Looking Ahead:
New Tools, New Areas for Research

Robert M. Kaplan
Director, OBSSR
NIH Associate Director for Behavioral and Social Sciences
“If we’re going to create jobs now and in the future, we're going to have to out-build and out-educate and out-innovate every other country on Earth.”

President Obama
Signing of America Invents Act
Thomas Jefferson High School
September 16, 2011
Science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.”
NIH Extramural & Intramural Funding
FY 2011 Enacted: $30.9 Billion

Spending at NIH
$5.0 B
16%

- $3.3 B Intramural Research
- $1.5 B Research Management & Support
- $0.2 B Buildings and Facilities, Other

Spending Outside NIH
$25.9 B
84%

- Supports over 325,000 Scientists & Research Personnel
- Supports over 3,000 Institutions
Investing in Basic Research

The Nobel Prize in Physiology or Medicine 2011

Bruce A. Beutler  Jules A. Hoffmann  Ralph M. Steinman

NIH-supported Nobel Prize Winners: 135
In 2010, NIH research supported 488,000 jobs at 3000 institutions, small businesses nationwide.

In 2010, NIH funding generated $68 billion in new economic activity—double taxpayers’ investment.

NIH serves as foundation for entire U.S. medical innovation sector that:
- Employs 1 million U.S. citizens
- Generates $84 billion in wages, salaries
- Exports $90 billion in goods, services

Source: An Economic Engine: NIH Research, Employment and the Future of the Medical Innovation Sector, United Medical Research, May 2011
We Cover a lot of Turf

• Academic Disciplines
  – Anthropology
  – Child Development
  – Cognitive Science
  – Communication
  – Criminology
  – Cultural Studies
  – Economics
  – Education
  – History
  – Linguistics
  – Neuroscience
  – Law
  – Philosophy
  – Political Science
  – Psychology
  – Sociology

• Professional Schools
  – Clinical Psychology
  – Gerontology
  – Medicine
    • Pediatrics
    • Family Medicine
    • General Internal Medicine
  – Nursing
  – Social Work
  – Public Health
  – Public Policy

• Together these make up the majority of students and faculty at most research intensive universities
OBSSR Mission

• Stimulate BSSR throughout NIH’s 27 ICs
• Serve as NIH’s lead for BSSR within and outside the federal government.
• Development and implementation of a trans-NIH plan to increase the scope and support of BSSR.
• Develop initiatives (research and training) designed to foster BSSR.
• Fund research *through* the NIH ICs, not directly, making collaboration of paramount importance to OBSSR’s mission. NICHD has been a key, consistent collaborator since OBSSR’s inception in 1995.
NIH Behavioral and Social Sciences Research

- **Basic research** on behavioral and social mechanisms that affect health at the individual and population levels, & bio-behavioral-social interrelationships
- **Translational research** on the conversion of basic knowledge into practice that improves health at the individual and population levels
FY 2010 non-ARRA $3.53 billion
• Oxford Health Alliance's key message:
• 3 risk factors –
  – tobacco use, poor diet, lack of physical activity
• Contribute to Four chronic diseases –
  – heart disease, type 2 diabetes, lung disease and some cancers
• Which, contribute to more than 50 per cent of deaths in the world
• Theme 1: Investing in Basic Research
• Theme 2: Accelerating Discovery Through Technology
• Theme 3: Advancing Translational Science
• Theme 4: Encouraging New Investigators and New Ideas
Theme 1:
– Back to Basics
The National Institutes of Health (NIH) Director Francis Collins, M.D., Ph.D., announced the launch of the Basic Behavioral and Social Science Opportunity Network (OppNet) on November 16, 2009. OppNet is a trans-NIH initiative to expand the agency’s funding of basic behavioral and social sciences research (b-BSSR). BSSR furthers our understanding of fundamental mechanisms and patterns of behavioral and social functioning, relevant to the Nation’s health and well-being, as they interact with each other, with biology and the environment. Research results lead to new approaches for reducing risky behaviors and improving health. Read More >
FY2010: $12 million
$10M in ARRA funds
$2M for HIV/AIDS-related research projects

FY2011-2014:
Fixed percentage of each IC’s base appropriation

FY2011: $10 million
FY 2012-2014: $20 million each FY
• Accelerating Discovery Through New Technology
• Representative Sampling, Representative Design, Ecological Validity
  – The paradigm exemplified by Darwinian evolutionary biology was lost to psychology for over a hundred years, and Brunswik's development of a set of principles appropriate to the tasks of psychology has been afforded scant attention (Petrinovich, American Psychologist, 1979, 34(5), 373-390)

• Bringing the lab to the people
High Throughput Exposomics

OBSSR Lead Kay Wanke

NIH Genes, Environment and Health Initiative
Exposure Biology Program

Genes, Environment and Health Initiative: The Vision

EXPOSURE BIOLOGY PROGRAM
- Develop technology and biomarkers
  - Diet
  - Physical Activity
  - Environmental Exposures
  - Psychosocial Stress and Addictive Substances

GENETICS PROGRAM
- Identify genetic variants
  - GWA Studies
  - Data Analysis
  - Replication
  - Sequencing
  - Database
  - Function
  - Translation

GxE
The Exposome (from Kevin Patrick, UCSD)

Historical approaches to measuring behaviors and environment -

Self report via questionnaires every few day or months (if that…)

Biomarkers of exposure, some good but others that are often indirect and imprecise or focused on only one thing

Direct measurement of the environment across a broad geographic area yielding only crude inferences about person-level exposures in time and space. Moreover, these are almost always focused only on air and water.
The Exposome (from Kevin Patrick, UCSD)

“At its most complete, the exposome encompasses life-course environmental exposures (including lifestyle factors), from the prenatal period onwards…”

-- Christopher Paul Wild
Together these lead to whether disease occurs or health is promoted…

(from Kevin Patrick, UCSD)
“Unlike the genome, the exposome is a highly variable and dynamic entity that evolves throughout the lifetime of the individual...”

-- Christopher Paul Wild
Genome

Exposome

In utero…

(from Kevin Patrick, UCSD)
Genome

Exposome

childhood…
In adolescence…

Genome

Exposome
In adulthood…
In old age...
“The imbalance in measurement precision of genes and environment has consequences, most fundamentally in compromising the ability to fully derive public health benefits from expenditure on the human genome...”

“There is a desperate need to develop methods with the same precision for an individual’s environmental exposure (and behaviors) as we have for the individual’s genome.”

-- Christopher Paul Wild
The game is changing

5+ Billion Mobile Phone users
- UN International Telecomm Union (2011)

14.2 Million iPads sold, 2010
(75% of the market)
- Wikipedia (2011)

(from Kevin Patrick, UCSD)
Growth of Mobile

• **Problem:** Measurement of analytes (glucose, lactate O2 and CO2) that indicate metabolic abnormalities

• **Solution:** Miniaturized wireless implantable biosensor that continuously monitors metabolism
  - Inserted by needle subcutaneously
  - Operated remotely using a PDA
  - Multi-analyte sensor
  - One month continuous monitoring

Diane J. Burgess, University of Connecticut
NHLBI, R21HL090458
**Problem:** Create a low-cost quality microscope to use in low resources settings.

**Solution:** A specially-developed lens fits to a cell phone to create a microscope

**Field testing:** Malawi, Mozambique and Brazil

LUCAS images of CD4+ and CD8+ T cells compared to a regular microscope image.
EVERY BITE YOU TAKE

If a camera snaps everything you eat, you can’t lie about it later. That’s why scientists are building high-tech gadgets to measure the human ‘exposome’.

BY BRENDAN BORRELL
Improving Dietary Assessment Methods Using the Cell Phone and Digital Imaging

PI: Carol Boushey, Purdue University

- Uses a mobile phone as a food record
- Image processing to identify food in real time
  - Supplement with search list
  - Calculates volume to estimate portion size
- Calculates nutrient and food intake
**Problem:** Population-scale measurement of physical activity

**Solution:** Miniature, low-cost devices that measure human motion using redesigned accelerometers in a user-friendly format

Stephen Intille, PhD, Northeastern University
NHLBI, U01HL091737
Merged GPS & Activity Data

Research Question: Which park features support the most physical activity?

(from Kevin Patrick, UCSD)
Detect Bouts of Activity

Research Question: Are small, low quality neighborhood parks better than large regional parks for continuous minutes of MVPA?

How long do participants engage in periods of intense physical activity?

Where are participants getting sustained activity?

(from Kevin Patrick, UCSD)
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What will be required?

Move well beyond the “electronic medical record” as we know it

New research designs – RCTs will not be able to keep up...

New methods of data fusion and synthesis – multilevel, multidimensional, spatial/temporal

New generation of (and many more) health data analysts

New approaches to handling privacy of health-related information

New approaches to health data security

New approaches to health technology design and experience
• Advancing Translational Science

• Translation beyond “Bench to Bedside”
The Cost of Health Care
How does it compare?

Over the past decade, healthcare costs have risen faster than salaries...

percent increase (1999–2009)

100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%

Average U.S. Salary
Healthcare Premiums

38%
131%
The Cost of Health Care
How does it compare?

If other prices had grown as quickly as healthcare costs since 1945...

- A dozen eggs would cost $55
- A gallon of milk would cost $48
- A dozen oranges would cost $134
About $750 Billion in Waste

How much is waste?

- Unnecessary Services: $210 Billion
- Fraud: $75 Billion
- Excessive Administrative Costs: $190 Billion
- Inefficiently Delivered Services: $130 Billion
- Prices That Are Too High: $105 Billion
- Missed Prevention Opportunities: $55 Billion
• In a survey of consecutive patients scheduled for an elective coronary revascularization procedure at Yale New Haven Hospital in 1997-1998
  – 75% believed PCI would help prevent an MI
  – 71% believed PCI would help them live longer

(Holmboe ES. JGIM 2000; 15:632)
• While even through the latest meta-analysis in 2009 (61 trials, 25,388 patients):
  – “Sequential innovations in catheter-based treatment for non-acute coronary artery disease showed no evidence of an effect on death or myocardial infarction when compared to medical therapy.”

(Trikalinos TA. Lancet 2009; 373:911)
Is Informed Consent “Real”? 

In a survey of consecutive patients consented for an elective coronary angiogram and possible percutaneous coronary intervention at Baystate Medical Center in 2007-2008:

- 88% believed PCI would help prevent an MI
- 76% believed PCI would help them live longer

(Rothberg MB. Annals Intern Med 2010; 153:307)
• Conducted by University of Michigan

• Nationwide random-digit dial telephone survey

• Probability sample of 2575 English speaking Americans age 40+

• Reported a discussion of 1 of 9 medical decisions with a health care provider within the past 2 years

• Response rate 51%
• **Surgery**
  – Back surgery,
  – Knee/hip replacement
  – Cataract extraction

• **Cancer screening**
  – Prostate,
  – Colorectal
  – Breast

• **Medications**
  – Hypertension,
  – Hyperlipidemia,
  – Depression
• Clinical experts identified 4-5 facts a person should know, for example, common side effects of medications or surgery
• Respondents were asked the knowledge questions related to their decision
• For 8 out of 10 decisions, fewer than half of respondents could get more than one knowledge question right.
Patients: Making Decisions in the Face of Avoidable Ignorance

Clinicians: Poorly “Diagnosing” Patients’ Preferences

Poor Decision Quality
Unwanted Practice Variation
Shared Decision-Making Model

• Key characteristics:
  – At least two participants – [clinician] and patient – are involved
  – Both parties share information
  – Both parties take steps to build a consensus about the preferred treatment
  – An agreement is reached on the treatment to implement

Tools designed to help people participate in decision making

Provide information on the options

Help patients clarify and communicate the values they associate with different features of the options.

(The International Patient Decision Aid Standards Collaboration)
In 86 trials in 6 countries of 34 different decisions, use has led to:

- Greater knowledge
- More accurate risk perceptions
- Lower decision conflict
- Greater participation in decision-making
- Fewer people remaining undecided
- Fewer patients choosing major surgery, PSA tests

(O'Connor et al. Cochrane Database of Systematic Reviews 2009, Issue 3. Art. No.: CD001431)
(Stacey et al. Updated Cochrane Review of Patient Decision Aids
• Encouraging New Investigators and New Ideas
OBSSR Activities

Systems Science Institute
Pittsburgh, May 2011
OBSSR Lead Patty Mabry

mHealth with Qualcomm, June 2011
OBSSR Lead Wendy Nilsen

Big Data Initiative: Data Visualization
OBSSR Lead Tisha Wiley

Harmonizing Psychosocial Information in the EMR
OBSSR Lead Maureen Boyle
“Social scientists are getting to the point in many areas at which enough information exists to understand and address major previously intractable problems that affect human society.”

–Gary King, Science, Feb 11 2011

“Visualizations are absolutely critical to our ability to process complex data and to build better intuitions as to what is happening around us.”

--Peter Fox & James Hendler, Science, Feb 11 2011

“In an uncharted world of boundless data, information designers are our new navigators.”

--Natasha Singer, NYT, April 2, 2011
Lines tell the story better than tables

Placement of bars can help clarify relationships

From Hegarty. Topics in Cognitive Science 3 (3) 446–474, July 2011
Visualizations Provide a New Way of Seeing Complex Data

TRADITIONAL VISUALIZATIONS

- Bar chart showing percentage of victims by gender.
- Scatter plot showing life expectancy by geographic region.

NEW VISUALIZATIONS

- Interactive visualization for children per woman (total fertility).
- Tree diagram for environmental quality.
- Interactive data exploration tool.
• Visual Analytics for Complex Data in Health Research: A Sandbox Workshop for Social Science Researchers
• Questions and Suggestions