Nature of Medical Data

6.872/HST950

Peter Szolovits

Outline

- Recall context of current medical practice
- History of medical record keeping
- Organization of medical records
- Computerized medical records
  - Why
  - Key issues
  - Failures and successes
- Current approaches

Implications of Health Care Organization for Informatics

- Money determines much
  - Medicine spends 1-2% on IT, vs. 6-7% for business overall, vs. 10-12% for banking
  - "Bottom line" rules, therefore emphasis on
    - Billing
    - Cost control
    - Quality control, especially if demonstrable cost savings
    - Retention and satisfaction (maybe)
  - Management by accountants

Why Keep Records?

- Basis for historical record
- Communication among providers
- Anticipate future health problems
- Record standard preventive measures
- Identify deviations from the expected
- Legal record
- Basis for clinical research

Who Keeps Records?

- Doctor
- Nurse
- Office staff, admissions
- Administrator
- physical therapist
- lab personnel

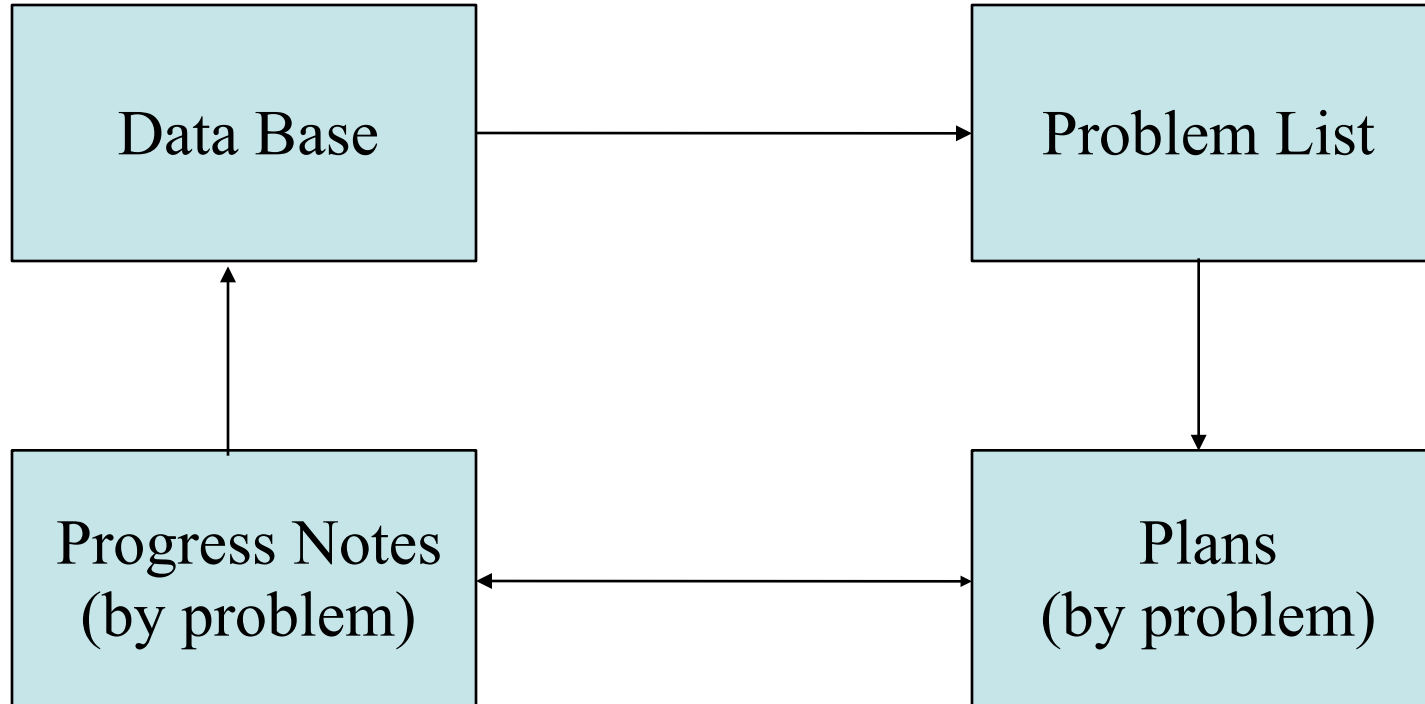- radiologist
- pharmacist

- patient

Forms of Clinical Data

- Numerical Measurements
  - Lab data
  - Bedside measurements
  - Home instrumentation
- Recorded signals (e.g., ECG, EEG, EMG)
- Images (X-ray, MRI, CAT, Ultrasound, Pathology, …)
- Genes (SNPs, expression arrays, pedigrees, …)

- Coded (?) discrete data
  - Family history
  - Patient's medical history
  - Current complaint
    - Symptoms (patient)
    - Signs (doc)
  - Physical examination
  - Medications
- Narrative text
  - Doctor's, nurse's notes
  - Discharge summaries
  - Referring letters

Organization of Data

- Doctor's journal (traditional)
- Time order of collection, per patient (Mayo)
- Source of data
- Problem-Oriented Medical Record (POMR) (L. Weed, 1969)
  - Notes organized by problems
  - SOAP: subjective, objective, assessment, plans

POMR

```
┌─────────────────┐                    ┌─────────────────┐
│                 │                    │                 │
│    Data Base    │ ─────────────────▶ │  Problem List   │
│                 │                    │                 │
└─────────────────┘                    └─────────────────┘
        ▲                                       │
        │                                       │
        │                                       ▼
┌─────────────────┐                    ┌─────────────────┐
│                 │                    │                 │
│ Progress Notes  │ ◀────────────────▶ │     Plans       │
│  (by problem)   │                    │  (by problem)   │
│                 │                    │                 │
└─────────────────┘                    └─────────────────┘

diagnostic, therapeutic,
patient education
```

The Data Base

- Identifying information (name, age, sex, race, religion, insurance info, etc.)
- Patient profile (occupation, education, marital status, children, hobbies, worries, moods, sleep patterns, habits, etc.)
- Medical history
  - Chief complaints
  - History of present illness
  - Past medical history
  - Review of systems
  - Family history
  - Medications
- Physical examination
- Laboratory data and physiologic tests (complete blood count, electrocardiogram, chest x-ray, creatinine, urinalysis, vital capacity, tonometry, etc.)

The Problem List

- "those features in the patient's psychobiological makeup that require continuing attention"
  - Social history
  - Risk factors
  - Symptoms
  - Physical findings
  - Lab tests
- Causally organized; e.g., GI bleeding caused by duodenal ulcer appears under the ulcer

Example Problem List

No	Active	Date	Inactive	Date
1	Hypertension	1953		
2	Recurrent bronchitis	1958		
3	Penicillin allergy	1958		
4			S/P pyelonephritis	1960
5	Gallstones	Oct 1972	→Cholecystectomy	Mar 1973
6	Arthralgias	Mar 1973	→#9	June 1973
7	Pleurisy	Mar 1973	→#9	June 1973
8	Proteinuria	Apr 1973	→#9	June 1973
9	SLE	June 1973		
10	Unemployment	Nov 1973		

Problem-Related Plans

- Diagnostic: lab tests, radiology studies, consultations, continued observations, …

- Therapeutic: medications, diet, psychotherapy, surgery, …

- Patient education: instruction in self-care, about goals of therapy, prognosis, …

Plans per problem

1. Diarrhea

   Dx:

   - stool for occult blood, culture, ova, and parasites, microscopic fat; and muscle fibers
   - Sigmoidoscopy
   - Barium enema if persistent

   Rx: Avoid foods that exacerbate

   Ed: Informed that more info is needed to make a diagnosis, will aim for symptomatic therapy for now.

Plans per problem (cont.)

2. Pyuria
   Dx:
   - BUN
   - Repeat urinalysis
   - Urine culture

3. Obesity
   Rx: 1500 kcal diet, Weight Watchers
   Ed: Dangers of obesity cited. *Goal*: 170 lbs.

Progress Notes

- Subjective: interval history, adherence to program
- Objective: physical findings, reports of lab, x-ray, other tests
- Assessment: Appraisal of progress, interpretation of new findings, etc.
- Plan: Dx, Rx, Ed.

Example SOAP Note

#3 RHD with mitral stenosis

S: 2 flight dyspnea, mild fatigue. No orthopnea, hemoptysis, ankle edema. Child has strep throat.

O: BP 120/70. P 78 regular
Neck veins normal, lungs clear.
Grade iii diastolic rumble, wide opening snap, P_2 slightly ↑

A: Stable. Catheterization still not indicated. Risk of strep throat present.

P: Dx: Cardiac fluoroscopy

Rx: Continue chlorothiazide and penicillin V 250mg b.i.d.—2 weeks

Ed: Reinstructed about antibiotic coverage for tooth extractions, sched. for next month. (Will contact oral surgeon.)

POMR characteristics

- Augment with data flow sheets
- Importance of clinical judgment
- Benefits:
  - Communication among team members, explicitness
  - Education and audit
  - Clinical research

POMR evidence

- Difficult adoption
- Some duplication
- Some doctors liked it
- Paper-based POMR slow, computer-based maybe faster
- Demand-oriented MR: by time, by source, by problem, etc. Dynamic arrangement.

Mayo experience

- Paper records, mostly
- Pneumatic tube delivery, therefore limited size
- Formal procedures for reaping and organizing records at discharge
- Comprehensive index

The Computer-based Patient Record

- IOM Study: Dick, R. S. and Steen, E. B., Eds. (1991). The Computer–Based Patient Record: An Essential Technology for Health Care. Washington, D.C., National Academy Press.
- Made strong case for CPR
- Recommended CPRI (Institute), but it never caught on
- Today's standards grow more out of communication standards: HL7 (labs) and DICOM (digital images)

Paper record: Strengths

- Familiar; low training time
- Portable to point of care
- No downtime
- Flexibility; easy to record subjective data
- Browsing and scanning
  - Find information by unanticipated characteristics (e.g., Dr. Jones' handwriting)

Paper record: Weaknesses

- Content: missing, illegible, inaccurate
  - E.g., one hospital study: 11% of tests were repeats to replace lost information
  - Too thick (1.5 lbs avg.)
  - Fail to capture rationale
  - Incomprehensible to patients and families

Sample paper record defects

- 75% of face sheets had no discharge disposition, 48% no principal Dx
- Agreement between encounter (witnessed) and record: 29% med hx, 66% Rx, 71% info re current illness, 72% tests, 73% impression/Dx, 92% chief complaint
- 20.8% of Medicare discharges coded incorrectly (DRG inflation)

More paper record defects

- Unavailable at up to 30% of patient visits
  - Two clinic visits in a day
  - Docs keep records in their office
  - Failure to deliver
  - Misfiled in file room
- Discontinuity across institutions
  - In/outpatient records separate

Ethnographic Design

- Xerox PARC analysis of office work
  - Sociologists, Anthropologists, Engineers
  - Much of work is
    - communication,
    - assignment of responsibilities,
    - problem solving

Medicine is an Information Industry

- 35-39% of hospital operating costs due to professional and patient communications
- Physicians spend 38%, nurses 50% of their time charting
- Exponential growth of medical knowledge and literature

Individual Users of Patient Records

- Providers
  - Chaplains
  - Dental hygienists
  - Dentists
  - Dietitians
  - Lab technicians
  - Nurses
  - Occupational therapists
  - Optometrists
  - Pharmacists
  - Physical therapists
  - Physicians
  - Physician assistants
  - Podiatrists
  - Psychologists
  - Radiology technologists
  - Respiratory therapists
  - Social workers

- Management
  - Administrators
  - Financial managers and accountants
  - Quality assurance managers
  - Records professionals
  - Risk managers
  - Unit clerks
  - Utilization review managers

- Reimbursement
  - Benefit managers
  - Insurers (Fed, State, private)

- Other
  - Accreditors
  - Gov't policymakers, legislators
  - Lawyers
  - Health care researchers, clinical investigators
  - Health Sciences journalists and editors
  - Patients, families

Institutional Users of Patient Record

- Healthcare Delivery
    - Alliances, associations, networks, systems of providers
    - Ambulatory surgery centers
    - Donor banks (blood, tissue, organs)
    - HMO's
    - Home care agencies
    - Hospices
    - Hospitals
    - Nursing homes
    - PPO's
    - Physician offices, group practices
    - Psychiatric facilities
    - Public Health Departments
    - Substance abuse programs
- Management and Review
    - Medicare peer review organizations
    - Quality assurance companies
    - Risk management companies

- Reimbursement
    - Business Health coalitions
    - Employers
    - Insurers
- Research
    - Disease registries
    - Health data organizations
    - Health care technology developers and manufacturers
    - Research Centers
- Education
    - Allied health professional schools, medical, nursing, public health schools
- Accreditation
    - Accreditation organizations
    - Inst. licensure agencies
    - Prof. Licensure agencies
- Policymaking
    - Fed, State, Local gov't agencies

Primary Uses
of Patient Record

- Patient care delivery (Patient)
  - Document services received
  - Constitute proof of identity
  - Self-manage care
  - Verify billing
- Patient care delivery (Provider)
  - Foster continuity of care
  - Describe diseases and causes
  - Support decision making about Dx and Rx
  - Assess and manage risk
  - Facilitate care via Clin. Practice Guidelines
  - Document patient risk factors
  - Assess and document patient expectations and satisfaction
  - Generate care plans
  - Determine preventive advice
  - Remind clinicians
  - Support nursing care
  - Document services provided

- Patient care management
  - Document case mix
  - Analyze severity of illness
  - Formulate practice guidelines
  - Manage risk
  - Characterize use of services
  - Basis for utilization review
  - Perform quality assurance
- Patient care support
  - Allocate resources
  - Analyze trends and develop forecasts
  - Assess workload
  - Communicate between departments
- Billing and reimbursement
  - Document services for payment
  - Bill for services
  - Submit insurance claims
  - Adjudicate insurance claims
  - Determine disabilities (workmen's comp)
  - Manage & report costs
  - Perform actuarial analysis

Secondary Uses of Patient Record

- Education
  - Document health care professional experience
  - Prepare conferences and presentations
  - Teach students
- Regulation
  - Evidence in litigation
  - Foster postmarketing surveillance
  - Assess compliance with standards
  - Accredit professionals and hospitals
  - Compare health care organizations
- Policy
  - Allocate resources
  - Conduct strategic planning
  - Monitor public health

- Research
  - Develop new products
  - Conduct clinical research
  - Assess technology
  - Study patient outcomes
  - Study effectiveness and cost-effectiveness of care
  - Identify populations at risk
  - Develop registries and databases
  - Assess cost-effectiveness of record systems
- Industry
  - Conduct R&D
  - Plan marketing strategy

User Requirements

- **Record Content**
  - Uniform core data elements
  - Standardized coding systems and formats
  - Common data dictionary
  - Information on outcomes of care and functional status

- **Record Format**
  - "Front-page" problem list
  - Ability to "flip through" the record
  - Integrated among disciplines and sites of care
- **System Performance**
  - Rapid retrieval
  - 24/7
  - Available @ convenient places
  - Easy data input

User Requirements (cont.)

- Linkages
  - To other info systems (e.g., radiology, lab)
  - Transferability of information among specialties and sites
  - With relevant literature
  - Other registries and institutional databases
  - To records of other family members
  - E-billing
- Training and Implementation
  - Minimal training required
  - Graduated implementations

- Intelligence
  - Decision support
  - Clinician reminders
  - "Alarm" systems, customized
- Reporting
  - "Derived documents", e.g., insurance forms
  - Easily customized output, UI
  - Standard clinical reports, e.g., discharge summary
  - Custom and *ad hoc* reports
  - Trend reports and graphics
- Control and Access
  - Easy patient access
 - Safeguards of confidentiality

Why is this hard?

- **Characterize edema:**
  - Where?
  - When?
  - How often?
  - Temporal variation?
  - Severity
  - Symmetry
  - What other characteristics?
- *Uncertainties* in all of the above

- Thousand diseases, syndromes, clinical states
- Few thousand symptoms, signs, observables
- Few thousand specific lab tests
- Thousands of meds, variations, combinations, routes, dosage schedules, …
- ??? Treatments

Not just database, knowledge representation

- "Sometime before his 5th birthday, Johnny had scarlet fever, which caused changes in his heart sounds."

- LEG <S> WEAKNESS PROXIMAL ONLY

- (EDEMA with
  LOCATION = FACIAL or PERI-ORBITAL,
  PAINFULNESS = not PAINFUL,
  SYMMETRY = not ASYMMETRICAL,
  ERYTHEMA = not ERYTHEMATOUS)

What is the "Right" representation?
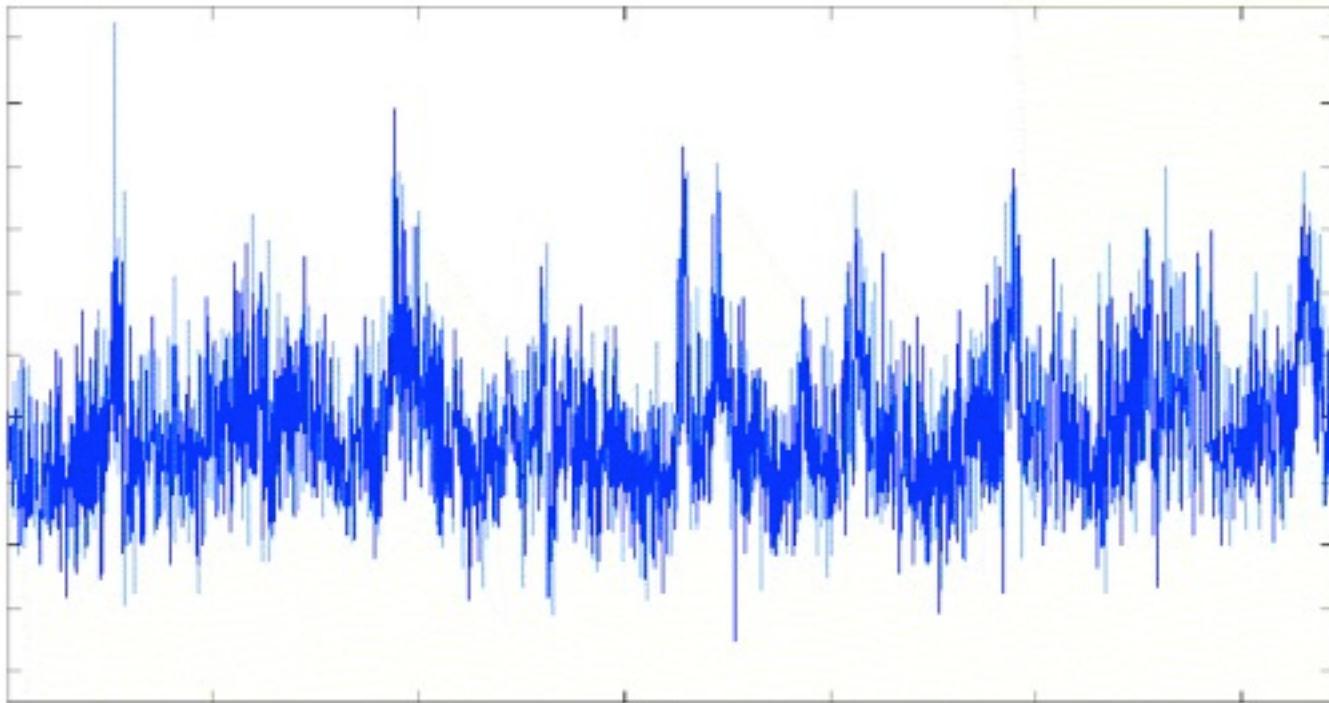
Inadequate Coding Systems

- Low degree of refinement
  - E.g., ICD-9's categories for Chronic Bronchitis
    - Simple
    - Mucopurulent
    - Obstructive
    - Other
    - Unspecified
- Poor coverage of symptoms
- Difficulty of automatic coding
  - Gabrieli's 10M-phrase thesaurus

Data for Lotte Ingriddotter

(as of Mon Sep 4 02:02:15 EDT 1995 , patient number 6)

Name, Address, and Phone

```
Lotte  Ingriddotter
34 Oak St
Melrose, NY 10101
Tel:  8005551212
```

General Information

Date of Birth: 16-FEB-85 (age 10)   Sex: F   Race: W

Problems for Lotte Ingriddotter

- THYROID-CARCINOMA from 23-JAN-92 [query OMIM database | query MEDLINE]
- HYPOTHYROIDISM from 23-JAN-92 [query OMIM database | query MEDLINE]
- SECONDARY-HYPOTHYROIDISM from 23-JAN-92 [query OMIM database | query MEDLINE]
- HYPOPARATHYROIDISM from 23-JAN-92 [query OMIM database | query MEDLINE]

Web Decision Support (allows compound OMIM and MEDLINE queries)

| LAB TESTS | CLINICAL MEASURES | FLOW-SHEETS | VISIT HISTORY |
| Detailed | Detailed | | |

| GROWTH CHARTS | AVAILABLE DOCUMENTS |

http://luke.lcs.mit.edu/medweb-bin/problem-info?problem_name=HYPOPARATHYROIDISM&p

For relevant article, see Kohane, Isaac et al. "Building National Electronic Medical
Record Systems via the World Wide Web." *JAMIA* 3, no. 3 (1996). (PDF)

Events:	Birth	1 mo.	2 mos.	4 mos.	6 mos.	1 year	15 mos.	18 mos.	4-6 years	14-16 years
Dates:	2/16/85	3/16/85	4/16/85	6/16/85	8/16/85	2/16/86	5/16/86	8/16/86	2/16/89	2/16/99
HBV	2/24/85	5/4/85			7/8/86					
DTP			5/4/85	6/30/85	8/29/85	3/23/86			11/6/90	
Polio			5/4/85	6/30/85	8/29/85				11/6/90	
Hib			5/4/85	6/30/85	8/29/85	3/23/86				
MMR							4/28/86		?	
Td										?
Varicella							4/28/86			

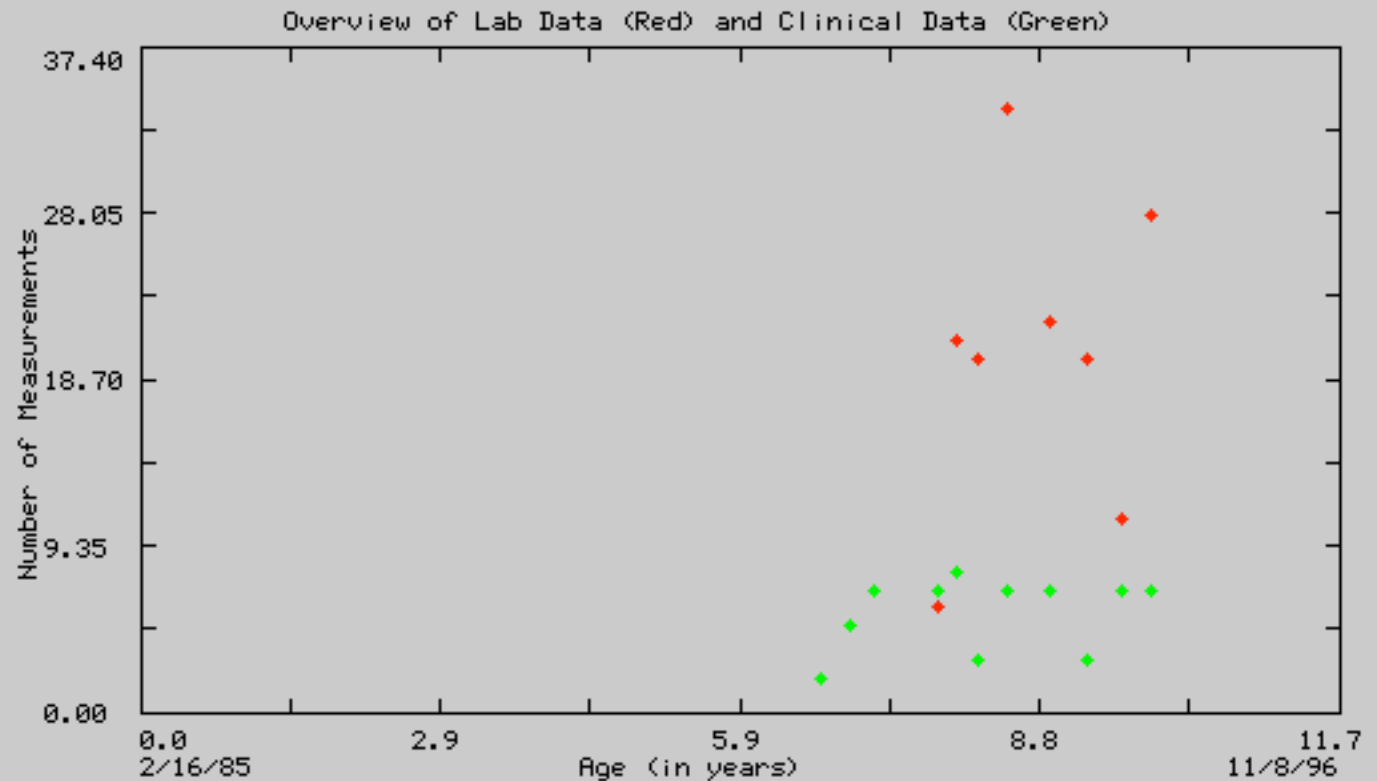| Vaccine	Vaccine type	Date given	Vaccine lot #	Doctor or clinic	Date next dose due	Manufacturer
Polio (OPV or eIPV)	Orimune	5/4/85	66036	The EMRS Demo Clinic		Wyeth-Ayerst
	Orimune	6/30/85	49597	The EMRS Demo Clinic		Wyeth-Ayerst
	Orimune	8/29/85	95718	The EMRS Demo Clinic		Wyeth-Ayerst

Immunizations

Clinical Measurements
11 Height
11 Weight
10 Heart Rate
8 Diastolic Bp
8 Systolic Bp
7 Tanner Breast
7 Tanner Pubic Hair
1 Bone Age

Frequent Lab Measurements
8 PTH1
8 25OHD
8 1,25OHD
7 ALKP
7 CA

Overview of Lab Data (Red) and Clinical Data (Green)

Number of Measurements

37.40

28.05

18.70

9.35

0.00

0.0
2/16/85

2.9

5.9

Age (in years)

8.8

11.7
11/8/96

Standard Flowsheets

Thyroid
Adrenal
Diabetes Mellitus
Growth

Electrolytes
Hematology and Coagulation
Hepatic Metabolism
Blood Gases

View the Data

Select Measurements by Date
Customized Flowsheets
Graphs

Labs Summary

Laboratory Studies for Lotte Ingriddotter, Unlimited

(as of Mon Sep 4 02:11:28 EDT 1995 , patient number 6)

If you are seeing garbage on your screen, it means that your browser does not support tables, a new feature in HTML. See the World Wide Web Consortium home page for a list of clients that do support tables. Netscape 1.1 supports tables.

Laboratory Studies for Lotte Ingriddotter

Test Date	Test Type	Result	Units	Normal Low	Normal High
01/06/95 11:41	CRU	176.1	MG/DL		
01/06/95 11:41	PHOSU	6.6	MG/DL		
01/06/95 11:41	CAU	21.3	MG/DL		
01/06/95 11:38	LYTES				
01/06/95 11:38	NA	141	MMOL/L	135	148
01/06/95 11:38	K	3.8	MMOL/L	3.0	4.5
01/06/95 11:38	CO 2	27	MEQ/L	19	25
01/06/95 11:38	CR	0.6	MG/DL	0.3	0.7
01/06/95 11:38	PHOS	4.6	MG/DL	4.5	5.5
01/06/95 11:38	TP	8.3	GM/DL	5.5	8.2
01/06/95 11:38	AST	24	U/L	2	40
01/06/95 11:38	ALKP	142	U/L	100	320
01/06/95 11:38	ALT	12	U/L	3	30
01/06/95 11:38	25OHD	21	ng/mL	9	74
01/06/95 11:38	1,25OHD	12	pg/mL	15	60
01/06/95 11:38	PTH1	<10	pg/mL		
01/06/95 11:38	TSH	8.57	UVL		

Test Date	Test Type	Result	Units		
01/06/95 11:38	**T4**	**13.2**	**ug/dL**	**6.4**	**13.3**
09/22/94 16:39	T4	14.7	ug/dL	6.4	13.3
05/26/94 16:48	T4	14.0	ug/dL	6.4	13.3
01/13/94 15:33	T4	14.0	ug/dL	6.4	13.3
08/12/93 14:11	T4	8.9	ug/dL	6.4	13.3
04/26/93 16:17	T4	11.0	ug/dL	6.4	13.3
02/11/93 15:06	T4	12.9	ug/dL	6.4	13.3

Plot of THYROXINE for Lotte Ingriddotter
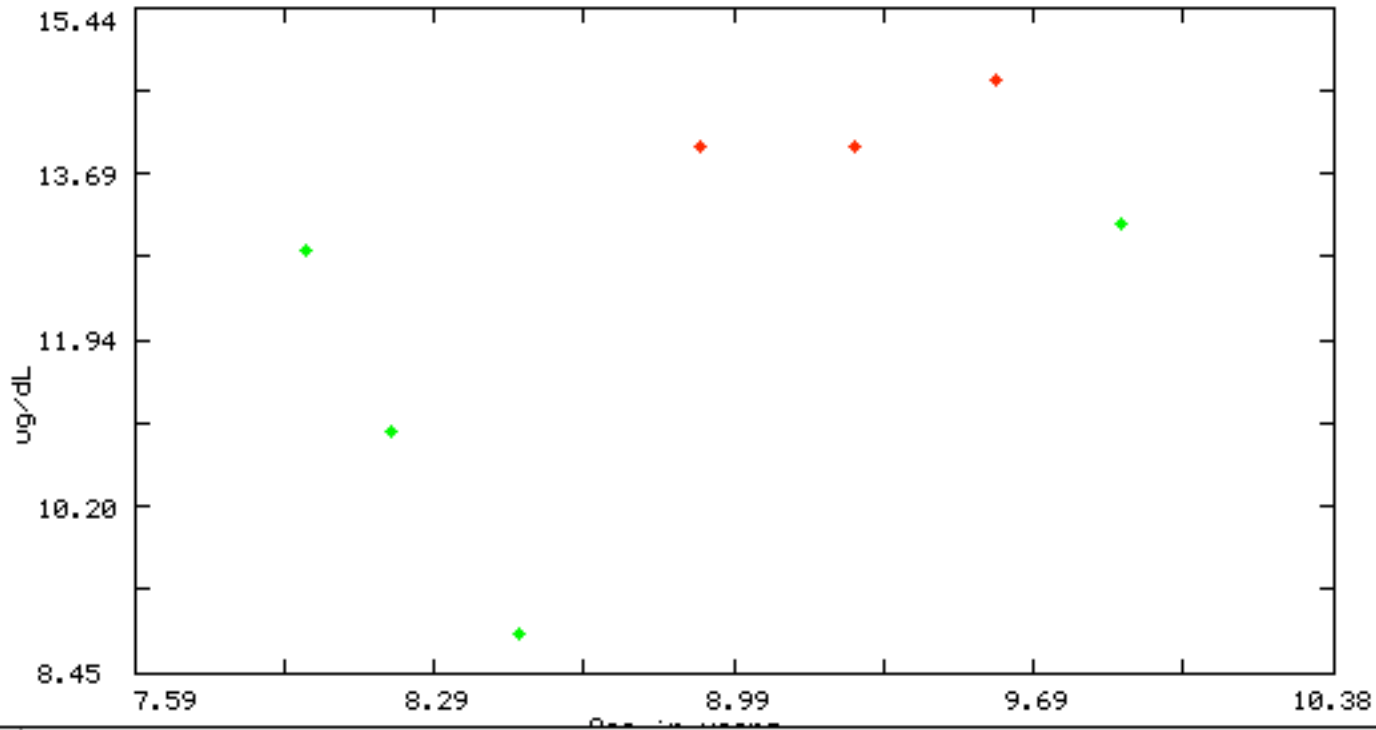
05/26/94	9.27	138	23.51
09/22/94	9.6	27	-0.78
01/06/95	9.89	27	-0.97
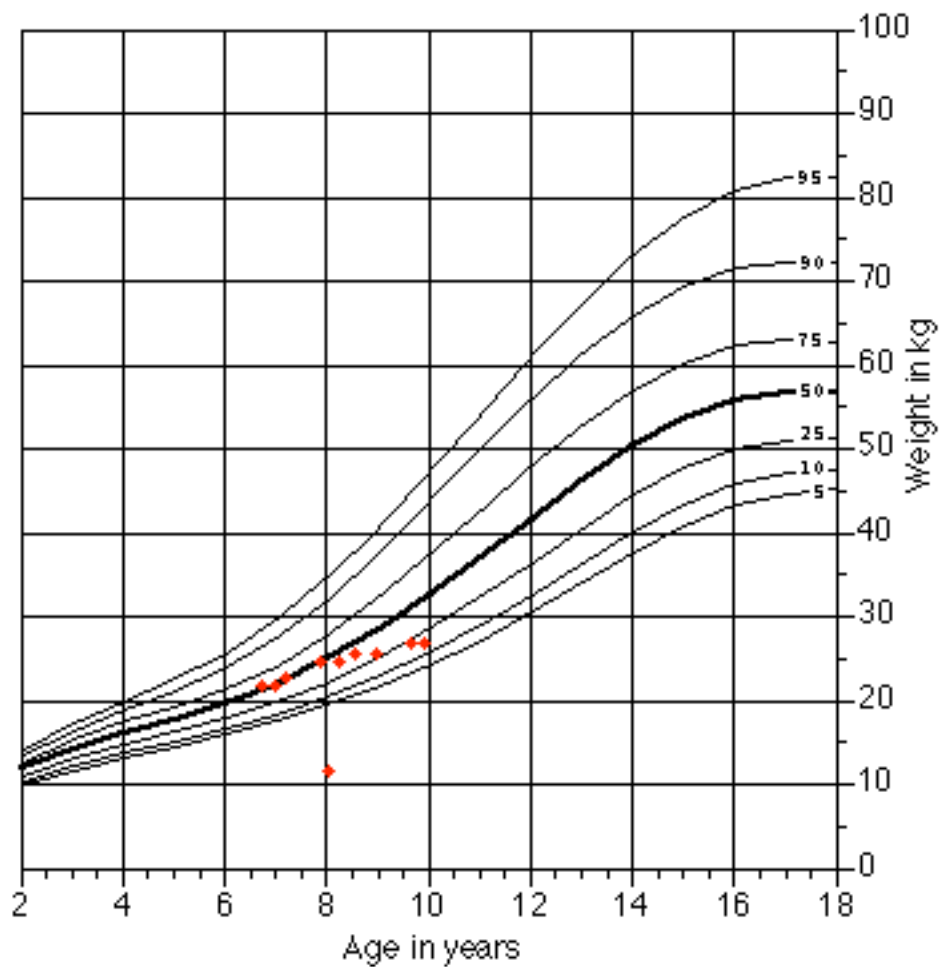
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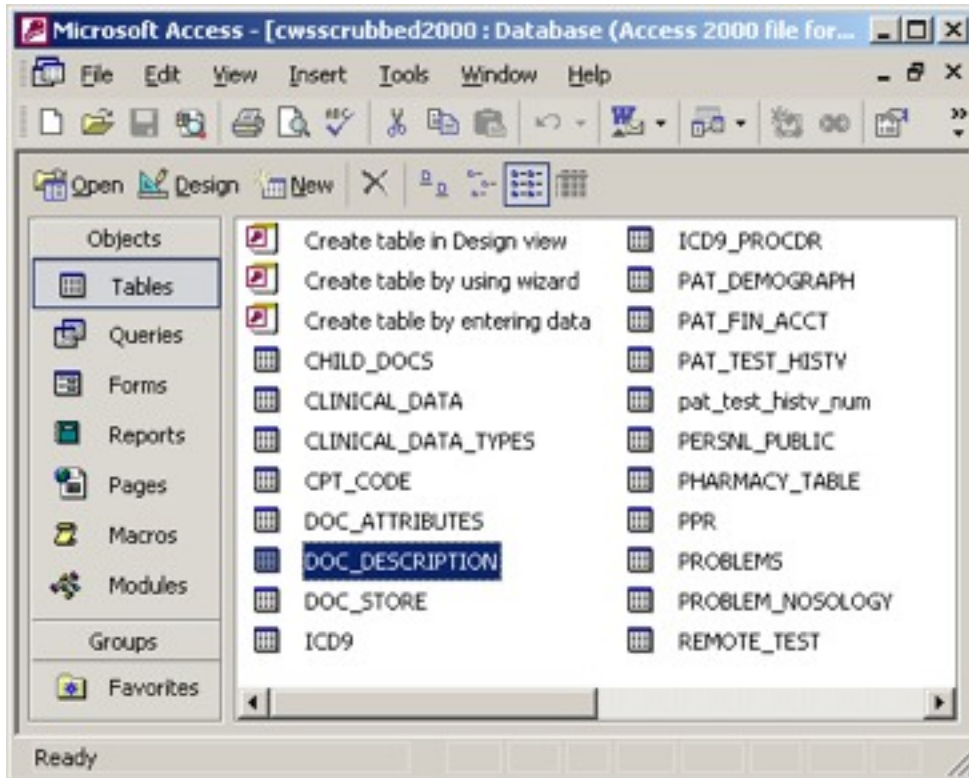
- Documents
  - DOC_STORE
  - DOC_ATTRIBUTES
  - DOC_DESCRIPTION
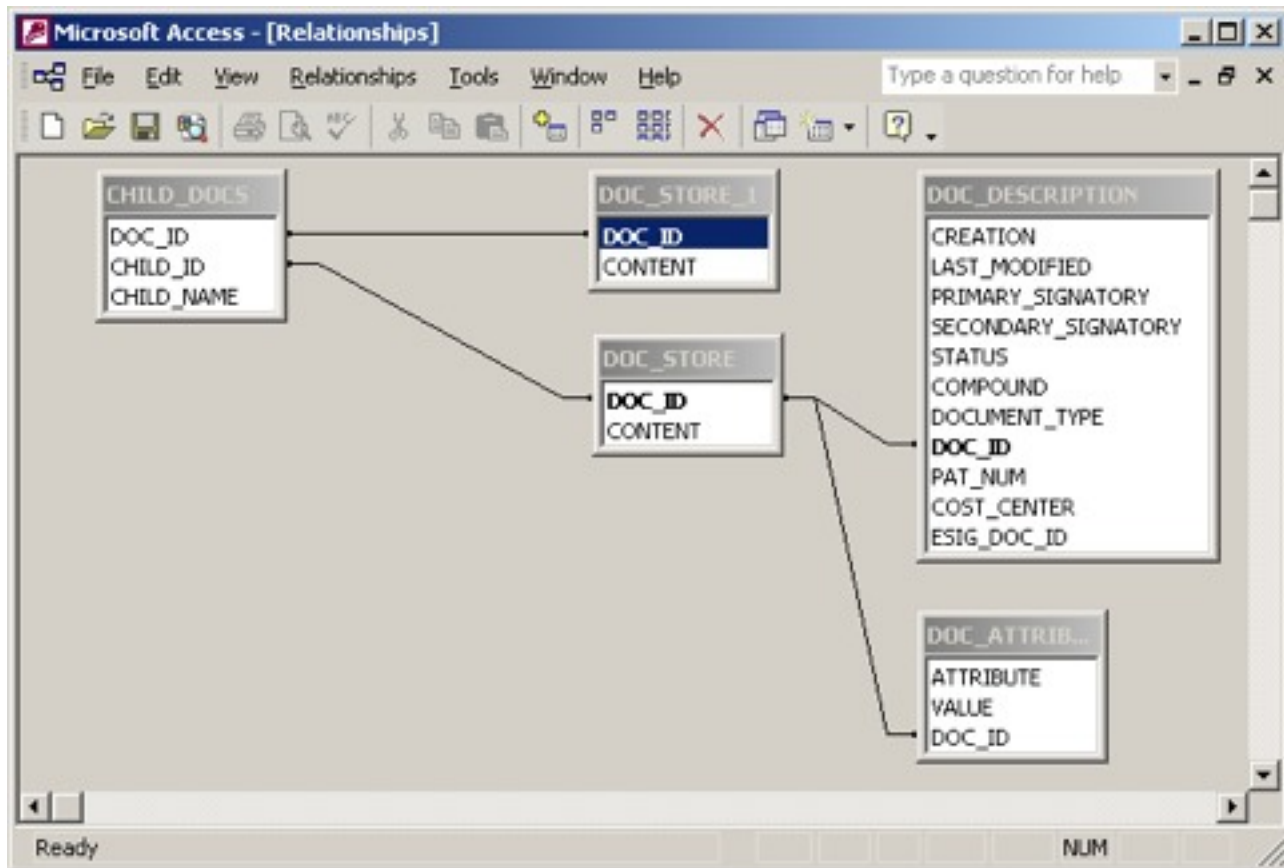 - CHILD_DOCS
- Doctors
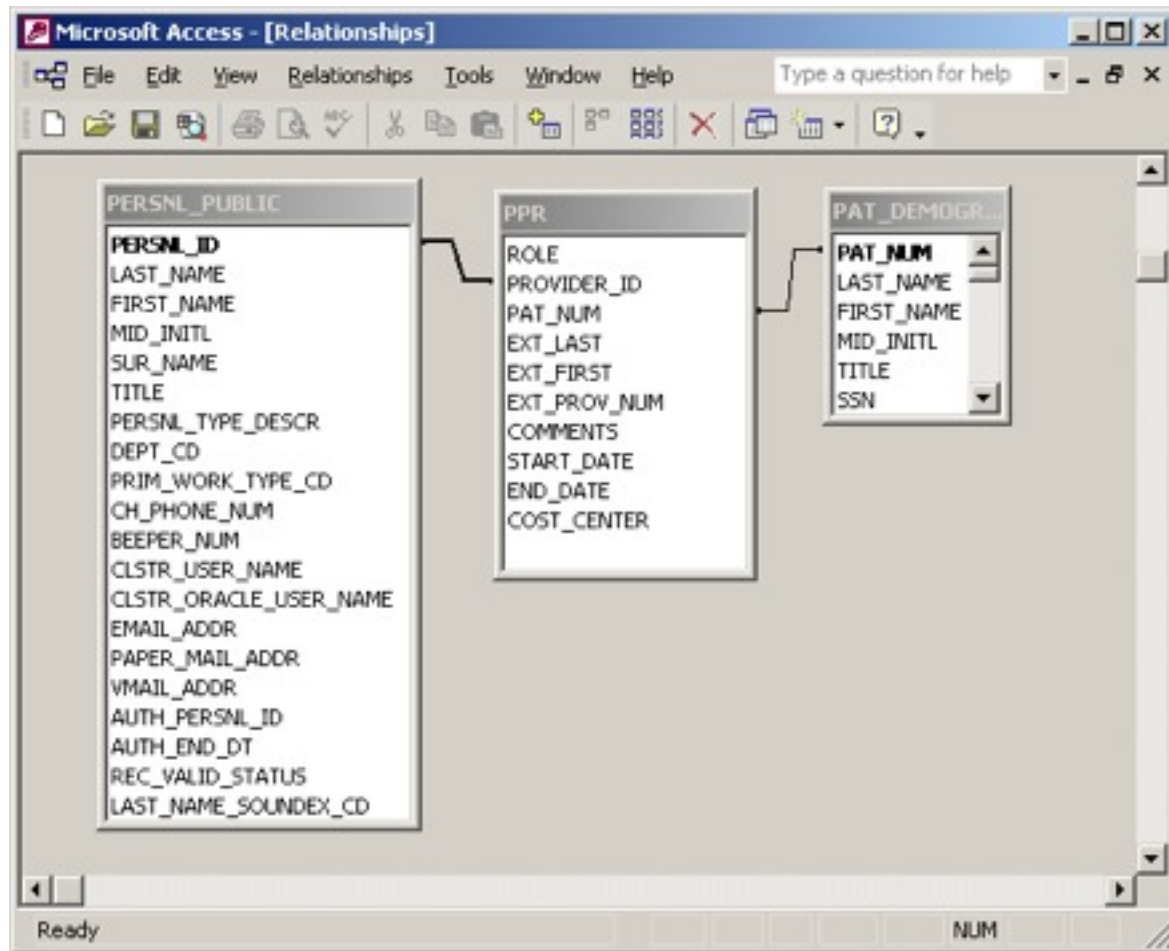 - PERSNL_PUBLIC
  - PPR
- Patients
  - PAT_DEMOGRAPH
  - PAT_FIN_ACCT
- ...

Database Demo

What Have We Learned?

- Real world is ugly!
  - Poor (inchoate) design
  - Non-adherence to design (+historical debris)
- Standards desperately needed:
  - Terminology & Concepts
  - Structure of relationships
  - Communication
- But, world is quite complex, and different complexity is appropriate for different uses

Current Status of EMR

- Fully computerized in many hospitals
  - billing, labs, pharmacy, medication administration
- Some computerization
  - Physician orders, visit histories, discharge summaries, vaccination records, emergency dept notes, pathology & radiology notes
- Little computerization
  - Anything outside hospitals & large clinics
  - History, physical, plans, rationale, …

Current Ideas

- Improved Coding
- Data Capture
  - Dictation to text, or speech understanding
  - Text to meaningful code extraction
  - Comprehensive instrumentation
  - Capture at point of generation
- Integration to Workflow
  - Direct physician order entry, protocols, expert systems
- "Aware" environments

HST.950J / 6.872 Biomedical Computing
Fall 2010