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# A crash course: Complete essentials

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## Quick Guide: How to install and use the Quality-of-Life-Recorder

This is a brief and very practical introduction to the Quality-of-Life-Recorder. It contains all necessary information to aid you from its installation to the first questionnaire session. Section 11 of this guide can be printed and serve as an everyday-help to clinical users of the electronic questionnaire.

Reading this document, setting up the Quality-of-Life-Recorder for use with one of the provided questionnaires and completing a first test-questionnaire will take less than an hour, depending on your computer experience. - Have fun!

### This quick guide contains the following sections:

1. Overview
2. What is the Quality-of-Life-Recorder?
3. What do you need?
4. What else should you consider to use?
5. Patients' data protection - Are there legal obligations?
6. Installation: Basic setup
7. Installation: Advanced and network setup
8. The Quality-of-Life-Recorder, AnyQuest for Windows, eIBSQOL and other applications
9. Setting up the environment according to local needs
10. Which patient identification options should be recorded?
11. Presenting a questionnaire to a patient
12. Authors, license, further information, disclaimer

### 1. Overview

For normal users, this is the overview. For those without fear, it may be all they need to read in this file. :-)

- Install the software running [anypak.exe](#), [demopak.exe](#) or the specific package you have.
- Consider data protection and patients' privacy well.
- Start "DESIRED\_QUESTIONNAIRE YOUR\_LANGUAGE" or "AnyQuest for Windows" for configuration.
- Press "Help" button. Go to the table of contents, read at least the license agreement and the introductory comments, if you like. Close the online-help again.
- Press "Setup" button.
- Setup site specific options (only once), mainly patient identification options to ask for and sound.
- Exit the Quality-of-Life-Recorder to save changed configuration.
  
- Having read at least section 11 of this guide is very highly recommended now.
- Invite the patient to provide a QoL assessment with a standardized invitation.
- Move the task-bar away, configure it as described in section 11.
- Start "DESIRED\_QUESTIONNAIRE YOUR\_LANGUAGE".
- Press "Go!" to start a questionnaire session.
- Recommended: Enter patient identification data yourself or let a qualified person do that, to ensure data reliability.
- Give the system to the patient, let him complete the questionnaire, informing him, that you're around when he should require assistance.
- Review generated printout together with patient.
- Exit the Quality-of-Life-Recorder.

If you require more details, please go on reading this file or use the remaining on-line-help. It provides further sources of information including a literature reference.

## **2. What is the Quality-of-Life-Recorder?**

The Quality-of-Life-Recorder is a tool, that allows patients to fill in questionnaires directly at a computer. For patients with no computer experience, you should use a touch-screen or a pen-computer. The Quality-of-Life-Recorder will work on such devices, but if you are on a very small budget, it will also work on any usual PC with its mouse, track-ball or any other pointing device.

It is so easy to install and to use, that you can operate it already, if you have very basic computer knowledge.

This tool can be available to you within the following packages:

anypak.exe - A shareware package distributed via my WWW-site. General purpose, several example questionnaires provided.

glaxopak.exe - eIBSQOL: Indication specific, everything-prepared, supported and distributed by Glaxo Wellcome plc.

eortcqlq.exe - eQLQ, electronic EORTC QLQ: a preliminary, everything-prepared, implementation of the EORTC QLQ-C30 and some of its modules in several languages to serve as basis for evaluation and discussion within the EORTC QL-study-group.

## **3. What do you need?**

The minimum computer system required is a PC compatible with...

- 80386sx CPU
- 8 MB RAM
- 10 MB free hard disk space
- VGA graphics card and display
- any pointing device (e.g. a mouse)
- MS Windows 3.x compatible operating system

This is indeed a more basic system than you will find available at any shop today, so you could use an old PC of yours. The Quality-of-Life-Recorder itself will run quite well on such a system because it does not require many resources.

The Quality-of-Life-Recorder also runs on Windows 95, Windows 98, Windows NT 3.x, Windows NT 4.0 as well as on Linux + Wine + xfsft and several other emulators e.g. for the Macintosh.

If you have not received an everything-prepared package, you may either require to obtain electronic questionnaire definition files or prepare them from your paper versions yourself.

## **4. What else should you consider to use?**

For data protection issues, if you can have set it up, the free operating system Linux is recommended in connection with Wine and the font server xfsft, because it is probably the most secure platform you can use as well as a totally free one.

If you do not know how to do that, then if your budget should allow it, Windows NT 4.0 would be the system of choice. So, for a more secure system, you require:

- Windows NT 4.0 or Linux together with Wine and xfsft, and to run these operating systems smoothly:
- Pentium CPU with 75 MHz or above
- 32 MB RAM or more

To make the system very easy to handle for patients untrained in computer use, a touch-screen, a touch-screen add-on or a pen-computer are highly recommended. Please review the section "hardware" of the on-line help to get more information. This also comments on sound output and other possibilities.

If you plan to use a laptop or a pen-computer, please make sure that its display has a good readability; especially a high contrast is useful. A colour TFT display is recommended if you have patients with reduced visual capabilities.

If you want to get immediate printouts with results, a printer is of course required. However, you could also use a print-preview utility like FinePrint (shareware) for this purpose.

If you want to set up a very comfortable system, you should use Pen-Computers which are integrated into a wireless network. This would allow to measure patients' Quality of Life anywhere in your hospital, and to have the data stored on a central server, to produce a printout on the ward that it requires, immediately after the patient finishes a questionnaire without any required additional steps.

## **5. Patients' data protection - Are there legal obligations?**

European or national law regarding the protection of patients' data and privacy may require special precautions before recording patients' data. It may be necessary and reasonable to contact a person who handles these issues at your institution or a knowledgeable person from the local data processing staff for advice. Scientific use of data may be subject to other regulations than use for routine treatment.

The following list suggests some options to take into consideration. In any case, you should try to make a computer based system at least as well secured against theft, abuse or destroying of data as a conventional paper based system.

However, if security issues prevent you from using electronic questionnaires, think over the security of paper based data.

It may be very reasonable or required, to record only a coded patient identification instead of patient names, together with or without patients' date of birth, depending on your exact situation.

In the absence of other data protection measures, it may be critical to make sure that computer systems which provide access to recorded data are not used in an undesired way. This means e.g., that a laptop containing patients' data must be kept physically safe from unauthorized access. If you use a single computer system for the purpose of data collection, it may be reasonable or required - depending on the safety requirements and safety levels provided by your operating system and third party tools - to remove software that could be used to view or copy data by unauthorized persons from such a system.

It might as well be reasonable or required to protect such a system by means like removing or locking its floppy drives.

It may be required to guarantee a safe encryption of recorded data using additional tools, especially when you are going to communicate these data or store them off-site.

Usually, the more you know about national law and computer security, the more you can do legally and with the feeling of treating your patients' data right.

## **6. Installation: Basic setup**

The Quality-of-Life-Recorder comes as everything-prepared self-installing package.

It will install itself into `c:\anyquin`, so that you need write access to the drive `c:` which usually is your first local hard-drive.

The Quality-of-Life-Recorder itself does not write anything into your `\windows` or `\winnt` directories.

1. To start the installation, please run the file [anypak.exe](#), [glaxopak.exe](#) or [eortcpak.exe](#).
2. Read all information screens carefully; if you understand them, then answer "yes" twice. Afterwards press the button "Install to c:\anyquin".
3. After setup has completed, read any final messages of the setup program, then press "ok" to end it.

The created program group "[AnyQuest for Windows](#)" will remain open to give you easy access to the new software; later you can close it and access the Quality-of-Life-Recorder via the Start-Menu or the Program Manager.

## 7. Installation: Advanced and network setup

By fixing the default installation path completely in the basic setup, we want to ensure easy support of users with basic computer knowledge.

More advanced users, however, can use the included on-line help and then tailor their setup completely to their needs. This includes configuration for multiple concurrent studies, multiple QL-Recorders and so on.

If you wish to install the Quality-of-Life-Recorder onto a network drive or onto another harddrive, you can only do this by moving the resulting [c:\anyquin](#) away to your target drive and updating all required shortcuts, program group entries and AnyQuest configuration files as described in the AnyQuest for Windows on-line help-file.

## 8. The Quality-of-Life-Recorder and AnyQuest for Windows vs. its applications

The eIBSQOL is an electronic version of the IBSQOL Quality-of-Life-questionnaire. Its preparation has been supported by Glaxo Wellcome plc.

The electronic EORTC QLQ is an electronic version of the EORTC Quality-of-Life-questionnaire. It is a preliminary package, available only within the EORTC QL-study-group for evaluation and discussion.

Both packages have been built using AnyQuest for Windows, a software implementing the general concept of a Quality-of-Life-Recorder by Jörg Sigle.

After installation your Start-menu or your Program-Manager will contain a variety of new entries. One will read "[AnyQuest for Windows](#)", and another one "[How to use AnyQuest for Windows](#)".

If you installed either the eIBSQOL or the electronic EORTC QLQ packages, there will be additional entries reading "[eIBSQOL English](#)", "[QLQ-C30 French](#)" and so on.

All of these entries will bring up a special version of the software which offers a simplified menu, only including options related to presentation and evaluation of the designated questionnaire.

The icon labelled "[AnyQuest for Windows](#)" will bring up a full version of the Quality-of-Life-Recorder software which also includes more advanced options for questionnaire design. The help files may be different between the packages, but all will include a full explanation of AnyQuest's possibilities.

## 9. Setting up the environment according to local needs

After starting AnyQuest for Windows, you will see a screen that offers buttons either to "Go!" or to "Setup".

Please chose "[Setup](#)" to set some configurable options to exactly fit your individual needs.

After you press "[Setup](#)", the window disappears and you can use AnyQuest's menu to find out what's available. Changed settings will remain effective even after exiting and restarting, but you need to chose the settings you like once for every pre-prepared or self-made configuration, including different languages or sets of questionnaires, you wish to use.

All options are explained in the included on-line-help file, but here is a list of the most important ones, together with their position in the menus:

- "File" - "Clear all"

This removes all currently questionnaires from AnyQuest's mind. Use it before you prepare a new configuration, or between looking at several questionnaire definition files.

- "File" - "Load"

This opens a dialog that allows you to load questionnaire definition files. Use this to prepare a set of (one or many) questionnaires which will be asked in one session.

- "Navigation" - "Patient identification options to ask for..." - "..."

This is by far the most important option. The recommended setting totally depends on your environment, the purpose of your data collection and is also affected by how much you know about operating a computer securely and about local law. Please review the information in the on-line help regarding "data protection" and the hints given below when you decide about what patient identification data shall be recorded.

- "Sound" - "..."

The sound production of AnyQuest can be configured to be either completely quiet, to use Wave-files or to confirm or announce several actions by some signals. If you are going to interview patients with little or no computer experience, or if you use a touch-screen or pen-computer, it is highly recommended to activate a signal that confirms given answers. The experience shows that this is a great help for patients.

Depending on your patient population, your environment (and your personal preferences) you should select a signal that is loud enough but still not annoying.

If the given configurability is too little, you should consider using a soundcard that has the ability to control the volume of the PC-speaker output. AnyQuest for Windows allows the connection of individually recorded sounds to any event, too, but this is advanced users' work described in the on-line-help.

- "Display" - "Reset cursor position..."

Using this option, you may make the cursor move to a defined point whenever a new question is shown, to avoid a tendency to select the answer where the cursor already is.

Although useful from a scientific point of view, this option is quite annoying when used without suitable input devices like touch-screen or pen-computers.

- "Display" - "Show Can't / Don't want to answer"
- "Display" - "Show additional text input windows"

This options can be left turned OFF as long as your system has a keyboard, or any possibility to type [Ctrl]-[F5] during the questionnaire session, or if you want to force patients to give an answer to any question even if they feel they can't or don't want to answer an individual one.

If during a session the patient signals that he has trouble and asks for your assistance, you can always press [Ctrl]-[F5] to bring up the specific fields to state "Can't to answer this question" or "Don't want to answer this question". After checking one of these options, you can even record a reason if you want to.

Then, you press [Ctrl]-[F5] again to hide the respective answer fields again.

Only if your system has no possibility to press [Ctrl]-[F5], you should turn on the first option by

default and set the additional option according to your needs.

- ["Printing"](#) - ["Printer setup..."](#)

You can set up a printer or a fax device in advance, otherwise the program will ask you automatically after the first completed questionnaire.

All configuration options are stored in the file [anyquin.ini](#) or an alternative configuration file specified when invoking AnyQuest for Windows.

## 10. Which patient identification options should be recorded?

**Please note** that all data you selected for recording, must be entered. It may be sufficient to enter only a single character in the respective screens, but definitely, they cannot be left empty.

So the most robust and recommended option would be to record a well-defined patient identification code, generated by an algorithm that makes it at least difficult or even impossible for an unauthorized person to identify the patient to whom a given data set refers. A date of birth should be recorded, if age computation and documentation is required.

It is recommended, that these data are entered by qualified personnel in front of the patient. First, this gives him an example of how to use the input device (e.g. a touch-screen, a pen, a mouse...), and second, this ensures data reliability.

Here are the details and other options:

Depending on the operating system you use, it might be more or less difficult to protect recorded data from unauthorized access.

Generally, it should be rather safe to record only a coded patient identification, as long as the key to these icons is kept in a safe place (this may be a safe computer system or in an encrypted file even on an otherwise unsafe system).

If you want the Quality-of-Life-Recorder to record and print the age of a patient, it requires his date of birth.

For general practice use, it may be desired to record patients' initials or patients' names, but then recorded individual files are definitely attributable to a single patient, and may thus become subject to special legal terms. These data are very critical to handle or communicate.

If you want to process your data in third party systems later and record all patient identification data somewhere else anyway, then you may only need a reliably entered patient ID code to enable the target software to import individual patients' data.

According to my own experiences, you cannot rely on patients initials for identification of individuals. People will mix the sequence of christian and family names, they will enter two or three initials and so on.

In several applications, it may even be desirable to check the entered patient ID by recording further redundant data.

## 11. Presenting a questionnaire to a patient

Finally...!

This is easy:

- Invite the patient to fill in the questionnaire. You should use a standardized invitation like:

"Dear patient. We have prepared a questionnaire to find out, how you would rate your own Quality-of-Life from your own point of view (and NOT merely from the doctors'...)..."

If you work scientifically, it would be very useful to publish the invitation you used because it may well be the most important determinant of patient compliance.

Scientific guides on how to present questionnaires to patients are available.

- If not done already, move the task-bar on your system away from the bottom, e.g. to the top of your screen. Set its properties to "automatically in the background" and, optionally, "always in the foreground". (So, a patient won't be distracted by the taskbar, and won't activate it accidentally when trying to click the "Continue"-button.)
- Start the language or questionnaire set specific preparation of the Quality-of-Life-Recorder via your Start-menu, your Program-Manager or a prepared link.
- Show the patient the system. In front of him, start the session pressing "Go!". Note that the program's menu disappears now.
- Ask him for his name and date of birth, if you do not already know them, or get his patient ID code.
- Enter the required data, thereby demonstrating and explaining to the patient how to use your mouse, touch-screen, pen or other input device. And: ensuring ID-data quality.
- When the first introduction screen appears, hand over the system to the patient.
- Assist him in finding and pressing the "Continue..." button after he has read the first introduction.
- Watch the patient filling in the first question, if necessary (mostly: not necessary) give some additional explanation of how to use the hardware, or: give positive feedback when you see that he knows that well.
- Step into the background, telling the patient, that you are around in case he should have questions or difficulties.
- Avoid to counsel the patient in which answer to select.
- Avoid to explain unclear questions or make unvalidated translations or explanations of translations to people who have difficulties in understanding a question or an answer field label.
- Know every important thing about [keyboard support](#), but don't confuse the patient with that.
- If a patient has such difficulties and decides he can't or doesn't want to answer a question, proceed as described above, in the section about individual configuration.
- If a patient finds that he erratically answered a question, and that question has already disappeared, you can help him by using the Page-Up-Key to show the last question(s) again. (This option has one minor flaw and pitfall: if there were some questions before the currently displayed one, they will be shown too. This can cause difficulties in extremely rare circumstances; it may be improved until the final release version).
- If a session must be interrupted or aborted, do this by selecting one of the controls normally used to close a window (Windows 3.x: System menu, top left; Windows 95: same or Close window button, top right). Then select whether to abort or temporarily save that session. You can resume saved sessions later, and the navigation window will indicate the availability of resumable sessions.
- After the last question has been answered, the Quality-of-Life-Recorder shows a "Thank you." You can thank the patient for his cooperation, too.
- Automatically, all entered data will be processed, saved, printouts generated if configured.
- Now, the navigation menu appears again. You can press "Exit" to leave the

Quality-of-Life-Recorder.

## **12. Authors, license, further information, disclaimer**

AnyQuest for Windows and the concept of the [Quality-of-Life-Recorder](#) are copyrighted products of [Dr. Jörg M. Sigle](#), Germany. The electronic EORTC QLQ is an application of this product. This product comes under a special license agreement, described in the on-line-help file.

The original IBSQOL questionnaire was developed by [Beth Hahn](#); © Glaxo Wellcome plc., 1999.

The original EORTC Quality-of-Life-Questionnaire was developed by [the QL-study-group of the EORTC](#). It is a copyrighted instrument which may be used freely for academic research, while a fee has to be paid when it is used in industrially supported research.

Names of people involved in the development of the Quality-of-Life-Recorder, contact addresses, literature references and sources of further information are given [here](#).

If you have questions not answered in this quick guide, please consult the remaining online-help. It has introductory sections, sections for advanced users and another hands-on "[quick guide](#)" leading you step-by-step through the preparation and presentation of an electronic questionnaire as well as towards data export into third party applications.

Should you still have questions, suggestions or other feedback, please contact the authors or people whose addresses are given [here](#).

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