Can stem cells be used to improve palate repair (both primary and secondary)?
Patient/carer ranking: 10
Clinician ranking: 13

Original questions:
- *can palate stem cells be grown to form a graft that would fill a fistula, where previous surgery had left, rather than use a graft from the cheek?*
- *will stem cells be used to close the hole in the palate?*
For infants born with cleft lip/palate what is the most effective care pathway for promoting mother/infant bonding?
Original question:
- Bonding - The importance of ensuring all care is evidence based to allow confidence in ensuring babies born with this defect are given same chance of the bonding process (skin to skin, breastfeeding, rooming in) as babies born without this defect.
How can reflux be treated best in babies with cleft lip/palate?
Patient/carer ranking: 5
Clinician ranking: 24

Original question:
- *Please do research into the violent reflux that is (I am told) so prevalent in Pierre robin babies (it certainly was extreme in our daughter).*
How can we improve the diagnosis of cleft palate?
Patient/carer ranking: 7
Clinician ranking: 28

Original questions:
- How can a cleft of the soft palate be missed and what actions would be taken to stop this from happening?
- Does 3d/4d scanning help define the problem better than 2d?
- During pregnancy when is it possible to tell if the baby has a cleft lip?
- Are there certain key signs/symptoms that health professionals should be aware of?
In individuals with cleft lip/palate what is the most effective speech therapy to eliminate cleft type speech characteristics?
Patient/carer ranking: 1  
Clinician ranking: 15

Original questions:
- *What type of therapy input is most effective in remediating cleft type characteristics?*
- *What can we do to improve the speech outcomes for children with cleft?*
In individuals with cleft lip/palate when is the most effective age to begin speech therapy?
Patient/carer ranking: 24
Clinician ranking: 7

Original questions:
- *The effectiveness of speech therapy treatment in cleft preschool and school aged children*
- *What are the benefits of early speech and language therapy for a child with cleft lip and or palate?*
- *We feel S/T is not appropriate to our son at the age of 14 years of age. We are disappointed in how he sounds and are very concerned for his future*
In infants with cleft lip/palate, what is the most effective post-op care for primary palate repair? (including probiotics, splinting, feeding and dummies)
Patient/carer ranking: 17
Clinician ranking: 23

Original questions:
- *Do arm splints worn by infants post op make any difference to fistula rates?*
- *What can be done post-operatively to improve the chances of a successful procedure?*
- *Are current postoperative nursing practices required: eg arm splints; soft diet; isolation in cubicles; dummies not allowed?*
What and when is the best protocol for repair of the lip and palate, including technique/timing and sequence?
Patient/carer ranking: 2
Clinician ranking: 5

Original questions:
- *What are the best ways to cosmetically improve the appearance of a cleft lip scar?*
- *In cleft lip repair, is there any evidence for the use of absorbable sutures, permanent sutures or glue for optimal skin closure? What is the socioeconomic cost of each method?*
- *Does the timing of the repair to a cleft palate have any lasting affect on speech development?*
What are the educational, employment and personal (eg relationships) outcomes for individuals with cleft lip/palate during childhood, adolescence and in the long term?
Patient/carer ranking: 20
Clinician ranking: 1

Original questions:
- How do children deal with cleft palate at school?
- What success in life does a child born with a cleft lip achieve?
- Are they discriminated when seeking employment?
- Has having a cleft lip stopped you achieving your goals?
- What are the long term (ie adulthood) prospects for individuals with cleft eg. education, employment, relationships?
What are the factors that predict the psychological outcomes for individuals with cleft lip/palate?
Patient/carer ranking: 31
Clinician ranking: 9

Original questions:
- What are predictors of good/poor psychological outcome?
- Why do some people cope with having a cleft and others not?
What are the genetic causes of cleft lip/palate?
Patient/carer ranking: 9
Clinician ranking: 32

Original questions:
- *When will we find a gene specific to cleft lip and palate?*
- *What gene causes cleft lip/palate?*
- *Is there any way of finding out if the cause of cleft lip/palate in any particular child is genetic?*
What can be done to improve the experience of families of a baby with cleft lip/palate at time of birth in hospital?
Patient/carer ranking: 11
Clinician ranking: 27
What can be done to prevent cleft lip/palate?
Patient/carer ranking: 4
Clinician ranking: 12

Original questions:
- How can cleft lip and or palate be prevented?
- Once you've had a child with cleft is there a way to avoid or reduce/improve the likelihood for future babies?
- Is there anything parents can do to minimise clefting before pregnancy e.g. Taking folic acid?
What exposures pre- and during pregnancy increase the risk of having a baby with a cleft?
Patient/carer ranking: 8
Clinician ranking: 35

Original questions:
- Can consumption of alcohol in the early weeks of pregnancy cause clefts?
- Is Cleft Lip/Palate in babies related to diet?
- Can radiation from echocardiography machine affect pregnant women?
- Are there any medications that may lead to cleft lip/palate?
- Is there a connection between a virus caught by the mother and formation of cleft lip and palate?
What interventions would enhance the educational outcomes for children with cleft lip/palate?
Original question:
- *Is there an intervention that can improve educational achievement in children with CL/P?*
What is the best feeding method for babies with cleft lip/palate, including those with syndromes (including breast feeding, nasogastric tubes and weaning times?)
Patient/carer ranking: 10
Clinician ranking: 18

Original questions:
- Which feeding interventions are most effective for babies with cleft lip/palate?
- When is it necessary or beneficial to use tube feeding?
- Is one feeding method (bottle/teat type) easier for the infant than another?
- What are the relative successes of different feeding options (breastfeeding, bottle, others)?
What is the best management plan around the surgical procedure for primary cleft lip/palate repair? eg pain control, fluids.
Patient/carer ranking: 28
Clinician ranking: 32

Original questions:
- When a baby has had a cleft repair operation, what other pain relief can be offered that is not morphine?
- What can parents do to optimise time and outcome of surgery?
What is the best treatment for otitis media with effusion (OME - glue ear) in individuals with cleft lip/palate?
Patient/carer ranking: 7
Clinician ranking: 10

Original questions:
- What is the optimal treatment for glue ear in cleft patients: Grommets vs hearing aids?
- Does aggressive management of glue ear as babies lead to better speech outcomes?
- Should grommets be inserted at time of palate repair?
What is the best way to prevent tooth decay in children with cleft lip/palate?
Patient/carer ranking: 21
Clinician ranking: 8

Original questions:
- How to prevent decay?
- Generally - what is the best way to prevent dental decay in patients with clefts. In particular is it better to provide fluoride from tablets or toothpaste or both. How should dietary advice best be provided to families too?
What is the heritability of cleft lip/palate?
Patient/carer ranking: 15
Clinician ranking: 36

Original questions:
- Is there a hereditary chance of cleft lip / palate?
- Did I inherit it from my mum?
- Why me? What are my daughter’s chances of having a baby with a cleft?
- My son and I both were born with Cleft Lips and Palate, my daughter was not and her son was not, why does it seem to be only in the male line?
What is the impact of an antenatal diagnosis of cleft lip/palate on the mother, child and the family?
Patient/carer ranking: 17
Clinician ranking: 27

Original questions:
- How much do we know about ante-natal diagnosis?
- What is the difference in psychological adjustment following antenatal and postnatal diagnosis of a cleft?
- Is antenatal diagnosis useful? – Risk vs. benefits?
What is the impact of having a baby born with cleft lip/palate on maternal/child attachment?
Patient/carer ranking: 34
Clinician ranking: 31

Original questions:
- What is the impact of very early attachment relationship issues on psychological wellbeing of parent and child?
- Does having a baby with a cleft have any impact on how well the parents bond with their child?
What is the impact of parenting approach on the outcomes for children with cleft lip/palate?
Patient/carer ranking: 35
Clinician ranking: 13

Original questions:
- *What is the affect of parenting style on the later development of children with a cleft?*
- *Does parenting style make a difference in promoting resilience in children with CL/P*
What is the most effective intervention for children with cleft lip/palate to minimise the impact of bullying?
Patient/carer ranking: 5
Clinician ranking: 19

Original questions:
- What are the most successful strategies to combat bullying for children with speech difficulties?
What surgical outcomes are important to patients with cleft lip/palate and are they met?
Patient/carer ranking: 34
Clinician ranking: 6

Original questions:
- How happy are patients after surgery with outcome and appearance of their cleft lip and palate? Are their expectations a reality or too high?
What types of psychological intervention (individual therapy, community or school based) and at what time (from diagnosis to adulthood) are most helpful for patients with cleft lip/palate and their families?
Patient/carer ranking: 6
Clinician ranking: 3

Original questions:
- *When are the important times to offer additional support?* - *what kind of support do people want?*
- *Does early psychological intervention for families with children with congenital visible deformity improve 'psychological resilience' in those children when they grow up?*
- *How can parenting behaviour be taught to optimize the outcome of cleft children as adults?*