NCVHS Strategic Retreat:
Issues Deserving Attention to 2010

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Living in the Fast Lane:

If everything is under control, you are going too slow.

\- Mario Andretti

I. Overview of Dominant Goals for past decade
II. Dominant Goals for next decade
III. Priorities if we are to accomplish II.
IV. NCVHS focus for next 4 years

1991-99 Goal - Computer-based Patient Records (CPRs) for Clinicians.

1999-01 Goal - Safety & CPRs.

2001-06 Goal – Safety/Quality with Electronic Health Records.

Aims for Health Care Delivery System

- Safe
- Effective
- Patient-Centered
- Timely
- Efficient
- Equitable

- IOM:Crossing the Quality Chasm, 2001

The Message

"In the absence of a national commitment and financial support to build a national health information infrastructure, the committee believes that progress on quality improvement will be painfully slow."

– *Crossing the Quality Chasm: A New Health System for the 21st Century*, IOM, 2001
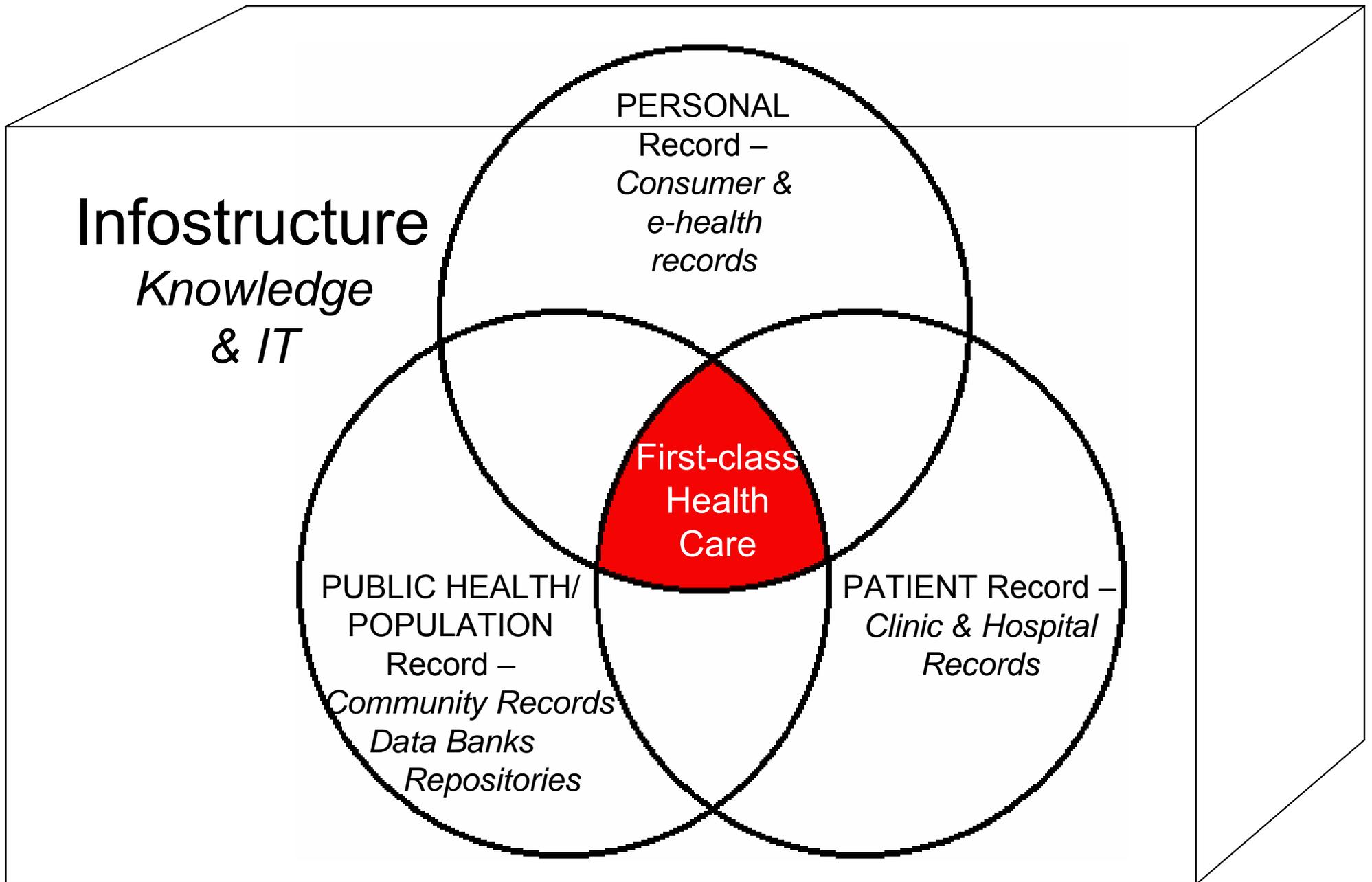
What we needed v.'98-'05: NHII ➡ NHIN

- Health IT to achieve
  - Individual Clinical Care
  - Population Care
  - Health & Prevention

Berner ES, Detmer ED, Simborg D. Will the wave finally break? A brief view of the adoption of electronic medical records in the United States. J Am Med Inform Assoc. 2005 January-February;12(1):3-7.

Aim: Transform Systems

from Costly, Inefficient, & Highly Variable Systems

to Systems that are equitable, safe, patient-centered, efficient, effective, & timely.

Infostructure
Knowledge & IT

PERSONAL
Record –
Consumer & e-health records

First-class Health Care

PUBLIC HEALTH/ POPULATION
Record –
Community Records Data Banks Repositories

PATIENT Record –
Clinic & Hospital Records

Interlocking computer-based health records (C3PRs)
supported by knowledge & IT infrastructure

USA & World: Learning from Abroad
- 2006 Take home lessons

Detmer DE, Steen EB: Learning from Abroad: Lessons and Questions on Personal Health Records for National Policy. AARP Policy Report #2006-10, March 2006. see http://www.aarp.org/research/health/healthliteracy/2006_10_phr_abroad.html

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Similarities in the HIT Environments*

- Strong emphasis on standards to enable connectivity & interoperability.
- Privacy is a priority & is recognized as a greater challenge in those countries where both federal (national) & state/provincial laws must be aligned. Privacy commissioner provides a visible focal point for privacy policy & enforcement.
- Unique personal health identifiers are planned or are in use at the national level & at the province level across Canada. [The major exception from the USA!]
- The public is increasingly using the Internet & does so for health purposes much of the time.
- (Rising concern over sustainability of healthcare system.)

*see Detmer & Steen at http://www.aarp.org/research/health/healthliteracy/2006_10_phr_abroad.html

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Conclusions (1) : Government's Role

Nations Studied

Prime Value:

Social solidarity;
Health through services

Concern about sustainability

Social Solidarity ≈ Trust

Policy Outcome: Privacy
Policy moves on to dealing
with confidentiality, security,
& sanctions for breaches

USA

Prime Value:
Individual Autonomy &
Personal Control; Health
through research & discovery

Individual Autonomy &
Control ≈ Trust
(or, mistrust & ongoing suspicion*)

Policy Outcome: Privacy
Policy becomes endless debate
with health & privacy in conflict

* Onora O'Neill: Autonomy and Trust in Biomedical Ethics
Cambridge University Press 2001

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Conclusions (2) :
Consumers/Citizens & National Policy

USA Only

ePersonalHRs are a 'hot topic'

Equity of access is not a key
    healthcare policy or issue

Individual control/autonomy
    emphasized over education

No policy for personal
    authentication

Mostly rhetoric & meager Federal $
    investment

Nations Studied

EMRs & Public/Population 'hot'

Policy assures equity of access to
care (esp. primary)

Education emphasized over
    patient control

Personal Unique Health ID /
National IT Card

Strongest concern is for
confidentiality & security over
privacy

Action & Substantial $ / £ s

National Academies Informatics Planning Workshop
May 1, 2006

- Academy-wide initiative will be forthcoming

2006 –

Goal: Informatics to Assure Value*
for Individuals & Populations

*Value = Quality & Safety / Cost

The Future of Care: Manage Change supported by Information Technology with Informatics.

- Build Knowledgeable Teams
- Reinvent Workflow
- Integrate Innovations
- Remove 'Outdated' Practices
- Reduce Variation
- Improve Safety/Quality while Reducing Costs
- Manage the Base of Knowledge

- National Academies Study
  "Building a Better Delivery System"
  National Academy Press, 2005

Health Informatics ≠ Health IT

"A scientific field that draws upon the information sciences & related technology to enhance the size & use of the knowledge base of the health sciences to improve health care, basic biomedical & clinical research, education, management, & policy."

Five Key Dimensions of National & Global Health Informatics Infrastructure

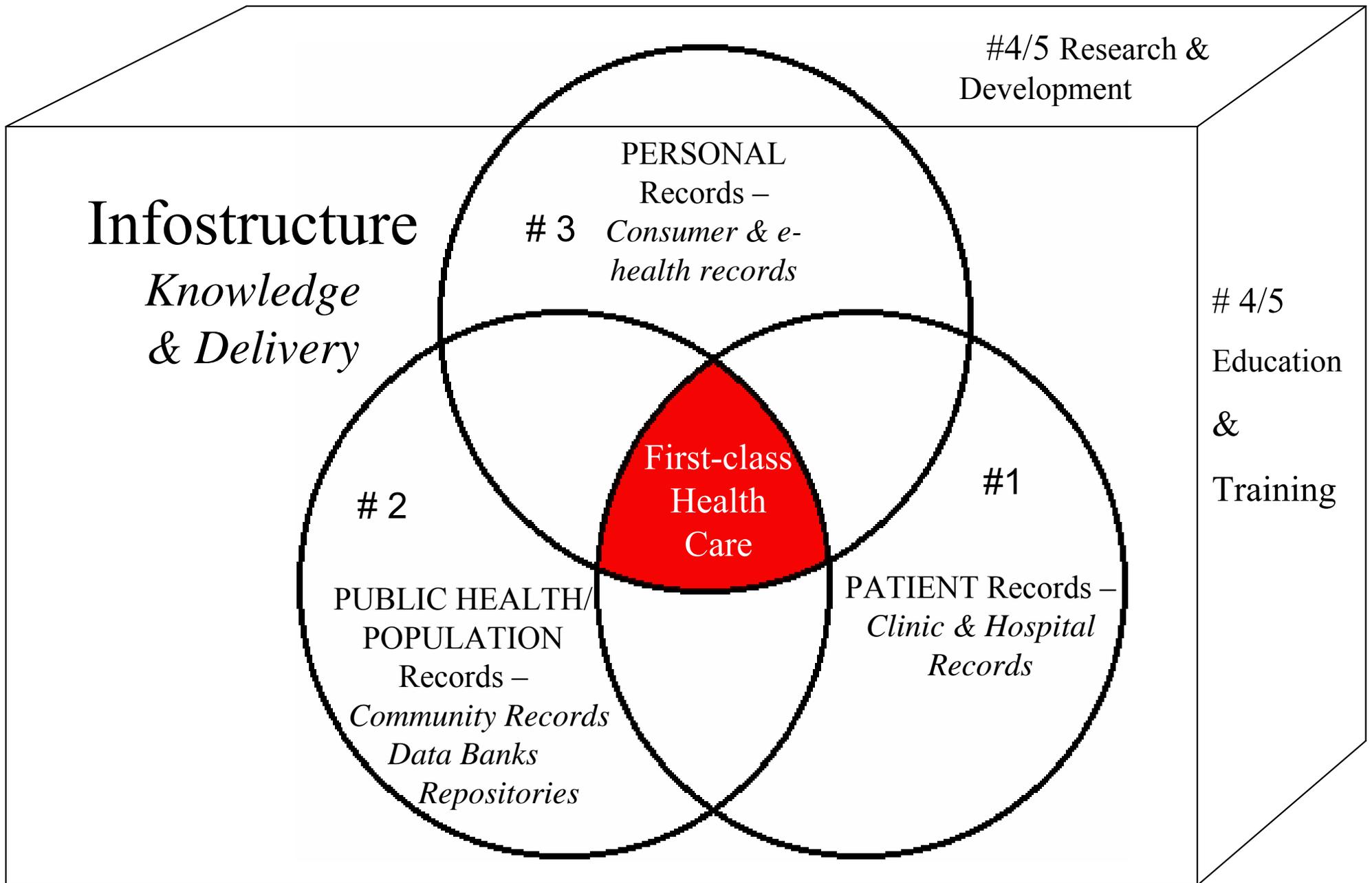Care-related Communications/Records

     1) Personal

     2) Patient

     3) Population / Public Health

Research & Development

Education & Training

Infostructure
Knowledge & Delivery

#4/5 Research & Development

#4/5 Education & Training

PERSONAL Records – *Consumer & e-health records*

#3

#2

PUBLIC HEALTH/ POPULATION Records – *Community Records Data Banks Repositories*

#1

First-class Health Care

PATIENT Records – *Clinic & Hospital Records*

Interlocking Computer-based Health Records (C3PRs) supported by knowledge (Research & Development / Education & Training with IT infrastructure)

My Suggestion: NCVHS should develop 3 ad hoc work groups (committee members & others)

I. Work Group on Research & Development
    Pursue top three items relevant to NCVHS

II. Work Group on Education & Training
    Pursue top three items relevant to NCVHS

III. Work Group on Value in Health Care,
    e.g., Value = Quality & Safety/Cost
    Pursue top 3 items relevant to NCVHS

IV. ??? Value Group

I. Work Group on Research & Development
Pursue top three items relevant to NCVHS

Top 7 Informatics Research Issues reflect the Value-driven mindset

AMIA / ACMI Survey (Starren, Balas, Detmer 2006)*

1. Interoperability
2. Workflow
3. Quality/Patient Safety
4. Decision Support
5. Information Filtering/Aggregation
6. Impact of Informatics
7. Human Computer Interface

*not for quotation

A Roadmap for National Action on Clinical Decision Support*

June 13, 2006

Arguably, the first Education
Infrastructure initiative
of the NHIN

(AMIA for ONC)

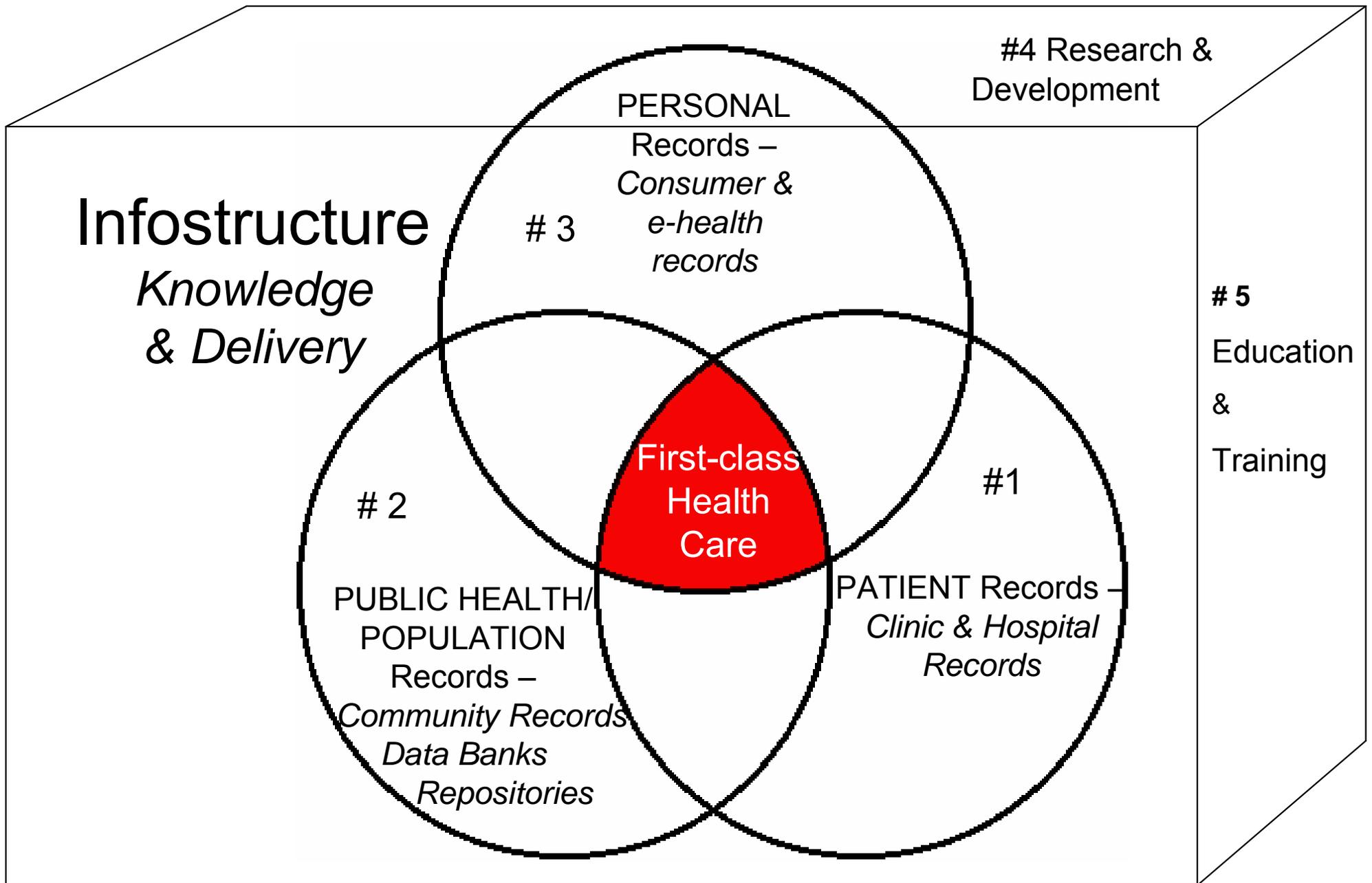http://www.amia.org/inside/initiatives/cds/

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Generate Strategic Report & pursue a few policy priorities of NCVHS NHIN Research & Development Agenda

Example: Recommend an opt-out personal health identifier for:

» Care &

» Prior approval to notify via email of IRB approved research studies of potential interest & sound educational materials

Infostructure
Knowledge & Delivery

#4 Research & Development

#5 Education & Training

PERSONAL Records – *Consumer & e-health records*

#3

#1

First-class Health Care

#2

PUBLIC HEALTH/ POPULATION Records – *Community Records Data Banks Repositories*

PATIENT Records – *Clinic & Hospital Records*

Interlocking Computer-based Health Records (C3PRs) supported by knowledge (Research &Development / Education & Training with IT infrastructure)

II. Work Group on Education & Training

Pursue top three policy items relevant to NCVHS

An investment in knowledge always pays the best interest.

- Benjamin Franklin

Informatics Domains

- Bioinformatics
- Clinical Informatics (Covvey)

  "hyper-applied" health information technology

  research/academic training emphasized by NLM's training programs & several other university based programs

  a middle zone that might be called "applied clinical informatics."

- Public Health Informatics
- Public Policy Informatics

NCVHS Ad Hoc Work Group Education & Training

- Comprehensive
- Forward looking
  - Workforce Implications
    - Primary Care for USA; Developing Skills of Citizens
    - Demand for Informaticians & Informationists
- Recommendations for all Government Agencies
  - FDA - Clinical Trials, Post-market Surveillance, +/- EHR Regulation
  - NIH - NLM - Implement its Long Range Strategy with Knowledge Bank
    - Research infrastructure NCRR
  - AHRQ – Safety & Quality; Workflow
  - DoD, VAH - Vista for all?!
  - State Roles
  - Federal Investment needed
  - Standards Setting across domains -

AHIMA /AMIA Workforce Initiatives

Workforce White (Lime) Paper

AMIA's Education Strategy:

Informatics to transform Health & Healthcare

- Web Learning – 10,000 x 2010 (10x10)
    - Applied Clinical Informatics
    - MS Biomedical Informatics
    - Public Health Informatics

- Legislation for Increasing Funding for Informatics Workforce - Congressman David Wu

IV. Final Suggestion for NCVHS

Ad hoc group on Value in HealthCare, e.g.,
            Value = Quality & Safety/Cost

            Pursue top 3 items relevant to NCVHS

*Committee members plus others

Assuring Value in Clinical Settings 2006-

- Complete the HIT & Informatics Infrastructure
  - Administrative Simplification with Standards
    - Ex. SSA requests made by State Disability Determinations Services – Charles Urban
- Change Management & Work Redesign
- Enhance Clinical Decision Support
  - Find Best Practices & Scale Up
    - Disease Surveillance
    - Chronic Illness Management
    - Health Maintenance/ Prevention

Support Web-based programs that increase knowledge & skills for citizen/patient use of eiPHRs.*

Review the EU's e-Citizen program & adapt it for US use to engage serious health, computer, & numeracy literacy issues.

*e = electronic i = integrated & intelligent   PHRs

(personal health records)

The field of knowledge is the common property of all mankind.

- Thomas Jefferson, 1807

Generic Final Slide

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Detmer DE: Public Policy Issues for Computer-based personal records, Electronic Health Records and the National Health Information Infrastructures. In Lehmann HP, Abbott PA et al: Aspects of the Computer-Based Patient Record (2nd edition), Springer-Verlag, 2006.

Debate & Conclude Position on U.S. Public Domain Standards

- Federal government support for development & maintenance of standard educational vocabularies.
- System purchasers working with vendors test & improve current standards for greater interoperability & scalability.
- JCAHO requires vendors to meet standards.