

This work is licensed under a [Creative Commons Attribution-NonCommercial-ShareAlike License](https://creativecommons.org/licenses/by-nc-sa/4.0/). Your use of this material constitutes acceptance of that license and the conditions of use of materials on this site.



Copyright 2006, The Johns Hopkins University and Chris Beyrer. All rights reserved. Use of these materials permitted only in accordance with license rights granted. Materials provided "AS IS"; no representations or warranties provided. User assumes all responsibility for use, and all liability related thereto, and must independently review all materials for accuracy and efficacy. May contain materials owned by others. User is responsible for obtaining permissions for use from third parties as needed.



# Research Ethics and Human Rights

*Dr. Chris Beyrer*

Depts. of Epidemiology and  
International Health

Johns Hopkins School of Public Health

**Section A:**  
**The Universal Declaration of  
Human Rights**

# Human rights and research ethics

- ◆ Human rights and research ethics share the same roots in Nazi Germany
- ◆ Universal Declaration of Human Rights passed by United Nations on December 10, 1948
  - Defines the human rights of persons and violations of those rights
  - A universalist document

# Universal Declaration of Human Rights

Important resolutions include:

- ◆ Article 4: Prohibits slavery
- ◆ Article 5: Prohibits torture
- ◆ Article 18: Freedom of thought
- ◆ Article 19: Freedom of opinion and of expression
- ◆ Article 25: Standard of Living (includes access to medical care as a human right)

# **Universal Declaration of Human Rights: A universalist document**

- ◆ Importance of being a universalist document
- ◆ Recent challenges to the universalist characteristics include:
  - the Declaration is a tool of the West or U.S.
  - Challenges to what is a fundamental right (respect for authority, right to work, ect)

# Universal Declaration of Human Rights: A universalist document (cont.)

- ◆ The Declaration originated from two events:
  - The atrocities of Nazi Germany
  - Reaction to European colonialism
    - Asian and Africa governments insisted during the drafting of the Declaration that their people shared the same rights as colonialist

**Section B:**  
**The interaction between human  
rights and research ethics**



# The interaction of human rights and research ethics

- ◆ Gross abuses of research ethics can be human rights violations
  - ex: offering an experimental drug to a patient without their informed consent
- ◆ Human rights violations may lead to health risks and health problems that need to be investigated to document both the health problems and human rights violations

# Human subjects research with those whose rights have been violated

- ◆ Under what context can the rights of human subjects whose human rights have been violated give informed consent?
- ◆ When would the study propose an unacceptable level of risk?
- ◆ When would it generate no expected benefit?
- ◆ Who can review the ethical premise of the research?
- ◆ How can you best protect the study subjects and field teams?

# Human subjects research with those whose rights have been violated (cont.)

- ◆ Do we have an ethical obligation to conduct research on those whose rights have been violated?
- ◆ Is it too difficult to ensure the safety of subjects, colleagues, ourselves?
- ◆ Are there circumstance where we could not ethically conduct research?

**Section C:  
Case Study:  
A U.S. Women's Jail**

# Health and Rights Issues

- ◆ Local Women's Jail and Detention Center have poor standards health care, hygiene, nutrition
- ◆ Lengthy time delays from entry to receiving medication
- ◆ High prevalence of HIV/AIDS, substance use, mental health dx,
- ◆ Question from legal group around time delay for ARV drugs (average 3 months)

# Ethical concerns in research in prisons

- ◆ Potential for exploitation
- ◆ Questions about ability to give consent
- ◆ Harm: retribution from guards, staff, other prisoners
- ◆ Expectation of benefits may be low

# Human Rights Considerations

- ◆ Detainees are denied many human rights
- ◆ Denial of medications in prison is a violation of right to health
- ◆ Systematic delays in health services are a state failure to protect rights
- ◆ Inmates do have the right to see legal counsel

# Human Subjects Protections Approach

- ◆ Lawyer's group working on women's rights issues in prison told us that the Warden and Prison officials would never agree to an evaluation of health services
- ◆ We argued that the research into health services and access needed to be done
- ◆ Discussions with women after detention found strong support for going forward



# Research Approach

- ◆ Confidential interviews done in the context of attorney-client meetings
- ◆ Attorneys trained to do interviews
- ◆ No permission sought from authorities
- ◆ Privately funded
- ◆ JHU CHR asked to review study, with full disclosure that permission was not being sought

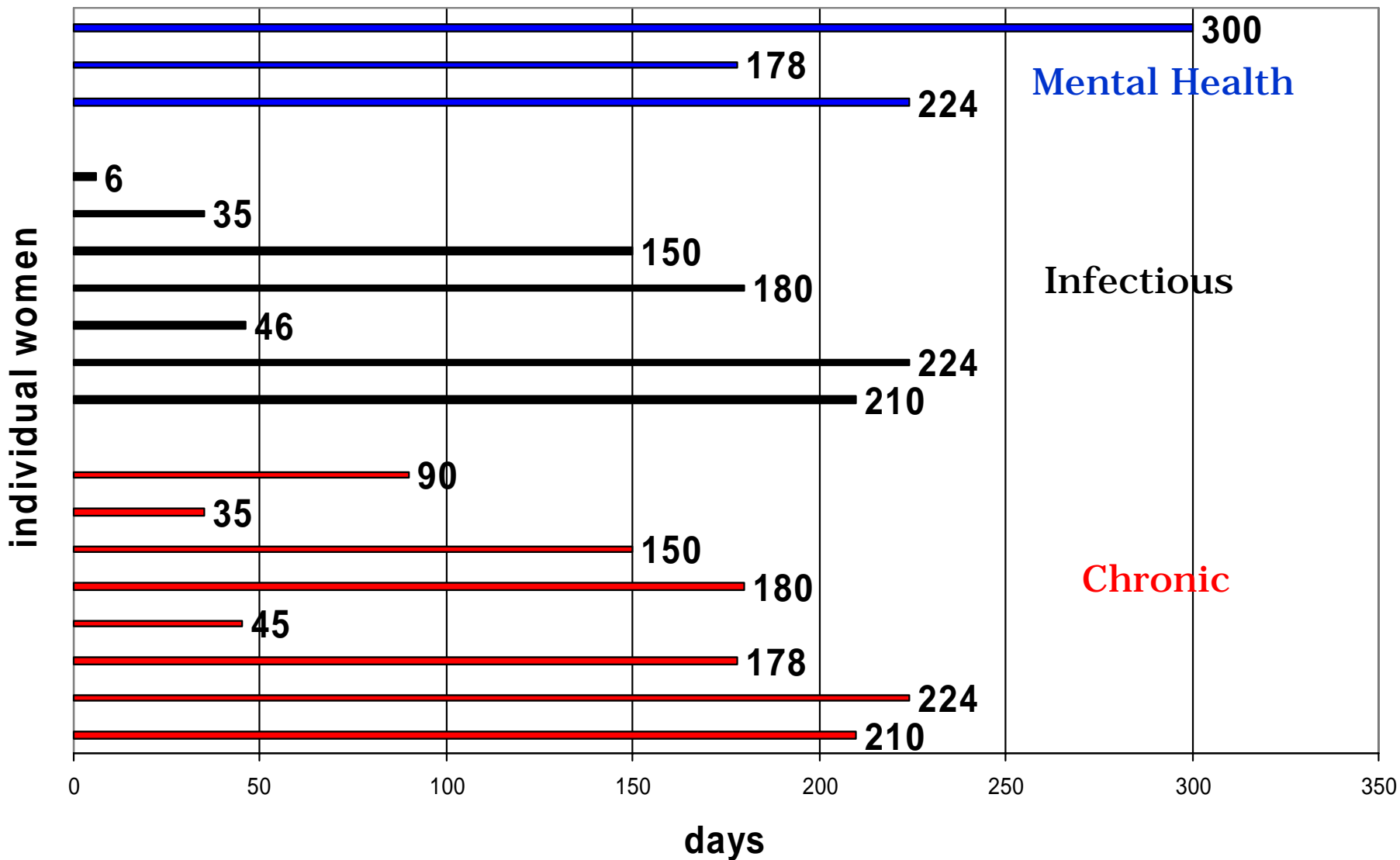
# CHR Process

- ◆ PI requested meeting with the IRB Chair
- ◆ Discussion focused on risks vs benefits
- ◆ Main benefit question was about realistic expectation that study results could lead to reform, and better health services
- ◆ We argued that we would use the data for advocacy for the women, and others in detention
- ◆ Study approved in Fall 2004, completed April, 2005.

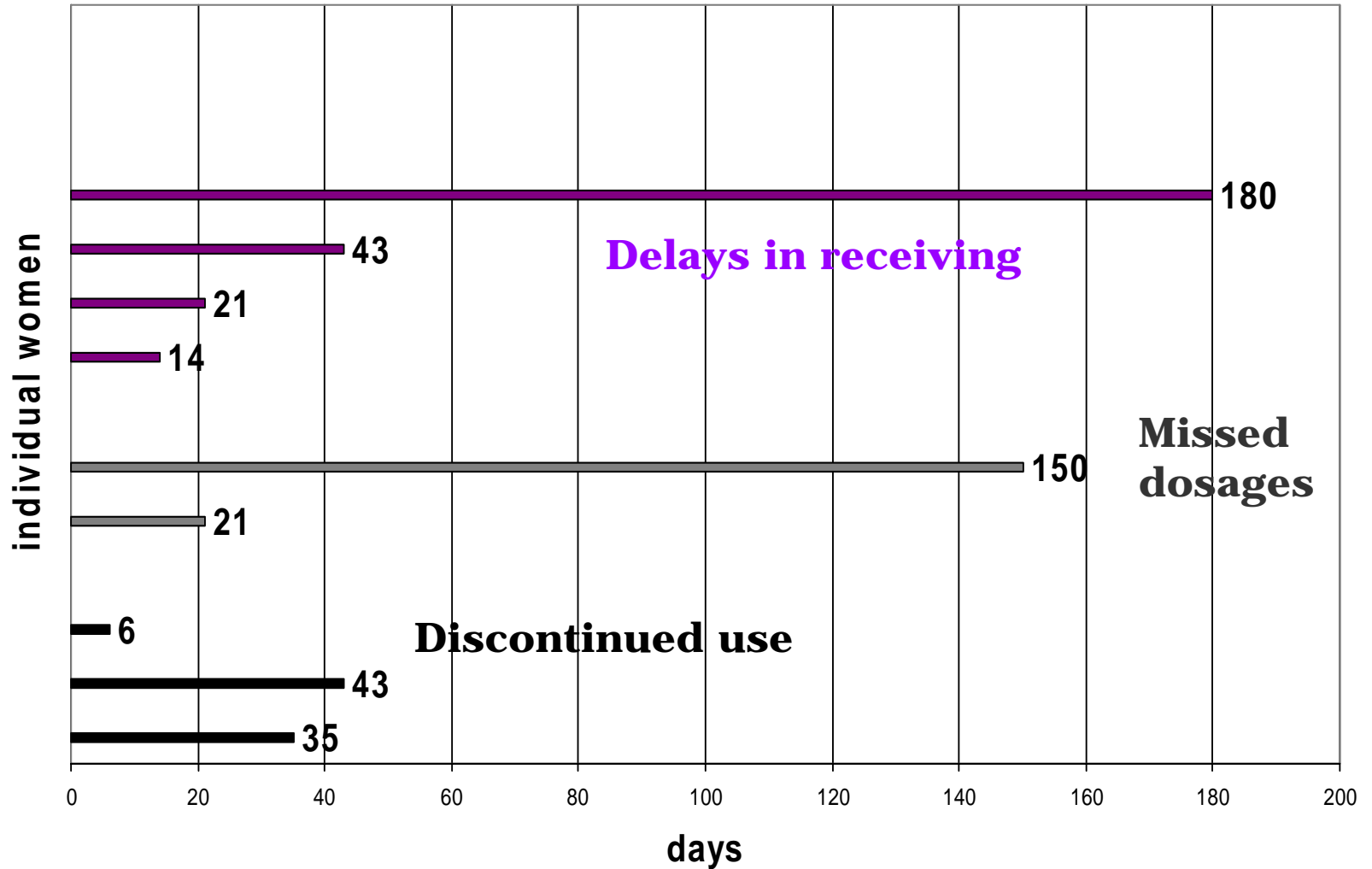
**Table 3. Among Incarcerated women reporting a medical condition, n=55**

<p><b>Are you receiving treatment or medications for (this/any of these) condition(s)?</b></p> <p>Yes</p> <p>No</p>	<p>39 (70%)</p> <p>16 (30%)</p>
<p><b>Do you still have a medically diagnosed condition?</b></p> <p>Yes</p> <p>More than one</p> <p>No</p>	<p>35 (64%)</p> <p>10 (18%)</p> <p>10 (18%)</p>
<p><b>Has jail affected access to medications?</b></p> <p>Yes</p> <p>No</p>	<p>29 (53%)</p> <p>24 (44%)</p>
<p><b>Have you developed a new medical condition or serious injury?</b></p> <p>Yes</p> <p>No</p>	<p>17 (35%)</p> <p>31 (65%)</p>

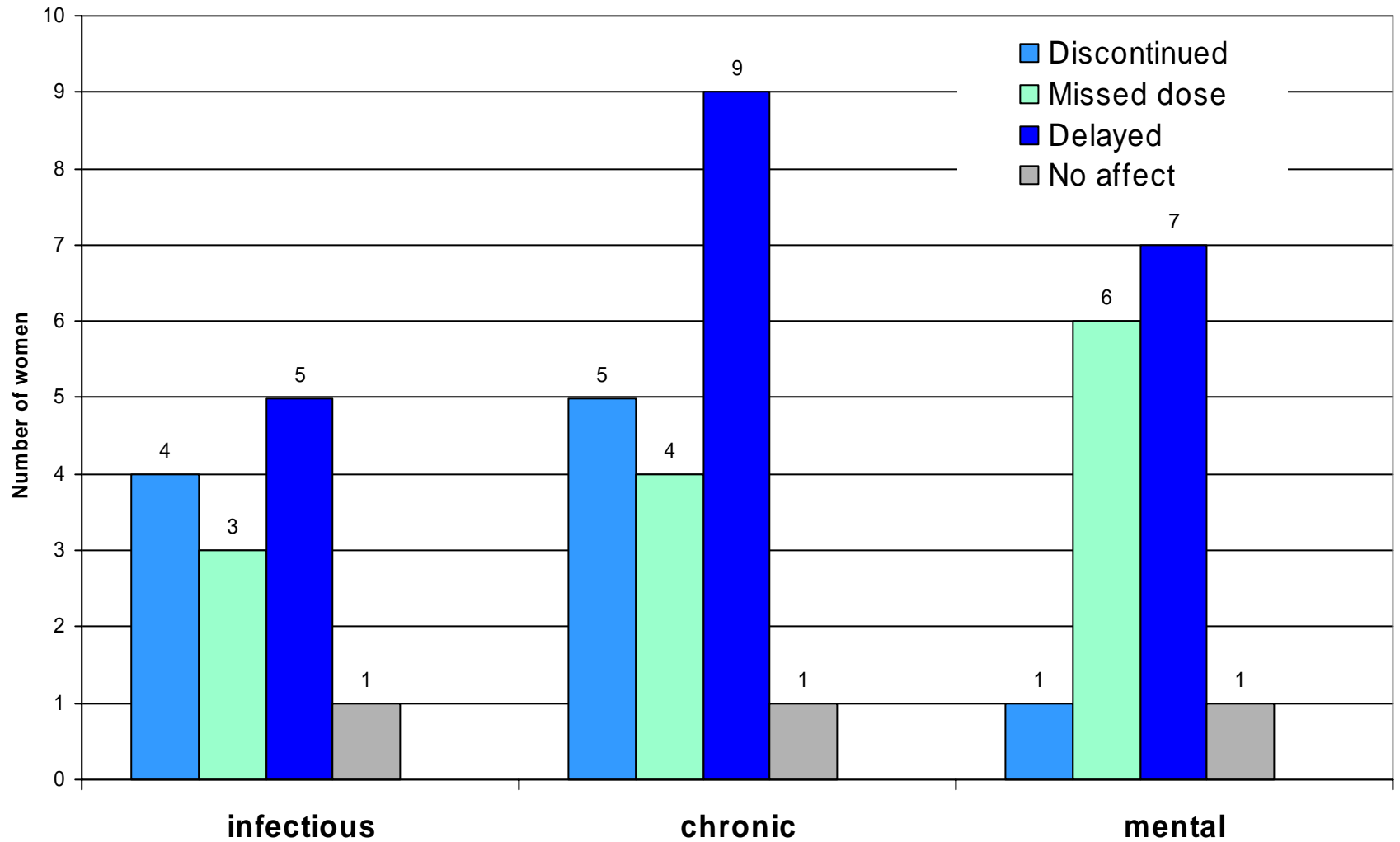
# Number of days incarcerated without medical treatment



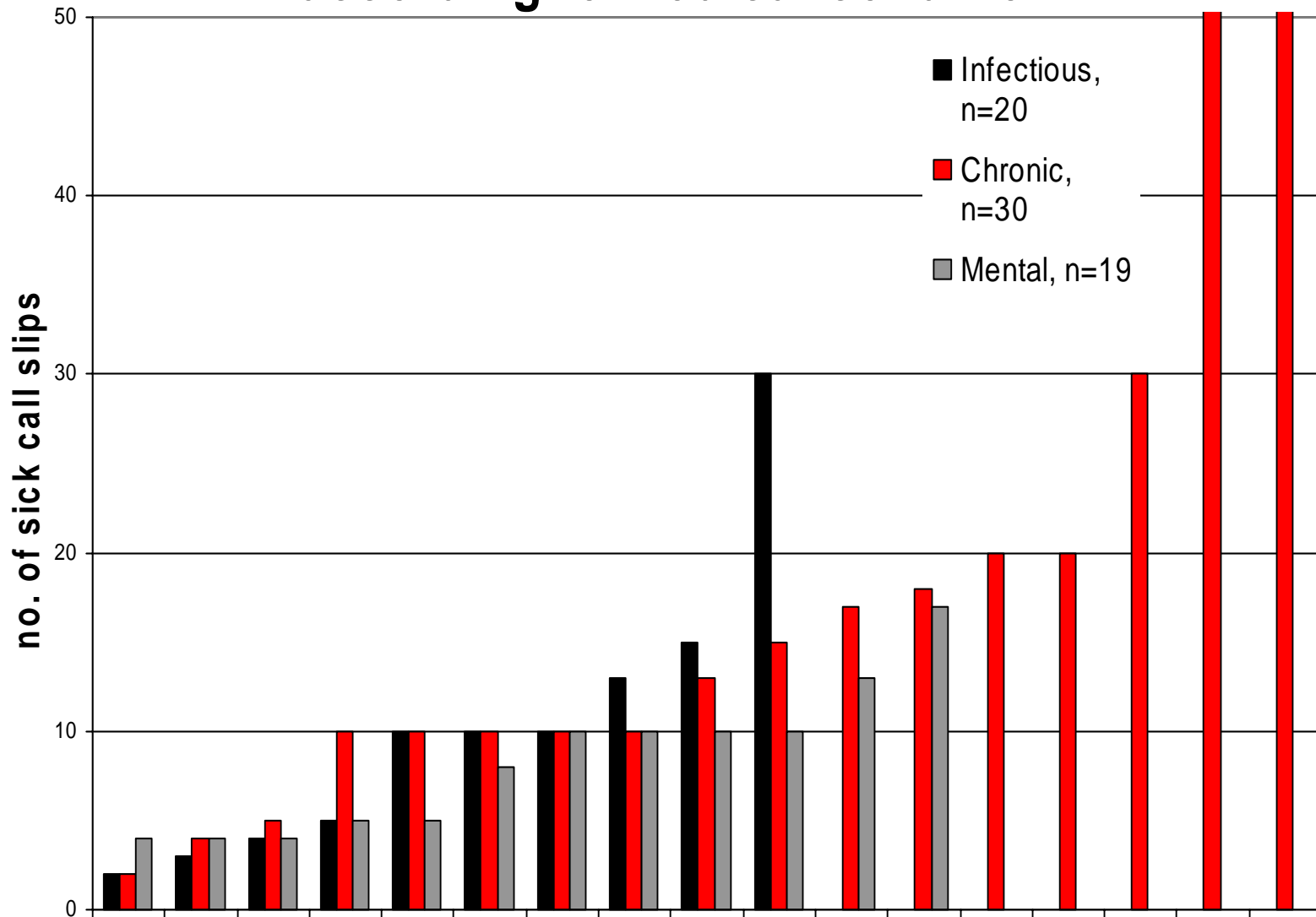
# Number of days incarcerated among HIV+ women



# How has incarceration affected access?



# Number of sick-call slips according to medical condition



# Women's Health Survey

## Conclusions

- ◆ Women with chronic conditions
  - incurred more medical conditions-irrespective of length of stay
  - Reported worse access to healthcare services
  - Submitted more sick-call slips
- ◆ Denial of treatment for serious medical conditions (chronic, infectious, mental health) is common
- ◆ Ongoing violations of the right to a minimum standard of health



# Advocacy for change

- ◆ On June 29<sup>th</sup>, 2005, DC Council held hearings on “Health Care in the DC Correctional Facilities.”
- ◆ We testified and presented study findings
- ◆ DC Prisoners Legal Services Project filed a lawsuit against the District of Columbia for violations of DC and US law
- ◆ Dept. of Corrections agrees to hold meeting to discuss study results, reponses

# Closing remarks

- ◆ Important relationships between research ethics and human rights
- ◆ There is ethical mandate to investigate and document the truth of human rights violations and the subsequent health problems that stem from them.