



**Healthy London
Partnership**



North West London
Whole Systems Integrated Care

North West London CYP asthma meeting

Supported by and delivering for:



Public Health
England



SUPPORTED BY
MAYOR OF LONDON

London's NHS organisations include all of London's CCGs, NHS England and Health Education England

Severe Asthma Network

Dr Louise Fleming



Time to Pull Down the Ivory Tower and Put up the Big Tent



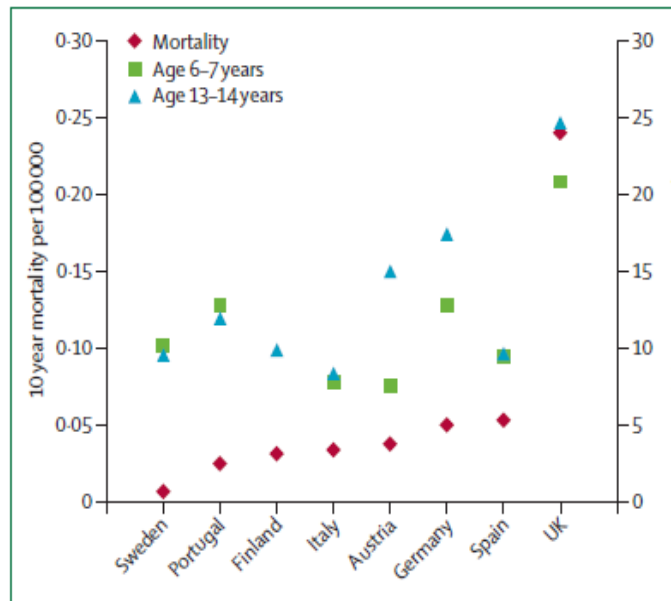
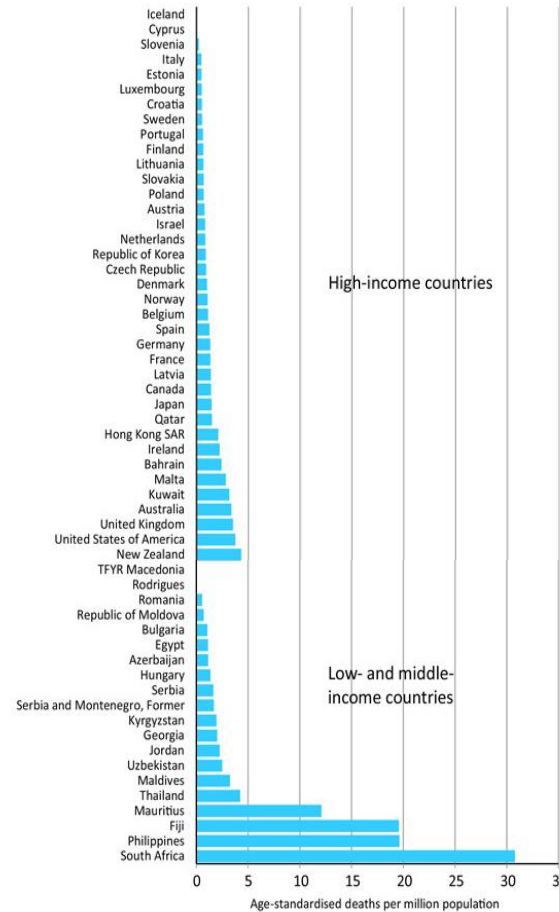


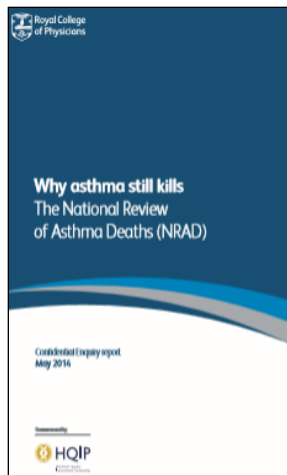
Figure 5: Asthma mortality rate in children aged 0-14 years, and proportion aged 6-7 and 13-14 years with wheeze, in eight western European countries

Wolfe, Lancet 2013;381:1224-1234



Age-standardised mortality rates for asthma, ages 2001 - 2010

Source: WHO Detailed Mortality Database, February 2014 update



- *Review of 195 deaths (28 CYP)*
- *Highlighted widespread inadequacies in care*
- *Particularly in children risk of adverse outcomes poorly recognised*

nuffieldtrust Evidence for better health care

Our priorities Research Health & social care explained News & comment

UK young people let down on long-term illness, new international report finds

Young people in the UK are making healthier life choices for themselves than before, but are more likely to die from asthma or have a poor quality of life from long-term conditions compared to counterparts in other high-income countries.

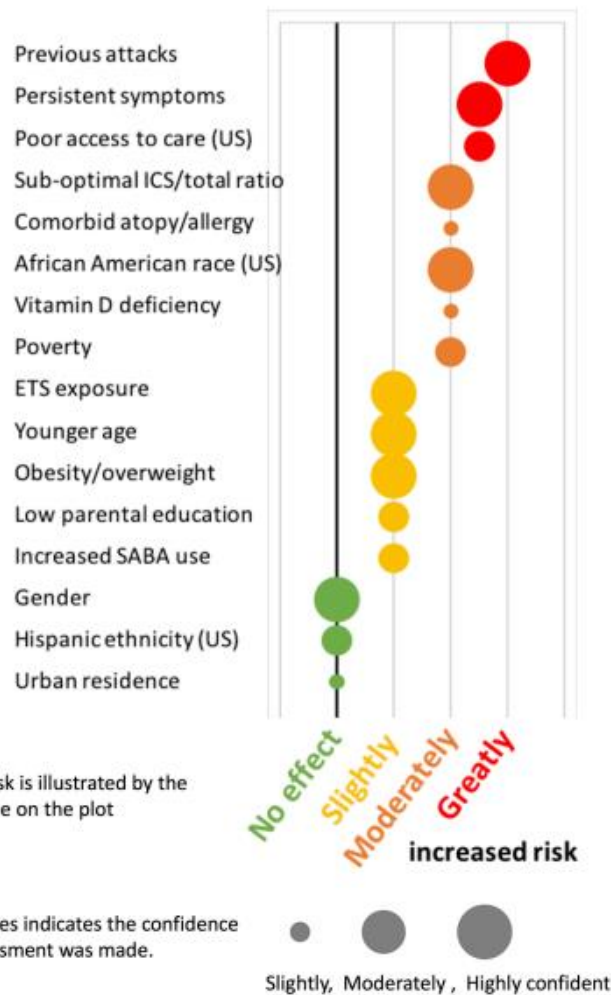
BBC NEWS

Home UK World Business Politics Tech Science Health Family & Education

Asthma: Young people in the UK 'more likely to die'

20 February 2019 129

GETTY IMAGES



ICS = inhaled corticosteroid; SABA = short-acting beta₂ agonist; ETS = environmental tobacco smoke

tion 28 asthma - Goo... X | nuffield asthma deaths - G... X | n UK young people let down... X | n Child asthma admissions: p... X | Asthma: Young people in th... X

ldtrust.org.uk/news-item/child-asthma-admissions-part-of-a-care-failure-iceberg

Mail - L.Fleming@r... | New Tab | TaskRabbit connect... | U13 Iron Challenge | Homework - St Mic...

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Child asthma admissions: part of a 'care-failure' iceberg

What should be done about persistently high emergency admissions for children with asthma?

QualityWatch

Blog post

Author
Dr Andrew Whittamore

Paediatric Asthma Care: Fragmented and Fatally Fallible

- Regulation 28 Reports
 - Failure to understand the chronic nature of asthma
 - Poor asthma control without recognising known risks
 - Failure to refer to respiratory experts
 - Failure of any single clinician to take an overview of care

Levy et al BJGP, submitted for publication

Organisation of Care

806

Thorax 2001;56:806-814

Clinical review

Asthma programme in Finland: a community problem needs community solutions

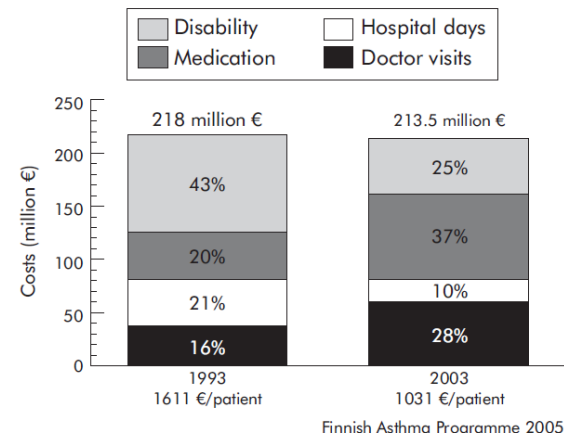
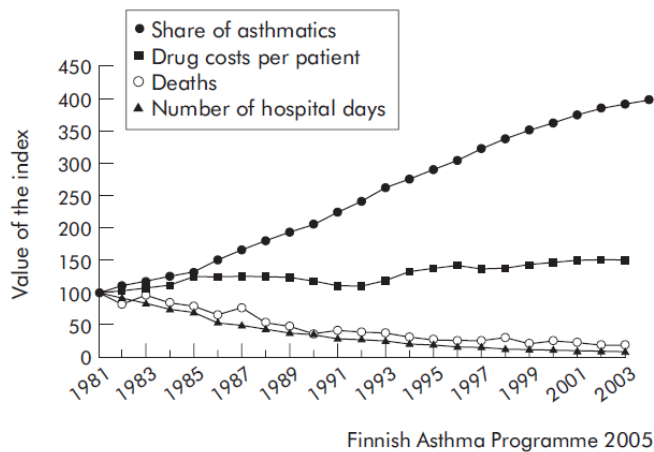
T Haahtela, T Klaukka, K Koskela, M Erhola, L A Laitinen, on the behalf of the Working Group of the Asthma Programme in Finland 1994-2004

ASTHMA

A 10 year asthma programme in Finland: major change for the better

T Haahtela, L E Tuomisto, A Pietinalho, T Klaukka, M Erhola, M Kaila, M M Nieminen, E Kontula, L A Laitinen

Thorax 2006;61:663-670. doi: 10.1136/thx.2005.055699



Problems with Current Model

- Poorly defined care pathways / thresholds for onward referral
- Does a severe asthma centre have a “local” role to play?
- Referral to a “severe asthma” service
 - What is severe asthma?
 - Very little detail as to what service should be provided
 - The value of referring to a specialist team is unclear
 - Referral pathways may vary for different resp conditions (CF versus asthma)
 - In some areas there isn’t a clearly defined service (nationally)
 - Transition

Adult Severe Asthma Service

A Network-Based Approach for Specialised Severe Asthma Services

A proposal to support specialised commissioning for adult severe asthma services

Sent to NHS England on 14 July 2014



Hub and Network Model

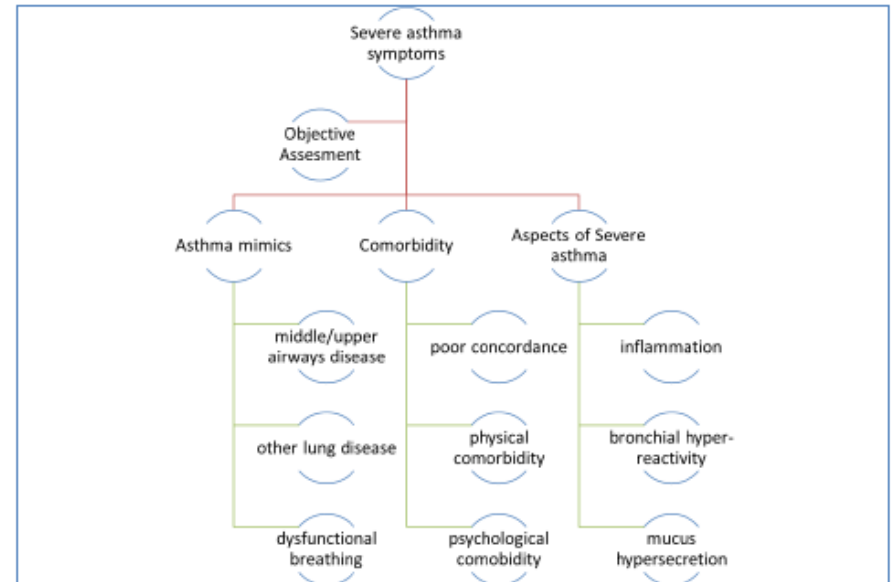


Figure 1: Example of the complex severe asthma pathway which needs to be addressed in specialist severe asthma clinics.

The Difficult Asthma Patient

S3 The uk's largest severe asthma multidisciplinary team meeting: experience from the first 18 months

D Ryan¹, R Niven¹, H Burhan², J Corless³, S Diver¹, S Fowler¹, D Menzies⁴, R O'Driscoll⁵, S Scott⁶, N Sehgal⁷, A Vyas⁸, D Allen⁷, J Blakey⁹, B Kane¹

Author affiliations



Chest clinic



OPINION

Specialised commissioning for severe asthma: oxymoron or opportunity?

Binita Kane,¹ Sophie Cramb,² Val Hudson,² Louise Fleming,³ Clare Murray,⁴ John D Blakey^{5,6}

National CQUIN 2016 - 17

- 2016-17: assessment of children and young people with problematic severe asthma
- Dedicated MDT (Respiratory Paediatrician, CNS, physiotherapist and psychologist)
- MDT assessment within 12 weeks
- Data entered on national registry

NHSE (London Region) Specialised Commissioning

- Recognition of the need to build upon existing work
- Overarching aim to improve standards of care for children with severe asthma across London
- London Paediatric Severe Asthma Network (LPSAN) established at the request of NHSE

Local CQUIN 2017 - 19

- In addition to the 12 weeks MDT assessment:
- Establish a network model
 - Establish a network of care working alongside primary and secondary care
 - Clear information about who is responsible
 - Describe and develop care pathways
- Establish a clinical network between specialist centres (LPSAN)
 - Share learning
 - Develop guidelines and protocols
 - Research and academic opportunities

UK Paediatric Difficult Asthma Network Registry

Welcome to the UK Paediatric Difficult Asthma Network Registry

Over 1 million children in the UK are diagnosed with asthma. Most of these are well controlled however some continue to have frequent symptoms and asthma attacks despite high intensity treatment – these children have problematic severe asthma (PSA). This has a significant impact on their quality of life and represents a significant burden to the NHS. At present we do not know how many children there are in the UK with PSA and whether they are being assessed appropriately.

The aim of this registry is to help us to understand more about the clinical characteristics of these children and ensure that they receive the appropriate multi-disciplinary assessment. It will enable us to track clinical progress. It will also help us to identify children with severe therapy resistant asthma and enable the development of targeted treatment.

Dr Louise Fleming

*Clinical Senior Lecturer Imperial College, London and
Honorary Consultant Respiratory Paediatrician, Royal Brompton
Hospital*

Web Registry Powered by Dendrite Clinical Systems Ltd



For help with registration,
email support@e-dendrite.com
or contact Dendrite Clinical Systems
+44 (0)20 8739 0700



NHS
England

Please [click here](#) for access to the
demonstration registry.

LOGIN

REGISTER

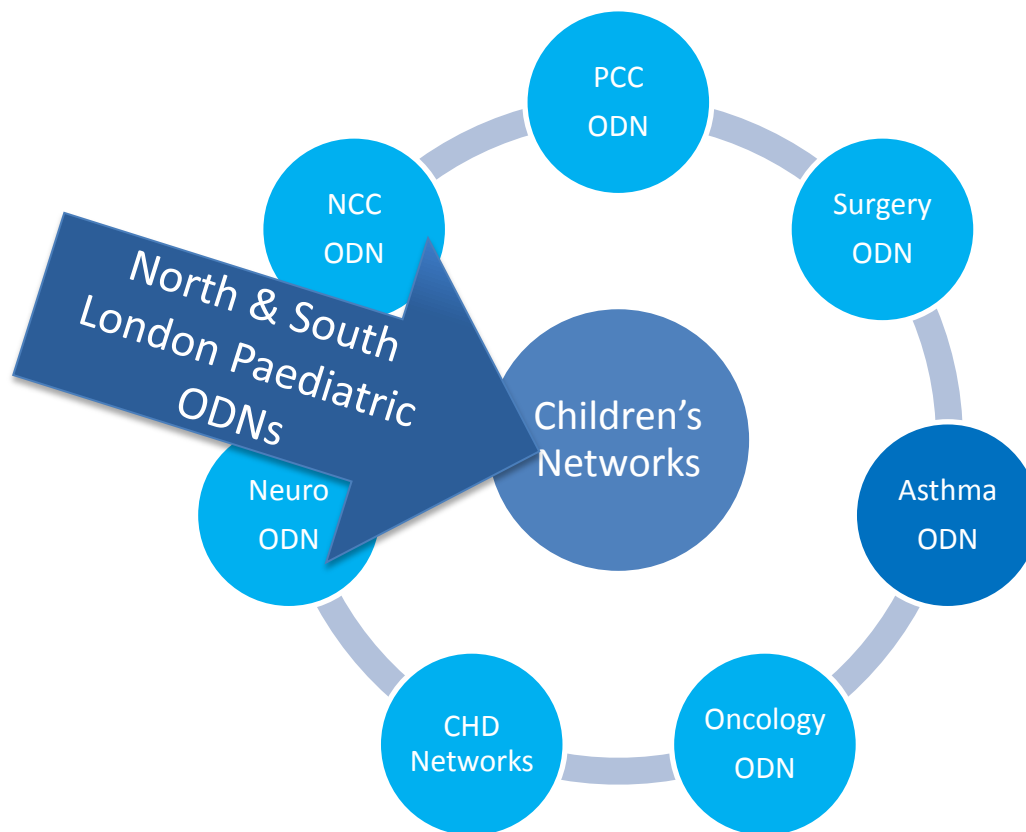
A networked solution

“linked groups of professional and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing and professional (and organisational) boundaries, to ensure equitable provision of high quality, clinically effective services”

The Scottish Office Department of Health, 1999 The Introductions of managed Clinical Networks within the NHS in Scotland
Cited in Bringing Networks to Life – An RCPCH guide to implementing Clinical Networks 2012



Opportunities to develop overarching Children's Strategic Networks to ensure alignment between networks and offer sustainability opportunities

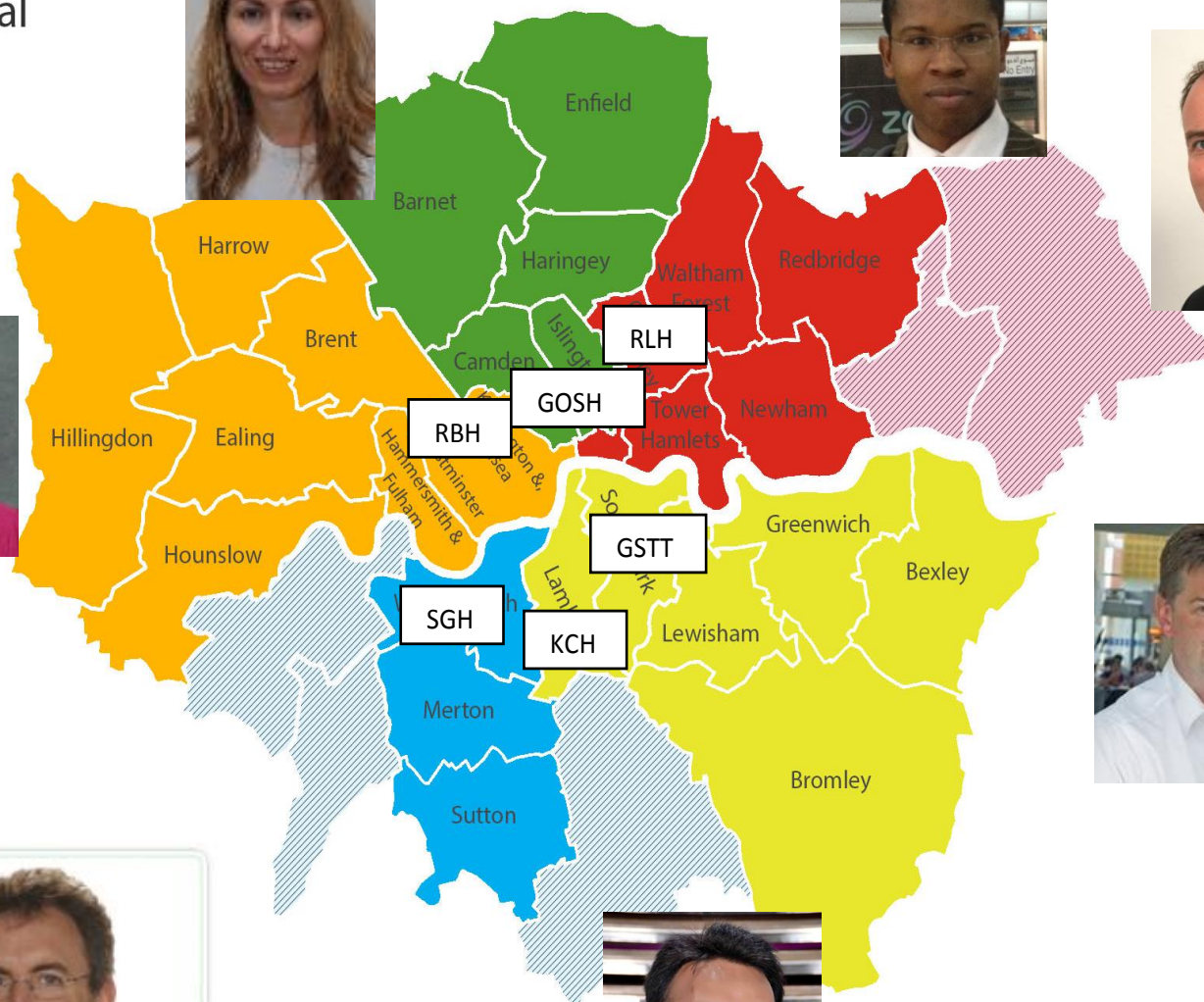


Long term funding options are still being investigated, but initial work on building foundations and network alignment can progress

Potential Benefits of a Network Model

- **Severe asthma centre as part of a local network**
 - Well defined pathways of care
 - Collaborative working
 - Severe asthma teams undertake full MDT assessment
 - Act as gatekeepers for expensive drugs and interventions (for example initiation of treatments such as omalizumab)
 - Joint clinical MDTs between severe asthma centre and other local healthcare providers
 - Clear lines of responsibility
 - Patients repatriated to local centre once issues contributing to poor control have been addressed and /or they have been established on an appropriate treatment
- **Network between severe centres**
 - Ensuring consistent care
 - Sharing difficult clinical cases
 - Research collaboration

- ⊠ North Central
- ⊠ North East
- ⊠ North West
- ⊠ South East
- ⊠ South West



RBH Difficult Asthma Service

Who are we:

- Children's Nurse Specialists:
 - Pippa Hall, Lead CNS
 - Angela Jamalzadeh
 - Rachael Moore-Crouch (maternity leave)
 - Laura Baynton
 - Sammy Ndlovu-Dawika
- Respiratory Paediatricians
 - Dr Samatha Sonnappa
 - Professor Sejal Saglani
 - Professor Andrew Bush
 - Dr Louise Fleming
- Psychology
 - Dr Fran Beresford
 - Megan Reay
- Physiotherapists
 - Charlotte Wells
 - Georgie Housley
- Research Fellows
 - Dr Louise Selby
 - Christina Pearce
- Research Nurses
 - Yvie Bingham
- Pharmacists
 - Sukeshi Makhecha

Other Teams

- Safeguarding
 - Lorna Waite
- Upper airway team
 - Dr James Hull
 - Dr Julia Selby (SLT)
 - Mr Guri Sandhu (ENT)
- Allergy team (St Mary's)
 - Dr Claudia Gore
 - Professor Adnan Custovic
 - Dr Paul Turner
- Shared care partners

Working Within NWL

- Annual shared care event
- 2 day preceptorship
- Joint MDTs
- Outreach clinics (St Mary's, West Middx, Hillingdon)
- Healthy London Partnership
- North and West London Regional Paediatric Allergy and Asthma Network Meeting
- SLAs: omalizumab

Who Should be Referred?

All children:

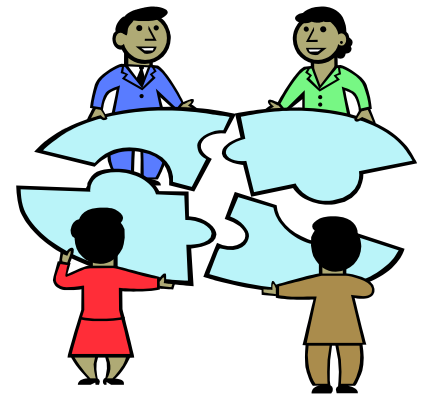
- Under consideration for other biological agent such as omalizumab, other monoclonal antibody
- Prescribed maintenance corticosteroids
- Admitted to PICU

Consider referral

- Children with poor control despite high dose ICS plus additional controller(s)
- Other considerations:
 - Diagnostic uncertainty
 - Complex psychosocial / safeguarding issues
 - Dysfunctional breathing
 - Enrolment in clinical studies

What Does Our Service Provide?

- Structured (re)assessment by the specialist MDT
- Diagnostic and other specialist tests for children with problematic severe asthma, problematic severe wheeze, complex breathlessness
- Access to (novel) therapeutics
- Participation in research



Recent Changes

- Full assessment at first appointment (12 week target)
- NHS Asthma lead
- Electronic monitoring part of standard care
- Guideline for mepolizumab (anti IL-5)
- Further development of complex breathlessness service
- Joint MDTs with local teams

Taking Forward the Network

- Challenges
 - CQUIN for severe asthma centres only
 - Engagement with secondary care
 - Logistical and financial support
 - Formalising network (TORs, SLAs etc)
- Opportunities
 - Build upon existing networks and collaborations
 - WSIC
 - NHS 10 year plan
 - HLP support
 - Peer review