The Intersection of Technology, HAART Adherence, and Drug Abuse Treatment

CFAR
Network of Integrated Clinical Systems (CNICS):
The Use of Real-Time, Patient-Centered, Clinical Metrics

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CNICS
CFAR Network of Integrated Clinical Systems
CNICS

• 9 Sites (UAB, UW, UCSD, UCSF, CWRU, Harvard/Fenway, Johns Hopkins, UNC, Vanderbilt)

• Research elements:
  • Merged data from clinical EMR systems (diagnoses, meds, labs, etc.)
  • Vital statistics (currently active, lost to follow-up, deceased [augmented by US Social Security Death Index])
  • Clinical specimen repository (PBMC’s, cell pellets, plasma)
  • Patient reported outcomes (also called patient-based metrics)
Fenway Health

• Founded 1972
• One of the Largest Providers of Out-Patient HIV services in New England (1500 primary care HIV patients)
• Primary care, HIV care, OB/GYN, mental health (psychiatry, individual and group therapy), substance abuse, dental, optometry, pharmacy
• The Fenway Institute (HIV Prevention Research, Data Center (CNICS, LGBT Population Research Center), LGBT Health Policy, Training (medical students, residents and fellows, mental health professionals, dental, optometry)
• First installed an EMR in July 1997 – Logician/Centricity
Fenway’s EMR
GE/Centricity
Fenway’s EMR
GE/Centricity
Fenway’s EMR
GE/Centricity
Fenway’s EMR
GE/Centricity
Patient Reported Outcomes Collection

- Tablet PC with touch screen or in-room wired PC
- Web-based, survey software application over wireless network
- SSL/TLS encryption
- Interface with one item presented at a time
- Large, easy to read type and navigation buttons
- Program prevents duplicate/ambiguous answers, permits mistakes to be easily corrected
- Automated skip patterns incorporated into questionnaire to omit sections that are not applicable
- Spanish version now functioning
Patient Reported Outcomes Collection
Patient Reported Outcomes Collection
Patient Reported Outcomes Collection
Key Domains

• Body Morphology (FRAM)
• Depression (PHQ-9)
• Anxiety (PHQ)
• Medication adherence

• Drug and alcohol use (AUDIT-C, ASSIST)
• Quality of life (EUROQOL)
• Symptoms
• Risk Behavior
## Patient-Based Measures Provider Feedback

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ-9 Overall depression score last 2 weeks</td>
<td>Mild depression (5-9)</td>
</tr>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>PHQ-9 Suicidal ideation score last 2 weeks</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Substance use within last 3 months</td>
<td>Marijuana</td>
</tr>
<tr>
<td>Tobacco use: No</td>
<td></td>
</tr>
<tr>
<td>Alcohol Score (AUDIT-C)</td>
<td>Not at-risk alcohol consumption (&lt;5)</td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Antiretroviral adherence</td>
<td>Good</td>
</tr>
<tr>
<td>Adherence in the past 4 weeks</td>
<td></td>
</tr>
<tr>
<td>Last missed</td>
<td>I never skip medications</td>
</tr>
<tr>
<td>High risk behavior-last 6 months</td>
<td></td>
</tr>
<tr>
<td>Anal sex condom use: All the time</td>
<td></td>
</tr>
<tr>
<td>Vaginal sex condom use: never had vaginal sex</td>
<td></td>
</tr>
<tr>
<td>Sharing needles or injection equipment: never used non-medical drugs by injection</td>
<td></td>
</tr>
</tbody>
</table>
Upcoming Changes

• Computer adaptive testing (CAT)
  • Selects questions based on patient’s response to prior items
  • Iteratively estimates a patient’s standing on a domain
  • Administers the most informative items
  • Desired level of precision can be obtained using the minimal number of questions
  • Decreased response burden with greater precision
Why do we care about CAT?

• Selects questions based on patient’s response to prior items
• Iteratively estimates a patient’s score
• Administers the most informative items
• Desired level of precision can be obtained using the minimal number of questions
• Decreased response burden with greater precision!
Precision of PHQ-9 versus PROMIS CAT

![Graph showing precision of PHQ-9 versus PROMIS CAT](image)
Data Quality Assurance
Individual Site Responsibilities

- Each site conducts a detailed audit of data types collected
- Inter-site comparison of data to look for inconsistencies
- Random chart audits
- On-going training of clinicians with EMR access informed by chart audits
Data Quality Assurance
Central Site Responsibilities

• Centralized data mapping specifies how data are being integrated into CNICS standard codes with known and comparable meanings

• This enables us to integrate comparable data across cohorts with known meaning and content

• Creates the bridge between CNICS and cohorts in NA- ACCORD and other IeDEA regions

• Collect measures of certainty for diagnoses and treatment that includes data source and reliability defined hierarchically

• Conduct centralized audits to identify data quality issues

• Feedback loop with cohorts to reconcile data exceptions

• Creation and maintenance of cohort data dictionaries to track meaning of cohort codes and to document their data quality issues
CNICS Data Submission Activity (2009)

- Medications – Diabetes, Hypertension, Hepatotoxic, Lipid lowering
- Diagnoses
  - Substance Use (alcohol, tobacco, etc.)
  - Anxiety, mood disorders
  - Liver and Kidney disease
- Malignancy – comprehensive data collection
- Insurance
Study Aim 2

- To determine the effect on care processes and patient outcomes of integrating PROMIS II CAT PROs into routine clinical care
- Data provided with individually tailored treatment recommendations using a comprehensive health improvement (chronic care) model
- Quality improvement initiatives to involve stakeholders and overcome barriers to routine PRO collection and feedback
- Randomized controlled trial to determine the intervention's impact on process outcomes and clinical outcomes
# CNICS Patients by Site (Nov 2009)

<table>
<thead>
<tr>
<th>CNICS Sites</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>CWRU</td>
<td>1,627</td>
</tr>
<tr>
<td>Fenway</td>
<td>1,544</td>
</tr>
<tr>
<td>Johns Hopkins</td>
<td>4,539</td>
</tr>
<tr>
<td>UAB</td>
<td>2,624</td>
</tr>
<tr>
<td>UCSD</td>
<td>3,604</td>
</tr>
<tr>
<td>UCSF</td>
<td>2,860</td>
</tr>
<tr>
<td>UNC</td>
<td>1,278</td>
</tr>
<tr>
<td>UW</td>
<td>2,903</td>
</tr>
<tr>
<td>Vanderbilt</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20,979</strong></td>
</tr>
</tbody>
</table>
Questions

• How feasible is it to use such a system among drug-abusing populations with HIV in various settings, e.g. outpatient, FQHC’s, NGOs, etc.)

• What principles should guide research priorities on technology in order to achieve a balance between the costs of research and the need to mount interventions

• Do we have a “gold standard” for measuring ART adherence?

• Which groups and approaches are the best candidates for the efficacious use of these technologies?

• What secondary benefits and innovative applications may be developed as a result of adherence-related technologies?
Questions

- What incentives (social/moral, economic) exist for developers/distributors of this technology for use with marginalized populations or in resource-limited settings?

- How do we handle the fact that effective programs and applications which target behavior change often are not operable across other platforms?

- How do we begin to tackle some of the ethical issues inherent in using technologies to affect health behaviors (e.g. HIPAA, surveillance data, and reporting of illegal behavior)