PUBLIFORUM

TA-P6/2004 e

Report of the Citizens Panel

PubliForum
«Research on Human Beings»

Bern, 23 - 26 January 2004

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SAMW
Schweizerische Akademie der Medizinischen Wissenschaften

ASSM
Académie Suisse des Sciences Médicales

ASSM
Accademia Svizzera delle Scienze Mediche

SAMS
Swiss Academy of Medical Sciences

Bundesamt für Gesundheit
Office fédéral de la santé publique
Ufficio federale della sanità pubblica
Swiss Federal Office of Public Health

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PubliForums, publifocus and PubliTalk are, namely, examples of these participatory methods. The „TA-Participation"-series of publications contains the results of such projects carried out within the framework of *TA-SWISS*.

The conclusions in this report were made by the Citizens Panel of the PubliForum „Research on Human Beings" in January 2004. The sole responsibility for its content lies with the Citizens Panel.

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ISBN-Nr. 3-908174-14-7

Office of the State Secretary of the Swiss Science Agency

Swiss Academy of Medical Sciences

Swiss Federal Office of Public Health

TA-SWISS, Centre for Technology Assessment

PubliForum

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March 2004 **TA-P6/2004 e**

Contents

I Introduction

Research on human beings has proven to be necessary for the advance of science, particularly in the domain of biomedicine. The participation of human beings as subjects of scientific experiments, however, has caused a number of issues to emerge, ranging from questions of an ethical, medical, and legal nature, to those of a social and economic dimension. Who, then, is to decide the direction in which research is focused and whether a given project is justified? How can the persons involved be guaranteed without exception the maximum protection, in particular when the most vulnerable groups, such as children or invalids, are involved? In what manner is the utilization of research samples to be regulated, as well as that of the data obtained during medical treatments? The PubliForum held on research involving human beings provided the opportunity for a group of citizens with not specialized knowledge in the area, to delve into these complex issues. Although their reflections and recommendations are primarily directed to decision-makers from the world of politics, science, and other circles concerned, they are also available for all those interested in the debate.

Scientific research and the accumulation of knowledge are veritable vectors of progress, especially in medical domain. Certain results, however, cannot be obtained without conducting experiments on human beings. As a matter of principle, persons participating in such studies should do so only after having been fully informed on how the research project is planned to unfold, on the risks and benefits that can be expected, and only after having given consent of their own free will. Yet it is difficult to strictly adhere to these principles in all situations. Certain persons are likely not to be able to understand the information given them, or to be unable to voice their consent to freely participate in a research study, e.g., children or the mentally disabled. But just the same, such groups of particularly vulnerable individuals should also be able to take advantage of advanced scientific research and new medical treatments.

Above and beyond research experiments with human beings as subjects for e.g. clinical tests, research also makes use of tissue samples and personal data of subjects or patients. Should personal data also be permitted for use in studies relating to the social sciences? And what about the consent of the persons implicated in these types of studies, and the protection of their personal data?

Furthermore, the sole and unique question at stake in terms of research is not that of "how" a research study is conducted, but also that of "what" research studies should take place. How are decisions to be made on investments to combat this or that illness? In what direction should research be targeted? To what degree is research directed towards satisfying the needs of public health, and to what degree is it motivated by financial interests?

TA-SWISS has already been successful in organizing three PubliFora on different topics in 1998, 1999 and 2000 (Electricity and society, Genetic Technology and Nutrition, and Transplantation Medicine, respectively). Given the fact that a bill is currently being drafted in Switzerland on a framework law regulating research on human beings (cf. Annex A), TA-SWISS decided to launch a PubliForum dedicated to this topic. The organizers were convinced that the Citizens Panel would not fail to identify the major stakes they deem are involved in this vast issue.

In view of the innumerable aspects that could potentially be dealt with and the limited amount of time at the Panel's disposal, the citizens were obliged to select those aspects particularly vital in their eyes. During the first two days of the PubliForum, the Panel discussed the stakes with the resource persons (experts) whom they themselves had chosen from a list of specialists who had expressed their readiness and availability to participate. Finally, on the third day the Panel retired to deliberate and formulate its opinions and recommendations, as laid down in the following document they ultimately transmitted. This product was made possible thanks to the commitment of each and every member of the Citizens Panel. The constructive exchanges which took place would hardly have been possible were it not for the mediators Mr. Ulrich Egger (Egger Phillips & Partner) and Ms. Danielle Bütschi. The latter were in fact vested with the task of mediation and the moderation not only of the discussions held among the members of the Panel, but also that of the dialoging which took place between the Panel and the resource persons.

At present, the Citizens Panel report continues to be diffused among those groups concerned. Especially targeted are the political circles as part of a first phase leading up to the initiation of the formal consultation procedure on the draft law on research on human beings. In a subsequent phase, capitalization of the results of the PubliForum should continue during the course of the debates in Parliament.

The organizers would like to express their profound gratitude to the citizens who authored this report, and their high respect for the work they have accomplished. They wish you good reading and thank you in advance for your assistance in acquainting those around you with the views held by the Citizens Panel on research on human beings.

The Organizers
February 2004

Members of the citizens' panel on 26 January 2004

II Citizens Panel

Surname	Forename	Residence	Age	Occupation
Aubert	Valerie	Préverenge	39	Secretary
Aubort*	Cynthia	Trelex	27	Health care assistant
Boxler	Marius	Kriens	60	Teacher
Bucci	Monica	Camorino	30	Industrial psychologist
Bürgi	Franz	Magden	40	Commercial employee
Burnand	Frédérique	Rivaz	47	Cantonal schoolteacher
Daucourt	Xavier	Porrentruy	37	IT specialist
Fuss	Marcel	Thun	25	Car mechanic/automotive electrician
Gloor	Heidi	Thalheim	64	Kindergarten teacher, Therapist
Hablützel**	Marcel	Winterthur	61	Director
Hodel	Erwin	Gstaad	66	Retired railway station chief
Hofmann	Peter	Biel	46	Gardener
Holz-Markun	Silvia	Ranzo	66	Journalist
Knupp	Kathrin	Massagno	25	Commercial employee
Kruisinga**	Pim	Pregassona	51	Financial analyst
Mecklenburg**	Riccarda	Bassersdorf	38	Member of board of directors AZ Media
Portmann	Daniel	Koppigen	37	Heavy equipment operator
Randin-Monney	Gérard	Ependes	61	Railway clerk
Rodel Stellini	Eléonore	Lausanne	70	Display window decorator
Scharen	Adelheid	Frauenkappelen	68	Qualified Nurse, therapist
Schmutz	Margreth	Rheinfelden	53	Psychological counselor, SGIPA
Schor	André	Cortaillod	69	Retired postal clerk
Schwab-Blank	Pia	Sumiswald	38	Catechism teacher, housewife
Schweizer	Erwin	Thayngen	70	Chief technician, packing machines
Stadelmann-Vogt	Greti	Teufen	58	Home economics teacher, secretary
Studer	Monika	Winznau	58	Production worker
Trüeb	Joseph	Estavayer-le-Lac	45	Engineer HES
Tschabold	Daniel	Biel	23	Student
Yanef	Maryline	Grancy	46	Nursing Home Activity Director

* participated in the first preparatory weekend, but not in the PubliForum event of 23 – 26 January 2004
** participated in the first and second preparatory weekends, but not in the PubliForum event of 23 – 26 January 2004

Decisions are being taken

III Topics Chosen and List of Recommendations

1. Protection of the individual: How can the protection of the individual be ensured?

- The protection of particularly vulnerable people must be guaranteed in the context of all research
- With regard to third party liability insurance, uniform periods of liability for direct costs should be established. The insured must be adequately and accurately informed as to insurance coverage and its area of jurisdiction. The jurisdiction should be the locality or canton in which the research subject resides.
- Medical and above all psychological assistance must be available during and after the experiment.
- In order to protect the interests of persons in the care of a guardian, a place for mediation should be provided so that any problems arising can be resolved. The advice of an independent expert should be taken in such cases.
- Information for research subjects must be provided both in writing and in their mother tongue.
- Standardization of administrative proceedings would simplify the approval process and speed up the entire procedure.
- Each research subject must be able to leave the research project or revoke his consent without having to give a reason.

2. Ethics: How are decisions made regarding permission for research studies and their application?

The number of Ethics Commissions should be reduced while ensuring:

1) Cultural and regional diversity as well as
2) Safeguarding the quality of decisions.

- Experience sharing among Ethics Commissions should be facilitated.
- Mandatory ethical training for doctors and researches should be introduced.
- The right of the research subject not to be made aware of findings must be guaranteed.

3. Encouraging research: How can research on particular groups of people be encouraged?

- The special promotion of research on children and for children, pregnant women and disabled persons must, subject to special protection needs, become part of the new law. Possible measures are:
  - Incentives for industry, for example, by extending the duration of patents
  - State sponsorship financed by a "pennies for research" research tax (a fund generated by a sales tax imposed on the turnover of medicines)
  - Where appropriate, a mandatory requirement to carry out research benefiting these groups should be introduced, without which the licensing of the product could be placed in jeopardy.
- The law should provide incentives for research into the use, on the aforementioned groups, of medicines no longer protected by patent.
- Findings from the 'off label' use[1] of medicines on children and pregnant women should be recorded in international registers which are available to the public.

[1] *The medicines in question are used 'Off Label', i.e., under the supervision of a doctor but without permission of the authorities for use under the current indications, and where the risk to these patient groups (children, pregnant women) is not known precisely.*

4. Protection from abuse: How can abuse be prevented?

- There should be regional ombudsmen to whom research subjects can turn wherever abuse is so much as merely suspected.
- The law should be made concrete and explicit mention made of abuse. The law should be guided by international regulations.
- The law should be precise and reflect the needs of research as well as research subjects.
- In order to ensure that supplementary agreements and additional conditions are freely upheld, government incentives should be created.

5. Information: How accessible are research results?

- A register or database of all studies should be created which is generally available even to lay persons. This applies to the public availability of both positive and negative results.
- It should be ensured that all researchers who are responsible for communicating with patients or research subjects have completed training in communication skills.
- The falsification or manipulation of results must be punishable with a severity which is stipulated by law.
- With regard to the availability of results to research subjects and the communication of results, this should be guided by the Additional Protocol on Biomedical Research, particularly in terms of the Right to information (Article 28), Duty of care (Article 27), and Availability of results (Article 28).

6. Research and funding: Who pays for what?

- The state supports non-lucrative research (e.g., orphan diseases[2], research on children, pregnant women and disabled persons) through substantial financial contributions to the Swiss National Science Foundation. These resources should be supplemented through other revenue such as, for example, the introduction of a new research tax (a fund generated by the sale of medicines).
- In the interest of simplifying administrative procedures, indemnity insurance cover for research subjects should be regulated at national and, if possible, also at international level.

7. Data Protection: How is data protection regulated?

- We consider mandatory consent as well as the right to withdraw indispensable.
- An adaptation of regulations is urgently needed, that is, an internationally binding and comprehensive law must be created.
- Special protection must be provided for genetic information.
- Not all data should be accessible to insurance companies
- Patients should have to right not to know (the results of experiments). The wishes of the patient must be respected in all cases.
- The manner and means of encrypting data must be decided on a case by case basis.
- Everything not governed by the Law on Therapeutic Products must be embedded in law.

8. Swiss legislation in the international context: How is research on human beings regulated elsewhere?

- The Draft Additional Protocol of the European Commission's Convention on Human Rights and Biomedicine should serve as the basis and model for the drafting of the future law (on research on human beings).

[2] *Orphan diseases are illnesses whose occurrence is rare.*

- With regard to the transfer of research projects (abroad), we call for a requirement that sponsors and researchers who are based in Switzerland, and who plan research projects in a country which is not a signatory of this Protocol, must fulfill the regulations in force there, as well as the basic ethical norms and security guarantees contained in this Protocol. Where necessary, Switzerland may take appropriate measures.
- The capacity and authority for monitoring (for research on medicines as well as other fields) should be strengthened.
- The law must contain clear information on encoding and ensuring anonymity.
- The impartiality of members of the ethics commissions must be guaranteed.
- An impartial advice and information service must be created to which citizens (patients and research subjects) can address themselves for information on the research and its effects.

Listening and forming an opinion

IV Report of the Citizens Panel

The Report was entirely written up by the citizens themselves, with the exclusion of the next five footnotes (in italics) which were subsequently added by the Support Group in order to provide increased clarity to the points of information given to the Panel by the resource persons.

1. PROTECTION OF THE INDIVIDUAL: HOW CAN THE PROTECTION OF THE INDIVIDUAL BE ENSURED?

Questions from the Citizens Panel:

- *How can the protection of the individual be ensured during and after the research project? Additional protection for*:
  - *Children*
  - *Disabled persons*
  - *Mentally disturbed persons*
  - *Other persons not competent to give consent or make decisions*
  - *Unborn children*

- *Who gives consent to the research, particularly for these categories of persons?*
- *What are the implications for those who give consent?*

1.1 Responses of the resource persons: summary of the Citizens Panel

The Law on Therapeutic Products ensures the protection of patients, their integrity, dignity and health in exemplary manner. The fundamental principle is: research must be beneficial and have realistic aims. The foreseeable benefits must be greater than the risks undertaken. The research subjects must be carefully briefed and give their (informed) consent to the project. The research protocols are examined by an Ethics Committee consisting of persons qualified and competent in the field.
The research subject has the right to withdraw from the experiment at any time without having to provide grounds.
A checking mechanism[3] confirms that a research subject is not taking part in more than one research project at the same time, and that any results may thus be distorted and thus not valid.
Parents or legal representatives, and above all the individuals in question, must give their consent to the project.
For especially vulnerable people, increased protection is required.
After completion of the research project, medical and psychological follow-up support are lacking.
With regard to the information provided for research subjects, deficiencies are still apparent.

[3] *Today, this type of mechanism exists solely on a local/regional level in only the canton Ticino and in the region of "Basiliensis" and stems from private initiatives. Therefore, these controls are both incomplete and implemented on a voluntary basis. For the moment, it is still the responsibility of the person conducting the investigation to undertake an autonomous control.*

Monitoring inspections[4] are still inadequate and too infrequent (5 to 8%). Too much bureaucracy can, however, hinder research. There is a lack of consistency with regard to indemnity insurance for research subjects[5], and the possibility that insurance coverage may need to be valid abroad should be taken into account. Religious and spiritual aspects are neglected.
Caution should be exercised in recruiting subjects over the internet.

The Citizens Panel regrets that it received no response to the third question.

1.2 Opinion of the Citizens Panel

Generally speaking, protection of the individual is ensured. Certain aspects could be improved, namely, those affecting particularly vulnerable people. Overprotection may of course impede advancements in research.

1.3 Recommendations of the Citizens Panel

- The protection of especially vulnerable persons in the research setting must be guaranteed.
- With regard to indemnity insurance, uniform time periods for the direct assumption of costs following the research should be established. The person in question must be adequately and accurately informed as to insurance coverage and its jurisdiction. The jurisdiction should be the locality or canton in which the research subject resides.
- Medical and above all psychological support must be guaranteed during and after the research.
- In order to protect the interests of persons under guardianship, a place for mediation should be provided so that any problems arising can be resolved. The advice of an independent expert should be taken in such cases.
- Information for research subjects must be provided both in writing and in their first language.
- Standardization of administrative proceedings would simplify the approval process and speed up the entire procedure.
- Each and every research subject must be able to withdraw from the research project or revoke their consent without having to provide grounds.

[4] Clinical studies using human beings as subjects are authorized by the Ethics Commissions if they do not come under the Law on Therapeutic Products. The Ethics Commissions conduct no control on the implementation of the studies and on whether the conditions established have been respected. To date, only the canton Ticino can boast of an independent organ set up to defend the interests of the research subjects with respect to study implementation and complaints.

[5] Personal liability insurance (indemnity insurance to benefit subjects of research) should be tailored to the risks and specific circumstances of the research project in question. Standardization of such insurance policies could prove to be to the detriment of research subjects.

2. ETHICS: HOW ARE DECISIONS MADE REGARDING PERMISSION FOR RESEARCH STUDIES AND THEIR APPLICATION?

Questions from the Citizens Panel:

- *Who decides, from an ethical perspective, to grant permission for research projects, what criteria are used in making decisions, and who has established these criteria?*
- *What ethical criteria are used to permit the application of research findings?*

2.1 Responses of the resource persons: summary of the Citizens Panel

All research projects must be submitted to the Ethics Commission for examination. The composition of the Ethics Commission is balanced[6] (doctors, lawyers, citizens) and its members are qualified and competent. The Commission reflects the values of society. It has the authority to halt a project if doubts or problems arise. At the legal level, reference can be made to the Helsinki Declaration and human rights can be invoked. It is proposed that the name of the Commission is changed to, for example, 'Committee for Ethics and the Protection of Research Subjects'.
Too many Ethics Commissions[7] (32) complicate the approval process, especially when a research project extends to several cantons. Optional ethics courses in the training of doctors and researchers should be made mandatory.

2.2 Opinion of the Citizens Panel

The Ethics Commissions are a very good solution to the approval process. The decision-making criteria correspond to our expectations and are well safeguarded. The approval process could nevertheless be shortened or simplified without undermining the quality of decisions.

2.3 Recommendations of the Citizens Panel

- The number of Ethics Commissions should be reduced while ensuring:
  1. cultural and regional diversity as well as
  2. safeguarding the quality of decisions.
- Experience-sharing among Ethics Commissions should be encouraged.
- Mandatory ethical training for doctors and researchers should be introduced.
- The right of the research subject not to be made aware of findings must be guaranteed.

[6] *The composition of the Ethics Commissions set up to evaluate research projects using human beings as subjects has been laid down in the law. The Commissions are to include doctors, lawyers, representatives hailing from the domain of ethics in the strict sense (moral philosophers, priests) and representatives from the health-care branch. The role each of them plays is that of a citizen!*

[7] *As far as Switzerland is concerned, certain experts do not share this opinion. Nearly one-third of the existing Ethics Commissions are located in the cantons of Geneva, Vaud, and Zürich which are equipped with major university hospital centers. Several cantons which have no such hospitals serving them have signed agreements to create intercantonal Ethics Commissions with the result that since the 1990s, the number of Ethics Commissions has been in a constant decline.*

3. RESEARCH PROMOTION: HOW CAN RESEARCH ON PARTICULAR GROUPS OF PEOPLE BE PROMOTED?

Question from the citizens panel:

- *How can research on children, pregnant women and disabled persons be promoted?*

3.1 Responses of the resource persons: summary of the Citizens Panel

Research on children, pregnant women and the psychologically or mentally impaired is neglected on account of the high standards of protection which are rightly in force. In order to rectify this unwanted result, steps may be taken on three levels:
– Incentives
– Government promotion
– Mandatory commitments.
If research on these groups is carried out, it must benefit the groups themselves. It must also be ensured that the research takes place in an appropriate environment and is accompanied by an informed consent that is tailored to the group in question.

3.2 Opinion of the Citizens Panel

We are of the opinion that research on these special groups must be promoted, without any reduction in protection. With regard to possible measures to promote research, we agree with the opinion of the experts.
While research activity on pregnant women and children has increased, research on disabled persons has been neglected due to the high costs.

3.3 Recommendations of the Citizens Panel

- The special promotion of research on children and for children, pregnant women and disabled persons must, subject to special protection needs, become part of the new law. Possible measures are:
  – Incentives for industry, for example, by extending the duration of patents
  – State sponsorship financed by a "pennies for research" research tax (a fund generated by a sales tax imposed on the turnover of medicines)
  – Where appropriate, a mandatory requirement to carry out research benefiting these groups should be introduced, without which the licensing of the product could be placed in jeopardy.
- The law should provide incentives for research into the use, on the aforementioned groups, of medicines no longer protected by patent.
- Findings from the 'off label' use[8] of medicines on children and pregnant women should be recorded in international registers which are available to the public.

[8] *The medicines in question are used 'Off Label', i.e., under the supervision of a doctor but without permission of the authorities for use under the current indications, and where the risk to these patient groups (children, pregnant women) is not known precisely.*

4. PROTECTION FROM ABUSE: HOW CAN ABUSE BE PREVENTED?

Question from the Citizens Panel:

- *How can society and individuals be protected from the abuse of research results, for example, for military purposes?*

4.1 Responses of the resource persons: summary of the Citizens Panel

Abuse in research occurs when it is carried out:
- secretly or by deceit,
- forcibly (torture),
- against the will of the research subject
- without approval of the appropriate authorities
- by taking advantage of dependence
- with deliberate malice
- accepting a possible result of injury through gross negligence or deliberate intent
- involving immoral or perverted practices.

The wider application of results that have been achieved through unethical research is itself abusive.

Self-regulation:
From the legal point of view, it is impossible to subject the motives behind research projects and researchers to an examination. Abuse is often apparent only where there is actual injury. Where no injury occurs, it is always difficult to prove abuse. Anything is permissible which is not explicitly prohibited by law. Therefore personal responsibility on the part of both research subject and researcher must be strengthened. Research should not take place behind closed doors. The outward flow of information should be encouraged so that duplication of tasks and any overlapping can be avoided.

Rewarding inquiry:
Research results can have positive or negative effects, for example, dynamite: an enormous benefit in tunnel building, and yet a great danger in terrorism.

Use of performance enhancing drugs (doping):

The use of performance-enhancing drugs is an easily understandable example that illustrates the abuse of research findings. National and international regulations have practical application in this area. In the long term, performance-enhancing genetic modification must be kept under review. The industry should make it known whenever newly developed drugs can potentially be misused in order to enhance performance.

4.2 Opinion of the Citizens Panel

The abuse of research findings is a broad theme. It is therefore important to define clearly the aims and benefits of research so as to avoid abuse. Society is of course largely powerless to prevent the abuse of positive research findings. However, if abuse occurs, it must be possible to intervene and the legal means for applying sanctions must exist.
The desire for clear boundaries and maximum protection of experimental subjects and the desire to allow unrestricted research are sometimes in conflict.

The use of performance-enhancing drugs is a special case, since abuse, and the punishment of abuse, are very well regulated; however, other forms of abuse are much harder to prove. It is not realistic to apply the regulation of performance-enhancing drugs to other areas.
It is important to ratify and uphold the existing conventions (the Council of Europe's Convention on Human Rights and Biomedicine, as well as the Additional Protocol on Biomedical Research). We are of course aware that there are regulations whose provisions are not observed by influential firms and even by states for the reason that they have no fear of any retaliatory measures being taken.

4.3 Recommendations of the Citizens Panel

- There should be regional ombudsmen to whom research subjects can turn whenever abuse is so much as merely suspected.
- The law should be given substance and notice must be taken of abuse. The law should be guided by international regulations.
- The law should be precise and reflect research needs as well as the needs of research subjects.
- In order to ensure the observance of conventions complementing the law and supplementary framework conditions, government incentives should be created.

5. INFORMATION: HOW ACCESSIBLE ARE RESEARCH RESULTS?

Question from the Citizens Panel:
- *How, for whom and to what degree should research results (including negative results) be made available (e.g., to developing countries)?*

5.1 Responses of the resource persons: summary of the Citizens Panel

Information reaches in a transparent manner, either published in printed form in specialist journals and reviews or on the internet, all those for whom it is intended, i.e., circles of interest. Presently efforts are being made, in Switzerland and elsewhere, to enter all current clinical studies in an up-to-date register and make public all results – positive as well as negative. However, there are cases where certain research results are not publicized.

5.2 Opinion of the Citizens Panel

It is very important that the complete results, including negative findings, be made available to one and all, regardless of any implications, economic or otherwise.
Manipulation of results can occur either while they are being interpreted, or as a function of when and how they are being transmitted.

5.3 Recommendations of the Citizens Panel

- A register or database of all studies should be created which is generally available even to lay persons. This applies to the public availability of both positive and negative results.
- It should be ensured that all researchers who are responsible for communicating with patients or research subjects have completed training in communication skills.
- The falsification or manipulation of results must be punishable with a severity stipulated by law.

- With regard to the availability of results to research subjects and the communication of results, this should be guided by the Additional Protocol on Biomedical Research, particularly in terms of the Right to information (Article 28), Duty of care (Article 27), and Availability of results (Article 28).

6. RESEARCH AND FUNDING: WHO PAYS FOR WHAT?

Question from the Citizens Panel:

Who pays for what?

- *According to what criteria (law, regulation, self-regulation, economic factors, damages) do the various players decide and act?*
- *What are the consequences of these decisions and actions?*
  …for public health (the public interest)?
  …for health care costs?
  …non-lucrative (unprofitable) research?

6.1 Responses of the resource persons: Summary of the Citizens Panel

There are three main sources of funding:
– The pharmaceutical industry
– The public purse (Swiss National Science Foundation)
– Private institutions.

Industry makes decisions primarily according to economic criteria and carries out largely product-orientated research (basic and clinical research). Its aim is access to new medicines and medical products.
A further criterion is social responsibility and the associated enhancement of image.
The public purse sponsors mainly non-commercial basic research where it is convinced of its scientific value, thus promoting growth.
Investment by private institutions (e.g., Krebsliga) is guided by the aims which are proper to their own cause, and promote basic as well as clinical research.
All three funding sources have financial limitations. While the public purse suffers from budgetary constraints, the investment capabilities of industry depend on business trends.
The statements on the effects on health care costs were not completely unanimous.
When the deployment of financial resources leads to real progress, public health is enhanced.

6.2 Opinion of the Citizens Panel

The financing of commercial research appears to be ensured by the financial strength of the pharmaceutical industry. In contrast, we consider the financing of unprofitable projects to be insecure and under threat.
Bureaucratic obstacles to the approval process (e.g., the high cost of insurance coverage, the number of ethics commissions) threaten the competitive standing of Swiss research.

6.3 Recommendations of the Citizens Panel

- The state supports non-lucrative research (e.g., orphan diseases[9], research on children, pregnant women and disabled persons) through substantial financial contributions to the Swiss National Science Foundation. These resources should be supplemented through other revenue such as, for example, the introduction of a new research tax (a fund generated by the sale of medicines).
- In the interest of simplifying administrative procedures, indemnity insurance cover for research subjects should be regulated at national and, if possible, also at international level.

7. DATA PROTECTION: HOW IS DATA PROTECTION REGULATED?

Questions from the Citizens Panel:
- *How is data protection involving research on human beings regulated nationally and internationally? Under what conditions may data be released?*
- *What do you propose so that misuse of data cannot take place in Switzerland or abroad?*

7.1 Responses of the resource persons: Summary of the Citizens Panel

Only research into medical treatments is governed by its own specific law at national level. In all other cases general, non-standardized regulations apply. It is worth noting that in other countries legal documents specifically regulating data protection in the field of research are only rarely encountered.
Medical data relating to individuals, for example, genetic information, which may be indicative of future developments, particularly merits protection.
The following points require special attention:
- The gathering of data from and creation of biological material
- Consent of the person from whom the data or biological material originates
- Biobanks
- Protection of privacy
- General right to oppose the utilization of data
- The encryption of findings relating to individuals (not everything can be made anonymous)

7.2 Opinion of the Citizens Panel

There exists a great information deficit; citizens are often poorly informed and have no idea how their personal data, for example, in the area of biobanks, is used.
Research on medicines is well regulated, but other fields of research, sociological research, for example, require stricter guidelines.

7.3 Recommendations of the Citizens Panel

- We consider mandatory consent as well as the right to withdraw indispensable.
- An adaptation of regulations is urgently needed, that is, an internationally binding and comprehensive law must be created.
- Special protection must be provided for genetic information.
- Not all data should be accessible to insurance companies

[9] *Orphan diseases are illnesses whose occurrence is rare.*

- Patients should have to right not to know (the results of experiments). The wishes of the patient must be respected in all cases.
- The manner and means of encrypting data must be decided on a case by case basis.
- Everything not governed by the Law on Therapeutic Products must be embedded in law.

8. SWISS LEGISLATION IN THE INTERNATIONAL CONTEXT: HOW IS RESEARCH ON HUMAN BEINGS REGULAT ED ELSEWHERE?

Questions for the Citizens Panel:
- *How is research on humans regulated in other countries and how is it monitored?*
- *Under what circumstances do you see a danger that research on humans be transferred abroad and what consequences are associated with this?*
- *How should adherence to the planned law be guaranteed?*

8.1 Response of the resource persons: Summary of the Citizens Panel

Legislation in the area of research is complex and fragmented (there are laws for every relevant field of research and every sector).
There are two fundamental documents: the guidelines of the World Health Organization and the European Commission's Convention on Human Rights and Biomedicine, which will probably will be ratified by Switzerland in the year 2006. There is a danger of overregulation: the Additional Protocol of the European Commission's Convention on Human Rights and Biomedicine appears to be necessary and sufficient, and Swiss law can be inspired by it.
Article 29[10] of the Additional Protocol, which applies to research carried out in countries which have not signed the aforementioned Protocol, is of crucial importance.
In addition, there exists European guidelines on research involving medicines. There is a danger that certain research projects be relocated abroad for economic, legal or scientific reasons, which would have significantly negative consequences.
The question of encoding and ensuring anonymity in the context of research into living tissue is exceptionally fraught with problematic aspects.

8.2 Opinion of the Citizens Panel

Switzerland is well positioned in the European context.
It can be seen that the specialists are not unanimous as to how many ethics commissions are needed. The majority of experts welcome diversity and variety. The price that should be paid for this seems though to be a certain administrative slowness. There are thus conflicting rules of conduct: speed, transparency and quality of monitoring.

[10] *Article 29: Research in States not party to this Protocol: Sponsors or researchers within the jurisdiction of a Party to this Protocol that plan to undertake or direct a research project in a State not Party to this Protocol shall ensure that, without prejudice to the provisions applicable in that State, the research project complies with the principles on which the provisions of this Protocol are based. When necessary, the Party shall take appropriate measures to that end.*

8.3 Recommendations of the Citizens Panel

- The Draft Additional Protocol of the European Commission's Convention on Human Rights and Biomedicine should serve as the basis and model for the drafting of the future law (on research on human beings).
- With regard to the transfer of research projects (abroad), we call for a requirement that sponsors and researchers who are based in Switzerland, and who plan research projects in a country which is not a signatory of this Protocol, must fulfill the regulations in force there, as well as the basic ethical norms and security guarantees contained in this Protocol. Where necessary, Switzerland may take appropriate measures.
- The capacity and authority for monitoring (for research on medicines as well as other fields) should be strengthened.
- The law must contain clear information on encoding and ensuring anonymity.
- The impartiality of members of the ethics commissions must be guaranteed.
- An impartial advice and information service must be created to which citizens (patients and research subjects) can address themselves for information on the research and its effects.

References

The legal texts mentioned in the Report, as well as other references cited, are available for consultation at the website www.publiforum.ch or can be requested from TA-SWISS.

V Annex

A) Why hold a PubliForum dedicated to Research on Human Beings?

The unceasing advances being made in the world of science demand that society regularly update its rules and standards. Although Switzerland is not to be outdone in terms of regulations on this type of research, recent scientific progress represents a challenge to the norms in force. On the one hand, the stakes have changed with the emergence of new research technologies and methods such as the utilization of embryonic stem cells or other samples of biological material. On the other hand, Swiss legislation on the protection of research subjects is for the major part cantonal in origin, and hence not entirely systematic in character. For this reason, in 1998, the Federal Council (government) tasked the Administration to design a project for a federal framework law on research involving human beings. However, in order to comply with the scientific realities of the moment, it was decided before anything else to draft the law on surplus embryos from in-vitro fertilization and on human embryonic stem cells, i.e., the Embryo Research Law (ERL). Thus it transpired that the establishment of a global framework law on research involving human beings was postponed to a later date. If no referendum is demanded, the Embryo Research Law will enter into force in the summer of 2004.

TA-SWISS has been assigned the task of providing sound quality information to parliament on the benefits and risks emerging for society with the advent of new technologies. In order to fulfill its mission, TA-SWISS organizes multidisciplinary studies handing the floor over to the experts, as well as studies employing participative methods with the aim of exploring and documenting the simple citizen or layman's point of view. For indeed, numerous technological ventures are intrinsically associated with moral issues and choices grounded in the values of society. It is therefore desirable that representatives from the ranks of the common citizen be able to voice their opinions on the stakes involved, and that their desires, hopes and fears be included as early as possible into the emerging debate so as to facilitate the harmonious integration of technological innovations into society.

Research on human beings comprises a good number of aspects which raise issues having moral, medical, legal, social, and economic implications. To begin with, TA-SWISS addressed the issue of research on surplus embryos and embryonic stem cells by commissioning a study (Human Stem Cells, 2003) and a Publifocus [11] (Focus Group on Human Stem Cells, 2003).

With the formulation of the ERL nearly completed, the Administration was, from 2003 on, once again able to concentrate its resources on the draft law on research involving human beings. Ever mindful of keeping up with the latest happenings on the political scene, TA-SWISS had already programmed a PubliForum on the topic with the support of the Federal Office of Public Health (SFOPH), the Swiss Academy of medical Sciences (SAMS), and the Secretariat of the Swiss Science Agency. In addition to financial and organizational support, this cooperation enabled the PubliForum to stay in touch with any new developments in the draft law being formulated by the Federal Office of Public Health.

Initiation of the consultation procedure on the draft law on research on human beings is planned for early 2005. The scheduling of the PubliForum for January 2004 was programmed so that the results might be available at the beginning of the draft law formulation phase and for the opening of the consultation procedure. In this way, the viewpoint of the "citizens" would have the best likelihood of being included in the debates and in the positions taken by the competent circles concerned.

[11] *A participative method which is "softer "(in terms of investment) than a PubliForum and is based on group discussions organized in Switzerland's different linguistic regions.*

Submission of the report to a politician, Hans Widmer, Member of Parliament

B) Organizing and Running the PubliForum

The participative method known as the PubliForum is based on a model developed in Denmark known as the "consensus conference", which was adapted to the particular requirements of Switzerland, particularly to its linguistic diversity. The main actors in a PubliForum are the members of the Citizens Panel, approximately 30 in number, who have expressed their willingness to dedicate about ten days to discovering a theme heretofore unknown to them, to dialoguing with experts in the field and with their fellow citizens, and to authoring a written report on their hopes, fears, and recommendations.
In order to ensure that the PubliForum would be conducted in a competent, well-balanced and transparent manner, the groundwork preparations were supervised by a support group[12] composed of representatives from the fields of medicine, research, industry, the administration, and members of (political and patients) interest groups. This support group oversaw the compilation of a set of documentation on the theme of interest, drafted by the scientific journalist Ms. Lucienne Rey (TextRey), which was subsequently to be placed at the disposal of the citizens. It also assisted in recruiting resource persons and in conferring the final stamp of approval on the selection of citizens for the panel. The diverse professional backgrounds of the support team's members paved the way for the PubliForum to take place in conditions marked by transparency and a multiplicity of points of view and interests.
The citizens recruitment procedure was launched in the spring of 2003 with the mailing of an invitation to participate in the PubliForum to more than 10,000 individuals chosen at random from throughout Switzerland. Their addresses had been purchased from a private firm, the sole criteria being the gender, age, and linguistic region of the persons who would be contacted. Out of the 10,000 invitations sent out, about one hundred positive replies were received, accompanied by the duly filled-out, short questionnaire which had been sent out along with the invitation. The questionnaire was intended to provide the organizers with information about the profession and the motivation of those interested in participating. Out of these 100 or so potential candidates, 29 were chosen in such a way as to form a well-balanced panel in terms of gender, age, representation of Switzerland's linguistic regions and, inasmuch as possible, different professions.

In preparation for the PubliForum main event, the selected participants met for a first preparatory weekend at the Münchenwiler Castle, near Murten, in early November 2003. During the weekend, they became acquainted with one another, were introduced to the method in which a PubliForum operates, and were provided with information on the theme of "Research on Human Beings". Four specialists were commissioned to give as unbiased and even-handed a presentation as possible on the various aspects of the issue, and a large set of documentation was placed at their disposal. On the second day of this first weekend, the citizens dedicated their efforts to choosing the aspects they would like to delve into more deeply during the PubliForum event.
Early in December 2003, a second preparatory weekend was held at the Swiss Red Cross Training Center in Notwill, not far from Luzern. There the participants undertook to hone down and formulate their questions. They also went on to choose the resource persons (specialists) who would be invited to the PubliForm to reply to these questions. As for the resource persons, they were chosen from a list of over 100 experts on the basis of questionnaires which they had filled out in expressing their readiness to be of service to the citizens. The idea was for the citizens to be able to decide on their own with whom they would like to dialogue out of a range of specialists representing various professions and interests (medicine, research, health-care personnel, law, ethics, politics, and patients groups). These questionnaires allowed the citizens to get an idea not only of the resource person's professional achievements, but also of his or her position with respect to the implications and challenges of research on human beings. In the

[12] *See the list of support group members hereto annexed.*

end, the citizens chose 17 resource persons who would be invited to reply to their 8 principal questions. The organizers had recommended that the panel choose something like 2 or 3 resource persons for each of their questions so as to be able to compare different points of view.

The PubliForum main event was held from Friday, 23 January to Monday, 26 January 2004 at the Inselspital in Bern. Mrs. Bettina Schulte, Head of the Specialist Unit for Biomedicine at the Federal Office of Public Health, was called upon to convene the PubliForum. In her opening remarks, she underscored the numerous challenges associated with regulating research on human beings and the corresponding interest that the Citizens Panel report would undoubtedly elicit.
Following these remarks, the dialogue between the Panel and the resource persons – open to the general public – was able to get underway. During these first 2 days, the citizens listened to the resource persons and discussed the issues with them on the basis of the questions which the Panel had formulated. With 17 resource persons present and each of them disposing of 20 minutes time to interact with the Panel, the two-day programme represented a full workload characterized by very intense interchange. The discussions were marked by a spirit of extreme openness and an unmistakable culture of dialogue. A number of disagreements among the experts came out into the open, leaving the citizens free to take a stand dictated by their own personal convictions.
On Sunday morning 25 January, the members of the Citizens Panel retired "behind closed doors" to compile a common report. In the first phase, they divided themselves up into groups to draft the individual chapters. Later on, each of the chapters was minutely discussed in a plenary session, so that in the end each member of the Panel would be able to identify himself with the report in its entirety and not only with those chapters his or her group had worked on. These final discussions and the task of writing up the report went on until well into the wee hours of Monday morning.

The Citizens Panel report was publicly presented to representatives from the realm of politics at the closing ceremonies held on Monday, 26 January 2004. On this occasion, Mrs. Christiane Langenberger, member of the Council of States and President of the Committee for Science, Education and Culture (CSEC) was invited along with Mr. Hans Widmer, National Councillor and member of the CSEC to receive the report directly from the hands of the citizens. However, Mrs. Langenberger and Mr. Widmer had already received a copy to familiarize themselves with that same morning, and thus were able to form an opinion on the contents of the report beforehand. Both of them stated they were impressed by the quantity and the quality of the work accomplished by the Panel in so short a time and on so complex a theme. As was pointed out by Mrs. Langenberger and Mr. Widmer, the Citizens Panel had indeed succeeded in making its fundamentally positive attitude toward such research understood, while at the same time identifying the subtle issues at stake which necessitate particular attention, such as the protection of especially vulnerable persons, the promotion of research on "neglected" groups (children, pregnant women, and handicapped persons), and the question of data protection. In concluding, they stated that the concrete and pertinent recommendations of the Panel would provide policy-makers with food for thought. Both Mrs. Langenberger and Mr. Widmer made the commitment to be instrumental in diffusing the Panel's report among the members of their respective circles, notably within the CSEC which will be tasked with examining the draft framework law on research involving human beings.
Mr. Stauffacher, President of the Swiss Academy of Medical Sciences, equally expressed high praise for the work the Panel had done, highlighting the clear-sighted vision of the participants in dealing with so complex an issue. Mrs. Verena Schwander of the Federal Office of Public Health and project director for drafting the law on research involving human beings expressed her profound interest in the recommendations of the Citizens Panel and gave her assurance that they would be examined during the process of formulating the law.The closing remarks were made by Mr. Hug, President of the TA-Swiss Executive Committee, who warmly thanked the citizens for their high-quality work and their commitment.

C) Programme

First preparatory weekend, Schloss Munchenwiler (bei Murten)

Saturday, 1 November 2003

10:00 **Introductions**
Organizers and participants introduce themselves

11:00 **PubliForum 'Research on Humans'**
What is a PubliForum?

11:30 **Research on Humans: Definitions and Questions**
General introduction by Dr. Bertrand Kiefer, Journal 'Medecine et Hygiene'
Questions and discussion

12:15 Lunch

13:45 **Scientific and medical aspects of research on humans**
Presentation by Prof. Fritz Buhler, Cantonal Hospital, Basel, European Centre of Pharmaceutical Medicine
Questions and discussion

14:30 **Research on humans: ethical questions**
Presentation by Dr. Andrea Arz de Falco, Federal Office of Public Health
Questions and discussion

15:15 Coffee

15:45 **Legal issues raised by research on humans**
Presentation by Dr. Christoph A. Zenger, University of Berne, Institute for Public Law
Questions and discussion

16:30 Break

16:45 **What are the chances and risks of research on humans?**
Discussion in workshops

17:45 **Format and ground rules of the PubliForum**
Organizers present the main stages and ground rules
Plenary discussion

Sunday, 2 November 2003

9:00 **Review of the first day**
Plenary discussion

9:30 **Which issues would we like to consider during the PubliForum?**
Discussion in workshops

10:30 Coffee

11:00 **Which issues would we like to consider during the PubliForum?**
Feedback of workshop findings in plenary session

12:00 Lunch

13:45 **Look ahead to the next step**
Selection of resource persons, meeting with the support group, contact with the media

14:15 **Which issues would we like to consider during the PubliForum?**
Plenary discussion

15:15 Break

15:30 **Which issues would we like to consider during the PubliForum?**
Plenary discussion

16:30 **Review of the weekend**

17:00 End of the first preparatory weekend

Second preparatory weekend in Nottwil

Saturday, 6 December 2003

10:00 **Current status of the work, organization of the day**

10:30 **Formulating questions, agreeing answers and compiling a report: Some tips**
Walter Grossenbacher (TA-SWISS)

11:00 **Which questions do we want to consider during the PubliForum? (continued)**

Coffee break

Which questions do we want to consider during the PubliForum? (continued)

18:00 **A parliamentarian's experience of the PubliForum**
Pierre-Alain Gentil (Council of States)

18:30 **Summary of the day and preparation for tomorrow's session**

19:30 Dinner and free time for citizens panel members

Sunday, 7 December 2003

9:00 **Which resource persons to choose?**

Coffee break

Which resource persons to choose?

12:30 Lunch

14:00 **Which resource persons to choose?**

Pause

Which questions do we want to consider during the PubliForum? Final decision on the questions (translation)

Summary and further work

16:30 End of the second preparatory weekend

PubliForum Main Event in Inselspital, Bern

Friday, 23 January 2004, Inselspital, Bern

10:00 **Welcome**
Dr. Sergio Bellucci, Managing Director, TA-SWISS

10:05 **Opening remarks**
Dr. Bettina Schulte, Federal Office of Public Health, Head of the Specialist Unit for Biomedicine

10:20 **Questions from the Citizens Panel**

1. Protection of the individual

How can the protection of individuals be ensured during and after the research project?
Additional protection for:
- *Children*
- *The disabled*
- *The mentally ill*
- *Other persons not competent to give consent*
- *Unborn fetuses*

Who gives consent for research, particularly on these groups?

What are the implications for those who give consent?

Resource persons:
- **Severine Boillat**, Institute for Health Law, University of Neuenberg
- **Dr. med. René Hefti**, Foundation for Holistic Medicine Clinic for Psychosomatics/Medichthys
- **Prof. Dr. med. Christian Kind,** East Switzerland Children's Hospital
- **Prof. Dr. med. Michel B. Vallotton**, Central Ethics Commission of the Swiss Academy of Medical Sciences

12:15 **Buffet lunch**

14:00 **Questions from the Citizens Panel**

2. Ethics

From an ethical perspective, who decides to give permission for research projects, what criteria are used to decide, and who established these criteria?

From an ethical perspective, according to what criteria is access to research findings permitted?

Resource persons:

- **Dr. med. Suzanne Braga**, Swiss Society for Medical Genetics
- **Dr. med. Robert Kenzelmann**, Swissmedic
- **Prof. Dr. Beat Sitter-Liver**, Professor of Philosophy

15:15 **Questions from the Citizens Panel**

3. Information

How, to whom and to what extent are research findings (negative as well) made available (e.g., to developing countries as well)?

Resource persons:
- **Dr. Marianne Maman**, Novartis Pharma AG-Clinical Development and Medical Affairs
- **Prof. D. med. Michel B. Vallotton**, Central Ethics Commission of the Swiss Academy of Medical Sciences

16:00 Coffee break

16:30 **General discussion between the Citizens Panel and resource persons**

18:00 **Conclusion**

Saturday, 24 January 2004, Inselspital, Bern

08:30 **Questions from the Citizens Panel**

4. Research and money

Who finances what?

According to what criteria (legal/regulatory/self-regulatory/economic factors/compensation) do the various parties make decisions and act?

What are the implications of these decisions and actions?
…for public health (public interest)?
…for health care costs?
…non-lucrative research?

Resource persons:
- **Prof. Dr. med. Franco Cavalli**, National Council, Istituto Oncologico della Svizzera Italiana
- **Dr. med. Peter Kleist**, Novartis Pharma Schweiz AG
- **Dr. Yilmaz Aysim**, Swiss National Science Foundation

09:45 Coffee break

10:15 **Questions from the Citizens Panel**

5. Protection from abuse

How can society and individuals be protected from the abusive use of research findings?
For example, the use of performance-enhancing drugs, or military applications

Resource persons:
- **Dr. Matthias Kamber**, Federal Office of Sports
- **Prof. Dr. Rainer J. Schweizer**, University of St. Gallen, Research Team for Jurisprudence
- **Dr. Michael Seiberling**, Swiss Pharma Contract Ltd.

11:30 Break

11:45 **Questions from the Citizens Panel**

6. Encouraging research into targeted areas

How can research on children, pregnant women and the disabled be encouraged?

Resource persons:
- **Dr. med. Hermann Amstad**, Swiss Academy of Medical Sciences
- **Dr. Peter Kleist**, Novartis Pharma Schweiz AG

12:30 Buffet lunch

14:00 **Questions from the Citizens Panel**

7. Data protection

How is data protection with regard to research on humans regulated nationally and internationally?

What do you suggest so that the misuse of data does not occur in Switzerland or abroad?

Resource persons:
- **Prof. Dr. Rainer Schweizer**, University of St. Gallen, Research Team for Jurisprudence
- **Dr. Caroline Trouet**, Center for Biomedical Ethics and Law, Belgium

14:50 Questions from the Citizens Panel

8. Swiss legislation in the international context

How is research on humans regulated in other countries and how is it monitored?

When do you see a danger that research on humans moves to other countries and what are the implications of this?

How should observance of the planned law be safeguarded?

Resource persons:
- **Prof. Dr. Rainer Schweizer**, University of St. Gallen, Research Team for Jurisprudence
- **Dr. Caroline Trouet**, Center for Biomedical Ethics and Law, Belgium

15:45 Coffee break

16:15 **General discussion between the Citizens Panel and resource persons**

18:00 **Conclusion**

Sunday, 25 January 2004

The panel members compile the Citizens' Report (not open to the public).

Monday, 26 January 2004, Inselspital, Bern

10:00 **The Citizens Panel presents its report**

10:30 **Reaction from the audience and discussion**

11:00 **Conclusions**

Dr. Hans Widmer
Member of the Committee for Science, Education and Culture (CSEC National Council)

Christiane Langenberger
President of the Committee for Science, Education and Culture (CSEC Council of States)

Prof. Dr. med. Werner Stauffacher
President of the Swiss Academy of Medical Sciences (SAMS)

Dr. Verena Schwander
Federal Office of Public Health

Dr. Klaus Hug
President of the TA-Swiss Executive Committee

12:00 **Refreshments and conclusion of the PubliForum**

The citizens' panel is preparing itself over four days

D)

D) Organization

D1) Support Group

- **Bondolfi Alberto**, Centre Lémanique d'Ethique, Universities of Lausanne and Geneva, member of the group of experts tasked with developing the draft law on research on human beings
- **Dormann Rosmarie**, Former member of the National Council
- **Egger Matthias**, University of Bern, Institute for Social and Preventive Medicine
- **Glassey Olivier**, Observatoire EPFL Science Politique et Société, Federal Institute of Technology in Lausanne
- **Kessler Margrit**, President of the "Organization of Swiss Patients" Foundation
- **Kummer Hans**, President of the "Cantonal Ethics Commission (KEK) of the two Basels"
- **Lüscher Thomas**, University of Zürich, Department of Internal Medicine, Cardiologist
- **Meier-Seethaler Carola**, Psychotherapist, member of the Swiss National Advisory Commission on Biomedical Ethics
- **Mühlemann Kathrin**, University of Bern, Institute for Infectious Diseases, member of the Executive Committee of the Swiss Academy of Medical Sciences
- **Niese Detlef**, Clinical Research and Development, Novartis Pharma AG
- **Pellaud Francine**, Maître assistante (Research Assistant) in Educational Sciences, University of Geneva, and member of the TA-Swiss Steering Committee
- **Sprumont Dominique**, Assistant Director of the Institute for Law on Health Issues, University of Neuchâtel
- **Waldner Rosmarie**, Scientific journalist, Zürich, member of the TA-Swiss Steering Committee, President of the Support Group

D2) Sponsoring Committee

- **TA-SWISS**, Berne, represented by Bellucci Sergio, Director
- **State Secretariat of the Swiss Science Agency**, Bern, represented by Fitzli Dora, Policy Advisor
- **Federal Office of Public Health**, Bern, represented by Krapf Dolores, Jurist
- **Swiss Academy of Medical Sciences**, Basel, represented by Leuthold Margrit, Secretary General

D3) Organization

- **Stantchev Alexia**, TA-SWISS, PubliForum Project Manager
- **Bobst Tamara**, TA-SWISS, Trainee, Assistant in the PubliForum project
- **Grossenbacher Walter**, TA-SWISS, Responsible for Public Relations
- **Membrez Françoise**, TA-SWISS, Secretariat
- **Rüegsegger Adrian**, TA-SWISS, Responsible for domain «Biotechnology and Medicine»
- **Vouilloz Nicole**, TA-SWISS, Trainee
- **Walpen Brigitta**, TA-SWISS, Secretariat

D4) Moderation and Mediation

- **Bütschi Danielle**, Co-moderator
- **Egger Urlich**, Philips & Partner AG, Zürich, Moderator and Mediator