Clinical Research Data Repository

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Intro & background & significance

Aggregated Clinical Data Repository

Hospital

OPD

ED

IPD

Hospital

OPD

ED

IPD

Hospital

OPD

ED

IPD

Hospital

OPD

ED

IPD

Hospital

OPD

ED

IPD
Site Server
- Local de-identified DB
- Web Services

Portal Server
- Temporary Aggregation DB
- Web Services

Users
Introduction

• Clinical data repository built within single institution
• Peculiarities of this specific research ID
• ELSI issues
Background

• Electronic Health Records (EHR) v.s. Clinical research
• Quality and safety of care.
Significance

• Cost
• Complexity prohibit
• Standardized clinical data format
Missions

• The Core Project
  – Formulate an information infrastructure (network, computation and storage)
  – Cultivate all the Local User Group (LUG) s
Missions (CON.)

• The Data-source
  – all the data ETL (extraction, transformation and load) processes,
  – local computational resources and local privacy/confidentiality assurance.
  – local access control to the clinical data repository and coordination to LUGs.
Clinical Research

• Type of Study
  – Diagnosis (Biometrics) : 4 proposals
  – Epidemiology : 5 proposals
  – Quality and Patient Safety : 5 proposals
  – Treatment (Drug-Response) : 4 proposals

• Will open to all researchers in the participating hospitals in the next phase
Expected Results

- More studies will be generated on
  - Etiology
  - Diagnosis
  - Treatment
  - Prognosis
  - Management of diseases
  - Quality and patient safety
  - Health policy issues
## Clinical Research

- **Diagnosis (Biometrics)**

<table>
<thead>
<tr>
<th>#</th>
<th>Proposal Topic</th>
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<tbody>
<tr>
<td>1</td>
<td>Comparing all relevant factors of blood glucose control in diabetic patient among Taiwanese and French population</td>
</tr>
<tr>
<td>2</td>
<td>Comparing the relationship of Glucose and Glycosylated hemoglobin in Asian and Caucasian patients.</td>
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<tr>
<td>3</td>
<td>Correlating the risk factors that exacerbate children with Systemic Lupus Erythematosus between Asian and Caucasian population.</td>
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<td>4</td>
<td>Comparing the risk factors and analyzing, for the sub-types of Ischemic stroke in Taiwan and France</td>
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## Clinical Research

### Epidemiology

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<tr>
<td>1</td>
<td>A study of rare diseases (Genetic diseases, Adrenoleukodystrophy, mermaid syndrome); A comparative study between Asians and Europeans</td>
</tr>
<tr>
<td>2</td>
<td>A study related to Health and developmental disorders among children diagnosed with Autism, ADHD or Epilepsy</td>
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<tr>
<td>3</td>
<td>Climate change and its influence on health conditions and clinical manifestations of the patients visiting medical centers: An International study</td>
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<tr>
<td>4</td>
<td>Significance of road traffic rules on Road accidents presented at Emergency room</td>
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<tr>
<td>5</td>
<td>A study of substance abuse: Comparing treatment regimens, mental and social recovery of substance abuser in Asia and Europe</td>
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## Clinical Research

### Quality and Patient Safety

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<tr>
<td>1</td>
<td>Evaluating Extracorporeal shock wave and Endoscopic lithotripsy treatment and analyzing the reasons for revisit and emergency visits by these patients</td>
</tr>
<tr>
<td>2</td>
<td>Evaluation of safety and potential risks on renal toxicity induced by contrast medium.</td>
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<tr>
<td>3</td>
<td>What strategies are effective for strengthening data analysis and use, and the transformation of data into knowledge for action?</td>
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<tr>
<td>4</td>
<td>Compassionate response of Taiwanese and French clinicians to the patients with the abnormal test values</td>
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<tr>
<td>5</td>
<td>The number of emergency visits and imaging check ups of the patients before undergoing appendectomy.</td>
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### Clinical Research

#### Treatment (Drug-Response)

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<tr>
<td>1</td>
<td>The differential diagnosis and treatment of acute tonsillitis and pharyngitis</td>
</tr>
<tr>
<td>2</td>
<td>A study on the drug resistance patterns developed in population due to utilization of anti-biotic in Outpatient department in hospitals of Taiwan and France</td>
</tr>
<tr>
<td>3</td>
<td>A study of efficient mono-therapy (antiepileptic drug) in various type of epilepsies.</td>
</tr>
<tr>
<td>4</td>
<td>Analysis of metabolic abnormalities and efficacy of antipsychotic drugs among Asians and Caucasians.</td>
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Expected Difficulties

- ELSI and privacy issues
- Lack of data standard
- Scale and complexity of information
- Growing capacity of storage (2 Terabyte per hosp per year)
- High demand of computational resource to maintain multiparty private computation (shared results without sharing data)
Future Development

• The proposed clinical data repository will provide better value for Taiwan’s research community

• Taiwan’s Electronic Health Record is among the best in the world
  – unique patient ID, confidentiality of data and privacy laws

• “Clean room” approach
Thank you for your attention