

Subject:  <b>RESEARCH PARTICIPANTS' RIGHTS</b>	Issued By:  ADMINISTRATION		
	Approved By: Kathleen R. Hurtado President & CEO		
Policy #: 100	Issue Date: June 15, 2005	Revised Date: June 2, 2008	Effective Date: June 15, 2008

References: Revised from LAC + USC Healthcare Network Policy #100 and original HRA Patients' Rights Policy dated 7-11-75 and updated as of 6-15-2005.

**PURPOSE**

To ensure that Research Participants are informed as to their rights and that those rights are protected at all times.

**POLICY**

HRA's programs and services shall comply with all U.S. and California legal and regulatory mandates that provide for Research Participants' rights when receiving treatment, health evaluations, and/or observation.

**GUIDELINES**

1. **POSTING BILINGUAL COPIES OF RESEARCH PARTICIPANTS' RIGHTS:** In common areas to which Research Participants have access – as well as in areas where Research Participants may receive treatments, evaluations and/or observations – Research Participants' rights must be posted in both English and Spanish;
2. **RESEARCH PARTICIPANTS WITH MENTAL DISORDERS:** Areas providing care for the mentally disordered shall comply with all aspects of the California Welfare and Institutions Code. (For more info look here: [http://www.leginfo.ca.gov/html/wic\\_table\\_of\\_contents.html](http://www.leginfo.ca.gov/html/wic_table_of_contents.html));
3. **RESEARCH PARTICIPANTS' RIGHTS ORIENTATION:** All HRA Staff Members, Volunteers, Students and Independent Contractors who come in contact with Research Participants must receive an orientation covering Research Participants' rights and responsibilities as follows:

**RESEARCH PARTICIPANTS' RIGHTS**

1. **NOT TO BE DISCRIMINATED AGAINST:** Research Participants must have reasonable access to available medically-indicated treatments regardless of gender, race, color, age, creed, national origin, religious background, marital status, sexual orientation, claims history and/or their source of payment for care;

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2. **TO HAVE CONSIDERATE AND RESPECTFUL CARE:** Considerate and respectful care must be afforded to all Research Participants, including, but not limited to the following: consideration of psychosocial, spiritual, and cultural values which may influence their perception of illness.  
  
For more information, please see HRA's Considerate and Respectful Care Policy located here: <http://www.health-research.org/files/Considerate.pdf>;
3. **TO KNOW THE NAMES OF CAREGIVERS:** Research Participants have a right to know the name of the physician who has primary responsibility for coordinating their care and the names and professional relationships of other physicians and non-physicians who will see them;
4. **TO RECEIVE INFORMATION ABOUT THEIR CONDITION THEY CAN UNDERSTAND:** Research Participants have a right to receive information from their physician about their illness, course of treatment, and their prospects for recovery in terms that the Research Participant can understand;
5. **TO RECEIVE ENOUGH INFORMATION TO GIVE INFORMED CONSENT:** Research Participants have a right to receive as much information about any proposed treatment or procedure they may need in order to give informed consent or to refuse a course of treatment;
6. **TO ACTIVE PARTICIPATION:** Research Participants have the right to actively participate with their physician in decisions regarding their medical care and any ethical issues that arise regarding such care. To the extent permitted by law, this includes the right to refuse treatment;
7. **TO PRIVACY:** Research Participants must be afforded full consideration of privacy concerning their medical care program. Case discussions, consultations, examinations and treatments are confidential and should be conducted discretely. The Research Participant has the right to be advised as to the reason for the presence of any individual;
8. **TO CONFIDENTIAL TREATMENT:** Research Participants must be afforded confidential treatment of all communications and records pertaining to their care and their stay in the hospital and/or treatment center. A Research Participant's written permission shall be

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obtained before their health/medical record is made available to anyone not directly concerned with their care;

9. **TO REASONABLE RESPONSES:** Research Participants have a right to receive reasonable responses to any requests they may make for service within a hospital's and/or a treatment center's capacity and mission and within applicable laws and regulations;
10. **TO LEAVE TREATMENT CENTER:** Research Participants have the right to leave the hospital, and/or treatment center, even if it is against the advice of physicians;
11. **TO CONTINUITY OF CARE:** Research Participants have the right to a reasonable continuity of care and to know, in advance, the time and location of appointments and the identity of persons providing their care;
12. **TO REFUSE TO PARTICIPATE IN RESEARCH:** Research Participants have a right to be advised if healthcare providers propose to engage in or perform human experimentation affecting their care or treatment. The Research Participant has the right to refuse to participate in such research;
13. **TO BE INFORMED OF CONTINUING HEALTHCARE REQUIREMENTS:** Research Participants have a right to be informed of any continuing healthcare requirements following discharge from the hospital or treatment center;
14. **TO HAVE THEIR BILL EXPLAINED:** Research Participants have the right to examine – and to receive an explanation of – their bill regardless of source of payment;
15. **TO BE MADE AWARE OF RULES & POLICIES:** Research Participants have the right to be made aware of hospital and/or treatment center rules and policies that apply to their conduct while a Research Participant;
16. **TO HAVE RESEARCH PARTICIPANTS RIGHTS TRANSFERRED TO SURROGATE:** Research Participants have the right to have all Research Participant rights apply to a person who has legal responsibility to make medical decisions on their behalf;
17. **TO APPOINT A SURROGATE:** Research Participants have a right to formulate an advance directive that will guide physicians and staff should the Research Participant become unable

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to actively participate in decisions regarding their treatment or the withholding of treatment. This includes the right to appoint a surrogate to make health care decisions on their behalf to the extent permitted by law (provisions of care are not conditioned to the existence of an advance directive and an advance directive may be withdrawn by the Research Participant at any time);

18. **TO HAVE COMPLAINTS FORWARDED TO ADMINISTRATION:** Research Participants have the right to have their complaints forwarded to the hospital's and/or treatment center's administration for timely response.

**RESPONSIBILITY**

**All Research Participants, Staff Members, Volunteers, Students and Independent Contractors who come into contact with Research Participants are subject to this policy. Failure to comply with applicable provisions of Research Participants' rights policies shall result in disciplinary action and/or may lead to civil and/or criminal charges in accordance with the law.**

**REFERENCES**

California Code of Regulations, Title 22, Section 70707  
California Welfare and Institutions Code, Section 5325  
DHS Policy #322