Research partnerships with community health centers: Collaborative approaches considered from a research ethics perspective

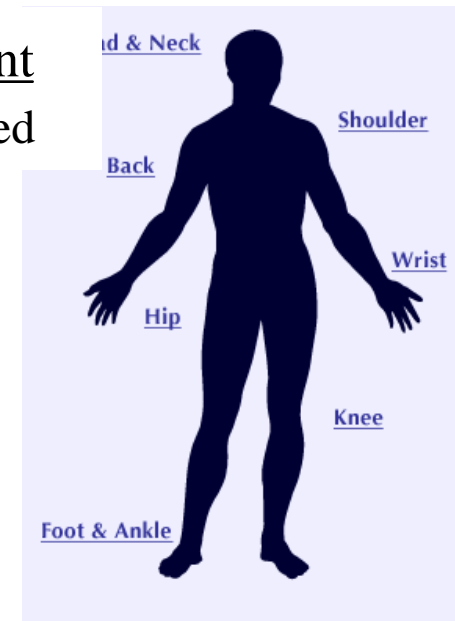**Milton "Mickey" Eder, PhD**, Research Programs
Linda Diamond Shapiro, AM, MBA, External Affairs
135th Annual APHA Meeting, Washington DC
November 5, 2007

access **community**
HEALTH
NETWORK
Caring. Committed. Connected.

Concepts of Research Ethics
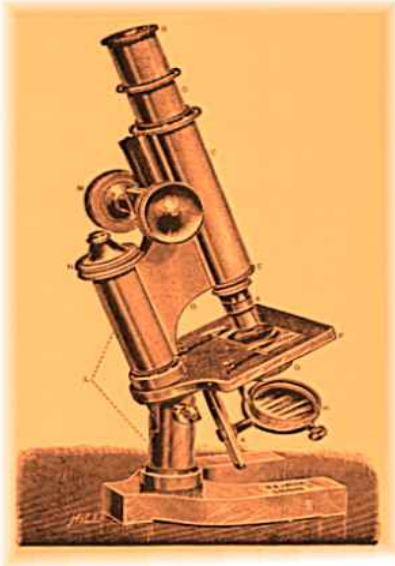
Consent

Voluntary & Informed

Concepts of Research Ethics

"Clinical Research" (Experimental conduct)

Begin with laboratory and animal experiments
Scientifically qualified individuals
Evaluate risks and benefits for subjects

Consent

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ACCESS community HeaLTH NeTWOrk
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Images: www.widenclinic.com/images/human_figure.gif; www.oralpath.com/departments/microscope.jpg

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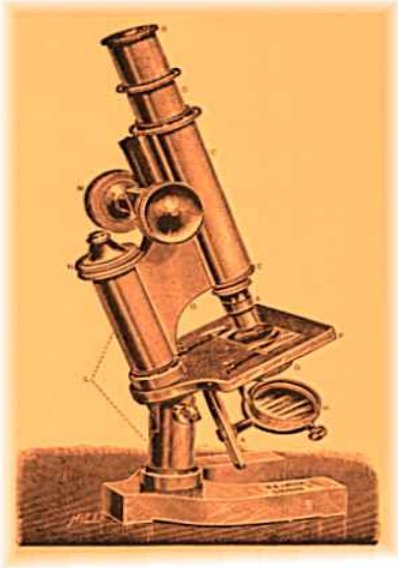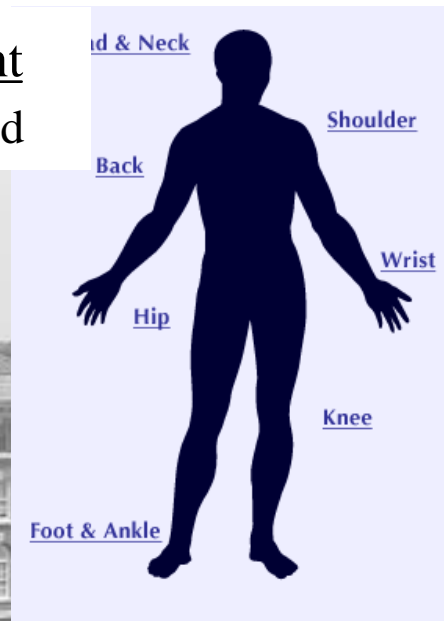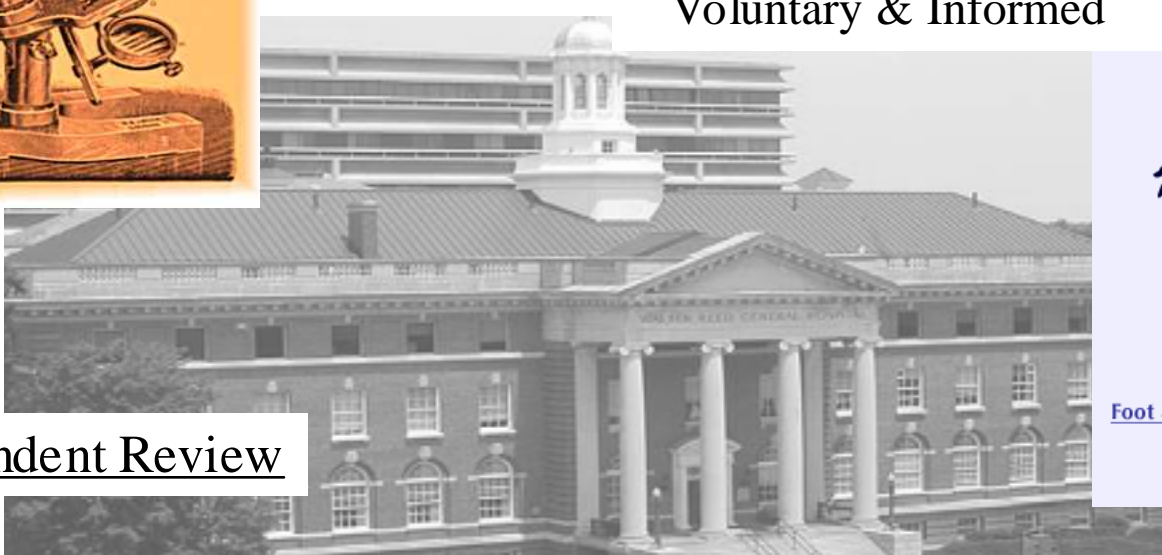
Consent
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Shoulder

Wrist

Knee

Independent Review

Images: www.widenclinic.com/images/human_figure.gif   www.oralpath.com/departments/microscope.jpg
www.nlm.nih.gov/hmd/medtour/images/wreed.jpg

The NIH Clinical Research Enterprise

Clinical and Translational Science

Link academic health centers into a network

AHCs develop relationships with community partnerships

Shared Interests in the Research Question
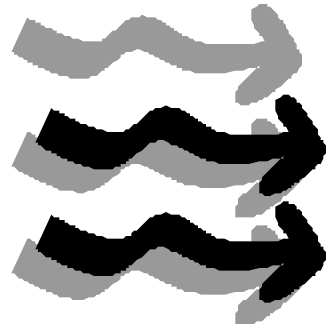
Research paradigms – top/down or bottom/up

Contrasting missions, priorities and relationships

Talk, talk and talk some more …proposal development, funding negotiation, IRB application , etc.

Aligning research intent with the health center clinical and administrative practices:

Collaboration – to work with another or others to achieve a particular purpose

Engaged staff breaks down barriers for potential study participants

Make "informed consent" a process and not an event

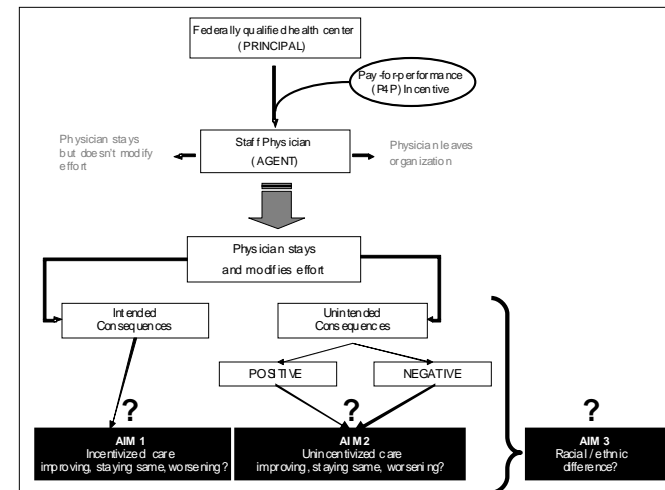access community HeaLTH NeTwork
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Engaging health center staff in study design

Beyond power and recruitment

Verifying community resources and facilities for research within proposals

Acknowledging full operational and research management costs
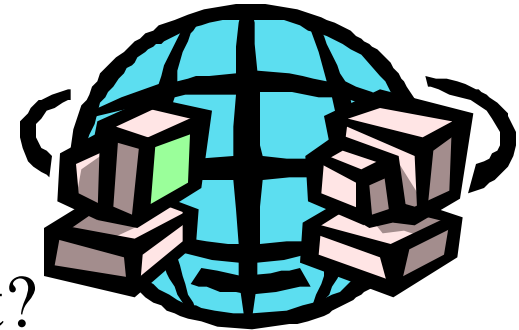
Non-existent or low indirect cost rate

Will CTSA funds reach community partners?

Can we collect cost data for community oriented translational research?

Clarity regarding the collection, storage and sharing of protected information

Who are we protecting and from what?

Protecting identities and personal information about human subjects has financial, technical and staffing components

Strengthening the health center workforce to participate in research processes

Understand health center staff knowledge, attitudes and beliefs about research

Human subjects protection training – an inconvenient nuisance or the basis of trust?

Does translational research need ongoing research expertise **IN** the community?

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Health Center engagement: interpreting and disseminating results

What results matter for building translational research capacity? Number recruited, refused (reasons?), left and withdrawn; researcher response to unanticipated events

Community Translational Research – consider the person psycho-socially, behaviorally, culturally, linguistically, economically…

¿¿¿ Ponderables ???

How do we define community?

Will translational research improve the capacity of community health centers to support research?

Will translational research contribute to the reduction of health disparities?