

22-5-2024

Start of renewed registry

Dear (potential) members of the IHPBA-APHPBA Gallbladder Cancer Registry,

We're happy to announce that starting 2024, dr. Philip de Reuver and dr. Elise de Savornin Lohman (the Netherlands) have taken over the daily coordination of the registry from dr. Sirohi and dr. Jagannath, whom we'd like to thank for all their hard work.

In order to renew momentum for the registry, we've set up a completely new data collection interface. Moreover, the steering committee has decided that we will also be prospectively collecting data on patients with gallbladder cancer. We feel that this will enhance the quality of the data, encourage participants to keep the registry up to date and will provide us with opportunities to put the new definitions as established by the recent consensus meeting into practise.

Sincerely,

Dr. Philip de Reuver and dr. Elise de Savornin Lohman

On behalf of the Gallbladder Cancer Registry steering committee.

Methodology

For the registration, we will be using Castor EDC, which is a secure, online data management tool, financed by the Dutch research group. The tool is easily accessible and convenient to use.

Although the tool is intuitive and does not require in-depth explanation, instructions on use of the database will be still provided by the Dutch daily management team. All patients presenting with gallbladder cancer from now on onwards are eligible for inclusion.

Inclusion criteria

Any patient with gallbladder cancer aged >18

Outcomes

Primary: Overall survival

Secondary: Baseline characteristics, incidence rates, treatment patterns (medical and surgical)

Variable definitions

The variables that will be collected are extremely similar to those in the retrospective registry. All variables are defined in such a way that regardless of the specific outcomes of the consensus criteria, data will be able to be analyzed according to the established definitions.

Use of own data

The new data management system allows all local investigators to track their number of inclusions live, and compare it to the others in the database. Moreover, every investigator is able to download their own data for personal use. In order to utilize data from other centers, a research proposal needs to be sent to the steering committee and approved by all members.

Interested?

Please visit our website: www.gbcregistry.com, or send an e-mail to the study coordinators (Philip.dereuver@radboudumc or elisedesavorninlohman@gmail.com)