

# Sustaining Access to Medicines in Europe: Examining consumers' priorities and concerns

## **The UK experience**

*As part of the international campaign on access to needed drugs, in November HAI Europe and Medico International challenged public health stakeholders to identify key areas to be addressed in order to ensure sustainable access to medicines within Europe. Long seen as a problem for the developing world, Clara MacKay of the UK's Consumers Association, described at the meeting how access to medicines and healthcare has become a central concern for consumers, healthcare providers and government officials in one of the wealthiest countries in the world.*

By Clara MacKay<sup>1</sup>

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How can governments ensure the consumer's right to the best possible treatment in light of rational treatment guidelines, growing drug promotion and limited budgets? In many ways this is a loaded question with too many dimensions to answer in a short article. To begin, there is a question about how treatments get developed and made available; let alone how people gain access to them.

It is somewhat embarrassing to address the issue of access in relation to such a wealthy country as the UK. Its problems do seem trivial in comparison to those faced by other countries. However, there are interesting points to be made and lessons to be learned from the UK's experience. For example, when you ask UK consumers what they want from the health service and what their concerns are, they answer: information and anxiety about access.

## **General dynamics of access in the UK**

How does the UK's healthcare system work? The centre of the system is the National Health Service, better known as the NHS, which has been around for more than 50 years. Everyone loves it, 90% of the population supports it, but there is anxiety about its capacity to deliver treatments and medicines.

The NHS is a national institution. It is state-funded and state-provided. This means that the service itself is a public service. However, this is something that is starting to change. In the past few years a much closer working relationship has developed between the NHS and the private healthcare sector on a number of fronts--including the direct purchase or leasing of health care from the private sector. As you know, the drug industry is a key UK industry and therefore there is an inclination on the part of the government to keep the sector prosperous and happy.

Health services in the UK are mainly free at the point of delivery. There are some areas including dentistry and prescription drugs that use set charges (fairly reasonable ones) that patients pay. Interestingly enough, the government introduced prescription charges only one year after the introduction of the NHS to combat concerns about rising patient demand and the increasing drug bill.

#### *Shift in policies*

It is important to describe a number of things happening in the health sector which affect access. Some of the more obvious factors are related to the structure of the health care system and its policies. In the UK, there is a national system--but in reality, decisions about resources and how they are spent are being pushed out to regions and local areas and now to individual doctors in groupings called Primary Care (PC) Trusts. For this reason, access can vary from place to place and from PC Trust to PC Trust.

#### *Information provision*

Information provision is at the heart of the access debate. There needs to be access to information about medicines and other treatments related to outcomes, quality, and existing alternatives. At present, there is a shockingly small amount of information available describing how well treatments work.

#### *Patient rights*

The UK is not leading the world on patient rights. In fact, the current government abolished the Patients Charter; the nation's only thin statement of rights a few years ago. This document had set out things such as a patient's right to a second opinion; the right to admission to hospital within a certain amount of time, etc. The emphasis has now moved from patients' rights to patients' responsibilities. Today, there is a document called "The Patient's Guide to the NHS" which tells patients very little about not much--but it does remind us not to bother doctors unnecessarily or not to skip appointments without cancelling them formally.

In fact, while few people could tell you what was in the Patients Charter, almost everyone in the UK knew it existed. So it did serve a purpose which was to make people aware of "health" as a right.

### *Redress and independent advocacy*

This is a critical issue for access. Redress and advocacy are important for all patients especially vulnerable patients such as the elderly and people with learning difficulties who currently receive the worst health care in the UK. Consumers in these groups are neither profitable nor especially "sexy" for health care providers or the industry from a commercial sense - their care often does not involve drug therapy. When one looks at redress issues and patterns - it is potently clear that these groups are poorly spoken for. Complaints about care usually come from middle class, educated consumers. Less than 10% of the complaints made each year come from or on behalf of the most vulnerable groups.

### *Patient groups*

Interestingly patient groups are big business in the UK. There are currently about 2,500 of them and it is a growing sector. Patient groups can be extremely powerful advocates on behalf of patients but at the same time they need to be extremely careful about their position of trust.

CA's work on advertising has found that consumers are becoming less and less confident in the information they receive from the government because of their fears about rationing. Consumers increasingly view patient organisations as "independent" and credible sources of information. So there is a real need for patient groups to take care of how they work. Although CA has not done a full analysis, our assessment is that there are a number of factors involving patients groups and access at work here:

- patients are increasingly turning to patient groups as an independent source of information
- as funds get tight, organisations need to maintain their public profile and standing and drug treatments often offer a focus for a lobby
- patient groups are getting closer and closer to industry

Some manage this kind of alliance very well. Others are very cavalier or unaware of the implications of these relationships.

### *The patient/professional relationship and social judgements*

Too little attention is paid to the impact of the patient/professional relationship when it comes to access issues. On a basic level, patients have values and views that they apply when they are discussing different types of treatments, interventions or risk, for example. However, clinicians also have their own set of values and principles and views that they apply in taking decisions.

Prescribers' values can certainly influence the kind of care a patient receives. In the worst case scenarios, value judgements are made about who is a more worthy patient and what conditions are worthier. Sometimes it shows itself as discrimination based on age or on the fact that someone has Down's syndrome or is a drug addict. Often these value judgements are justified and legitimised in formal policy.

## **CA research on access**

### *Examining NICE*

Consumers' Association had done recent work involving the National Institute for Clinical Effectiveness (NICE) which is the UK's 4th hurdle agency with responsibility for assessing the clinical and cost-effectiveness of treatments and for making recommendations about whether or not these treatments should be provided by the health service. While carrying out separate research on DTCA, CA discovered that the UK government was planning a review of NICE, two years or so after it had been set up. We also found that the concerns and issues of the industry and government were shaping the whole agenda for this review for patients--with no consideration of the patient perspective or outcome. In response, CA organised a one-day public hearing requesting patient organisations to come and give their views about how well they think NICE works. The results were extremely interesting. A number of key themes and issues emerged, including:

- NICE contributes to the tendency for patient groups to position themselves as lobbies for "access" to drugs--even if they don't often have any evidence themselves to support this position. The idea behind this seems to be that it is better to get something on the market on the chance that it might be effective, rather than nothing at all. Some question whether other non-drug issues such as rehabilitative care are being overlooked now that the debate is so drug-oriented.
- The existence of NICE in itself promotes a focus on drugs and within that gives a high, public profile to drugs with large, single disease type applications (usually costly) such as drugs for multiple sclerosis (MS), Alzheimer's disease, and cancer. This fact attracts and encourages a combination of single disease patient groups and drugs.
- In practice there is much less emphasis on other drugs and other treatments. If drugs are approved, local areas try to provide them and therefore lack money to promote other rational treatments and less high-profile services.
- Leading on from that, the process of a NICE review may actually forge even greater alliances between drug companies and patient groups, to the extent that a number of patient organisations are concerned about the level of industry infiltration in such groups. As a case in point, when CA announced its NICE inquiry as a means to find out patients' views, one drug company sent a letter to patient groups offering its support and help in preparing their contribution to the inquiry.

The public hearing on NICE revealed complete confusion about what NICE is trying to measure--is it effective or is the evidence already there robust? It also showed limited attention is paid to how drugs work in daily practice, that is, outside of clinical trials. The inquiry highlighted the fact that little attention goes to what patients view as an important measure of effectiveness. For example, an MS patient may feel that improvement in cognitive function is more important than mobility. Almost always "measures" are based on clinical trials. When patient groups try to answer this question, the evidence they provide is often regarded as soft and not valid.

Other results from the inquiry suggest a number of areas that need improvement. CA found a complete lack of transparency about how effectiveness, especially cost effectiveness, is decided. There was also a lack of proper information about the medicines under review. It seems that officials are looking at the information available instead of at what is actually needed.

#### *Other research on access issues*

In addition to its work on NICE, CA has done research on other areas that are interesting for this discussion on access. For example, the organisation has looked at access to dentistry and on how rationing in the UK is done. Rationing is often dressed up as priority setting. In reality it is about taking decisions about who you can exclude from health care with the least amount of exposure or public outcry.

Dentistry is less high profile than the drugs debate. The current government policy states that everyone should have access to dentistry as part of the health service. This is a key public health issue and one where access clearly divides the poor from those better off. When CA conducted its research on dentistry it found a crisis in the availability of state dentistry. Provision is limited and in some cases non-existent. The outcome of the dentistry research strongly confirms that access is random, not substantiated by issues of effectiveness. However, the fact remains that dental health will never receive the same attention as medicines.

#### **Looking ahead**

How can governments possibly eliminate the negative impact of factors or dynamics that create what we call in the UK "the lottery" or care. And by that I mean the situation whereby the reality is that assessing good quality, appropriate care and treatment is a bit of a gamble - you may get lucky - but there is no guarantee. CA has learned a lot from watching EU member states, including the UK, move towards allowing DTCA. While there is increasing emphasis on drugs, one has to look at the cost and determine if it is really a rational treatment. As mentioned, patients in the UK are less and less confident in information provided by government agencies and health professionals are increasingly anxious about access issues. At the same time, research has shown that people do not believe that drug companies will provide reliable information. As a result, patient organisations will become more heavily relied upon to provide

information. For that reason, it is worrisome that more and more patient organisations are becoming so closely linked with the drug industry--in different ways and for different reasons.

There is a growing need to ensure access to healthcare. Lessons can be learned from the struggles taking place in a developed country like the UK faced with limited budgets, a strong pharmaceutical industry and various treatments. The current answer seems to be that ensured care remains rather basic. To improve access to quality and essential healthcare, a few areas must be strengthened:

- **More independent information** must be made available on drugs and other treatments, outcomes, standards etc.
- **Patient rights must become a renewed topic.** Consumers need access to independent advocacy and patients groups must understand the importance of independence from the industry. There is now a growing lobby within the UK for an independent National Patient Body with remit to ensure equitable distribution of healthcare, among other things. This type of action needs to be supported by statutory patient rights.
- For the system to improve, there must be **greater transparency** about its processes and decision-making. What is cost effectiveness? Who decides what is clinically effective?
- The government/NHS relationship must be reviewed. While it is clear that the government supports the NHS's goals, there are growing tensions about **how to manage public and private sector interaction and possible conflicts of interest.**
- **The system needs to broaden its focus** to include important, non-drug treatments.

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## References

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