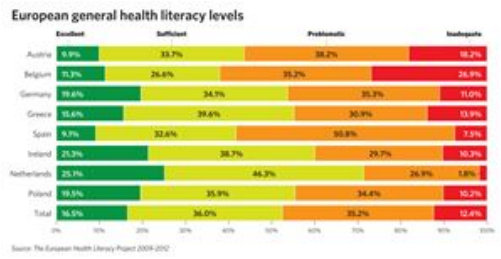
The (un)informed patient

By Cynthia Kroet - Today, 03:50 CET

Having the correct information about treatment can have life-or-death consequences, but patients are often left in the dark.



Healthcare professionals generally think that they have clearly explained possible treatments to patients and given sufficient information for an informed choice. However, research studies repeatedly show that the perception of patients is different. Although the successful treatment of most conditions depends on the understanding and co-operation of the patient, patients frequently complain of a lack of information. Improving access to healthcare often involves improving patients' access to information.

In June 2013, the EU updated legislation covering the information that must be conveyed to patients in the packaging of medicines. The theory is that patients are told the possible risks and side-effects of the drugs that they take. In practice, the information is likely to be so complicated as to be ignored by patients.

The transmission of information from doctor (or drug company) to patient is very important – and very difficult. It is not just that patients frequently forget what they have been told, and neglect to follow instructions. The PIP breast implant scandal affected some 400,000 women in 65 countries. It turned out that breast implants by the French company Poly Implant Prothese (PIP) had a higher rupture rate than implants from other brands. In such cases, getting hold of information – and knowing what importance to attach to it – have serious health consequences. The safety of patients can depend on getting access to information and acting on it.

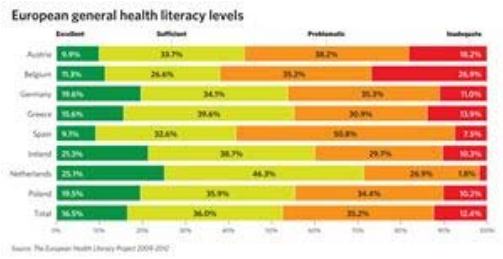
The European Commission has proposed greater supervision of the organisations in member states that are responsible for the inspection of medical devices that are implanted in the human body. Last week (2 April), the European Parliament approved these new rules, siding with stronger supervision and improved traceability.

But the legislation is no guarantee that patients will be well informed about the procedures and possible risks. The legislation might strengthen the hands of regulators, but it will not necessarily make for a better informed patient.

Advocates of eHealth services are convinced that digital technology can provide ways to improve the flow of information between health professionals and patients. Patients will be able to convey information about their condition to clinicians and practitioners. In turn, clinicians can convey information and explanations of treatments. Developments in electronic health records and healthcare information systems promise to put the patient at the centre of the information network. eHealth is becoming more widely used in EU member states, with Denmark, Estonia, Sweden and Finland leading the way.

Unsurprisingly, Neelie Kroes, the European commissioner for the digital agenda, is championing the potential of digital technology to improve healthcare. She has said: “By making the most use of digital tech, we can reduce costs, put the patient back in control, make healthcare more efficient and help European citizens to take an active part in society for longer.”

Hospitals and healthcare services have been using electronic services for traditional medical recording and reporting. But most advocates of eHealth see that it will involve a switch, so that patients have access to their own medical data, which is increasingly the case in some countries, notably the



Netherlands and Denmark. At the moment, only 9% of hospitals in Europe allow patients to have online access to their medical records.

However, at the same time, patients have much more information available on the internet about medical conditions and treatments – unmediated by consultations with medical professionals. There is currently a mismatch between the information available to patients about health and disease in general and their own personal conditions. Additionally, healthcare organisations are often unwilling to make freely available on the internet information about quality and cost of care.

Serge Bernasconi, chief executive officer at the devices industry association, Eucomed, says:“Currently, there is little information available for patients about which therapies and products are available in which country, what their value is and how they are best used in the entire care pathway. This information is available as technology assessment reports, but they are often not easy to understand for patients.”

In this field, as in so many other realms of healthcare, there is an obvious risk of a divide opening up: the informed, connected patients will be given ever greater access to information that can improve their healthcare; the uninformed, excluded patients are in danger of being left behind. For the EU, this is a disturbing prospect.