Context: Providers Who Capture and Use Data

Practice-Based Research Networks

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Ad Hoc Workgroup for Secondary Uses of Health Data

of the

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

What is a Practice-Based Research Network?

- A collaborative of physicians committed to performing research of importance and relevance in their clinical practice
- Experienced clinicians located in a community setting principally involved in patient care
- Exist beyond the needs of a single study

Primary Care Practice-Based Research Networks (PBRN)

are

clinical laboratories

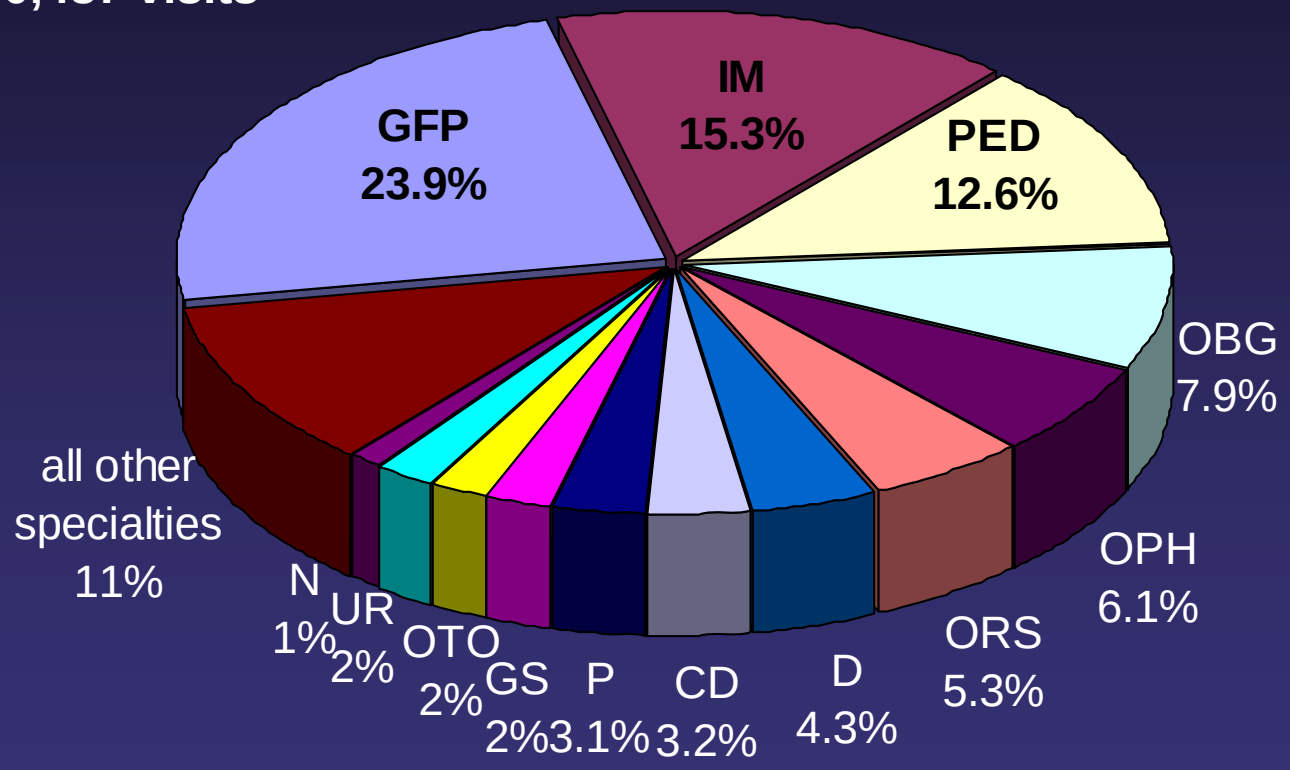
for Primary Care research

and dissemination

Distribution of Office Visits by Physician Specialty

United States, 2001

Total 880,487 visits



Source: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics, 2001 data.

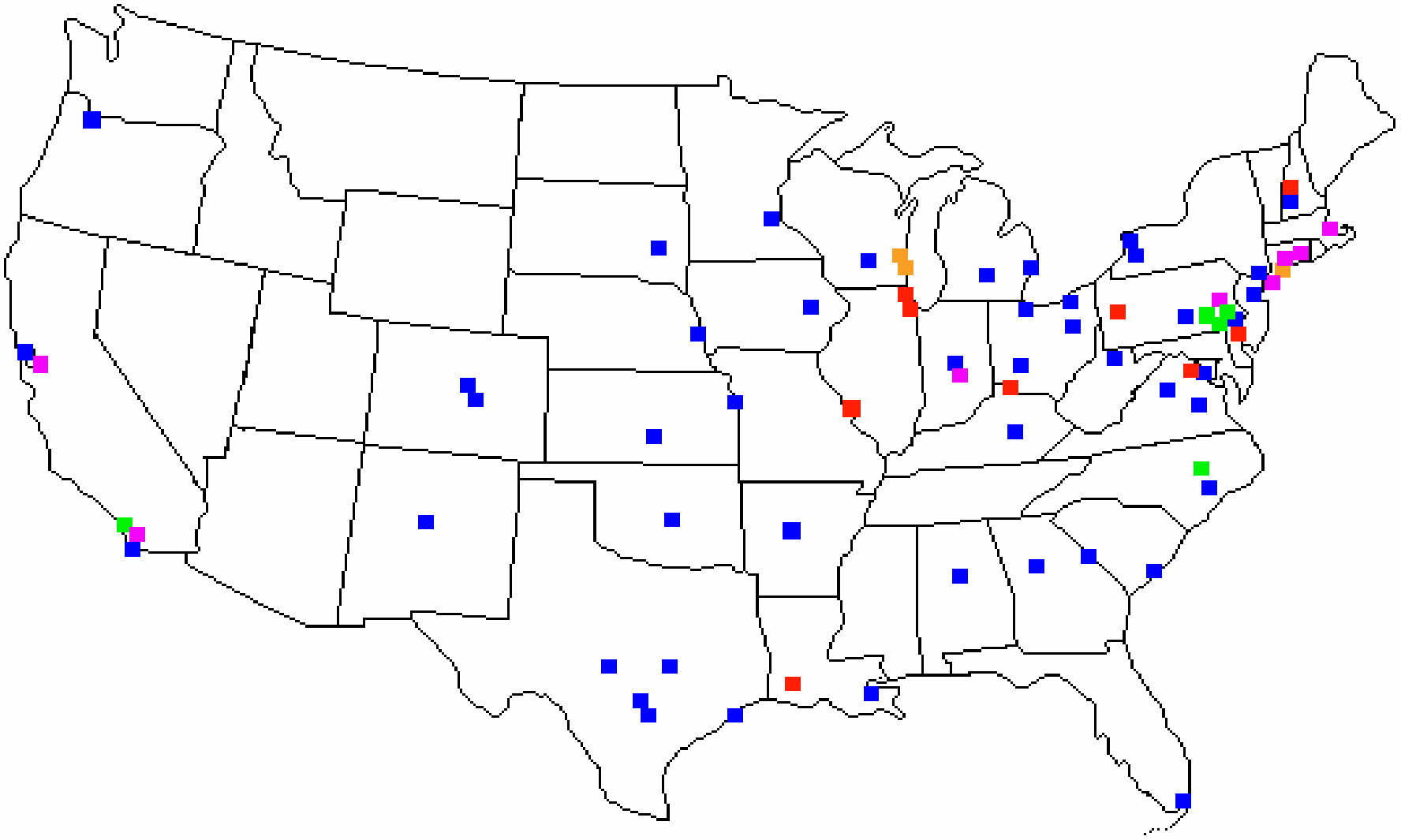
Federation of Practice-based Research Networks (FPBRN)

- **Established in 1998**
- **Representative elected governance**
- **57 networks (PBRNs) representing over 8500 physicians**
- **Members include AAFP, AAP, ACP-SGIM, AANP**
- **Over 2700 participating clinics**
- **Potential patient population of over 16 million**

"the most promising infrastructure development that [the committee] could find to support better science in primary care."

Committee on the Future of Primary Care
Institute of Medicine 1999

Geographic Location of Headquarters for Primary Care PBRNs in the US



Why Capture Data in PBRNs?

- Patients demographically closely resemble the general population seeking medical care
- Provide services (and accessibility) to widely diverse populations
- Diverse locations, multiple delivery systems

How is Data from PBRNs Used?

- Translation of research into practice
- Quality
- Effectiveness vs. efficacy
- Provider generated performance measures
- Safety
- Biosurveillance
- Health disparities
- Clinical Trials
- Community Based Participatory Research

Interoperability

: ability of two or more systems or components to exchange information and to predictably use the information that has been exchanged

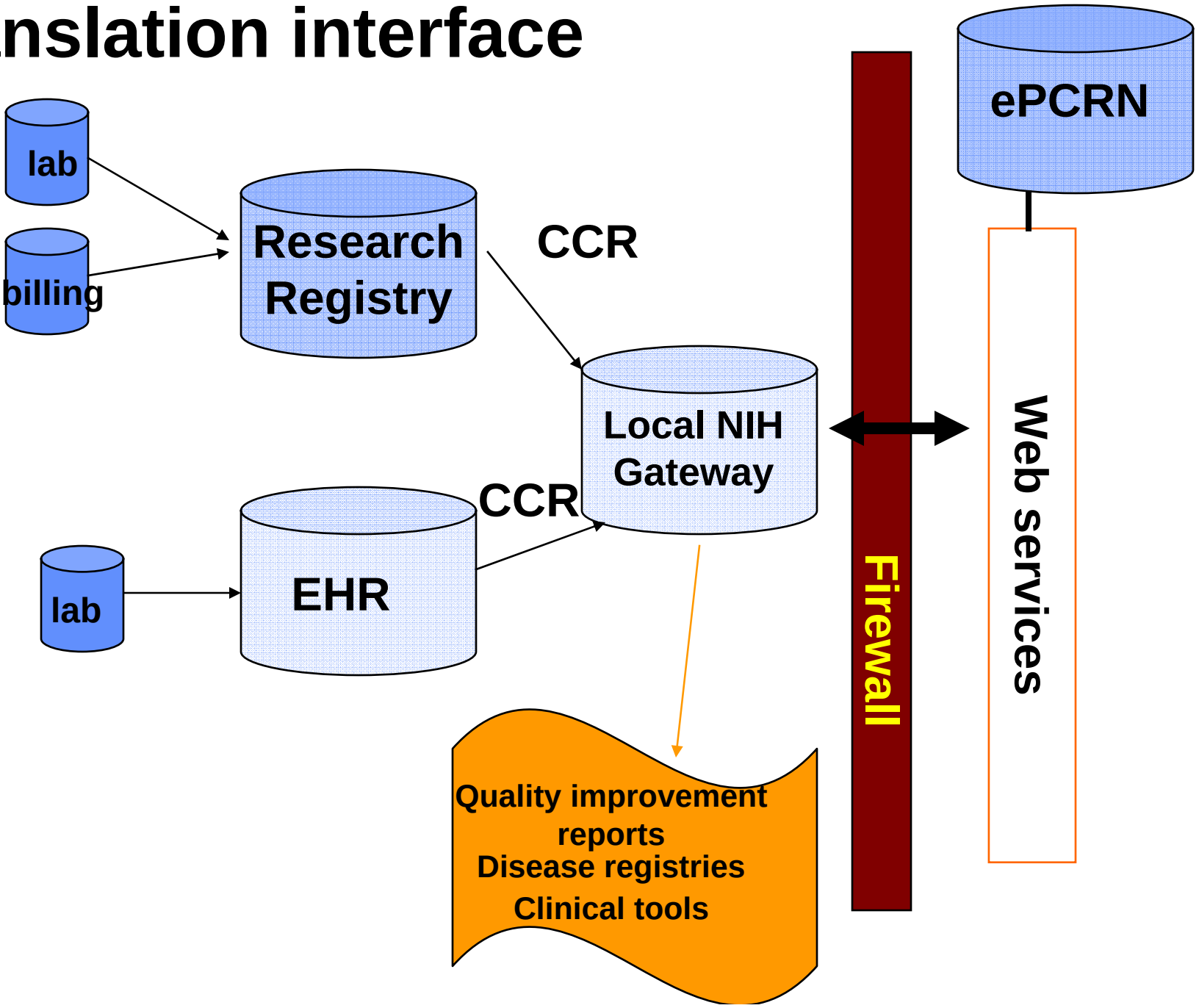
source: IEEE Standard Computer Dictionary: A Compilation of IEEE Standard Computer Glossaries, IEEE, 1990

- **Syntactic - the ability to read**
- **Semantic – the ability to understand**

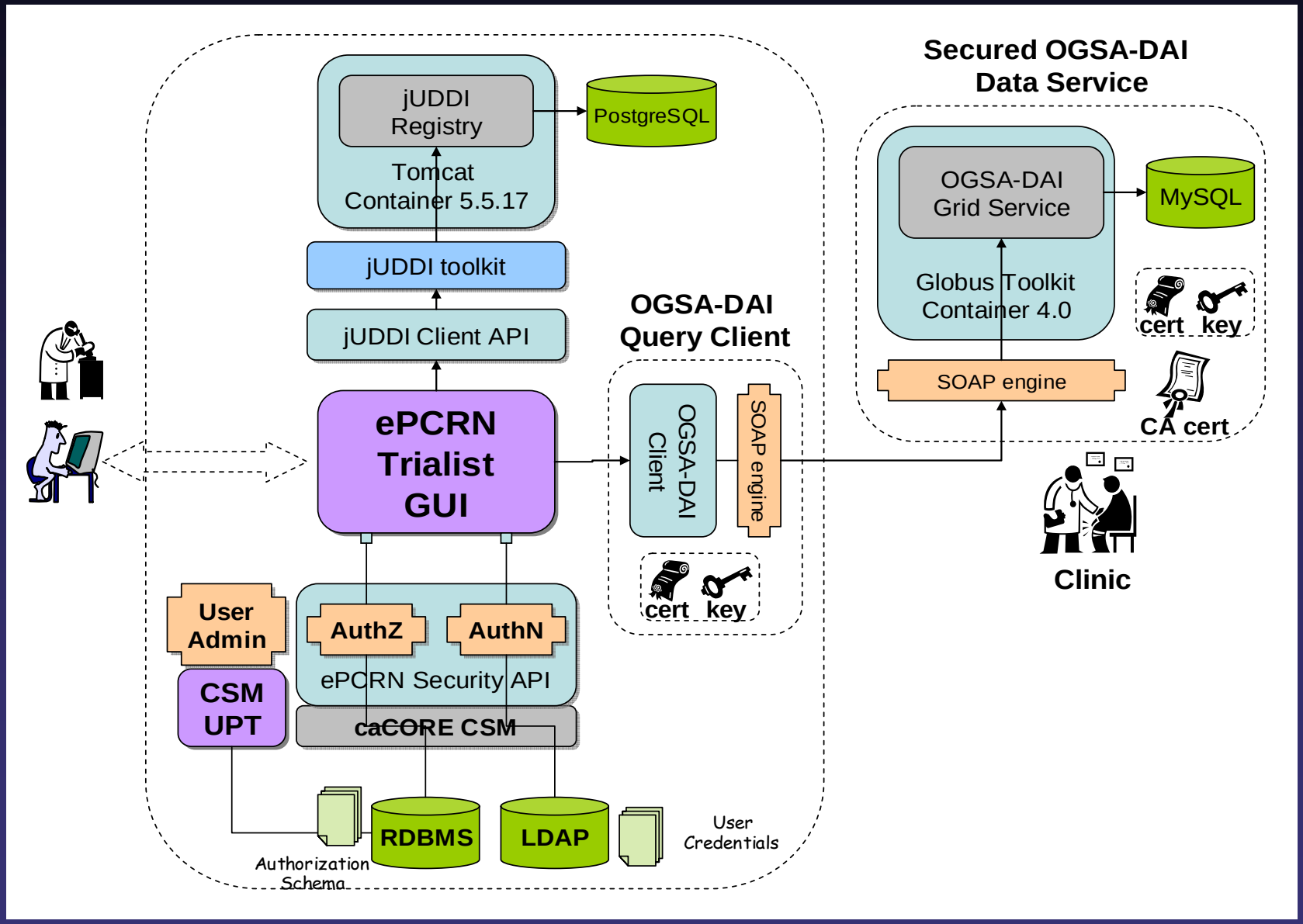
NIH funded e*lectronic architecture for primary care PBRNs that:*

- facilitates clinical research in primary care practices anywhere in the US
- promotes the rapid integration of new research findings into primary care
- Funded by NHLBI, NCRR, NIDDK, NCI, AHRQ

Translation interface



Federated NIH Gateway (ePCRN)



Patient specific profile

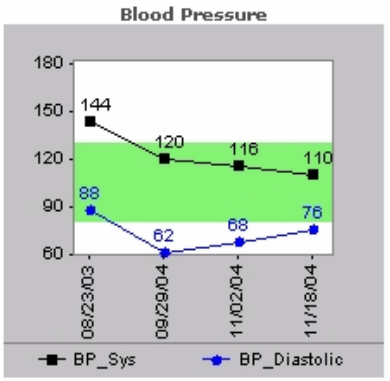
- Current disease status
- Graphic history of previous test results
- Recommended tests for the current visit

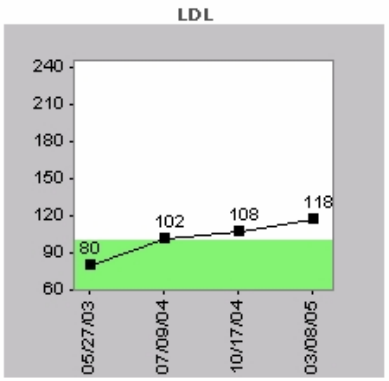
Diabetes Patient Profile - Confidential

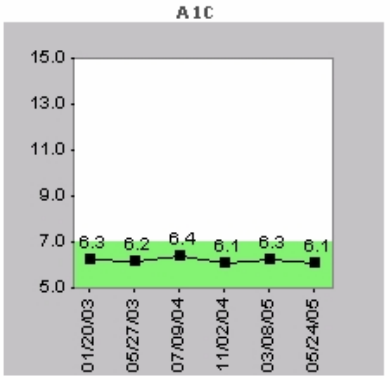
Log Off

Date: 4/11/2006
Name:
Type: 2
D.O.B.:
Last Visit: 5/24/2005
Provider:

Clinic:
EMDI #:
Complications: HYPERTENSION, DEPRESSION-MED TRT
Dx Date:
Eye Exam: No retinopathy present. - 5/8/2003
Foot Exam: Abnormal - 11/18/2004







Microalb Creatinine Ratio
Value: 5.9 Date: 7/9/2004

Smoking
Value: No Date: 5/24/2005

Cessation Advised
Value: NA

Aspirin
Value: Yes Date: 11/18/2004

ALERT! Based on DQIP performance measures this patient requires:
Foot Exam
Eye Exam
A1C Test
LDL Test
Microalbumin or
Microalbumin/Creatinine Ratio Test

BP: _____
Foot Exam: nl abn
Eye Exam Date: _____
retin noretin referred

Quality Improvement

DUSTY ROADS CLINIC
(07/15/2003 to 07/15/2004)

GOOD, JOHN (73 patients)

	Patient Name		Current A1C		Last A1C		A1C Statistics		Current LDL			BP
	Last Name	First Name	value	date	value	date	change	due	value	date	due	Systolic
1)	MOUSE	MICKEY	10.4	4/20/2004	5.8	12/3/2003	↑ 4.6		**140 (H)**	4/20/2004		102
2)	DUCK	DONALD	9	5/18/2004	6.8	9/23/2003	↑ 2.2		70	6/6/2003	yes	126
3)	MOUSE	MINNIE	8.2	12/8/2003	6.6	5/20/2003	↑ 1.6	yes	**110 (H)**	12/8/2003		108
4)	PIG	PORKY	7.8	3/18/2004	7	8/1/2003	↑ 0.8		70	6/4/2004		124
5)	JETSON	JANE	7.8	6/30/2004	8.2	4/26/2004	↓ 0.4		75	5/4/2004		118
6)	JETSON	GEORGE	7.6	3/23/2004	8.6	9/9/2003	↓ 1		**109 (H)**	3/23/2004		**138 (H)**
7)	FLNITSTONE	FRED	7.5	7/29/2003	7.4	5/7/2003	↑ 0.1	yes	58	4/19/2003	yes	**144 (H)**
8)	RUBBLE	BARNIE	7.4	12/10/2003	5.4	5/12/2003	↑ 2	yes	84	12/10/2003		**140 (H)**

Facilitating Our Secondary Use of Data

- Standard data structure
  - The Continuity of Care Record (CCR)
    - balloted ASTM standard for medical record export written in standard W3C XML
  - The Continuity of Care Document (CCD)
    - HL7 “compatible” CDA document.
- Standard data elements
  - SNOWMED
    - most comprehensive global nomenclature