

**A l t e r n a t i v e s 2 0 0 1 : R e s e a r c h
P l a n k S u m m a r y
A u g u s t 2 3 - 2 6 , 2 0 0 1
P h i l a d e l p h i a , P e n n s y l v a n i a**

**CSX RESEARCH PLANK:
Principles & Policy Positions**

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CSX Research Principles

- **We believe that research ought to and can enhance consumer choice, power, and knowledge.**
- **We oppose the unethical treatment of people participating in research, and oppose the use of unethical research.**
- **We believe that the civil rights of every research participant are always more important than the success or rigor of any research effort, or the “public good” that may be served by such research.**
- **We believe that participant choice is the core principle of all research and should animate every research decision and protocol.**
 - **Choice is only real when complete and understandable information is provided to all participants (true *informed* consent).**
 - **Choice is only real when there is no coercion, and those people who decline to participate in research are respected.**
- **We believe that research which involves the collection of data about humans (from clinical trials to focus groups and outcome evaluations) can pose risks**

to participants.

- **We believe that all research should strive to minimize risks to participants by providing supports and implementing safeguards.**
- **We believe that all research should be reviewed by an external board composed of experts (including the participants of research) for benefit and subject safety.**
- **We believe that the CSX community needs to be meaningfully and respectfully involved over time and with real power in all levels of research and evaluation.**
- **We believe that CSX researchers should seek ways to collaborate with both traditional researchers and research institutions, as well as seek support for CSX-driven and conducted research.**
- **Research should be funded to address the priorities of the CSX community.**
- **We believe that research protocols must address the needs of culturally and otherwise diverse populations.**

CSX Policy Positions: Research Involvement

- Research can be a voice of the CSX community. The CSX community needs to organize, educate, and empower consumers to recognize the value of research, and to use research to promote the goals of the CSX community.
- The CSX community encourages CSX researchers to reach out and support the CSX advocacy movement.
- The CSX community calls for mechanisms to support consumer access to research data and the broad distribution of data to research participants and the CSX community.
- The CSX community recognizes the need for the following educational initiatives to be funded:

- **Educate the CSX community about research methods.**
- **Educate the CSX community around different models of CSX participation in research**

- **Educate CSX research participants/subjects about the risks, benefits, and rights of participants involved in research.**

- The CSX community promotes the partnership of CSX researchers and established research institutions, and efforts for consumer involvement in all aspects of research, human subjects protections, and the investigation of issues that are important to the CSX community.
 - **CSX researchers are encouraged to seek ways to partner with other disability and health advocacy movements.**

 - **CSX researchers are encouraged to seek ways to partner with other mental health organizations where goals are common.**

- The CSX community advocates for consumer involvement in (1) setting research agendas such as federal research priorities, (2) reviewing research grants, (3) writing research announcements and setting proposal requirements, (4) participating on advisory boards, and, (5) being members of editorial boards for peer review research journals.

- The CSX community recommends that public and private research agencies fund the following:
 - **Technical Assistance Center for CSX Research and Training.**
 - **CSX Research and Evaluation Training Institute and/or Conference.**
 - **Clearing house for CSX research and data.**
 - **Develop a directory of CSX researchers.**
 - **Dialogue process between traditional mental health researchers and CSX researchers.**

- The CSX community recommends that CSX researchers undertake the following:
 - **Create standards of excellence for CSX involvement in research.**
 - **Develop an evaluation protocol for determining the quality of CSX participation in research.**
 - **Identify and recognize exemplary CSX research and models of CSX**

research involvement (e.g., awards).

- The CSX community supports equal pay for equal work at all levels of research participation.

CSX Policy Positions: Research Involvement

- The CSX community promotes the collection of data in all research endeavors that is relevant to diverse CSX populations such as age, gender, sexual preference, ethnicity, disability.
- The CSX community advocates for all research protocols to be culturally sensitive to language and regional differences of participants.

- The CSX community calls for the elimination of stigmatizing language by researchers and in research publications. This can be accomplished by supporting consumer training of researchers and editorial boards about how to use stigma-free language.

CSX Policy Positions: Design & Implementation

- The CSX community supports efforts to dispel or critique false research.
- The CSX community opposes the misuse of research to degrade or coerce CSXs.
 - In issues of recruitment, cross-over, withdrawal, and the selection and use of control groups, the values represented by the CSX movement require that the well-being of CSX research participants is held ABOVE the “gold standard” of scientific rigor.
 - Where peer alternatives are researched, the CSX community advocates for the meaningful and respectful involvement of CSXs on all levels, and that both qualitative and quantitative data are collected and analyzed.
- The CSX community recommends that in biomedical research follow-up research should be funded to monitor any long term side

effects of the study.

- The CSX community recommends that public and private research agencies fund the development of (1) CSX instruments and scales, (2) fidelity models and implementation studies of peer services, and, (3) the study of negative outcomes of coercion, seclusion, restraints, involuntary commitment, and all other forms of involuntary “treatment.”

CSX Policy Positions: Human Subjects Protections

- The CSX community demands meaningful and respectful involvement of CSXs within the NBEC (National Bioethics Commission) as well as other committees or commissions that are setting policies regarding human subjects protections.
- The CSX community proposes the establish a CSX Commission for the Protection of Human Research Subjects.
 - **This commission will review human subjects protections and identify both unethical and exemplary practices in research.**
 - **This commission will develop human subject protection statements and policies.**
- **The Research Plank recognizes the following:**
 - **There is a tension in the CSX community between supporting the principle of consumer choice and insuring the protection or safety of research participants.**
 - **Some consumers argue that breakthroughs in biomedical research, especially pharmaceutical research, are important for consumer choice and recovery.**
 - **Ways to do biomedical research while minimizing risk must be explored to find a way to strike a balance between choice and protection.**
- Subsequently, there is no consensus at this time regarding CSX opposition to challenge studies, wash-out studies, and the use of placebos even though such research practices could pose a risk to the individual.
- Researchers should respect CSXs who decide to decline participation in research projects. The CSX community calls

for the abolishment of the practice of repeated contacts of researchers to recruit a potential subject who has declined participation, and/or the use of “converters” to recruit people who have previously declined.

CSX Policy Positions: Internal Review Boards (IRBs)

- The CSX community supports the meaningful and respectful involvement of CSXs on IRBs.
 - **Prior to service, CSXs must receive training for participation on IRBs.**
- The CSX community calls for the review by an IRB of all forms of research and evaluation (including quality improvement data collection and the use of focus groups) conducted by public and private agencies or groups

CSX Policy Positions: Informed Consent Protocols

- **The CSX community demands full disclosure of risks and benefits to potential research participants including but not limited to the following recommendations:**
 - **In any research project that involves CSXs as subjects, a booklet should be developed which contains the important information needed by a CSX when deciding whether or not to participate in the research project.**
 - **The consent form must be *fully* comprehensible to the participant.**
- **The consent form should be developed by someone other than the researcher directing the study.**
- **There should be repeated full disclosure at regular intervals during a study.**

- **A consent monitor and/or research ombudsperson independent of the research project should be created.**
- The informed consent process should only be used to fully inform the research participant and should NEVER be primarily used as a legal means to limit liability to the research institute.
- Adequate consent processes do not necessarily justify the assumption of research risks by study participants. Researchers have the primary responsibility for participant safety and must be regulated, controlled, and monitored for human subjects protections.

Next Steps

- The Research Plank Committee will continue the consensus process at both the national and local levels.
 - **Create a web-based survey**
 - **Create a toolkit to assist people in facilitating additional research dialogues**
 - **Work with biomedical scientists to explore ways to protect research participants in pharmaceutical research.**
 - **Write a white paper (November 2001)**
- The Research Plank Committee will support the work of all the CSX planks
 - **Conduct literature reviews**
 - **Provide clearinghouse services for (1) current and unpublished research, (2) research resources, and (3) researcher contact information.**