Health Information Database Application

巨量醫療健康生活資料分析與應用 Big Data for Biomedical Applications







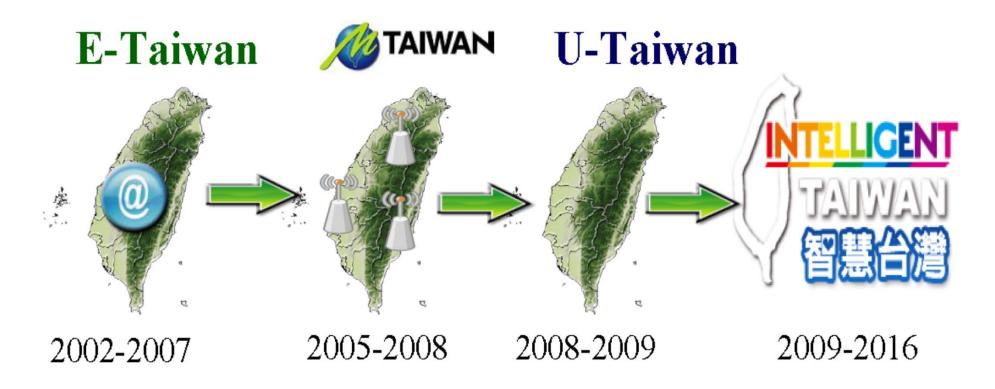


Chien-Yeh Hsu 徐建業 PhD 臺北護理健康大學資訊管理系所 National Taipei University of Nursing and Health Sciences

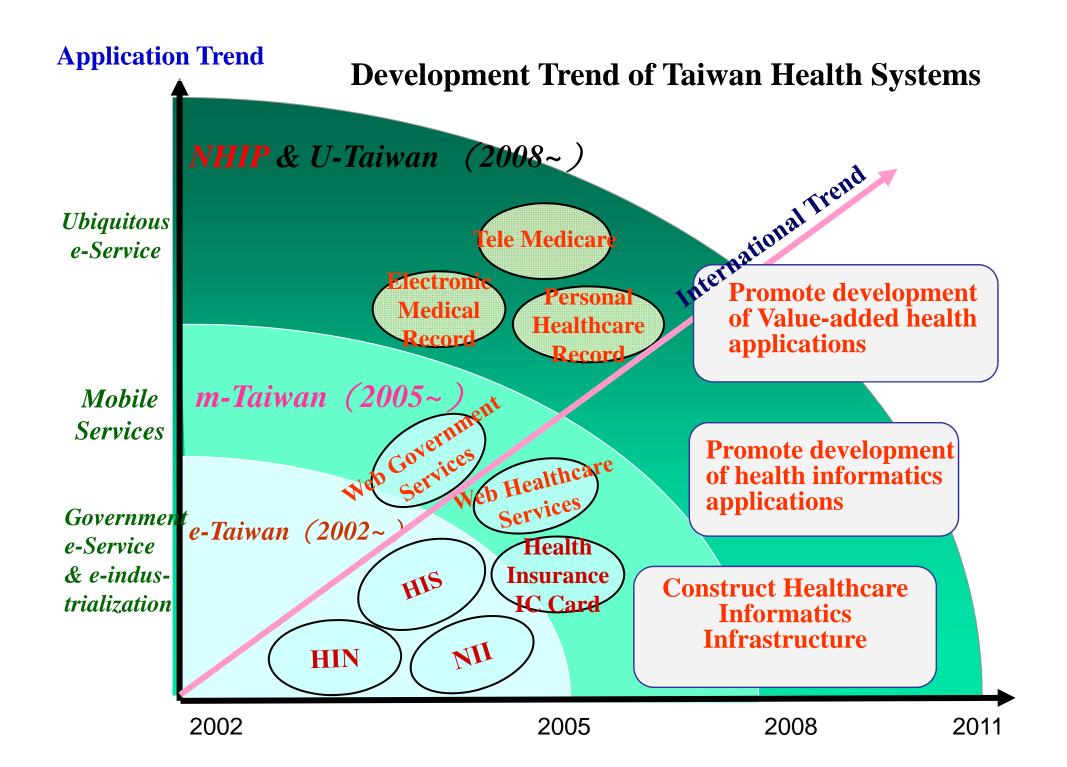
臺北醫學大學 Taipei Medical University

台灣護理資訊學會台灣醫學資訊學會

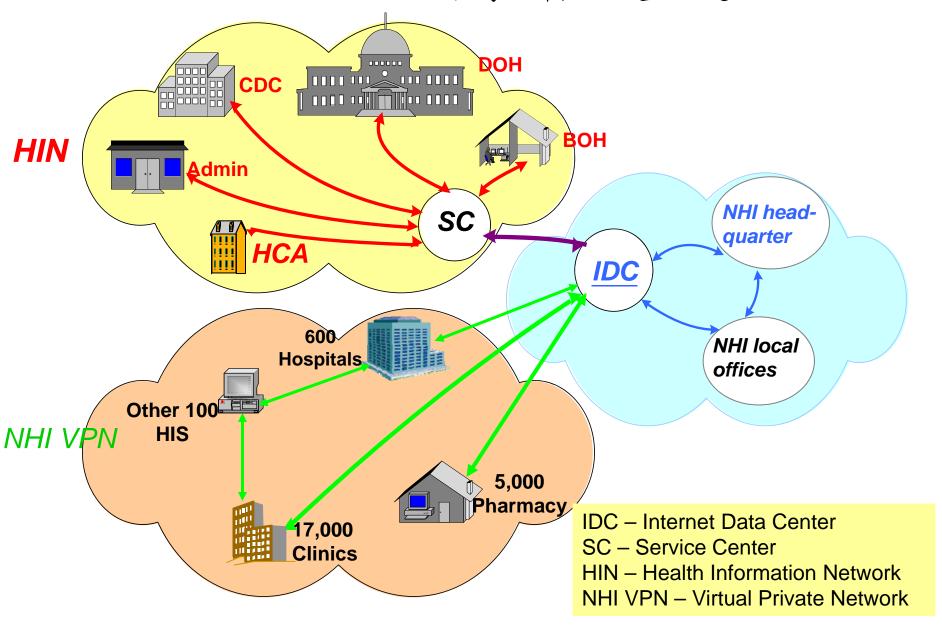
Roadmap for ICT Development in Taiwan







The NHI VPN國家衛生基礎設施



衛生署「健康雲」規劃

◎【1-1】個人健康照護資訊

整合雲端服務

[執行單位] 醫學資訊學會

◎【2-1】診所病歷雲端備份服務[執行單位]衛生署醫事處、工研院

護雲端服務計畫

肾立醫院、資策會

程序 是健康 慢行病 管理 醫療 亞急性

預防 4. 健康資料

健康衛教

分析回饋

急性醫療

【4-1】健康資料加值中心網路化服務 [執行單位]衛生署統 照護計室、資策會

居家照護

機構照護

社區照護

3. 復健及後續性服務

○【3-1】遠距健康照護服務計畫 [執行單位]衛生署照護處、工研院 1-1 個人健康照護資訊整合雲端服務

【2-2】署立醫院醫療照

「執行單位] 衛生署醫管會、

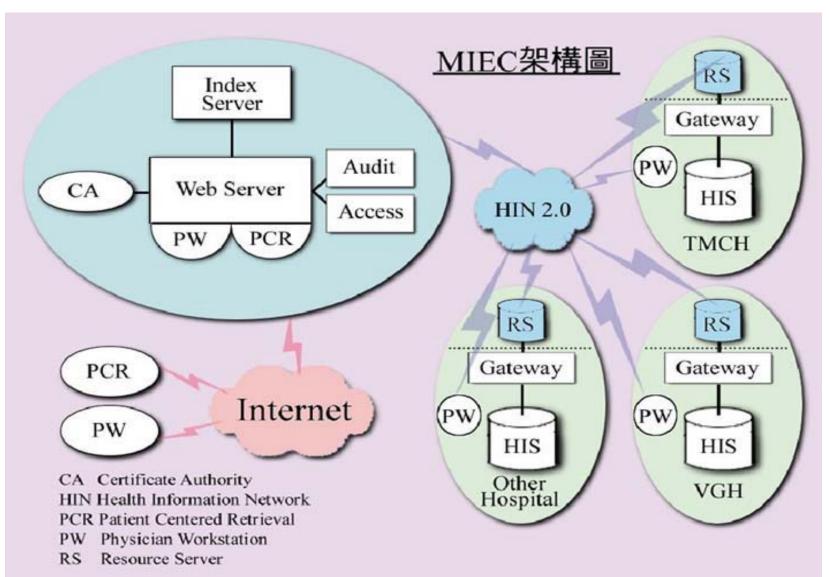
- 2-1 診所病歷雲端代管及備份服務
- 2-2 署立醫院醫療照護雲端服務
- 3-1 遠距健康照護服務計畫
- 4-1 健康資料加值中心網路化服務

資料來源:資策會-創研所整理,2010

Establishing EMR in Taiwan

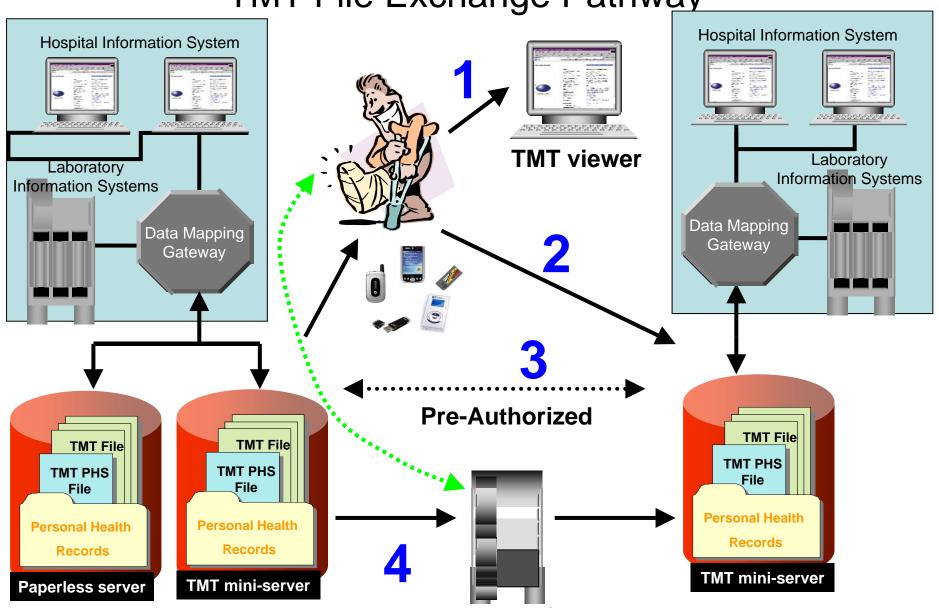
- Vision: At any hospital, a patient can get his/her integrated medical records using the health insurance IC card under the agreement and authorization of the patient.
- Goal: By 2012, 80% hospitals(400, no clinics) DICOM and report, Test reports, and medications, 60% hospitals can exchange EMRs.
- By 2014-(2016) complete EMR and exchange for all hospitals

Medical Information Exchange Center – MIEC 2000

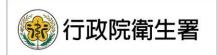


個人化健康資訊整合架構

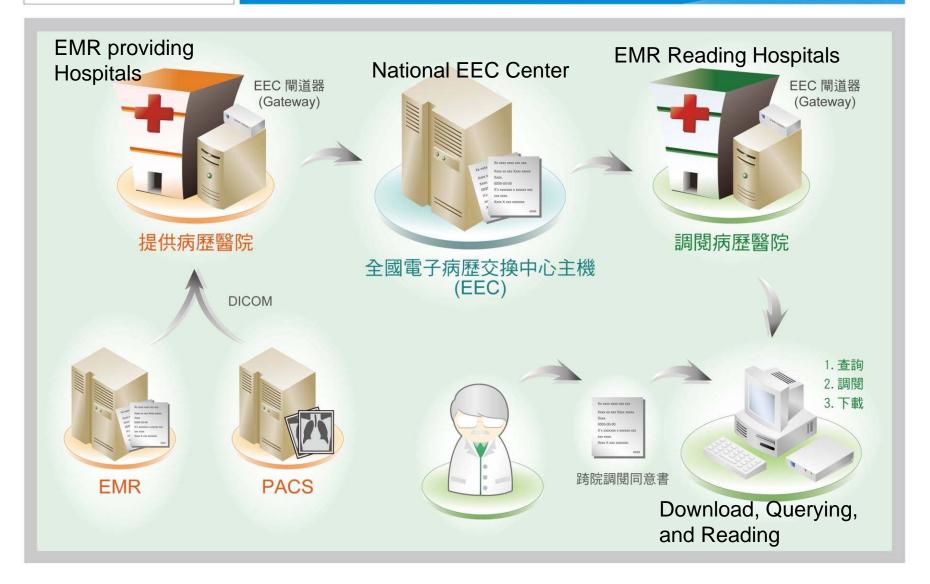
TMT File Exchange Pathway



Internet Health and Life Supporting Data Bank

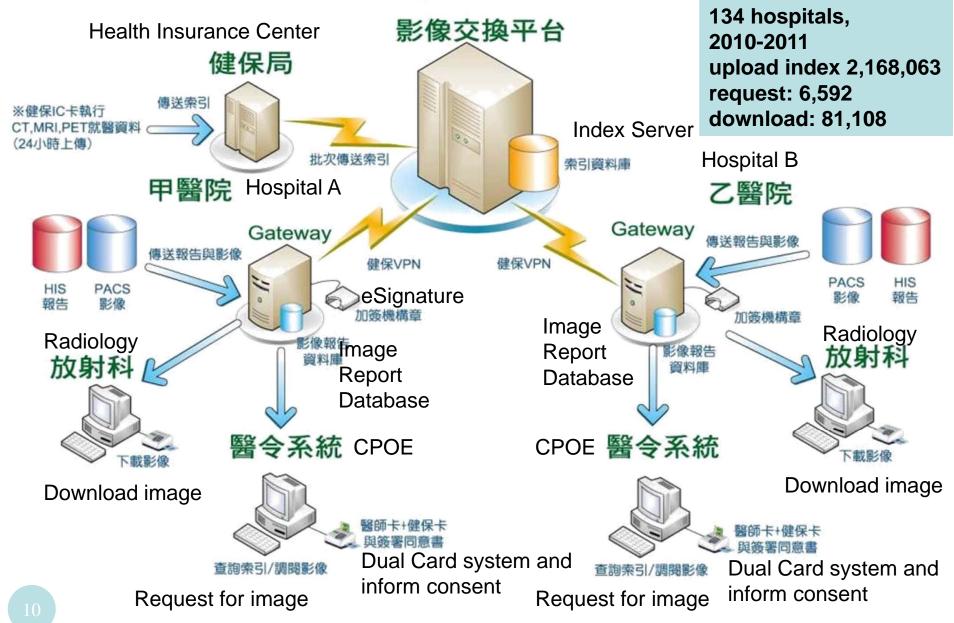


EEC環境建置架構圖 EMR Exchange Center

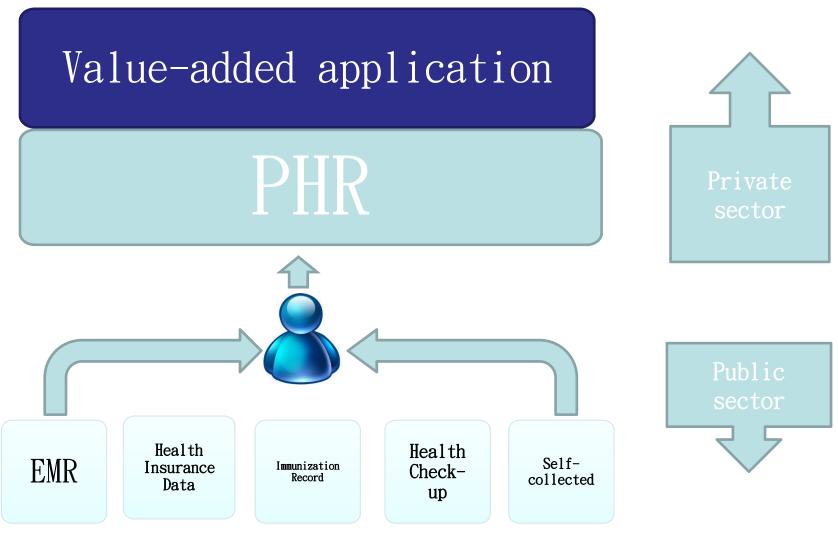


Ministry of Health Image Exchange Center



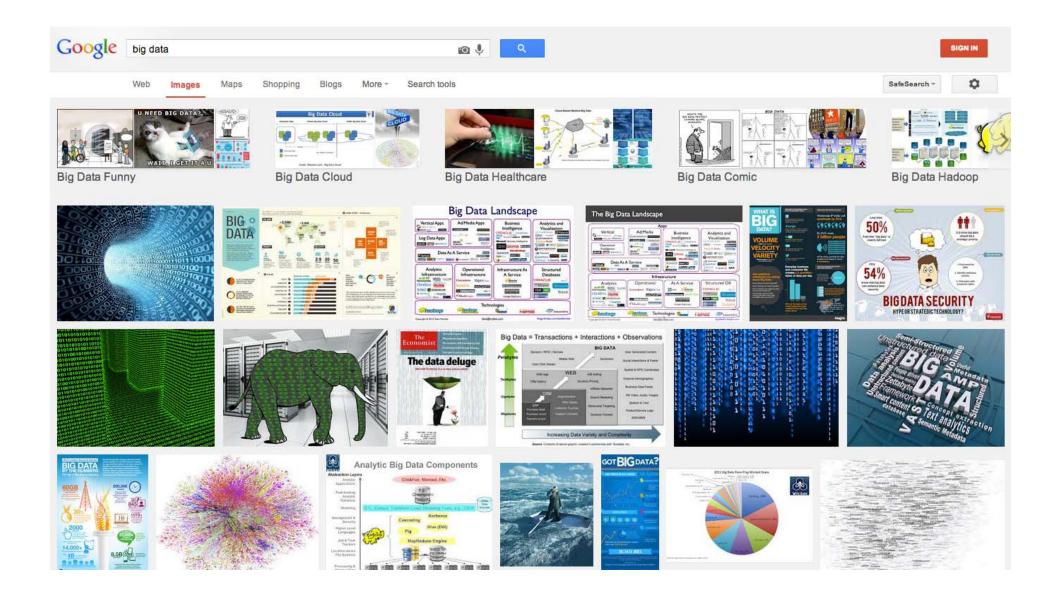


Personally controlled EHR



Min-Huei (Marc) Hsu, Director of Medical Informatics Center, Ministry of Health and Welfare, TAIWAN

Let's ask google about "big data"



What is BIG DATA?

Wikipedia: a collection of data sets so large and complex that it becomes difficult to process using onhand database management tools. The challenges include capture, curation, storage, search, sharing, analysis, and visualization. The trend to larger data sets is due to the additional information derivable from analysis of a single large set of related data, as compared to separate smaller sets with the same total amount of data, allowing correlations to be found to "spot business trends, determine quality of research, prevent diseases, link legal citations, combat crime, and determine real-time roadway traffic conditions".

What Is Big Data?

- High-volume (大量)
- High-variety (多種類)
- High-velocity (快速)
 - sources such as online personal activity, commercial transactions, and sensor networks
- Relating to health is a component of a growing field.
 - e.g., e-health, m-health, digital health, health information technology, health 2.0, e-medicine, etc.

5 Vs of Big Data

- Volume, Veracity(準確), Velocity,
- Variety, and Value(價值)
- Banking/Marketing/IT:
- Volume, Velocity, and Value
- Healthcare/Life Sciences:
- Veracity(準確性), Variety, and Value

How Big is BIG DATA?









What about human brain? The Human brain's memory storage capacity compares to something closer to around 2.5 petabytes (or a thousand Terabytes); which hold three million hours of TV shows. You would have to leave the TV running continuously for more than 300 years to use up all that storage.

http://www.scientificamerican.com/article.cfm?id=what-is-the-memory-capacity

The BIG DATA Challenges in Biomedical Science

Technology:

- Storage
- Query (Search)
- Sharing
- Transmission
- Computation & Analysis
- Visualization

Policy:

- Data sharing and access
- Workforce Education and Training
- Sustainable funding support

BIG DATA Sharing Challenges in Biomedical Science

- Lack of incentive, motivation and means
- Culture change from DIY (Do It Yourself) to DIT (Do It Together)
- Technical infrastructure to address unique requirements of clinical research IT, e.g. confidentiality and security issues!
- Lack of metadata in biomedical datasets (not being effective with universal frameworks or standards, but rather successful with research focused and project driven)

Opportunities to BIG DATA Science

- Infrastructures, policies and incentives to promote data sharing
 - Fosters the development, dissemination, and effective use of computational tools for the analysis of datasets whose size and complexity have grown by orders of magnitude in recent years
- Integration of molecular and clinical datasets for analysis
 - Collaboration & interoperability
 - Logistical and analytical challenges and needs
 - How to contextualize and comprehend?
- Data should not be integrated for the sake of integration, but rather as a means to address specific biomedical questions and needs

BIG DATA Impacts to Translational Bioinformatics?

The growth of biomedical research data is evident in many ways:

- •GenBank (which as of August 2012 contains more than 143 billion DNA bases from more than 156 million reported sequences), and within the published PubMed literature that comprises over 21 million citations and is growing at a rate of more than 700,000 new publications per year.
- •Translational and clinical research has experienced similar growth in data volume, in which gigabyte scale digital images are common, and complex phenotypes derived from clinical data involve data extracted from millions of records with billions of observable attributes

The biomedical research community is within a few years of the "thousand-dollar human genome needing a million-dollar interpretation".

Leveraging Big Data to Prevent Disease

Disease prevention requires two steps.

1.Identify modifiable risk factors for disease

 e.g., diet, exercise, smoking, alcohol consumption, and environmental pollution.

2.Interventions to improve disease risk factors

To help that person achieve these goals.

Bio-Medical and Health Informatics needs Analytics

醫院資訊系統快 速的發展

Healthcare organizations rapid adoption of HIT to improve business operation & patient care

各類數具快速大量 的累積 Increasing volume of BIG DATA generated by range of HITs

– EMR , CPOE,

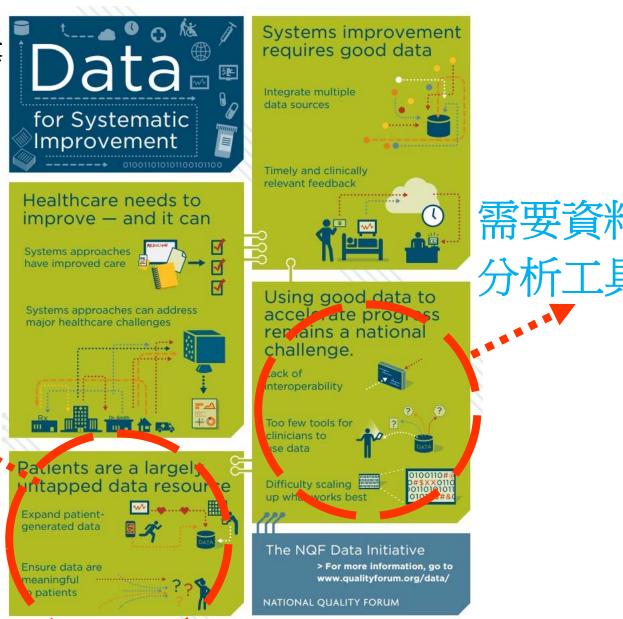
LIS, RIS, e-

Pharm etc

需要分析資料來改 善健康照護 Growing demand for analytic skills and processes to stay competitive, streamline workflow & improve patient care

美國<mark>國家品質論壇</mark> 進行品質改進 促進醫療照顧服務

> 來自病人 的資料複雜 且大量



http://www.qualityforum.org/data/

The Value of use of health related data

- Secondary Use(加值應用或二次運用)去識別化之 健康資料為世界趨勢
 - 美國早已在20年前開放全國住院資料供研究者使用, USA started from 20 years ago
- 新的治療方式、疾病的診斷、藥物之副作用、疾病之關聯性...等, for discovery of New treatment, diagnosis methods, side effects of drugs, relationship between diseases
- 若沒有完整開放健康加值資料將嚴重損害廣大病人之權益, open data will fit the benefits of majority of people

International Cooperation Example Global Alliance

Just announced: 7 June 2013

70 organisations joining to promote sharing and standardisation of genomic data

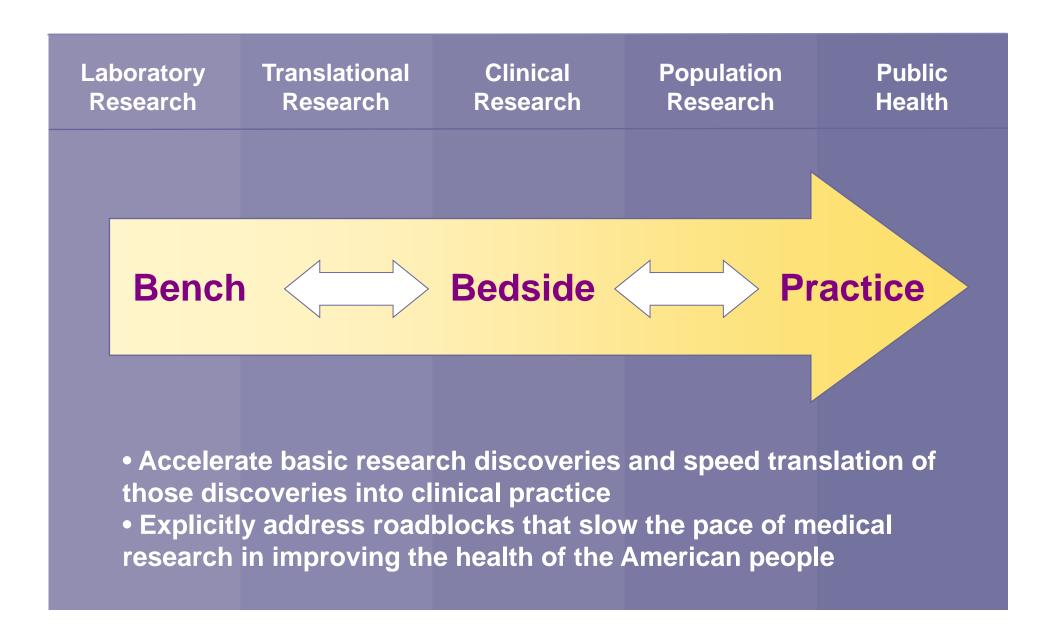
- A Global Alliance for sharing genomic and clinical data
- A White Paper circulated in early 2013 has the support of nearly 70 organisations in Asia, Australia, Africa, Europe, North America and South America who are committed to creating a common framework that supports data analysis and protects the autonomy and privacy of participating individuals.
- http://www.ebi.ac.uk/about/news/pressreleases/Global-Alliance

Integrated Biomedical Informatics for Clinical Research

醫學研究之道,就是整合研究數據

- 2003年9月30日,美國國家衛生研究院(NIH)院長塞 鳥尼(Elias Zerhouni)宣佈:對美國政府資助的醫學 研究進行重整。
- 「研究路線圖」的計畫 NIH Roadmap
- National Electronics Clinical Trials and Research (NECTAR) network
- 建立完整的路線圖以及徹底更新醫學數據的收集、儲存及共用 methods for collecting, storage, and sharing
- 把龐大且分散的資料庫結合成一個巨大的資料庫 integrating data bases
- 發展軟體,使實驗計畫的撰寫能夠簡化並標準化 developing software for helping experiment design and common data element
- 減少紙張的使用 reducing paper use

Roadmap Standard Models



BIG DATA in Biomedical Research...

Starts with "Quality Datasets"

... needs a re-usable, extensible, sharable and interoperable informatics infrastructure to enable and streamline collaboration and data sharing for translational research...

• Databanks related to health

Health-related Databanks

Process and Outcome			
Mortality	Morbidity	Disability	Others
Death reporting	insurance utilization	1.Catastrophic disease certificate databank 2.Disability certificate databank	1.Birth reporting 2.Health care organization/servic e databank 3.Special survey for care providers
Health determinant			
Health behavior	Economic status	Family status	Ethnicity
Health and nutritional survey	Household income and expenditure survey		Indigenous people databank

Use of cloud technology to provide health information value-added services加值應用

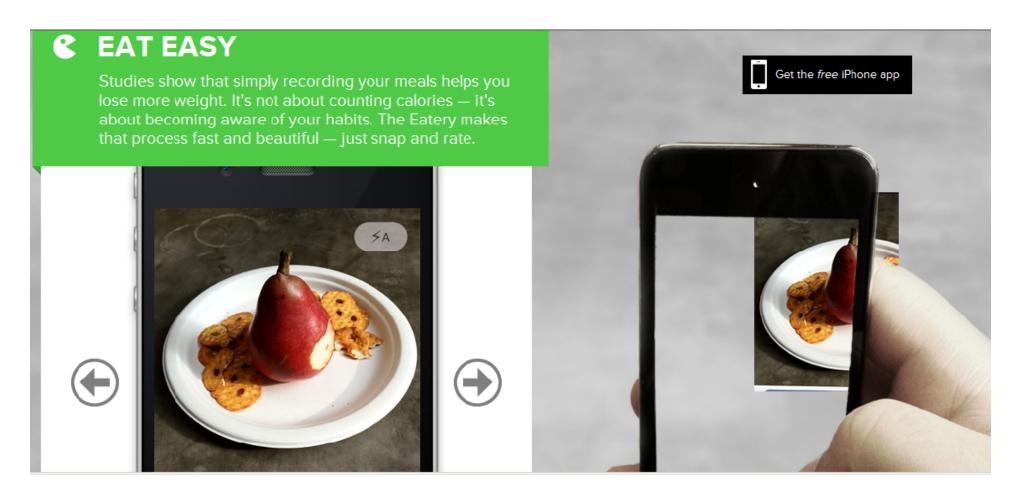
Bio-medical and Healthcare Data are BIG Data = EMR data + genomic data

BUILDING A CLOUD-BASED CLINICAL DATA REPOSITORY (CDR)

Facebook can predict your breakups

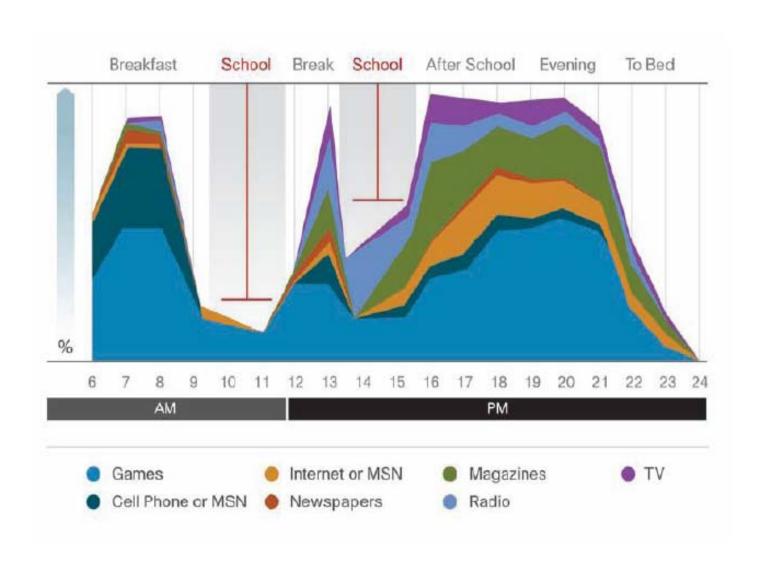


Eating Habits

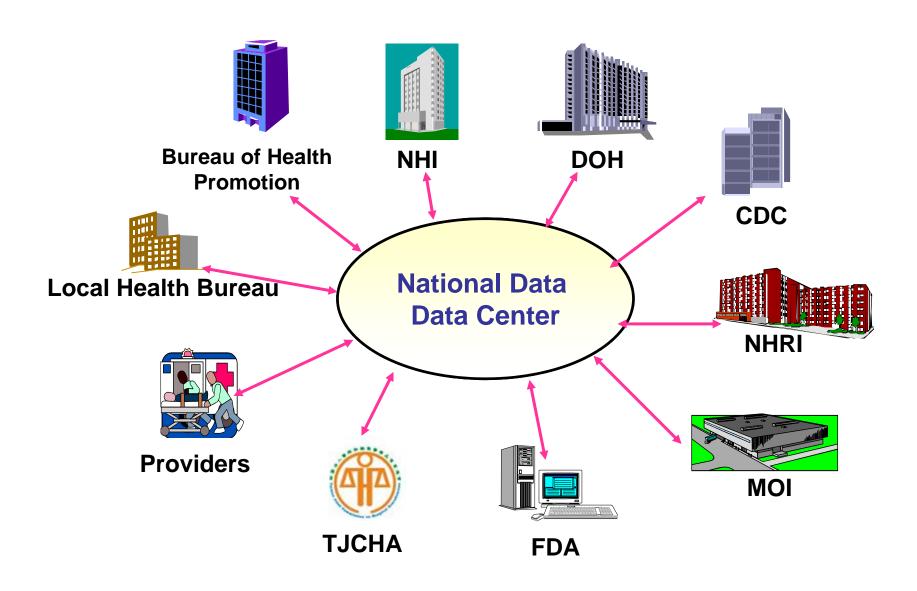


Stop counting calories start eating better https://eatery.massivehealth.com/

Disconnect in School



National Health Data Center



NHIRDB in Taiwan

- NHIRDB (National Health Insurance Research Database)
 - 12 years of de-identified claim database for 23 million people
 - Cohort DB (Five 1-million people groups for 13 years)
 - Disease-specific DB (16 disease groups)
 - Random sample DB (outpatient 1/500, inpatient 1/20)

generates >100 researchpapers a year

>> Data files

Each year, BNHI collects data from the National Health Insurance program and sorts it into data files, including registration files and original claim data for reimbursement. These data files are de-identified by scrambling the identification codes of both patients and medical facilities and sent to the National Health Research Institutes to form the original files of NHIRD.

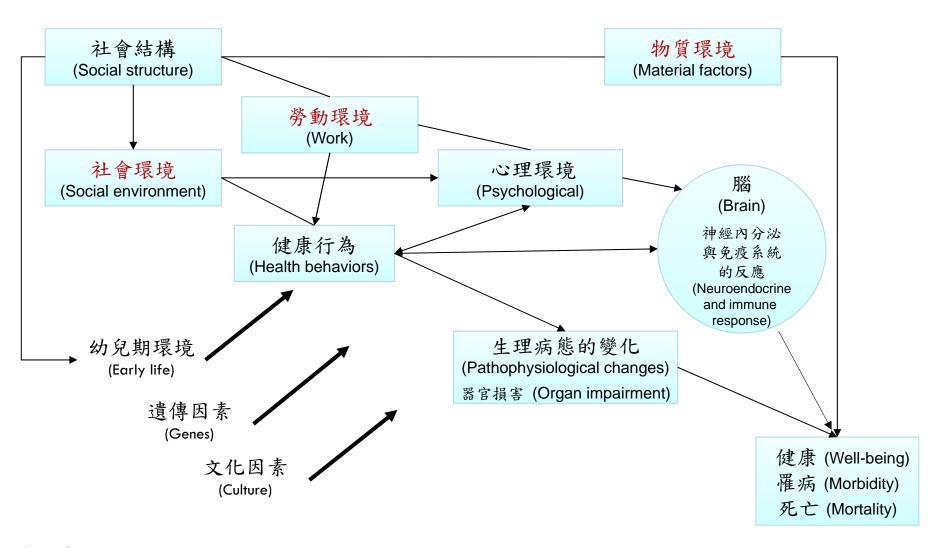
The registration files include:

- Registry for contracted beds (BED)
- Registry for contracted specialty services (DETA)
- Registry for contracted medical facilities (HOSB)
- Supplementary registry for contracted medical facilities (HOSX)
- Registry for board-certified specialists (DOC)
- Registry for medical personnel (PER)
- Registry for catastrophic illness patients (HV)
- Registry for medical services (HOX)/td>
- Registry for drug prescriptions (DRUG)
- Registry for beneficiaries (ID)

The Original Claim Data include:

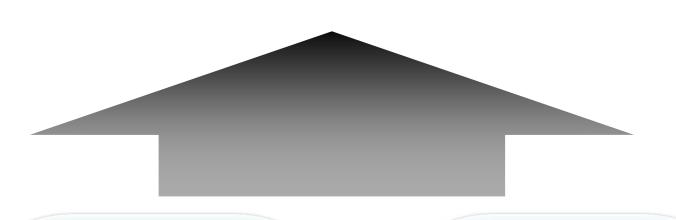
- Monthly claim summary for inpatient claims (DT)
- Monthly claim summary for ambulatory care claims (CT)
- Inpatient expenditures by admissions (DD)
- Details of inpatient orders (DO)
- Ambulatory care expenditures by visits (CD)
- Details of ambulatory care orders (OO)
- Expenditures for prescriptions dispensed at contracted pharmacies (GD)
- Details of prescriptions dispensed at contracted pharmacies (GO)

健康資料加值應用思維 健康與社會關聯



資料來源(Source): Social determinants of health,2006

Integrated Data Analysis



健康與社會的關聯

Social Determinants of Health

Socioeconomic status Work environment Childhood environment Health behavior

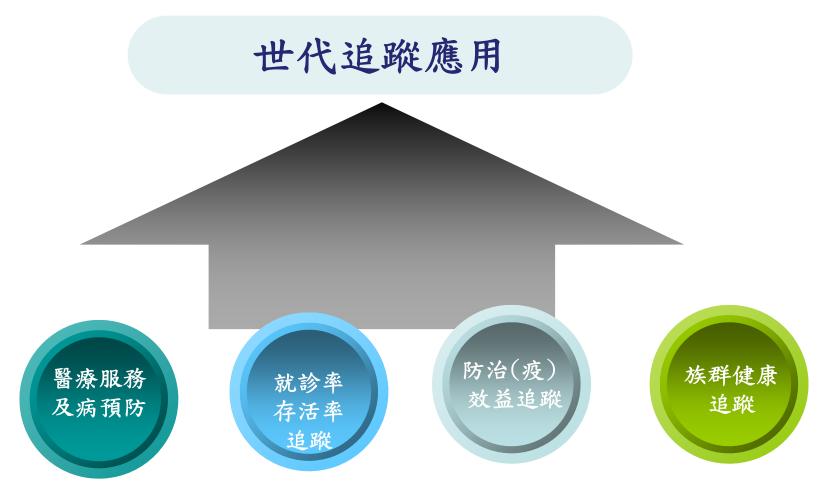
Indicators of Health Service

Accessibility
Availability
Efficiency
Effectiveness
Appropriateness
Safety

衛生政策的評估

Of Medical, healthcare, epidemic prevention or control, Healthcare policy

Value-added application



• Examples of value-added application

Big Data 醫療應用

Drug for reducing mortality

Statin(降膽固醇用藥,可減少全身的發炎反應) Use and Reduced Cancer-Related Mortality, Sune F. Nielsen, N Engl J Med 2012; 367:1792-1802

Predict disease outcomes

Diabetes Care. 2015 May;38(5):746-51. Epub 2015 Feb 9. Long-term
 Mortality Risk After Hyperglycemic Crisis Episodes in Geriatric Patients With Diabetes: A National Population-Based Cohort Study.

Better anesthesiology

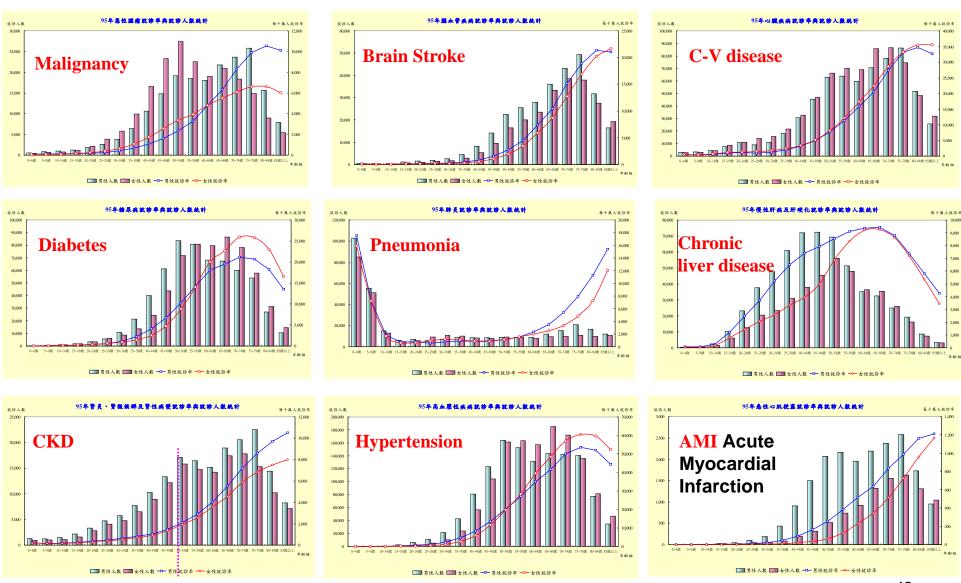
 Anesthesiology. 2010 Aug;113(2):279-84. Anesthetic management and surgical site infections in total hip or knee replacement: a population-based study.

New drug

Capturing disease risk factors

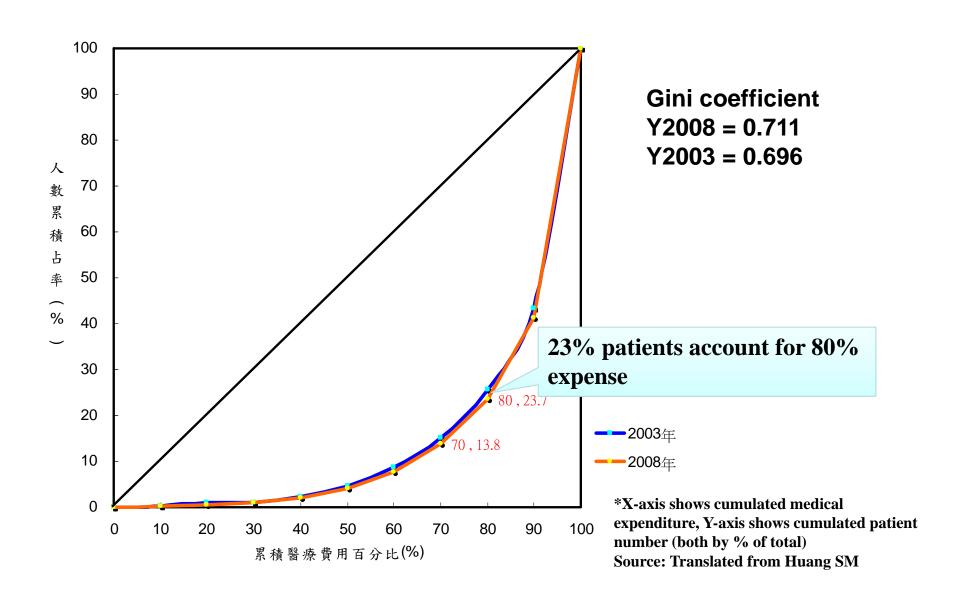
 L. Li,, Disease Risk Factors Identified Through Shared Genetic Architecture and Electronic Medical Records. Sci. Transl. Med. 6, 234ra57 (2014).

Disease Prevalence by Medical Visits

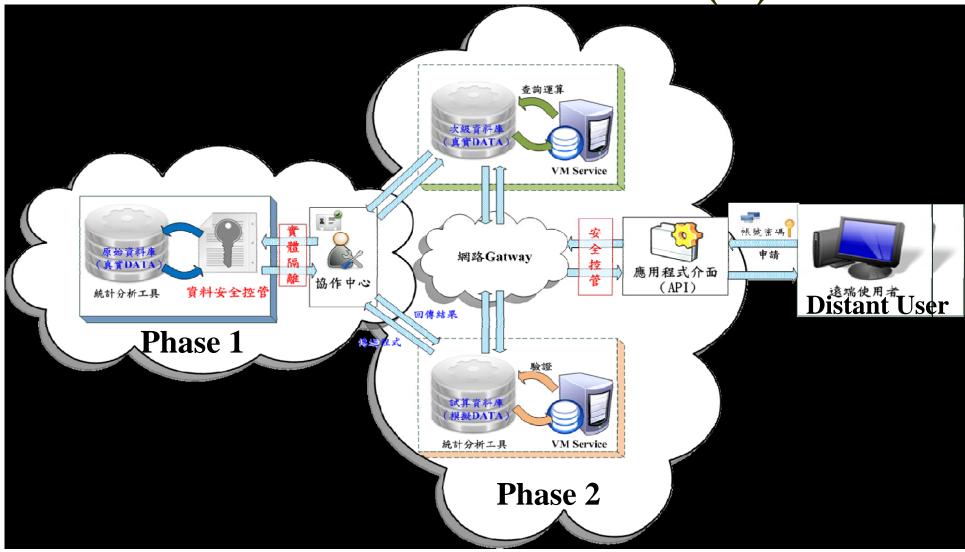


Source: Translated from Huang SM

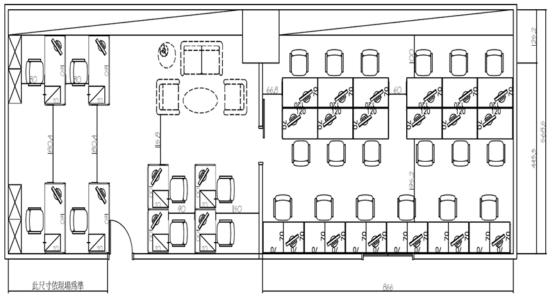
20 – 80 Rule?



Collaboration Center for Valueadded Application of Health Databanks – a Pilot (2)



行政管理医 獨立作業區



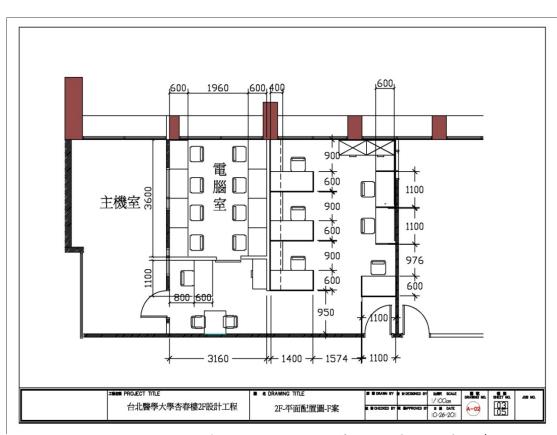


衛生福利部統計處





臺北醫學大學健康暨臨床研究資料加值中心平面圖與 現況圖Taipei Medical University



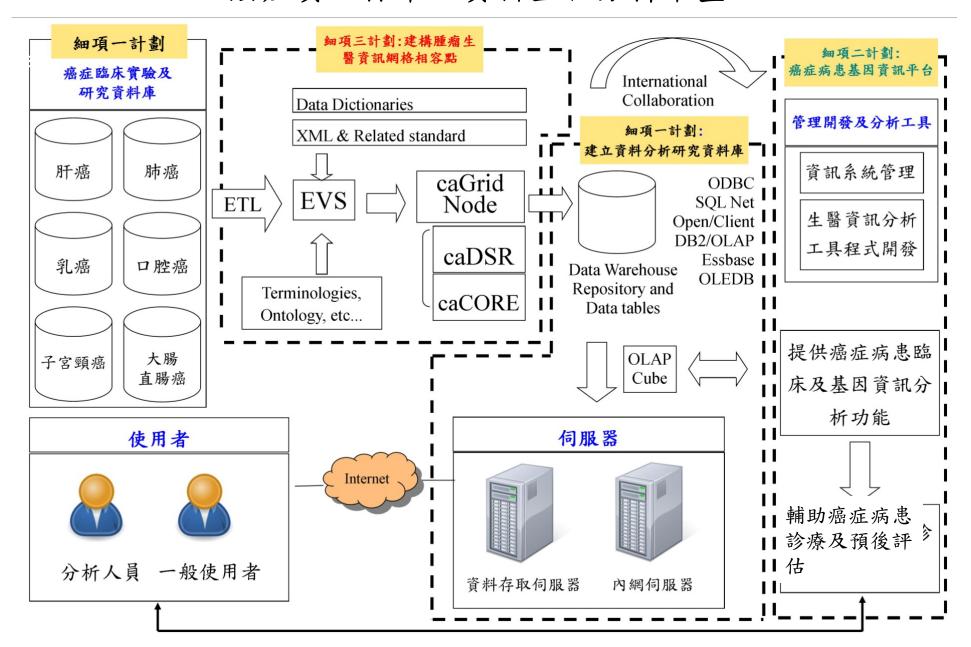
左側隔間使用者坐位8個,2名管理人員坐位(左邊隔間左下角以及右邊隔間左下角)



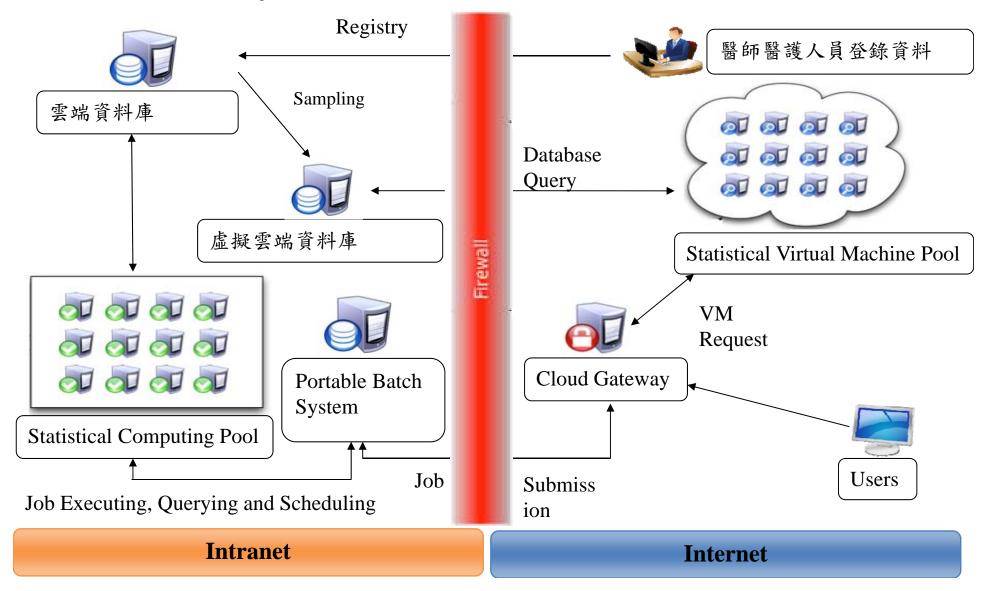


主動式具有分析評估能力的主題式資料架構 2010 Data Architecture by Subjects with Active Analysis **Public Health** and Assessment Integrated Data Center for Administration **Bio-medical Informatics Regular Data Provide Epidemiology** Released Health Insurance **Data** DB **Health Care** T De-Management identification Cause of Death DB Redundant / Others 未通過專法,本中 **Feedback** 心不直接釋出資料 Cancer Register Data Released after DB IRB approval Limited Continuity Research Tool Kits Household (census Register Data DB User Set

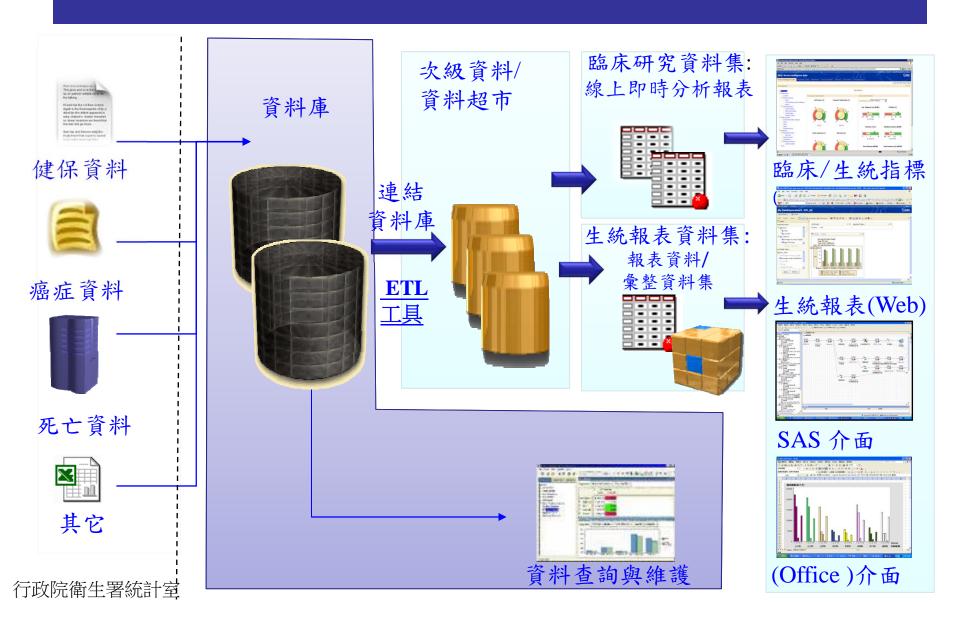
健康醫療BIG DATA 應用範例 癌症資訊標準化資料整合分析平臺



Architecture for Health/medical Database and Analysis 健康醫療資料分析研究資料庫



現行健康資料加值應用平台

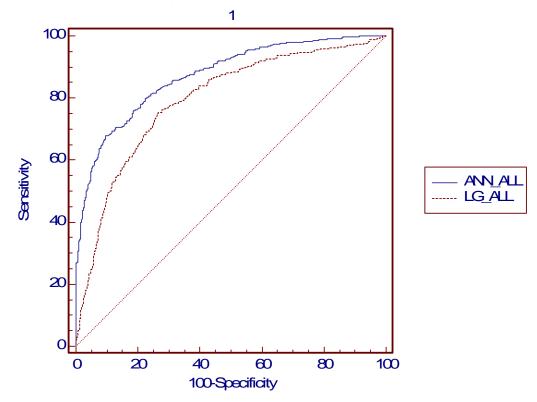


現有資料庫種類(33種) different databases

代號	統計項目	資料提供單位
1	全民健保處方及治療明細檔-中醫門診、西醫門診、牙醫門診、住院、藥局 prescription details	健保局
2	全民健保處方及治療醫令明細檔-中醫門診、西醫門診、牙醫門診、住院、藥局	健保局
3	全民健保承保檔	健保局
4	全民健保重大傷病檔	健保局
5	戶籍資料檔 census file	內政部
6	死因檔 cause of death	統計室
7	醫事機構現況檔	統計室
8	醫事機構服務量檔	統計室
9	醫療院所評鑑等級	醫事處
10	出生通報檔	國民健康局
11	癌症登記檔(含癌症登記檔、癌症診療資料庫、短表、長表)	國民健康局
12	家庭醫療保健消費調查資料檔	統計室
13	醫事機構基本檔 medical institutes	健保局
14	原住民檔(區分出生、死亡、戶籍)	原住民委員會

糖尿病確診後罹患為肝癌之預測模型-預測表現

	Sensitivity	Specificity	AUC	SE	95% CI	Significance level
ANN	0.802	0.773	0.873	0.0123	0.747 - 0.798	P < 0.001
LG	0.751	0.736	0.793	0.0148	0.708 - 0.762	



糖尿病確診後罹患為肝癌之預測模型 應用系統

糖尿病確診後轉化為肝瘍之預測系統 請輸入下列數值進行預測 得到糖尿病後有得過幾種不同種類之疾病: 性別: 男▼ 酒精性肝硬化: 有 🔻 其他種類肝硬化: 有 🔻 酒精性肝炎: 有 🔻 病毒型慢性肝炎: 有 ▼ 其他慢性肝炎: 有 ▼ 酒精性脂肪肝: 有 🔻 其他性脂肪肝: 有 ▼ 高脂血症: 有 🔻 年齡: 41~50 歳 ▼ send reset 預測結果:

注意!!您得到肝瘟機率較高

Confidence level = 0.99999987142700

CLOUD COMPUTING FOR PERSONALIZED HEALTH CARE Achieving Meaningful Use of EMR/PHR

Meaningful Use of Health/Medical Information -- 4P Medicine

- Personalization
- Participation
- Prediction
- Prevention
- More Ps
 - Healthcare Promotion
 - Precision medicine
 - Payment system

Dr. Leroy E. Hood

A Definition of Personalized Medicine

 Personalized medicine is the use of information from a patient's Phenotype/genotype to: initiate a preventative measure against the development of a disease or condition, or select the most appropriate therapy for a disease or condition that is particularly suited to that patient.

健康照護雲端運算服務--A Personalized Wellness Ecosystem on Cloud

- 個人健康管理議題是全球健康醫療關注的焦點
- Pervasive Personal Health Management Service
 - Context aware health monitoring健康監測
 - Personal Health-aware devices個人裝置
 - Intelligent alert management智慧管理
 - Pervasive lifestyle incentive management生活方式
 - Pervasive access to healthcare information健康資訊
 - Preventive Care & Chronic Disease Mgmt疾病管理
 - Social Health Promotion社會健康

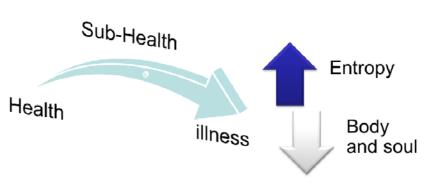
Source: Pervasive Healthcare as a Scientific Discipline, Methods Inf Med 2008.

Meaningful Use of EMR

- The importance of this project
 - Build infrastructure so that citizens own their health record and receive basic health care services at the right time and right place
 - Fee for illness → Fee for health

Business Model

Focus on healthcare industry



- Benefit
 - Reduce the waste in medical resources
 - Improve healthcare quality
 - Promote the health for all citizens

Interventions to improve disease risk factors

- To help person achieve these goals.
- In the past
 - a brief word of advice from one's physician at the annual checkup.
 - e.g., avoid smoking, exercise, and eat healthy foods.
- Big data offer
 - outside of the clinic in a personalized manner.
 - more sophisticated program would include algorithms that provide personalized feedback to assist with behavior modification at key moments of decision making.
 - e.g., suggesting healthy recipes while the patient is shopping; encouraging exercise at the end of the workday, or giving a personalized warning about location based environmental triggers for asthma

Example 1: Big Data and Physical Activity

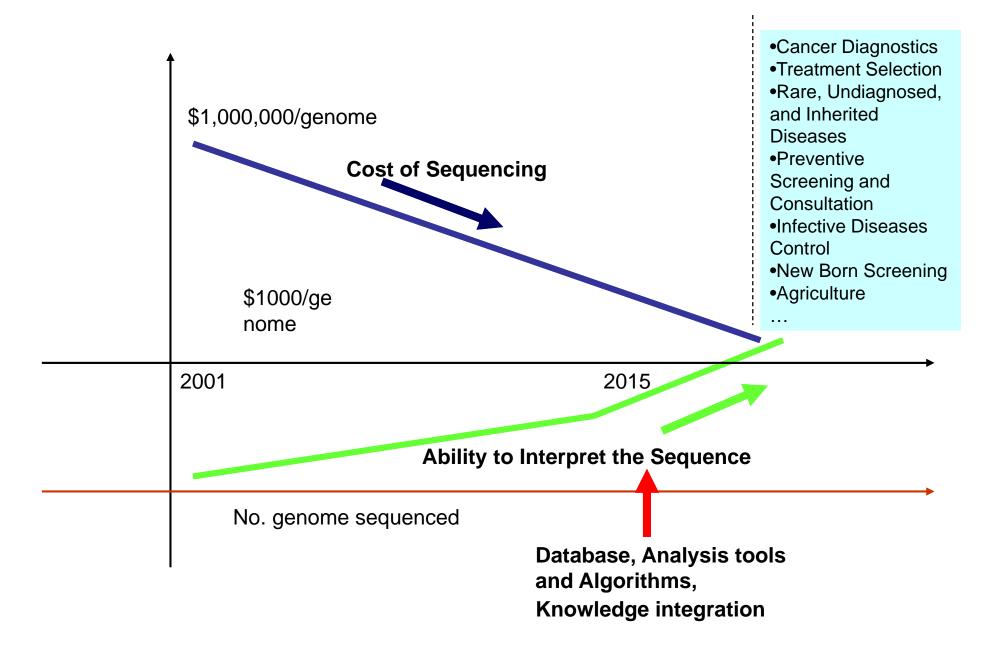
- Smartphone apps that have the potential to passively and continuously track physical activity.
- More detail data
 - how physical activity is affected by the social and environmental context.
- Directly help
 - real-time reminders to increase physical activity before the end of an unusually sedentary day to avoid missing one's daily activity target.
 - linking groups in order to increase motivation.

Example 2: Big Data and Asthma

- Sensor snaps onto asthma metered-dose inhalers, that passively captures the time, location, and GPS coordinates of inhaler use by communicating with a smartphone.
- App allows users to provide further contextual information, such as symptoms, perceived triggers, activity at time of use, and whether.
- Creating a data feedback loop to improve adherence behavior.
 - Reducing asthma symptoms and improved control.
 - city of Louisville, Kentucky, has adopted this technology to address their elevated asthma burden.

Van Sickle D, et al. Resp Drug Delivery Europe, 2013 MacDonald C. The Environmental Magazine, 2012

Personalized & Preventive Healthcare



Cloud computing will quickly change the use of medical information

- The fact that Google and Microsoft are heavily invested "in the cloud" extends to their new offerings for medical records services, such as Microsoft's HealthVault and Google Health.
- Google 23andMe, 3.9 million USD and more, The integration of biological information, the use of new technology to establish a standardized DNA database, work with pharmaceutical and biotech industry to develop new drugs and personal medicine, Alzheimer's foundation, Direct-to-Consumer research: recruit 10,000 patients with Parkinson's disease to enroll. Brin's Search for a Parkinson's Cure, Brin proposes a different approach, one driven by computational muscle and staggeringly large data sets.
- For example, a mutation to the GBA gene is 5 times more likely to have Parkinson's
- 23and Me: Parkinson's Genetics initiative
- 1. Tool Construction: Survey 2. Recruitment: 10,000 subjects with Parkinson's. 3. Data aggregation: Community members DNA analyzed and surveys. 4. Analysis: database query based on 3,200 subjects. The results are returned in 20 minutes. 5. Presentation: People with GBA are 5 times more likely to have Parkinson's. Total time elapsed: 8 months
- Traditional Model
- 1. Hypothesis: 2. Studies: 3. Data aggregation: 5,500 subjects 4. Analysis: 5. Writing: 6. Submission: 7. Acceptance: <u>NEJM</u> 8. Publication: The paper notes that people with Parkinson's are 5.4 times more likely to carry the GBA mutation. Total time elapsed: 6 years

數據之"天龍八不"

- 不准用
- 找不到
- 拿不到
- 打不開
- 不會用
- 看不懂
- 不合用
- 不夠用

2014 中研院open data seminar ODTW Meetup 2014 #3

從生態資料整合經驗看 LOD 建置

Public View

正確的方式

錯誤的方式

- 填寫各式各樣的統計表格
- 使用困難,不方便
- 需要花錢買

- 開發各式各樣的數據處理及分析工具
- 連結數據資料庫與分析工具
- 開放數據資料庫,使數據可以 被搜尋到
- 方便的雲端化數據分享與處理

Internet





Data Sets

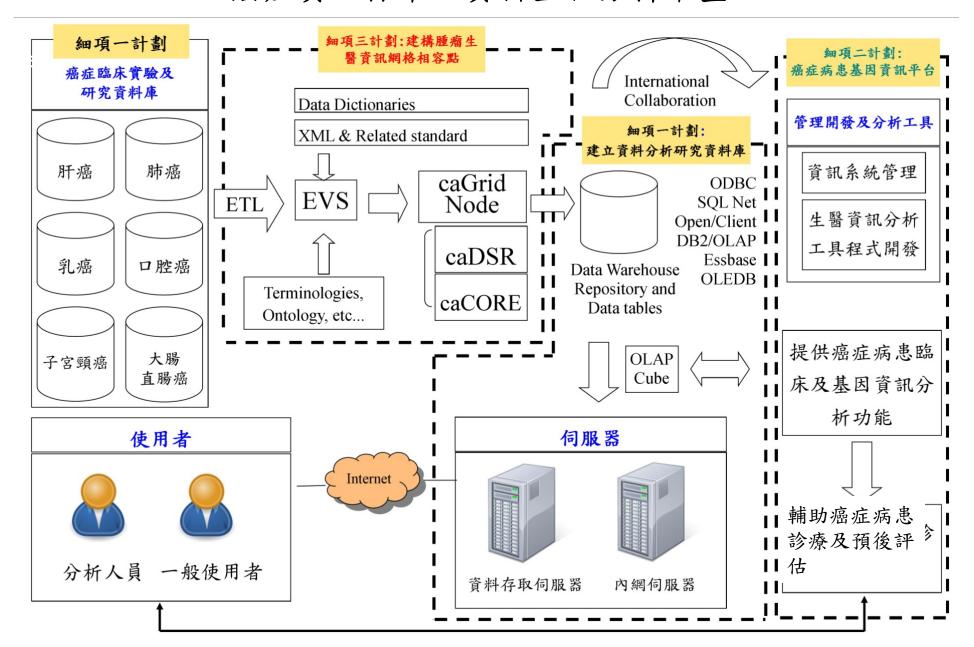






許多都是政府支持的研究或是公家收集並擁有的資料庫

健康醫療BIG DATA 應用範例 癌症資訊標準化資料整合分析平臺



Privacy and data management

- Who owns your genome/EMR data?
- Who controls access to your data?
- Who will store the genome, images, medical records?
- How do you control access?
- Why protect patient data?
 - Right to privacy
 - Could affect insurance costs
- Can we share data to improve:
 - Drug research?
 - Treatment research?
- How to manage the information
 - Privacy: patient records, including genomes should stay within each medical system (country)
 - Standards: personal genomes and other genetic data need standards
 - Language: genomes are just data, but metadata (name, address, medical history) will be in local languages

Want can Data Governance Accomplish?資料治理的重要

The Data Governance Institute www.DataGovernance.com

- Enable better decision-making
- Reduce operational friction
- Protect the needs of data stakeholders
- Train management and staff to adopt common approaches to data issues
- Build standard, repeatable processes
- Reduce costs and increase effectiveness through coordination of efforts
- Ensure transparency of processes

The most common objective of Data Governance programs is to standardize data definitions across an enterprise or initiative. (for example: 電子病歷標準)

Tunical Data Governance Focus Areas



Seven phases of Data Governance Life Cycle Methodology



What Do We Need To Get There? New-Style Leadership New Skills 人才需求

- Next Generation of ICT-engaged Clinical Leaders
- Executive Level-performing CIOs
- Medical/Clinical Informatics
- Patient Informatics
- Enterprise data warehouse architects/data modelers, master data managers
- Data Scientists (epidemiologists are the "new cool")
- Analysts both business & clinical systems and clinical data analysts
- Project managers

Source: Gartner, 2013

Data Analyst

Learn how to manipulate and analyze data

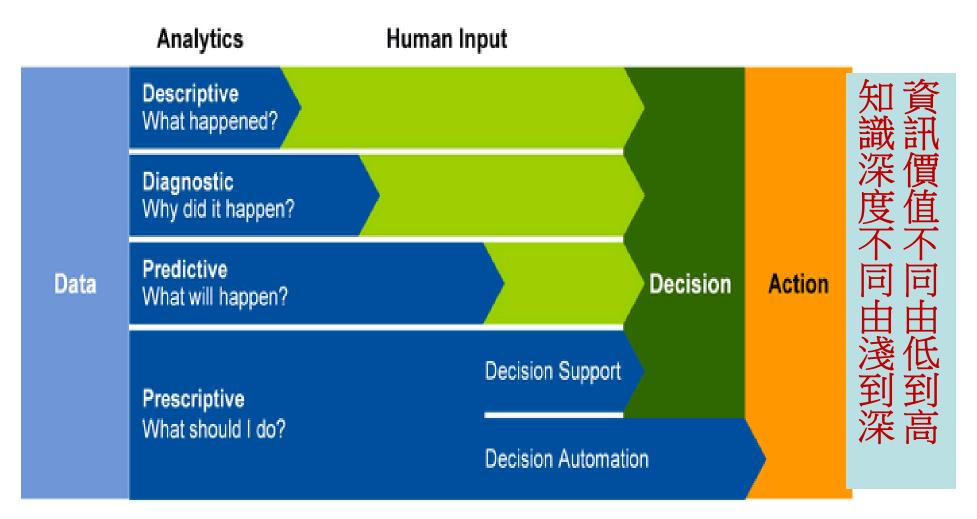
Data Scientist

 Learn how to make inferences and predictions from data.

Data Engineer

 Learn how to build data pipelines to work with large datasets.

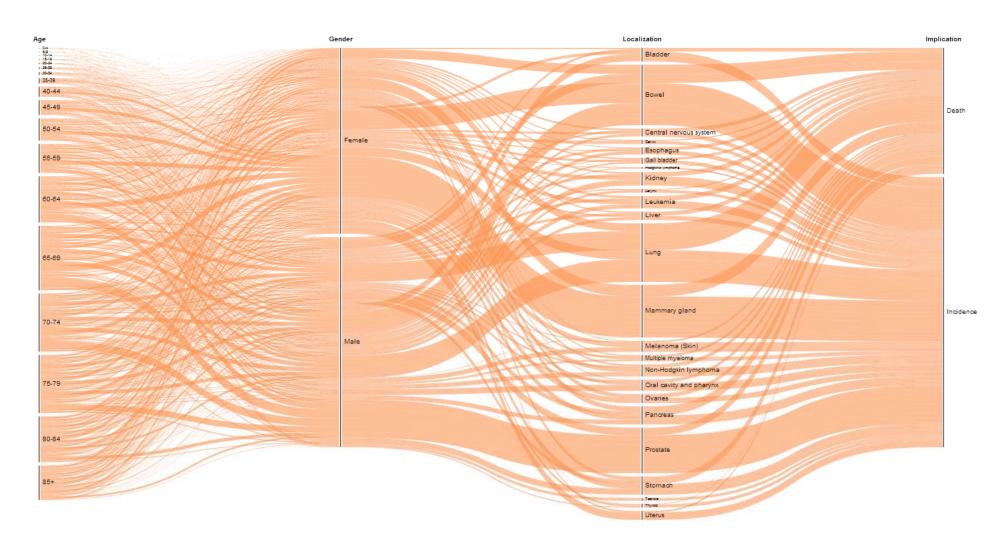
Four Types of Analytics Capability



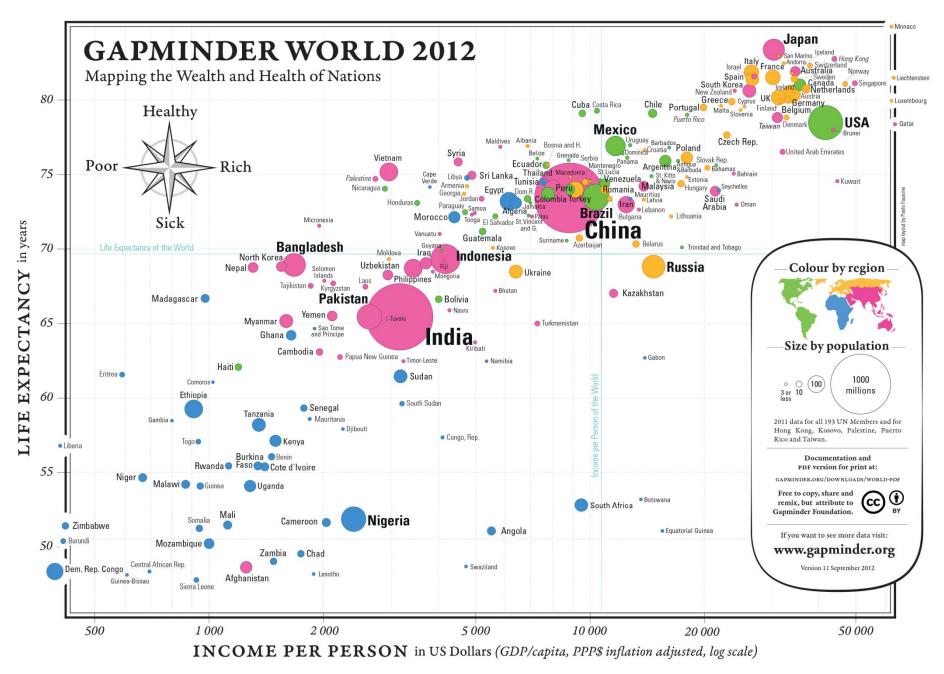
Gartner Says Advanced Analytics Is a Top Business Priority

Analysts to Explore Analytics Capabilities at the Gartner Business Intelligence & Analytics Summit 2014, October 21-22 in Munich, Germany (http://www.gartner.com/newsroom/id/2881218)

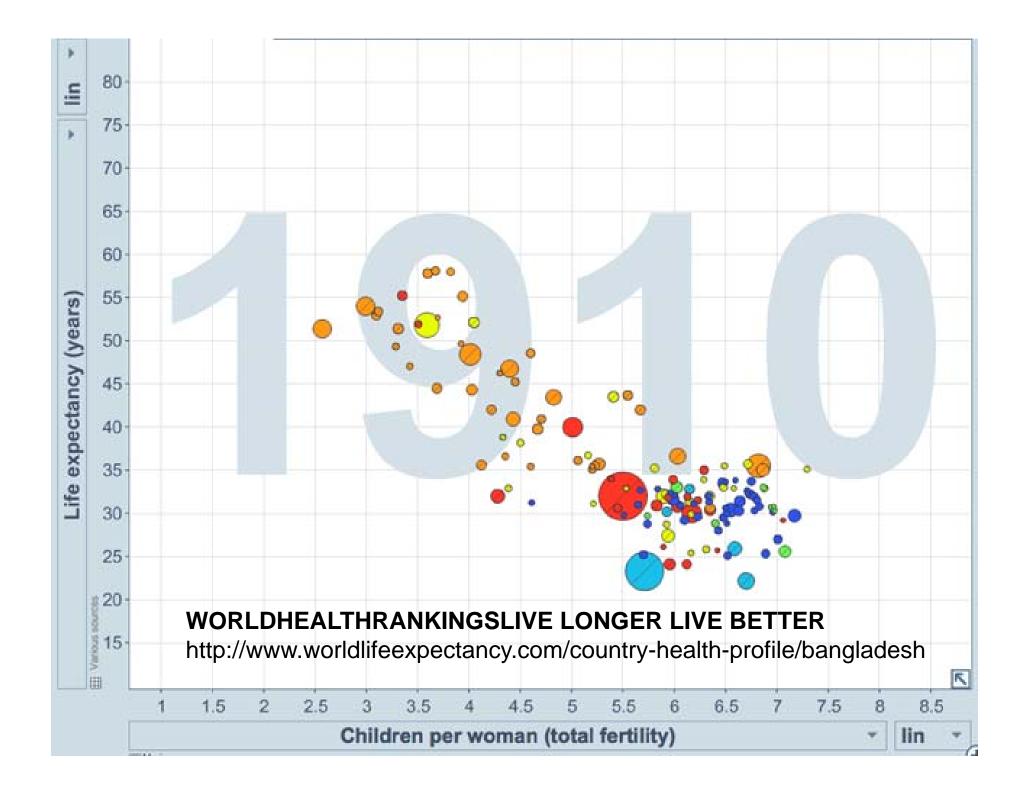
Visual Telling of Flow of Cancer Statistics

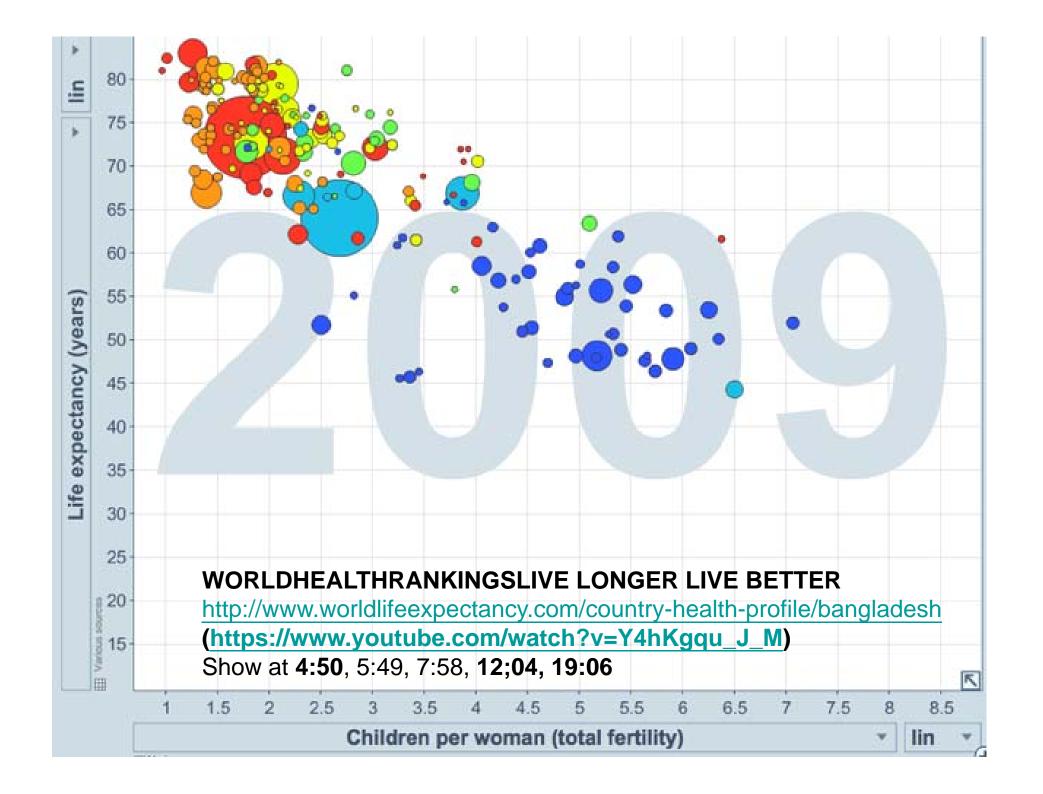


http://www.visual-telling.com/?p=343



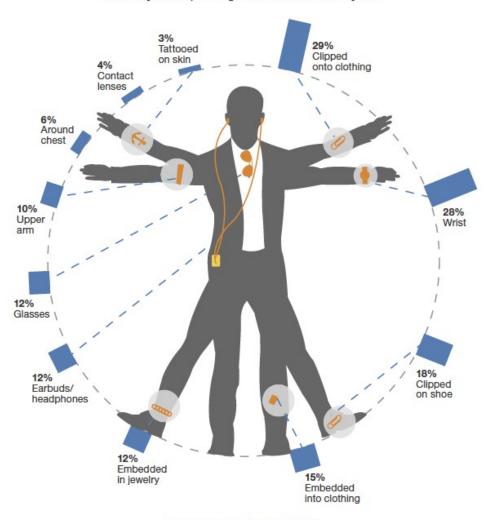
This graph from Hans Rosling's Gapminder.org shows by country how long people live₄ and how much money they earn.(https://www.youtube.com/watch?v=Y4hKgqu_J_M)





穿戴式装置的多元性

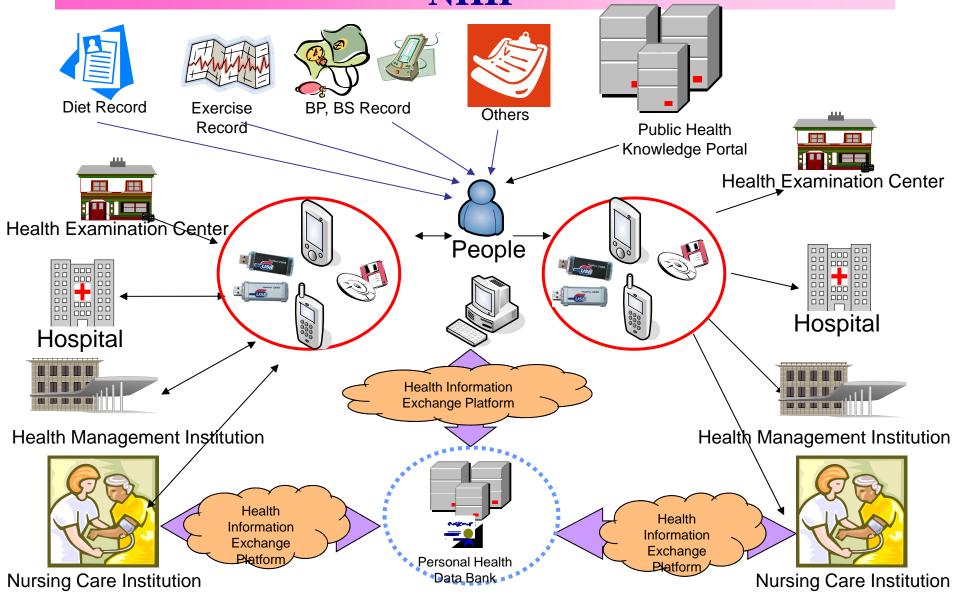
"How would you be interested in wearing/using a sensor device, assuming it was from a brand you trust, offering a service that interests you?"



Base: 4,657 US online adults (18+) (multiple responses accepted)

Source: North American Technographics® Consumer Technology Survey, 2013

Personal Health Information Application Scenario NHIP



Q&A

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Taiwan Association for Medical Informatics, TAMI

Thanks you!