

# **SIGN/BTS**

## **BRITISH GUIDELINE ON THE MANAGEMENT OF ASTHMA**

*Conference report • August 2011*



**KNOWLEDGE AND PRACTICE: IMPROVING ASTHMA CARE**  
Launch of the updated SIGN/BTS British guideline on the Management of Asthma

Tuesday 10<sup>th</sup> May 2011 • Royal College of Physicians of Edinburgh

ABPI Scottish Respiratory Industry Group (SRIG)\*, SIGN and Asthma UK Scotland.  
\*(AstraZeneca, Boehringer Ingelheim, Chiesi, GSK, Napp, Novartis, MSD, Pfizer)

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## INTRODUCTION

In 1999 the British Thoracic Society (BTS) and the Scottish Intercollegiate Guidelines Network (SIGN) agreed to jointly produce a comprehensive new asthma guideline, both having previously published guidance on asthma. The original BTS guideline dated back to 1990 and the SIGN guidelines to 1996. Both organisations recognised the need to develop the new guideline using explicitly evidence based methodology. The joint process was further strengthened by collaboration with Asthma UK, the Royal College of Physicians of London, the Royal College of Paediatrics and Child Health, the General Practice Airways Group, and the British Association of Accident and Emergency Medicine (now the College of Emergency Medicine). The outcome of these efforts was the British Guideline on the Management of Asthma published in 2003. Since 2003 sections within the guideline have been updated annually and posted on both the BTS ([www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk)) and SIGN ([www.sign.ac.uk](http://www.sign.ac.uk)) websites.

The 2011 revisions include updates to monitoring asthma and pharmacological management, and a new section on asthma in adolescents.

It is hoped that this asthma guideline continues to serve as a basis for high quality management of both acute and chronic asthma and a stimulus for research into areas of management for which there is little evidence.

### Target users of the guideline

The guideline will be of interest to healthcare professionals involved in the care of people with asthma. The target users are, however, much broader than this, and include people with asthma, their parents/carers and those who interact with people with asthma outside of the NHS, such as teachers. It will also be of interest to those planning the delivery of services in the NHS in England, Wales, Northern Ireland and Scotland.

### Implementing the guideline

The updated SIGN/BTS British guideline on the management of asthma was launched at the Knowledge and Practice: Improving Asthma Care event on Tuesday 10th May 2011, Royal College of Physicians of Edinburgh, organised in association with the ABPI Scottish Respiratory Industry Group (SRIG),<sup>1</sup> the Scottish Intercollegiate Guidelines Network (SIGN) and Asthma UK Scotland. The meeting focused on raising awareness of the updated guideline, sharing good practice and success in implementing the guideline locally and looking to the future to improve implementation through the Managed Clinical Networks (MCN) in Scotland.

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<sup>1</sup> (AstraZeneca, Boehringer Ingelheim, Chiesi, GSK, Napp, Novartis, MSD, Pfizer)

## KEY MESSAGES FROM THE 2011 UPDATE

- Current control is a good predictor of future exacerbations and titrating treatment against current control using a validated scoring system such as the Asthma Control Test remains the gold standard for monitoring care.
- Asking closed questions when assessing patients, eg “Do you use your blue inhaler every day?” rather than open questions such as “How is your asthma?” will yield more useful information on a person’s condition.
- There is little evidence that addition of biomarkers (eg peak expiratory flow, spirometry, bronchial hyper-responsiveness and exhaled nitric oxide) to validated symptom scores improves asthma control.
- Adolescents may be missing out on health care and may suffer substantial health consequences. There is still under-diagnosis of asthma in this group, particularly if you are female, a smoker, have low physical activity and a high body mass index, family problems and are socially disadvantaged.
- Preference for inhaler device should be taken into account as a factor to improve adherence in adolescents.  
Transition from paediatric to adult services is important and key aspects are:
  - adolescents should be seen on their own for at least part of the consultation
  - it is important to discuss confidentiality and its limits with the adolescent
  - adolescents may also need some guidance on work choices.

## CONFERENCE PROGRAMME

10.00 -10.30 Registration and coffee

### Session 1

*Chair: Dr Kia Soong Tan, Consultant Physician, Wishaw General Hospital*

10.30 Welcome and introduction

*Dr Kia Soong Tan, Consultant Physician, Wishaw General Hospital*

10.35 Patient's perspective

*Mr Mike McGregor, Lay representative*

10.45 Introduction to the BTS/SIGN Guideline

*Dr Bernard Higgins, Consultant Physician, Freeman Hospital, Newcastle upon Tyne*

10.55 Monitoring and control

*Dr Stephen Turner, Clinical Senior Lecturer, Royal Aberdeen Children's Hospital*

11.05 Pharmacological management

*Professor Neil Barnes, Consultant in Respiratory Medicine, London Chest Hospital*

11.15 Asthma in adolescents

*Dr James Paton, Reader in Developmental Medicine, University of Glasgow*

11.25 Patient version of the guideline

*Ms Cher Piddock, Clinical Lead, Asthma UK*

11.35 Question and answer session

12.00 Lunch

## Session 2

*Chair: Dr Graham Douglas, Consultant Physician, Aberdeen Royal Infirmary*

- 12.45 Implementation of local clinical guidelines  
*Dr Christine Bucknall, Consultant Respiratory Physician, Stobhill General Hospital, and Dr Duncan MacIntyre, Consultant Physician, Victoria Infirmary, Glasgow*
- 13.05 Panel Discussion
- 13.15 Introduction to workshops: Implementation of BTS/SIGN Guideline: setting the scene  
*Dr Ali El-Ghorr, Implementation Adviser, SIGN*
- 13.30 Parallel Workshops

### Workshop 1

Monitoring and control

*Dr Jakki Faccenda, Consultant Physician, Borders General Hospital*

### Workshop 2

Pharmacological management

*Mrs Phyllis Murphie, Respiratory MCN Clinical Lead/Lead Respiratory Nurse, Dumfries and Galloway Royal Infirmary*

### Workshop 3

Asthma in adolescents

*Mrs Sonya Crawford, ASL Nurse, NHS Lothian/City of Edinburgh*

### Workshop 4

Patient information

*Ms Maureen Carroll, CHD and Respiratory Network Manager, Hairmyres Hospital, East Kilbride and Dr Lorna Thompson, Programme Manager, SIGN*

- 14.45 Coffee

## Session 3

*Chair: Dr Charlie Clark, Public Health Consultant and Child Health Commissioner, NHS Lanarkshire*

- 15.05 Implementation of the BTS/SIGN Guideline through MCNs  
*Ms Maureen Carroll, CHD and Respiratory Network Manager, Hairmyres Hospital, East Kilbride*
- 15.35 Feedback from workshop
- 16.05 Question and answer session
- 16.15 Call for Action  
*Mr Gordon Brown, National Director of Asthma UK Scotland*
- 16.30 Close of meeting  
*Dr Graham Douglas, Consultant Physician, Aberdeen Royal Infirmary*

## SESSION 1 PRESENTATIONS

### The patient's perspective

*Mr Mike McGregor, Lay representative*

It has been my privilege for the past few years to act as a lay representative on the SIGN Asthma Steering Group. It is very encouraging to observe and to participate, in the re-examination and renovation of the guidelines.

The patient's perspective on the guidelines, based on their everyday experience of the condition, must differ from patient to patient, and so it's necessary to know the patient's:

- background
- treatments
- perspectives
- hopes for the future.

### Background & Treatments

In my case, I have a family history of long term conditions. It took an episode of total breathlessness in my late 50's to send me to my GP. I was prescribed a reliever inhaler, and later, a preventer inhaler was added, along with a peak flow meter and personal asthma plan. A severe attack a few years later landed me in the Edinburgh Royal Infirmary. Follow-up consultations resulted in higher preventer doses of budesonide, along with theophylline tablets at night, and to date, this regime has worked well. I have been able to control things to the extent that last year, I was able to ditch unused time-expired prednisolone, and order fresh to keep for any unexpected exacerbation. I have an annual review of my asthma with a nurse at my GP's practice.

### Perspectives

- Practitioner nurses may be aware of the BTS/SIGN guideline and the various steps, but I feel less confident in their assessments than with experienced asthma nurses.
- Reviews sometimes seem very cursory.
- I'd like more reference in my presence to assessment techniques and records, possibly held on computer systems.
- There is value in face to face reviews. Telephone or online reviews would not, for me, be satisfactory.
- I am totally in favour of GPs delegating reviews to fully trained asthma nurses who have adequate familiarity with the BTS/SIGN guideline and their implementation.
- Also, as much patient involvement in the management of their own condition as possible.

- I welcome management plans (PAAPs).
- I applaud schools asthma awareness campaigns.
- I also welcome the move towards free prescriptions on the NHS in the devolved administrations of the UK, ending the anomalies as to who should receive these.
- It is to be hoped that the Scottish Administration will now put in place a National Asthma Strategy, despite the current economic stringencies.

### Hopes for the Future

- More patient friendly and satisfactory ways of daily medication than inhalers.
- A regular – say 3-yearly – check-up from a specialist consultant.
- Now in my seventies, I want to see what is being done in the field of asthma treatment for the elderly.

In the meantime, I am involved, with several colleagues here today, in the production of a lay version of the asthma guideline. This will be a help to patients, parents, or their carers.

### Introduction to the BTS/SIGN Guideline

*Dr Bernard Higgins, Consultant Physician, Freeman Hospital, Newcastle upon Tyne*

Prior to the first BTS/SIGN guideline published in 2003, the BTS published two guidelines in the BMJ in 1990 and one in Thorax in 1993. SIGN 6 (hospital acute) SIGN 33 (primary care) and SIGN 38 (acute) were published in 1996, 1998 and 1999 respectively.

The BTS/SIGN British guideline on the management of asthma has been important in driving best practice in:

- accurate diagnosis in patients presenting with suspected asthma
- management of acute asthma
- pharmacological treatment eg combination inhalers to improve safety and adherence
- education and self management eg action plans to improve asthma control and reduce hospitalisation

The next steps will be to update the sections on:

- pharmacology
- organisation of care
- non-pharmacology
- immunotherapy.

## Monitoring and control

*Dr Stephen Turner, Clinical Senior Lecturer, Royal Aberdeen Children's Hospital*

Asthma control is "The extent to which the manifestations of asthma have been reduced or removed by treatment".

Asthma controls is an:

- assessment of the current day-to-day level of clinical control
- assessment of future exacerbation risk to the patient.

There is no gold standard for measuring control. There are four settings for monitoring:

- maintenance
- step-up treatment
- step-down treatment
- stop preventer.

Monitoring can be symptom based eg RCP3, ACQ, ACT/CACT, AQLQ/PAQLQ or reliant on biomarkers eg PEF, FEV<sub>1</sub>, BHR, sputum eosinophilia, ENO.

The 2011 update found:

- that a symptom score is the best measure of control
- that closed questions yield more information
- little/no evidence for the addition of biomarkers to symptom scores.

## Pharmacological management

*Professor Neil Barnes, Consultant in Respiratory Medicine, London Chest Hospital*

What is good asthma control?

- no (or minimal) daytime symptoms
- no nocturnal symptoms or awakenings
- no (or minimal) need for "rescue" treatment
- no limitations on activities
- (near) normal lung function
- no exacerbations.

Patient surveys have shown what is important to patients in terms of their asthma management. About 40% of patients want to be liberated from using their rescue medications, such as b<sub>2</sub>-agonists. More than half of patients want their asthma to be controlled so that they can lead a normal lifestyle. However, the most important aspect to patients is the prevention of asthma exacerbations.

Best predictor of an exacerbation is an increase in daytime symptoms. Daytime symptom score should be assessed each evening, just before going to bed.

Symptoms are chest tightness, wheezing, breathlessness and cough.

The relative rate of mortality is around 2 and 3 deaths per 100 patient years for people at Step 1 and Step 5 respectively compared to between around 0.25 and 0.5 for those at Steps 2, 3 and 4.

## Asthma in adolescents

*Dr James Paton, Reader in Developmental Medicine, University of Glasgow*

The evidence base for asthma in adolescents is limited. Much recent work has focused on the prevalence of asthma and ecological risk associations (ISAAC studies). There is little evidence on research and diagnosis and with treatment studies there is a problem with analysis, eg:

- Paediatric Studies - up to 12 yrs
- Adult studies - from 12 yrs.

Adolescents are defined by the WHO as young people between the age of 10 and 19 years of age.

Self reported prevalence in Western Europe Centres (n = 44) from Lai et al Thorax 2009; 64: 476-483 was:

- |   |       |
|---|-------|
| • Current wheeze                                | 14.3% |
| • Asthma ever                                   | 15.8% |
| • Severe asthma                                 | 6.2%  |
| • Symptoms of severe asthma without asthma ever | 15.2% |

The guideline makes the good practice point “Clinicians seeing adolescents with any cardiorespiratory symptoms should ask about symptoms of asthma.”

When diagnosing asthma in terms of exercise related symptoms watch out for:

- (normal) exercise induced dyspnoea. No other features, no response to pre-B2
- vocal cord dysfunction
  - abrupt onset, rapid resolution, tracheal wheeze, normal expiratory function
  - exercise induced during competitive aerobic activities
- hyperventilation syndrome
- psychogenic cough
- supraventricular tachycardia.

Adolescents and their families should be discouraged from smoking and be given help to stop smoking.

The preferences of adolescents should be taken into account when considering pharmacological management and devices.

In transition to adult services:

- young people should be given the opportunity to be seen without their parents
- transition services must address the needs of parents/carers
- transition services must be multidisciplinary and multiagency
- coordination of transitional care is critical ( identified coordinator)
- young people should be encouraged to take part in transition/support programmes

- the involvement of adult physicians prior to transfer supports attendance and adherence to treatment
- transition services must undergo continued evaluation.

### Patient version of the guideline

*Ms Cher Piddock, Clinical Lead, Asthma UK*

#### Aims

A SIGN group was formed to translate the clinical guideline into a patient version based on the main guideline recommendations. The patient guideline is not intended to be a general information leaflet but aims to help support and empower patients to self manage their asthma. People want more information about asthma and how to manage it.

#### Process

The patient version is drafted by the SIGN group paying attention to clinical explanations and ease of read. Then there will be:

- peer review from the main group
- consultation for 4 weeks
- SIGN editorial review
- Crystal Mark Award from the Plain English Campaign
- final sign off from the chief editor of SIGN.

#### Content

The group isolated recommendations, formed a question around the recommendation and worded the answer. A logical order was worked out removing any points too complicated for this format and adding more detail when needed. Work was done making language easier to understand. The patient version is currently at draft stage.

#### Challenges and considerations

- Health literacy of patients is an important consideration, in terms of:
  - basic health knowledge
  - reading, comprehending and evaluating health information
  - verbal communication with health professionals
  - the ability to make informed health decisions.
- Raising awareness of the patient version when it is published
  - how to refer to it
  - when to direct patients to it.
- Evaluating the usefulness of the patient version.

## SESSION 2 PRESENTATIONS

### Implementation of local clinical guidelines

*Dr Christine Bucknall, Consultant Respiratory Physician, Stobhill General Hospital, and Dr Duncan MacIntyre, Consultant Physician, Victoria Infirmary, Glasgow*

To implement best practice you first need to understand the current situation and identify anything which needs fixing. It is necessary to understand how 'the system' manages this aspect in order to work out how to change this for the better then monitor the impact to see improvement.

In 2009 the BTS National Asthma Audit found that 35% of patients were not followed up after discharge. The results of the audit were presented at a medical division meeting. Senior nurses from all medical wards were invited to attend and identified that patients were not being referred to respiratory nurse specialists after transfer from acute ward.

System changes that were implemented:

- Nurses registered patients transferred from acute ward via respiratory nurse specialist (RNS) answer phone
- RNSs introduced new chart for documenting inhaler technique/medicines review/action plan
- Created specific asthma review clinic slots with respiratory secretary acting as link, making sure that appointments were made and details sent to patients.

After one year, the proportion of patients receiving no follow up after discharge fell from 35% to 10%.

Barriers to implementing best practice include:

- difficulty in changing an organisation/system
- Don Berwick: "current system perfectly designed to give current results"
- lack of managerial/service development input – no-one's job to change things
- shifting sands of middle grade medical support.

The MCN is a cross-section of those involved in the care of a patient group. It provides effective representation of patient interests and a route into management. The MCN supports the development and implementation of appropriate strategies and guidelines which reflect national guidelines and take into consideration all aspects of the patient pathway.

The local role of the MCN is:

- Developing local guidelines which foster a sense of local ownership. The guidelines can be brief with specific emphasis, hold local contact detail and provide individualised patient record.
- Education and support which can include briefings, local meetings and training courses.

The MCN may also be involved in monitoring a number of service agreements:

- QoF
  - asthma register
  - measure of reversibility
  - smoking status in teenagers
  - review in last 15 months.
- Locally enhanced service (LES)
- Medical Profile
  - asthma mortality rates
  - emergency admission rates
  - readmission rates.

### Introduction to workshops: Implementation of BTS/SIGN Guideline: setting the scene

*Dr Ali El-Ghorr, Implementation Adviser, SIGN*

SIGN's vision is to be a world leader in implementation support. Our implementation strategy had four strands:

- Improved processes:
  - robust dissemination process
  - more interactive website eg downloadable audit tools, rockets.
- Awareness raising and education:
  - local clinical champions
  - awareness raising activities eg guideline summaries in the BMJ, local news reports
  - patients as champions for change
  - training modules linked to CPD eg NES educational material.
- Networking:
  - linking with professional networks
  - linking with national projects, eg NHS Evidence, QoF
  - meetings with NHS Boards.
- Implementation support resources:
  - algorithms and care pathways
  - SIGN Apps
  - resource implications calculator
  - data sets
  - electronic decision support tools
  - slide sets.

## WORKSHOP SUMMARIES

### Workshop 1 Monitoring and control

*Facilitator: Dr Jakki Faccenda, Consultant Physician, Borders General Hospital*

*Scribe: Jim Honeyman*

#### Education

- School nurses are critically important. Who is responsible for ensuring they are trained in asthma? (depends on their employer eg local authority or health board).
- Patients access through the media/opportunist interventions during consultations.
- Use opportunistic intervention if accessing other parts of care eg in hospital for other reason/GP and/or practice nurse. Engage using asthma action plans.
- A & E attenders are priorities especially those receiving repeat prescriptions for salbutamol.
- QoF letters to help education; what patient can expect.
- Include ACT score questionnaire to reinforce levels of asthma control especially if low (would be worthwhile auditing).
- A telephone questionnaire is less formal and can encourage patient attendance (texting service is very useful).
- Patient apathy to letter services exists.
- The pharmacist's role is very important as patients have to access pharmacy to get medicines. This may be the only opportunity to educate patients but conditions must be well planned eg availability of a consulting room/no queues, privacy etc.
- Education led by primary care team is important to reinforce the seriousness of asthma as a condition. Shock tactics may work in some people.
- Multicultural versions/learning disability educational/minority group education.
- Can we make it mandatory for GPs to have an annual asthma update – bearing in mind how busy GPs are.
- Educate on a variety of subjects to ensure engagement.
- Structured educational programmes.
- Make more use of Scotland-based media to tackle complacency of asthma management in Scotland NOT David Beckham taking his inhaler.
- Use positive reinforcement in messaging eg Paula Radcliffe and her achievements to illustrate what is possible if asthma is kept controlled.
- Could storylines be seeded into popular soaps etc? eg the Chlamydia story in Emmerdale.
- Sunday Post/local newspaper articles. Need to engage health journalists.
- Must make sure messaging is correct eg confusion over LTRA usage versus inhalers.

- Self medication potentially creates issues eg excessive use of reliever inhalers. Need to educate to help patients understand when they need to consult if taking too much reliever.
- Internet access and use of local initiatives to help direct patients to appropriate information.
- Disposal of devices etc when patients move on through the school system. There is a lot of wastage of volumatics etc that are not used.

### Monitoring

- Are systems being followed?
- Does double payment drive the right outcomes?
- Is there clarity about who should do what?
- Standardised templates are easy to use.
- Continuing standards after an LES is an ongoing challenge.
- Campbell's software is user friendly compared to SPICE which does not provide consistently good data.
- Minimal data entry is preferred.
- Aspire to have one national standard tool which would operate across a variety of systems. This would generate national data. Could the MCNs drive this forward?
- Better clarity is required in self management plans. Green and red are better but orange seems to be fudged. It could be more explicit.
- Consultant driven guidance is patchy.
- Doubling up dosing is misunderstood. Will this achieve any improvement in control?

### Compliance

Patient knowledge and understanding of compliance is important as part of an educational message.

- Helps people to understand what each device is. Patients don't want to use inhalers.
- Telephone consultations are convenient for patients and allow targeting in consultations.
- Can we avoid medicalising patients if possible?
- Helps people to understand process of disease.
- Helps people to understand the importance of compliance.
- Repeat messages as often as possible to increase adherence.
- GP levels of knowledge are poor compared to other HCPs.
- At a glance understanding of devices and usage of medication is important.
- Pharmacy-led interventions to encourage compliance. Device/molecule switching without consultation can create different issues eg patients not gaining control due to different generics from each pharmacy outlet due to cost/value to them.
- Minimise swapping/changing.
- Use of ACT supports education of patients.

### Control

- GINA level of control is the aim.
- Target Step 1 patients whom we are not picking up currently. Data showing death rates in this group are a surprise).
- Patients who are registered and who have not picked up inhalers for a long time but suddenly appear in practice to collect prescriptions need to be flagged up across practice and local pharmacy outlets to allow more team working.

### Barriers to implementation of guideline

- Time.
- Screening during flu vaccination has helped (slightly longer appointment).
- There are major barriers to stepping up/down based on multiple pathology issues.
- Patient engagement to adhere to messages being given.
- The quality of asthma reviews?
- Good communication in practice eg the asthma nurse feeding back to the rest of the practice. Is this consistent?
- Copying discharge letters and access to them.
- Treatment pathway cohesion and communication about patient/care/pathway when information/letters leaving secondary care are variable eg electronic due to distribution lists and hard copy for a variety of reasons.
- Teamwork in secondary care to keep tabs on respiratory patients coming into the hospital setting.
- Could telehealth be used more effectively? There is little or no focus on asthma at present.
- Skype?
- Convenience priority for patients, hence adherence to what they are being told.
- Standardised action plans that are understood and acted on.
- Links to youth clubs/schools for awareness raising.

## Workshop 2 Pharmacological management

*Facilitator: Mrs Phyllis Murphie, Respiratory MCN Clinical Lead/Lead Respiratory Nurse, Dumfries and Galloway Royal Infirmary*

*Scribe: Lynne Brooks*

- Engage those who are not interested
- Improve multidiscipline working/communication
- Access to health care can be difficult
- Education is needed across the board
- Use of IT could
  - improve clinics
  - aid GP systems
  - help with education
  - include 'phone Apps, texting
- Poorly managed patients are a priority
- SIGN could publicise patient information in different formats
- Telephone reviews could be effective
- Send ACT out to PTS
- Patient asthma plan
- Using texts.

### Key areas to improve care

- Being aware of social deprivation
- Improving outcomes for patients at step 1
- Free prescriptions
- Keeping it simple
- Device to suit individuals
- Get patients using lots of salbutamol on to ICS as there is a need to treat underlying inflammation
- Follow up patients who have attended A & E, out of hours
- Not just money
- Making sure medicines management see the guideline.

### Key aids to guideline implementation

- Time to educate
- Addressing levels of 'did not attends'
- Linking inhaler access to review? Not for paediatrics
- Access to clinics
- Incentives: payment, publishing results?
- IT templates
- Payment by results
- Adapting the language we use with patients
- Out of hours care plans for patients?
- Audit B<sub>2</sub> agonist high users
- Educate patients on emergency prescribing

- Patient education on the severity of asthma
- Explaining pharmacology to the patient: Why inhaler? Why steroid?
- HCPs make telephone clinic appointments
- Using general chronic illness letters
- Nurse telephones to follow up DNAs
- Multidiscipline clinics
- Having an A4 summary of the guidelines
- Using inhaler checklists
- Sample action plans
- Using IT – Asthma UK
- Having clinics out of hours
- Mentoring and competency framework
- Nurse education – accessible most areas – some geography issues, time to engage in education is still a real problem
- More use of video conference
- Being aware of the number of people involved in patient care and effective multidisciplinary communication
- Taking a record of previous devices which have failed
- Issue three repeat prescriptions then stop if there is no review
- Providing more education on devices
- Pharma companies ensuring supply and recognising the need for placebos to give training on inhaler technique
- Inhaler technique is key
- Use relatives of the patient for education/adherence.

### Workshop 3 Asthma in adolescents

*Facilitator: Mrs Sonya Crawford, ASL Nurse, NHS Lothian/City of Edinburgh*

*Scribe: Karen Thomson*

- Adolescents and teenagers are NOT the same thing
- Instigate a gradual transition process
- Start early. Everyone needs to collaborate with this process of transition  
This can be slow depending on the individual
- Adolescents should be seen on their own as part of the consultation  
Primary care has strong relationships and this can work well, it may not be the same in secondary care
- Measure how many teenagers are seen on own
- Make use of Apps and links with allergy Facebook
- Supporting parents to take a step back
- Separate clinic and A/T
- Sharing information
- Asthma a PSE lessons (and other conditions)
- Appointments to suit
- Checklists
- Our expectations of A/Ts are too low
- Links in secondary school are not clear
- Lack of understanding of asthma
- Changing attitudes. Being realistic about future work and education on occupational advice.
- Transition between P7 and S1
- Could apply technology (Apps) to motivate the adolescents to build their ownership and gain involvement in the process. Engagement is going to help drive ownership. Education across all stakeholders including schools.
- Consistency in the ages is not standard across the Health Boards. Some of the kids don't want to be in either service . Need to consider expectations of all involved, child, parent, clinician etc.

## **Workshop 4 Patient information**

*Facilitators: Ms Maureen Carroll, CHD and Respiratory Network Manager, Hairmyres Hospital, East Kilbride and Dr Lorna Thompson, Programme Manager, SIGN*

*Scribe: Gordon Thomson*

### **What value will an evidence based patient information booklet offer to patients and their carers?**

- Different patients have different needs
- The SIGN booklet will serve a purpose for a specific group of patients and/or carers
- The voluntary sector is vital in relation to mainstream information
- Some patients will feel reassured by this booklet under the SIGN banner.

### **What are the key information needs of asthma patients and their carers?**

- Look to Asthma UK's top 5 reasons to call advice line
- What does good control look like?
- Need paediatric and adult versions, both bridging adolescence
- Should not duplicate what is already out there
- Stress the need to take medication, to keep well
- Core content
  - Diagnosis, with pictures
  - Non-pharmacological
  - Pharmacological
  - Devices
  - Treatment expectations and self management
  - Special: pregnancy, (occupation overview only)
- It would be good to evaluate the usefulness and outcomes of any documents produced.

### **Where and when should patient information be given and by whom?**

- Leaflets/Apps/web based (social networking?)
- All are important to allow information to be available for different groups
- Foreign languages should be available, perhaps DVDs for some sections
- Quality control is important if patients are accessing the web.

## DELEGATE FEEDBACK

### What specific actions do you intend to take as a result of the day?

- Deliver best patient care.
- Negotiate longer asthma appointments to help facilitate better provision of SMP. Review practice management of patients post exacerbation.
- Disseminate the guideline to colleagues.
- Address patients' expectations more closely.
- Use spirometry for diagnosis.
- Use SIGN guidelines and discussion from the day for further developments with local Respiratory Service.
- Improve asthma education of pupils and staff within school.
- Consider training needs in my area to promote changes in guidelines.
- Audit tools re QoL questionnaires and adolescent developmental checklists.
- Look into pharmacists' opportunities for implementing the guideline.
- Implement reviewing adolescent patients in clinic on their own, then with parents/carer.
- Listen more to patients, ask the right questions.
- Impart the appropriate info to the patient (education).
- Update and implement local guidelines.
- Look at the BTS Audit guidelines for annual audit rather than using QoF criteria.
- Assess patients on sole SABA for increased treatment.
- Offer more education to patients/parents.
- Find the best personal action plan.
- Review patients who have had exacerbations of asthma, seen by GP out of hours and not followed up by practice nurses.
- Feedback and audit.
- Change my practice improve history taking.
- Look at pharmacological management.
- Share updated guideline within MDT.
- Confirm that monitoring symptoms (+PEFRs if appropriate) is good/evidence based asthma monitoring.
- Improve ways of controlling/monitoring patients' asthma.

**Do you have any comments/suggestions as to what SIGN can do to support the implementation of its guideline?**

- Mail shots of algorithms to all GPs registered with diabetes/CHD interest groups.
- Local meetings to update GPs
- Access to tools and resources such as web links to ‘checklists’ etc
- A reminder email of the key points after an interval
- Simplify it for patients
- Clearer guidance as what to include within self management plans
- Get around GPs and bring secondary care to these sessions
- Provide concise summary that can be incorporated into local primary care asthma guidelines
- Education and advertisement to both primary and secondary care
- Publish summary of changes
- Be sure to incorporate new information into guidelines (eg immunotherapy)
- Smaller guideline; guideline is already too long to be easily useable
- More IT for patients
- Publicise and provide information
- Dissemination to Practice Nurse Groups
- Education meetings on stepping up and down
- Education on IT on how to access guidelines and Apps
- Advertise in Primary Care
- Small local, satellite workshops
- Web-based portal for strategic/use of action plans – accessible from primary/secondary care and patient.

## TAKE HOME MESSAGES

### Key to improving the care of patients with asthma across Scotland

1. Education as an ongoing priority for all stakeholders including: HCPs, patients, schools
2. A standardised system for data collection across the whole of Scotland
3. Improved quality of communication amongst HCPs and between HCPs and patients
4. Smarter use of IT
  - to improve clinics
  - GP systems
  - 'phone Apps
  - texting
  - education.
5. Improvements for poorly managed patients
6. Local meetings to update GPs
7. Starting transition early and better engagement with adolescents to help drive ownership
8. Consistent application of standard age ranges for transition across the Health Boards
9. Considering expectations of all involved, child, parent, clinician, etc
10. Offering information as leaflets/Apps/web-based (social networking) as different patients have different needs.

### Key to enabling implementation of the guideline in Scotland

1. Flexibility within system to accommodate patients needs
2. Engagement of HCPs and patients – winning hearts and minds to fight apathy
3. Embracing new technologies to facilitate interface between patients and HCPs
4. Better multidisciplinary working/communication
5. Small local, satellite workshops
6. Better access to services
7. Using checklists to ensure nothing is overlooked and being aware of what is in the guidelines to support this
8. Making the most of peer support - aligning education and mentorship. Using the P7 and S5/6 link and established pathways.

## CALL FOR ACTION

*Mr Gordon Brown, National Director of Asthma UK Scotland*

Guidelines must be monitored and enforced for them to be meaningful.

The renewed guidelines we have been discussing today are designed to improve the care and support of people with asthma, but our Call for Action is for them to be properly monitored and enforced through a National Respiratory Strategy, which we have long believed, and campaigned for, would be a giant leap forward for people with asthma. Surprisingly - accustomed as we are to hearing Scotland declared to be leading the way with policy, after initiative, after new discovery - it is an area where Scotland is lagging behind the rest of the UK.

Northern Ireland published their national respiratory strategy in 2006, with Wales hot on their heels, and England is in the midst of producing a national framework; leaving Scotland the only part of the UK not pursuing a similar course. Such a strategy, based on the guidelines which have been discussed today, would ensure a better world where:

- *treatment for asthma was standardised across Scotland*
- *primary and secondary care were linked more effectively*
- *self management becomes the norm for treatment for asthma*
- *clear and consistent standards were set for asthma treatment.*

The Government needs to give a firm commitment that this is something it will - at the very least - consider again and this will be one of the mainstays of our campaigning work over the next few months. When we listen to people's stories it does help us build the case for such a strategy. For example, one of our favourite stories is the case of a woman with severe asthma who regularly travels to different parts of Scotland and is regularly admitted to emergency care in them. She told us: "Unfortunately, I won't know what care I will receive until I come-to in the ambulance or in a hospital bed and ask where I am. I hope it's x and hope it's not y."

When I told this story to a medical professional the response was a dismissive "well, she should be managing her asthma better and she wouldn't be admitted to hospital all the time". A frustrating response because it did miss the point somewhat; yes in an ideal world no one should end up regularly being admitted to hospital because of asthma. But the fact is, for whatever reason, she was – and the care she received was so variable she would almost (in her words) be better off driving from one health authority to another at the first sign of an attack.

This is clearly not right.

Another example of the variation of care currently being seen in Scotland was highlighted last week as part of our World Asthma Day media campaign. Our survey of GPs in Scotland, carried out in conjunction with the Primary Care Respiratory Society UK, indicated that asthma education for healthcare professionals is a low priority despite half of GPs agreeing that the number of deaths from asthma in Scotland could be reduced with better care. Over two thirds of GPs in Scotland feel GPs' asthma knowledge could be improved and over half recognise their own knowledge could be improved. This reflected separate survey results from PCRS which show that of the GPs questioned, more than half answered questions on UK-wide clinical guidelines for asthma incorrectly.

Our Call for Action, renewed today is for all commissioners of education and training in Scotland to prioritise asthma education. Training is important as research shows healthcare professionals trained in asthma management achieve better outcomes for their patients. In fact, the survey showed that 58% of GPs surveyed from Scotland agree that the number of emergency hospitalisations could be reduced with better care.

We want all GP surgeries to order a copy of our *Good Asthma Care for Adults and Children with Asthma*, which outlines what a best practice asthma service should be in line with recommended clinical guidance and ensure that everyone responsible for asthma care is appropriately trained to deliver it.

My final call for action today is for you all to help get asthma taken more seriously. Our Get it Off Your Chest campaign asks people to speak out about the impact of asthma on their lives by sharing their stories online at [www.asthma.org.uk/getitoffyourchest](http://www.asthma.org.uk/getitoffyourchest). This will help us influence not only training budget holders, but healthcare professionals, the public, teachers and Scottish Government. Together we can inspire others to take asthma seriously and ultimately save lives.