



MIDAS

Medical Imaging Data Access and Sharing

A meeting of the SINAPSE (Scottish Imaging Network A Platform for Scientific Excellence) collaboration

e-Science Institute, Edinburgh

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Report Authors

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Abstract: MIDAS (Medical Imaging Data Access and Sharing) meeting was organised by SINAPSE with the aim of reviewing the status of medical imaging data transfer and sharing between the NHS and Higher Education. The meeting brought together representatives from both the NHS and the Universities. The current situation was reviewed in a series of talks in a plenary session, and in the following parallel sessions. The feedback of these parallel session was the starting point for the open discussion where a series of action points for future improvements were agreed.

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1. INTRODUCTION

1.1. OBJECTIVES

The main objectives of the meeting were to:

- Bring together key representatives from the National Health Service (NHS) and Higher Education Institutes (HEIs) interested in management of research imaging data in both domains and at the interface between the two sectors. The list of participants can be found in Appendix A.
- Review the current situation in Scotland including an overview of the National PACS (Picture Archive and Communications System) and local NHS-HE (Higher Education) solutions.
- Show the potential benefits of a more coordinated NHS-HE medical imaging data access policy.
- Add value by enhancing opportunities for use of medical imaging data in research in the NHS through the e-Health strategy.

This meeting provided a forum for discussing the needs and challenges for researchers working with medical imaging research and key metadata. The forum enabled a comprehensive discussion of the broad range of aspects involved in this: networks, data protection, ethics, etc. by bringing together representatives from both sectors - NHS and HEIs.

1.2. VENUE AND ORGANISATION

The meeting was organised by the SINAPSE (Scottish Imaging Network. A Platform for Scientific Excellence, www.sinapse.ac.uk) collaboration (IT and Image Analysis Subcommittee) and was held at the e-Science Institute (eSI), Edinburgh on the 18th of March 2009.

A plenary session in the morning was followed by three parallel sessions:

1. Data transfer (networking & security) presented by Mr Malcolm Teague, NHS-HE Co-ordinator JANET (UK).
2. Information Governance (data protection, ethics, auditing) presented by Ms Patricia Ruddy, Data Protection Officer to NHS National Services Scotland.
3. Data de-identification & data linking presented by Ms Alison Bell, Senior Data Analyst – HIC, Dundee.

The feedback from the parallel sessions initiated the final open discussion and resulting action points. A detailed agenda can be found in Appendix B.

2. SUMMARY OF ACTION POINTS

1. A **national minute of agreement** is required between NHS and HEIs to enable image data transfer between organisations.
2. The implementation at local level within the framework provided by a national minute of agreement should follow exemplar models adapted to local constraints.
3. There should be a research representative on the NHS PACS board to raise awareness of the need for collection and classification of research image data in the NHS.
4. A national “champion” is needed to promote improved image data management at the NHS-HE interface, opportunities for research with imaging in the NHS and a research culture.
5. Summarise the barriers to research use of imaging in the NHS and HEIs and potential solutions identified at the MIDAS meeting.
6. Existing local NHS-HE image data transfer solutions should be systematically evaluated to:
 - a. Provide a detailed description;
 - b. Evaluate strengths and weaknesses (focused meetings with key people with the correct knowledge to understand and implement solutions);
 - c. Obtain opinions of suitability of each model from practicing research imagers.
7. Use exemplar research questions to illustrate potential benefits of an improved image data management infrastructure (especially healthcare).
8. Feed the key points from MIDAS into CSO Consultation on Research Strategy (late April).

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3. MEETING NOTES

3.1. PLENARY SESSION

The morning plenary chaired by Prof Richard Lerski was devoted to defining the current situation, including the opportunities and problems.

3.1.1. Meeting Objectives by Dr. Jano van Hemert

The objectives of the meeting were presented as to:

- Bring together key people from NHS and HEIs.
- Review the current situation for image data management and sharing.
- Discuss the benefits of a more coordinated image data access.
- Have parallel discussion sessions addressing key topics to develop ways forward.

3.1.2. SINAPSE Project Overview by Prof. Joanna Wardlaw

The key points presented were that:

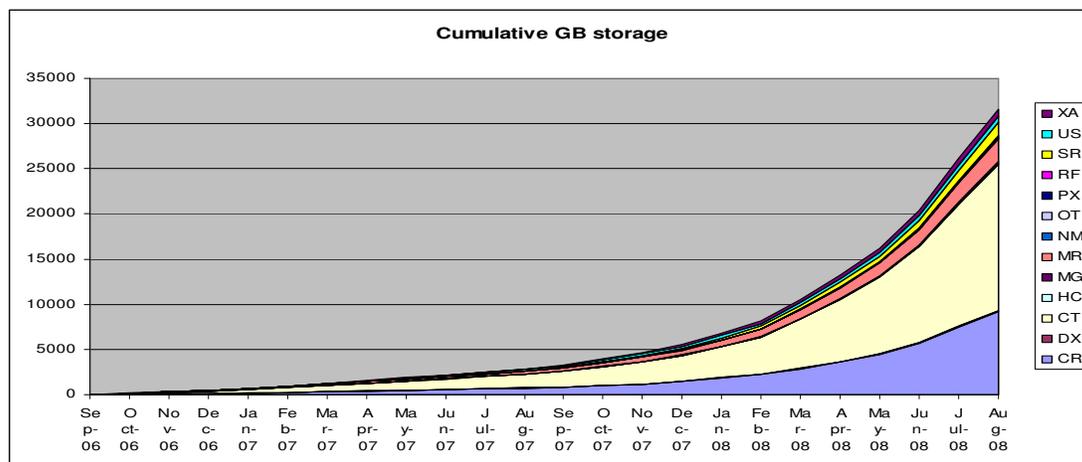
- The SINAPSE mission was for a single national imaging research laboratory across Scotland.
- There was a need for multicentre imaging studies as single centre studies are too small to provide reliable or generalisable results.
- There was a need to train imaging researchers to disseminate best research practices and ensure high quality research outputs.
- It was important to be able to transfer images from research patients acquired on research scanners into the NHS network for radiological reporting and as part of clinical management while at the same time retaining (or transferring in from the NHS) appropriate data for complex image processing in the university network.. This was highlighted using the example of the TMRC-funded acute stroke imaging project.
- There were examples of serious patient care issues that had occurred because mechanisms for viewing image data acquired on HEI scanners in the NHS were not available
- The SFC Brain Imaging Research Centre (SBIRC) in Edinburgh had achieved a streamlined mechanism for direct transfer from the research MR scanner hosted on the university network into the NHS PACS system for clinical reporting and viewing following establishment of a local minute of agreement between NHS Lothian and the University of Edinburgh, but this had taken many years and involved many interim and impractical solutions due to concerns amongst IT staff “on the ground” about interpretation of data protection rules.
- There was a need for a national solution for secure data transfer in both directions to avoid each centre having to go through the same process.

3.1.3. National PACS by Dr. Hamish McRitchie

The key points presented on the national PACS were:

- The original drivers and specification were concerned with service delivery, service improvement, economic and political strategy.
- There had been no research drivers at the time and hence research requirement had not been considered.
- Furthermore research interests were not represented on the PACS board and hence the needs or strategy for research was not considered.
- A description of National system requirements was given including that all radiology information systems require a CHI identifying number and that the PACS programme is part of the eHealth programme.
- The limitation of the National PACS was that it had been designed around routine service requirements, however the volume of data going in, in particular CT data, is much greater than expected (see Figure 1).
- There are measures to ration space usage under consideration including:
 - o Limit total data per health board (with no additional cost)
 - o Limit data per examination (with no additional cost)
 - o Lossy compression of data in central archive
 - o Data deletion after 7 years.
- To use the PACS for research would require:
 - o That the requirements were defined.
 - o The Scottish Government and Health service providers were persuaded that it was important and necessary.
 - o The cost of storage would need to be negotiated.
 - o The service would need to be negotiated.
 - o Key people were able to influence the product design to ensure that it met requirements.

Figure 1: Cumulative storage in the National PACS since implementation in September 2006. Note the largest most rapid expansion in space usage is with CT.



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3.1.4. Local Experience Setting up the NHS-UoE Networking in the Clinical Research Imaging Centre (CRIC) by Ms. Elizabeth McDowell

The key points highlighted were that:

- The development was based on experience and modelled on SBIRC strategy.
- There was a Minute of Understanding (MOU) between Lothian University Hospitals NHS Trust and University of Edinburgh signed for SBIRC and CRIC which outlined the IT objectives and responsibilities
- There were focussed meetings held on a regular basis.
- The resulting Network diagram is shown in Figure 2 (next page). The NHS will manage the firewall.
- Workflow (Figure 3, next page) developed together with key points:
 - o Every scanner booking must go through TRAK.
 - o TRAK holds NHS patient bookings to avoid clash.
 - o Part of all scans will be transferred back to the NHS for reporting.
- Data storage based on:
 - o The Edinburgh Compute and Data Facility (ECDF) <http://www.ecdf.ed.ac.uk/>
 - o Non-DICOM will be stored at the CRIC
 - o Local NHS server in CRIC; only selected images will go to the National PACS but current model requires radiologist to select key images so is not ergonomic.
- Challenges:
 - o Getting the right people at key meetings
 - o Different DICOM versions
 - o Anonymising data
 - o Double data entry: link to TRAK via ODBC (Open Database Connectivity)

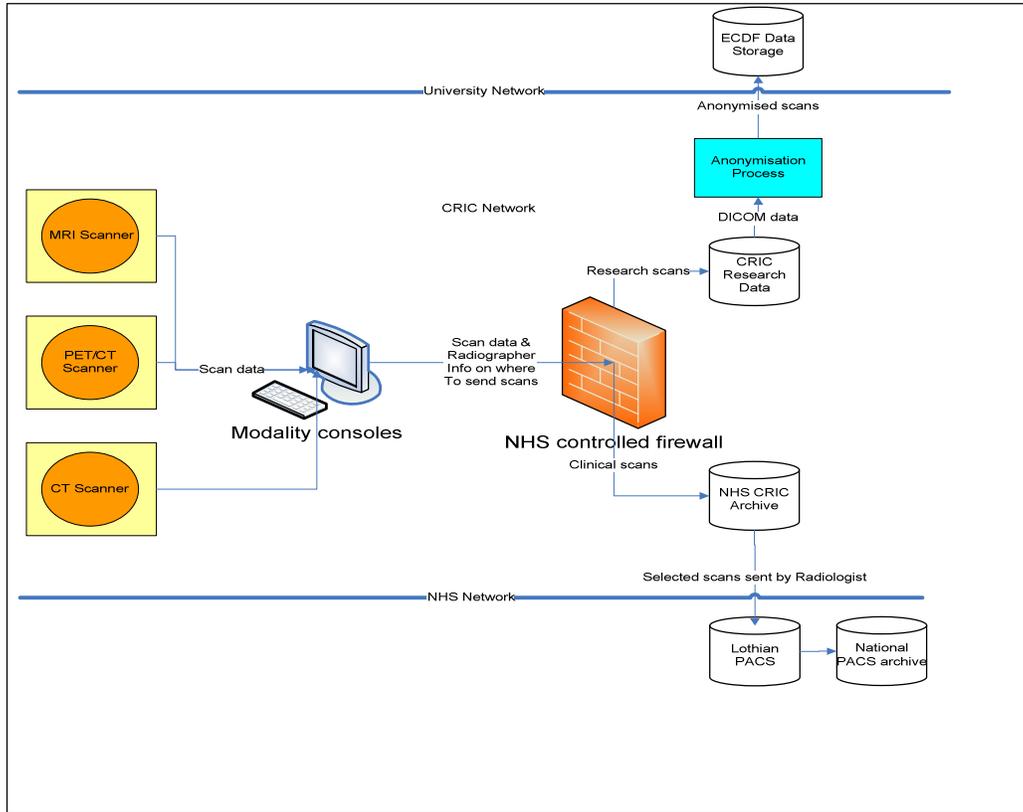
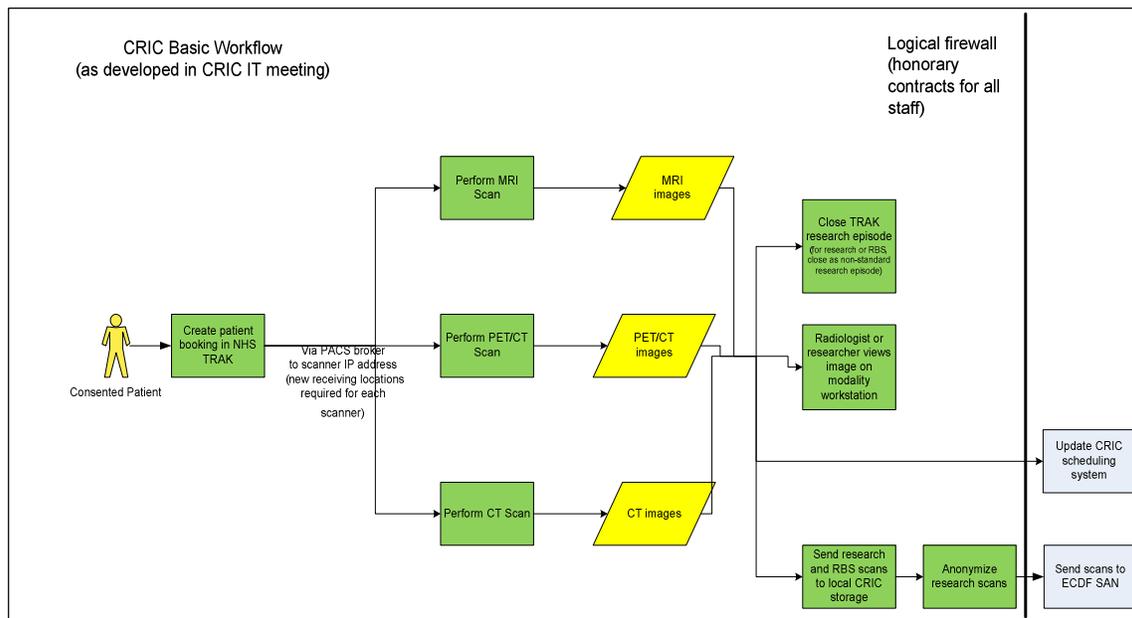


Figure 2: CRIC Network diagram (see above)

Figure 3: CRIC basic workflow (see below)



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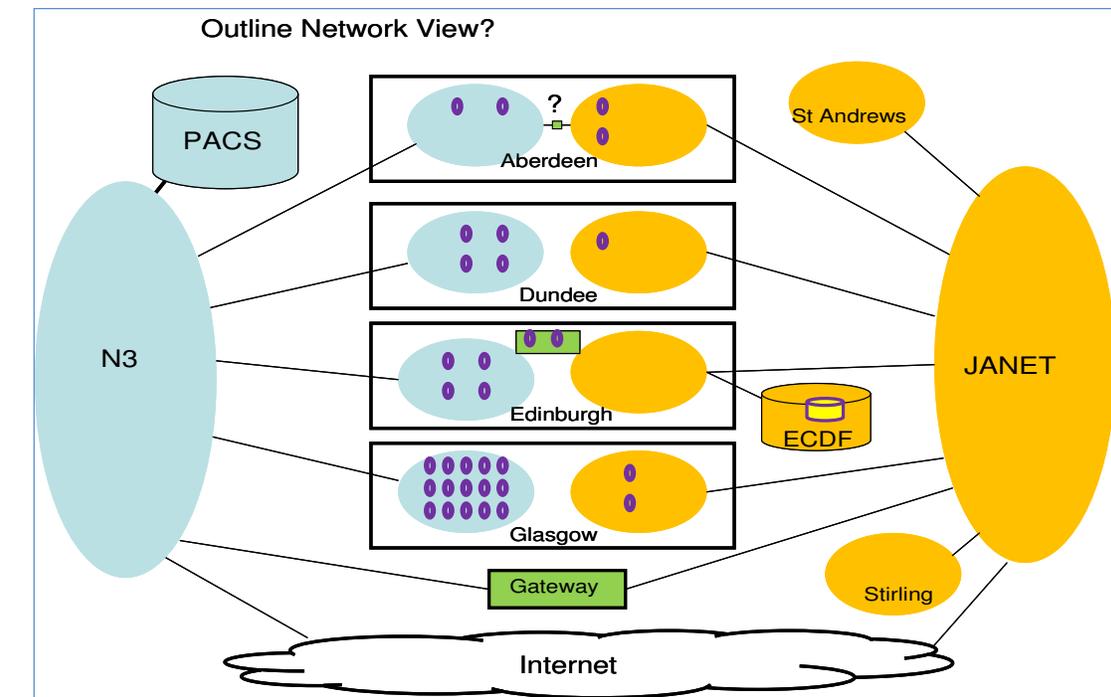
3.2. PARALLEL SESSIONS

3.2.1. Data Transfer (Networking and Security) by Mr. Malcolm Teague

This presentation discussed the following points

- The different connectivity situations in the Universities were shown (Figure 4).
- Described NHS-HE connectivity project for UK Gateway covering the:
 - o Objectives.
 - o Physical deployment.
 - o Next steps.
- Requirements for NHS-HE connectivity:
 - o Imaging data acquired in HE scanners available to NHS (pulling & pushing).
 - o Imaging data captured on NHS scanners available to research (flagged, appropriately). Covers systems in SINAPSE centres and rest of NHS.
 - o Imaging data for research to provide efficient analysis in a highly controlled environment.
 - o Automation to reduce NHS burden
 - o Workflow (can be complicated, quality assurance needs to be considered)
 - o For flagging of data on scanners the scanner providers need to be on board.
 - o Standards for coding are important e.g. snomed.
 - o Data travel should be kept to a minimum conducive with an effective solution.

Figure 4: NHS-HE Connectivity



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- Issues for NHS-HE connectivity:
 - Later need for different data.
 - NHS security requirements (NHS Boards are legal entities)
 - PACS constraints (space, lack of colour).
 - Making research data public.
 - Snomed etc. not universally used.

- Local models (option appraisal): Aberdeen, Edinburgh, Dundee and Glasgow, reflecting different hosting of research scanners on NHS or university networks (see Figure 4) and consequent barriers to transfer into the NHS for reporting (if in the University) or analysis of data (if in the NHS) – each has strengths and weaknesses but provide a core of models to evaluate and consider for potential wider implementation or further development.

- Crucial to avoid reinventing the wheel in each centre – a National agreement on data sharing is essential.

- One option to consider is the potential use of National PACS for research data transfer between acquisition and analysis site; to store (limited) appropriate research data; because all research images need a report and once implemented, PACS provides the only reporting mechanism. This requires research to be part of the PACS future agenda e.g initially by asking for a research representation to be included in the PACS board.

- Parallel requirement for improved and centralised research image data storage and compute analysis capacity in the Universities – a “SINAPSE PACS” is under development.

- Involvement of stakeholders:
 - NHS PACS Board
 - NHS R&D officers
 - NSS IT security
 - NHS Boards
 - eScience people
 - JISC/JANET
 - CSO

 - Department of Health (Research capability program)

3.2.2. Data De-Identification and Data Linking by Ms. Alison Bell

This presentation and discussion covered:

- Requirement for a generic (national) standard and agreed process of anonymisation.
 - o A. McCallum stated such standards exist in Lothian.
- Need for definition of acceptable level of anonymisation:
- A measure of the anonymisation of a data set, i.e. identify a person in X people.
- Possible solutions:
 - o Keep the identifiable data on a NHS server. Anonymise and encrypt it once it leaves NHS
 - o Key people together (DP, & researchers) to agree the anonymisation solution – either at a national level or start at a health board level.

3.2.3. Information Governance by Ms. Patricia Ruddy

This presentation and discussion covered an overview of the strands of information governance which include:

- o Confidentiality and the Caldicott requirements
- o Data protection
- o Freedom of information
- o Information security (access control)
- o Records Management
- And a discussion on some of the information governance challenges around research uses of patient data, including the matter of consent; and the important considerations associated with data sharing.
 - o
- Discussion/ feedback:
 - o Privacy (Data Protection)
 - o Data security, including different policy/standards between different organisations
 - o Secondary uses of clinical data: both research and teaching
 - o Information should be shared but under what conditions?
 - o National policy
 - Build on work already done (SBIRC/CRIC MoU, TMRC, etc)
 - Health Boards (teaching hospitals)
 - PACS
 - o A champion for our cause (CSO...).
 - o Make use of the eHealth strategy document.

3.3. AFTERNOON PLENARY SESSION

The afternoon plenary session was chaired by Dr. Jano van Hemert and encompassed an open discussion and the drawing up of a roadmap.

3.3.1. Open Discussion

The final debate covered the following points:

- A National level agreement for HEI-NHS data movement is crucial.
- The major barrier to implementation of a sensible NHS-HE image data link in centres that do not have this already is reluctance through misunderstanding and fear of data protection regulations at local IT level.
- 'Bottom-up' approach needed:
 - o Review local solutions to identify variation and viability
 - Assess for scalability
 - Visits between centres may help, including key agreed IT people.
 - Describe each model using S.W.O.T. analysis.
 - Option appraisal needed to avoid reinventing the wheel.
 - o There was unanimous agreement that locally-derived information to inform a national strategy was essential
- 'Top-down' approach also required:
 - o Identify a Champion (CSO)
 - o Feed into CSO Research Strategy Consultation (end of April)
 - o Promote appointment of research representative onto PACS board (SINAPSE can supply).
- Parallel approach required.
 - o Focused meetings with key practical people to understand solutions and to link in with option appraisals.
 - o Information governance to be involved in appraisal.
 - o Identify research questions that allow us to show impact of improvements, especially healthcare.
 - o Work with manufacturers to address issues related to information governance.

4. APPENDIX A: PARTICIPANTS

1. Dr Paul Armitage (SINAPSE IT committee, University of Edinburgh)
2. Ms Allison Bell (Senior Data Analyst – HIC, Dundee)
3. Dr David Brennan (SINAPSE IT committee, Glasgow)
4. Mr George Cameron (Biomedical Imaging Centre, Aberdeen)
5. Dr Ian Cavin (Medical Physics, NHS Tayside)
6. Mr Peter Clinch (IT Officer Medical Physics, University of Dundee)
7. Ms Mandy Crighton (e-Health Programme Manager, NHS Lothian)
8. Dr Janet De Wilde (SINAPSE Coordinator)
9. Mr Stuart Docherty (CMVM, University of Edinburgh)
10. Ms Marshall Dozier (Academic Liaison Director, MVM and Senior Liaison Librarian, Medicine Main Library, University of Edinburgh)
11. Dr Andrew Farrall (SBIRC, DCN, University of Edinburgh)
12. Ms Susan Graham (Records Manager, University of Edinburgh)
13. Prof Donald Hadley (SINAPSE, Institute of Neurological Sciences Glasgow)
14. Prof Richard Lerski (SINAPSE IT committee, University of Dundee)
15. Dr Duncan Martin (SBIRC, University of Edinburgh)
16. Dr Alison McCallum (Director of Public Health & Public Policy NHS Lothian, Caldicott Guardian)
17. Ms Elizabeth McDowell (WTCRF, University of Edinburgh)
18. Mrs Mags McGeever (DCC Edinburgh)
19. Dr Hamish McRitchie (Consultant Radiologist, NHS Borders)
20. Dr Alison Murray (SINAPSE Deputy Director, University of Aberdeen)
21. Mrs Yvonne Oliver (Division of Radiography(SHSC), Glasgow Caledonian University)
22. Mr Jeb Palmer (DCN, University of Edinburgh)
23. Dr Ian Piper (Glasgow, Dept. Clinical Physics)
24. Ms Alison Povall (DIT Relationship Manager, CLSM, University of Aberdeen).
25. Dr John Reid (Divisional Medical Director, NHS Forth Valley)
26. Dr David Rodriguez Gonzalez (SINAPSE IT committee, NeSC, University of Edinburgh)
27. Ms Patricia Ruddy (Data Protection Officer, NHS National Services Scotland)
28. Dr Roger Staff (SINAPSE IT committee, University of Aberdeen)
29. Ms Sharon Stewart (Glasgow CU, Division of Radiography)
30. Mr Malcolm Teague (NHS-HE Co-ordinator JANET(UK))
31. Dr Jano van Hemert (SINAPSE IT committee, NeSC, University of Edinburgh)
32. Dr Gordon Waiter (SINAPSE IT committee, University of Aberdeen)
33. Prof Joanna Wardlaw (SINAPSE Director, University of Edinburgh)
34. Dr Charles Weller (Business Development Manager, CRC Dundee)
35. Dr Angus Whyte (DCC, Edinburgh)
36. Mrs Alison Will (Information Governance Team, NHS Grampian)

5. APPENDIX B: AGENDA

9:00 – 9:30	Registration Coffee/tea – Chapterhouse		
PLENARY SESSION			
Chair Prof Richard Lerski Dundee Newhaven Lecture Theatre			
9:30 - 9:45	Introduction and Objectives of the meeting - Dr Jano van Hemert		
9:45-10:00	SINAPSE Project Overview - Prof Joanna Wardlaw		
10:00-10:30	Keynote: National PACS/ scene setting - Dr Hamish McRitchie		
10:30–11:00	Case study: Local Experience setting up the NHS-UoE networking in the new Clinical Research Imaging Centre (CRIC) - Ms Elizabeth McDowell		
11:00–11:30	Coffee/tea break – Chapterhouse		
PARALLEL DISCUSSION SESSIONS			
11:30–13:00	1. Data transfer Mr Malcolm Teague Break out Area	2. Information Governance Ms Patricia Ruddy Newhaven Room	3. Data de-identification and data linking Ms Allison Bell Cramond Room
13:00–14:00	Lunch – Chapterhouse		
SETTING THE FUTURE SESSIONS			
Chair Dr Jano van Hemert– Newhaven Lecture Theatre			
14:00–15:15	Open Discussion		
15:15–15:30	Conclusions & Roadmap		