STANDARDS FOR THE SCOTTISH DIAPHRAGMATIC HERNIA CLINICAL NETWORK (SDHCN)

The background

No specific standards exist for the management of Congenital Diaphragmatic Hernia (CDH), although guidelines for neonatal management are readily available. Two Cochrane reviews pertain to the management of CDH (iNO and late *vs* early surgery).

The generic Standards for MCN include the following

Standard 1: Organisation – Management Arrangements and Accountability

Standard 2: Clinical – Delivering CDH clinical network care

Standard 3: Multidisciplinary working

Standard 4: Staff education and Training

Standard 5: Audit, Monitoring, Research and Development

Standard 6: Patient Focus and Public Partnership

Most other MCN have developed at least 5-6 standards.

Individually developed standards should:

- have a sound evidence base
- focus on clinical issues
- directly relate to the objectives of the MCN
- be clear and measurable
- follow the patient pathway, and
- be consistent with other MCNs of the same topic across Scotland

From the generic standards, I suggest that we should have at least one standard from the clinical subgroups (generic standard 2), and one standard from each of the categories 3-6.

Suggested standards for SDHCN:

Standard 1 Clinical – Antenatal Care

Standard 2 Clinical – Counselling

Standard 3 Clinical – In patient management

Standard 4 Clinical – Follow-up

Standard 5 Multidisciplinary working

Standard 6 Staff Education

Standard 7 Audit & monitoring

Standard 8 Patient information

STANDARDS FOR THE SCOTTISH DIAPHRAGMATIC HERNIA CLINICAL NETWORK (SDHCN)

Standard 1: Clinical (Antenatal Care)

Standard Statement 1:
Following identification of a congenital diaphragmatic hernia (CDH) on booking scan or fetal anomaly scan (FAS), the expectant mother will be offered a further detailed examination at a specialist fetal medicine service within 2-5 working days.

Rationale

At present, the best available prognostic antenatal criteria are based on liver position, lung head ratio and fetal echocardiography.

Time interval to referral is based Fetal Anomaly Screening Programme (FASP) guidelines.

Reference:

- http://fetalanomaly.screening.nhs.uk/
- Jani JC, Benachi A, Nicolaides KH, et al. Prenatal prediction of neonatal morbidity in survivors with congenital diaphragmatic hernia: a multicenter study. Ultrasound in Obstetrics & Gynecology;33(1):64-9, 2009
- Jani J, Cannie M, Sonigo P, et al. Value of prenatal magnetic resonance imaging in the prediction of postnatal outcome in fetuses with diaphragmatic hernia. Ultrasound in Obstetrics & Gynecology;32(6):793-9, 2008

Essential Criteria

1.1	With the introduction of routine anomaly scans, the expectation is that around 60% of patients will be identified antenatally.
1.2	A minimum dataset for antenatal scans has been agreed by the SDHMCN.
1.3	Data on fetal anatomical and physiological parameters are collated in a location that is accessible for staff involved in counselling, perinatal and postnatal treatment.

Indicator of Standard

1	Referred to Specialist Fetal Medicine Unit (Y/N)

STANDARDS FOR THE SCOTTISH DIAPHRAGMATIC HERNIA CLINICAL NETWORK (SDHCN)

Standard 2: Clinical (Antenatal Counselling)

Standard Statement 2:
When a CDH has been diagnosed antenatally, families will be offered multidisciplinary counselling. Ideally, counselling should include obstetricians, neonatologists, and neonatal surgeons but not necessarily all at one visit.

Rationale

To ensure that families are fully informed of the likely peri- and postnatal management possibilities.

Reference:

- Aite L, Trucchi A, Nahom A, Casaccia G, Zaccara A, Giorlandino C, Bagolan P. Antenatal diagnosis of diaphragmatic hernia: parents' emotional and cognitive reactions. Journal of Pediatric Surgery;39(2):174-8, 2004

Essential Criteria	
2.1	An information leaflet that has been designed and endorsed through the SDHMCN will be offered to the families in conjunction with counselling.
2.2	Counselling should ideally be planned to occur during two separate sessions in the second and third trimester.
Indicator of Standard	
2	Counselled by Obstetrician/Neonatologist/Surgeon (Name, Date)

Standard 3: Clinical (Inpatient Management)

Standard Statement 3: **Neonates born outwith specialist centres should be discussed with the relevant specialist centre within 2 hours of diagnosis.**	
Rationale To ensure that recommended management principles are employed from outset and to encourage discussion regarding optimal timing of transfer	
Reference: o SDHCN Steering Group opinion of best practice.	
Essential Criteria	
3.1	Each specialist centre should have a designated pathway for contact and discussion
3.2	The Neonatal Transport Service should be contacted by the referring hospital following discussion of the eligibility and appropriateness of transfer
Indicator of Standard	
3	Time to Referral (measured in “Birth Details”)

STANDARDS FOR THE SCOTTISH DIAPHRAGMATIC HERNIA CLINICAL NETWORK (SDHCN)

Standard 4: Clinical (Inpatient Management)

Standard Statement 4: **Newborns with CDH will be managed according to agreed guidelines that have been ratified by the SDHCN**	
Rationale Survival from CDH has been shown to improve with adoption of neonatal management guidelines.	
Reference: o Antonoff MB, Hustead VA, Groth SS, Schmeling DJ. Protocolized management of infants with congenital diaphragmatic hernia: effect on survival. Journal of Pediatric Surgery;46(1):39-46, 2011 o Bagolan P, Casaccia G, Crescenzi F, Nahom A, Trucchi A, Giorlandino C. Impact of a current treatment protocol on outcome of high-risk congenital diaphragmatic hernia. Journal of Pediatric Surgery;39(3):313-8, 2004	
Essential Criteria	
4.1	Inpatient management guidelines, produced by the SDHMN, offer guiding principles for management of ventilation, manipulation of pulmonary vascular reactivity and timing of surgery
4.2	Principles of management will be available on the website
4.3	Aspects of management will be discussed at educational study days to ensure information is current
Indicators of Standard	
4a	Repair done (Y/N)
4b	If no repair done, reason why not
4c	Maximum Peak Inspiratory Pressure on IMV
4d	Highest and lowest pCO_2 in first 24 hours

Standard 5: Multidisciplinary Working & Follow-up

Standard Statement 5: **Outpatient follow-up will be conducted to an agreed protocol**	
Rationale Children who survive CDH are known to have long-term morbidity, with some aspects only becoming apparent at a later stage	
Reference: o Gischler SJ, Mazer P, Duivenvoorden HJ, van Dijk M, Bax NM, Hazebroek FW, Tibboel D. Interdisciplinary structural follow-up of surgical newborns: a prospective evaluation. Journal of Pediatric Surgery;44(7):1382-9, 2009 o Lally KP, Engle W. Postdischarge follow-up of infants with congenital diaphragmatic hernia. Pediatrics;121(3):627-32, 2008	
Essential Criteria	
5.1	Specific needs should be assessed for individual patients with emphasis on nutritional, respiratory and developmental outcome
5.2	Multiple health care practitioners may be involved in ongoing care and these personnel should be aware of the potential morbidity in CDH
5.3	Local follow-up should be encouraged if adequate resources are available to offer a streamlined service
Indicator of Standard	
5a	Record of different specialities that have reviewed in out-patients
5b	Post-discharge Hearing screening

Standard 6: Staff Education

Standard Statement 6:
The Network will provide regular education for staff involved in managing patients with CDH and each specialist centre will be represented and will encourage and facilitate staff to attend. **Telehealth links will be utilised to facilitate this where appropriate.**
Rationale Ensure staff are aware of current management options and outcome data
Reference: o http://www.sdhcn.nhs.uk o http://www.sctt.nhs.uk/
Essential Criteria

6.1	The Network will arrange yearly educational days with locations to be rotated to encourage attendance from all centres
6.2	Topics covered will include presentations that will focus on each discipline involved in the care of families and patients with CDH
6.3	Educational days will be advertised in all paediatric and maternity units with adequate notice
Indicator of Standard	
6	Network to record date of education day, topics and attendance (each centre)

STANDARDS FOR THE SCOTTISH DIAPHRAGMATIC HERNIA CLINICAL NETWORK (SDHCN)

Standard 7: Audit & Monitoring

Standard Statement 7:
The network will record activity, management and outcome of patients with CDH

Rationale

A national database will provide a greater understanding of the aetiology, demographics, management strategies and outcome for CDH in Scotland.

Reference:

- Doyle NM, Lally KP. The CDH Study Group and advances in the clinical care of the patient with congenital diaphragmatic hernia. Seminars in Perinatology;28(3):174-84, 2004
- Ontario Congenital Anomalies Study Group. Apparent truth about congenital diaphragmatic hernia: a population-based database is needed to establish benchmarking for clinical outcomes for CDH. Journal of Pediatric Surgery;39(5):661-5, 2004

Essential Criteria	
7.1	Completion of SDHCN core dataset for CDH by each centre
7.2	Regular distribution of data during staff education days, website and newsletters
Indicator of Standard	
7	Network completion rate of core dataset

Standard 8: Patient Information

Standard Statement 8:
An information leaflet will distributed to parents of children with CDH (including prospective parents) with details of possible clinical expectations and links/contact details for further information and support.

Rationale

Parents will be provided with an information leaflet that covers antenatal and post-natal management possibilities to reinforce/augment information given at counselling, during in-patient stay and following discharge (or death)

Reference:

- Aite L, Trucchi A, Nahom A, Casaccia G, Zaccara A, Giorlandino C, Bagolan P. Antenatal diagnosis of diaphragmatic hernia: parents' emotional and cognitive reactions. Journal of Pediatric Surgery;39(2):174-8, 2004
- Weiner EA, Billamay S, Partridge JC, Martinez AM. Antenatal education for expectant mothers results in sustained improvement in knowledge of newborn care. Journal of Perinatology;31(2):92-7, 2011
- Keatinge D, Stevenson K, Fitzgerald M. Parents' perceptions and needs of children's hospital discharge information. International Journal of Nursing Practice;15(4):341-7, 2009

Essential Criteria

8.1	SDHCN has produced written information covering antenatal and postnatal management
8.2	The leaflet is also be available as a document on the website
8.3	The leaflet will be reviewed every 2 years to ensure accurate contemporaneous information is included

Indicator of Standard

8a	Parents offered Information leaflet antenatally (in “Birth details”)
8b	Parents offered Information leaflet after birth (in “Outcome-Discharge”)

Summary of Standard Statements

Standard Statement 1:

Following identification of a congenital diaphragmatic hernia (CDH) on booking scan or fetal anomaly scan (FAS), the expectant mother will be offered a further detailed examination at a specialist fetal medicine service within 2-5 working days.

Standard Statement 2:

When a CDH has been diagnosed antenatally, families will be offered multidisciplinary counselling. Ideally, counselling should include obstetricians, neonatologists, and neonatal surgeons but not necessarily all at one visit.

Standard Statement 3:

Neonates born outwith specialist centres should be discussed with the relevant specialist centre within 2 hours of diagnosis

Standard Statement 4:

Newborns with CDH will be managed according to agreed guidelines that have been ratified by the SDHMCN

Standard Statement 5:

Outpatient follow-up will be conducted to an agreed protocol

Standard Statement 6:

The Network will provide regular education for staff involved in managing patients with CDH and each specialist centre will be represented and will encourage and facilitate staff to attend. Telehealth links will be utilised to facilitate this where appropriate.

Standard Statement 7:

The network will record activity, management and outcome of patients with CDH

Standard Statement 8:

An information leaflet will distributed to parents of children with CDH (including prospective parents) with details of possible clinical expectations and links/contact details for further information and support.