PREAMBLE
We seek to understand and control the forces that govern our lives, to participate in shaping our futures. We are no longer confident that specialists and administrators—the staff of our social institutions—will govern them wisely and justly without our participation. Health services cannot be excluded from the demand for greater public accountability and participation. Health is too important to be left solely to doctors and to hospital administrators.

We must find new ways to inform ourselves and to take part in the government of our hospitals, clinics, and public health departments, as well as in the regulation of medical researchers and practitioners and all others entrusted with the government of our body.

While greater public accountability and participation are not a cure-all for the present complex health crisis, they are vital elements in its treatment and in the prevention of new problems.

HEALTH GOVERNMENT
The federal, state, and local governments, health administrators, and health "providers" and insurers have been unable to curb skyrocketing medical costs, secure quality service, or provide care that is comprehensive, preventive, and accessible to all. A greater citizen, or "consumer," participation in the regulation of the health services on all levels is urgently needed. The success of several comprehensive health planning (CHP) agencies—where consumers have 51 percent representation—in curbing unnecessary hospital constructions or renovations suggests the viability of this approach. And yet, CHP agencies as presently constituted are not the answer. The consumer representatives on their boards are impeded by the lack of resources necessary to fulfill their regulatory function; moreover they are not elected and hence are often neither representative nor accountable to the public.

Should they be elected, as proposed here, new mechanisms must be devised to insure continual interaction between consumer representatives and consumers in the interim between elections. Above all, the CHP agencies currently have only limited power to promote the plans they make; they lack "clout."

Hence we resolve that:

1. The CHP mandate be extended to include all health services operating in the community, including those of public health departments.
2. CHP agencies should be autonomous public authorities and not subject to any state agency.
3. The clout of CHPs should be increased by increasing their right to stop the flow of all public funds to programs that do not have their approval and authorizing them to suspend licenses.
4. Research assistants, information analysts, and computers should be made available to the CHP boards for independent review of data submitted by health providers.
5. Consumer representatives should be paid at the same rate as doctors serving on the boards.
6. Consumer representatives like those on the boards of CHPs should be placed on all boards or councils that regulate or finance health services, from Medicaid to Medicare to those of private or not-for-profit health insurance corporations.
7. Consumer representatives should be elected by the citizens of the areas they serve in biannual elections that coincide with congressional elections.
8. The Department of Public Health should negotiate with schools of public health, medical schools, community colleges, and others to secure adult education opportunities for citizens who wish to acquire the necessary background to become consumer representatives.

In addition to involving citizens in all agencies that oversee the expenditures of health units and systems, citizens should be represented in the new organizational bodies that are being set up to supervise the medical practices of hospitals.

Under the recently enacted H. R. 1, each state must set up by the end of 1975 a Professional Standard Review Organization (PSRO) which will review medical...
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Now that machines can often keep a body alive long after any hope for the revival of consciousness is lost, we must participate in defining the criteria for death—the point at which the machines will be turned off.

As long as people are subjects of experimentation, how can they best be safeguarded from undue pressures and hazardous procedures? How can we curb scientists who are anxious to achieve a breakthrough from abusing inmates, poor or uninformed patients, or the very young, without stifling the progress of medical research?

How can we make certain that our values—not just those of the practicing physicians—will be systematically taken into account in deciding whether new procedures (for example, amniocentesis, by which fetuses can be checked for such genetically caused malformations as mongolism and for other characteristics, such as sex) should be made available to all, rather than only to those individuals, or for those purposes approved of by doctors?

Should public funds be used to promote experiments to grow babies in test tubes? Or should such studies be discouraged regardless of the source of funds? Should mass screening programs for illnesses for which there is no known cure—sickle cell anemia, Tay-Sachs, dysautonomia—be introduced by the force of the law despite the fact that people identified as carriers suffer social discrimination, loss of jobs, and increased life insurance rates?

These and many other questions have not only medical but also ethical and le-
findings and conclusions of the Commission, together with its recommendations, including such recommendations for action by public and private bodies and individuals as it deems advisable.

The commission would be composed of fifteen members drawn from the general public and the fields of medicine, law, theology, biological science, physical science, social science, philosophy, humanities, health administration, government, and public affairs. It would also be backed up by a research staff.

Furthermore we resolve that:

11. The duties of the statewide PSROs be expanded to include review of local cases to insure that researchers do not abuse their subjects and that practitioners are familiar with and heed national guidelines on ethical practice; that they inform the national commission of new issues arising locally for which there are as yet no guidelines; and that they draft guidelines on the basis of their experience. Existing hospital ethical review committees and those founded in the future could become part of this national network of ethical supervision and public accountability.

12. To increase the sensitivity of doctors and other health professionals to these matters, we call on Congress to enact bill S. 974, submitted by Senators Javits, Williams, and Mondale, which amends the Public Health Service Act to provide "in the training of health professionals, for an increasing emphasis on the ethical, social, legal, and moral implications of advances in biomedical research and technology."

13. Opportunities for citizens to be informed on these matters must be expanded. We resolve to censure the Food and Drug Administration for not releasing detailed information on the dangers of birth control pills directly to the public, but relying instead on doctors to disseminate the FDA's warning among their patients. In the future all such warnings should be provided directly to all citizens.

14. Hygiene-civics should be made a topic open to every high school student and a core subject for forward-looking adult education programs. Without greater citizen education and information on the subject, the government of health will never be responsive to our health needs.

15. In the area of experimentation with human subjects, we are ready to take the next step, that is, forming a regulatory board. Following suggestions made by Drs. Bernard Barber and Jay Katz in testimony before a recent hearing conducted by Senator Edward Kennedy, a board should be set up to insure that all experiments with humans will be in line with ethical guidelines and that these guidelines will be continually revised to cover new problems as they arise.

Greater public accountability and participation will not abolish the health crisis; many other correctives ranging from national health insurance to decriminalization are necessary. But without a democratization of health government, additional solutions are much less likely to come about.