

# Micro-costing of UCLP from birth to 5 years old

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## Scientific outline

### Participants

Identification: Patients will be identified from a local database of cleft patients in Bristol and the South West. The patients will not have identifiable data collected – this will be pseudonymised by the researcher. The postcode of the patient's home address will be used to calculate the distance from the hospital and the distance shall be recorded in the database, the postcode will not be recorded. A database for the extraction of information will be used to record the outcomes.

### Inclusion and exclusion criteria

Participants will be included if they:

- were part of the CCUK database; and
- have a diagnosis of unilateral cleft lip and palate
- living the South West of England

Exclusion criteria:

- Patients who have moved away from the area and have no further data on outcomes.
- Have a diagnosis of facial cleft, bilateral cleft, submembraneous cleft or cleft palate.
- Began treatment in a different country or area where the history of their treatment is not easily obtainable or is not in English.

Design and Methods: This is a retrospective economic study of all patients born with a unilateral cleft lip and palate that are under treatment by the South West Cleft Team (Bristol) and were born between January, 2007 and June, 2011. The investigator (GS) will collect the data from the hospital records of patients by visiting the hospitals in the South West of England. The total number of patients possible to be included is 63. However once the notes have been scrutinised note all patients identified may meet the criteria. It is likely that most data will be contained in the notes at both the hospital hub, Bristol Dental Hospital. It may be necessary to visit the spoke hospital where patients are routinely seen for cleft care as they will have routine appointments at these clinics. Data is collected from prebirth to the age of 5 years. Where possible we plan to micro-cost the elements of resources used with appropriate unit costs from either local or national sources. This may at a later date be contrasted with top-down methods of cost calculation. Where cost calculation is not fully possible there may have to be some cost estimation involved.

#### Data Collection: Costs to the NHS

Using a formulated database collection of data will include for example:

- Treatment or care received for the mother if an antenatal diagnosis of UCLP is made.
- Any early life costs i.e. neonatal care, feeding bottles and teats.
- Attending specialised cleft clinics.
- Surgical treatment and time spent in theatre
- Clinic appointments including specialities involved.
- Laboratory costs for dental models
- Photographs taken by medical photography
- Attendance at a Cleft Team audit clinic

For a full breakdown of data collection please see *Appendix 1*.

What should not be counted as costs:

- Costs associated with treatment, appointments for medical care not involving the UCLP ie. trauma, treatment as part of a syndrome that includes treatment out of the head and neck region.

Costs to the parent or guardian: Identifying much of the costs incurred by the family of the child will require assumptions to be made. For example the loss of earnings based on time off work will require the assumption of a parents' hourly wage. By collecting the distance between home and hospital will give an idea of travel costs. It may also be beneficial to calculate the furthest possible distance within a hospital catchment thereby giving a maximum travel cost possible. Costs associated to the parent or guardian of the child will be based on the following:

- *Time off work*- assumptions can be made based on appointment attended. For example, attending an hour appointment could require 0.5 day off work.
- *Loss of leisure time*- can include assumptions made about recovery from surgery and loss of annual leave allowance.
- *Travel to hospital plus subsidiary*- based on distance calculations from home to hospital