
- Natural numbers are easier to understand than percentages.
- Use negative and positive framing for balance (e.g. a 5% chance of harm is equivalent to a 95% chance of no harm).
- Communicate uncertainty and caveats of data.
- Use a mixture of numerical and pictorial representations.
- Make risk relevant to your audience, e.g. your chances of developing a particular condition are equivalent to your chances of winning the lottery.
- Develop communications with the end user to understand their motivations and test that messages are understood.

### **Medical apps have great potential but are not well regulated.**

- Medical apps provide the opportunity to personalise information (e.g. decision aid app which tailors the information provided based on patient input.)
- Information can be delivered quickly and updated as evidence evolves.
- It should be recognised that not everyone is happy with the internet, and some will prefer paper-based information.
- Lack of regulation is a problem, a 'kitemark' equivalent is needed for apps. The National Information Board is doing some work in this area.
  - This is not just a problem with apps: the wider internet provides a wealth of unregulated information on health topics.
  - NHS Choices is established as a 'safe' (reputable) website for health information, which links to other, high quality online material. Something similar could be developed for the app market, which would direct patients to vetted and approved apps.<sup>2</sup>

### **High quality resources** currently available for patients usually **arise from consultation with members of the public:**

- E.g. Feedback to the MS society suggested that the information available in their literature was overwhelming. They therefore tailored the information to their audience's needs by producing a set of more focussed information sheets. A simple factsheet approach was

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<sup>1</sup> <http://www.pifonline.org.uk/communicating-risk-in-health-information-new-pif-factsheets-and-event/>

<sup>2</sup> Note from secretariat: The myhealthapps website might be able to fulfil this function to some extent. <http://myhealthapps.net>

devised for people who have just been diagnosed, to avoid overwhelming patients early on. Additional information sheets supported patients as the disease progressed.

- **Setting a clear objective** for a piece of information improves success with the end user.
- **A process of iteration and collaboration with patients** is invaluable in producing high quality communications which meet their needs. E.g. Breast Cancer Care developed an infographic to replace their text-based factsheets. In testing drafts with the end user, it became apparent that less is more and simplicity is key.

**Considering communications as an ongoing dialogue** rather than the end of the scientific process is advantageous because:

- Dialogue helps ensure that research is aligned to the needs and interests of patients.
- It is easier to communicate the end result if there are previous communications to build on.
- It would be valuable to create a culture where people feel a sense of involvement in scientific research.

### **Communicating unfamiliar concepts**

- When **communicating uncertainty with patients, it was suggested that** they value:
  - Transparency about uncertainty.
  - Information on who produced and funded the evidence, where the studies were based and which cohorts were involved.
  - Recognition that people are interested at different levels: some will take a great interest in uncertainty and others will want a concrete recommendation. Tiered information is more widely accepted.
- Strategies for productively communicating information which patients have never previously been exposed to depend on the end user. Proactively seeking to engage is important.
- There is distinction to be made for information targeting the public as opposed to patients. Communicating to ill patients requires specific considerations including:
  - Communication strategies should be mindful that **patients are often vulnerable and anxious**.
  - The reading and numeracy ages of patient literature has been found to be too high for an average member of the public.
  - It is important to communicate as plainly as possible to avoid giving confused messages in often time-pressured situations.

**Understanding of best practice in communication will evolve** as we gather more evidence.

- There is evidence underlying the general principles for effective communication of evidence on treatments; however, the granularity is lacking. Linking with organisations that work with relevant communities is important as they may have collected the evidence for their own internal purposes, even if this has not been disseminated more widely.