



Severe Paediatric Asthma Collaborative in Europe (SPACE) Registry

Annual follow up

Patient code number: _____

(Note: this will be automatically generated by the online database at data entry – please do not change this code as it is linked on your site)

Date of follow-up: _____

Is the patient still under follow-up at your department?

Yes

No

If no, reason:

Transitioned to adult care

Not followed up by the centre anymore

Other reasons

BACKGROUND INFORMATION

Lung function at follow up:

Date: _____

Weight (kg): _____ Height (cm): _____

Was LABA administered in the 12 hours (formoterol, salmeterol) or 24 hours (vilanterol) prior to lung function test? Yes No

Pre-bronchodilator

Please enter the raw spirometry values, the predicted values and z-scores can be automatically calculated on the SPACE website.

	Value	Z-score
FEV1 (L)		
FEV1 (% predicted)		
FVC (L)		
FVC (% predicted)		
FEV1:FVC ratio		
FEF 25-75%		
FEF 25-75 (% predicted)		

FeNO (ppb) (while on biologic, not during exacerbations, latest result since last follow up)

	Date	Result
Latest since last follow up		

Blood eosinophil count (while on biologic, since last follow up) (cells/ μ l)

	Date	Absolute number of eosinophils
Latest since last follow up		

Total IgE * (since last follow up)

	Date	Result	Units
Latest since last follow up			kUL / IUml

****to be filled in only if the patient is/was NOT on Omalizumab***

ASTHMA CONTROL at annual follow up (not during an exacerbation)

❖ Composite Asthma Severity Index (**CASI** questionnaire)

Daytime symptoms score: _____
 Night time symptoms score: _____
 Lung function score: _____
 Treatment score: _____
 Exacerbation score: _____

Total composite asthma severity index (*automatically calculated on website*): _____

❖ Test of adherence to inhalers (**TAI** questionnaire)

Answered by patient/parents score (total score from questions 1-5): _____
 Answered by patient/parents score (total score from questions 6-10): _____

Total TAI score (*automatically calculated on website*): _____

❖ Paediatric asthma quality of life questionnaire (**PAQLQ**) score

Domains:

Activity Limitation (total score from questions 1,2,3,19,22): _____
 Symptoms (total score from questions 4,6,8,10,12,14,16,18,20,23): _____
 Emotional Function (total score from questions 5,7,9,11,13,15,17,21): _____

Total PAQLQ score (*automatically calculated on website*): _____

❖ Childhood Asthma Control Test (CACT – years 6 to <12)

Total score: _____

OR

Asthma Control Test (ACT)

Total score: _____

❖ **GINA** assessment

In the past 4 weeks, has the patient had:

Daytime asthma symptoms more than twice/week?	
Any night waking due to asthma?	
Reliever needed for symptoms more than twice/week?	
Any activity limitation due to asthma?	

The following degree of control will be automatically calculated on the website:

Well controlled Partly controlled Uncontrolled

Since last follow up, in relation to asthma:

Number of episodes requiring systemic steroid for ≥ 3 days	
Number of unscheduled medical attendances (GP/ emergency department)	
Number of episodes requiring non-invasive ventilatory support	
Number of episodes requiring intubation and ventilation	
Number of hospital admissions (>4 hours of hospital stay) for acute asthma	
Persistent chronic asthma symptoms (<i>most days for >3 months</i>)	Yes/No
Number of ICU admission	

RESPIRATORY TREATMENTS at annual follow up

Anticholinergic	√
Ipratropium Bromide	
Tiotropium	

Combination inhaled treatment	√	Total daily steroid dose (µg)
Formoterol & Beclometasone		
Formoterol & Budesonide		
Formoterol & Fluticasone propionate		
Salmeterol & Fluticasone		
Vilanterol & Fluticasone furoate		
Other: _____		

Inhaled steroid (single inhaler)	√	Total daily steroid dose (µg)
Beclometasone		
Beclometasone extra fine		
Budesonide		
Ciclesonide		
Flunisonide		
Fluticasone Furoate		
Fluticasone Propionate		
Mometasone		
Triamcinolone		
Other: _____		

Systemic corticosteroid	√	Frequency	Total daily steroid dose (on days the patient takes systemic corticosteroids), mg
Prednisolone		Daily/ Every other day/ Other: _____	
Dexamethasone		Daily/ Every other day/ Other: _____	
Other: _____		Daily/ Every other day/ Other: _____	

Leukotriene receptor antagonist	√
Montelukast	
Zafirlukast	

Long acting beta agonist (single inhaler)	√
Formoterol	
Salmeterol	
Vilanterol	

Monoclonal antibody	Start date	Dose (mg)	Frequency
Mepolizumab			Bi-weekly / Monthly / Other: _____
Omalizumab			Bi-weekly / Monthly / Other: _____
Dupilumab			Bi-weekly / Monthly / Other: _____
Tezepelumab			Bi-weekly / Monthly / Other: _____
Other:			Bi-weekly / Monthly / Other: _____

Is the patient still on a monoclonal antibody? Yes No



If YES:

Is the patient on the same monoclonal antibody as at recruitment? Yes No

If NO, please ensure current monoclonal antibody is in the medication section above.

Is the current monoclonal antibody administered off-label? Yes No

If YES: For age
 For indications (criteria for prescription)
 Other reasons

If NO:

Please provide information on all previously used but discontinued monoclonal antibody treatment(s) since last follow up

Monoclonal antibody discontinued:

Omalizumab / Mepolizumab / Dupilumab / Tezepelumab / Other _____

Start date (month/year): _____ Stop date (month/year): _____

Reason for discontinuation:

- Non-responder / partial responder
- Uncontrolled co-morbidity (e.g. atopic dermatitis)
Please specify: _____
- Side effects
Please specify: _____
- Other
Please specify: _____

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Start date (month/year): _____ Stop date (month/year): _____

Reason for discontinuation:

- Non-responder / partial responder
- Uncontrolled co-morbidity (e.g. atopic dermatitis)
Please specify: _____
- Side effects
Please specify: _____
- Other
Please specify: _____

Since recruitment/last follow up, did the patient experience side effects related/possibly related to biologic? Yes No

If YES:

Which biologic?

Omalizumab / Mepolizumab / Dupilumab / Tezepelumab / Other _____

Injection site side effects:

Erythema / Edema / Noduli / Other _____

Systemic side effects:

Anaphylaxis / Arthralgia / Parasitic Infection / Urticaria /

Angioedema / Rash / Other _____

Omalizumab / Mepolizumab / Dupilumab / Tezepelumab / Other _____

Injection site side effects:

Erythema / Edema / Noduli / Other _____

Systemic side effects:

Anaphylaxis / Arthralgia / Parasitic Infection / Urticaria /

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Injection site side effects:

Erythema / Edema / Noduli / Other _____

Systemic side effects:

Anaphylaxis / Arthralgia / Parasitic Infection / Urticaria /

Angioedema / Rash / Other _____

ADDITIONAL INFORMATION

Will the patient be happy to take part in future trials? Yes No Undecided

Provide any additional information

– The End –