

Europe must tackle health illiteracy to avoid a health ‘underclass’

→ Peter McIntyre

A quarter of Europe’s citizens may miss out on better health, unless policy makers address functional illiteracy and improvements in the way information is presented.

“**T**he most shocking thing is that 20%–30% of Europeans in each and every society are functionally illiterate. They cannot function adequately in our modern society, and that means they cannot function adequately in a modern healthcare system. That is an enormous challenge that our societies have to pick up.”

Ilona Kickbusch has been trying to put the concept of health literacy onto the European agenda for more than three years – and it seems that she and her co-thinkers are succeeding, even if many people still find the term baffling and many European languages do not even have a word for it.

Kickbusch, former director of Health Promotion, Education and Communication at the World Health Organization and former Yale Professor of Global Health, sees health literacy as a core component of inequality – a matter of life and death.

She defines health literacy as “the capacity to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the healthcare system, the market place and the political arena”.

Those that lack this ability are at a double disadvantage. “We know that people who are less educated and are poorer already have a lower health status and life expectancy. Now when they enter the

health system with low health literacy, they are again disadvantaged compared to other patients. The healthcare systems are not geared up towards responding to patients with low health literacy. Professionals are not even trained to recognise it.”

Health literacy is firmly on the agenda of the new EU Health Commissioner Androulla Vassiliou, who had barely started in the job when she spoke alongside Kickbusch at the European Patients’ Forum (EPF) spring conference on health literacy in Brussels in April. She warns that there is a danger of two classes of citizens in Europe if some people lack the capacity to describe symptoms, ask questions, evaluate health information, analyse risks and navigate complex healthcare systems.

“Inadequate health literacy can result in little or no knowledge of medical care and medical conditions, decreased understanding of medical information, reduced use of preventive services, poorer self-reported health, poorer compliance rate, poorer health status, increased hospitalisation, higher inequality and increased healthcare costs.

“My belief is that within every member state we should have a set of patients’ rights and within the patients’ rights should be reliable information to patients especially from health professionals, especially to understand whatever they are reading about



continent. The survey builds on work done by a team led by Jen Wang from the Institute of Social and Preventive Medicine at the University of Zurich.

His Swiss Health Literacy Survey, based on 30 measurable competencies, showed that 35% of Swiss people find choosing medication a highly complex process, and 34% say the same about treatment options. More than one in five regards choosing a doctor as a highly complex decision.

But there is an appetite for involvement—85% of patients want to participate in treatment decisions, while only 49% believe that they do so.

Perhaps the most revealing finding concerns sources of information that people find easy to understand. While 94% of Swiss patients find information from their doctor ‘easy’ or ‘somewhat easy’, only 76–77% say this about the media, the Internet and patient information leaflets. Hardest to understand are food labels, regarded as ‘easy’ or ‘somewhat easy’ by only half the population.

The survey put health literacy onto the agendas of the Swiss Federal Office of Public Health and other key bodies. In fact

themselves and their particular illness or medicine.”

Vassiliou points to a number of EU initiatives to improve information, including the EU Public Health Portal (<http://ec.europa.eu/health-eu/>) which provides health information in 22 languages. (It is worth noting that this is a nicely laid out site, but hardly aimed at people with low health literacy. On the first cancer page, the reader must understand “primary and secondary prevention”, “a cancer surveillance system” and “the incidence of malignant neoplasm of the breast”.)

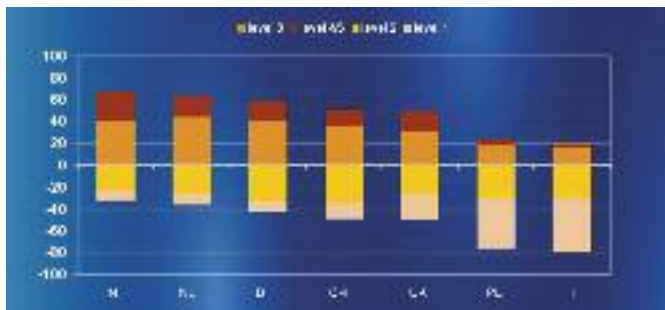
More to the point, perhaps, the EU Public Health Executive Agency is putting money towards a Europe-wide survey of health literacy that will create a network of organisations researching health literacy across the

Switzerland is one of only three countries in Europe (together with the UK and Ireland) to have any policies on health literacy. “Outside the English-speaking world, health literacy is not a very common topic in Europe yet,” said Wang. “The term for health literacy may not even exist in your country.”

Levels of basic literacy vary widely between countries. In the figure overleaf, only those above the zero line (levels 3 or 4/5) meet the minimum OECD skills to function in 21st century society. Those below the line are struggling, while those in the bottom band are functionally illiterate. In Poland and Italy, this amounts to almost half the population, and in the UK, almost a quarter. In Norway, the Netherlands and

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DOCUMENT LITERACY IN SELECTED COUNTRIES (16–65 YEARS)



This figure shows adult skills in deriving information from documents. Those above the zero line are considered to have adequate literacy skills to function in society. The yellow band consists of people who can derive information from written communication only if it is very clear and simple (level 2). Level 1 is considered functional illiteracy.

Source: *International Adult Literacy Survey, 1993–1997, Adult Literacy and Life Skill Survey, 2003*

Germany, only 9%–10% are in this bottom band.

In research in Ireland, one in five people were not fully confident that they understand all the information they receive from healthcare professionals. A full 60% did not fully understand the word ‘prognosis’ – a term often used in patient consultations.

Wang believes his research has the potential to increase accountability and help bridge the gap between patient information and health education. Whether the broader European research can achieve this is less certain. Although academic units in 16 European countries have signed up, Wang has been given the money to carry out the research in only six. He is looking for partners who can provide a further €1 million to make the research truly pan European.

PATIENT STORIES

Much of the discussion about health literacy is about how health professionals and authorities can communicate better with patients. But patient groups say that patients’ own stories can be the most helpful in explaining choices and issues to new patients.

Akiki Vrienniou from the Greek Multiple Sclerosis Society recalls how, despite being a university graduate, she struggled to take in the impact of her diagnosis. “When the doctor told me I had MS, I was totally confused because I did not know what this was and how it would affect my life. There are a lot of questions and doctors do not have the time to answer all these questions. They focus on the therapy.”

She compares the mental process of using information to make decisions with the physical process of digestion. “The digestive system keeps the nutritious things for the body to function and the rest is just

garbage and it goes out from the body. I think health information is more or less the same. At the end you need to reject unreliable information.”

Hildrun Sundseth, from the European Cancer Patient Coalition, believes that patient advocates play a critical role in helping newly diagnosed patients deal with the information jungle.

She was diagnosed with melanoma 15 years ago and was very bruised by the experience. “I rung up my consultant and she gave me my diagnosis over the phone two days before Christmas. I thought that was my last Christmas. I was sitting there crying.

“After Christmas I went to see my GP and he said, ‘I have someone on my patient list who has had the same condition as you for 20 years and she is still alive.’ That lifted me up.”

She says, “I feel sorry for doctors – they are human as well. But if you are giving information to patients, then you have to put the patient at the centre.”

WHO GIVES INFORMATION?

There is a debate over who can best give information. Naturally enough, at the EPF conference, patient groups were the clear favourites for this role.

Kickbusch says that health literacy implies a choice about where to get information, and there is a need for a significant extra effort to reach the 20% with low literacy. Patient groups will be central to the process. “There is a certain type of health literacy that only patients have. Without the experience of women with breast cancer, I guess they would still be cutting our breasts off.”

But while Vassiliou, the Health Commissioner, paid tribute to the work of patient groups, she also

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sounded a note of caution. “It is mainly the medical profession that can give this information, because they are the most qualified,” she told the EPF. “What is dangerous very often is that one patient gets information from another patient, but his or her circumstances might be very different. It is not very reliable to take for granted information from other patients. You have to corroborate the information you get from health providers and physicians.”

Strangely, perhaps, Michael Wilks, President of the Standing Committee of European Doctors (CPME), does not agree that doctors always know best. “We want information that is understandable and relevant to

that patient at the right time and I don’t think any doctor in the world is going to have that range of skills.

“We are trying to create a much more dynamic doctor–patient relationship, in which we get the concept of dialogue and problem solving, together with a joint plan; an agreement about how the doctor and patient go forward together in the interest of improving self-care and self-knowledge and improving trust – a very precious commodity for both of us.”

One way in which he feels this could be done is to ensure that the patient has the right to access their own electronic records. “Large parts of the medical profession have scepticism because they don’t want to lose control of that data. I think they need to be reminded that it is not their data. The record may be in their computer, but the information actually belongs to the patient.”

There were also strong calls at the EPF conference to recognise the key roles of nurses and pharmacists in the process of improving information to patients.

There is an ongoing debate about the role of the pharmaceutical industry in giving information. Currently, patient information leaflets inside medicine packets are the most difficult of all information to read (because of the tiny type) and to understand (because of the language).

PLAIN TALKING FOR CLINICIANS

The following list of user-friendly alternatives to common medical terms was published by the American Medical Association Foundation and American Medical Association in a helpful manual for clinicians, *Health literacy and patient safety: Help patients understand* (2007), which is available on the Internet.

Analgesic	Pain killer
Anti-inflammatory	Lessens swelling and irritation
Benign	Not cancer
Carcinoma	Cancer
Cardiac problem	Heart problem
Contraception	Birth control
Enlarge	Get bigger
Heart failure	Heart isn’t pumping well
Hypertension	High blood pressure
Infertility	Can’t get pregnant
Lateral	Outside
Menopause	Stopping periods, change of life
Menses	Period
Monitor	Keep track of, keep an eye on
Oral	By mouth
Referral	Send you to another doctor
Terminal	Going to die
Toxic	Poisonous

HEALTH LITERACY INITIATIVES

Health literacy initiatives in Europe are increasing rapidly, even if they do not always use this language. The growth of information services such as IQWiG in Germany, La haute autorité de santé (HAS) in France and NHS Direct in the UK reflects a growing desire to validate and disseminate clear accurate information.

In Ireland, the winners have just been announced in the first annual Crystal Clear Health Literacy Awards, established by the National Adult Literacy Agency. A €1,000 award went to Ursula Courtney, Director of Services at the ARC Cancer Support Centre, in Dublin, who established the ‘talk-together learn-together’ psycho-educative group for women with gynaecological cancers. Many described this as

“I put all the papers in a closed envelope. I have not read any of them. I could not understand it”

their first real opportunity to talk about their fears and thoughts about their cancer.

Albert Jovell, who is a professor of Public Health and Preventative Medicine in Barcelona, is also a cancer patient and President of the Spanish Patients' Forum. He has been instrumental in starting a 'patients university' in Barcelona, billed as 'a knowledge alliance of patients and citizens'. Jovell talks about the crisis in the whole family, when a patient is diagnosed. "They feel paralysed. They have three diseases, not only the physical disease but the emotional and social aspects. You have all these things we do not teach in a school of medicine. You can find a lesson on pain, but you cannot find a lesson on fear, ignorance or uncertainty."

There is no lack of information, but a lack of guidance through it. One patient told them, "I put all the papers in a closed envelope. I have not read any of them. I could not understand it."

On the other hand, doctors have told them they do not have time to talk to the patients properly, let alone the family. "It is very difficult for us to communicate with patients because the way we are trained to think is very complex. We follow organograms; we don't follow the normal language people use."

The patient university has both a physical and virtual presence. "We try to help patients and families navigate through the disease, like GPS navigation in cars. We started what we call the 'friendly hospital'. Every time the cancer patient comes to the hospital, there is someone who is going to take care of all the emotional and social aspects along the process. We say, don't walk alone with the disease."

In the UK, a dozen pilots are taking place of an 'information prescription' to support patients. The Long Term Conditions Alliance, a grouping of 110 patient organisations, won support for this from all political parties before the last election. However, David Pink, chief executive of the Alliance, sees dangers as well as benefits in the term 'health literacy'. "To some people it will tell us that the problem is in the patient. Blaming the people served for the failings of the service is a real temptation."

He is also concerned about the possibility of mixed motives. "Some healthcare professionals want information prescriptions simply as a way of trying to get patients to do as they are told, and patients are unlikely to do as they are told as soon as they have access to the full information. The Government's support may well be based on the hope and expectation that, with these prescriptions, patients will go home and manage their own diseases and won't demand so much from the health services and that costs will be contained."

Whatever the motivation, however, there is a consensus emerging, and Pink is clear who should be leading it. "Patient organisations should be leading the discussions about health literacy in Europe. Patient groups understand the patient perspective, they are trusted by patients and they understand that healthcare is something that must always be seen within the context of real lives of real people."

Key recommendations

The European Patients' Forum made a number of recommendations following its conference, including the following:

- More resources to extend the EU Health Literacy Research Project across Europe
- A guide on how to make information user friendly
- Explore an EU 'quality mark' for health information
- EU funding for NGOs to translate information into more languages
- A right for patients to access and 'own' their electronic health records
- An EU programme to involve patient experts in training healthcare providers on good communication
- Greater recognition of a patient rights agenda in promoting health literacy among marginalised groups
- A clearing house for patient organisations, so they can adapt existing high-quality information
- Health literacy as part of a broader patients' and citizens' information strategy across Europe