

GRHANITETM

(solid as a rock)

data linkage and information sharing

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Objectives

- ➤ Describe the GRHANITETM principles, methods and tools
 - * operational, ethics and governance processes, and standard operating protocols during the collection and linkage of individual identifiers.
- Demonstrate the viability of large-scale pseudonymised data repositories with the capability to perform automated and generic data linkage and acquisition.

Guiding principles

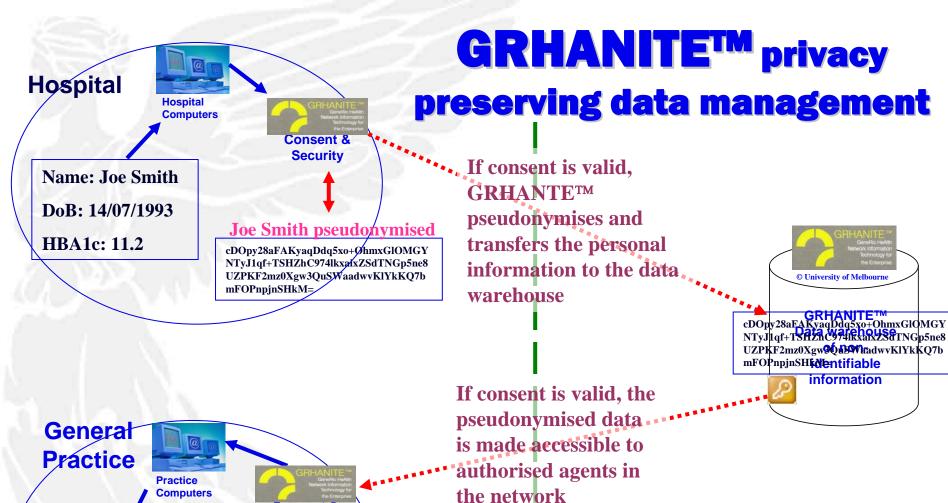
- Individual consent varies in extent and nature and over time;
- Data linkage requires:
 - accurate and reliable identification and authentication of individuals;
 - Capability to interface with many disparate technologies in a very generic manner;
- Automated communications require external connections, usually through corporate firewalls;
- Security must be inherent in the collection, linkage, aggregation, storage and analysis system; and
- Re-identification is often required e.g. clinical follow-up of abnormal tests or clinical trials safety monitoring

UPP 1. Anonymity & Pseudonymity

- Wherever it is lawful and practicable in the circumstances, agencies and organisations must give individuals the clear option of interacting by either:
 - 1. not identifying themselves; or
 - 2. identifying themselves with a pseudonym.
- * A pseudonym may be a name, term or combination of letters and numerals through which an individual can be addressed specifically



Pseudonymity and privacy preserving data management



Consent & Security

mFOPnpjnSHkM=

Joe Smith re-identifiable

cDOpy28aFAKyaqDdq5xo/OhmxGlOMGY

NTvJ1qf+TSHZhC974lkxaixZSdTNGp5ne8

UZPKF2mz0Xgw3QuSWaadwvKlYkKQ7b

Name: Joe Smith

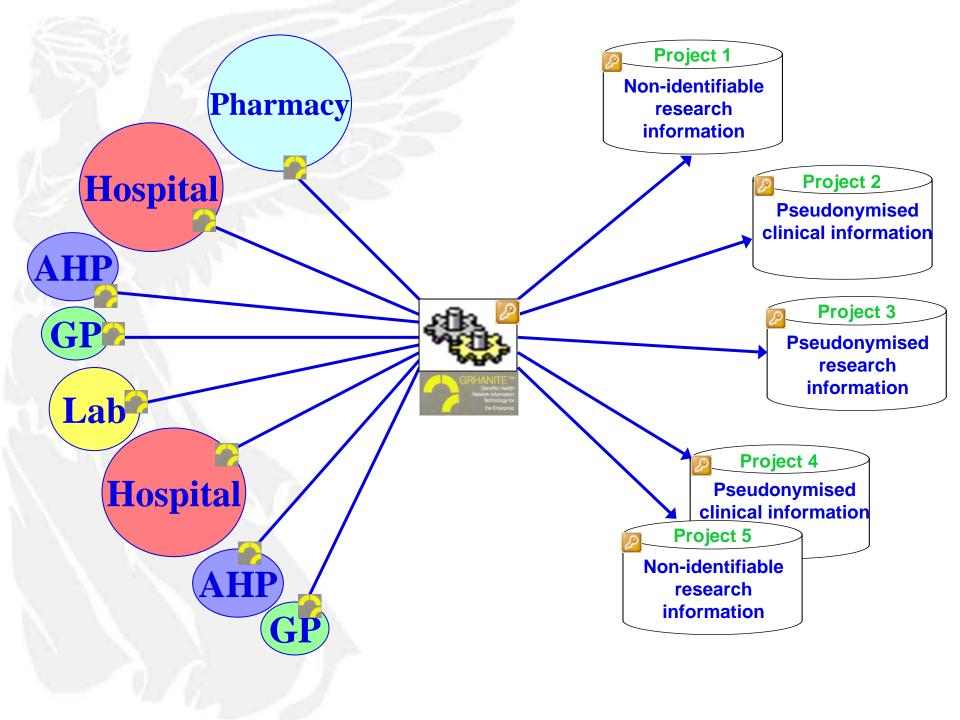
DoB: 14/07/1993

HBA1c: 11.2

1 Data only leaves a site with consent

2 All messages are pseudonymised

3 Re-identification possible only in the originating general practice/hospital



GRHANITETM features

- Connectivity to most major database technologies
- Integrated, flexible consent mechanisms
- Pseudonymisation prior to data extraction
- Secure project-by-project distribution of data
- Pseudonymised information storage
- Ethical and pseudonymised record linkage
- Tested technology
- Peer-reviewed methodology

GRHANITETM record linkage

- 1. For clinical data sharing
 - * A deterministic method used where only exact identifier matches are permitted
- 2. For research and audit applications
 - * A probabilistic technique utilising advanced phonetics, blocking and uniqueness weightings to give enhanced linkage performance
- * Both techniques use pseudonymised information and patient/client identifiers never leave the originating organisations.

Tested technology

- GRHANITE™ record linkage, using pseudonymisation techniques, has been tested in collaboration with BioGrid Australia (www.biogrid.org.au)
- 1. Sample: 45,000 records from 10 different data sources;
 - GRHANITETM probabilistic and hashed data linkage algorithm is as accurate and robust as existing techniques used by BioGrid;
 - Sensitivities and specificities of both techniques within 1%
- 2. Sample: 850,000 Victorians and 2006 Australian Census





Key Features

- 1. flexible consent processes during the secure collection of individual identifiers,
- accurate, reliable and confidential identification and re-identification of individuals for continuity of care, and
- 3. accurate, reliable and confidential linkage of pseudonymised data for research
- > safety, quality & continuity of care

Peer-reviewed methodology

- **■** GRHANITETM currently being used to extract data for national Chlamydia sentinel surveillance by Burnet Institute ACCESS project:
 - **★** 68 sites across Australia (30 general practices, 30 laboratories and 8 family planning centres),
 - * waiver of consent from the RACGP Ethics Committee.







Centre for Epidemiology and Population Health Research

> Home > Centre for Epidemiology and Population Health Research > Current CEPHR projects > The Australian Collaboration for Chlamydia Enhanced Sentinel Surveillance (ACCESS)

The Australian Collaboration for Chlamydia Enhanced Sentinel Surveillance (ACCESS)

Passive surveillance has indicated that chlamydia is a significant problem; however it has not provided a systematic means of measuring any changes in testing levels by specific target groups, or assessing time trends with any confidence. The ACCESS system will fill these gaps, and together with passive surveillance, give Australia a robust chlamydia surveillance system.

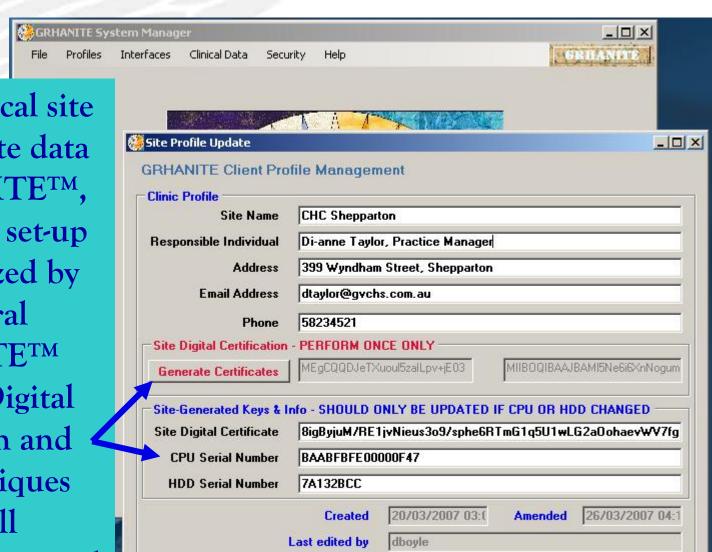


Click to zoom

GRHANITETM demonstration



© University of Melbourne

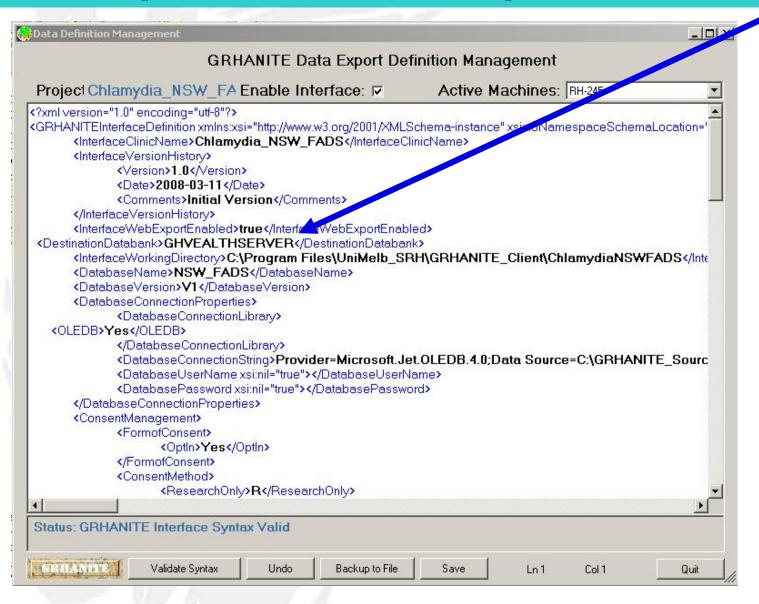


Save

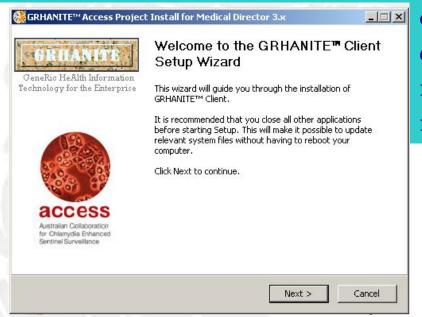
Quit

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

GRHANITETM can export de-identified data securely to any number of destinations. Each project has a 'definition' that holds information on what database to connect to, what data can be exported from that database, for which patients and under which conditions.



GRHANITETM Installer: Because there may be many clinical, audit or research uses of extracting de-identified data, GRHANITETM has a sophisticated system that allows the creation of installation USB Disks tailored to the requirements of each clinical site. This gives the capacity to implement GRHANITETM easily

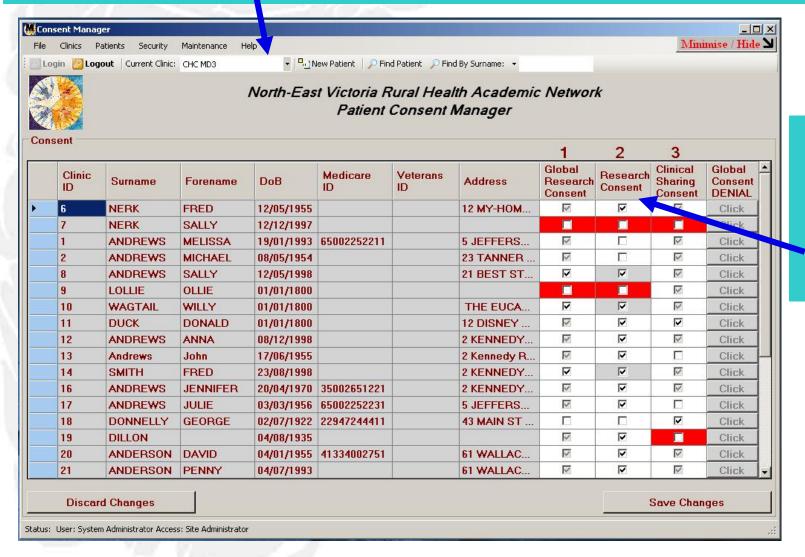


on a large scale across sites with differing database technologies, differing ethical requirements and differing data extraction requirements and rules.

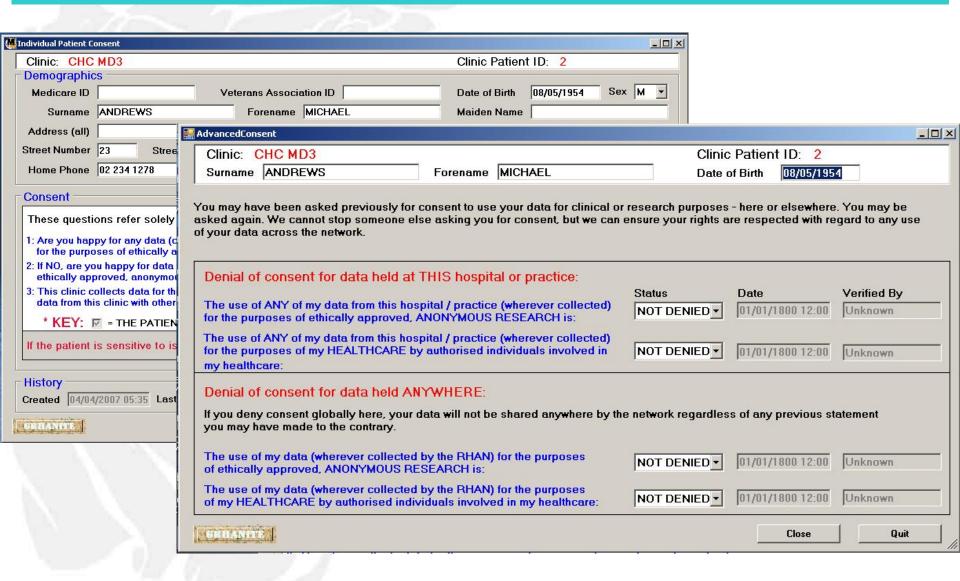


GRHANITETM normally operates without human intervention. The status of GRHANITETM and various management functions can be accessed from a system tray icon.

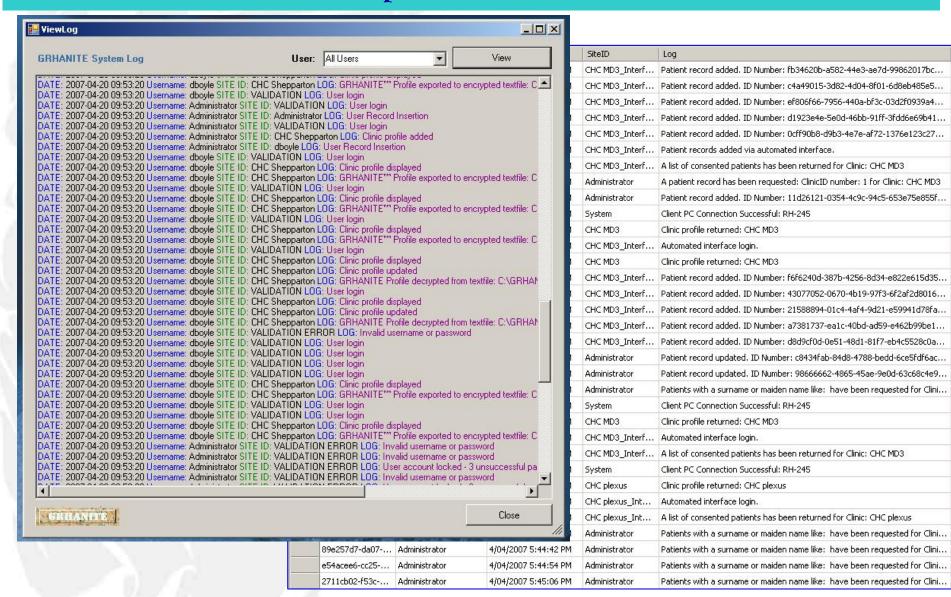
Authorized administrative or clinical staff can view and update consent via a consent management application. Where possible, this is done automatically 'behind the scenes' with GRHANITETM checking consent information that is commonly recorded within existing clinical applications.



Different types of consent can be managed Patients can grant or deny consent for the use of their data ANYWHERE across participating clinical sites. If consent is denied, ALL data is deleted from the central GRHANITETM Databank



All GRHANITETM activities are logged, and a full history of modifications to patient consent is maintained



GRHANITETM pseudonymises patient information BEFORE it leaves the health organization

<u> </u>	esults hessages hessages								
	Surname	Fname	DoB	AddrStreetNo	AddrStreet	AddrPCod			
1	VUzWhAn+u0RX0eEmJvSc0Q==		PyhgYR+pEeUEZqLmjgp37dS2GBTB6o5FzflhAv7DuoQ=	F7tS4qAgDGpqAQRrl4sdMg==	0Xbs8+oaBJvBE1Cf9elYKw==		DQTmpX		
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19	A5g0rRuxfnqZfndXpeF9rw==	V3uKd/jS				SkNhQA==	3+zKDIH		
20	r5B0JuscmsmsVtyT55NY5A==	Everything GRHANITETM does is encrypted GC,VQC BPf7Phcx yiwqQC+ viwqQC+ t1cQU9gi T1cQU9gi Everything GRHANITETM does is encrypted M8RSQ== M084SQ== M084SQ==							
21	36W/kDF/evHPpf9lLveUeA==								
22	PBzlwaXEC8gckroJzyl5JQ==								
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33	P6thlZP+aZII In4lknXG5nn==	III luRWhnF+aX5FtTuiDnHTA==	KH7/INZ+7lxD9x5xViSnn1SG/dn6F2Z+7H.Invvn3Fxn=	TfMNhllhH2FJ3Q2chARhsq==	II7TX15cz5mkiEfISnPClw==				

Every time data is exported, a log is generated explaining EXACTLY what has been exported and for whom

```
20070405094343_EXPORT_LOG.txt - Notepad
File Edit Format View Help
GRHANITE™ Data Export Report for data exported, 05/04/2007 09:43:43
GRHANITE™ is a trademark of the University of Melbourne School of Rural Health
site : CHC Shepparton
clinic : CHC MD3
* THE CONSENT PROCESS AT: CHC MD3 (CHC Shepparton)
* Data is only exported where explicit consent has been granted. Methods of
* obtaining consent vary. This clinic inteface is using the following method:
* OPT-IN consent is utilised - data is exported only if patients have opted-in
* Data is only exported if consent for the research use of data has been granted
The following data has been exported for consented patients:
                           : No patient-identifiable details extracted - dob is taken, but in encrypted form
Patient Demographics
                           : Diagnoses for consented patients
Patient Diagnoses
Detailed export description:
                   * TABLE : CM_PATIENT
* COMMENTS: Patient Demographics
                                     : No patient-identifiable details extracted - dob is taken, but in enci
                                 ENCRYPTED(reversible) DE-IDENTIFIED(cannot be recovered)
      Patient_UUID
                                                      False
      GENDER_CODE
                                 False
      MARITAL_STATUS_CODE
                                 False
                                                      False
      OCCUPATION ID
                                 True
                                                      False
      STATUS_CODE
                                 False
                                                      False
                                                      False
      DOB
                                 True
                                 False
                                                      False
      DECEASED_DATE
      CITY
                                 True
                                                      False
      POSTCODE
                                 False
                                                      False
      STAMP_CREATED_USER_ID
                                  False
                                                      False
      STAMP_CREATED_DATETIME
                                  False
                                                      False
      STAMP_USER_ID
                                  False
                                                      False
      STAMP_ACTION_CODE
                                  False
                                                      False
      STAMP_DATETIME
                                 False
                                                      False
      HEAD OF FAMILY ID Patient UUID True
* TABLE : MD_DIAGNOSIS
* COMMENTS: Patient Diagnoses
                                     : Diagnoses for consented patients
ENCRYPTED(reversible)
No.
      FIELD NAME
                                                      DE-IDENTIFIED(cannot be recovered)
      Patient_UUID
      DIAGNOSIS_ID
                                  False
                                                      False
      RESOURCE ID
                                  False
                                                      False
      DIAGNOSIS DATE
                                 False
                                                      False
      REASON
                                 False
                                                      False
      REASON CODE
                                 False
                                                      False
```

Data is encrypted prior to export using one of 10,000 randomly allocated encryption keys (RSA public key). The web server used to forward such data to its final destination cannot decrypt any data (decryption keys are only held by GRHANITE™ databanks and each databank has its own set of keys).

This protects data against unauthorized attack during transmission.

20070405094343 MD MEASURE.enc.txt - Notepad

File Edit Format View Help SITENAME:CHC Shepparton

2C16890AA66AFDB1C22565CA1D75573D0393E1979B3A8E483F37D15C7AA733EC771593311A48D13AA27F8CBD855EDDAE0BE63C93AD0B67B90B4CEFE38E2262 kZ7d6YGT7UFD3XGGm7ZthK0OLz]k1GBCYYT2yLC6ii3TNDgj9nOqoVkxgfUmH+PWQVBZcdh/oR5hqILc6ye2Qp+fTsKob+mGFG+/xh3]P2]HPDkYUmXdtYYBP44PZZ vxzja0m/qqk8c/+5sfka/HdygeznfeuovoHmirsq6yFMp3gaiHOba7p09iu04cRHL0hobxrHiw653T3rBjhzDsg2tvnjL/nxpvqqjHamveqdkrjnwH0h89ovypxBbz JzPE6Ys7wBcxyJoeTATsHwVBPi6wsMzfwo2jkLz1BPJ3mstBf5bqahzwq7OyqJ+5sc/nyOmmRpUQIphoQNTPrO1LOkVkQ3iYLRbGiQrcQkqtRBMCqqevjn6bnkE9a5 J2P4VIUn/HQE3Qu1Y/oow+hdsvb+ZGpWzwdgNwgxergetCsfZYhOpPHnzbqe9zqAPSMsjAeRAOoplldYDqjeypm7X1h/oRiefZdwYmghoGyus7Oh23NAEFECRXCBL55
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No person-identifiable information is extracted. Below is an example of the information that is used to link patients in the GRHANITETM Databank

	Patient_UUID	HashType	Hash							
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	09442fe8-e4b4-4653-a750-0184f39d5f44	5	INTGcWAgvq8m+hWQxxsuHKUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWQxxsuHKUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWQxxsuHKUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWQxxsuHKUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWQxxsuHKUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWQxxsuHKUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWQxxsuHKUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWqxxsuHkUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWqxxsuHkUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWqxxsuHkUhRtp4TT8aDBSEq4UgedmL9IUBvA9mDKZG4DfNqtWV/OX3BuGgdhEBOFv6PgU2zHpNCR1XMagvq8m+hWqxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx	/xaHi2JBsA7l0						
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24	09442fe8-e4b4-4653-a750-0184f39d5f44	8	WuWF65On43D7mYnUTa17EsQBjnUUgLDdJQ3cRowgheeOdhM7A3dlp27uI+8TliBX2Nf1dyPWUQOa7kr59nPfQnfHimwcPKUba	+M/YMCRhjQ						
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9	a1b51347-91ef-40ff-990b-043ba2a29421	8	rqz2XVN12uw6Wtg0nW1nI/LM1RsX0ntuUZGF+oqhBPZGQtiVpuFHFIYyUEhnBXt3ADxcUUgo/XIkIJWsW4i35dy+SYd8551toDT	7JsVyaSc=						
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	c2a9ac18-125b-423e-838c-05167a0e340e 5 3aqUId/ksBoNg7OLpJ1avqcsFJY869JRiiDoDbuL7LtH3HkCdzOjCWlF5kPvXBIqcNe3DErN/BL0aksjUBsUnzVbpS365dEjOKng7Nv									
9	c2a9ac18-125b-423e-838c-05167a0e340e	7	BWUFnW+qVQmxtyL92v gCgOBJ	kl5waruk=						
	c2a9ac18-125b-423e-838c-05167a0e340e	8	2QDF4deZTOcDtheWJPy This form of encryption is altrected	ĮVc19HfU≕						
	0aa28542-6831-4c88-a4cf-052c2697b100	5	SMCO0bdVMvme9F4/7wl VGziLvup	mJjAJyidTw=						
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	0aa28542-6831-4c88-a4cf-052c2697b100	8	Thursday And Angelong and San agreement	eRNxHg47jg=						
	1edaa12c-62ce-4d42-931f-05b8e06eab71	5	3R8U7gVRBjnfhybJcof6y protected against dictionary 1550jViq	Uyos=						

attack

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Typical GRHANITETM Databank data

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TYPE

HEIGHT

HEIGHT

MEASUREMENT

102

MEASUREMENT_DATETIME

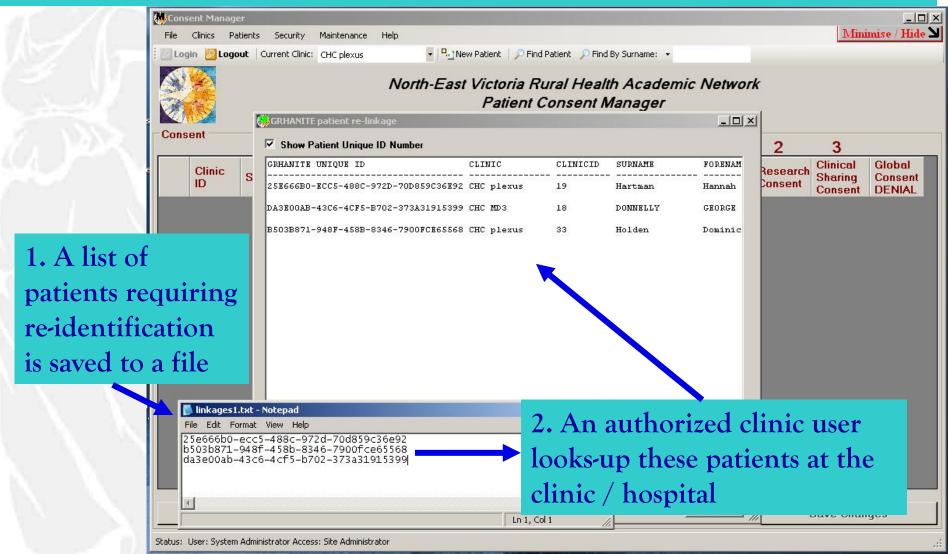
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	A7D44E22-5106-4F4B-9FC5-1ED131E36	6035	М	W9qT0EF	eQnpEyHddnumtn2kstZ5z0m56WPsKLcaou	KU=	zq0KpZecyNZ04JASt7Pm/Q==			4000	
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5	77CDF8BA-F361-42C4-ACB6-3C5AF27F0	036A	М	nAqZcJU z	6cKAb//wMkQLvgcvTPTNq+fssHSEqUbLo	aA8=	40bRrX8+PcsYBd+7Ax8Mhw==			4523	
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7	1BAAE2CE-5EF6-4061-950D-4C1BA686	5563F	F	mtmo3YiL5t n4vtjsS8fk+Orals81OehJrKvN0Gb4q1U= zqOKpZecyNZ(ZecyNZ04JASt	4JASt7Pm/Q== 4000			
3	E41D464D-C2FD-4EE1-9A2A-5CDD1A6BA3B2 M gha7ZKN1V faCHxKGloKR6x4g3GYA6FXRUu4lKMs9U= AgdQi/gog/C7vJ06wD5l2w=					512w==	1234				
	341A9327-4543-4E69-A25E-8D56	ome	data	has ad	ditional encryption be	-ca11	se it	has bee	n	4523	
0	Some data has additional encryption because it has been deemed sensitive. Date of Birth has been extracted here, but can only be decrypted for research use if a specific study requires age-related information						= 0	3000			
1							e, =ા	4523			
2							==	3256			
3											
4							=3	3000			
5	22D57F8D-F1E8-4605-B3DF-BDEB5UZF	-999E	F			AqdQJ/qog/C/VJUbWD5lZW==			1234		
6	AF2821A6-0868-46FA-819A-C342DEEF354C		F	hztApWnQNaJ839DyK7xRnWSB0uXHKUp7efLrW+LFnnQ= 40t		40bRrX8+PcsYBd+7Ax8Mhw==		4523			
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9	09700787-FB56-4308-8A01-DF31FB983F09		F	bguolbnjTqoEVJJfDj3C1EMZliky8Z+i0oCwrb+qo4l= A7xZIRQV/v7vvnK0RpYLC		pYLCQ==	3256				
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				30	341A9327-4543-4E69-A25E-8D56584264AC	DIAST		88		1-13 00:00:00	
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				32	341A9327-4543-4E69-A25E-8D56584264AC	DIAST		95	1.00.00.00.00.00	-24 00:00:00	
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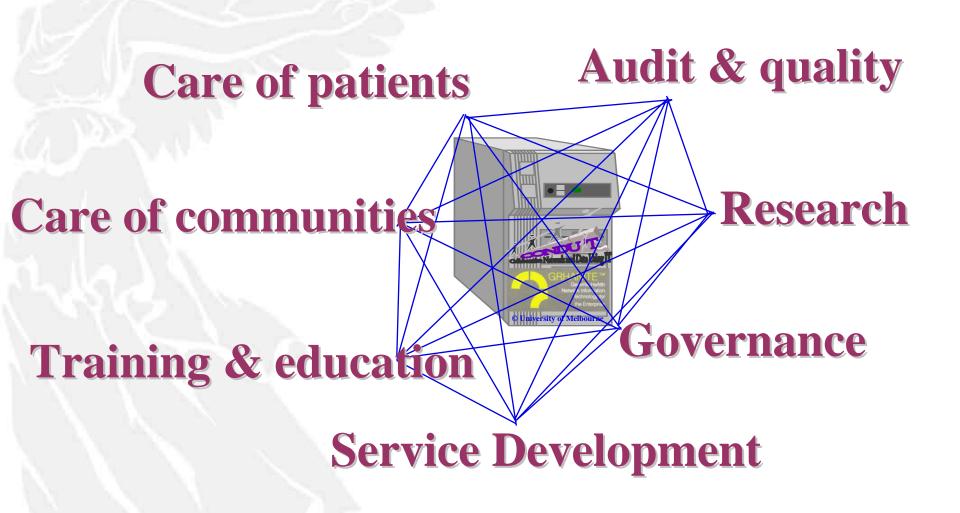
Patients CANNOT be identified in the GRHANITETM Databank. However, patient keys provided to authorized users at the originating clinical sites allow re-identification



Benefits

- Generic interfacing capability (no reliance on any individual standard or system)
- No collection or storage of person identifiers; (pseudonyms)
- No need for 3rd party key holders for record linkage;
- Strong technology and methodology arguments for opt-out or waiver of consent;
- Given the above, GRHANITE is a key enabling technology that:
 - Simplifies governance requirements
 - Facilitates clinical audit, research and clinical data sharing

Future & scope of GRHANITETM



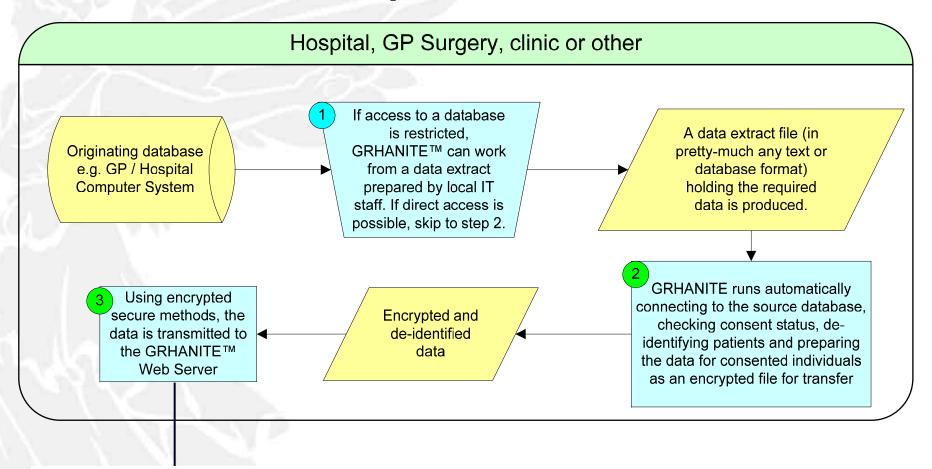


Any questions

www.conduit.unimelb.edu.au

www.grhanite.com

GRHANITE™ Operational Flowchart - 1



A web connection is required. Firewalls are not normally an issue

GRHANITE™ Operational Flowchart - 2

