Although it still feels like summer in the day the cyclists among you will be needing bike lights for the ride home, a reminder that nights are drawing in and our thoughts turn to forthcoming winter. There is much to look forward to: the BTS Winter meeting for example, but with colder weather comes an increase in respiratory viral infections, along with an increase in exacerbations of COPD. This can only mean one thing: it’s already time to start thinking about Winter Planning! John Seymour updates us on COPD care bundles which do seem to reduce re-admission rates. He tells us about their successful implementation in Frimley Park Hospital – many of you know that we are planning to roll out COPD Care Bundles in Kent Surrey Sussex; we will discuss this further at the next Respiratory Collaborative on Thursday 13th November. We have previously published our concerns around appropriate use and risks of high dose inhaled corticosteroids (ICS). In this issue Helen Marlow reminds us of the high dose ICS patient safety card. This is something that we plan to raise awareness about and hope clinicians will start to use more.

This edition of Breathing Matters coincides with IPF week, read about this inside – do let us know if you ran an event or similar to mark it.

As ever comments, criticisms and suggestions are encouraged, email us at eva.lazar@nhs.net

All in? COPD care bundles: little to lose, much to gain
Dr John Seymour, Consultant Respiratory Physician, FPH

Exacerbations of Chronic Obstructive Pulmonary Disease (COPD) typically account for around 10% of acute medical admissions, yet very different standards of post-hospital care exist. For healthcare professionals it is often not a question of what should be delivered, rather what can be delivered in the real world of NHS commissioning in 2014. The concept of care pathways or “bundles” to improve safety and care is not new: inpatient conditions from hip fracture to myocardial infarction are managed according to such pathways. Much of the focus in COPD relates to care after admission at the primary-secondary care interface. The reason for this emphasis is the available evidence base for certain “outpatient” interventions, alongside the high rate of readmission and healthcare utilisation following hospitalisation. Approximately one-third of patients are readmitted within 30-days, which has remained the case across multiple British Thoracic Society/British Lung Foundation national audits.

A group from London published a now widely quoted paper describing the impact of a COPD discharge care bundle at an acute teaching hospital Trust http://thorax.bmj.com/content/67/1/80 Using evidence based literature alongside commissioner and patient feedback, the bundle required that a COPD nurse be informed of all admissions, smoking cessation assistance be offered, a referral for pulmonary rehabilitation be made, written information be provided to the patient, and a follow-up appointment with an appropriate specialist made prior to discharge. Implementation of the bundle was associated with a significant uplift in smoking cessation and rehabilitation referrals compared to historical data. A downward trend in 30-day readmission rate was also reported.

We instigated a discharge care bundle and at our hospital (Frimley Park Hospital NHS Foundation Trust), but encountered challenges that would likely resonate with others. First and foremost is the concept that a COPD nurse be informed of all admissions. Our COPD nurse essentially works daytime hours, Monday to Friday. Cover for annual leave aside, they will inevitably miss some short stay admissions and/or weekend admissions. These patients are at risk of subsequent complication as with any other admission. In the 2011 paper described earlier, 94 patients were referred to the COPD nurse, as compared to 365 who were not. In the busiest quarter of 2013/14 (Q4), our bundle was completed in approximately two-thirds of admitted COPD patients (the total identified from a coding database). Therefore, whilst this seemed a high rate of pick-up, a significant proportion of patients were not captured.

When it comes to pulmonary rehabilitation and smoking cessation services, Frimley Park straddles three major clinical commissioning groups (CCGs) in different counties. The access and contact between these areas varies, as does the waiting list for pulmonary rehabilitation. For example, good evidence exists for early post-exacerbation pulmonary rehabilitation (PEPR) in closely supervised RCTs of well-motivated individuals, and is available to approximately half of admitted patients at our trust depending on the referring CCG. Conversely, our bundle lacks the provision of...
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<td>30-day readmissions (%)</td>
<td>17.5</td>
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<td>3-month readmissions (%)</td>
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<td>Time to readmission, days (mean, SD)</td>
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Consequently, our care bundle is probably longer and at first glance more unwieldy than many in use, but represents the predictable synthesis of opinion across our local CCGs. The advantage of a longer document is that it contains the multiple options for follow up, and (for us at least) can act as a single referral document and agreed means of communication with the different community respiratory providers. The bundle document also addresses the Trust’s wider strategy around end of life care and has a related referral trigger, which is not knowingly a component of other bundles currently in use.

Problems aside, the proof is in the impact. In our Trust during Q4 2013/14, we found that 103 patients captured with the discharge bundle compared to 53 who were not, had a significantly lower likelihood of COPD related readmission after 30 days (17.5% versus 34.0%, P=0.027). This trend persisted up to 3 months. Interestingly, there was no over-representation of short stay admissions in the group not captured by the bundle, and both groups had a similar proportion of admissions in the previous year (probably the most significant predictor of subsequent readmission). The impact or success of completing the individual bundle components remains to be analysed in this context.

Whilst our data were collected retrospectively, it does give some insight into the practical concerns and real life impact of introducing a COPD discharge bundle. On a larger scale, the British Thoracic society is soon to report its Care Bundle Project involving 18 Trusts around the country. This project analysed pathways – describing both inpatient and discharge care – for community acquired pneumonia and COPD. More locally, a draft quality enhancement proposal for a COPD discharge bundle in the Kent Surrey Sussex Academic Health Sciences Network was disseminated in July.

COPD care bundles are likely to have core components subject to local variation dependent on the service structure. We are unlikely to generate hard evidence that allows us to conclude that one bundle and its content is better than another. However, the introduction of any bundle is likely to have a significant impact on safety and quality with minimal investment where specialist nurse provision already exists. The impact of bundled care is also likely to impact adverse healthcare resource utilisation, which could make the delivery of such care more cost-effective and suitable for further re-investment in the future.


Please note that the COPD discharge bundle is only accessible for members of the South East Coast Respiratory Programme, when you visit http://www.networks.nhs.uk/nhs-networks/south-east-coast-respiratory-programme, please click on ‘Apply to join’


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GRASP - COPD

NHS Improving Quality is pleased to offer the GRASP toolkit to GPs, to help audit and improve the quality of care for patients with COPD (Chronic Obstructive Pulmonary Disease).

How will GRASP – COPD help GPs to improve the management of patients?

The GRASP-COPD tool will enable GPs to:

- Audit current management of COPD against current NICE guidance using a highly visual dashboard familiar to those already running GRASP-AF
- Through the ‘case finder’, identify patients who may have COPD but are not on a register, to enable the disease to be diagnosed at the earliest opportunity and commence treatment at an earlier stage
- Identify patients who may be inaccurately diagnosed or recorded on the register, and thus may not currently be treated according to the NICE guidance
- Ensure all patients on the COPD register have a validated diagnosis, for example, some patients may be added to the register following a provisional diagnosis in hospital without spirometry or follow up. GRASP-COPD will flag such cases for review
- Review patients who have a diagnosis of both asthma and COPD to ensure this is accurate
- Benchmark both the practice prevalence and management of COPD against local and national comparators

Background

Established on 1 April 2013, NHS Improving Quality (NHS IQ) is the driving force for improvement across the NHS in England. We are working to improve health outcomes for people by providing improvement and change expertise. Hosted by NHS England, we have created an improvement organisation that is aligned to the needs and challenges of the NHS. We are doing this by working to the five domains of the NHS Outcomes Framework. You can find out more at: www.nhsiq.nhs.uk/about-us.

What is GRASP?

GRASP stands for Guidance for Risk Assessment and Stroke Prevention. There are three tools in the suite: AF, heart failure and COPD.

Developed almost 10 years ago by West Yorkshire Cardiovascular Network, the Leeds Arrhythmia team and PRIMIS with NHS Improvement, GRASP-AF (atrial fibrillation) was originally created to support GPs to better manage stroke prevention in AF. To date, one third of general practices in more than 150 CCGs in England have downloaded and run the GRASP-AF audit, and uploaded their data to CHART Online, a comparative audit database managed by PRIMIS. Data from GRASP/CHART Online suggests that management of stroke risk in AF is currently preventing almost 1500 strokes and saving the NHS over £2m annually.

A heart failure version (GRASP-HF) has also been developed to support GPs in improving their management of this disabling long term condition.

The latest addition to the GRASP Suite is GRASP-COPD, which also builds upon the success of ‘GRASP-AF’. It was launched formally at a national Breathlessness symposium organised by NHS IQ in July this year, and is already being actively used by 91 practices.

The tool will run on all practice clinical systems in England. Participating practices are also able to, easily and securely, upload pseudonymised data to the online comparison database, CHART Online. This allows practices to benchmark their COPD data with other practices, CCGs or national figures.
Breathing Matters

The GRASP-COPD tool is free in England, and can be obtained by registering with the PRIMIS Hub (free of charge) at www.primis.nottingham.ac.uk/hub and downloading the CHART software. For practices already using GRASP-AF, the new tool can be downloaded from within the PRIMIS CHART update facility.

What does it look like?

As with all of the tools in the GRASP suite, GRASP-COPD presents practice data in a ‘dashboard’ showing key pieces of information as extracted from the practice system. This information includes:

- The number of patients with a diagnosis of COPD and the prevalence rate for the practice
- Key aspects regarding the care of patients identified as having COPD, including:
  - Medical Research Council (MRC) dyspnoea score
  - Airflow obstruction (AFO) severity classification
  - Details of treatment classified by AFO severity
  - Number of smokers and their smoking cessation activity
  - Number using oxygen at home and pulse oximetry recording
  - Flu and pneumococcal vaccination status

In Summary

Data suggest that up to 30% of patients on COPD registers may be inaccurately diagnosed and sub-optimally treated. However, we know that:

- Accurate diagnosis can improve outcomes, help manage demand and reduce waste.
- Accurate diagnosis is aided by a combination of history, physical examination and confirmation of airflow obstruction using spirometry.

- The number of COPD patients being treated according to NICE guidelines (specify measurable aspects)

A separate ‘datasheet’ view allows access to patient level data for all those included in the audit. The datasheet is an essential tool for finding out more about any patients that appear to have missing data items or inaccurate recording, and can help prioritise patients for review. There are pre-set filters (4 categories and group searches) and there is a facility to set up individualised filters.

NHS IQ believes that practice disease registers are the key to the effective management of patients and identification of risk. GRASP-COPD will validate existing COPD registers - an excellent starting point for improving care and patients’ experience.

For more information go to the website: http://www.nhsiq.nhs.uk/improvement-programmes/living-longer-lives/clinical-engagement-in-the-five-big-killers/grasp-suite-resources.aspx
I get a little behind with my journal reading from time to time, but an article at the beginning of this year grabbed my attention. It describes the case of an inpatient with COPD whose consultant had an end of life discussion with the patient and family, had agreed ceiling of care and futility of interventions such as NIV. However the patient deteriorated in the night and had been subjected to those very interventions. The article (which is recommended reading) can be accessed at http://thorax.bmj.com/collections/end_of_life_decisions2.

The case discussed in the article prompted a more explicit Ceiling of Treatment document to be created for that acute Trust. Interestingly their pilot work found that generic templates did not work well and disease specific Ceiling of Treatment documents were required.

This article prompted me to ponder on the subject of end of life (EOL) care for COPD and the fact that I didn’t have a structured and consistent approach to this in my practice. The NICE COPD guidelines advise palliative care to alleviate symptoms however they give no guidance on when to consider EOL discussions. Most would agree that end of life care should be available to patients with end stage COPD just as it is for patients with terminal malignancy – one difficulty in delivering this is the fact that the trajectory towards end of life is less predictable for COPD.

Several studies have highlighted predictors of mortality for COPD but many of these have been carried out in the acute and ICU setting. The underlying assumption is that by identifying these factors, we will focus our efforts on high-risk patients with a view to reducing mortality.

However a UK study comparing mortality at 180 days as predicted by clinicians for patients with an exacerbation of COPD with the actual 180-day mortality found that clinicians are generally pessimistic about the survival prospects and have specific problems in identifying those with poor prognosis.

As Samy Suissa’s excellent study shows us3 the most reliable predictor of mortality is the frequency of exacerbations, and the most reliable predictor of exacerbations is the frequency of exacerbations, Fig 1.

This means that patients having repeated exacerbations are already on an end of life trajectory. In this situation it is clearly important to review the medical care e.g. consider

- Is their inhaler technique satisfactory?
- Is there a second diagnosis that we are missing?
- Does the severity of the physiological impairment match an end of life situation?

But frequent exacerbations should be a trigger to consider an EOL conversation.

The first acute exacerbation requiring NIV is often seen as a marker of end of life. However this does not take into account the possibility that the need for NIV may be iatrogenic due to poor management of respiratory failure (i.e. the need for NIV was prompted by oxygen toxicity). A retrospective study showed survival at 1year, 2 years and 5 years following the first episode of NIV was 72%, 52% and 26% respectively – these are hardly figures that consistently indicate a near terminal condition.

This unpredictability of COPD death is discussed in Hilary Pinnock’s qualitative study4 which used sequential interviews with patients and their nominated carer/helper and their nominated health professional. The researchers found two main themes; firstly, the acceptance of COPD as a ‘way of life’, and secondly, the ‘chaotic’ stories of people with COPD which contrast with the much more predictable stories of people with cancer. Only 2 of the 21 patients (all with severe disease) had discussed death with their doctors. The authors suggest that a point of transition to palliative care is meaningless and impractical in COPD and propose that the palliative care

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**Figure 1**

Rate of next severe exacerbation or death per 10,000 per day

Time after first severe exacerbation (years)
The Gold Standards Frameworks\(^5\) gives helpful structure along with some specific COPD indicators. It demonstrates three models of end of life trajectory; incurable cancer, organ failure (COPD fits into this one) and frailty/dementia decline Fig 2. It also gives pointers for flagging up when a COPD patient may be approaching EOL—see Box.

One pathway in use and illustrated here is the North West end of life care model for COPD, Fig 3.

In some ways this article may pose more questions than answers but just because something is difficult shouldn’t mean we avoid doing it! The human drive to survive is strong and we need to appreciate the fact that a poor health status does not always mean that people wish to forego potentially life saving treatments such as NIV.

I suspect that there are several teams in our region who do have a systematic approach to EOL discussions and if you do have any guidance or examples of good practice please send them to us so we can share with others in the KSS Respiratory Network. In the meantime I would suggest that considering if its appropriate to start an EOL care discussion should be part of the process of winter planning.

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1. COPD, end of life and Ceiling of Treatment. D Robin Taylor Thorax 2014;69:498-500
2. Implications of prognostic pessimism in patients with chronic obstructive pulmonary disease (COPD) or asthma admitted to intensive care in the UK within the COPD and asthma outcome study (CAOS), multicentre observational cohort study. Wildman MJ et al. BMJ 2007; 335: 1132
4. Living and Dying with severe COPD. Pincock H et al BMJ 2011;342:d142
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Idiopathic pulmonary fibrosis (IPF) has been on the rise in the UK for decades, and now kills over 5,000 people a year. Awareness remains low, and there is no known cause or cure. Every year for IPF week the BLF tries to raise as much awareness as possible about this devastating disease. During IPF Week 2014, 28 September – 05 October, supporters will be encouraged to post pictures of themselves blowing bubbles on social media as a sign of solidarity for people living with IPF. They can also text IPF to 70500 to donate £5 to help us fund more research for IPF. The BLF will be premiering two exclusive patient videos and several blog pieces, including one from an IPF specialist.

Ruth Fleming
British Lung Foundation
IPF Project Manager

I will be travelling the length of the UK to visit different IPF support groups and talk about the work that the BLF does to support patients throughout the country. One of the things I’ll be talking about is our new and free IPF information packs. They were designed so that they could be offered as the first point of reference for newly diagnosed patients; they can be ordered for free on our website.

The week provides the perfect opportunity to bring together different organisations that have the same goal and to underline the need for an integrated approach towards a disease which we still know so little about. So don’t forget to post your bubble photo and order your free IPF packs for your patients!


Since this article was written perfenidone has become available for IPF, aiming to slow progression. There are strict criteria based on FVC and at the present time the patients needs to be referred to and seen by a ILD specialist centre to be considered for perfenidone.

POLL

Last edition’s poll was about the NRAD report’s recommendation that there should be a standard national template for asthma care. What a compliant group of people you are: the majority of you came out in favor of this with a roughly 2/3 to 1/3 split:

This edition’s poll relates to the educational article and perhaps poses a more controversial question?

Do you think that consideration of an end of life discussion should be a mandatory part of a winter planning assessment for COPD?

Yes: We are not offering our patients best care if we are not doing this

No: It is too difficult to predict end of life in COPD and the discussion can cause patients distress

Either Click here to vote or copy and paste this into your browser: http://www.networks.nhs.uk/nhs-networks/south-east-coast-respiratory-programme/polls/do-you-think-that-consideration-of-an-end-of-life-discussion-should-be-a-mandatory-part-of-a-winter-planning-assessment-for-copd/view or as we have heard that some of you have this route blocked by your work server, you can also vote by sending us an email eva.lazar@nhs.net
In April 1998, an NHS Executive circular acknowledged the danger of sudden cessation of systemic steroid therapy. It stated it was the responsibility of the prescriber to issue a steroid card to patients and that the dispensing pharmacist should check that the patient had one (and supply it, if necessary). The card recommended was a revised version of the 1961 card that is still in use today (the "blue steroid card"). Also in 1998 the Committee on Safety of Medicines raised awareness that prolonged treatment with high doses of inhaled corticosteroids (ICS), or higher than recommended doses of nasal corticosteroids, may result in clinically significant adrenal suppression, and that a Steroid Treatment Card should be issued for patients on ICS at the discretion of the doctor or pharmacist. This advice was strengthened in 2006: the MHRA recommended that "steroid treatment cards should be routinely provided for patients who require prolonged treatment with high doses of inhaled steroids", resulting in practitioners using the blue cards, often with the words: "prednisolone tablets" or "oral" crossed through.

The respiratory network in London, the London Respiratory Team (LRT), identified that the original blue steroid treatment card was inappropriate for use in patients with COPD on high dose ICS. A patient safety card was drafted along with prescribing guidance including all the factors for safe and effective ICS use. This was piloted in both hospital and primary care settings and then redrafted.

To date, this card has been endorsed by NHS England London Respiratory Clinical Leadership Group, BTS/SIGN Asthma Guidelines Committee, Primary Care Respiratory Society-UK (PCRS-UK), United Kingdom Clinical Pharmacy Association and Royal Pharmaceutical Society, with approval being sought from several more including the British Lung Foundation and Asthma UK. The Kent Surrey and Sussex Respiratory Network is planning to promote the ICS patient safety card to healthcare organisations across KSS; this article is the start of the process!

Aim of the ICS patient safety card

The card is written for patients, so that they understand the benefit of, and how to minimise, the potential harms of treatment, particularly adrenal suppression. At the same time there is an underlying objective that the process of attempting to issue the card would prompt a prescriber to consider whether the high dose of ICS is actually required, or whether a lower dose used appropriately would provide similar efficacy, with fewer side effects. Ideally this would result in avoiding the need to issue the steroid card in all but a few patients.

Recommendation

The KSS Respiratory Expert Advisory Group (REAG) discussed the use of an ICS specific patient safety card for adult patients on high dose inhaled corticosteroids, instead of the current blue steroid treatment card recently and agreed that the Respiratory Network should promote its use.

The ICS patient safety cards can be ordered from http://www.ashleyforms.co.uk/products-and-services/high-dose-ics-safety-card

References

In the last edition of Breathing Matters we noted that the All Party Parliamentary Group on Respiratory Health (APPG) had just released a report on Respiratory Deaths. The purpose of the group, which replaced the APPG on asthma in 2013, is to increase awareness of respiratory issues in Parliament and ensure that government policies continue to improve care and services for people with respiratory disease. This report was jointly commissioned by the BLF and Asthma UK and was developed by gaining expert opinion from over 50 organisations and individuals with expertise on Respiratory Disease.

Here we summarise the report:

The report comments that Respiratory disease affects 1 in 5 people in the UK, is responsible for 1 million hospital admissions and is the third biggest cause of death in the UK – no wonder we all feel so busy!

The report starts by making the point that respiratory services are relatively under-resourced compared to the other ‘big killers’ of cancer and heart disease. It links this under-resourcing with the fact that death rate for respiratory disease in the UK is high compared to similar nations, (twice the rate of Germany and three times the rate of Finland). In addition it comments that UK death rates for cardiovascular disease and cancer do not show this difference implying there is something specific around respiratory diseases in the UK. In 2012/13 the NHS spent £4.7 billion on respiratory disease, which was 4.9% of its budget. However, respiratory disease was responsible for over 7% of the burden imposed by disease in the UK in 2010.

The report states that reducing the impact on smoking on respiratory health is key – a point that we concur with though smoking is not relevant for all respiratory diseases and patients.

The most poignant are the two patient/carer stories – the mother of a 10 year old boy who died of asthma and a man who was 39 when he had first symptoms of COPD but whose diagnosis was delayed by around 10 years.

The APPG make 21 recommendations, the full document is accessible via the BLF’s website
And/or via Asthma UK’s website:
http://www.asthma.org.uk/Handlers/Download.ashx?IDMF=237de8ee-4bf1-4e8f-bc6f-b586a5a677b8

The report concludes that ‘We need to ensure investment and attention are given to building awareness, improving respiratory research and services, implementing the COPD and Asthma Outcomes Strategy and putting effective infrastructure in place for respiratory conditions. Only then will we be able to reduce respiratory death rates in line with the rest of the developed world.’ – It’s as if we had written the report ourselves!

A major concern however is whether this report will have any impact on the disparity between impact and funding of respiratory services.
News

Nebuliser Service Special event
Wednesday, 26th Nov 2014 1.30pm-4.30pm
Venue: The Charis Centre, Crawley, West Sussex

This is a half-day study event, aimed at specialist respiratory nurses and physiotherapists. The event is free to attend, please send expressions of intention to attend to eva.lazar@nhs.net. The agenda will be circulated for the members of the Oxygen Clinical network and for the Pulmonary Rehabilitation network and will be published on nhs networks site, nearer to the time of the event.

Agenda includes:

‘Practicalities of running a nebuliser service’
North West Surrey Community Team - Virgin Care

‘A guide to nebulised medication’
Dr Kate Steele, Consultant Respiratory Physician, WSHFT

For further information eva.lazar@nhs.net
Register with wendy.brown9@nhs.net

Key Advances in Cardiac and Pulmonary Rehabilitation Conference
9th - 10th of December 2014, Keele Hall, Keele University
Full price for 1 day £235.00
Early bird for 1 day £170.00
Full price for 2 days: £470.00
Early bird for 2 days: £340.00
An exciting and inspiring programme which will address issues central to the role of cardiorespiratory physiotherapists, nurses and other health professionals working with patents with cardiac/respiratory impairment and failure. For a full programme and to book visit www.regonline.co.uk/PRandcardiaccare2014

Clinical Research Network: Kent, Surrey and Sussex is looking for a Specialist Researcher (Respiratory) to fill a Band 7 - Full-time position
Based at Gillingham Business Park, ME8 0NZ
https://www.jobs.nhs.uk/j6/vacancy/146beaa37ae3cf1e99f7ff4262d1978c/?vac_ref=913521052
The CRN: KSS is looking to increase the number of local sites involved in clinical research relating to Respiratory Disorders. They are recruiting a Specialist Researcher to help achieve this in Kent, Surrey and Sussex and to enable local teams to deliver a high quality, efficient service to the meet the demands of the increasing research activity across the Network. The postholder will work closely with the local research Networks and NHS partners, to develop the NIHR respiratory research portfolio across the region

Breathing Matters by email
If you wish to receive our quarterly newsletter, Breathing Matters by email, please contact eva.lazar@nhs.net.
We try to keep the email traffic to a minimum and instead of emailing respiratory updates, we publish those on nhs networks site, for access to key documents, news and updates, events, training opportunities and also the previous editions of Breathing Matters. Please note that in order to access all documents, for example to see the COPD and Asthma dashboards, you will need to join the network (rather than visiting only). You can do that by clicking on ‘Apply to join’ in the top mid section. If you are not yet a nhs network member, you will need to register first: www.networks.nhs.uk/@register

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