Characterisation of patients with severe asthma in the UK Severe Asthma Registry in the biologic

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Appendix 1 - List of UK Severe Networks and Network Leads in UKSAR (2020)

Lead Centre & Data Collection Centres	Lead Clinician				
Belfast City Hospital	Professor Liam Heaney				
Royal Brompton and Harefield NHS Trust	Professor A Menzies-Gow				
St Georges University Hospital NHS Trust	Dr Jane Evans				
Diversingham Dagional Course Asthma Comuias					
Birmingham Regional Severe Asthma Service	Dr. Adol Monour				
University Hospitals Birmingham NHS Trust	Dr Adel Mansur				
Sandwell & West Birmingham NHS Trust	Dr Adeel Sahal				
Royal Wolverhampton NHS Trust	Dr Rachid Berair				
Queen Elizabeth Hospital Birmingham	Dr Duncan Wilson				
University Hospitals of Derby & Bunton NHS	Dr Deepak Subramanian				
The Dudley Group NHS Foundation Trust	Dr Martin Doherty				
Worcestershire Acute Hospitals NHS Trust	Dr Bethan Barker				
Gloucestershire Hospitals NHS Trust	Dr Simon Message				
South Thames and Kent Severe Asthma Network					
Guy's & St Thomas' NHS Trust	Dr David Jackson				
North Central & East London Severe Asthma Serv	ice				
Bart's Health NHS Trust Dr Paul Pfeffer					
Royal Free London NHS Trust	Dr Paul Dilworth				
Homerton University Hospital NHS Trust	Prof Raja Rajakulasingham				
East Midlands Severe Asthma Network					
University Hospitals of Leicester NHS Trust	Professor Salman Siddiqui				
Nottingham University Hospital NHS Trust	Dr Sherif Gonem				
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North West Midlands Severe Asthma Service					
University Hospitals of North Midlands NHS Trust	Dr Elfatih Idris				
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Yorkshire Asthma MDT (Yorkshire/Hull/Leeds)					
Sheffield Teaching Hospitals NHS Trust	Professor Ian Sabroe				
Hull University Teaching Hospitals NHS Trust	Dr Shoaib Faruqi				
The Leeds Teaching Hospitals NHS Trust	Dr Ian Clifton				
Chesterfield Royal Hospital	Dr Sally Davies				
Doncaster Royal Infirmary	Dr Aldrin Adeni & Dr Trevor Rogers				
Wakefield & Dewsbury Hospital	Dr James McCreanor & Dr Llinos Jones				
Bradford Royal Infirmary	Dr Dinesh Saralaya				
North Lincolnshire & Goole	Dr Umesh Bangalore Lakshminarayana				
	2. Chicon Bangarore Eurominiara yana				

York District Hospital	Dr Rebecca Thomas	
Airedale Hospital	Dr Su Ann Leong	
Grimsby Hospital	Dr Madhav Menon	
Harrogate Hospital	Dr Claire Taylor	
Barnsley District General Hospital	Dr Hazim Madhi	
Calderdale Hospital	Dr Johnnie Walker	
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East of England Severe Asthma Network		
Cambridge University Hospitals NHS Trust	Dr Robin Gore	
Wessex Network		
University Hospital Southampton NHS Trust	Dr Paddy Dennison	
Portsmouth Hospitals NHS Trust	Dr Thomas Browne	
Oxford University Hospitals NHS Trust	Professor Ian Pavord	
Churchill Hospital	Dr Henry Bettinson	
South West Asthma Network		
University Hospitals Plymouth NHS Trust	Dr Mitesh Patel	
University Hospitals Bristol NHS Trust	Dr James Dodd	
Royal Devon & Exeter NHS Trust	Dr Matthew Masoli	
Taunton & Somerset NHS Trust	Dr Robert Stone	
North West Network	Dr Aashish Vyas	
Wythenshawe Hospital	Dr Rob Niven	
Liverpool Royal Infirmary	Dr Hassan Burhan	
Salford Royal	Dr Ronan O'Driscoll	
Countess of Chester Hospital	Dr Stephen Scott	
Royal Albert Edward Infirmary Wigan	Dr Imran Aziz	
Lancashire Teaching Hospital	Dr Aashish Vyas	
North Manchester General Hospital	Dr Nita Seghal	
Wirral University Teaching Hospital	Dr John Corless	
Royal Preston Hospital	Dr Aashish Vyas	
Newcastle Severe Asthma Network		
Newcastle Upon Tyne NHS Trust	Dr Simon Doe	
Freeman Hospital	Dr Andrew Stanton	
NHS Greater Glasgow & Clyde	Dr Rekha Chaudhuri	
Gartnavel General Hospital	Dr Rekha Chaudhuri	
Garmavel General Hospital		

Thorax

Appendix 2: List of Fields collected at baseline (fields in red have been added from June 2020)

Variable	Туре	Responses
Identifiers		
Date First Seen	Date	
Patient ID	Numerical	Automatically generated unique UKSAR registration number
Patient Demographics		
Gender	Categorical	Female; Male
Age At First Assessment (Years)	Numerical	
Ethnicity	Categorical	Caucasian; South East Asian; North East Asian; African; Mixed; Other
Occupational Cause or Worsening of Asthma	Categorical	No; Yes
Height (m)	Numerical	
Weight (kg)	Numerical	
BSA (m2)	Numerical	Calculated dependent field
BMI (kg/m2)	Numerical	Calculated dependent field
Index of Multiple Deprivation	Numerical	
Bronchial Thermoplasty Patient	Categorical	No; Yes
Research Patient	Categorical	No; Yes
Initial Data Complete	Categorical	No; Yes
Medical History		
Rescue Steroids In Last Year	Numerical	
Invasive Ventilation Events Ever	Numerical	
A&E Attendances For Asthma In Last Year	Numerical	
Hospital Admissions For Asthma In Last Year	Numerical	
Age at Onset of Symptoms (Years)	Numerical	
Smoking Status	Categorical	Never smoked; Ex-smoker; Current smoker
Pack Years	Numerical	

Years Since Last Smoked	Numerical	
Nasal Polyps	Categorical	No; Yes
Atopic Disease	Categorical	No; Yes
Atopic Disease Description	Free-text	
Current Atopic Eczema	Categorical	No; Yes
Other Comorbidity	Categorical	No; Cardiac disease; Other
Comorbidity Description	Free-text	
Investigations		
Blood Eosinophil Count (N/109L)	Numerical	
Highest Blood Eosinophil Count [in available	Numerical	
medical records] (N/109L)		
Date Highest Eosinophil Count	Date	
IgE (IU/mL)	Numerical	
Prior Highest Sputum Eosinophils (%)	Numerical	
CT Scan	Categorical	Not done; Normal; Abnormal
Abnormal CT Scan Details	Free-text	
Date Of Bone Densitometry	Date	
Spinal Bone Density (T-Score)	Numerical	
Femoral Neck Bone Density (T-Score)	Numerical	
Additional Clinical Tests	Free-text	
Lung Function		
FEV1 (L)	Numerical	
Predicted FEV1 (L)	Numerical	Calculated dependent field
FEV1 (% Predicted)	Numerical	Calculated dependent field
Post-BD FEV1 (L)	Numerical	
Post -BD FEV1 (% Predicted)	Numerical	Calculated dependent field
FVC (L)	Numerical	
Predicted FVC (L)	Numerical	Calculated dependent field

FVC (% Predicted)	Numerical	Calculated dependent field
Post-BD FVC (L)	Numerical	
Post-BD FVC (% Predicted)	Numerical	Calculated dependent field
FEV1/FVC	Numerical	Calculated dependent field
Post-BD FEV1/FVC	Numerical	Calculated dependent field
Residual Volume (% Predicted)	Numerical	
Total Lung Capacity (% Predicted)	Numerical	
KCO (% Predicted)	Numerical	
PC20 Methacholine / Histamine (mg/mL)	Numerical	
Date of PC20 Methacholine / Histamine	Date	
FeNO (ppb)	Numerical	
FeNO Date	Date	
Allergen Testing		
Environmental Allergen Test	Categorical	No; RAST; SPT
RAST Positive	Categorical	No; Yes
SPT Positive	Categorical	No; Yes
Positive to Perennial Allergen	Categorical	No; Yes
Perennial Allergen Details	Free-text	
Asthma Control Questionnaire		
ACQ1 Woken at Night	Categorical	Never; Hardly ever; A few times; Several times; Many times; A great many times; Unable to sleep because of asthma
ACQ2 Symptoms in Morning	Categorical	No symptoms; Very mild symptoms; Mild symptoms; Moderate symptoms; Quite severe symptoms; Severe symptoms; Very severe symptoms
ACQ3 Limited in Activities	Categorical	Not limited at all; Very slightly limited; Slightly limited; Moderately limited; Very limited Extremely limited; Totally limited
ACQ4 Shortness of Breath	Categorical	None; A very little; A little; A moderate amount; Quite a lot; A great deal; A very great deal
ACQ5 Wheezing	Categorical	Never; Hardly any of the time; A little of the time; A moderate amount of the time; A lo of the time; Most of the time; All of the time

ACQ6 Puffs of SABA	Categorical	None; 1 - 2 puffs/inhalations most days; 3 - 4 puffs/inhalations most days; 5 - 8
		puffs/inhalations most days; 9 - 12 puffs/inhalations most days; 13 - 16 puffs/inhalation
		most days; More then 16 puffs/inhalations most days
ACQ7 FEV1	Categorical	> 95% predicted; 95 - 90%; 89 - 80%; 79 - 70%; 69 - 60%; 59 - 50%; < 50%
ACQ6 Score	Numerical	Calculated dependent field
ACQ7 Score	Numerical	Calculated dependent field
EuroQoL Questionnaire		
EuroQoL Mobility	Categorical	I have no problems in walking about; I have slight problems in walking about; I have
		moderate problems in walking about; I have severe problems in walking about; I am
		unable to walk about
EuroQoL Self-care	Categorical	I have no problems washing or dressing myself; I have slight problems washing or
		dressing myself; I have moderate problems washing or dressing myself; I have severe
		problems washing or dressing myself; I am unable to wash or dress myself
EuroQoL Usual Activities	Categorical	I have no problems doing my usual activities; I have slight problems doing my usual
		activities; I have moderate problems doing my usual activities; I have severe problems
		doing my usual activities; I am unable to do my usual activities
EuroQoL Pain / Discomfort	Categorical	I have no pain or discomfort; I have slight pain or discomfort; I have moderate pain or
	-	discomfort; I have severe pain or discomfort; I have extreme pain or discomfort
EuroQoL Anxiety / Depression	Categorical	I am not anxious or depressed; I am slightly anxious or depressed; I am moderately
		anxious or depressed; I am severely anxious or depressed; I am extremely anxious or
		depressed
EuroQoL Health Scale	Numerical	

Feel SHORT OF BREATH as a result of your	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
asthma		the Time; Hardly Any of the Time; None of the Time
Feel bothered by or have to AVOID DUST in	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
the environment		the Time; Hardly Any of the Time; None of the Time
Feel FRUSTRATED as a result of your asthma	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
		the Time; Hardly Any of the Time; None of the Time

Feel bothered by COUGHING	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
		the Time; Hardly Any of the Time; None of the Time
Feel AFRAID OF NOT HAVING YOUR	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
ASTHMA MEDICATION AVAILABLE		the Time; Hardly Any of the Time; None of the Time
Experience a feeling of CHEST TIGHTNESS or	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
CHEST HEAVINESS		the Time; Hardly Any of the Time; None of the Time
Feel bothered by or have to AVOID	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
CIGARETTE SMOKE in the environment		the Time; Hardly Any of the Time; None of the Time
Have DIFFICULTY GETTING A GOOD NIGHT'S	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
SLEEP as a result of your asthma		the Time; Hardly Any of the Time; None of the Time
Feel CONCERNED ABOUT HAVING ASTHMA	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
		the Time; Hardly Any of the Time; None of the Time
Experience a WHEEZE in your chest	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
		the Time; Hardly Any of the Time; None of the Time
Feel bothered by or have to AVOID going	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of
outside because of WEATHER OR AIR		the Time; Hardly Any of the Time; None of the Time
STRENUOUS ACTIVITIES (such as hurrying,	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some
exercising, running up stairs, sports)		Limitation; A Little Limitation; Not at all Limited
MODERATE ACTIVITIES (such as walking,	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some
housework, gardening, shopping, climbing		Limitation; A Little Limitation; Not at all Limited
stairs)		
SOCIAL ACTIVITIES (such as talking, playing	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some
with pets/children, visiting		Limitation; A Little Limitation; Not at all Limited
friends/relatives)		
WORK-RELATED ACTIVITIES (tasks you have	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some
do to at work)		Limitation; A Little Limitation; Not at all Limited
Asthma Medication		
Maintenance OCS	Categorical	No; Yes
Maintenance OCS (mg)	Numerical	
	Categorical	No; Yes
ICS	Categoricai	

Steroid Sparing Medication	Categorical	No; Yes
Steroid Sparing Medication Name	Free-text	10,103
Prior Biologic Therapy	Categorical	No; Yes
Theophylline	Categorical	No; Yes
Theophylline Level (mg/L)	Numerical	10, 165
SABA	Categorical	No; Yes
LABA	Categorical	No; Yes
LABA Name	Free-text	
LAMA	Categorical	No; Yes
LAMA Name	Free-text	
Leukotriene Receptor Antagonists	Categorical	No; Yes
Maintenance Macrolides	Categorical	No; Yes
Nebuliser	Categorical	No; Yes
Evidence Of Poor Adherence	Categorical	No; Prescription records; Objective measures; Clinical impression
% Expected ICS Prescriptions Filled	Numerical	
Prednisolone Level Measured	Categorical	No; Yes (2-4 hours); Yes (>4 hours)
Prednisolone Level (ng/L)	Numerical	
FeNO Suppression	Categorical	Not done; Negative; Positive

Systematic Assessment and Management Pl	an	
ERS/ATS Severe Asthma	Categorical	No; Yes; Currently being assessed
Other Factors Contributing To Symptoms	Free-text	
Patient Is Adherent With Treatment	Categorical	No; Yes
Management Plan	Categorical	Discharge to local service; Optimisation of current treatment; Biologic therapy; Bronchial thermoplasty; Maintenance oral corticosteroids; Steroid sparing agent; Enter into clinical trial; Adherence intervention; Other
Biologic Therapy Details	Free-text	
Steroid Sparing Details	Free-text	
Trial Details	Free-text	
Other Management Plan	Free-text	

Appendix 3: List of Fields collected at follow-up (fields in red have been added from June 2020)

Variable	Туре	Responses
Identifiers		
Date Seen	Date	
Patient ID	Numerical	Automatically generated unique UKSAR registration number
Summary		
Clinical Summary	Free-text	
Maintenance OCS	Categorical	No; Yes
Maintenance OCS (mg)	Numerical	
Biologic / SS ^a	Categorical	No; Biologic; Steroid sparing agent
Biologic Therapy Details	Free-text	
Biologic / SS ^a Stopped or Changed	Categorical	No; Yes
Reason Biologic / SS ^a Stopped or Changed	Categorical	Failed clinical response; Other reason
Other Reason Biologic / SS ^a Stopped or Changed	Free-text	
Maintenance Macrolides	Categorical	No; Yes
Rescue Steroids In Last Year	Numerical	
A&E Attendances For Asthma In Last Year	Numerical	
Hospital Admissions For Asthma In Last Year	Numerical	
Height (m)	Numerical	
Weight (kg)	Numerical	
Fat Free Mass (%)	Numerical	
BMI (kg/m2)	Numerical	Calculated dependent field
BSA (m2)	Numerical	Calculated dependent field
ERS/ATS Severe Asthma	Categorical	No; Yes
Serious Medical Event Since Last Entry	Categorical	None; Anaphylaxis; Severe infection; Malignancy; MI / CVA; Pregnancy; Other

Severe Infection Details	Free-text	
Malignancy Details	Free-text	
Pregnancy Details	Categorical	Not on Biologic; On Biologic with-held during Pregnancy; On Biologic
		continued during Pregnancy
Other Serious Medical Event Details	Free-text	
Further Details	Free-text	
Patient Status	Categorical	Actively managed; Discharged; Lost to follow up; Died; Transferred to
		other centre
Spirometry		
Predicted FEV1 (L)	Numerical	Calculated dependent field
Pre-BD FEV1 (L)	Numerical	
Pre-BD FEV1 (% Predicted)	Numerical	
Post-BD FEV1 (L)	Numerical	
Post -BD FEV1 (% Predicted)	Numerical	
Predicted FVC (L)	Numerical	Calculated dependent field
Pre-BD FVC (L)	Numerical	
Pre-BD FVC (% Predicted)	Numerical	
Post-BD FVC (L)	Numerical	
Post-BD FVC (% Predicted)	Numerical	
Pre-BD FEV1/FVC	Numerical	
Post-BD FEV1/FVC	Numerical	
FeNO (ppb)	Numerical	
Blood Eosinophil Count (N/109L)	Numerical	
Bone Density		
Date Of Bone Densitometry	Date	
Spinal Bone Density (T-Score)	Numerical	
Femoral Neck Bone Density (T-Score)	Numerical	

Asthma Control Questionnaire		
ACQ1 Woken at Night	Categorical	Never; Hardly ever; A few times; Several times; Many times; A great
		many times; Unable to sleep because of asthma
ACQ2 Symptoms in Morning	Categorical	No symptoms; Very mild symptoms; Mild symptoms; Moderate
		symptoms; Quite severe symptoms; Severe symptoms; Very severe symptoms
ACQ3 Limited in Activities	Categorical	Not limited at all; Very slightly limited; Slightly limited; Moderately
		limited; Very limited; Extremely limited; Totally limited
ACQ4 Shortness of Breath	Categorical	None; A very little; A little; A moderate amount; Quite a lot; A great deal; A very great deal
ACQ5 Wheezing	Categorical	Never; Hardly any of the time; A little of the time; A moderate amount of
		the time; A lot of the time; Most of the time; All of the time
ACQ6 Puffs of SABA	Categorical	None; 1 - 2 puffs/inhalations most days; 3 - 4 puffs/inhalations most
		days; 5 - 8 puffs/inhalations most days; 9 - 12 puffs/inhalations most
		days; 13 - 16 puffs/inhalations most days; More then 16 puffs/inhalation:
		most days
ACQ7 FEV1	Categorical	> 95% predicted; 95 - 90%; 89 - 80%; 79 - 70%; 69 - 60%; 59 - 50%; < 50%
ACQ6 Score	Numerical	Calculated dependent field
ACQ7 Score	Numerical	Calculated dependent field
EuroQoL Questionnaire		
EuroQoL Mobility	Categorical	I have no problems in walking about; I have slight problems in walking
		about; I have moderate problems in walking about; I have severe
		problems in walking about; I am unable to walk about
EuroQoL Self-care	Categorical	I have no problems washing or dressing myself; I have slight problems
		washing or dressing myself; I have moderate problems washing or
		dressing myself; I have severe problems washing or dressing myself; I am
		unable to wash or dress myself
EuroQoL Usual Activities	Categorical	I have no problems doing my usual activities; I have slight problems doing
		my usual activities; I have moderate problems doing my usual activities; I

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		have severe problems doing my usual activities; I am unable to do my usual activities
EuroQoL Pain / Discomfort	Categorical	I have no pain or discomfort; I have slight pain or discomfort; I have moderate pain or discomfort; I have severe pain or discomfort; I have extreme pain or discomfort
EuroQoL Anxiety / Depression	Categorical	I am not anxious or depressed; I am slightly anxious or depressed; I am moderately anxious or depressed; I am severely anxious or depressed; I am extremely anxious or depressed
EuroQoL Health Scale	Numerical	

Mini-AQLQ Questionnaire		
Feel SHORT OF BREATH as a result of your	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
asthma		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Feel bothered by or have to AVOID DUST in	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
the environment		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Feel FRUSTRATED as a result of your asthma	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Feel bothered by COUGHING	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Feel AFRAID OF NOT HAVING YOUR	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
ASTHMA MEDICATION AVAILABLE		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Experience a feeling of CHEST TIGHTNESS or	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
CHEST HEAVINESS		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Feel bothered by or have to AVOID	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
CIGARETTE SMOKE in the environment		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Have DIFFICULTY GETTING A GOOD NIGHT'S	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
SLEEP as a result of your asthma		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Feel CONCERNED ABOUT HAVING ASTHMA	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
		Time; A Little of the Time; Hardly Any of the Time; None of the Time
Experience a WHEEZE in your chest	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the
		Time; A Little of the Time; Hardly Any of the Time; None of the Time

Feel bothered by or have to AVOID going outside because of WEATHER OR AIR	Categorical	All of the Time; Most of the Time; A Good Bit of the Time; Some of the Time; A Little of the Time; Hardly Any of the Time; None of the Time
STRENUOUS ACTIVITIES (such as hurrying, exercising, running up stairs, sports)	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some Limitation; A Little Limitation; Not at all Limited
MODERATE ACTIVITIES (such as walking, housework, gardening, shopping, climbing stairs)	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some Limitation; A Little Limitation; Not at all Limited
SOCIAL ACTIVITIES (such as talking, playing with pets/children, visiting friends/relatives)	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some Limitation; A Little Limitation; Not at all Limited
WORK-RELATED ACTIVITIES (tasks you have do to at work)	Categorical	Totally Limited; Extremely Limited; Very Limited; Moderate Limitation; Some Limitation; A Little Limitation; Not at all Limited

^a Steroid sparing medication