

Cerebral Autoregulation Research Network (CARNet)

Initial meeting, 6th July 2011, Imperial College, London

Programme:

1. Introduction & Relevant Background – Chair: David M Simpson
 - 13:00-13:15 Opening Welcome & Review of Objectives
David M Simpson (University of Southampton)
 - 13:15-13:30 Experience of the *BrainIT* group
Ian Piper (Southern General Hospital, Glasgow)
 - 13:30-13:50 The *VPH Share* project
Keith McCormack (Sheffield Teaching Hospitals Trust / University of Sheffield)
 - 13:50-14:10 The *CARMEN* project experience
Steve Hobson (University of York)
 - 14:10-14:30 *PhysioNet*
Thomas Heldt (MIT)
 - 14:30-15:00 Coffee break
2. Open Forum Discussion of the SONAR initiative – Chair: Ian Piper
 - 15:00-15:20 Key elements of the proposal
Ian Piper (Southern General Hospital, Glasgow)
 - 15.20-16:00 Working group discussions
 - 16:00-16:15 Plenary feedback from group chairs
 - 16:15-16:30 Open discussion and consolidated proposal
3. Election of Steering Committee - Chair: Tony Birch (Southampton General Hospital)
 - 16:30-17:00 Elections
4. The way forward – Chair: RB Panerai
 - 17:00-17:20 Proposal of a 'boot-strapping' collaborative project
RB Panerai (University of Leicester)
 - 17:20-17:40 Open discussion
5. Action Points and concluding remarks
 - 17:40-18:00 The SONAR agenda and future meetings
David Simpson (University of Southampton)

1 Introduction

David Simpson welcomed all participants and outlined objectives and plans for the meeting. Objectives were

- For the network
 - Advance autoregulation research
 - Build a community to share data and methods
- For today
 - Establish network and core activities

- Nominations / Elections
- Name for the network
- Identify issues and ground rules
- Identify path forward
- Website

Presentations were then provided by invited speakers from network/data-sharing groups working in other fields to provide insight into options, challenges and ways forward for CARNet.

1.1 Experience of the BrainIT group

The general feedback and questions were about funding. The project has gained a number of grants from the EC in different calls (FP5 and FP7), but there had been a two year gap between these rounds. The delegates from the USA raised a point about NIH funding: that they require an overriding scientific question and that the NIH does not, as the EC has in the past, fund general network building exercises. This may impact how funding is approached in different countries.

1.2 The VPH Share project

The general feeling was that it will be a very good project and is very well funded (£14 million) but that it is 18 months away from being usable.

1.3 The CARMEN project experience

The discussion on this talk focused more on infrastructure and technical questions. The project has about 150 active users who all have the ability to upload their own data and “services” (tools and analysis techniques). The only real requirement on data or service type is specifying the meta-data that will describe accurately what is being uploaded to the project. Regarding security, the uploading user has control over the public/private visibility of all content. Any tool chain can be used with the project, whether it is proprietary or not, as there already is functionality built in for this scenario.

1.4 PhysioNet

Any storage project is set up in five stages and usually ends in a publicly accessible dataset. Most of the questions resolved around security and intellectual property rights. Firstly, users can still work on the dataset and data description after it has been moved to the public stage but there can also be more granular restrictions placed on the projects so a private section could be created in the fourth stage. PhysioNet isn't able to track down anyone who violates their terms of service for using the data, though if they do catch anyone they can be permanently banned from using the service. To use any of the hosted data in research the original PhysioNet paper should be cited. Hard numbers on publications that have used the data are hard to gauge because not all users cite the original paper, however there are about 1000 hits per day on the

website. Finally, artefact removal in the system is different for each data project so some are cleaned and annotated and others are raw and noisy (but still can be annotated).

2 Open forum discussion

2.1 Data Sharing/Ethics Issues

Why Share?

- Is “Reducing Patient Numbers” necessarily important? Perhaps it should be emphasised that the Network would INCREASE patient recruitment through collaboration?
- Suggested adding “Accelerate Research” as an aim in the mission statement.
- Some discussion about “open” data access, as is often mandated by Research Funding bodies. What are plans for “Dissemination” of network results? Will there be cost implications for this and is this also funding dependent?

Can We Share?

- There was a difference of opinion on whether anonymisation can be enough for data sharing without specific/additional consent also being obtained (see ‘Report of the Research Database Working Group of the NIGB’, September 2010 - <http://www.nigb.nhs.uk/pubs/RDreport.pdf>). There was a feeling that over-detailed consent forms would be a burden on the relatives/carers (especially at stressful times), and may impede recruitment.
- Anonymization can be challenging and is open to question: the point was raised that with MRI images there is the potential for reconstruction of a patient’s face, thus removing ‘anonymity’. However software was available for removing this information.
- The point was raised that consent must be obtained and recognised both in the country in which assent/consent was obtained but also in the countries in which the data would be analysed.

How to Share?

- Agreement there should be a combination of “Open Access” and Mixed Model (some open, some limited – depending on data-set, consent, etc.) access.
- Access to the original provider of the data should be possible. There was agreement that we must “understand the data” so we need access to centres and PIs who contributed the data – we need to be able to trust the data by credibility of the centre/PI.

2.2 Data Definition Issues

- It was pointed out that due to the nature of autoregulation research being so diverse it is very unlikely that a single definition of what data to include could be arrived at. Consequently it was felt that it would be more appropriate to upload a data in its original format, together with the necessary meta-data to describe it.
- Need to specify meta-data for each condition or protocol stage.
- Agreement that the meta-data system should cope with prospective studies so should have a meta-data field for “Study/Project”.
- Must have raw data but would also accept data that has been cleaned or processed as long as meta-data can describe the cleaning/processing steps.
- The point was raised that uncalibrated data could be accepted provided that meta-data describing either a calibration or that data should be used for “trend-analysis” only.
- IP asked Steve Hobson (Carmen Project) if those using their software tool (SDI?) which supported creation of meta-data was actually used by the local users to design their own meta-data fields or was it used only by specialists who assisted centres in designing local data meta-data fields? SH indicated he would find out.
- Data quality was raised as an important issue and there was agreement that some form of “feed-back form” should be used by data users to comment on the data quality.
- Agreed that the next step should be a survey of what data people already have.

2.3 Publication/Data Access Issues

- There was discussion covering all three workshop areas.
- In our mission statement there should also be a statement about “Promoting Collaboration”.

3 Election

Following the agreement to set up the network and the choice of the new name (CARNet), the following were elected to form the Steering Committee:

Chairman: David Simpson (DS)

Secretary: Stephen Payne (SJP)

Funding coordinator: Vera Novak (VN)

Technical coordinator: Martin Shaw (MS)

Projects coordinator: Jurgen Claassen (JC)

Ordinary member: Erik Gommer (EG)

4 The way forward

Ronney Panerai presented a proposal for a 'boot-strapping' collaborative project, which would focus CARNet activities on a specific project and start off collaboration. This project would focus on comparison of different experimental protocols and analysis methods, based on a large dataset. There is a need to find out what resources (data and analysis techniques) are available and it was agreed that the best way to do that is through a group wide email. This would identify what data members believe to be suitable for the boot strapping project. The initial data should only be used in this specific bootstrapping project and all users would need to sign an agreement to this effect. It must be stressed at this point that no data would be going into a central database.

The collation of the available data descriptions should be published for the group to see. For the initial project the format the data is in should not be an issue. The question of willingness to analyse the data from the project should also be asked in the group email. The project aims to build the CARNet community, in addition to addressing the main scientific question of the study.

There need to be well laid out ground rules for the group and the beginnings of these should be the creation of a mission statement for the group.

Send e-mail to enquire about the general interests of the members to help generate other projects and collaborations in the future.

Funding could be split into two paths, firstly for the bootstrapping project, then secondly for network building and sustainability. In general, funding should be as inclusive as possible for the members of the network. However, more local sources of funding may be available, and it was agreed that CARNet itself would have to be a multi-funded entity. It would also help to support applications for more (locally) restricted funding of members..

There is a need for a website for the group so that information (from this meeting and other more general group documentation) can be disseminated. There was also a suggestion to turn the site into a repository of knowledge on the subject of cerebral haemodynamics via a wiki.

A suggestion for the next main meeting of the group could be a satellite meeting at the ESNCH (European Society of Neurosonology and Cerebral Haemodynamics) which is to be held between the 19th and 21st of May 2012 in Venice. The suggestion of video-/tele-conferencing the next meeting was made, which will also need further investigation.

Action Points

1. Matthias Reinhard should be asked to contact the organisers of the ESNCH about a satellite meeting for CARNet in Venice next year.
2. Stephen Payne should email the group about starting to collect the information required for the initial project.
3. Vera Novak should email the group with initial suggestions about funding opportunities and asking for more.
4. David Simpson should create the initial mission statement for the group.
5. Martin Shaw should create an initial website for the group.

SJP 24th August 2011