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# Designing research databases: Its all about terminology standards

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# Designing research databases: It's all about terminology standards



## Faculty Candidate Presentation

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# Overview

- Orthodontics Collection
- Occulopharyngeal Muscular Dystrophy Patient Registry
- Whole-body cadaveric image database project

# Orthodontics Collection

# History

- 2005 anthropology student sent out letters to all dental practitioners in New Mexico (~100)
- One orthodontist responded with 30+ years of records
  - High quality X-ray equipment
  - Developed his own dental information system in the 1980's (Sun Sparks Workstations)
  - Preserved and catalogued all the pre- and post-treatment dental casts in archival boxes
  - Took intra-treatment photos of many of the cases post-1983









# Whole Collection Characteristics

- Represents the ethnic and racial diversity of the southwest United States 1972-1999
- 6363 unique patients
- 600 relationship sets
- Several multi-generational families
- 400,000 images (pre-, intra-, and post-treatment, intra-oral images and X-ray images)
- Many head X-rays have cephalometric measurements from manual or digital tracings (Sparks Workstation)
- Full facial photographs and paper treatment records



# De-Identified, Web-based Sub-Collection

- Basic patient demographics (age, orthodontic diagnoses, ancestry, and decade of treatment)
- Selected patient history
- Extraction patterns
- Intra-oral images
- Intra-treatment images
- X-ray images (lateral head and *Panaview*)
- Cephalometric measurements

# De-Identified, Web-based Collection

- Free to access and use:

<http://hsc.unm.edu/programs/ocfs/>

# Informatics Tasks

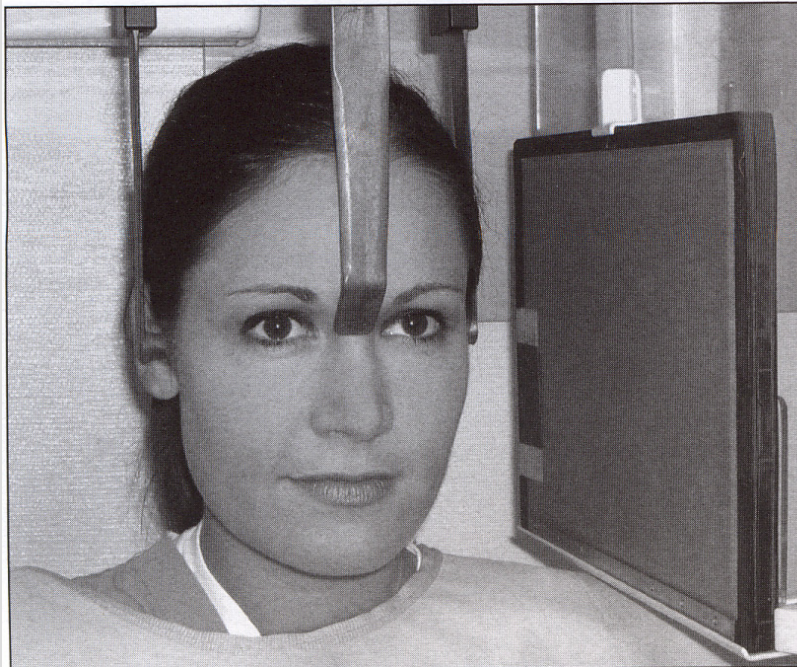
- 2006 developed a plan to accept and manage the collection in compliance with federal, state, and UNM regulations
- 2007 National Library of Medicine funding to develop digital version of the collection
- Solved the “cephalometrics problem”

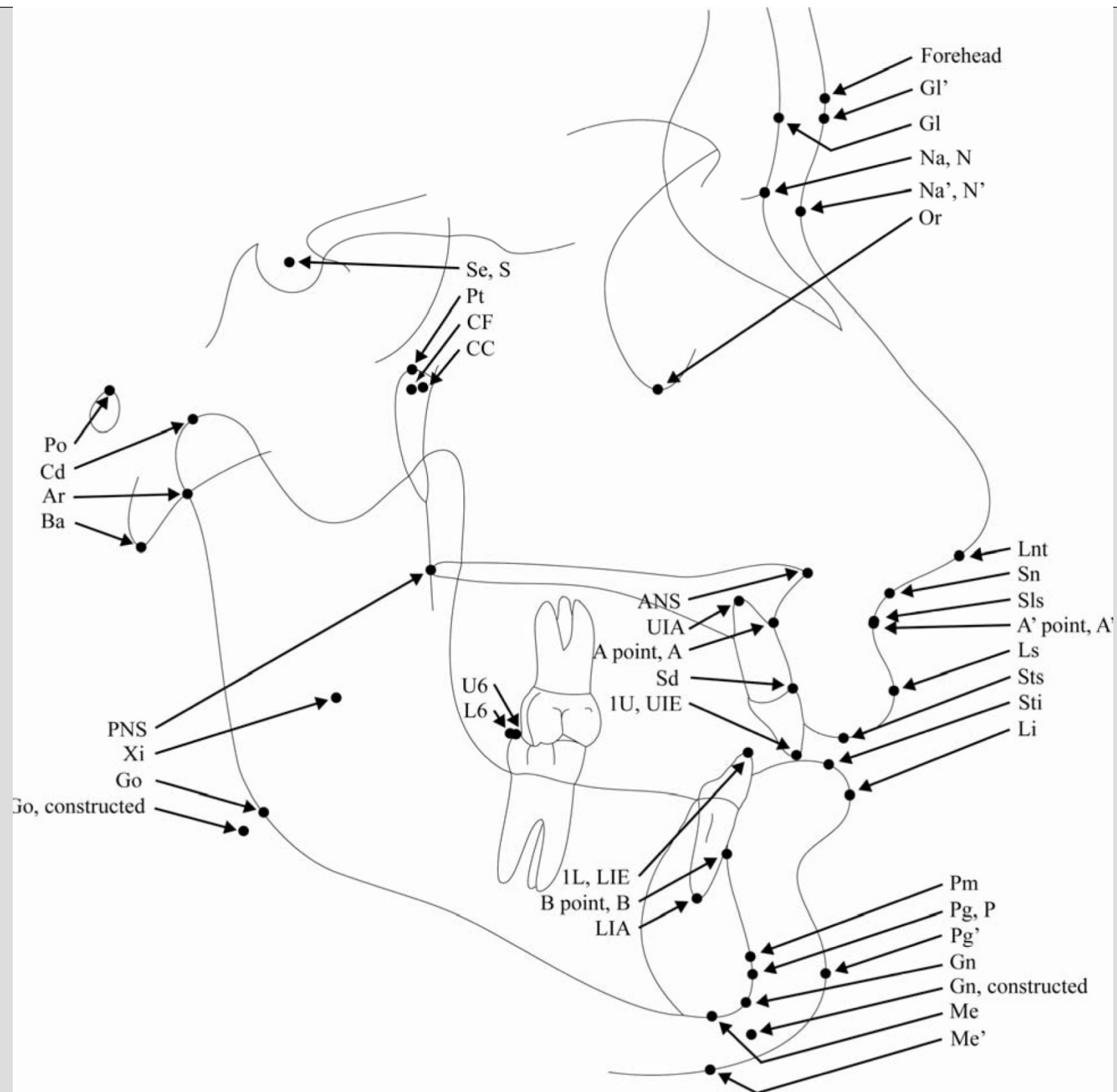


# What are Cephalometrics

- Head X-rays taken in a standardized manner
- Cephalometrics are measurements on the X-ray itself
- Mostly consist of lengths and angles
- Hundreds of cephalometrics have been defined
- Used by some orthodontists to help with treatment planning
- Used for research
- Defined in several cephalometric atlases

# What are Cephalometrics?

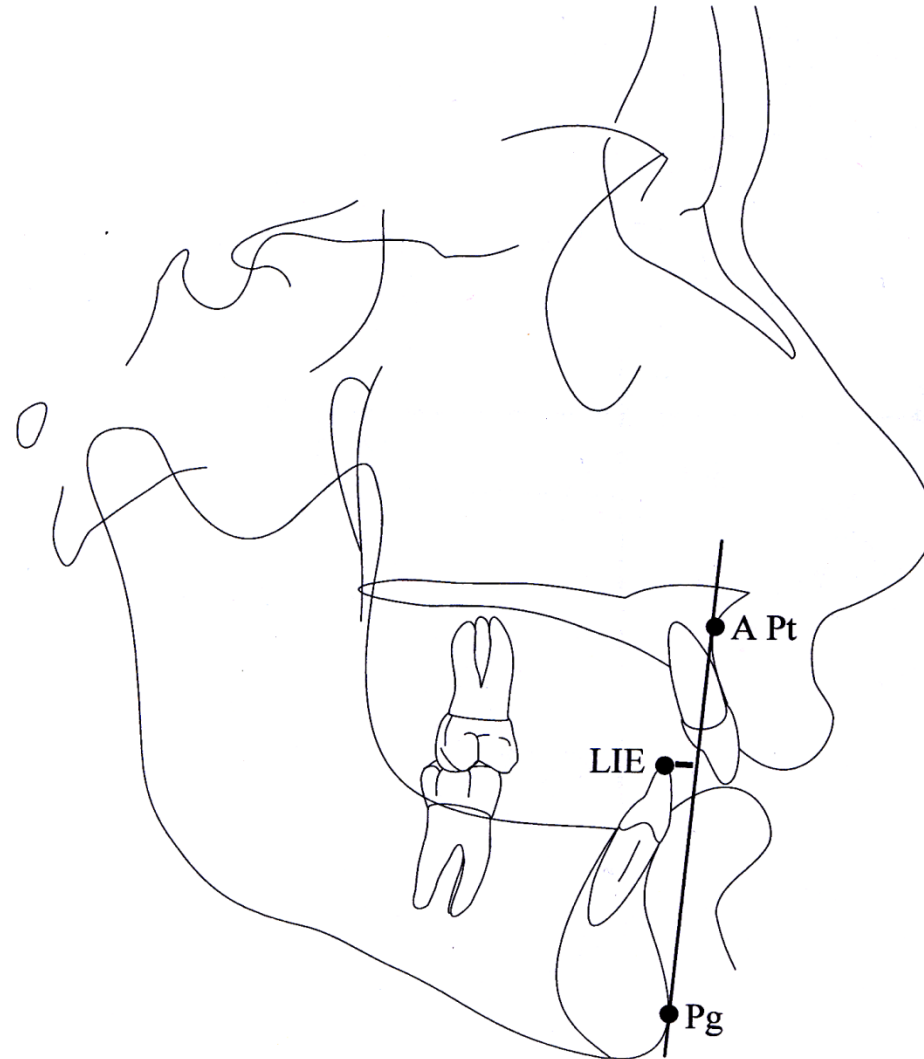




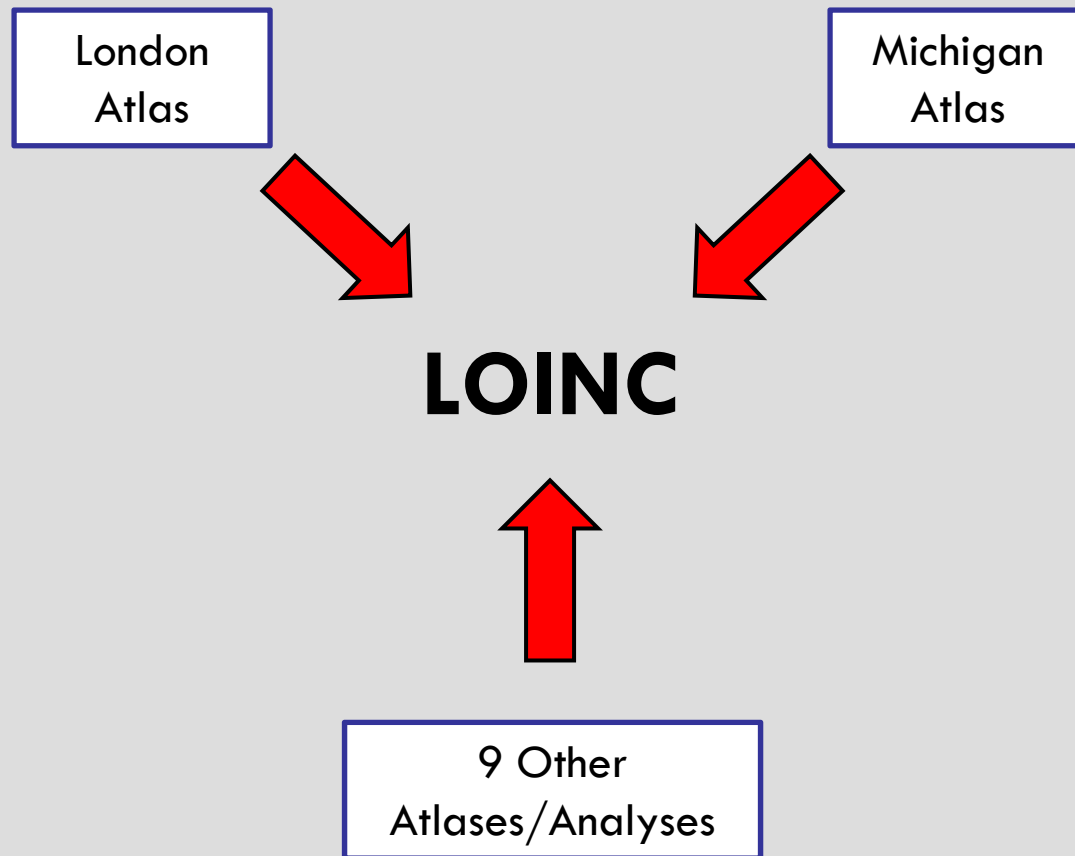


# Example

APO\_PTII



# What we propose



# Atlas References

## 1. “Michigan Atlas”

- Riolo ML, Moyers RE, McNamara JA, Hunter WS (1974). An Atlas of Craniofacial Growth: Cephalometric Standards from the University School Growth Study, The University of Michigan. Ann Arbor: The University of Michigan.

## 2. “London Atlas”

- Bhatia SN, Leighton BC (1993). A Manual of Facial Growth: A Computer Analysis of Longitudinal Cephalometric Growth Data. Oxford: Oxford university Press.

## 3. “Ricketts Analysis”

- Ricketts RM, Roth RH, Chaconas SJ, Schnlhof RJ, Engel A (1982). Orthodontic Diagnosis and Planning, Volumes I and II. Denver: Rocky Mountain Orthodontics

## 4. “McNamara Analysis”

- McNamara JA Jr, Brundon WL (2001). Orthodontic and Dentofacial Orthopedics. Ann Arbor: Needham Press.

## 5. “Soft Tissue Analysis”

- Holdaway RA (1983). A Soft Tissue Cephalometric Analysis and its Use in Orthodontic Planning, Part I. *American Journal of Orthodontics*, 84: 1-28.
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# Atlas References Continued

## 6. “Downs Analysis”

- Downs WB (1948). Variations in Facial Relationships: Their Significance in Treatment and Prognosis. *American Journal of Orthodontics*, 34:812-840.

## 7. “Tweed Analysis”

- Tweed CH (1954). The Frankfort Mandibular Incisal Angle (FMIA) in Orthodontic Diagnosis, Treatment Planning, and Prognosis. *The Angle Orthodontics*, 24: 121-169.

## 8. “Steiner Analysis”

- Steiner CC (1953). Cephalometrics for You and Me. *American Journal of Orthodontics*, 39: 729-755.

## 9. “Wits Appraisal”

- Reidel RA (1952). The Relation of Maxillary Structures to Cranium in Malocclusions and in Normal Occlusions. *The Angle Orthodontics*, 22: 140-145.

## 10. “Frontal Analysis”

- Grummons DC, Kappeneye van de Coppelo MA (1987). A Frontal Asymmetrical Analysis. *The Journal of Clinical Orthodontics*, 21: 448-465.
- Grummons DC, Ricketts RM (2004). Frontal Cephalometrics: Practical Application. *World Journal of Orthodontics*, 5: 99-119.

## 11. “Jarabak-Bjork Analysis”

- Jarabak JR, Fizzell JA (1972). *Technique and treatment with light-wire edgewise appliances*. Saint Louis: C. V. Mosby Co.

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- UNM School of Medicine
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# Occulopharyngeal Muscular Dystrophy Patient Registry

# What is Occulopharyngeal Muscular Dystrophy (OPMD)?

- Late-onset, progressive, genetic disease
- Most often affects the muscles of the head, neck and upper GI system
- Highest prevalence in US among Hispanic New Mexicans, but also in Canada and Spain
- A “rare disease” defined as  $< 200,000$  cases in US

# NIH Office of Rare Disease Research (ORDR)

- Established in 2002
- Launched the Global Rare Diseases Patient Registry and Data Repository
  - Standardize registry questions
  - Find common ground across registries
  - Create a common repository
  - Develop a method to share data
- Pilot began in 2012



# NIH Office of Rare Disease Research (ORDR)

- Selected 24 rare disease organizations
  - 12 with a registry in place
  - 12 without
- Defined Common Data Elements
  - **Current contact information**
  - **Socio-demographic**
  - **Diagnosis**
  - **Family history**
  - **Birth and reproductive history**
  - **Anthropometrics**
  - **Patient reported outcome**
  - **Medication and devices**
  - **Clinical research and participation**
  - **Contact/communication preferences**

# OPMD Registry

- Obvious benefits
- Must have OPMD or related to person with OPMD
- Answer questionnaire
  - 57 questions
  - 190 elements recorded
- <http://som.unm.edu/programs/opmd/>



# OPMD Registry

Source of data element	Number of data elements
• NIH Office of Rare Diseases Research Standard's CDEs	• V.1: 47, V.2: 42
• Swallowing Quality of Life outcomes tool	• 45
• Neuro-QOL Lower Extremity Function Item Bank	• 8
• PROMIS Physical Function Item Bank	• 3
• International Statistical Classification of Diseases codes	• 6
• Current Procedural Terminology codes	• 6
• U. of Rochester Myotonic Dystrophy and FSHD Registry	• 5
• Rare Diseases Clinical Research Network Contact Registry	• 1
• Sydney Swallow Questionnaire	• 1

## Analysis - Version 2

- Use of HL7 v2.3.1 (now deprecated)
- Combined sex into one element
- Use LOINC race and ethnicity not OMB
- No longer requires contact information

## Analysis - Version 2

- Yes/No questions reference a LOINC code
  - Incorrect question
  - Used for yes/no response
- Nationality
  - Uses ISO 3166 2-code
  - Links to ISO 3166 3 code

# Shameless Plug

- Our paper on our detailed analysis of the standard is scheduled for presentation next month at AMIA
- **S51: Papers - Case Studies to Improve HIT**  
10:30 AM - 12:00 PM; Jefferson West  
(Washington Hilton)



# Acknowledgements

- Shamsi Daneshvari, PhD
- La Tierra Segrada Society

# Whole-body cadaveric image database project

# The Situation

- The NM Office of the Medical Examiner has been collecting whole-body CT (and some MRI) cadaveric image since 2010
- Their database is designed only for case closure
- 5,249 cases in 2010
  - 35% deaths in all New Mexico (most from natural causes)
  - ~12 % Native American ~35 Hispanic
- No resources available to make this treasure trove of data available for research!

# Informatics Task

- Index the collection
- Create a metadatabase with 30 elements to tag images with
- Modified Delphi process with over 80 scientists from around the world
  - Biomedical informatics and standards experts
  - Anthropology
  - Forensic pathology and radiology
  - Medicine and many others

# Work in progress

- Delphi process is underway
- K-award submitted



Thank you!