electronic Primary Care Research Network (ePCRN)

The University of Minnesota, USA.
The University of Birmingham, UK.
The University of California San Francisco, USA.

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Outline

- Who is ePCRN?
- Why ePCRN is needed?
- What is ePCRN?
- What ePCRN needs?
  - obstacles, challenges and requirements
Project team

Minnesota:
- **Family Medicine**
  - Kevin Peterson
  - Joe Stone
  - Pat Fontaine
  - Carol Lange
  - Adam Wolff
  - Mark Janowiec

- **Computer Science**
  - Stuart Speedie
  - Jon Weissman
  - Seonho Kim
  - Mike Coonrod

- **San Francisco**
  - Internal medicine
    - Ida Sim

Birmingham:
- **Primary Care**
  - Brendan Delaney
  - Richard Hobbs
  - Darren Douglas
  - Hardeep Sandhar

- **Electrical Engineering**
  - Theo Arvanitis

- **Computer Science**
  - Marta Kwiatkowska

- **Joint appointments**
  - Adel Taweel
  - Lei Zhao
Problems and Challenges

- Subjects Identification
- Intervention Management
- Complexity of Managing (Primary Care) clinical trials
- Data Collection
- Paper Work
- Monitoring
- Communication
A big issue with capacity and methodology

- Even common clinical problems need far bigger numbers in RCTs than a single practice can provide.

- Primary Care RCTs need Research networks.

- Research Networks need infrastructure.
The NIH Roadmap for Medical Research

- Position NIH to address evolving public health challenges
- Accelerate the pace of discoveries
- Develop more rapid two way translation: from Laboratories to patients and vice versa
Main Goals

- To establish an RCT management system for US Primary Care
- To establish a secure distributed query process for US EHRs
- To establish a secure research portal for the US FPBRN
The Internet is about accessing information.

The eScience/Grid/Internet 2 is about sharing information, enabling:
- Large amounts of data widely distributed
- Robust security, provenance preservation
- Virtual community and communication
San Francisco, CA
Minneapolis, MN
Birmingham, UK
ePCRN Research Collaboration Centers
Relationships

- With the ‘Roadmap’ projects
  - Represent roadmap with CaBIG
  - BRIDG model
  - CDISC/RIM

- With WHO GlobalTrialBank

- With UK MRC e-Science projects
  - NHS CfH
CaBIG

- https://cabig.nci.nih.gov/

- Cancer Biomedical Informatics Grid

- Funded by National Cancer Institute
  - ePCRN part of two groups
    - CTMS - Clinical Trial Management Systems
    - EVS - Vocabularies and common data elements
RCT Design

- Modelling
  - Specification
  - Comparators

- Piloting
  - Accrual
  - Consent
  - Outcomes
“Operationalising” an RCT

- Ethics and research Governance
- Ascertainment
- Eligibility
- Baseline data collection
- Randomisation
- Prompt for intervention
- Follow up
- Analysis and archiving
ePCRN: Trials workpackage-1

- Develop use cases based on existing RCTs
- Develop generic use cases
- UMLS modelling of these use cases mapping to BRIDG and WHO
- Develop a generic Data model, mapping CDISC/RIM
ePCRN: Trials workpackage-2

- Trial design tools and virtual pilots
- Trial protocol capture and registration
- Trial management
  - Site management
  - Subject management
    - Identification of trial subjects
  - Intervention management
  - Data collection
    - Subject present
    - From EPR
USA EHRs have agreed to a common XML export standard using the AAFP ‘Continuity of Care Record’ (CCR)
Clinic-level (mySQL) databases hold the CCR exports
Use OGSA-DAI-based tools to extract data from the clinic-level databases.
The CCR standard also allows data to be uploaded to the EHR.
ePCRN: Translational workpackage
Portal and Security
(based on citrix)

1. Presentation Server Client
2. Secure Access Client
3. Web Browser
4. Birmingham University Campus Firewall
   Filter port 443 on address
   www.midrec.bham.ac.uk
5. MidReC En Linux Checkpoint Firewall
   Filtering logonpoints for studies on
   port 443 at 128 bit split dns for full
   VPN client
6. Jetnexus Loadbalancer sharing the load
   between the two Citrix VPN Appliances
7. Two Identical AAC
   Advanced Access Control Servers
8. Loadbalanced Citrix Farm
   of 6 Servers
9. NHS Gateway

The NHS Gateway will provide access to authorised personnel using a Secure RSA token and the Access Point will only allow users access to the two way link when rules have been configured on the firewall to control access.
IECRN demonstration

- June 1st 2006
- Major meeting of ‘Roadmap’ networks in Washington
- Demonstration of ‘find an eligible patient’ functionality
Identify & recruit eligible subjects remotely

→ counts of eligible patients

→ notify clinics of eligible patients for invitation/identification
UK projects

Phase 1

- Citrix site allows secure access to centralised RCT database via VPN tunnel
- Maratech and AGN for IP video conferencing
- Website for open access data collection and surveys
Access Grid

- Communication
- Collaboration
NHS links and future plans

Phase 2

- Develop OGSA-DAI based DQP system for UK EHRs
  • For anonymised identification of potential RCT subjects
  • For data collection where subject has consented

Application under consideration-S MRC
Clinical trial system

Figure 2: Project Phases

- **Access ePCRN Portal**
- **Design and modeling**
- **WP 1 + 2**
- **WP 2+4**
- **Local Queries**
- **Summary Data**
- **Primary care clinics**
- **Primary care reporting systems**
- **EHR**
- **Agent**
- **Grid-enabled Distributed Query & Data Access [OGSADAI/DQP]**
- **Design clinical trials**
- **Pilot trials**
- **Recruit participants**
- **Analyze studies**
- **Recruit participants**
- **Remote follow up of consented patients**

**Summary Data**

**Primary care clinics**

**Primary care reporting systems**

**EHR**
Thank you for your attention

QUESTIONS?