

Data item number	Data item name	Data format
0 REGISTRATION/CONSENT		
1	Patient identifier	
2	Date of consent	dd/mm/yyyy
3	Consent version	String restricted list
50 PARTICIPANT STATUS		
51	Admin code Ineligible/invalid data/data cleaning	restricted list
52	admin text	text
57	Type of entry	Drop down list
58	Withdrawn	Yes / No
59	Date of withdrawal	dd/mm/yyyy
64	Date of death	dd/mm/yyyy
65	Primary cause of death	Unknown / Known
100 DEMOGRAPHICS		
101	Gender	String restricted list
102	Date of Birth	dd/mm/yyyy
103	Ethnicity	Check box
104	Post code at diagnosis	String max 8
106	Country of birth	String
107	Date of arrival	date yyyy
108	Occupation at diagnosis	String restricted list
109	Employment status at diagnosis	String restricted list
125 FAMILY		
126	Ethnicity of mother	String restricted list
127	Ethnicity of father	String restricted list
128	Family history (1st degree relatives only)	String restricted list
129	Which family member	String restricted list
130	What condition?	String restricted list
131	Family History other description	String
150 COMORBIDITY (smoke, pre-existing, new)		
151	Smoking history	String restricted list
152	ComorbNot	Check box
153	Diabetes Mellitus	Category
154	DM date first diagnosed	date dd/mm/yyyy
155	Coronary heart disease	Category
156	CHD date first diagnosed	date dd/mm/yyyy
157	Heart failure	Category
158	HF date first diagnosed	date dd/mm/yyyy
159	Peripheral vascular disease	Category
160	PVD date first diagnosed	date dd/mm/yyyy
161	Hypertension requiring treatment	Category
162	HT date first diagnosed	date dd/mm/yyyy
163	Chronic kidney disease	Category
164	CKD date first diagnosed	date dd/mm/yyyy
165	Chronic obstructive pulmonary disease (excluding late onset ast	Category
166	COPD date first diagnosed	date dd/mm/yyyy
167	Asthma	Category
168	Asthma date first diagnosed	date dd/mm/yyyy

169 Cerebrovascular accident (stroke)	Category
170 CVA date first diagnosed	date dd/mm/yyyy
171 HIV / AIDS	Category
172 HIV / AIDS date first diagnosed	date dd/mm/yyyy
173 Latent or clinical TB	Category
174 TB date first diagnosed	date dd/mm/yyyy
175 Dyslipidaemia	Category
176 DL date first diagnosed	date dd/mm/yyyy
177 Primary malignancy (please specify - skin excluded)	Category
178 PM date first diagnosed	date dd/mm/yyyy
200 DIAGNOSIS	
201 Date of onset of symptoms	dd/mm/yyyy
202 Clinical diagnosis	LUID diagnosis
203 Date of diagnosis	dd/mm/yyyy
204 Diagnosis confidence (initial assessment)	String restricted list
205 Number of organs affected	1 or >1
206 Histology / Radiology	Drop down list
250 CORE FEATURES	
251 Height	decimal
252 ESRD	String restricted list
254 ANCA Immunfluorescence (IF) pattern at any point	String restricted list
255 ELISA specificity at any point	String restricted list
256 Systems involved at any point	String list (multiple option)
257 Induction treatment received	String list (multiple option)
258 Maintenance treatment received	String list (multiple option)
259 Biopsy performed	String restricted list
260 Vasculitis on biopsy	String restricted list
300 STUDY SAMPLES	
301 Clinical samples obtained	String restricted list
302 Date samples obtained	date dd/mm/yyyy
303 Biobank location	Text
304 Sample location	String restricted list
305 Type of clinical samples obtained	String list (multiple option)
350 ENCOUNTER	
351 Date of encounter	dd/mm/yyyy
CLINICAL OBSERVATIONS	
352 Weight	Integer, one decimal place
353 Pregnancy	
354 Contraception status	
355 Employment status	String restricted list
400 DISEASE ACTIVITY/DAMAGE	
401 BVAS	String restricted list
402 BVAS items	String restricted list
403 BVAS WG	
404 VDI score	String restricted list
405 VDI items	String restricted list
406 Disease activity since last return	
407 Nature of relapse	String list
450 THERAPY	
452 Drug class (corticosteroid)	radio

453 Drug Name	String restricted list
451 Drug time period	String restricted list
455 Dose per day (not frequency)	Decimal
456 Unit of Dose	Category
458 Start date	dd/mm/yyyy
460 Stop date	dd/mm/yyyy
462 One off date	dd/mm/yyyy
452 Drug class (immunosuppressant)	radio
453 Drug Name	String restricted list
451 Drug time period	String restricted list
455 Dose per day (not frequency)	Decimal
456 Unit of Dose	Category
458 Start date	dd/mm/yyyy
460 Stop date	dd/mm/yyyy
462 One off date	dd/mm/yyyy
452 Drug class (biologic)	radio
453 Drug Name	String restricted list
451 Drug time period	String restricted list
455 Dose per day (not frequency)	Decimal
456 Unit of Dose	Category
458 Start date	dd/mm/yyyy
460 Stop date	dd/mm/yyyy
462 One off date	dd/mm/yyyy
452 Drug class (acute therapy)	radio
453 Drug Name	String restricted list
451 Drug time period	String restricted list
455 Dose per day (not frequency)	Decimal
456 Unit of Dose	Category
458 Start date	dd/mm/yyyy
460 Stop date	dd/mm/yyyy
462 One off date	dd/mm/yyyy
452 Drug class (concomitant/trial specific)	radio
453 Drug Name	String restricted list
451 Drug time period	String restricted list
455 Dose per day (not frequency)	Decimal
456 Unit of Dose	Category
458 Start date	dd/mm/yyyy
460 Stop date	dd/mm/yyyy
462 One off date	dd/mm/yyyy
483 Plasma exchange	String restricted list
484 Date of Plasma exchange	dd/mm/yyyy
485 Volume of plasma exchange (L or ml/kg if<16 years)	Integer
500 BLOOD TESTS	
501 Immunology bloods	
502 ANCA IF	String restricted list
503 Anti-PR3 level	Number max 3
504 Above laboratory reference range?	String restricted list
505 Anti-MPO level	Number max 3
506 Above laboratory reference range?	String restricted list
507 Biochemistry bloods	

508 CRP	Number max 3
509 Above laboratory reference range?	String restricted list
510 Creatinine	Number max 3
511 Above laboratory reference range?	String restricted list
512 Units	Drop down list
513 eGFR (ml/min)	Number max 3
514 Below laboratory reference range?	String restricted list
515 Mode of calculation	Drop down list
516 Urine protein	Number max 4
517 Above laboratory reference range?	String restricted list
518 Mode of measurement	Drop down list
519 Units	Drop down list
520 Haematology bloods	
521 Hb	Number 0-20, one
522 Below laboratory reference range?	String restricted list
523 Units	Drop down list
524 HLA type	String
528 Anti-GBM antibody	String restricted list
529 Anti-GBM level	Integer
530 ANA	String restricted list
531 Total white cell count	Number max 2, one decir
532 Abnormal?	String restricted list
533 Neutrophil count	Number, one decimal
534 Abnormal?	String restricted list
535 Lymphocyte count	Number, one decimal
536 Abnormal?	String restricted list
537 Eosinophils	Number, one decimal
538 Above laboratory reference range?	String restricted list
539 Platelet count	Number
540 Abnormal?	String restricted list
543 ESR	Number 0-150
544 Above laboratory reference range?	String restricted list
545 Absolute CD19 count	Number
546 CD19 count units	Drop down list
547 IgG (g/L)	Number, one decimal
548 Abnormal?	String restricted list
549 IgA (g/L)	Number, one decimal
550 Abnormal?	String restricted list
551 IgM g/L)	Number, one decimal
552 Abnormal?	String restricted list
553 C3 (g/L)	Number
554 Below laboratory reference range?	String restricted list
555 C4 (g/L)	Number
556 Below laboratory reference range?	String restricted list
557 Rheumatoid factor	Number
558 Above laboratory reference range?	String restricted list
559 Type1 cryoglobulins (monoclonal immunoglobulin)	String restricted list
560 Type2 cryoglobulins (monoclonal RF (IgM) and polyclonal IgG)	String restricted list
561 Type3 cryoglobulins (Polyclonal RF (IgM) and polyclonal IgG)	String restricted list
562 Total cholesterol	Number, one decimal

563 Fasting?	Drop down list
600 BIOPSY	
299 Biopsy performed	Y/N
289 Date of biopsy	dd/mm/yyyy
518 Site of biopsy	String list
519 General findings	Drop down list
520 Size of vessel involved	Drop down list
521 Vessel specific findings	Drop down list
522 Organ specific findings (renal section below)	Drop down list
523 Berden score on renal biopsy	String restricted list
524 Number of Glomeruli with active vasculitic lesions	Number
525 No of Glomeruli with healed vasculitic lesions	Number
526 No of Normal glomeruli	Number
527 No of Globally sclerosed glomeruli	Number
528 Acute tubular damage	String restricted list
103 % tubular atrophy	Number 0-100
104 Tubular atrophy estimation	String restricted list
105 Interstitial inflammatory infiltrate	String restricted list
106 Arteritis / arteriolitis	String restricted list
107 Pauci-immune	String restricted list
108 IgG deposits	String restricted list
109 C3 deposits	String restricted list
110 C4d deposits	String restricted list
700 GENERAL IMAGING AND OTHER INVESTIGATIONS	
701 Date of general imaging test	dd/mm/yyyy
702 Modality	String list
703 Site investigated	String list
704 General findings	String list
705 Specific findings	String list
750 VASCULAR IMAGING	
751 Date of vascular imaging test	dd/mm/yyyy
752 Vascular imaging modality	String restricted list
753 Vessels imaged	String list
754 Laterality	String restricted list
755 Abnormal findings	String list
800 DIALYSIS	
801 Dialysis dependent	
802 Date of dialysis start	dd/mm/yyyy
803 Date of dialysis stop	dd/mm/yyyy
804 Number of plasma exchange sessions received	Integer
850 RENAL TRANSPLANTATION	
851 Donor type	String restricted list
852 Date of transplant	dd/mm/yyyy
853 Maintenance I/S	String restricted list
854 Maintenance I/S 2	String restricted list
855 Rejection episode	String restricted list
856 Date of rejection episode	dd/mm/yyyy
857 Date of graft failure	dd/mm/yyyy
858 Reason for graft failure	String list
900 COMPLICATIONS	

901 Infection	String restricted list
902 Organism (if known)	Free text
903 Infection severity	Number 1-5
904 Date of event	dd/mm/yyyy
905 Leukopenia	Drop down list
906 Leukopenia severity score	Number 1-4
907 Date of event	dd/mm/yyyy
908 Malignancy	String restricted list
909 Date of event	dd/mm/yyyy
910 Thromboembolic events	String restricted list
911 Date of event	dd/mm/yyyy

950 PROMS

EQ5D

1=Yes, 2=No

allow for day and month to be unknown

1=Yes, 2=No

allow for day and month to be unknown

1=Yes, 2=No

allow for day and month to be unknown

1=Yes, 2=No

allow for day and month to be unknown

1=Yes, 2=No

see LUID malignancy codes
allow for day and month to be unknown

Minimum of year (allow --/--/yyyy)

Grouped as per diagnosis LU table

Minimum of year (allow --/--/yyyy)

Possible / probable / definite (see sub sheet) Currently included as a t

Check box Currently included as a t

Diagnostic / Equivocal / None Currently included as a t

Original database history

cm

Yes/No/Transplanted

C / P / Atypical / Negative / Not tested

PR3 / MPO / PR3+MPO / Other / ELISA negative / No ELISA performed

rs)

nervous system/constitutional

rs)

Unknown / Oral corticosteroids / Pulsed IV corticosteroids / cyclophosph

rs)

Unknown / Oral corticosteroids / cyclophosphamide / Rituximab / MM

1=Yes, 2=No

1=Yes, 2=No

rs)

EDTA for DNA, EDTA for PBMC, PAX gene tube for RNA, Urine, Serum, E

e

Kg

1=Yes, 2=No, 3=N/A

check N/A for women outside child bearing pc Mandatory if 101=2

1=Yes, 2=No, 3=N/A

check N/A for women outside child bearing pc Mandatory if 101=2 and
Not working / disability benefit / employed full time / employed part ti

1=Yes, 2=No

BVAS v3, use DCVAS algorithm

LUID BVAS WG

1=Yes, 2=No

Use DCVAS algorithm

Tick all that apply during that period of EULAR / EUVAS definitions: rem
None / Renal / Lung / Systemic / Sino-nasal / Nerve / Skin / cardiovascu

1=Yes, 2=No

LUID meds LUID corticosteroids
1=pre-trial exposure; 2=start; 3=ongoing; 4=stop; 5=one-off

LUID unit table fixed specific to drug

1=Yes, 2=No

LUID meds LUID immunosuppressants
1=pre-trial exposure; 2=start; 3=ongoing; 4=stop; 5=one-off

LUID unit table fixed specific to drug

1=Yes, 2=No

LUID meds LUID biologics
1=pre-trial exposure; 2=start; 3=ongoing; 4=stop; 5=one-off

LUID unit table fixed specific to drug

1=Yes, 2=No

LUID meds LUID acute therapy
1=pre-trial exposure; 2=start; 3=ongoing; 4=stop; 5=one-off

LUID unit table fixed specific to drug

1=Yes, 2=No

LUID meds LUID concomitant/trial specific
1=pre-trial exposure; 2=start; 3=ongoing; 4=stop; 5=one-off

LUID unit table fixed specific to drug

Filter / Centrifugal

Litres

C / P / Positive / Negative / Not tested / Pending

Include normal range

Yes / No / Not performed / Pending

Include normal range

Yes / No / Not performed / Pending

Include normal range
Yes / No / Not performed / Pending

Yes / No / Not performed / Pending
mg/dL / umol/L

Yes / No / Not performed / Pending
MDRD / Cockcroft-Gault / CDK-Epi / Other / Unknown

Yes / No / Not performed / Pending
Spot PCR / Spot ACR / 24h urine protein
mg/mmol / g/24h / other

Yes / No / Not performed / Pending
g/dL / g/L
From transplant tissue typing
Positive / negative / not done / Pending

Positive / negative / not done / Pending

nal place

High / Low / Normal / Not performed / Pending

High / Low / Normal / Not performed / Pending

High / Low / Normal / Not performed / Pending

Yes / No / Not performed / Pending

High / Low / Normal / Not performed / Pending

Yes / No / Not performed / Pending

Million cells/L / cells/uL / % circulating lymphocytes / cells/mm³

High / Low / Normal / Not performed / Pending

High / Low / Normal / Not performed / Pending

High / Low / Normal / Not performed / Pending

Yes / No / Not performed / Pending

Yes / No / Not performed / Pending

Yes / No / Not performed / Pending

Yes / No / Not performed / Pending

Yes / No / Not performed / Pending

Yes / No / Not performed / Pending

Yes / No / Unknown

Fields 90-110 only visible if = 1

Skin / Kidney / Lung / Eye / ENT / Aorta / Temporal artery / Other arter

LUID

LUID

LUID

LUID

Focal / Crescentic / Mixed / Sclerotic /atypical Only visible if biopsy site

thrombosis ± tuft disruption ± cells in Bowmar Only visible if biopsy site

fibrosed areas crossing tuft and Bowman's spa Only visible if biopsy site

Only visible if biopsy site

Only visible if biopsy site

Present / absent / not commented upon

Only visible if biopsy site

Only visible if biopsy site

Estimated / measured

Only visible if biopsy site

Present / absent / not commented upon

Only visible if biopsy site

Present / absent / not commented upon

Only visible if biopsy site

Yes / No / Not commented upon

Only visible if biopsy site

Yes / No / Not commented upon

Only visible if biopsy site

Yes / No / Not commented upon

Only visible if biopsy site

Yes / No / Not commented upon

Only visible if biopsy site

As per DCVAS

Plain radiograph

Whole body

Inflammation

Joint erosions

CT

Whole body

Left / Right / Noth / Not applicable

Vessel narrowing

1=Yes, 2=No

If plasma exchange field ticked

New entry for each transplant

Live-related / live-unrelated / deceased before cardiac death / decease

Prednisolone / Tac / MMF / CyA / Aza / CD25 antibody / / / / / /

Prednisolone / Tac / MMF / CyA / Aza / CD25 antibody / / / / / /

cellular / humoral / none

Vasculitis / Rejection / IFTA / Vascular catastrophe / Other (free text) (C

Blood / Lung / urine / GI / CNS / skin / bone / other

According to CTCAE criteria (1-5)

1=Yes, 2=No

Severity

Diagnosis (Snomed)

Suspected DVT / proven DVT / suspected PE / proven PE

Frequency of data

Frequency of data collection	Level	Parent	Czexh	FVSG
		1 LABEL		
<i>Once</i>		2 REGISTRATION		
<i>Once</i>		2 REGISTRATION		
<i>Once</i>		2 REGISTRATION		
		1 LABEL		
		2 Participant status		
<i>Once</i>		2 REGISTRATION		
<i>Once</i>		2 Participant status		
<i>Once</i>		2 Participant status		
<i>Once</i>		3 Participant status		
<i>Once</i>		3 Participant status		
		1 LABEL		
<i>Once</i>		2 Demographics		
<i>Once</i>		2 Demographics		
<i>Once</i>		2 Demographics		
<i>Once</i>		2 Demographics		
<i>Once</i>		2 Demographics		
<i>Once</i>		2 Demographics		
<i>Once</i>		2 Demographics		
<i>Once</i>		2 Demographics		
<i>Once</i>		1 LABEL		
<i>Once</i>		2 Family		
<i>Once</i>		2 Family		
<i>Once</i>		2 Family		
Multiple		3 Family History		
Multiple		3 Family History		
Multiple		3 Family History		
		1 LABEL		
<i>Once</i>		2 Pre-existing co-morbidity		

	1 LABEL
<i>Once</i>	2 Diagnosis
<i>Once</i>	2 Diagnosis
<i>Once</i>	2 Diagnosis
<i>Once</i>	2 Diagnosis
<i>Once</i>	2 Diagnosis
<i>Once</i>	2 Diagnosis
	1 LABEL
<i>Once</i>	2 Core Features
<i>Once</i>	2 Dialysis
<i>Once</i>	2 Core Features
<i>Once</i>	2 Core Features
<i>Once</i>	2 Core Features
<i>Once</i>	2 Core Features
<i>Once</i>	2 Core Features
<i>Once</i>	2 Diagnosis
<i>Once</i>	3 Biopsy
	1 LABEL
<i>Multiple</i>	2 Samples
<i>Multiple</i>	Samples
<i>Multiple</i>	Samples
<i>Multiple</i>	Samples
<i>Multiple</i>	2 Samples
	1 LABEL
Multiple	2 Encounter
Multiple	2 Encounter
Multiple	
Multiple	2 Encounter
	1 LABEL
Multiple	2 Encounter
Multiple	3 BVAS
Multiple	2 Encounter
Multiple	3 VDI score
Multiple	2 Encounter
Multiple	2 Encounter
	1 LABEL
Multiple	Encounter

Multiple	2 Complications
Multiple	3 Infection
Multiple	3 Infection
Multiple	3 Infection
Multiple	2 Complications
Multiple	3 Leukopenia
Multiple	3 Leukopenia
	Complications
	Complications
Multiple	2 Complications
Multiple	3 Thromboembolic events
	1 LABEL
Multiple	2 Encounter

Norvas

Polish

Reuma.pt

Revas

