GRHANITE™ - Sustainability in Data Collection, Information Sharing and Research

GeneRic HeAlth Network Information Technology for the Enterprise

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Background

- HL7 and other messaging standards are at the heart of many national and international efforts to allow clinical information exchange. Such activities are effective, but costs are high, development timescales are long and interfaces are normally only developed between major clinical systems[1].
- Scotland has demonstrated another, pragmatic technique that can be used to link data for clinical care and research that is less dependent on messaging standard development. i.e. small systems can be linked as well as large ones [2].
- This Scottish system has proven itself through effectively providing an electronic health record for all patients in Scotland known to have diabetes [3],[4] (~190,000)

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The Scottish Experience

SCI-DC
SCOTTISH CARE INFORMATION DIABETES COLLABORATION

- Using a generic interface product developed by Dundee University (GENIE), data from any ODBC-compliant database can be extracted.
- This technology has been used to link data on a daily basis from over 1,000 general practice and hospital sites across Scotland.
- A central health record for diabetes (and cardiovascular disease) was constructed allowing patient care information to flow regardless of where the patient goes.
- This system is thought to provide the only fully population-based diabetes register (and care system) for a whole country in the world (Scottish population: ~5.1M).
- ~190,000 patient records are on the system, and there are >5,000 users spanning primary and secondary care (Nov 2006).
- Being a University of Dundee and National Health Service development, this system has achieved this for a total cost estimated to be around £10M – (~£10 (~$24 AUD) per patient with diabetes per year)
- Data from this system is at the core of Scottish Managed Clinical Networking for diabetes and underpins a wide variety of research programmes at the University of Dundee

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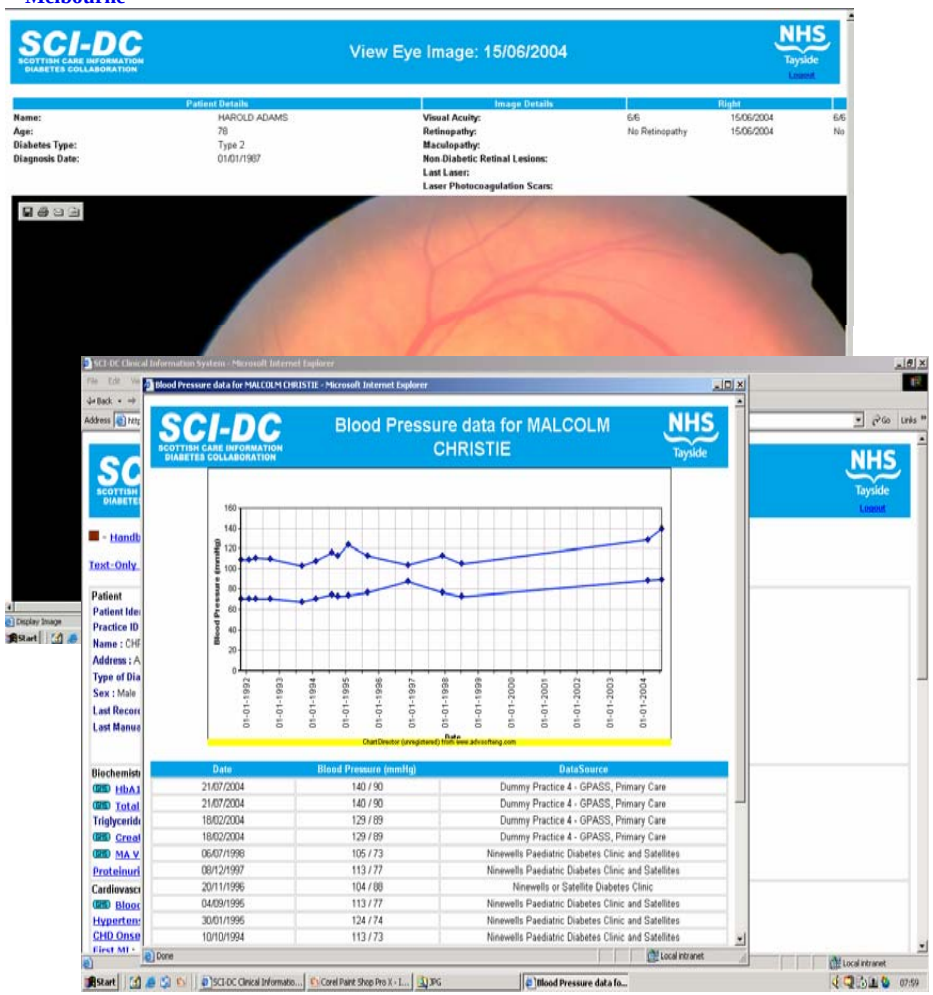
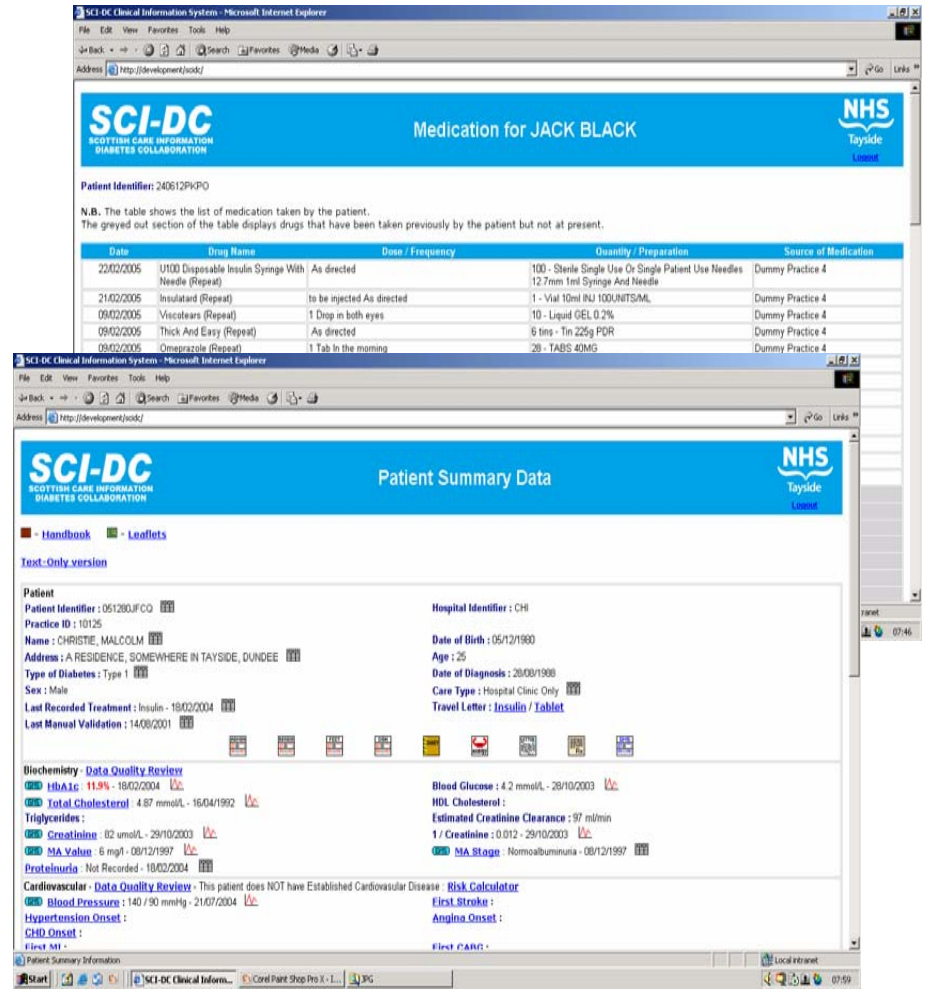
SCI-DC Sample Screens





GRHANITE™ is still under development, but capabilities like these are one goal of GRHANITE™.
A demonstrator application is due for completion by November 2007

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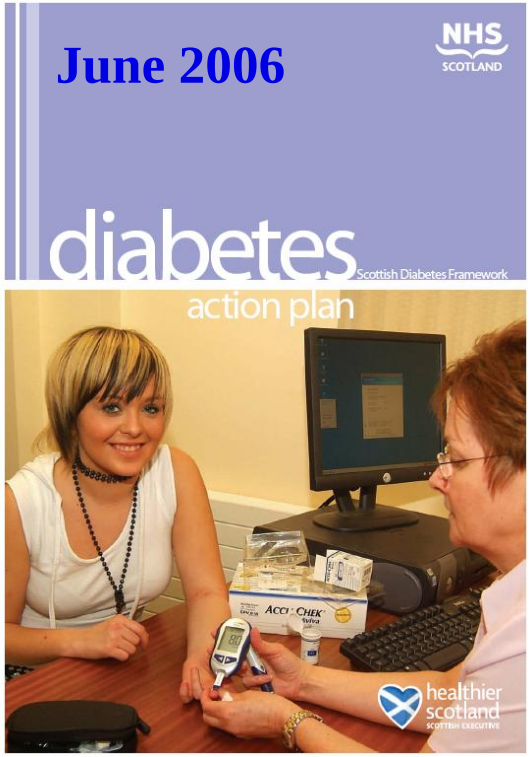
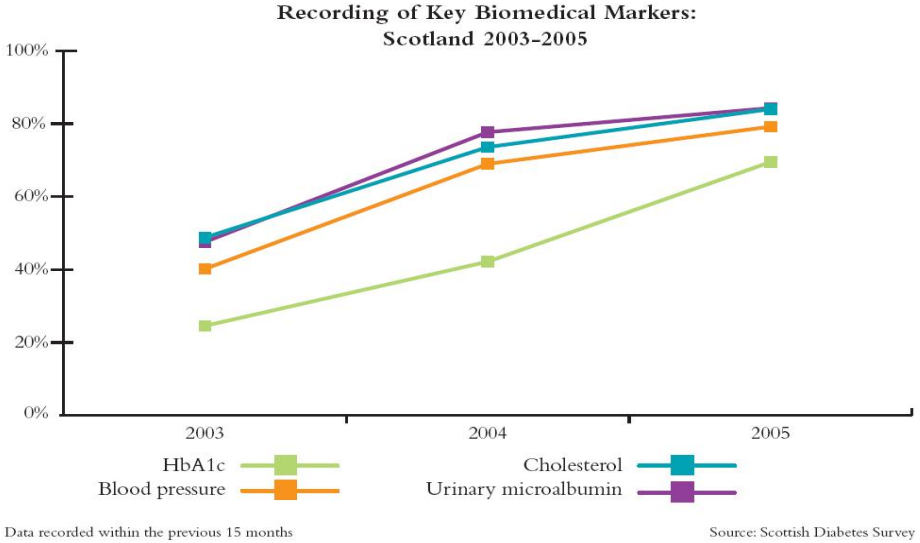
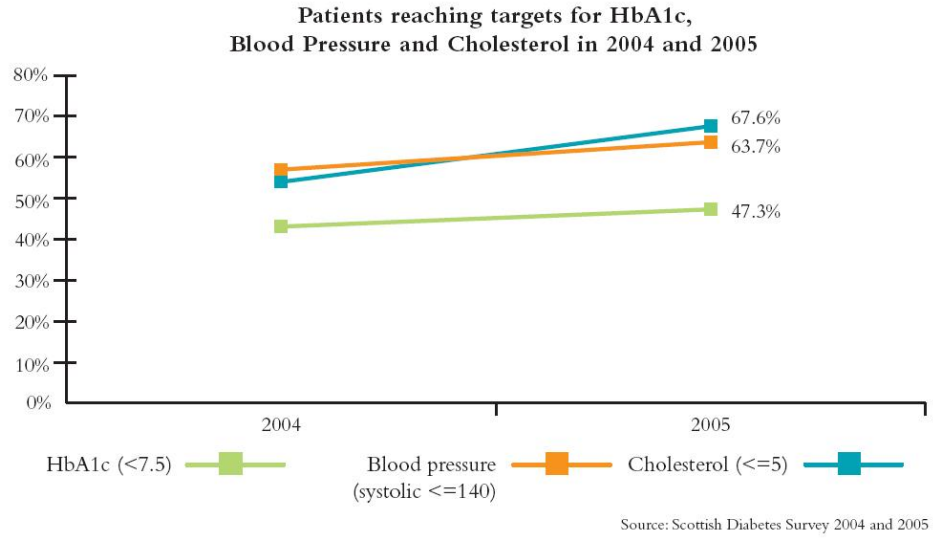
Evidence from Scotland demonstrates data quality improvement and improvements in patient outcome[4]

(People networks most important – IT underpins the network)



"In spite of the increasing numbers, more people with diabetes are now receiving the regular health checks they need."





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Australia - specific issues

Australia cannot implement strategies like those employed in Scotland without addressing the following issues:

- *No unique patient identifier (one is planned, but timescales are unknown)*
- *The divided commonwealth-state health financing system and the fee for service system discourages collaboration and shared-care systems*
- *Confidentiality, Ethics and Security are very public issues requiring the utmost respect with organisations such as the Australian Privacy Foundation carefully scrutinising activities in this area*
- *Information technology is a key enabler for improving communication, but improvements in patient outcome are a product of human intervention – effective collaboration across clinical communities is a necessity – as are structures that promote such collaboration*

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Approaches to resolving the issues

There is no reason the methodologies employed in Scotland cannot be utilised in Australia but the problems specific to Australia must be addressed at a fundamental level

Identified prerequisites:

- **Managing the people issues – establishment of collaborative networks**
  - This ePoster is primarily about the technical aspects of supporting collaboration. Technology is a key enabler, but is ONLY an enabler.
- **Managing consent processes**
  - Comprehensive consent management at source
  - Flexible consent processes managing consent for research, clinical information sharing, even audit.
  - Consent processes that are opt-in or opt-out allowing operation in a variety of health environments based on advice from local ethics committees.
  - Consent processes that will work for any size of organisation – from a single-handed GP to a 1,000 bed hospital.
- **Managing record linkage**
  - For clinical information sharing, linkage must be performed. Given there is no Australian unique identifier, this process must use identifiers such as name, address, date of birth, even phone number to ensure linkage is accurate. Linkage errors when sharing health records must not happen.
  - Sharing personal identifiers is not good practice. Ideally, a linkage process that does not need to divulge personal identifiers would be preferable.
- **Managing security**
  - If clinical data is to be moved electronically, security mechanisms must be there to protect the rights of the individual.
  - All communications must be encrypted and secured against hacking.
  - All communications must be secured using reliable means of confirming user and client PC identity. This is usually established via user logins and digital certification.
  - Mechanisms must be established to ensure data can only be accessed by authorised individuals on a need-to-know basis.
  - Audit trails and auditing procedures must be present in all processes.

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GRHANITE™ Technologies to resolve the fundamental issues

To-date, no application has been identified that can manage all the issues identified. GRHANITE™ technologies are being developed to fill this gap.

- GRHANITE™ has a generic interfacing capability that means it can link to any ODBC-compliant database. Users define the connection at install-time.
- It can use consent fields in a database, or can manage consent on behalf of the client database.
- It has a flexible (opt-in or opt-out) consent system that manages consent for whole organisations regardless of their scale.
- It manages consent for research, clinical and audit uses of data.
- No patient identifiers leave the organisation – non-reversible and dictionary attack-secured encrypted hashes are utilised for central linkage.
- The system manages its own X509 public and private key encryption processes to secure each site and each client PC connecting to the system – No need to purchase certificates. Techniques similar to Windows Activation are also utilised to guarantee the security of each connection.
- In addition to the above, messages are encrypted using constantly changing session encryption keys. Only publicly ratified and validated state-of-the-art encryption libraries are utilised.
- Code obfuscation is utilised.
- Approved health organisations only can install the product after the issuing of a passphrase-protected configuration file. Identified organisation administrators are responsible for allocating use accounts and user rights.
- GRHANITE™ performs a delta (Δ) data comparison to extract encrypted data changes each day or as otherwise scheduled – very small data quantities over the network.

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GRHANITE™ by Example

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Hospital

Hospital Computers

Consent & Security

Name: Joe Bloggs

DoB: 14/07/1993

HBA1c: 11.2

cDOpy28aFAKyaqDdq5xo+OhmxGlOMGY
NTyJ1qf+TSHZhC974lkxaixZSdTNGp5ne8
UZPKF2mz0Xgw3QuSWaadwvKlYkKQ7b
mFOPnpjnSHkM=

Joe Bloggs consented and de-identified

Web Services

So long as consent has been granted, Joe's de-identified record is automatically transferred to the databank

GRHANITE™ Databank

cDOpy28aFAKyaqDdq5xo+OhmxGlOMGY
NTyJ1qf+TSHZhC974lkxaixZSdTNGp5ne8
UZPKF2mz0Xgw3QuSWaadwvKlYkKQ7b
mFOPnpjnSHkM=

General Practice

Practice Computers

Consent & Security

Name: Joe Bloggs

DoB: 14/07/1993

cDOpy28aFAKyaqDdq5xo+OhmxGlOMGY
NTyJ1qf+TSHZhC974lkxaixZSdTNGp5ne8
UZPKF2mz0Xgw3QuSWaadwvKlYkKQ7b
mFOPnpjnSHkM=

Joe Bloggs attends GP and identity established. De-identified hashes matched

Web Services

Hash matching and session key management

Secure website link established to view Joe Bloggs record

Name: Joe Bloggs

DoB: 14/07/1993

HBA1c: 11.2

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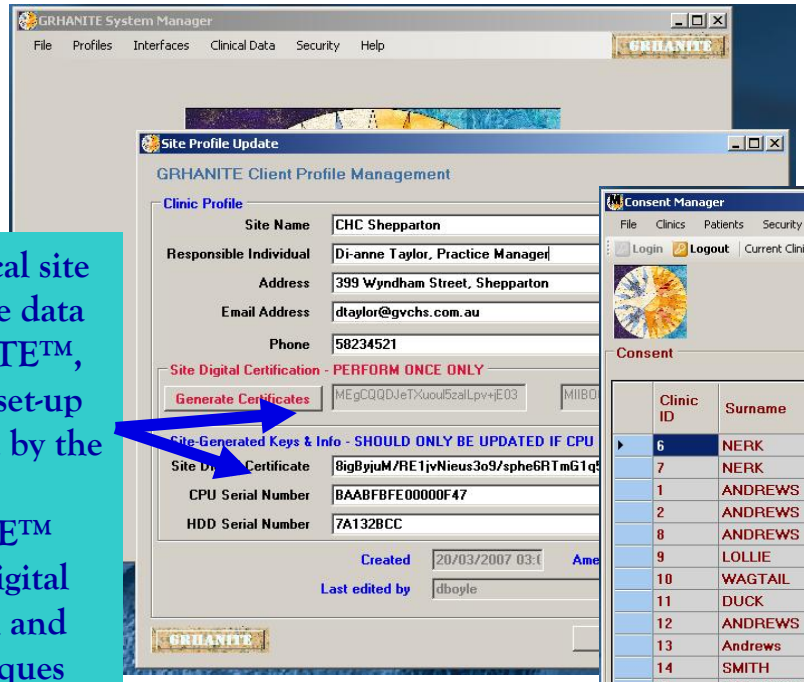
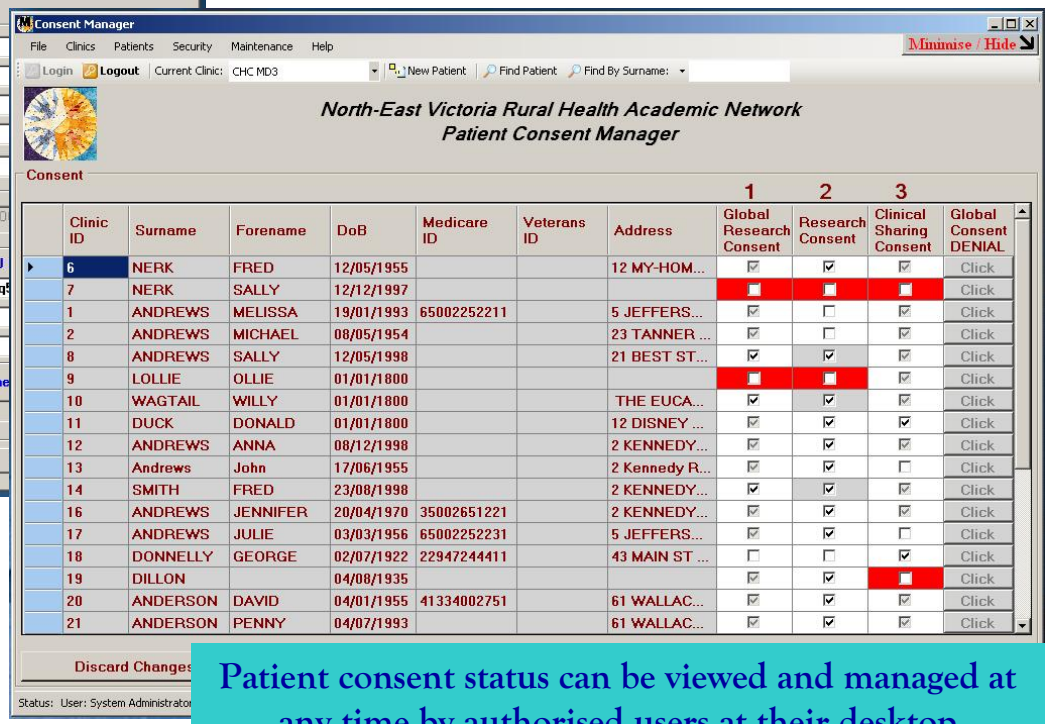
GRHANITE™



Before a clinical site can contribute data via GRHANITE™, they must be set-up and authorized by the central GRHANITE™ authority. Digital Certification and other techniques secure all communications and verify authenticity



Patient consent status can be viewed and managed at any time by authorised users at their desktop

- *GRHANITE™ is the technology underpinning the CONDUIT™ (Collaborative Networks Using Information Technology) project*
- *CONDUIT™ is the technical component of the North East Victoria Rural Health Academic Network (RHAN). This network has several goals, including managing the people aspects of establishing a Managed Health Network – initially for diabetes.*

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Results and Conclusions

- GRHANITE™ has been developed to demonstrator status and is ethically managing de-identified, linked, consented data from Medical Director V3 and Practix V1.3.
- A generic interface is being finalised – this will allow connections to most modern healthcare database systems – including ad-hoc systems.
- Collaborations have been established with organisations to support large scale development, testing and implementation.
- Techniques as utilised in Scotland are being used to ensure the large-scale applicability of the system.
- Diabetes service provision across North-East Victoria, Australia will be the first example of the clinical utility of the system.
- A diabetes demonstrator website is planned for completion by October or early November this year.
- Because of the comprehensive management of consent and security, we hope that this technology can finally remove the barriers to clinical information sharing between primary and secondary care.
- Comprehensive research data for consented patients should be a valuable by-product of the system. Crucially, this includes primary care data that is a largely un-tapped research resource in Australia.
- As far as we are aware, this is the FIRST TIME a central databank holding live clinical data has been able to do so WITHOUT holding patient identifiers. If we can do it, shouldn't everyone?

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