Putting the Cart Back Behind the Horse:

Converting a population based research database into an electronic clinical patient record

The Story

○ Crash course on Multiple Sclerosis

○ A little bit of History of the disease

○ The beginnings of the MS clinic

○ Databases

○ Necessity to access research data for daily clinical care

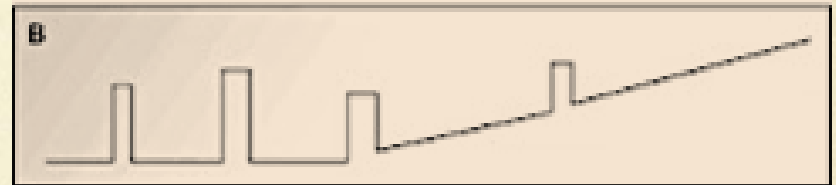# What is MS

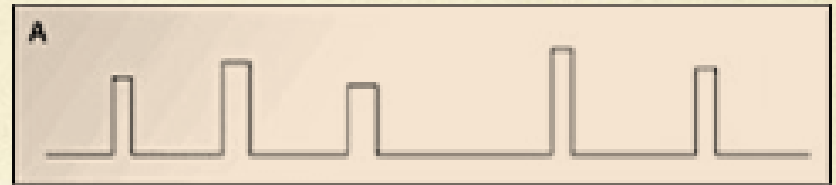- Chronic, progressive, disabling autoimmune disease of the CNS

- Most common cause of non-traumtic neurological disability in young adults

- Symptoms appear between age 15 and 50

- Disability ranges from mild to moderate to severe
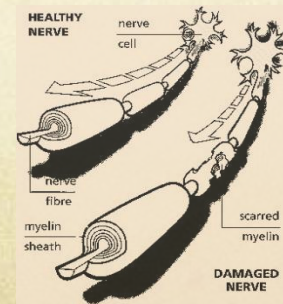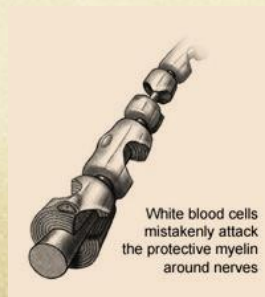
Types of MS

- Relapsing Remitting

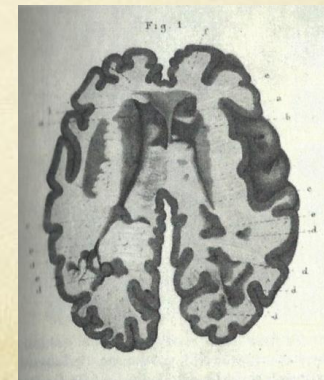- Secondary Progressive

- Primary Progressive

MS Symptoms

- Sensory

- Motor

- Visual

- Coordination

- Cognitive

- Bowel and Bladder

Framing a Disease

○ What is a disease before it gets a name?

○ Historical accounts 1395-1868

○ Multiple symptoms with no connection

○ Jean-Marie Charcot, disseminated sclerosis

○ Multiple Sclerosis

Diagnosis

Then: Diagnose and Adios

- Review symptoms and neurological examination

- Hot Bath test

- MRI late 1980's

- You have Multiple Sclerosis: Sorry we have nothing to offer

Now

- Review of symptoms and neurological examination

- MRI

- Lumbar Puncture

- If MS confirmed, then discuss the role of disease modifying and symptomatic therapies

Diagnosis and Adios

○ "Patients felt abandoned. Nobody wanted to see MS patients back in the early 70s because there was nothing they could offer in terms of treatment," Murray explains. "I didn't have anything particular to offer, but at least we could show we were interested by setting up a research program and taking care of their symptoms."

Databases

- 1950's and 60's saw epidemiological studies

- Local databases were incomplete

- Difficulties confirming the diagnosis

- 1974 attempts to establish a nation wide database (Canadian MS Network)

  - University affiliated centers providing multidisciplinary care

- MS CoStar 1980 (Dalhousie & UBC)

DMSRU?

○ Dalhousie Multiple Sclerosis Research Unit

○ Founded by Dr. Jock Murray in 1979-1980

○ Ambulatory care clinic and Research together

○ CoStar formed the basis for Data collection

○ Computerized database developed by Sue Ellen Murray

dBASE™

MS in Nova Scotia

○ Incidence/Prevalence based on 2010 data

  ○ Prevalence: 267/100,000 (CI: 257.1- 277.1)

  ○ Incidence: 5.17/100,000 persons per year (CI: 3.78 – 6.56)

  ○ 1990-2010 – prevalence rose steadily while the incidence stayed stable

    ○ Marrie et al, 2013: Canadian Journal of Neurological Sciences

DMSRU

- Ambulatory care center for MS
  - Seeing approx. 90% of MS cases in NS

- Common shared Research and Clinical database between Halifax and Sydney

- Over 6000 unique patients in database
  - With over 39,000 recorded visits

- 2500 unique patients actively followed yearly

The Beginnings

○ *CMAJ*: You also set up one of the first computerized patient databases in Canada…

○ Murray: Before most people had even turned on a computer! We didn't know what caused MS — it could be genetics or where they lived — so we set it up to track all the information we might want to know in the future and used it on every patient, at every visit. By the 90s, we had a curve to show how people did without therapy, so when the first treatments came out we could track the difference they made across a lot of variables. It changed the story from hopeless to hopeful.

www.cmaj.ca on January 12, 2015.

Neurological Data

○ Expanded Neurological Status Score (EDSS)
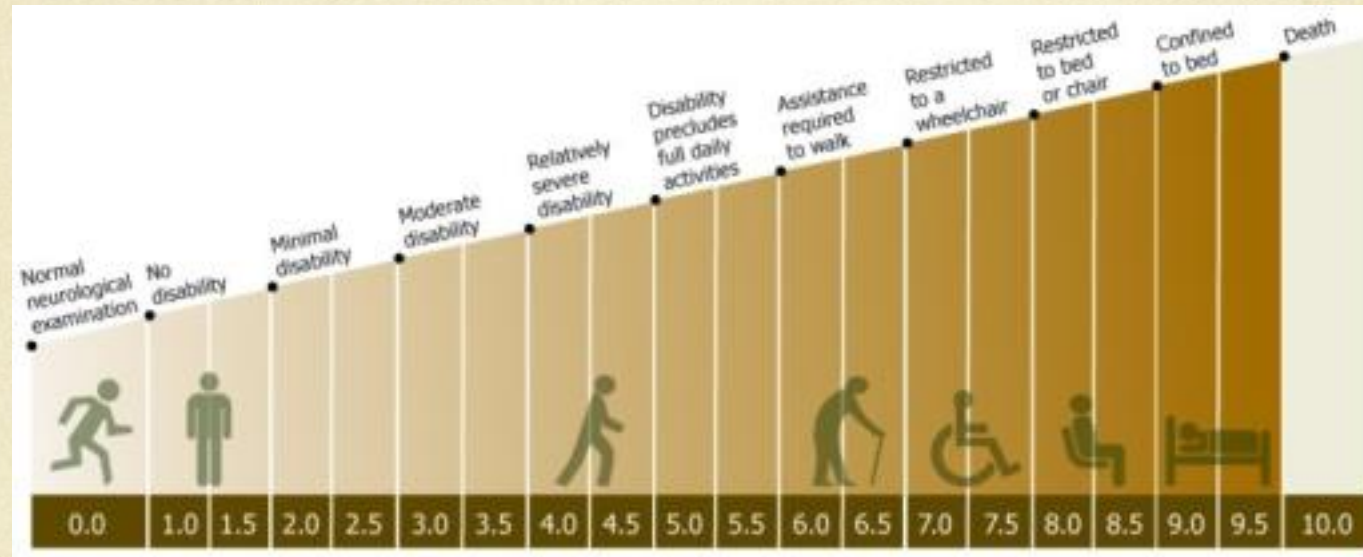
Evolution of Data

○ CoStar information looked at the patients history

    ○ Where have they lived

    ○ Onset of symptoms

    ○ Other illness

    ○ Family illness

    ○ Social information

○ Collected at confirmation of Diagnosis

    ○ Evolved into History form

    ○ CoStar ID# became current PatNo

    ○ PatNo unique identifier linking all DMSRU data files

1995

- Betaseron, the first approved treatment for MS

- Not a cure

- Reduced frequency and severity of MS relapses

- Influx of patients and increased complexity of MS care

- Soon followed by (1995-2000)
  - Avonex, Copaxone and Rebif
    - Universal drug coverage 1998 by NS DOH

Therapy Data

- Therapy Database begins

- Start & Stop data, reason for stopping

- Reason for not initiating treatment

- Updated at each visit

- Capture HRQOL data
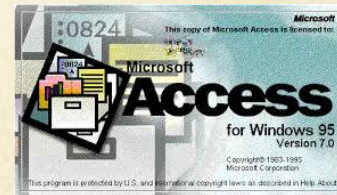
The Real World Study

- The cost effectiveness of the new disease modifying therapies in the real world.

- Utilized the natural history, therapy, &QOL data

- Unified all research data collection into SPSS
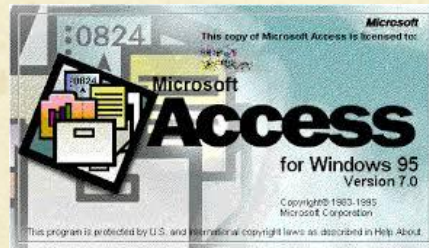
It all comes down to Numbers

- Early computers had limited memory

- Text takes up space

- A single digit can represent lots of text

- Data Dictionary for each variable

- Not friendly for clinical use

- SPSS converted code to text with one click

Data's not just for Research anymore

- Primary data
  - Clinical
  - Demographic
  - History
  - Therapy
  - HUI
  - Vitals

- Derived Data
  - Last History
  - Therapy Start

- Clinical Data
  - Captured in logs
  - Linked to Demographics

Mike and his Logs

- MRI Log

- Telephone Log

- Prescription Log

- Blood Log

- JCV log

- Research log

- DMT Logs

MS Therapies

- New therapies marketed since 2010
    - Tysabri
    - Gilenya
    - Tecfidera
    - Aubagio
    - Lemtrada

HPF vs. Shadow Charts

- Seek and you may find (if lucky) vs. one stop shopping

- Snap shots vs. the MS story over time

- Overview vs. Focus on MS

- CDHA based vs. NS, PEI, & NB

- HPF wins 2012

MRI Log

Mail Merge is used to create appointment letters and Follow up Sheets based on the data entered above

	A	B	C	D	E	F	G	H	I	P	Q	S	T
1							Links updated	2015/04/04					
2		**Questionnaire Update**											
3													
4			Name										
5	PatNO	Date	HCN										
7	3961	2015/04/04	HUN				Consent	On File					
9	0	Update this visit				Last completed on	2014/11/04						
11													
12													
13		**Marital status**					Update as needed						
14	1	Married					SINGLE						
15							MARRIED						
16							COMMON LAW						
17		**Number of Children**	**Update**				SEPARETED						
18		2					DIVORCED						
20							WIDOWED						
21													
22													
23													
24	2	**Years of Schooling**	**Update**										
25		14					Update as needed						
26							ELEMENTARY SCHOOL						
27		**Highest Level on File**					JUNIOR HIGH SCHOOL						
28		College					HIGH SCHOOL						
29							UNIVERSITY						
30							TECHNICAL/TRADE						
31							COLLEGE						
32							OTHER						
33							N/A						
34													
35													
36													
37	3	**You Live in**	BLACK POINT				Check if address has changed						
38													
39													
40													
41	4	**Current occupation on file**					Update employment status						
42		unemployed					FULL TIME						
44							PART TIME						
45		If Incorrect Please Update					UNEMPLOYED, LOOKING FOR WORK						
46							UNEMPLOYED, NOT LOOKING FOR WORK						
47							RECEIVING DISABILITY PENSION						
48		**Employment status**					HOME MAKER						
49		unemployed, Looking for work					STUDENT						
50							RETIRED						
51							N/A						
52													
53													

Neuro Summary Sheet

Neuro Summary

Expanding

- Cape Breton Regional Hospital MS Clinic
    - Can now access clinical data and viewers via a VPN portal

- Capturing more data to help monitor more complex therapies with greater potential risks

- Examining trend of MS over time
    - Relapses, symptoms, disability progression, treatments and side effects

Integration Difficulties

○ One size does not fit all

○ HPF glorified Microfiche

○ Not searchable

○ Everything is linked to a visit (maybe)

○ Privacy vs. usable patient data sharing for patient care

○ Enterprise solutions vs. clinic's need for efficiency

○ All data is manually entered

The future

- Continue to expand the clinical database to meet the care needs of our patients

- Acquire a system for direct data entry at source

- Maintain the flexibility of our database to adapt to a rapidly evolving treatment landscape

- To ensure our future
  - We cannot loose sight of our past

Questions