Executive Summary

The purpose of fingerprinting is to allow potential EMIF users to gain an understanding in the content, procedures and capabilities of the various data bases. The descriptive information collected through this process is incorporated in the EMIF catalogue browser that will support typing the information (Use case 2) and searching the fingerprints (Use case 3). Ideally this browser would help the end user in an initial assessment regarding the relevance of these data bases for their research questions.

Fingerprinting should not be confused with primary data extraction. Fingerprinting is based on responses of data custodians in questionnaires. Fingerprinting does not involve processing or retrieving actual patient data.

In this second version of the fingerprint questionnaire a total of 186 questions were asked, compared to the 26 questions in the first version. To create this version of the fingerprint questionnaire six sources of previous European similar experiences were analysed and merged. In this version a number of items are still requested in a free text (narrative) format.

The reason why we have chosen to use free text is that we need to understand the scope of possible answers before we can move to a multiple choice format

The main headings are:

1. Database Administrative Information

2. Database Characteristics,

3. Database Population

4. Data Held

5. Ability to Gather Supplementary Data

6. Ethical Issues

7. De-identification, Linkage

8. Data Set Description, Metadata

9. Examples of Events and Outcomes

10. Documents and Publications

11. Comments

12. EMIF Database Fingerprint Provenance.

13 databases provided answers to the questionnaire. They are very different in terms of underlying population, source of data, ethical rules, etc. The approximate total (cumulative) number of subjects is 52 million.

Answers are only available to the EMIF participants. We do envision that in future some of the information provided in this questionnaire will be distributed more widely. Before the information is distributed outside the EMIF consortium, we will seek approval of the organisations involved.

Contacts

EMIF-Platform: Johan van der Lei – Nigel Hughes
j.vanderlei@erasmusmc.nl - nhughes@its.jnj.com