

The transmission of data for the CONCORD study will be done to the highest levels of security.

Key points:

- File-names for cancer data are numeric (see section 2 below): outside the context of this study, the file names are not informative
- Variable names (VAR1-VAR37) are not informative (Annex 3, Data specification)
- The short descriptions of variables must not be included in data files
- All variables are either numeric or coded (Annex 3)
- Data files will be securely encrypted with strong passwords before transmission
- Electronic transmission will use accredited software
- Postal transmissions will use special courier services with recorded delivery
- CDROMs or other physical media must not be labelled with the name of the cancer registry

1 The structure of cancer data files

- 1.1 Cancer data **must** be supplied in files containing individual tumour records.
- 1.2 Each tumour record **must** start on a new line. All records **must** contain 37 variables. The variables in each record **must follow the order in Annex 3** (Data specification).
- 1.3 The variables in each tumour record **must** be separated by commas (,). Cancer data files should be saved either in 'comma-separated values' (*.csv) format or in text (*.txt) format. These formats can be created from all software packages.
- 1.4 Data files **must not** contain any text descriptions. The **first row** of each data file should include the **variable names** (VAR1-VAR37), as in the example below: only the first 8 variables are described in detail. Some variables can vary in length (e.g. VAR8, race/ethnicity, either 1 or 2 digits), so some tumour records may be longer than others:

```
VAR1 , VAR2 , VAR3 , VAR4 , VAR5 , VAR6 , VAR7 , VAR8 , . . . , VAR37
1840 , 120 , abc1234 , 13468 , 9 , 2 , 99999 , 1 , . . . , 99
1840 , 120 , xyz4321 , 24046 , 3 , 1 , 99999 , 99 , . . . , 99
```

The **second and third rows** (above) contain the coded data for the first two cancer patients:

Variable	Value	Short description	Meaning
VAR1	1840	Country	USA
VAR2	120	Registry	Hawaii
VAR3	abc1234	Person code	Unique person ID within registry
VAR4	13468	Tumour code	Unique tumour ID within registry
VAR5	9	IARC CHECK flag	No data for this tumour record
VAR6	2	Sex	Female
VAR7	99999	Region	Optional variable; not supplied
VAR8	1	Race/ethnicity	White, Hispanic

Variable	Value	Short description	Meaning
VAR1	1840	Country	USA
VAR2	120	Registry	Hawaii
VAR3	xyz4321	Person code	Unique person ID within registry
VAR4	24046	Tumour code	Unique tumour ID within registry
VAR5	3	IARC CHECK flag	Record checked and corrected
VAR6	1	Sex	Male
VAR7	99999	Region	Optional variable; not supplied
VAR8	99	Race/ethnicity	Unknown, or missing

2 Assigning names to your cancer data files

- 2.1 We intend to reduce the risk of data loss to the absolute minimum.
- 2.2 File-names are therefore **numeric codes**, not text. To simplify handling very large numbers of files, all file-names must have a standard structure, with five components. For example, the file-name **1840120021** is unique and informative within the CONCORD study, but it has no meaning elsewhere:

File-name component	Description	Meaning
1	Continent	North America
840	Country	USA
120	Registry	Hawaii
02	Cancer	Colon (second of the 10 cancers in CONCORD study)
1	Transmission	First transmission of the colon data file from Hawaii

- 2.3 Each registry has been sent a list of the file-names to use. You **must** use these file-names when sending your cancer data!

3 Three options for file transmission

- 3.1 Three options are available for you to send data files to the CONCORD team. Two electronic file transmission utilities are available: they are both free of charge, and they both provide automatic, secure encryption of your files before transmission. The third option is to use special courier services: if you use this option, you must encrypt your files yourself, but we suggest two ways for you to do this, also free of charge.
- 3.2 First, the CONCORD file transmission utility is a simple, secure, web-based system that is compliant with international security standards. It will automatically encrypt each file and protect it with a unique, strong, random password. We recommend this option. If you choose this option, **please go to Section 4**.
- 3.3 Second, the *HyperSend*® file transmission facility has been requested by some registries. [HyperSend](#) is a secure, web-based system that is compliant with the US Health Insurance Portability and Accountability Act (HIPAA). **Note:** *HyperSend* only supports Windows® operating systems, and it requires each user to download the *HyperSend* software (US export licence restrictions apply), so it is not viable for all CONCORD participants. *HyperSend* will also securely and automatically encrypt your files before transmission. If you choose this option, please **go to Section 5**.
- 3.4 Third, some registries will send data on physical media (e.g. CDROM) by special courier. If you choose this option, you **must** encrypt your files: please **see Section 6**.
- 3.5 For instructions on sending data on CDROM by courier, **go to Section 7**.

4 CONCORD file transmission utility

- 4.1 Go to <https://concord.lshtm.ac.uk/filesend>
- 4.2 **Enter the email address** with which your cancer registry is registered on the CONCORD website, then click **Next**.
- 4.3 Click **Browse** to locate and select the file(s) you wish to send.

- 4.4 Click **Send file(s)** when you have selected the file(s) you wish to send. You can send several files in a single transmission. Each file is separately and automatically encrypted at the point of transmission and protected by a randomly generated, unique, strong password. The password for each file is sent only to the CONCORD team; it is not stored anywhere.
- 4.5 A message will appear on your screen when your file(s) have been transmitted. You will receive an automatic email to confirm this.

5 **HyperSend®** file transmission utility

Download and installation (Windows® only)

- 5.1 **First, send an email** to concord.data@lshtm.ac.uk with 'HyperSend contact' in the "Subject" line. In the body of the email, write the email address of the person who will send the data. That person will be sent an invitation to create a CONCORD *HyperSend* account. [**Note:** some email systems reject these invitations as "spam" (unwanted email). If you have **not** received the invitation within one day (excluding weekends), email concord.data@lshtm.ac.uk again and we will explain how to bypass this problem.]
- 5.2 **Click on the web-link** in the email to accept the invitation. If you do not already have a *HyperSend* account, you will be guided through the brief steps to create one. This is free. You will then receive a message confirming that you have a CONCORD *HyperSend* account.
- 5.3 **Second, send an email** to support@covisint.com with 'Need HyperSend agent download' in the "Subject" line. In the body of the email, write (a) the name of your organisation, (b) the city and (c) the country where you are.
- 5.4 Your request should be approved within one working day (excluding weekends). You will receive instructions and a web-link to download the *HyperSend* agent. **Follow the directions** in the email to download the agent.
- 5.5 When you install the *HyperSend* agent, two folders will be created on your computer (usually *C:\HyperSend inbox* and *C:\HyperSend outbox*). A yellow triangular icon will appear in the "launch area" of your taskbar, typically in the lower right-hand corner of your screen, next to the clock. If you do not see the yellow icon in the launch area of your taskbar, click *Start*→*Programs*, position your cursor over *HyperSend*, then select *HyperSend Agent*.

File transmission

- 5.6 We have created a special account so that CONCORD partners can send data free of charge. *HyperSend* normally charges to send data, but you will **not** be asked to pay to send your data to CONCORD. Receiving data is always free of charge.
- 5.7 **Right-click the *HyperSend* icon** in the launch area of your taskbar. Select **Send** from the pop-up menu: this will launch your internet browser and display the **Send** page. You *may* be prompted to enter your username (this is the email address that you sent to CONCORD) and the password that you will have created when downloading the *HyperSend* agent.
- 5.8 To avoid problems that have arisen in the past, please follow the next two steps carefully: *you will only have to do this once*. We suggest using Internet Explorer (preferably version 8 or higher). The **Send** procedure may fail with Mozilla or other browsers; they do not currently appear to be supported by *HyperSend*.

- 5.8.1 **First**, ensure that your computer firewall will allow access to *HyperSend*, including pop-up menus, by adding the *HyperSend* web-site to your list of 'trusted sites'. To do this, in Internet Explorer, select *Tools*→*Internet Options*→*Security*. In the dialogue box, select *Trusted sites*→*Sites*→*Add*. Then add "https://*.HyperSend.com" to your list of trusted web-sites. Close the dialogue box.
- 5.8.2 **Second**, ensure that *HyperSend* can see the exact location on your computer of the file(s) you want to send. Again, select *Tools*→*Internet Options*→*Security*. Click the *Custom Level* button. The *Security Settings* pop-up window is displayed. Locate the 'radio button' next to the option *Include local directory path when uploading files to a server* and select *Enable*. Click *OK*. If you are prompted to confirm the change, click *Yes*.
- 5.9 Enter concord.data@lshtm.ac.uk in the **To** field on the **Send** page.
- 5.10 **Enter the name of the file** you want to send (e.g. 1840120021, 1840120041) in the **Subject** field. You should already have received a list of file-names to use; if not, please contact us. The file-name you enter will now appear on the **Track** and **Pick-up** pages of the *HyperSend* web-site, and in any emails you receive about the delivery.
- 5.11 Please **do not** use the **Message** box. If you wish to comment on your file transmission, include this in your email to concord.data@lshtm.ac.uk (see 5.17 below)
- 5.12 Click **Browse**, navigate to the file you wish to send, highlight it, then click **Open**. The location (full path) of your file will then be listed in the box *List of files that will be sent*.
- 5.13 Scroll down to the *Advanced Options* area at the bottom of the *Send* page. Click the box **Reverse the Charges**. Select the option **SSL [secure socket layer] plus Encrypted Envelope**: your data file will then be held inside an encrypted 'envelope' at every stage of transmission, including the brief period during which it remains on the *HyperSend* server. You will be asked to supply a password. Do not change other options on this page.
- 5.14 Click **Send**. The browser will take you to the **Track** page. The *HyperSend* icon in the launch area of your task bar will change from a triangle to a "key" symbol, then to an "upload" arrow. The file will then be uploaded from your computer to *HyperSend*.
- 5.15 If you are *not* prompted to enter a password for encryption of your file during transmission, place the cursor over the yellow *HyperSend* icon in the launch area of the task bar. You may have to exit *HyperSend*, then log in again. You should then be prompted for a password.
- 5.16 When the upload finishes, click the **Update status** button. Your file should be shown as having been sent. The file is now ready to be collected by the CONCORD team.
- 5.17 **Send an email** to concord.data@lshtm.ac.uk to notify us that you have uploaded one or more files to *HyperSend* (we will also receive an automatic notification). Include in your email the **name, email address and telephone number** of the staff member to whom we should confirm receipt of the file(s) and to arrange for password transmission to decrypt the file.

6 Encryption and passwords

6.1 If you use a postal courier, you **must** encrypt your data files before transmission. You can do this with:

- WinZip® (version 17 or later)
- 7-Zip (version 9 or later)
- Any other software that supports AES (Advanced Encryption Standard) 256-bit encryption.

6.2 WinZip® is not free, but we can send you a licence for version 17. The program can be downloaded from this web-site:

<http://www.winzip.com/win/en/wzfeatures-protect.htm>

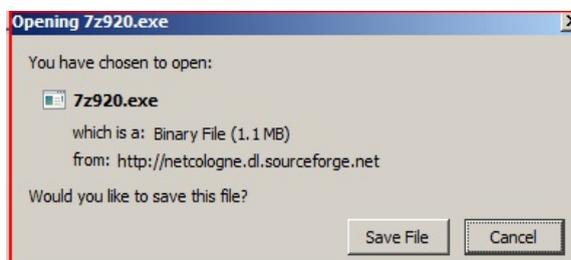
6.3 7-Zip can be downloaded free of charge. It is a widely-used, open-source tool for secure compression and encryption. Go to <http://www.7-zip.org/>.

6.4 When this window appears, click **Download**

Download 7-Zip 9.20 (2010-11-18) for Windows:

Link	Type	Windows	Size
Download	.exe	32-bit x86	1 MB
Download	.msi	64-bit x64	1 MB

6.5 Click **Save file** to save the file 7z920.exe to a suitable location on your computer. When the download is complete, double-click on this file to install 7-Zip. By default, the program will usually be stored in *C:\Program Files\7-Zip*. You can now run the 7-Zip program.



6.6 Each encrypted file **must** be protected with a unique, strong password.

6.7 We will send confirmation of receipt of each file to your registered email address.

7 Courier delivery

- 7.1 You may send your data by courier. The courier company should be instructed to obtain a signed confirmation of receipt from a staff member in the Cancer Survival Group, *and* to confirm directly to you that they have delivered your data.
- 7.2 You can send data on any storage device (CD or DVD preferred).
- 7.3 **Label the storage device *only*** with the country code (VAR1), the registry code (VAR2) and the date of transmission. Use an **indelible marker** pen. Do ***not*** write the name of your registry on the storage device, ***or*** the name of the cancer(s) in your data file.
- 7.4 Use a padded envelope.
- 7.5 **Label the package** with an address that contains sufficient detail for the package to be safely returned to you if delivery cannot be completed. If possible, ***do not*** explicitly identify your institution: use a Post Box number, or an acronym.
- 7.6 **Do not include any other material** in the package given to the courier.
- 7.7 When the courier has collected your package, please send an email containing ***all the following information*** to concord.data@lshtm.ac.uk:
- Name and address of the cancer registry
 - Name of the courier company, date of transmission and physical contents of the package
 - Name, email and telephone of registry staff member to whom receipt should be notified
 - An explanation of any non-standard file structure or non-standard codes you may have used
- 7.8 Please send courier deliveries to this **exact** address:

Professor Michel P Coleman
CONCORD
London School of Hygiene and Tropical Medicine
Keppel Street
London WC1E 7HT
United Kingdom

8 Other contact details

Ms Natalia Sanz
CONCORD Programme Manager
Cancer Research UK Cancer Survival Group
Department of Non-Communicable Disease Epidemiology
London School of Hygiene and Tropical Medicine
Keppel Street
London WC1E 7HT
United Kingdom

email concord@lshtm.ac.uk
telephone +44 20 7927 2854
fax +44 20 7436 4230
web http://www.lshtm.ac.uk/eph/ncde/cancersurvival/research/concord/concord_2.html