

in childreN with ClefT Palate Study event for the

development of a core

outcome set

6th March 2014.

Meeting room 11, MacDonald Manchester Hotel and Spa, London Road, Manchester, M1 2PG Tel 0161 272 3200. Contact on the 6th March 2014—Nicola Harman Hotel information: <u>http://www.macdonaldhotels.co.uk/our-hotels/macdonald-manchester-hotel-spa/useful-information/</u>

Agenda

	Arrival and registration (refreshments on arrival).—Breakout space
10.30	Parallel session for parents/patient representatives with Heather Bagley (Patient and Public Coordinator) - 10.30-11.00 Meeting room 11
11.00	Welcome and introductions
11.30	Introduction to the MOMENT Study
11.45	Introduction to core outcome sets and plan for the day
12.00	Methods—what we did and how we did it.
12.15	Results from qualitative interviews with parents and children
12.30	Results from the Delphi survey of health professionals and online surveys of parents, children and young persons. Part 1.
13.00	Lunch— Hotel restaurant
13.45	Results from the Delphi survey of health professionals and online surveys of parents, children and young persons. Part 2.
2.30	Coffee Break—breakout space
2.45	Summary
3.15	What happens next
3.45	Meeting close

MOMENT Consensus meeting agenda V1.0



Study event for the

development of a core

outcome set

Would you like to contribute more to the MOMENT study by using your experience to help with the final stages of the project?

Part of the MOMENT study involves the development of something called a core outcome set. An outcome is a result of treatment and can be thought of as the "what" to measure to find out if treatment has worked. The MOMENT study wants to find out what the most important outcomes/results of

treatment are and should be included in future research.

Why do we need a core outcome set?

A core outcome set represents the minimum set of results that should be measured in future research. To decide which treatments are best for patients, it is important to look at the effect those treatments have on patients. Researchers do this by measuring an 'outcome.

By having a set of agreed outcomes that are "core" to all trials it will be easier to compare and combine results of studies so that all of the evidence available can be used to help determine if one treatment is better than another.

Event details Date:

Thursday 6th March 2014

Venue: MacDonald Manchester Hotel, London Road, Manchester.

Time: 11am-4pm (lunch provided)

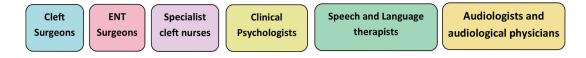
Who will be invited?

Parents of children with cleft palate and glue ear

Parents of children with cleft palate and glue ear who have taken part in qualitative interviews for the study, who have completed an online survey or who are on the CLAPA mailing list will receive an invitation to take part.

Health care professionals who provide care for children with cleft palate

Health care professionals who have taken part in all three rounds of an online survey and who have expressed an interest in taking part in further meetings about the core outcome set.



MOMENT Consensus meeting summary V2.0 19-2-2014

What will I need to do?

If you decide to take part we would like you to attend the meeting in person and to join a discussion about which outcomes should be included in the core outcome set.

A list of 47 outcomes have already been scored by parents and health professionals. Each outcome was given a score from 1 (not at all important) to 9

(extremely important). At the meeting we will present the results for each of the outcomes and how important each group though it was. We will also send you these results before the meeting including a reminder of what you scored if you took part in the online survey.

At the meeting we will discuss each of the outcomes in turn to find out:

Do the results show that the outcome is felt to be important enough to be part of the core outcome set, and can those at the meeting confirm that

Do the results show that the outcome is not important and should not be part of the core outcome set, and can those at the meeting confirm that. Where the results show that there are mixed feelings, we will discuss the outcome and vote, anonymously, on the inclusion or not of the outcome in the core outcome set.

What happens after the meeting?

The summary of the results and the summary of the meeting will be reviewed by two groups of people involved with the study, these are called the Study Advisory Group and an independent group called the Study Steering Committee. They will pay particular attention to the consistency of the results for each outcome to be included in the core outcome set. They will ensure the study results are presented transparently.

Useful Information

Travel expenses will be covered and if you prefer we are able to book your travel arrangements for you. Please note the current mileage rates are 40p for the first 150 miles of a round trip and 25p thereafter and we are able to cover up to the cost of standard train fare only. If you are attending as a parent of a child with cleft palate we are also able to cover the cost of any child care that you might need to attend the meeting. Travel (unless booked by ourselves) and childcare costs will be reimbursed following the meeting and expenses forms will be available to complete on the day.

What happens next?

If you would like to take part in the meeting please contact

to confirm your

attendance .

Alternatively if you have any questions please contact

Thank you for your support of the MOMENT Study!



