CHAPTER 6. CHOICE*

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Choices

The concept of choice has a long history in Western culture. In philosophy, from Aristotle onwards, choice has been conceptualized as the meeting place of the intellect and the will, the place where the intellect and the will interact in a variety of ways. In ethics, choice is the crucial point of the exercise of freedom and responsibility. In politics, it is a necessary condition of democracy and a basic element of sovereignty. These different understandings of choice are highly relevant. When we come to consider choice as a component of a framework of values in health policy, however, we have also to consider some more concrete concerns, such as the illness and the social situation of patients, the role of doctors, market dynamics and public policy directives. These many considerations indicate how multi-faceted is the idea of choice. The attempt to clarify what we mean when we speak about choice in health care is a task as complex as dealing with the history of ideas in the philosophical realm.

Semantics does not help us to clarify the matter. According the dictionary¹, choice means both an act and a possibility: the act of choosing between two or more possibilities, and the right or possibility of choosing. In other words, choosing is both about the choice of a possibility, and the possibility of a choice.

Looking at choice as part of a discourse on values in health policy, as defined in the Madrid Framework 2 , an even more complex picture emerges. In the context of such a framework choice can be intended to signify any of the following:

• a value or a worthwhile tool to put some (intrinsic or extrinsic) values into practice³;

^{*} To be published in MARINKER M. (ed), Values in Health Policy, Blackwell, London.

¹ Oxford Advanced Learner's Dictionary of Current English (1993). Oxford University Press, Oxford, p. 197.

² Marinker M. The Madrid Framework. EuroHealth 2005; 11 (No. 3).

³ Dunn W. N. (1981), Public Policy Analysis. An Introduction. Prentice Hall, Englewood Cliffs, p. 268.

- a requirement or an outcome;
- an individual or a social and collective matter;
- a market matter or one of public policy.

Furthermore, and specifically in relation to health care, choice can be observed *prima facie* as:

- a matter of health care or a matter of health policy,
 i.e., of treatments or of services;
- referring to individuals either as patients or as consumers;
- referring to very different objects of choice, such as surgery, hospitals, medicines, etc.;
- involving one or more patients, doctors, governments, companies and other stakeholders.

In the last decades, in addition to the foregoing characteristics, some unexpected and increasingly widespread facts affecting choice have emerged:

- patients suffering from serious or rare diseases are independently accessing information about their conditions, and are therefore able to challenge the doctors' diagnosis or treatment;
- people are able to buy medicines directly on the Internet, thereby bypassing the doctors' prescriptions, national regulations in respect of medicines, and the officially recognised suppliers of medicines;
- there are citizens' and patients' organizations that offer counselling;
- doctors are refusing to make a choice between different treatments, so leaving the choice to patients, who consequently have often to deal with differences of opinion between the doctors themselves;
- the choices that doctors make are increasingly disregarded by patients;
- within the constraints of current legislations, pharmaceutical companies seek to deliver information about their medicines directly to the public.

In the past the traditional view has been that patients accept that decisions are taken by fully responsible, and not to be questioned, doctors; that relevant information is reserved to experts; that the State, representing the

whole community, designs and implements policies of general scope; that citizens' organizations are engaged mainly in charity, assistance to patients being confined to non-medical matters; that pharmaceutical companies adopt a very low profile in their public relations and lobbying activities. What the new developments indicate is that (no matter whether we see them as positive or negative) they go well beyond the traditional view of choice-related matters in health care.

This being the case, the attempt to clarify what we mean when we speak of choice in health care and health systems, cannot be confined to a preamble in this chapter. It becomes its main purpose.

The Citizens.

My field of observation and reflection is delineated by the following statements:

- choice is about citizens;
- by citizens I mean to include the notions of consumers, patients, users, caregivers and so on;
- choosing can be defined as the practice, by citizens, of a relevant role in selecting both treatments and services;
- this role is not superseded by, but is rather interrelated with, those of other relevant actors in health care, for example, doctors;
- choice as a practice is conditional (positively or negatively) on a number of external factors, so that choices regarding health care are substantially interrelated with health policy;
- dealing with choice in health policy, therefore, implies considering those factors that can affect the choices of citizens, or that can be affected by them.

These statements, which are empirical and not valuedriven, are nevertheless consistent with the vision of citizens' choice as a value. This latter vision is well expressed by the European Charter of Patient Rights⁴:

⁴ ACTIVE CITIZENSHIP NETWORK (ACN) (2002), European Charter of Patient Rights, presented in Brussels on 15 November 2002, paper. See also KICKBUSCH I (2004) The need for common values, principles and objectives for health policy in a changing Europe. Paper presented at the European Health Forum Gastein 2004.

Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information.

The patient has the right to decide which diagnostic investigations and therapies to undergo, and which primary care doctor, specialist or hospital to consult. Health services have the duty to guarantee this right, providing patients with information on the various centres and doctors able to provide a certain treatment, and on the results of their activities. They must remove any obstacle that limits the exercise of this right. A patient who does not have trust in his or her doctor has the right to chose another one.

Of course recognizing choice as a *value* makes sense in the case of citizens. For other actors engaged in health - from governments to doctors - choice, though of the utmost importance, is best understood not as a value as such, but primarily as a duty, a function, and so on.

The last methodological warning I want to give is that I will deal with this issue from a European perspective, and in particular on the basis of the Active Citizenship Network's research and policy activities on patients' rights. It is not only a matter of competence. Rather, it must be said that the issue of patients' choice is in a sense at the core of ongoing dynamics of health systems in the European Union — and is thus emerging as a relevant heuristic tool. That said, in what follows I will try to show and discuss, some of the conditions and constraints on choice as a citizens' value.

The Janus-faced Paradox of Citizens' Choice.

My discussion on choice now moves from the realm of ideas to that of concrete reality, checking what choice means for the citizen's daily dealings with health systems. I will use some of the results from the Active Citizenship Network's Report on the implementation of the European Charter of Patients' Rights⁵.

⁵ ID. (2005) Citizens' Report on the Implementation of the European Charter of Patients' Rights. Working paper February 2005, edited by A. Lamanna, G. Moro and M. Ross. Paper, Rome. ACN 2005). The first stage, reported in 2005, was carried out in 2003-2004 in the 15 'old EU' countries. In all but two of them the results were comparable.

The research gave information on the state of patients' rights by identifying phenomena that can be considered indicators of attention towards those rights; and it reflected an approach to health care issues based on the point of view and the condition of citizens, patients or users of health facilities. Its findings, therefore, are especially valuable for the purpose of this chapter.

From the ACN survey, attention to the right to free choice was accorded one of the lowest rankings, by the health authorities, as following table shows (table 1).

Table 1. General classification of Patients' Rights according to the Degree of Attention.

DEGREE OF ATTENTION	RIGHT	SCORE
HIGH	Access - Physical	26
	Complain	26
	Privacy	25
	Information	24
	Safety	24
MEDIUM	Personalized Treatment	22
	Quality	21
	Innovation	20
	Avoid pain	20
LOW	Free choice	19
	Compensation	19
	Prevention	18
	Consent	18
	Access - Care	17
	Time	16

Score: min 9, max 27; average: 21 Active Citizenship Network, 2005

In all the countries surveyed, it was reported that there was a requirement for specific authorization in order to get some treatments. In 8 out of the 13 comparable countries, there were differential fees in the public and private hospitals, and supplementary insurance coverage for only some hospitals. There was also some evidence of incentives being given to seek treatment in private hospitals, and of indigent patients being restricted to

seek treatment only in certain designated hospitals. According to key witnesses, in more than half of the countries surveyed, new measures were adopted over the past year, further to restrict the possibility of citizens to choose their health care services.

In addition to this picture, the research adds much information regarding the situation of other, choice-related, patient rights, namely the rights to access, to information and to consent. All these rights can be considered as factors affecting the actual possibility for citizens to make choices about their health; factors such as barriers to access to services, lack of information, the habit of 'uninformed consent', all limit free and responsible choice.

As for the right of access to health services, the survey identified the following as the most common problems: the lack of public insurance coverage for services considered essential by the public; administrative and/or economic obstacles in accessing services; the impossibility in some European countries of getting access to medicines that are available in others. Specific examples, where the right to guaranteed equal access of health services without discriminating was not respected, were reported in more than half of the surveyed countries.

As for the right to *information*, the least available relates to hospital waiting lists for diagnostic tests and surgery; to complaints received from the public; to data for benchmarking; and, most frequently mentioned, to data on outcomes (patient satisfaction, clinical performance measures, etc.)

As for the right to consent, it must be pointed out that, while forms to obtain the patient's consent are widespread, in only some of the European countries were they used when patients underwent invasive diagnostic tests and surgical operations. Usually they were reserved only for use in the course of clinical research. Furthermore, while all the consent forms contained information on the nature of the procedure, only in two cases did they include information on risks and benefits, and in no case were existing alternative treatments mentioned.

Despite any limitations of the research, these data tell us something very interesting and really very concerning: in current health policies, the term 'choice' seems to carry highly ambivalent and contradictory meanings.

On the one hand, the availability of free, responsible choices by citizens is generally considered of crucial importance in making health systems perform more efficiently and effectively. Reforms aimed at establishing markets, or quasi-markets, are actually based on the supposition that citizens, choosing the most appropriate and effective services and professionals, will create the conditions for fair competition on quality, and compel health care stakeholders to improve their performances and avoid waste.

On the other, however, those who make health policies, and those who implement them, appear to attempt to make it as difficult as possible for the citizen or patient to exercise choice. Our research data revealed that this second task, making choice as difficult as possible, is achieved in the main by the following three strategies:

- creating bureaucratic barriers;
- hiding information;
- rationing services.

In other words, on one hand citizens' choice is required for the sake of sustaining well functioning health systems, and on the other hand it is hindered for the very same reason (usually in the name of financial sustainability).

But this is just one face of the paradox. It also has another face, which makes it even more interesting and concerning.

Obviously citizens cannot be invited to make choices outside their competence to choose. Also, in such cases, they should be helped to choose with the support of competent advice and fully available information. It is the role of health systems actors to perform these functions, to provide information, advice and counsel. However citizens are very often left alone to choose between alternatives, of which they are not aware, on the basis of information that they do not have. This is the second face of the paradox.

Such (un)informed consent is a clear indicator of this: citizens are called upon to choose, usually without information, in terms of risks, benefits, and existing alternatives. Further, according to an Active Citizenship Network's research on citizens' organizations in 26 'New

Europe' countries⁶, almost everywhere citizens' health care organizations are engaged in providing health information, and in the education of patients and public. In almost half of these countries advice services and call centres are provided by citizens' organizations, and in more than 1 in 4 countries, they provide medical counselling and training of professionals and patients. All of these activities would not need to be undertaken, were health systems and their actors operating effectively.

The second face of the Paradox of Citizens' Choice, therefore, can be expressed as follows. While there are some choices that citizens cannot make, or make alone, those who should make, or facilitate, such choices, seem to offload their responsibility back onto the citizens themselves.

The two faces of the Paradox of Citizens' Choice can be combined as follows. When citizens wish to make choices, they are not enabled to do so; when they wish to be advised or supported in making choices, they are left to their own devices.

It is well known that contradictions are innate in public policies, so we should not be too surprised by this situation. This, however, should not make us less concerned. Rather it should spur us to take a further step, to try to identify more factors related to the Paradox of Citizens' Choice, that might be accommodated by more pertinent public policy.

Information, competence, trust.

The Paradox of Citizens' Choice is linked to a number of factors of various kind - cognitive and operational; economic, social, cultural and political; global and domestic; specifically focused on health, and more general factors. Of course, it is impossible to identify all of them. However, the purpose of this book is to encourage constructive conversation. Therefore, in line with the purpose of this book, I will stress some of the more pertinent elements that contribute to creating the paradox of choice, according to which citizens' choice is both a winning strategy and a deadly danger, both necessary and

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⁶ ACTIVE CITIZENSHIP NETWORK (ACN) (2004), Public Institutions Interacting with Citizens' Organizations. A Survey on Public Policies Regarding Civic Activism in Europe. Paper, Rome.

impossible. It should be added that a policy on choice in health should, in any case, cope with these factors.

The Paradox of Citizens' Choice refers to a general cultural pattern. In relation to governments interacting with civic organizations, this has been called the Dr. Jekyll-Mr. Hyde Syndrome: citizens are at one and the same time considered and managed by governments both as a resource and as a threat 1. This syndrome, which implies in turn an over- and an under-estimation of the role of citizens in public life, is deeply rooted not only in political and administrative culture, but also in that of private actors, including companies, professionals and experts. With reference to welfare systems, and especially to health systems, it is translated in the double-headed statement that citizens are the very purpose of health systems, and at the same time their highest, unbearable, cost. Health, wellbeing, the safety of citizens are the very raison d'etre of health systems, of policy, and for professionals. Therefore one element of the paradox is that this priority is contradicted by other views and practices (especially in name of financial constraints). And this is precisely the starting point of the European Charter of Patients' Rights.

To this general paradigm, three specific factors that feed the paradox can be added. They are the existing informational asymmetries in health, uncertainty about the competence of citizens, and a lack of trust in the sources of information.

The first, and probably best known or most recognized, factor is informational asymmetry, something that happens 'when the producer does not supply the amount of information that maximizes the difference between the reduction in dead-weight loss and the cost of providing information'8. What is to be stressed here is that, in the case of health care goods, only a small proportion of them are search goods, that is, goods whose characteristics can be determined by consumers with certainty prior to purchase. Rather, for the most part, they are either

⁷ Id.

⁸ WEIMER D. L., VINING A. R. (1992), Policy Analysis. Concepts and Practice. Prentice Hall, Englewood Cliffs, p. 70. See also SHMANSKE S. (1996), Information Asymmetries in Health Services. The Market can cope, in The Independent Review, vol. 1 no. 2, Fall 1996, pp. 191-200.

experience or post-experience goods: that is, either goods for which consumers can determine their characteristics only after purchase, or goods for which it is difficult for consumers to determine quality even after they have begun consumption⁹. Obviously, while in the case of search goods informational asymmetry is negligible, the last two types of goods imply a significant degree of informational asymmetry.

The second factor is the issue of citizens' competence in health care. What is commonly agreed is that:

- citizens have experiences related to their possible or actual illnesses;
- they have perceptions related to the services they receive (this is the basis of consumer satisfaction surveys);
- they have highly subjective opinions about how things should work.

In other words, citizens' competence is usually considered as something belonging to the realm of subjectivity, meaning that citizens can manage feelings and opinions, but not information. For these reasons, they are usually supposed not to be able to make choices, but rather to constitute the targets of public action and professional performance. Of course, citizens are not, and cannot be, changed into doctors or experts in health economics.

Nevertheless, on the basis of their own experiences, of 'social technology transfer', and of deposits of memory of collective actors, they produce and use limited but reliable information both on health care and services¹⁰.

⁹ WEIMER D. L., VINING A. R. (1992), Policy Analysis. Concepts and Practice. Prentice Hall, Englewood Cliffs, p. 70.

¹⁰ MORO G. (2002) Involving the citizen in the debate on the selection and prioritising of health targets and their implementation. Paper presented at the Conference on "Health Targets in Europe: polity, progress and promise", London, 7 June, 2002. See also WILDAVSKY A. (1993), Citizens as analysts, in Speaking Truth to Power. Transaction Publishers, New Brunswick, pp. 252-279. See also MARINKER M (ed) (2002), Health targets in Europe. Polity, progress and promise. BMJ Books, London.

The Paradox of Citizens' Choice seems to interact with the foregoing as follows. The ability of citizens to make choices is denied in those instances where they are clearly competent to choose, and this ability is expected and required in those instances where they are not. In both cases, even though accepted in theory, in practice the autonomous subjectivity of citizens is denied.

In primary markets, informational asymmetries can be reduced by informative advertising and warranties on the sellers' side; and in secondary markets, by the intervention of private third parties, such as certification or auditing services, and professionals 11. This leads us to consider a third factor, trust. All possible measures aimed at reducing informational asymmetries can be effective and successful insofar as those who carry them out are trusted by the public. A source of information can be highly competent and honest, but if it is not trusted, those concerned will not be confident of its advice. The problem is that trust and confidence are among the scantest common goods in contemporary societies, and this affects daily face-toface relations (triggering a vicious circle with social capital) 12. It also affects the public arena, bringing into question the reliability both of political actors (such as political parties) and other public and private actors (such as companies, the media and public administration itself) 13. Obviously, this is not at all foreign to the concerns of health care and health policy. Distrust in medical doctors is a well-known phenomenon, as well as suspicion of the motives of companies engaged in health care. This worrying situation, by the way, does not seem to be taken seriously into account in the EU debate about

 $^{^{11}}$ WEIMER D. L., VINING A. R. (1992), Policy Analysis. Concepts and Practice. Prentice Hall, Englewood Cliffs, pp. 73-77.

¹² Cf. PUTNAM R. D. (1993), La tradizione civica nelle regioni italiane (Making Democracy Work). Mondadori, Milano; ID. (2000), Bowling Alone. The Collapse and Revival of American Community. Simon & Schuster, New York; SZTOMPKA P. (1999), Trust. A Sociological Theory. Cambridge Un. Press, Cambridge.)

¹³ Cf. SCHMITTER P. C., TRECHSEL A. H. (eds.) (2004), The future of democracy in Europe. Trends, analyses and reforms. Council of Europe Publishing, Strasbourg; ZADEK S. (2004), The Civil Corporation. The New Economy of Corporate Citizenship. Earthscan, London and Sterling.

proposals for direct-to-consumer-information on medicines by pharmaceutical companies. And distrust extends to citizens themselves who are usually distrusted, for example when they try to communicate information on their diseases.

In the field of health care there are therefore three factors that seem to worsen rather than resolve the paradox of citizens' choice. Citizens, when they make choices about health care, are faced with significant informational asymmetries. In some cases citizens are not in fact competent to make choices, and these are precisely the situations where citizens are called to take decisions by themselves, replacing other actors who should but do not exercise their responsibilities. Patients have no trust in those sources of information that could reduce these asymmetries; and they themselves are not trusted.

These three factors are, without doubt, of the utmost importance. Any discussion about choice in health care from the citizens' point of view has to cope with them. They cannot be ignored. However, rather than foreclosing further constructive conversation on this matter, I want now to attempt an exercise of 'looking differently' at the problem.

Looking differently.

Looking with different eyes at the Paradox of Citizens' Choice, and at its related factors, we could envisage an approach to choice capable both of reinforcing knowledge, and becoming a reference for designing a policy aimed at empowering citizens as choice actors on health issues, putting them in a position properly to exercise this role.

First of all, although it might seem an obvious point, no one can replace citizens in making choices on health-related issues. The temptation to replace citizens may have, and has had, quite varying, even opposite, inspirations and motivations — for example, a left-wing enlightenment or a right-wing paternalism; authoritarian state planning or consumers' orientation. The substitution of the citizen's right of choice is, in any case, nothing but a shortcut. In turn, the right and duty of citizens to make choices cannot release other actors from the task of exercising their own choices, whether they are governments, professionals or companies. The weight of these choices cannot be offloaded onto citizens. In other words what this means is that health care policy must be

managed in a governance framework, which at one and the same time calls for clear divisions of labour, and cooperation among the $actors^{14}$.

Another factor to be taken into account is that, in present welfare systems, various dimensions of health are often overlapping and not easy to distinguish, one from another — in particular, for example, the distinction between health care and health policy. The first includes treatments and drugs; the second, quality and cost of structures and services. Choices made in one dimension have effects in, and are influenced by, choices made in the other, and vice versa. Something like a 'clear-cut' choice is difficult to find in practice. The public discourse on citizens' choice should be based on what actually happens, rather than on what should happen, and does not.

Linked to this commitment to reality, another element has to be considered. This is the need to revise the notion of the citizen as a pure, unrelated individual, an entity abstracted from his/her ties and the social fabric where he/she lives. When we deal with the choices of individuals, we are in fact speaking about persons who are parts of a number of networks, have multiple interests and concerns, have family and neighbourhood links, have independent access to health information through the media and the Internet. The individual who makes choices is thus both complex and in-related; and these choices are influenced or supported by a number of factors and actors that may render the individual more expert or, on the contrary, less expert, confused and uncertain. None of this is can be clearly understood if we only look on people as islands. This understanding of the relatedness of the individual is not at all incompatible with the newly recognized value of the patients' experience and evidence. Finally and importantly, all this makes clear that citizens (and patients) are neither autonomous nor artless; both these views are in fact myths. We need to go beyond myths.

It should be recalled that citizens are also selforganized, acting collectively to protect rights and pursue common goods, from advocacy to the delivery of services. Community-based, voluntary, consumer, and patients' organizations, are some of the forms taken by

MORO G. (2002), The Citizen Side of Governance, in The Journal of Corporate Citizenship, issue 7, Autumn 2002, pp. 18-30.

13

citizens who have a new attitude to the exercise of power and responsibility in the public arena¹⁵. With reference to choice, and to the factors highlighted in the previous paragraph, they play a relevant role in:

- informing, advising and assisting patients, both on medical and non-medical issues;
- advocating and bargaining on choices with public authorities and other stakeholders;
- 'lending trust' 16 to public and private actors, helping to ensure their reliability as sources of information;
- auditing, monitoring and reporting on health actors' behaviours, so functioning as third parties in relation to informational asymmetries;
- pushing medical doctors and other actors (such as pharmaceutical companies) to be fully responsible in choosing and delivering information;
- giving priority to individual differences, in the delivery of services, and emphasising the ability to tailor, or adapt, the service to the users' needs;
- taking part in managing conflicts between alternative competing needs, especially in situations of scarcity.

The role of citizens' organizations must not be overestimated. But neither should it be underestimated. According to all available data from surveys, pretty much everywhere such organizations are at the top in rankings of social trust.

None of this resolves the Paradox of Citizens' Choice, and I have not aimed to do so here. Rather, these observations reveal that matters are much more complex than is usually considered, and so may be of some worth in attempting to manage the ensuing problems.

¹⁵ ACTIVE CITIZENSHIP NETWORK (ACN) (2004), Public Institutions Interacting with Citizens' Organizations. A Survey on Public Policies Regarding Civic Activism in Europe. Paper, Rome. See also PETRANGOLINI T. (2002), Salute e diritti dei cittadini. Cosa sapere e cosa fare (Health and Rights. What to know and what to do). Editori Riuniti, Roma.

¹⁶ ZADEK S. (2004), The Civil Corporation. The New Economy of Corporate Citizenship, Earthscan, London and Sterling, pp. 38-50.

Memo for a policy.

In concluding, I return to the Madrid Framework, the point of reference of this book. As to policy on choice the Framework highlights two main issues. The first is the potential conflict between those choices made with regard to collectivities, if not to whole populations, and those made with regard to the needs of individuals and specific groups. The second is that, since choice in health policy implies the gain of 'something' but not of 'everything', the resulting menu of choices must be 'transparent' and challengeable by citizens. Both these elements pose real and serious problems that deserve the highest level of our attention.

In a sense, these two considerations — the conflict between the individual and the group, the possibility of obtaining some goods but not others — characterise not only health policy, but policy making in general. The typical problem for public policy (and for politics) is precisely how to make choices that look at problems in a rounded way — by attempting to reduce the gap between the specific needs and conditions of people, as well as taking into account cultural, religious, social, economic and other differences; and by adopting the minimum standard for a democracy, that policy choices are made transparent, so that people, especially those directly involved and affected, are able to question them.

In another sense, however, these statements are insufficient and more is required. Firstly, in contemporary societies, 'the interest of the whole population' is very difficult to identify because of the existence of multiple identities, networks, and the overlapping of interests. As we have seen, the individual is not as 'individual' as the traditional representation of society suggests. So, the problem of making policy choices is to define the general interest, not by deducing them from some a priori scheme, but by starting from an acknowledgement of the many differences in a society. Things, therefore, are much more complex than is suggested by the task of managing the divide between general and special interests. A policy on choice in health (and in welfare in general) must essentially be a matter of managing diversity.

Secondly, it seems to me that, following the way in which I have defined and argued for citizens' choices in this chapter, these must be part of the general process of policy making, and neither over- nor under-estimated. In

this sense, a new democratic standard should clarify and establish that citizens must have a say and a role in defining the menu itself. It is not enough to be given the opportunity to question it *after* it has been defined. Consultation policies, involving individuals as well as organizations, increasingly now at local, national and trans-national levels¹⁷, though at the moment absolutely insufficient, nevertheless go in this direction.

Thirdly, it is necessary to avoid any risk of policy bricolage, and recognise that conflict cannot be eliminated by policy making. On the contrary, conflict is one of its constitutive elements. A without-conflict definition or implementation of a policy simply does not exist, either in principle or practice. What is important, from this point of view, is rather to make sure that citizens can participate in policy conflicts on an equal basis, recalling that citizens' positions are often those closest to common concerns.

Fourthly, it is far too reductive to consider choice as something that happens only at the moment of the definition of a policy (i.e., the idea of a unique and definitive macro-decision). Throughout the whole policymaking cycle a number of choices (macro and micro) are being made. As we have seen, several choices, to the detriment of citizens' and patients' rights, have been made in European countries, particularly in the implementation of policy, that could possibly have been identified and avoided with the active participation of citizens' organizations. The problem, thus, is how to ensure that citizens' choices are taken into consideration as a relevant part of the policy making process, and recognised as a distinguishing and valueadded element. This should be the concern not only of citizens' organizations, but also of governments, policy makers, experts, and the whole policy community.

Fifthly and lastly, a policy on choice should have as its final aim the empowerment of citizens as choice owners, in two senses. The first is that citizens must be provided with enabling know-how and skills on choice-related

¹⁷ See, for example, EUROPEAN COMMISSION (2002), Towards a reinforced culture of consultation and dialogue. General principles and minimum standards for consultation of interested parties by the Commission. COM(2002) 704; OECD (2001), Citizens as Partners: OECD Handbook on Information, Consultation and Public Participation in Policy-Making. Paris, OECD.

issues, and helped to feel themselves really able to exercise their own rights and powers on choice. The second is that citizens can demand of all health actors, and impose on them, that they take responsibility for, and are held accountable for, their own choices.

