

A Metadata Catalogue for the Netherlands Cancer Registry

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INTRODUCTION

The Netherlands Cancer Registry (NCR) is a patient-centered population-based registry that contains key data of all patients with cancer in the Netherlands. This data is used, amongst others, for scientific research and for this purpose, researchers can request subsets of the data. Currently, [the information that is provided about the data](#) is quite limited. This makes the request process more cumbersome than it needs to be, both for the researcher and for IKNL, the organization that maintains the NCR. With more information about the NCR, it would be easier for the researcher to formulate his research question and data request.

OBJECTIVES

To make the NCR more FAIR, and specifically to address the F in FAIR, we are working on a metadata catalogue for the NCR. This catalogue will contain an overview of variables that can be requested, grouped by tumor type. For each variable, it will provide essential information such as a definition, allowed values for the variable and their meaning, time period in which the variable was collected, and region where the variable was collected.

MATERIALS AND METHODS

In the pilot phase, we will use a catalogue called [ELVIS](#) (Electronic List of Variables In Systems) that was built by the Cancer Registry of Norway (CRN). ELVIS consists of a React frontend with a Java backend connected to a MySQL database that contains the metadata. CRN's intention is to make ELVIS open source in the future, and as a pilot project IKNL has been given access to the source code. ELVIS was adapted for the NCR and the adaptations mainly consisted of:

- Translation of the Norwegian part of the catalogue to Dutch
- Disabling functionality that is currently not needed
- Adaptation of the color scheme to fit the IKNL color scheme
- Replacement of the CRN metadata with NCR metadata

We intend to publish the catalogue for two tumor types this year and evaluate it with end-users.

RESULTS

Figure 1 shows a screen shot of ELVIS from the CRN site. In the left menu (based on ICD-10), breast is selected so all variables for breast are shown. By clicking on the button next to the variable the variable can be added to a wish list.

Figure 2 shows a screen shot of the ELVIS version for the NCR. Colors are modified to match with the IKNL color scheme and the menu on the left is now based on the tumor types as used in the NCR. The variables are still from CRN since the underlying database has not yet been filled with NCR metadata. Clicking on the variable name brings the user to a page with more details.

Figure 3 shows these details for a specific variable. In this case the Values tab was selected, which gives an overview of the allowed values for a variable.

Figure 4 shows the wish list. This wish list can be exported and attached to a data request. This is the first step in the integration of the catalogue and the data request process. The main purpose in this first step is uniformity of variable names in data requests.

CONCLUSION

Adapting ELVIS to our needs was straightforward. The main challenges in this project are determining the end-user needs and collecting the metadata. The latter are distributed across the organization, hence the focus on only two tumor types for now. Over time, other tumor types will be added, and the functionality of the catalogue may be expanded, for example with a tighter integration with the data request process.

Running a pilot with existing software gives us an opportunity to collect user feedback for the next phase of the project, which is the development of a catalogue prototype that fits the needs of the users and is maintainable by IKNL. This catalogue will make the NCR more Findable.

FIGURES

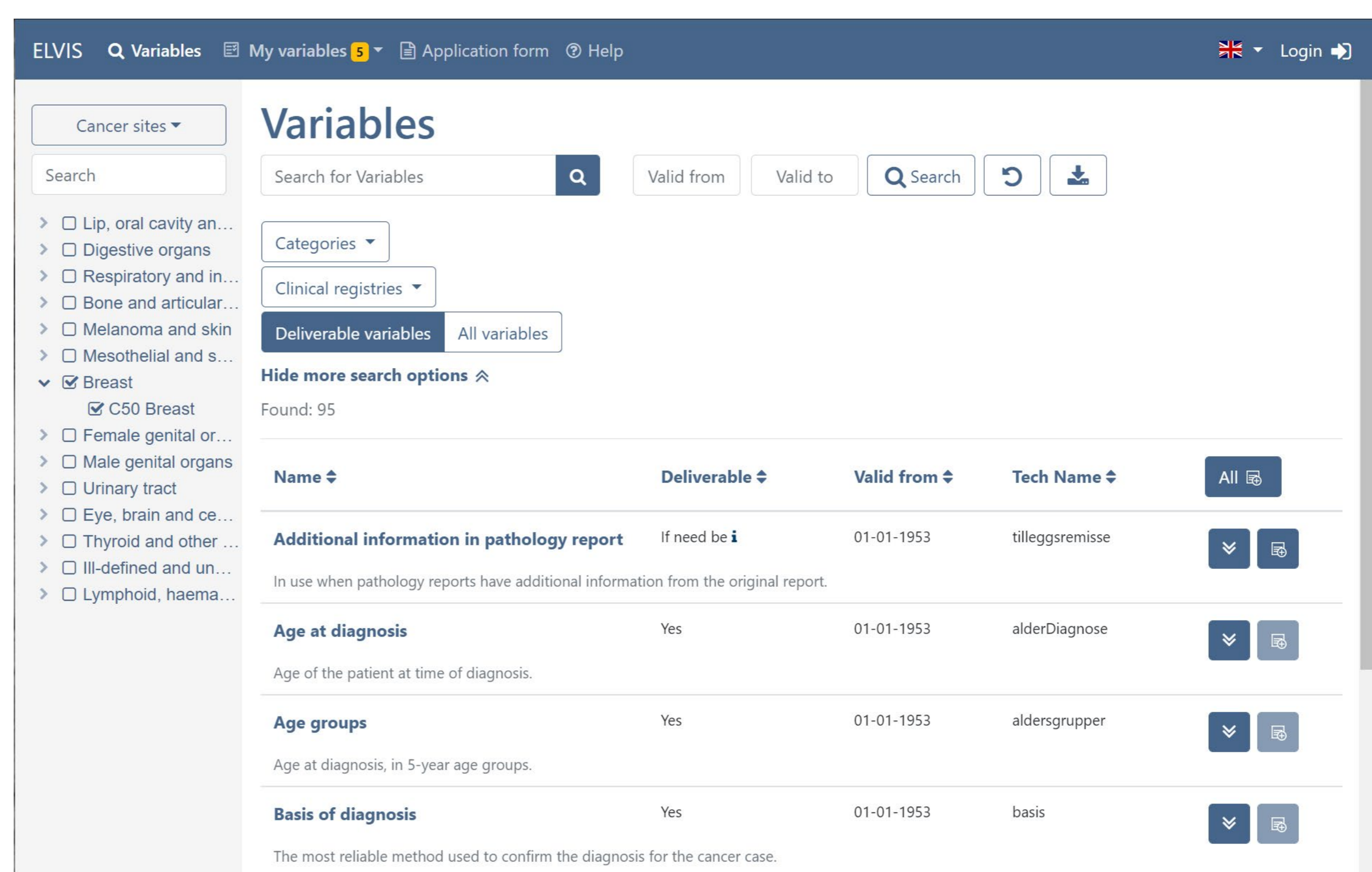


Figure 1: Screen shot of ELVIS from the CRN site.

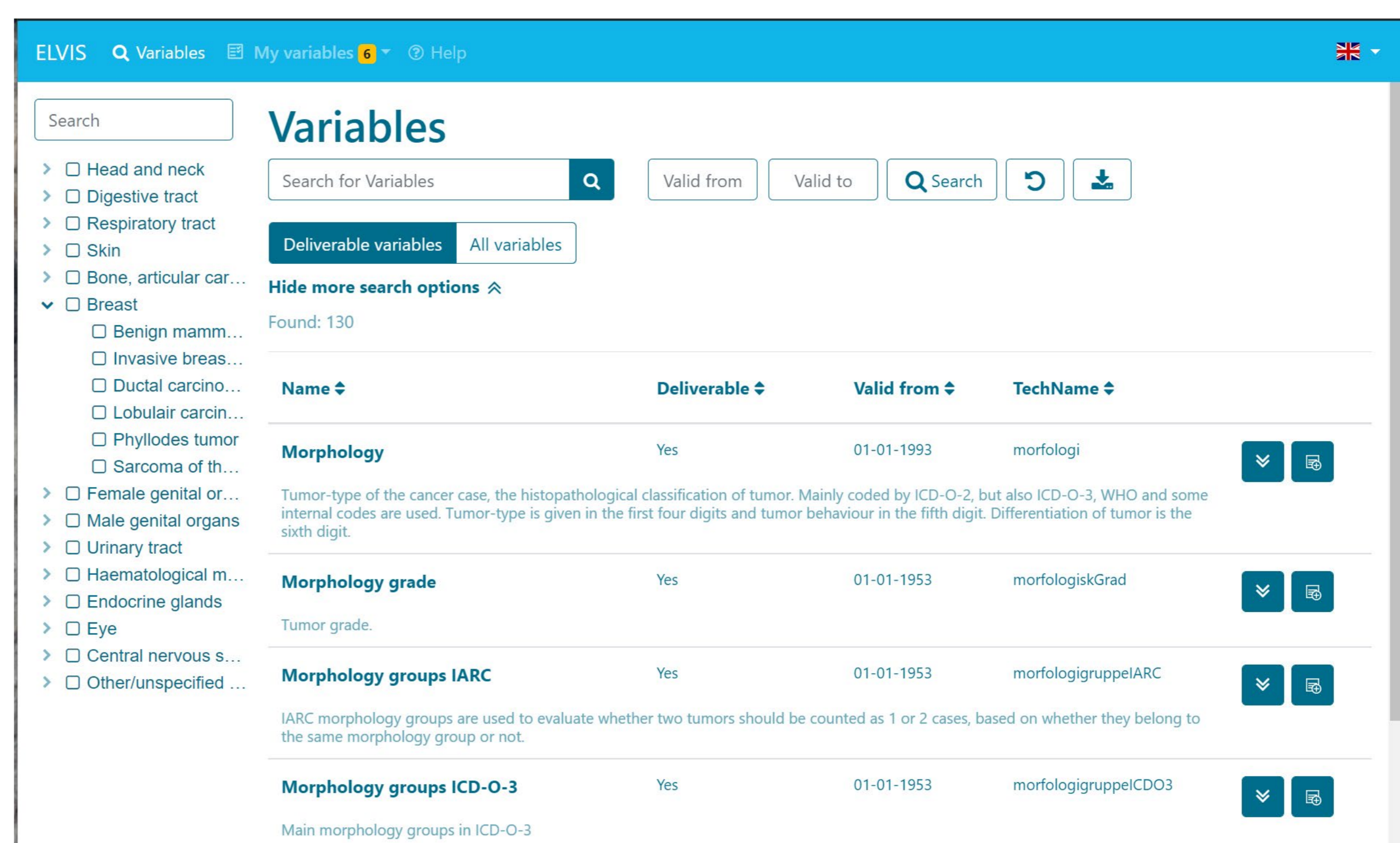


Figure 2: Screen shot of the ELVIS version for the NCR.

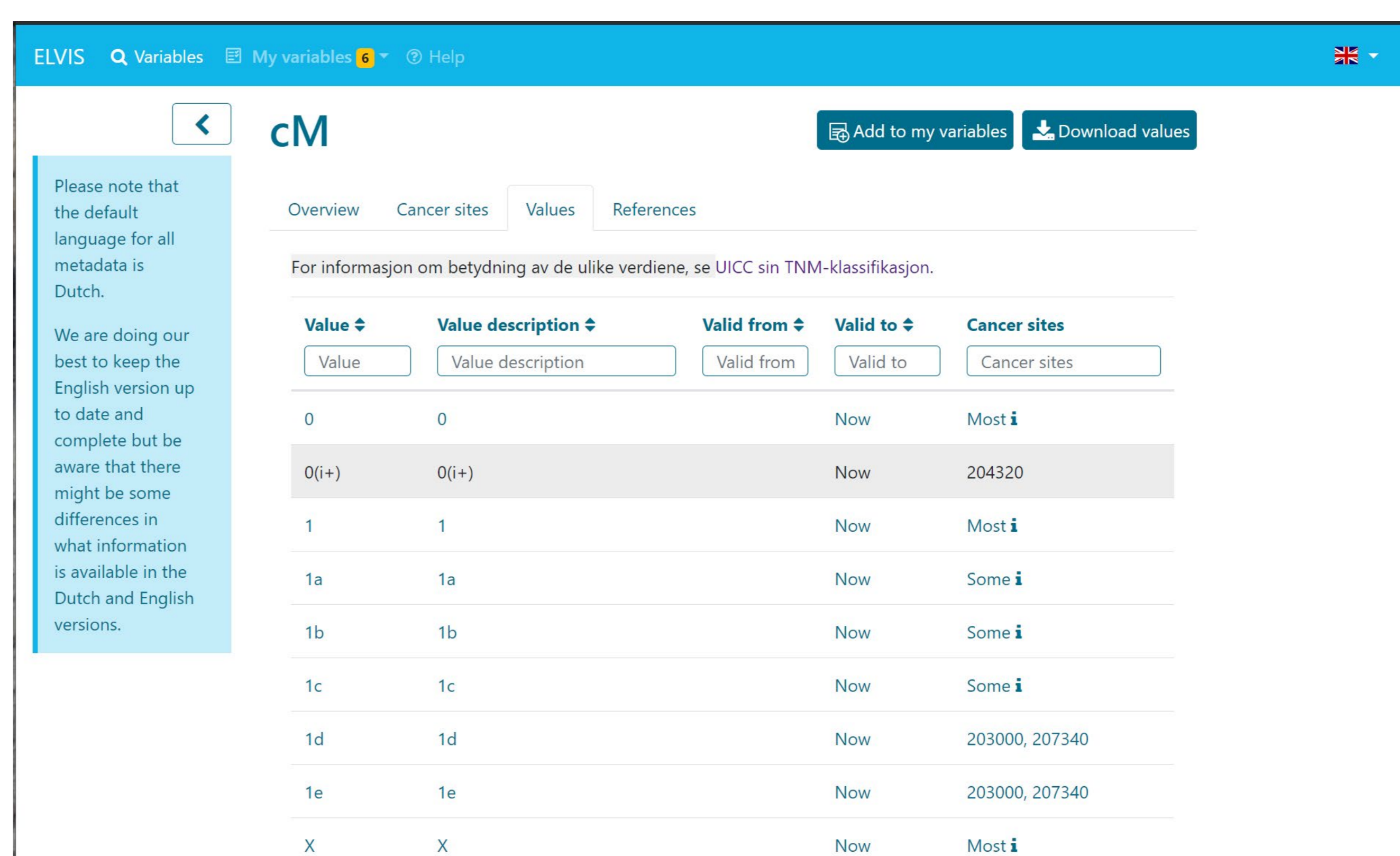


Figure 3: Screen shot of variable details.

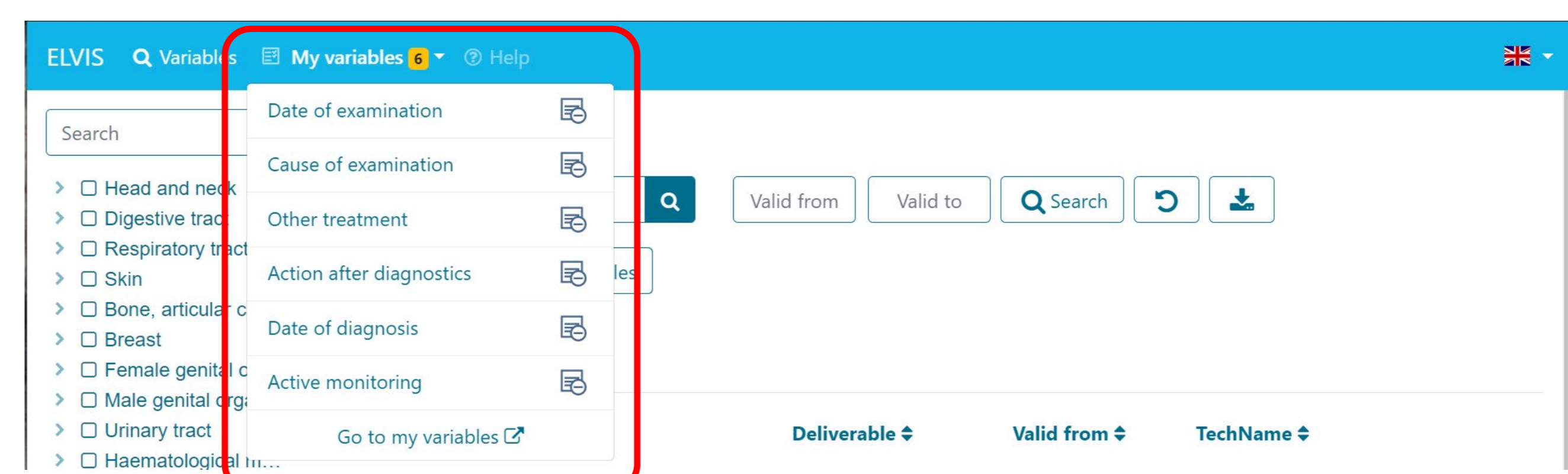


Figure 4: Screen shot of the wish list ("My variables"). The red box is not part of ELVIS but drawn here for emphasis.