



NARRATIVE: GUIDED BY CITIZENS

Report # 1

Converting public resources into health and quality of life

How can we distribute the budget that is available for health care in a way that is as fair and just as possible? What criteria should we use for reimbursement of drugs and medical devices, for procedures and services provided by health care workers and for care provided in hospitals and other institutions? These criteria need to be relevant, carefully balanced and supported by a social consensus, but at present the government does not know what the population's preferences are in regard to reimbursement of health care. The King Baudouin Foundation therefore presented these questions to a group of 32 citizens: 16 men and 16 women, including equal numbers of French and Dutch speakers and representing a mix of all ages and backgrounds. These citizens spent three weekends in closed discussions. Their conclusions are as follows:

Less emphasis on length of life and more on quality of life

A health care system built on solidarity must be all about quality of life. For decades the health care system has focused on saving lives and extending life. Citizens feel that this has led to the patient's quality of life all too often being put in second place. They see this as wrong. Quality of life should be the most important measure of all in health care. That is because it makes no sense to give a patient more years of life if the patient does not feel that these offer either quality or meaning.

What is more, quality of life means more than simply being sick or healthy. It is about more than objective measures of mobility, whether a person is able to wash independently or whether they can go to work. Quality of life is about how people feel when they have a disease. It is about the extent to which the disease impacts their life, their welfare and their human dignity. Or, as one citizen put it, *'maintaining your dignity and pride as a human being. That is what quality of life is all about'*. What is more, the patient does not exist in a social vacuum. He or she has family members and other people who are also involved. Their quality of life can be affected too. *'Some diseases, like Alzheimer's, not only affect the patient but they make the whole family sick'* was one comment expressed at the Citizens' Laboratory. So those close to the patient must be taken into account as well.

Quality of life is absolutely the highest priority among the 19 criteria and six conditions for reimbursement that the citizens developed (see figure 1 on page 5). These criteria and conditions form an important and valuable touchstone for decision-making on reimbursement in health care.

Less technocracy and more humanity

The human being behind the disease - the patient - should be the central focus of health care, not the disease, not the medical solution, not the care provider and not the insurance institution.

This means that we must try much harder than we do at present to work on the basis of the patient's overall care needs, including all the various aspects of this. This should include not only

medical needs but also psychological and social needs, as well as the impact of 'being a patient' on the preservation of an individual's dignity, decision-making autonomy and welfare.

In short, citizens are asking for a more 'holistic' or 'global' approach to the patient, in which physical, psychological, social and existential dimensions are all kept in balance. Naturally the patient's own experiences and contributions are indispensable in this process. Patients are the greatest experts because of their experience of their own health and needs.

Less supply-driven innovation and more demand-led renewal in health care.

The shift in emphasis towards quality of life and a focus on the patient demands a different understanding of innovation in health care. At present, innovation and renewal in health care are driven primarily by the supply side: decisions are made in the boardrooms of the pharmaceutical and medical industry about the new medications or devices that will be developed. Equally, professional associations of health care workers, hospital groups and care institutions make proposals about the new treatments that they wish to integrate in the reimbursed health care system.

The citizens very clearly asked the following question: do these supply-driven forms of innovation perfectly match patients' needs, or are they inspired mainly by commercial considerations among the providers themselves? Is it not the role of the government to make changes if such a situation exists? Should they not be involving citizens and patients more often so that real care needs can be used as the starting-point for innovation in health care?

Less waste and greater effectiveness

The citizens experience for themselves every day that there is still waste in the health care system: *investigations are duplicated, expensive medications are prescribed when there are cheaper alternatives, time-consuming and/or obsolete treatments are given, there is a lack of efficiency ...* these are just a few examples of failures to spend public resources in a well thought-out way. Efficacy and cost-effectiveness should therefore be placed more in the foreground. From the perspective of citizens *it makes no sense to reimburse treatments if they do not work.* What is more, ineffective treatments may in fact harm the patient.

Less rigidity, more flexibility.

This also means that existing treatments have to be assessed regularly to ensure that they offer added value: are they effective, do they meet the patient's needs adequately, is their cost justified? Objective measures must be used for this, but it is also necessary to take into account the experiences and perspectives of patients themselves.

The citizens do not see this as in any way paradoxical. They consider that it should be possible to reconcile objective guidelines with the subjective experiences of patients and those close to them. It is about seeking a delicate balance between a solid scientific basis ('evidence based') on the one hand and expertise born of experience in a specific context on the other. That is because not all needs and solutions can be measured and converted into statistics. At the same time, products only have to be reimbursed if they actually offer added value. In many cases it is necessary to go right down to the level of the individual patient to discover that added value. This is why some reimbursement decisions should be taken a way that is closer to the patient and less centralised.

Less profit, more transparency and negotiation

During the Citizens' Laboratory the participants encountered a number of stories about very expensive medications, costly hospital admissions and very high fee supplements. They have problems with this, because they feel that this approach undermines the sustainability of the system and also corrodes solidarity. Health care providers, care institutions and the medical industry should be reimbursed fairly for the work that they do, but they do see the lack of transparency in relation to these high prices as a problem.

Since health care is not a normal marketplace in which supply and demand are in balance, the citizens propose that the leverage of society should be used to negotiate lower prices and – as long as levels of quality are identical - to allow the forces of competition to operate. If Belgium's 'collective buying power' is too small for this - for example in the case of medications and medical devices - then negotiations with the pharmaceutical and medical industry should be conducted at the European level.

Less short-term thinking, more sustainability and more prevention

Health care policy today is very much focused on the short term. What is the impact of this or that treatment on this year's budget? Or next year's budget? Or perhaps the year after? That is usually as far as it goes. The citizens recognise that this is important, since even today choices have to be made to ensure that budget limits are not breached. Nevertheless, citizens want to see a health care system that thinks in much more long-term ways. Investing today in health for tomorrow, in the future health of our children and grandchildren, and for our own old age. *Even limited investments today could perhaps lead to high cost savings tomorrow or the day after.*

This health care system should also ideally make a shift from its focus on curative care to a focus on preventative care. *A lot of attention is paid to curing and treating diseases, but the aim of health care should be primarily to keep people healthy.* This demands a different focus, a different attitude and a different approach from both doctors and other health care providers, from the medical industry, health insurers and the government. In fact it involves everyone outside the health care system, including all citizens of all ages.

The participants therefore call on everyone involved in health care policy to formulate long-term and short-term objectives and convert these into an appropriate policy. What is more, preventative work in health care is not only a task for the health care sector. Citizens are calling for other sectors such as education, welfare, employers and scientific researchers to take up their responsibilities in this area.

Solidarity, justice and responsibility are all interrelated

The participants consider that the values of 'solidarity' and 'justice' are intimately related to each other. For them, solidarity means everyone contributing according to their means to a health care system that does not exclude anyone. Or it means a health care system that offers fair access to all those who have a need for care. In a society built on solidarity, everyone is entitled to the best possible quality of life and welfare. The citizens therefore identify the principles of solidarity and

justice mostly as a question of a collective effort (solidarity) and as an individual right to health care (justice).

From the perspective of citizens, solidarity and the right to health care take precedence over numbers of patients and the social cost of the disease ('social need'). The participants expressed this for example by including the 'rarity of the disease' and 'affordability for the patient' as criteria. In the same way, they objected to 'age' being used as a criterion or condition. This objection was made for two reasons: age must not be used to exclude people from health care, but at the same time prolonging life must also not be an end in itself unless it is also associated with quality of life and if the patient's freedom to choose is not taken into account.

Solidarity can only be maintained if every individual also accepts his or her own responsibility. According to the citizens, people are responsible for their behaviour and consequently for their own health, but only up to a certain point because environmental factors also play a decisive role.

The citizens link individual responsibility strongly to social responsibility. Social responsibility involves allowing everyone who has a need for care to have fair and affordable access to health care.

Individual responsibility can be used as a lever to raise awareness and in the area of prevention. Nevertheless, an individual choice (to lead a healthy or unhealthy lifestyle) has an impact on everyone and on solidarity.

How can better decisions be made?

The citizens hope that their weighted set of criteria and conditions can serve as a basis for a new decision-making system in relation to reimbursement. This will mean that the social values which are closest to their hearts - solidarity, fair access, objectivity, human dignity, decision-making autonomy, responsibility, sustainability, participation and everyone's right to a good and healthy life - remain anchored within the Belgian health care system.

Since all decisions have to be made on the basis of the patient's overall need for care, the decision-making process should be widened and more parties should participate in it. This should take place at every stage in the process: when initiating a request for reimbursement, when preparing to make the decision, when making the decision and during regular evaluation of decisions that have been made. Getting more of those involved around the table (in the form of multidisciplinary consultations) is the only way to realise the ambition to bring about a global and holistic approach to care. Clearly citizen-patients will also have a part to play in this process.

Figure 1:19 criteria and 6 conditions for reimbursement.

The intensity of the colour in which the criteria/conditions are shown indicates their relative weighting: the more intense the colour, the higher the weighting.