HANA the National Head and Neck Cancer Audit – Patient Information

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Background

Clinical audits can provide an excellent way of improving the patient experience. Audits enable hospitals to monitor the standard of care received by their patients and record information on treatment. All data collected is subject to strict rules of confidentiality, so patients do not need to worry about it getting into the wrong hands. Clinical audit is a continuous process of looking at the care provided and asks:

- What should we be doing?
- Are we doing it?
- How can we improve?

Audits can be used to assess various aspects of patient care including:

- Structure – such as the availability of on-call consultants to deal with post-operative problems
- Process – such as whether a mouth cancer operation took place on the planned date
- Outcome – such as the number of cancer patients who remain disease free for 5 years

If an audit asks the right questions the data collected can also be used as a research database providing a valuable resource for researchers that will inform best practice in the future. It can answer important questions such as:

- What treatment works best?
- How can we improve a patient's quality of life?
- Can we assess the risks of a particular treatment more accurately?

What is HANA?

HANA is the new National Head and Neck Cancer Audit for England and Wales. It aims to improve the quality of services and the outcomes achieved for patients. A team of surgeons, oncologists, dentists, nutritionists, speech and language specialists and cancer audit experts have developed and will manage HANA. HANA will collect information about the diagnosis, management and treatment of every patient newly diagnosed with head and neck cancer, and their outcomes. The findings from HANA will contribute to changes in clinical practice ensuring that patients receive the best care possible and experience an improved quality of life.

Who manages HANA?

HANA is the short name given to the England and Wales **H**ead **A**nd **N**eck **A**udit and Registry. The previous National Head and Neck Cancer Audit, DAHNO (Data audit for head and neck oncology) ran for 10 years until 2014 and collected much valuable information relating to the care pathway. This information has now been transferred to HANA.

In July 2015, the Healthcare Quality Improvement Partnership awarded the National Head and Neck Cancer Audit contract to the charity Saving Faces–The Facial Surgery Research Foundation in partnership with the audit technology company Dendrite Clinical Systems Ltd. The commissioning arrangements for HANA changed again in May 2017. HANA continues as a national audit, but is funded by Saving Faces who manage the audit with input from head and neck cancer and audit experts who sit on its steering committee.

What does HANA measure?

HANA will collect information from all hospitals within England and Wales that diagnose and treat patients with cancers affecting all subsites in the head and neck such as the voice box (larynx), sinuses, jaws and mouth (oral cavity). HANA will focus on the quality of care delivered and patient outcomes and aims to assess:

- Service delivery and organisation
- Characteristics of newly-diagnosed head and neck cancer
- How the cancer was detected and the referral pathway
- Diagnosis, staging and planning of initial treatment
- Treatments received
- Complications of treatment
- Overall and disease-free survival
- The causes of delay in the treatment pathway

How is HANA data processed?

The hospital trust providing your care will send your information to Dendrite Clinical Systems Ltd electronically using secure data transfer methods.

Dendrite will act as guardians for your data and will store it securely. They may link your HANA data to other NHS databases held by NHS Digital and Public Health England. These databases hold patient information relating to hospital stays, radiotherapy given, chemotherapy given and cancer survival. Your name, date of birth and NHS number will be used to link HANA to the NHS databases. The linked information will help us to check whether HANA data is accurate. Data linkage will also provide information that will help us to improve our understanding about treatment choices and how best they can be combined to benefit patient care and survival.

When a patient's personal identifiers are no longer needed for recording and analysing their presentation, investigation, treatment and the clinical, emotional and sociological outcome of that treatment their identifiers will be permanently removed from their record.

Reporting HANA data

No personal identifiers will be used in HANA reports. Once a year Dendrite will combine the information from every individual hospital seeing and treating head and neck cancer patients in England and Wales. They will process and analyse the data and organise it by region, hospital trust and consultant. They will then remove your name, date of birth, NHS number and any other information that could be used to identify you from the reports produced. Dendrite will work with Saving Faces to produce regular HANA reports and local action plans. HANA results at regional, hospital trust and consultant levels will be compared with each other, and also with national standards of care for patients with head and neck cancer which have been set out by NICE (The National Institute for Health and Care Excellence) and British Association of Head and Neck Oncologist (BAHNO).

Who will benefit from HANA data?

Stakeholders – hospital and general practice staff, patients, carers, managers and the public will use HANA reports to assess the quality of care provided. They will also be able to see how closely local practice aligns to NICE and BAHNO guidelines. HANA published its first Clinical Outcomes Publication in February 2017 and will continue to publish reports. This will enable stakeholders to check progress and assess what improvements have been made. We will produce guidance and best practice examples for hospitals and trusts to help them achieve further improvements in patient care. These will be circulated to all stakeholder groups and presented at meetings of stakeholders.

The new information collected by HANA will also help to define, add to and refine existing quality standards.

HANA data may be shared for research purposes within the European Economic Area in a form that will not identify individual patients. The research will always be in line with the overall purpose of the audit aims, for example:

- Defining audit standards
- Publishing papers in medical journals to provide information about the best standards of care
- Providing information for public health

How reliable is the HANA data?

As HANA is a large national audit some items are bound to be inaccurate or missing. Linking your data with information in other NHS databases will help us to check whether the data provided by each hospital is complete and accurate.

Once your information has been added to HANA only your clinicians and their hospital / Trust's relevant administrative staff will be able to access, check and change it. Dendrite will keep a record of all changes that are made.

How we keep your information safe

Data protection and privacy is an important part of HANA so no individual patient names can be identified in the results.

Saving Faces and Dendrite will make sure the data collected is subject to strict rules of confidentiality as laid down by Acts of Parliament, including the Data Protection Act 1998, the Health and Social Care Act 2001 and the EU General Data Protection Regulation 2018. The national clinical cancer audits have been given permission to use and store patient data in accordance with these strict regulations.

How long do we keep your information?

By collecting a large amount of information, it is easier to identify the most effective treatments, which can benefit patients. This can change cancer care so that in future patients will survive longer and have a better quality of life after treatment.

We will retain the HANA data for a period of up to 20 years to enable us to collect, assess and report on the complications and outcomes of treatments.

Can I opt out of HANA?

National clinical audit is most effective when it has information from as many patients as possible. If you do not want your information to be collected for the HANA audit, please tell the people who are treating you and they should inform their hospital's staff not to transfer your data to Dendrite. It is possible that some HANA information may already have been transferred to Dendrite. When the people who are treating you inform Dendrite about your decision, Dendrite will make sure that any HANA information that can be removed from the audit database is destroyed. This will not affect your treatment in any way.

Contact details

If you have any general questions about this audit, please contact hana@savingfaces.co.uk