eQLQ
An electronic version of the EORTC QLQ
using the Quality-of-Life-Recorder
and AnyQuest for Windows

Dr. Jörg Sigle*

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*Im Vogelsang 2, 75438 Freudenstein, Germany,
Tel. +49-7043-9506864, Fax +49-7043-9506865, joerg.sigle@jsigle.com, http://www.jsigle.com

1   Description of available ressources

A preliminary collection of eQLQ ressources was prepared from material that had been offered previously to members of the EORTC QoL Groups Executive Commitee for a pilot test. The following elements are available as self-installing software files:

- a basic software package, providing the Quality-of-Life-Recorder software AnyQuest for Windows in a layout customised for the EORTC QoL Group,

- a variety of prepared questionnaire configurations, including the EORTC QLQ-C30 Version 3.0 and some modules in English, French and German languages.

The included version of AnyQuest for Windows has been customised to show EORTC logos and to present itself as electronic version of the EORTC QLQ, and has been personalised for QoL Group members. Its menus have been simplified; commands which could accidentally modify questionnaire contents, are not available.

The focus of AnyQuest lies on providing an extremely easy and versatile man-machine-interface, that can be used by untrained patients to fill in questionnaires. On the other side, AnyQuest provides collected data immediately in an open, versatile and self-explanatory format, ready to pass them on to other specific processing tools, and enabling scientists to easily pool data from different questionnaires and studies. AnyQuest's focus does not lie on advanced data processing or visualization itself, neither is it a replacement for every other data input software used in common database packages or applications.

In the prepared configuration,

- questionnaires can be presented to patients,

- computed results can be printed out automatically after each session, including both:

  - single printout with results from the current session,
  - cumulative printout including results from previous sessions, showing the patient's course over time,

- collected data are stored locally, and can be exported as a table into third party analysis or processing software,

- and basic search, display and print functionality is there for locally stored data.

The software can be used together with any Windows pointing device, be this a mouse, trackball, track-pad, track-point, or any kind of touch-screen. Please keep in mind that mice, some track-pads and track-points found on some laptops may be difficult to use for untrained patients. You may try to reduce their pointer movement speed to the minimum, but even then, some devices may move the pointer too fast. In this case, you could use an external mouse or trackball, or a touch-screen which works as external mouse replacement (e.g. "Touch-Window"). They are not too expensive.

If you don't have a printer, but would like to see a result printout anyway, or if your printer is not on line at all times during questionnaire administration, please inform me.

If you don't want to have a printout at all, please inform me as well.

Within this pilot test, issues like presenting sets of questinnaires, configurations for multiple studies on one hardware device, data protection measures, integration into existing IT environments, automatic postprocessing and transfer of questionnaire data via networks, and transfer of additional questionnaires into the system, some special features, and, finally, using AnyQuest under operating systems other than MS Windows are not addressed.

This manual does not cover too many details, to keep it short.

To make this pilot testing most efficient, please contact me directly if you require any information, if you have difficulties in using the software, or if you should find any unexpected behaviour of the software.

Participants of the pilot test, please contact me to learn about important new features of the current packages.

2 Installation

Installation is very simple, but you may wish to consult your local PC support:

- either, if you feel not comfortable completing tasks like this,

- or if you have system access only as a user, so you are not allowed to install software on your own.

As a member of the EORTC QoL Group, you should have received a CD-ROM containing all currently available ressources. If possible, please take this CD-ROM to the machine which you want to use for presenting electronic questionnaires. If this is not possible, please use another PC to copy the `*.exe` files for the basic software package and the questionnaire modules you require to a floppy disc, or to make it available trough an Ethernet network or infrared or similar connection.

If you did not receive the files on the original CD-ROM, then you should check any `*.exe` file for viruses before proceeding.

On the target PC, you need read/write-access to the primary hard-disk-drive `C:`

First, locate the self-installing software packages on the CD-ROM:

- On the CD-ROM, please open the top level file `index.htm` using a WWW/HTML-browser (Internet Explorer, Netscape...). Select your preferred language, and follow these links: CD-Copy of WWW-Site -> main-directory -> QL-Recorder -> questionnaire-library -> eQLQ.

Then, run each required file on the target PC:

- You can run each self-installing `*.exe` file by clicking or double-clicking on itself (without a browser) or on its link (within a browser).

- If you're using a browser, it may show you a dialog afterwards which lets you execute the file directly from the CD.

- If this does not work with your local browser configuration, you can alternatively open `c:\jmshome\qlr\libeortc` on the CD-ROM and find the `*.exe` files there.

- Please read the screen output of each self-installing software package. You'll probably want to answer "Y" for "Yes", wait some time, answer "Y" again, wait, maybe "Y" again (depending on your system), then press the button "Install...", then wait.

- A newly opened window will show the newly created start menu contents. If it hides the setup program, either close it or switch back to the setup-program using [Alt]-[TAB].

- When the setup-program has finished, please press the button "OK".

I recommend you to configure your Windows Task-Bar[1] *not* to come to the foreground automatically, and *not* to stay visible all the time. You can verify this configuration by starting AnyQuest later: The Task-Bar should not be visible, and it should not appear when you touch the bottom border of the screen with your pointing device. If you prefer your Task-Bar to appear automatically when your mouse touches the screen border, then you should probably move[2] the Task-Bar to the top, left or right borders instead of the bottom one, because otherwise, patients trying to press the "Continue..."-button within AnyQuest, might occasionally reach the Task-Bar instead - and be confused.

Specific instructions are available on how to prepare a QL-Recorder installation which is secured against abuse of the computer system, even if it is based upon Windows 9x, but this is not trivial and shall not be addressed here. If you want to restrict access rights below `c:\anyquin` on a Windows NT filesystem, please ask (!) me for detailed instructions.

The questionnaire definition file has been tested using screen resolutions of 640x480, 800x600 and 1024x768. 1152x864 and other 4:3 resolutions should work, but 1280x1024 and other non-4:3 resolutions may give undesirable results and should be avoided (or at least, tested, before using them for patients).

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[1]How to get to the Task-Bar configuration: click-right somewhere on the Task-Bar, select "Properties"...

[2]Click-left somewhere on the Task-Bar, keep the mouse button pressed and drag the Task-Bar to another border of your screen. Release the mouse button there.

3   Selecting the printer and changing the default configuration

AnyQuest will ask you for the printer to use for any prepared configuration after the first completed questionnaire session with that configuration. Probably you'll just click "OK" to use your default printer.

If you want to change the printer or any other option (patient identification to collect, sound signals,...) later, you can chose "Setup" from the "Navigation" dialog, then use the available menu commands to set any available parameter. Each setting will only affect the currently used configuration, but it will be stored permanently for this configuration.

If (and only if) you use a touch-screen or pen-computer, you may press [Ctrl]+[F11] when a question is being displayed. Afterwards, AnyQuest will move the pointer away from the answer fields when each next question is displayed. As this behaviour is annoying when using anything else but a touch-screen, I deactivated it for the supplied default configurations. If you tried this option anyway, you can deactivate it again by pressing [Ctrl]+[F11]. The current setting will be stored for the currently used configuration when AnyQuest is closed.

If you wish to protect your configurations from being permanently changed, please write protect the files under `c:\anyquin\config\*.ini`.

4 How to handle the QL-Recorder during data collection

4.1 Prerequisites

- You should be familiar with the handling of the LQ-Recorder before presenting electronic questionnaires to patients.

- Place your QL-Recorder, where it can be used conveniently by patients. Make sure that the display can be read clearly, without reflections of room lights. If you use a laptop, protect its hard-disk from magnetic fields (loudspeakers, motors of electric appliances). Make sure that it won't run out of power in the middle of the session.

4.2 Administering the electronic questionnaire

4.2.1 Preparation

1. Power on, connect, and set on-line your printer, your network or other peripherals, if required.

2. Power on your computer and wait until Windows has started; log on if required.

3. From the Windows Start-Menu, chose e.g.: "Programs" - "AnyQuest for Windows" - "QLQ-C30 English".

4.2.2 Administering one questionnaire to one patient

1. Invite your patient to fill in the questionnaire.

2. The patient should watch you during the next steps, so he can see how to use your pointing device.

3. Start the questionnaire administration by pressing the button "Go!".

4. Collect the patient identification data[3]. Enter these data yourself to ensure their correctness. If you want to correct a typing error here, use the button labeled "<<<" on the screen or the backspace key on your keyboard[4].

   If you use a touch-screen, you can use the buttons displayed on the screen conveniently, and your patient can see how the touch-screen works. If you don't have a touch-screen, you may wish to use the keyboard because this is faster - but less instructive for your patient.

   Entering the date of birth, please be sure to use the format Day-Month-Year. The program will understand "31.12.64", "311264", "31.12.1964", "31121964", "010135", "01.01.35", "1.1.35", "01011935", "01.01.1935", "1.1.1935". You should gernerally enter four-digit-years; the program will add 1900 if you supply two digits for the year.

5. Now invite your patient to continue himself:

   "Now, please read every question displayed here (point at the screen with your forefinger)*, and answer it yourself, by either clicking [pointing, pressing...] either here at "Continue..."* (point at the "Continue"-button at the bottom of the screen) *or at one of the answer fields that will appear here* (point diffusely at the middle to lower part of the screen)*.*

   If you ever need to make a correction, or if you feel you cannot or do not want to answer a single question, or if you require assistance for any other purpuse, please call me; I'll stay nearby.

   Here (point at the graph displayed in the lower rigth corner of the screen)*, you can see, which part of the questionnaire you have completed already.*

   When you have answered all questions, please call me as well."

   Then, hand the pointing device (mouse, pen, touch-screen...) over to your patient.

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[3]In the prepared configuration, the program will ask for a patient's initials and his date of birth. You can change this easily, but in this case, you should be familiar with applicable data protection regulations.

[4]If you notice a typo when the respective patient identification is not displayed anymore, you must go through any remaining patient identification screens, filling in random data where required, then abort the whole session and start over. This will not take more than 10 seconds, however.

6. Watch your patient for one or two clicks to see whether everything works well. Then, continue your own work.

7. After the last question, a message saying "Thank You!" willl appear. After clicking "OK", printouts are generated immediately. You can discuss them with your patient. The program goes back to its initial state.

4.2.3   Interrupting a questionnaire session

Occasionally, you may need to interrupt a session, e.g., when your patient gets too tired, or when he must go to see another colleague within your hospital immediately. This is less probable during the administration of a short questionnaire, but when you will use the QLQ-C30 together with one or more of its modules, or together with third party questionnaires, it can certainly become an issue.

You *cannot* interrupt a questionnaire session while entering the patient identification data, but you can interrupt the session at any time while the patient is answering questions:

1. Interrupt the session by pressing the small button labeled "X" in the top right corner of the screen[5].

    A dialog window appears, asking, whether you want to "Continue" the session, "Abort" it completely (Cave!) or "Save" it for later completion.

2. Before you click "Save", you can enter a comment into the respective field, e.g.: "Patient too tired, needs pause"

3. Then click "Save".

    The current state of the questionnaire session is stored, and in the "Navigation" dialog, a new button labeled "Resume" appears.

4.2.4   Resuming an interrupted and saved session

When the button "Resume" is displayed in the "Navigation" dialog, this tells you that there are interrupted and stored sessions available.

If you click at this button, a list showing all interrupted sessions appears. The program can keep up to 99 interrupted sessions at the same time.

1. Click "Resume".

2. Select the one interrupted session you wish to resume from the list. If the list is very long, you can use the [PageUp] / [PageDown] keys to navigate through it.

3. Click "Resumed selected session".

    The interrupted and saved session appears exactly as it was left before.

4.2.5   Switching off the QL-Recorder

1. To close AnyQuest for Windows, select "Exit" from its "Navigation" dialog, or press [Alt]-[F4].

2. Log out, if required.

3. Shut down Windows, wait until your machine switches itself off.

4. Switch off any peripheral devices if required.

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[5]If, by mistake, you hit one of the other buttons displayed next to the "X", and your window changes its size or is minimized, please maximize it again by either pressing the "Maximize"-button, or clicking at the representation of that window in the task-bar.

4.2.6   Special keys during questionnaire administration

Useful hardware dependant keys, varying from laptop to laptop

[Fn]+[F7] / [Fn]+[F8] Adjust loudspeaker volume

[Fn]+[F9] / [Fn]+[F10] Adjust display backlight level

The keys listed above work for the Palmax PD-1000 mini-pen-computer. Please try to find out which keys are actually used on your laptop!

Important and useful keys of AnyQuest for Windows

[PageUp] / [PageDown] Step back or advance one question at a time - useful, if the patient wants to correct a given answer[6].

> If a patient wants to correct a given answer, press [PageUp] once to display it again. He can then give the correct answer, and everything will continue normally.

[Ctrl]+[F5] Display or hide the special answer fields for "I can't answer this question" and "I don't want to answer this question".

> If a patient indicates that he cannot or doesn't want to answer a single question, switch these additional answer fields on by pressing [Ctrl]+[F5]. Ask him to select one of the two, now additionally displayed options. A dialog will appear, asking, why he couldn't or did not want to answer this question. If you are interested in this, please record his comment, otherwise leave the text entry field empty. Then, click "OK" to close this dialog. Press [Ctrl]+[F5] again to hide the additional special answer fields[7].

> This feature is especially useful during questionnaire development and field-testing, because the comments will be exported together with collected questionnaire data in a convenient way - thereby reducing the need to manually keep a field-testing-diary for such comments.

[Alt]+[F4] Interrupt a questionnaire administration session, or close AnyQuest for Windows, or end an MS Windows session / shutdown Windows.

Keys you should not require to use

[Cursor Arrows] Can move the pointer within AnyQuest.

[TAB], [Shift]+[TAB] Can move the pointer to the preceeding or next available answer field, and even move to the preceeding or next question. This depends however, on details within the questionnaire design.

[Spacebar] Works like a mouse click.

[Ctrl]+[F1] .. [Ctrl]+[F11] Set or reset several flags that control the display of several questionnaire elements or other features during the questionnaire presentation.

[Home] / [End] Jump to the start or to the end of the current questionnaire.

[Alt]+[TAB] The usual key to switch between different active Windows applications. In a real LQ-Recorder setup, you should have this key disabled, following special instructions.

[Windows-Key] Can display the Start-Menu even when your Task-Bar is not visible.

Details regarding these and many other keys are explained within AnyQuest's on-line-help.

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[6]Generally, you should only need to step back - you may need to advance only, when you stepped back too often.
[7]The current setting of the "display special answer fields" flag is saved when AnyQuest is closed, if the respective configuration file is not write protected.

5 Processing of collected data

5.1 Preface

Many steps required for data postprocessing can be configured and automated. AnyQuest for Windows offers several features that support its integration into existing IT environments, e.g. it can trigger the immediate automated import of data into any available database application, or the automated packaging of data from many patients into an encrypted file that can either be transferred manually or automatically, via e-mail, ftp or any other desired network protocol.

AnyQuest's on-line-help covers data formats, data export and integration possibilities to a fair level of detail.

Here, however, I only want to describe ways to manually transfer collected data into a third party statistical evaluation software, by first exporting data from many patients into one table, which can be imported by some other software.

I also suggest ways to proceed in preparing this table for specific potential needs of different third party software. In any case, if you encounter a specific problem while trying to export your data, please do not hesitate to contact me for assistance.

5.2 Preparing collected data for import into third-party software

1. Start AnyQuest for Windows (just as you would do for questionnaire administration).

2. Click "Setup", then select "File" - "Generate data export File...".

3. Select options (or leave default settings) according to your third party software requirements; be careful to use the correct decimal separator.

   Depending upon your requirements, you can unselect "Language and version information", "Other meta information" (currently including number of questions and result formulas, result ranges) or "Raw data" (encoded answers to individual questions), to keep the resulting exported table smaller. Whatever you export at one point in time, your original data will of course stay unchanged.

   For clinical or therapy study use, you would mainly use "Computed results", maybe "Additional text information" (including comments, when a patient could not or did not want to answer individual questions), and maybe "Language and version information".

   "Additional meta information" could supply details about the questionnaires used to third party automated processing tools (e.g., information regarding the possible result range would be necessary when you'd want third party software to generate bar-graphs).

   "Language and version information" may be necessary, when you are co-operating internationally, or when you're cross-validating different versions of the same questionnaire.

   "Raw data" are probably only necessary during questionnaire development or validation, or when you try to examine alternative result computation algorithms.

   You can generate export files with different options checked and then view the resulting file e.g. in Excel to understand the detailed meaning of each option.

   The selected options will be saved for the currently used configuration, when you close AnyQuest.

4. Click "OK", then "OK" again.

5. Close AnyQuest for Windows.

6. Open the resulting file (e.g. `c:\anyquin\data\anyquin.dif`) using your target application:

   (a) If it doesn't automatically recognize the format of `anyquin.dif`: This is a table within a plain ASCII/ANSI[8] text file. Its columns are separated by a special character (default: tab), its first line contains the table headings, the three following lines contain additional notes, all following lines contain data, one line per questionnaire session.

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[8]The fixed backbone is ASCII, but questionnaire designers may chose to use ANSI characters for output result labels, or for data, and, aditionally, patients may chose to write ANSI comments which also result in ANSI data. Moreover, special applications may use special character sets, but this will be denoted in the result file.

(b) Excel or other spreadsheet applications can open such a file immediately, using their default settings.

(c) If you need to edit this file before importing it, this can be done e.g. by opening it in a plain text editor (MS Edit, MS Wordpad, or even MS Word); but if you use tools like Wordpad or Word, you must make sure that after editing, you save it again as plain text file, without introducing additional format data. Most text editors will not display the tabulated contents of the file in a correctly tabulated way, but this is intentional and does not affect their usability for some basic editing tasks.

(d) Before you can feed such a file into certain database applications or certain statistical analysis software, it may be necessary that you remove the three lines between column headings and collected data. For this purpose, you can use one of the tools described in (c).

When importing into a database application, you will probably have to tell your importing application, which column of the AnyQuest generated table (e.g. "QLQC30 Physical function") shall be mapped onto which data field of your target database (e.g. "C30PF").

If you cannot define this mapping within the import functionality of your database, another alternative might be to use e.g. MS Excel to remove unneeded columns from AnyQuests export file, and/or to replace AnyQuest's column headers by those of your target database.

(e) Some statistical software may require the use of separate files for column names and data. To get these, open the file `anyquin.dif` with a text editor, save the first line as `anyquin.nam`, remove all lines not containing data, and save the remainder as `anyquin.dat`.

5.3   Evaluating data from multiple centers

If at least two people participate in the pilot testing, multicenter data evaluation can be demonstrated.

In a completely manually operated setup, this will involve:

1. at the peripheral sites:

   (a) packaging/encrypting AnyQuest generated data files,

   (b) sending the package to the center,

2. at the center:

   (a) unpackaging/unencrypting each received package,

   (b) renaming the extracted data files, using an origin-site specific prefix,

   (c) collecting all (renamed) data files from all centers in one directory,

   (d) then using the AnyQuest "Generate export file" function once onto all files.

This procedure will automatically ensure that the generated file export file will contain columns for the data from *any* questionnaire used at *any* center - without any configuration required.

If you want to try it out, I can send you more specific instructions later.

For a true multicenter setup, each center may use a personalised version of AnyQuest for Windows, so the data origin is imprinted in each individual data file.

All steps denoted above may be partly or completely automated; more automation is generally useful for larger studies only.

All steps denoted above may also be executed when, at any point in time, data from many individual studies carried out in the past shall be evaluated together.

5.4   Using AnyQuery

AnyQuery is a little tool (which is in an early development stage) to find results of individual QL measurements, and to display them in a way similar to the immediately produced single printout. The tool is quite simple and self-explanatory; it comes together with an on-line-help file[9].

Its basic functionality:

- A password is required to display data with AnyQuery. The default password is: anq

- First, define the path to your QL-data: click the button with the directory tree, then follow your local directory structure and click any file out of
  `c:\anyquin\data\*.anq`

- Then, click at the button with the magnifying glass ("search"), fill in the dialog as requried, and so on.

6   Beyond the basics

This manual does definitely not cover much of AnyQuest's available functionality, e.g.: its support for effective transfer of arbitrary paper questionnaires into electronic versions, interactive editing functions, basic multimedia support, support of multiple co-existing configurations, possibilities for integration into existing infrastructure, or possibilities which are there to generate tailor-made applications.

The on-line manual of AnyQuest for Windows offers you a comprehensive documentation of its possibilities. Other ressources on this CD-ROM offer you anything from basic information over quick guides for users and questionnaire designers towards examples of application specific manuals, and even instructive video clips.

Many more complex configurations can be set up with this software, depending upon your local infrastructure and your local needs. The software package as it is presented here, however, is suitable to give you a simple quick-start with this tool. Depending upon your feedback, future versions of the software may be better adopted to your specific needs as well.

In any case, I would like to invite you to collect your questions which may arise during your using the software, either for me to answer them directly, or to discuss them within the QL group.

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[9]...which apparently, cannot be displayed by some versions of Windows NT - sic!