

The HUNTER: Hepatocellular Carcinoma Expediter Network Registry

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Background: Research into HCC is challenging due to limited numbers of patients who remain sufficiently fit to treat. Furthermore, patients typically present to a single centre, providing small and localised samples for research. Historical biobanks can be utilised, but without adequately funded programmes of research, robust data are limited. In association with the Italian (IACR) and Spanish (AECC) associations for research on cancer, Cancer Research UK have awarded an Accelerator grant entitled HUNTER: Hepatocellular carcinoma Expediter Network, which aims to overcome these challenges.

Objective: To create a patient registry supporting the prospective recruitment of 1500 patients (1000 with HCC, 500 controls) over the next 4 years that is:

- ✓ A secure, internet-based and code-linked anonymised data collection system.
- ✓ Easily accessible to HUNTER researchers across the UK and Europe, by individual user log-in.
- ✓ Intuitive to use, enabling easy functionality for collaborating sites when adding and updating patient data.
- ✓ A comprehensive dataset which supports research on: diagnosis, staging, treatment response and biomarker discovery in addition to novel therapeutic strategies.

Registry status: The HUNTER Registry has now been created (<https://hunter-registry.ncl.ac.uk>) by the Newcastle University Education Support Unit and modified by the HUNTER team to capture all required data. The registry went live in December 2019 and is now in active use, with forty prospective patients recruited by March 2020.

1. Using the registry: Logging On

Collaborators will login to the HUNTER registry's secure web-portal using a personal username and password allocated by the registry team.

Users can request a password reset by clicking here, this is encouraged to maintain security of the registry

2. Using the registry: Patient Enrolment and Overview

Users will add a new recruit to the registry by clicking here

Patient ID	Site Name	Investigator	Unique ID	Date of inclusion (dd/mm/yy)	Previous treatment for HCC	Date of treatment	Actions
UNEW_001_JAMC_HN_HCC	Newcastle (UNEW)	REEVES	JAMC	12/12/2019	1	None	[edit] [delete]
UNEW_002_JODA_HN_HCC	Newcastle (UNEW)	REEVES	JODA	16/12/2019	1	None	[edit] [delete]
UNEW_003_ELED_HN_HCC	Newcastle (UNEW)	REEVES	ELED	19/12/2019	1	None	[edit] [delete]
UNEW_004_KAWI_HN_HCC	Newcastle (UNEW)	REEVES	KAWI	19/12/2019	1	None	[edit] [delete]

The magnifying glass takes the user to the patient dashboard where they can edit/update or view a record

The dashboard gives an overview of all patients recruited and allows users to filter and export data.

3. Using the registry: The Patient ID

Once a patient has been successfully enrolled, the registry will automatically allocate a unique patient ID based on: **A:** Site name, **B:** Sequential number, **C:** Unique 4 letter ID, **D:** Study and **E:** Type of recruit

UNEW_001_JAMC_HN_HCC

A
B
C
D
E

4. Using the registry: Patient Dashboard

From the Patient Dashboard users can create, view and edit the visit forms available for each patient.

Records patient consent and exclusions

Records background information, general health and disease history

Further visit fields log: response to treatment, symptoms, staging and biological data

Summary: We anticipate that the registry will reduce data recording errors and facilitate high quality, large-scale, prospective data collection and sharing between sites. The Newcastle site is currently open with Cambridge and Imperial to follow shortly.

Contact: robyn.watson@ncl.ac.uk if you require access to the HUNTER Registry or have any further queries