Telemedicine and Ethical Considerations

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Telemedicine and Ethical Considerations

PLAN

- Introduction: What is a medical record?
- Security and Privacy and Ethics
- Accountability, Confidentiality, and Ethics
- Workplace considerations
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Telemedicine and Ethical Considerations
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Computers: Changing the way we communicate, learn and live......... and treat?

Source: http://www.geocities.com/ariniem/pics/evolution.jpg
Nature and Scope of Biomedical Research Regulation
NATURAL ALLIES OF ETHICS

• Law
• Human Rights theory
• Civics
• Religion
• Customs and traditions
• All of the above are mingled and interwoven with ethics; but ethics is separable from each and all of them
• Ethics is limited to acts, actions and behavior that are free, purposive, intentional and liable to impact on other creatures
Regulation of Biomedical Research: An Example of Internormativity

Ethics

Standards of conduct

Law  Soft law

Profession  Industry  Institution  Funding agencies
Ethical issues in Africa

Ethics can be evoked by many issues that may be directly or indirectly linked and sometimes inseparable from Clinical Trials

- Equity
- Health inequality
- Socioeconomic inequality in health and health differentials
- Gender
- Age
- Violence
- Poverty
- Health Economics and Legislation
- Race and Ethnicity

Information Technology - Virtual libraries;
Other Research & Science issues
Table 4  Training needs of ERCs in Africa, ranked by respondents

<table>
<thead>
<tr>
<th>Training needs</th>
<th>Very important</th>
<th>Quite important</th>
<th>Important</th>
<th>Not important</th>
<th>Total institutions*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scientific design issues in intervention trials</td>
<td>27</td>
<td>2</td>
<td></td>
<td></td>
<td>29</td>
</tr>
<tr>
<td>Determination of potential risks of malaria vaccine research</td>
<td>25</td>
<td>3</td>
<td></td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Determinations to run phases (I,II,III) in a country or community</td>
<td>25</td>
<td>2</td>
<td>1</td>
<td></td>
<td>28</td>
</tr>
<tr>
<td>Monitoring and oversight</td>
<td>23</td>
<td>5</td>
<td>1</td>
<td></td>
<td>29</td>
</tr>
<tr>
<td>Post-trial access to benefits (e.g., successful intervention)</td>
<td>20</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>28</td>
</tr>
<tr>
<td>The interpretation of preclinical studies</td>
<td>19</td>
<td>7</td>
<td>3</td>
<td></td>
<td>29</td>
</tr>
<tr>
<td>The use of placebo in controlled trials</td>
<td>16</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Assessment of understanding for informed consent</td>
<td>16</td>
<td>10</td>
<td>1</td>
<td>1</td>
<td>28</td>
</tr>
<tr>
<td>Assessment of anticipated benefits</td>
<td>15</td>
<td>8</td>
<td>5</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Assessment of cultural sensitivity for informed consent</td>
<td>15</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Community participation</td>
<td>14</td>
<td>11</td>
<td>3</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Determination of appropriate subject selection in vulnerable population</td>
<td>14</td>
<td>8</td>
<td>5</td>
<td>1</td>
<td>28</td>
</tr>
<tr>
<td>Determination of appropriate subject selection with regard to women</td>
<td>13</td>
<td>6</td>
<td>8</td>
<td>1</td>
<td>28</td>
</tr>
<tr>
<td>Incentives for participation</td>
<td>12</td>
<td>10</td>
<td>5</td>
<td>1</td>
<td>28</td>
</tr>
<tr>
<td>Social and behavioural studies</td>
<td>12</td>
<td>10</td>
<td>6</td>
<td>1</td>
<td>29</td>
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<tr>
<td>Privacy and confidentiality</td>
<td>11</td>
<td>13</td>
<td>4</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Determination of appropriate subject selection with regard to minors</td>
<td>11</td>
<td>9</td>
<td>6</td>
<td>1</td>
<td>27</td>
</tr>
</tbody>
</table>

*Some respondents did not answer some questions.
Table 1  Number and nature of ethics review committees (ERCs) surveyed per country

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of ERCs</th>
<th>Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burkina Faso</td>
<td>2</td>
<td>All research-institute based</td>
</tr>
<tr>
<td>Cameroon</td>
<td>2</td>
<td>All research-institute based</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>2</td>
<td>All research-institute based</td>
</tr>
<tr>
<td>Gabon</td>
<td>1</td>
<td>Research-institute based</td>
</tr>
<tr>
<td>Gambia</td>
<td>1</td>
<td>National</td>
</tr>
<tr>
<td>Ghana</td>
<td>5</td>
<td>4 research-institute based, 1 university based</td>
</tr>
<tr>
<td>Kenya</td>
<td>1</td>
<td>National</td>
</tr>
<tr>
<td>Malawi</td>
<td>1</td>
<td>University based</td>
</tr>
<tr>
<td>Mali</td>
<td>1</td>
<td>University based</td>
</tr>
<tr>
<td>Mozambique</td>
<td>1</td>
<td>National</td>
</tr>
<tr>
<td>Nigeria</td>
<td>4</td>
<td>1 university based, 3 research-institute based</td>
</tr>
<tr>
<td>Rwanda</td>
<td>1</td>
<td>National</td>
</tr>
<tr>
<td>Senegal</td>
<td>1</td>
<td>National</td>
</tr>
<tr>
<td>Sudan</td>
<td>1</td>
<td>University based</td>
</tr>
<tr>
<td>Tanzania</td>
<td>4</td>
<td>1 national, 2 university based, 1 research-institute based</td>
</tr>
<tr>
<td>Uganda</td>
<td>1</td>
<td>University based</td>
</tr>
<tr>
<td>Zambia</td>
<td>1</td>
<td>Research-institute based</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>1</td>
<td>National</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>31</strong></td>
<td></td>
</tr>
</tbody>
</table>
Table 2  Constraints hindering operations of ethics review committees (ERCs)

<table>
<thead>
<tr>
<th>Constraints</th>
<th>Number of ERCs*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficiency of resources</td>
<td>25/30</td>
</tr>
<tr>
<td>Lack of/insufficient expertise on ethical review</td>
<td>13/30</td>
</tr>
<tr>
<td>Pressure from researchers</td>
<td>11/30</td>
</tr>
<tr>
<td>Lack of active/consistent participation of members</td>
<td>11/30</td>
</tr>
<tr>
<td>Lack of recognition of the importance of ERC functions</td>
<td>11/30</td>
</tr>
<tr>
<td>None or poorly supported by the institute</td>
<td>10/30</td>
</tr>
<tr>
<td>Not completely independent</td>
<td>4/30</td>
</tr>
<tr>
<td>Pressure from sponsors</td>
<td>3/30</td>
</tr>
<tr>
<td>Unequal treatment of applicants in review</td>
<td>1/27</td>
</tr>
<tr>
<td>Biased committee members</td>
<td>0/27</td>
</tr>
</tbody>
</table>

*Respondents skipped some questions.
Composition, training needs and independence of ethics review committees across Africa: are the gate-keepers rising to the emerging challenges?

A Nyika,¹ W Kilama,¹ R Chilendi,¹ G Tangwa,² P Tindana,³ P Ndebele,⁴ J Ikingura⁵

Historical Perspectives of Ethical Committees in Cameroon -1

Before the year 2000

✓ The National Ethics Committee is created by a specific ministerial directive in 1987.

✓ Some institutional Ethical Committees
  - 1988 Ethical Committee of the Faculty of Medicine and Biomedical Sciences in Yaounde
  - 1994 Ethical Committee of the Institute of Plants and medicinal Research in Kumba
  - 1998 Ethics Committee for the Foundation for Research in Tropical Diseases and the environment (REFOTDE) in Buea

Cameroon Bioethics Society is created in 1990 (CBS)
After 2000

✓ Explosion of Institutional Ethical Committees

- 2004 Ethics Committee of the Cameroon Baptist Convention Health Board Institutional Review Board (CBCHB_IRB) in Bamenda
- 2004 Ethics Committee of the University of Buea
- 2004 Ethics Committee of the Provincial Hospital of Bamenda
- 2006 Ethics Committee of CIRCB in Yaoundé
- 2006 Ethics Committee of the Biotechnology Centre in Yaounde
- 2007 CAMBIN Cameroon Bioethics Initiative à Ydé
- ???? HGOPY
- ???? CHU
- ???? IMPM_IRB
- FMBS 11/2011
Historical Perspectives of Ethical Committees in Cameroon -3

Actual Situation

✓ Two Ethical Committees Officially recognized by the Ministry of health
  - National Ethics Committee (Decision Creating NEC)

- Ethics Committee of the CIRCB (Decision creating the CIRCB + decision naming the various members)

✓ Census of all the IRBs and ECs by the Ministry of Public Health (Division of Operational Health)
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The Medical Record

- Everything about you performed by a care provider
  - Doctor, nurse, phlebotomist, radiology technician
- Every activity
  - Exams, meds, lab tests, x-rays
- Paper form
- Electronic
«3ème Journées Camerounaises d’Informatique Médicale et 7ème Conférence HELINA. Yaoundé 28-11-2011»
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Benefits of electronic medical records

Improved patient care

Accessible patient data—anywhere

More time with patients

Improved patient communications and collaboration
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Main concerns about Electronic Medical Record

1. The commitment to patient privacy
2. Improvements in healthcare economics and quality
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The issues with Ethical considerations

- Privacy
- Confidentiality
- Security
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Security, Privacy, Confidentiality

- **Privacy – The Right**
  - Right of the individual to have anonymity
- **Confidentiality – The Expectation**
  - Obligation of the user of an individual’s information to respect and uphold that individual’s privacy
- **Security – The Mechanism**
  - Policies, procedures, mechanisms, tools, technologies, and accountability methods to support Privacy
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Privacy
- Consent is required
- Minimum Necessary
- Patient Rights
  - Inspection, Proposing Amendment, Disclosure, Accounting
- Exceptions
  - Public Health, Legal Obligations for Disclosure
Security – The Three “A”s

- **Authentication**
  - You are who you say you are

- **Authorization**
  - You can see and do what you are permitted by policy to see and do

- **Accountability**
  - You are held responsible for what you see and do
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Authentication

- Passwords – simplest form of authentication
- Can be very secure, but one breach can spread rapidly
- Can be too secure – if you forget your password
Biometric Authentication

- Identify who you are by a physical attribute
- Signature
- Facial Points
- Voice Print
- Typing Style

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Biometric Authentication

- Fingerprint
  - Optical, Digital
  - Hmmm… would someone in a hospital have access to a severed finger?

- Iris
  - Highly accurate
  - Same issue as with a dead finger
  - Requires a camera
Authorization

- I’m a valid user of the system, and I’ve been authenticated. I want to see EVERYTHING on EVERYONE!!!
- The system can define who is authorized to see and do what
Authorization Models

- **User Based**
  - I have certain authorization rights based on who I am as an individual

- **Role Based**
  - I have authority based on my role e.g. doctor vs. nurse vs. lab technologist

- **Context Based**
  - Who you are + Where you are + What you are + When you are What you are
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Accountability

- You are held responsible for what you see and do
- Difficult to develop systems-based ways of ensuring accountability
- An ethics problem
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Accountability

- Security can help ensure accountability
  - Audit Logging – “We know where you’ve been”
  - Password policies
  - Alert capabilities
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Workplace Ethics

- Many people may have access to patient data
- Trust
- Knowledge of Rules
- Awareness of Consequences
Ethics?

What Ethics?

Appropriate Ethics?
Two truisms

The whole is greater than the sum of its parts

It is important to keep your eye on the ball – but you should never lose sight of the goal
Thank you