



RIN Consultative Group for Life Sciences and Medicine NOTE FROM THE FOURTH MEETING – 25 APRIL 2007

Action points in italics

Present:

John Coggins (Chair) (University of Glasgow)
George Banting (University of Bristol)
Stéphane Goldstein (RIN)
Kevin Hiom (MRC Lab of Molecular Biology)
Michael Jubb (RIN)
Howard Meltzer (University of Leicester)
Oliver de Peyer (MRC National Institute for Medical Research)
David Shotton (University of Oxford)
Vince Smith (Natural History Museum)
Patricia Spoor (University of Leeds)

Apologies:

Stephen Kennedy (University of Oxford)
Emily Quinton (University of Birmingham)
Nicola Seare (Leicestershire, Northamptonshire and Rutland Strategic Health Authority)

1. **Minutes of the meeting of 28 November 2006 and welcome** (*paper RIN/LSM/07/01*)

John Coggins welcomed the newest member, Howard Meltzer, who, as an epidemiologist, is providing one of the key and hitherto missing areas of expertise on the Group.

The minutes were approved.

2. **Matters arising**

□ **Membership:** although epidemiology is now represented on the Group, there is still need to recruit additional members, in particular to cover clinical research perspectives – see also below.

□ **Workshop on unique identifiers:** groundwork to prepare for this has been delayed. Given available resources, it was agreed that the best approach to this event could be to offer RIN's services to an individual, such as [Andy Powell](#) (Head of Development at the [Eduserv Foundation](#)), who might be enthusiastic about pursuing the agenda through a workshop; Vince Smith and David Shotton would be happy to suggest further speakers. Organisations such as the Natural History Museum or the Linnean Society might be willing to host the workshop. The size of the audience would depend on the focus of the meeting; an approach based on technical concerns could significantly reduce the level of interest. This suggests that there may be a case for splitting the meeting in two to attract distinct audiences (e.g. an expert seminar followed by a broader workshop). Andy Powell should be able to help with identifying different groups' expectations from such a meeting.

□ **Vince Smith** to circulate an outline suggested scope for the workshop, with a view to hold this during the autumn.

□ **RIN** to approach Andy Powell on the basis of the Group's suggestion.

□ **Freedom of information:** the response to the RIN's mini-consultation had been disappointing. Nevertheless, the LIS Consultative Group is keen to pursue the idea of a workshop, probably to take place in early 2008.

□ *RIN to keep the Group abreast of developments regarding this workshop.*

3. What role for the RIN with regard to clinical research? (paper RIN/LSM/07/02)

Addressing this question is a big challenge for the RIN.

At the outset, there is an underlying issue about the very definition of clinical research (e.g. does it include audit and surveillance studies, which are governed by distinct rules and regulation?). There are different perspectives also depending on whether data relates to individuals that are alive or dead.

How might RIN approach any activity relating to clinical, bearing in mind the Advisory Board's keenness to encourage the organisation's involvement with research information in an NHS setting? When dealing with such issues, there is a danger in defining a remit too broadly. Moreover, there is recognition that, within the Consultative Group, there are very different perspectives on the use of research data, reflecting the division in membership between basic/biological and more applied perspectives; can such differences in themselves be a basis for a useful confrontation of views?

There are major challenges relating to access and the different levels anonymisation or pseudonymisation of data, and the nature of consent associated with this. In areas other than clinical research, the RIN has a reasonably clear view about the sort of evidence that it can gather in its observatory role, with a view to drawing out lessons from such evidence. However, given the ethical and legal constraints that apply to clinical research, identifying the key issues and associated key players / relationships within a healthcare setting is more problematic.

One possible line of investigation might be to look at licensing for the publication of human-derived data in the context of obtaining informed consent. Another major issue is the quality of the data that is being accessed.

Could RIN have a facilitating role with regard to such issues?

The Group discussed the possibility of organising a RIN-sponsored conference on access to clinical research data. Input could be sought from the [Science Commons](#) project. Associated with such an event might be organisations such as the MRC, Wellcome Trust, Academy of Medical Sciences, and initiatives such as [UK Biobank](#), which are all contributing to shape the environment in which the biomedical data agenda is developing. Exploring the scale of this agenda might be a useful foundation activity.

The Wellcome Trust is the only medical research charity that the RIN has had any dealings with. The Group suggested that Cancer Research UK is the one other major charity that the RIN might usefully interface with.

In the meantime, the proposed meeting with a selection of medical librarians and others should help the RIN to scope out some of the key challenges and problems regarding clinical research information – although not necessarily from a data perspective.

The question about how the RIN should equip itself to best seek

□ *Howard Meltzer to circulate background documentation on current frameworks regarding the use of data in different circumstances.*

□ *RIN to liaise with relevant partners and consider the usefulness of organising a conference along the lines suggested by the Group.*

□ *RIN to press ahead with arrangements to organise a meeting with medical librarians and others, if possible before the summer break.*

advice on such issues (notably through the setting up of expert panels or specialist groups) was left open for the time being.

4. Proposed workshop for life sciences and medical learned societies (oral)

The series of meetings with learned and professional societies is important in relation to the development of the RIN's interface with the research community. An initial list of relevant organisations covering the life sciences had been circulated to the Group earlier in the year, and members' views were further solicited about which societies to approach – bearing in mind the split between the research-centred ones and the practice-led medical Royal Colleges.

Members variously suggested the Society for Endocrinology, the Company of Biologists and the Linnean Society, along with the Biosciences Federation, which had already expressed an interest in taking part. The Academy of Medical Sciences was also suggested, but following an earlier approach from the RIN, it had indicated that the initiative does not fall within its area of interest. John Coggins was awaiting a response from the Royal College of Physicians and Surgeons of Glasgow, but acknowledged that the medical Royal Colleges are mostly not very focused on research issues.

The Group reflected on the usefulness of adding a clinical trials and public health perspective, perhaps with involvement from the [International Conference on Harmonisation](#).

□ *RIN to continue with preparations for the life sciences learned society workshop, taking stock of the Group's advice.*

5. Taking forward recent RIN reports: researchers and discovery services; and researchers' use of library services (paper RIN/LSM/07/03)

These two reports are important contributions to the development of the evidence base that RIN is gathering. An important challenge now is to act on the evidence. Whilst it is relatively easier to take forward findings with the LIS community, it is more difficult to do so with researchers.

Members concurred that the researchers' views reflected in both reports are indeed familiar. The group agreed about the challenge of the 'last mile', i.e. securing access to relevant material, including metadata. There are also different perspectives, across disciplines, to searching for information – e.g. in evidence-based medicine, searching is highly integrated in the research process. Much valuable data is also hidden or difficult to locate within online Government reports.

The reports highlight differences in views also between users (researchers) and providers (librarians); the challenge is to reconcile these two views for the benefit of research. In this context, training (including the less formal sort), tailored to users' needs, is a key factor. At the same time, there is a growing case for providing tools that are sufficiently intuitive to require little or no training.

With regard to backfiles, members agreed their use is very field-specific, with some communities having little demand for them. The role of repositories is relevant here, although members did not necessarily agree with the idea of institutional repositories.

Finally, members highlighted the problem of fabricated or

sloppy data.

6. Forthcoming RIN projects (paper RIN/LSM/07/04)

Members noted the RIN's intention of commissioning a series of case studies later in the year.

The Group was particularly interested in the study on costs/income flows in the scholarly communications process; this was recognised as a very important piece of work, in terms of the possible implications for funding policy.

☐ *All to suggest possible candidate areas for case studies.*

7. Communications issues (oral)

Members noted the significant development of the website since the last meeting. .

☐ *All to provide views on how the website might be further developed, notably using interactive features such as the RIN team blog and wikis, to help fulfil the RIN's role as a provider of information..*

8. RIN update (paper RIN/LSM/07/05)

This was noted without discussion.

9. Review of the RIN (paper RIN/LSM/07/06)

Following the meeting of the Advisory Board earlier in the day, members were alerted that the review consultants may perhaps be contacting members of the Group.

Members expressed the hope that the review will lead to increased resourcing for the RIN.

Members asked what bodies tend to come to the RIN for advice. They were advised that requests had come largely from organisations in the library community, and to an extent from publishers; with researchers, the flow of communication has been more from RIN.

10. Other business

Members noted the recent publication of the RIN's draft principles on stewardship of research data, which had been discussed at length by the Group in the previous year – the current draft takes account of the views and concerns expressed at the time.

☐ *All to help disseminate the principles for consultation.*

Date of next meeting: date in September to be confirmed, with a 13:00 start