French National Consultative Committee for Ethic and deliberative democracy
The case of the citizens’ conference (December 2013)

Françoise Dreyfus
University Paris 1 Panthéon-Sorbonne/CESSP

Introduction

“Participation”, “concertation” and/or consultation became at the beginning of the 1970’s a kind of slogan used to characterize different processes or arenas where, beside administration or public other decision makers, people concerned by the debated questions were taking part through unions or other representatives; these practices were seen as a first step towards less top down decision making and a change from traditional ruling (even if these devices were mainly without real influence on the final decision). At the end of the decade the so called “third generation of human rights” started to be enforced, giving the citizens the right to know why and how administration is acting, and entrenching the principle of more transparency instead of secret (Dreyfus, 1999).

Among various measures aiming to increase the citizens’ in public policies, the 1983 Law about the democratization of public inquiries and environment protection into planning provided new rules stating the obligation to get written opinions of the public about planning propositions. The study of the process and its defects has shown that participation was weak, “competent” citizens or NGO and mainly interests holders playing the game (Blatrix, 1996). To make short a long story, a 1995 Law about the reinforcement of the environment protection has created the National Commission for the Public Debate (experimented since 1992), which became an administrative independent authority according to a 2002 Law extending also its missions; the core of them being to attend to the respect of public participation within the process of planning projects elaboration, to organize itself the public debate, or to entrust the owner with
the duty to organize it. In practice the institutionalization of the citizens’ right to participate in decisions affecting the environment and the national development may be seen as an improvement of democracy, or otherwise like a mean for neutralizing –to some extent- social mobilizations against the projects in stake (Blatrix, 2002). It is no the place here to survey all the cases in which citizens’ participation is organized, mainly at the local government level, and what are its outcomes (Blondiaux et al., 1999). Until now, as noticed by Blondiaux and Sintomer (2002, p. 19), notwithstanding the conceptual vagueness of the use in France of “deliberation”, “concertation”, “participation”, a growing number of devices are referring to them. Among the several devices, aiming to enrich the public debate and provide useful opinions for the decision makers, citizens’ conferences –inspired by the Danish example – are more and more set up by public authorities. Though many of them, since the first one about the genetically modified organisms\(^1\) (Boy, Donnet Kamel, Roqueplo, 2000), are dealing with questions regarding environment involving scientific aspects as well as economic stakes\(^2\), some recent ones concern other kinds of objects, that may arose emotional reactions within the population, but are not directly and/or immediately impacting specific people. The consensus conference about the “prevention of second offense” (February 2013)\(^3\), the citizens’ conference about “the end of life” (December 2013) belong to this category; in both cases the problem had already been examined many times by experts, or so called “qualified persons” (referring to the official language used in France) as the members of the National Consultative Committee for Ethic (in the case I shall study), who gave also their opinions and advices.

Between these different advices intended for helping the decision makers’ to make up their mind about policies, which one will prevail if they are contracting each other?

Before trying to find out the possible way the Parliament will follow after having gotten all the expert and lay opinions expressed through the public debate, mainly the citizens’ conference advice issued on the 14\(^{th}\) of December 2013, we shall examine 1) the NCCE

\(^1\) In 1998, Conférence de citoyens sur « Les OGM dans l’agriculture et l’alimentation » organisée par l’Office parlementaire des choix scientifiques et technologique (OPECST) .


\(^3\) Its organization and working were not shaped like the citizens’ conference; to some extent, the jury does not currently represent the population but more or less elites.
role in the public debate, 2) how has been organized the citizens’ conference and how it has worked (as far as we know), 3) its advice and its possible outcome.

1. The National Consultative Committee for Ethic

Ethical issues about how scientists can deal with life, death, fertilization, cells (among others) are difficult to decide insofar as they involve religious and philosophical beliefs that may not fit with scientific improvements. The fast advances of research mainly in genetic biology have therefore led governments, since around forty years, to create specific committees in order to be provided with pluralist opinions as well as expert advices on the related issues.

In France, the National Consultative Committee for Ethic in sciences for life and health was created by a decree dating back to 1983/02/23; its existence and role were confirmed by the bio ethic Law promulgated on the 29\textsuperscript{th} of July 1994.

In 1983 its composition and, more precisely, which public authorities will be entitled to nominate its members, was harshly debated within the government, although the NCCE powers were apparently weak. As shown by D. Memmi, who has studied the working of the NCCE along its first ten years, its advices have built normative representations of “what can be done legitimately with the human body “ (Memmi, 1996). These norms, without any legal force, have been produced by people belonging to various social universes: among the 38 NCCE members appointed for four years, 5 of them belonging to the main philosophic and spiritual families are nominated by the President of Republic; 15 are scientists and physicians chosen by the chair persons of the research institutions mentioned in the decree; 19 “specially qualified” people are chosen by different public institutions (parliament, high courts, ministries). The President of Republic appoints the NCCE chairperson for a two years renewable term, as half of the members are also appointed each two years for their four years term, which is renewable once.

Since the 2004 bio ethic Law\textsuperscript{4}, the status of the NCCE has changed: it is now an independent authority though previously it was a committee of “wise persons” (Bachir, 1996) in charge of advising the ministry of health, as well as the different public authorities entitled to ask it its advice. Since its creation it was also entitled to decide by

\textsuperscript{4} Loi n° 2004-800 du 6 août 2004
itself to report on a question and was committed to organize once a year a conference about ethical issues in the field of biology and health. In this last respect, its duties have been extended by the 2011 bio-ethic law\(^5\), which provides that all draft law must be preceded by a public debate organized by the NCCE after consultation of the parliamentary permanent concerned committees and the Parliamentary office for evaluating the scientific and technological choices\(^6\). However, though according to the law the meeting of citizens’ conferences is a compulsory step before presenting a draft law to the Parliament, its debate about “the end of life” is a piece of a complicated puzzle and a long lasting debate among the NCCE members\(^7\) as well as in other arenas\(^8\) and medias. Without entering the details of all the questions in stake, we must notice that whether assisted suicide or active euthanasia is not allowed, the 2005 Law about the rights of patients and the end of life, (among which the rights to refuse to be cure longer, to give anticipated written directives concerning the end of his/her life) is interpreted by some people as opening the possibility of passive euthanasia, although others disagree strongly with this idea; moreover the law is often unknown by the medical staffs and poorly implemented for various reasons; in some cases, the courts have to judge medical behavior considered as criminal or to decide what physicians are allowed to do and in which conditions.

The cases pending before the courts (or judged) nourish media debates giving them the opportunity to get the opinions of the concerned families, the “ordinary” citizens, physicians, scientists …They open also the way to mobilizations in favor or against assisted suicide, which turn into political confrontations insofar as it is linked with other “moral” questions like gays’ marriage, medically assisted procreation, which have been on the governmental and parliamentary agendas since the presidential election in 2012. In this context, the President of Republic asked the NCCE to give its advice on the end of life. It did not go much further than in its previous advices and did not reach a consensus on the most controversial questions, the majority refusing to legalize euthanasia or assisted suicide. However, it is noticeable that eight NCCE members signed two

---

\(^5\) LOI n°2011-814 du 7 juillet 2011
\(^6\) This “Parliamentary office for evaluating the scientific and technological choices” has been created in 1983 by the Parliament.
\(^8\) The ministry of Health had convened in 2012 a committee chaired by the former NCCE chairman « Penser solidairement la fin de vie », Commission de réflexion sur la fin de vie en France, La Documentation française, décembre 2012.
dissenting opinions, published together with the advice issued in June 2013⁹. Following this first step, the citizens’ conference was convened later in 2013.

2. The working of the deliberative democracy device

The organization and monitoring of the citizens’ conference was entrusted to the French Institute of Public Opinion (IFOP); we shall see that the whole process, from the selection of the panel to the guidance of the meetings, followed very precise procedural rules insuring the quality of this minipublic’s deliberation concluded by the citizens’ advice (Fung, 2003).

The panel was composed of 18 persons selected in order “to mirror at best the diversity of the French population and to show the various possible points of view about the end of life”. The panel cannot be seen as a representative sample of the population, but it is balanced according to socio demographic criteria as the gender, age, occupation, level of diploma, region of residence and category of town, and it conforms to the structure of the French population.

Though the political preferences and religious beliefs were not part of the criteria, they were taken into account to select the panel members. The selection lasted five weeks all around France through face to face interviews with people belonging to a larger sample already constructed by the IFOP.

An important feature must be mentioned: on the NCCE request the recruited citizens did not get any payment for their participation to the conference.

The panel was meeting during four weekends to think about the conditions of life end; twelve experts were chosen by the NCCE, in accordance with the 2011 Law provision stating “the experts who take part in the citizens’ training are chosen according to criteria of independence, pluralism and pluridisciplinarity”, to be heard by the laypersons’ panel during the two first weekends. For the third one, the panel had requested to hear five professionals¹⁰ and two families (having been with a parent ending his/her life). The last weekend was devoted to the discussion between the citizens, the writing and adoption of their advice. The panel explained at the press conference convened two days after its last meeting that its collective opinion was

---

¹⁰ The general director of health at the ministry of Health; a general practitioner; a lawyer; a specialist of health economy and a responsible of medical students’ training.
reached after deliberation by consensus; the vote being only used at the very final step when it adopts its advice.

We do not know anything about the members of the panel as individuals, except that when agreeing to participate in this citizens’ conference, they have shown a civic commitment (Dalton, 2007); we can neither analyze their behavior, their arguments and, more important, we don’t know if one of them took a leading position during the deliberation (Kuyper, 2012). What we know, because it is underlined in the preliminary observations of the citizens’ advice, is that they found the information provided by the experts as well as the professional’s testimonies extremely useful to be aware of all the implications of the matters they had to deal with; in particular, they learned what are the patients’ rights, unknown from the public who knows what is forbidden but not what can be asked and legally done at the end of life.

In accordance with the provision of the 2011 Law, the experts were displaying various points of view allowing the members of the panel to make up their own mind on the different questions in stake. For instance, the chairmen of the Portuguese council of ethic and of the Belgian one who attended the two first weekends could explain why in Portugal the “end of life” is subject to almost the same rules as in France, when on the other hand the right to be helped to die is entrenched in Belgium. Moreover these both positions were equally represented among other people heard by the panel, but we ignore if some of these used more convincing arguments supporting their opinion than others and by consequence influence the content of the citizens’ advice and recommendations.

Having heard the explanations displayed by the citizens during the press conference\textsuperscript{11}, we have the feeling that “decisions resulting from deliberation may be more fair and legitimate because they result from reasons rather than arbitrary advantages. They may be wiser because they allow a broad range of perspectives and information to be pooled together. Discussion may help individual participants to clarify their own views” (Fung, 2003, p. 344).

It is time now to see the answers the citizens’ conference gave to the questions in stake and to try to evaluate the possible influence of its recommendations on the legislator.

3. Ambitious recommendations to the legislator

\textsuperscript{11} The press conference is available on the web site of the NCCC.
The recommendations formulated by the citizens’ conference are, on the one hand, following the same path than the NCCE advice n° 121 about the necessity to implement effectively the right to palliative cure, the right to get deep sedation, and the compulsory respect of anticipated directives which may have been given by patients. On the other hand, the citizens are strikingly going further: they face without ambiguity the most difficult questions -the assisted suicide and euthanasia-; they explain clearly that the panel members had different interpretations regarding the meaning of assisted suicide and euthanasia, different positions about the possibilities to allow them, and they provide the arguments supporting each of them and the final propositions the deliberation has led to. I shall only present these final propositions without entering the detail of the argumentation developed in the advice.

The panel pronounced itself in favor of the medically assisted suicide, considering that patients have a legitimate right to be helped to die when they are at the end of life or when their illness is irreversible. Some conditions must of course be respected among which the patient’s expressed will to be helped is essential; in this respect, the anticipated directives somebody has given must be followed when he/she is no more able to express his/her will. In all cases lethal medicine may be administered by a third party according to the opinion of twelve members of the panel, the other six considering that a third’s intervention belongs to the category of euthanasia. For the panel, as far as assisted suicide is taken into account, euthanasia must not be allowed as a solution for ending life; however, given some cases when a patient cannot give its consent (i.e. a young man being in brain dead since months or years after a car accident), it proposes what it calls “euthanasia by exception” opening the possibility for a medical commission to decide, under conditions, the end of life.

Finally the advice expressing the consensus between the citizens states that the 2005 Law must be refurbished; four points must be taken into account:

- a huge increase of the palliative medicine beneficiaries fitting with the needs level
- the allowance of sedation in terminal phase
- the legalization of medically assisted suicide
- the creation of euthanasia by exception.

Compared with the NCCE advice, the citizens’ one shows that lay opinion is obviously more “advanced” than what the experts and so called “qualified” people dare express.
Various reasons may probably explain the NCCE “timorous” behavior displayed through its advice. The socio-biography of some members, their religious beliefs, the fear to involve the physicians and medical staffs in risky situations, but also professional interests may have contribute to prevent the majority to take position in favor of assisted suicide and/or euthanasia. The cautiousness of these established elites forming the NCCE contrasts with the citizens’ open-minded way to deal with the difficult ethical questions; it is also clear that the citizens were more focused on the respect of the individual’s dignity and will (when expressed), while stating precise conditions for helping the life end.

Both advices are only consultative and, as we know, they are considered to be apolitical; the decision to amend the 2005 bio ethic Law and the scope of the changes to be introduced depend upon the government and the Parliament.

The decision makers will be confronted to an interesting dilemma: which opinion will be prevalent to their eyes or, to put it in another way, will the NCCE legitimacy prevail on the citizens conference’s one? The latter being more representative of the population – even at its very small scale- its advice may be seen like picturing public opinion much better than the experts’ opinion\textsuperscript{12}. But other reasons may lead to refer better to the citizens. The NCCE members who issued the advice n°121 (at the very end of half of them term) were appointed when the right wing political majority was governing; whether it does not mean that all the NCCE members were appointed according to their political preferences (if known), the ministers and the chairman of each house of Parliament, who are entitled to nominate members of various kinds of commission, customarily chose people in accordance with their political closeness. In September 2013 the renewal of half of the members took place, the President of the NCCE having already been replaced in November 2012 by President Hollande; analyzing the appointments of the new members, we notice that six persons have been renewed for a second term; among the ten nominated by ministers, two were renewed; among eight belonging to research field, the four who have been renewed had signed the dissenting opinion of the advice n° 121. It is quite probable that if the NCCE, in its new composition, would have to give again an advice about the end of life, it would resemble to the citizens’ advice. Anyway, it is not the point.

\textsuperscript{12} I shall not discuss here the more general question concerning the legitimacy of advices or decisions mini-publics are issuing, the grounds on which they may be based.
The use of deliberative democracy tools is seen often as a way to depoliticize, or to neutralize, the approach of the problem in stake; in the case of end of life, we consider it like a “society question” involving beliefs and values more than political opinions, strictly speaking; it is alike death penalty or abortion towards which representatives in Parliament were voting according to their conscience and not to their partisan belonging. Nevertheless, some political choices may be linked with personal beliefs and values or with supposed electors’ expectations about the best way to solve the problem.

The fact that the 2011 Law imposes public debate through citizens’ conferences “when a reform regarding ethic and society questions raised by the progress of knowledge in the fields of biology, medicine and health” shows to some extent that the politicians do not want to decide “alone”. They are looking for a large range of information, opinions provided by the experts and the public. In this respect the citizens’ conference is useful because it “contribute information about their preferences and values that is unavailable to policymakers” (Fung, p.343) and as noticed by S. Chambers “ it can have interesting and salutary effects on policy making by adding a citizen perspective... and bridging the gap between lay citizens and policy experts” (Chambers, 2009, p. 330).

However, when the representatives sitting in Parliament are leaning on scientific and moral advices from the NCCE and the citizens, they are sustaining the legitimacy of their policy choices (Goodin and Dryzek, 2006, p.232). Beside the traditional democratic legitimacy (given by the election), the legitimacy of knowledge which allows the NCCE to say what is ethic (Memmi, 1996), and the other kind of democratic legitimacy hold by the citizens’ conference can, each of them, be used to support the first one. But the scientific or the citizen’s legitimacy may be undermined, when the Parliament does not take into account the result of the consultation or if, like in the case of the end of life, the NCCE’ and the citizens’ advices being different, one of them will automatically be ignored.

It will be quite interesting to observe the position the Parliament will adopt and which path it will follow when the draft law will be in discussion. In many respects, the value of the citizens’ conference as a tool for associating the civil society to public decisions will be in stake. Anyway the symbolical competition between representatives’, NCCE’ and citizens’ legitimacy may not be avoided.

Be the citizens’ advice followed would apparently demonstrate that a fair deliberation between citizens well informed is actually helpful for the decision makers ready to listen
to other opinions than experts’ one. However, it may also be a political trick: as the NCCE members who issued the advice were appointed by the former governing majority, their opinion may be suspected to be a partisan point of view and dismissed as such.

On the other hand, the representatives may adopt a cautious position, given some hostile reactions against the citizens’ advice, which content and form are criticized by “pro life” lobbies. They may take argument of the weak representativeness of the eighteen citizens –like the ministry of Interior opposing to the draft law about the second offense prevention, the fact that “it lies on a fragile legitimacy, the consensus conference, and the gathered knowledge does not reflect all the opinion trends”.

The possible prudent preference for experts’ opinion rather than lays’ one, relying on the NCCE scientific legitimacy may also be explained by some common sociological features between representatives and NCCE members; whatever the position of the representatives in Parliament, it will probably open the door to various criticisms on behalf of scientific or religious beliefs blurring political oppositions.

**Conclusion**

According to the NCCE chairman, who had written in conclusion of the advice n°121 that the debate about the end of life is not over and must go ahead, the public debate is a tool for allowing the civil society to take part in the public decision. It helps to go beyond irreconcilable positions, aims to clarify the common stakes that include individual preferences, and put in light the complexity of questions. It helps to go beyond the deep differences of views and agree to values we are sharing: individual’s autonomy, protection of the weaker, freedom of thinking.

To some extent, the citizens’ conference confirmed this optimistic view. However, it is far from sure that the “successful” democratic deliberation having reached a consensus is able *per se* to influence the decision, which will occur later and probably take into account different points of view. Whether the Parliament will amend the 2005 Law apparently in accordance with the citizens’ recommendations, its choice may be

---

13 "Quel poids notre société va-t-elle donner à l’opinion de 18 personnes au regard d’avis beaucoup plus établis rendus par la commission Sicard en décembre 2012 ou par le CCNE en juillet 2013 ?
http://www.alliancevita.org/2013/12/conférence-de-citoyens-sur-la-fin-de-vie-douteux-sur-la-forme-dangereux-sur-le-fond/

determined by many other reasons (Friberg-Fernros, Schaffer, 2014); meanwhile the
citizens’ advice may be used to show that when the elected representatives are
performing their legislative job, they do not let aside the propositions coming from other
arenas.
The increasing use of deliberative tools, although being trendy, does not change “the fact
that deliberative mechanisms are not a self-executing system of governance. Deliberative
minipublics require a great many structures or processes within society to implement a
deliberative outcome “(Kuyper, p. 19). Moreover, to be implemented the outcome must not
contradict other interests able - because powerful- to orient the final political decision.

References:


démocratie participative : la conférence française de citoyens sur l’usage des organismes
génétiquement modifiés en agriculture et dans l’alimentation », Revue française de
science politique, vol. 50, n°4-5, 779-809.

Blatrix, Cécile, (2006), « Vers une “démocratie participative” ? Le cas de l’enquête


