

Main Study ID.....
SITE.....

UKVAS ID.....
Patient Initials.....

AFFIX BARCODE HERE

PART A:

Study Name:.....
Lead Clinician:.....
Main Study ID:.....



RKD - Registry and Bio Resource
Cork University Hospital Patient Registration Form

DATE OF VISIT.....

Patient Details	
UK VAS ID (if applicable)	
Name	
Address	
MRN	
Date Of Birth	
Mobile NO	
Home No	
Email	
GP Details	
GP Name	
GPAddress	
GP Phone	

Note. This page of document is to remain on site at Cork University Hospital



PART B: RKD - Cork University Hospital Registration Document
Study Name:..... Lead Clinician:.....
Main Study ID:..... Date of Visit:.....

Demographics			
COUNTRY OF BIRTH		DATE OF ARRIVAL IN IRELAND	/ /
EMPLOYMENT STATUS	not working	disability benefit	
	retired	employed full time	
	student	employed part time	
	homemaker		
Ethnicity			
White: Any other white background:.....	British	Irish	
Asian or Asian British: Any other Asian background:.....	Indian	Pakistani	
	Bangladeshi		
Black or Black British: Any other black background:.....	Caribbean	African	
	African		
Mixed Any other mixed background:.....	White & Asian	Not stated	
Chinese or Other Ethnic Group Any other Ethnic Group :.....	Chinese		

CORE FEATURES			
ANCA IF PATTERN	C	Atypical	
	P	Negative	
	Not tested		
ELISA SPECIFICITY	PR3	ELISA NEGATIVE	
	MPO	NO ELISA PERFORMED	
	OTHER.....		
SYSTEMS INVOLVED AT ANY POINT	Kidney	CNS	
	Lung (granuloma)	PNS	
	Lung (haemorrhage)	Abdominal	
	ENT	Eye	
	Trachea	Cardiovascular	
	Mucotaneous	Other	
	Musculoskeletal		
INDUCTION TREATMENT RECEIVED	Oral Corticosteroids	MMF	
	Pulsed IV corticosteroids	Methotrexate	
	Cyclophosphamide	None	
	Rituximab	Plasma Exchange	
	Azathioprine	Other	
MAINTENANCE TREATMENT RECEIVED	Oral Corticosteroids	Azathioprine	
	Cyclophosphamide	Methotrexate	
	Rituximab	None	
	MMF	Other	
BIOPSY PERFORMED	Yes	If Yes: Vasculitis YES/NO (please circle)	
	No		
ESRD	Yes	Transplanted	
	No		
Control Sample	Yes/No (please circle)		
Pedigree Section	Is this Patient linked to a registered control individual (please circle)		Yes/No
If Yes, Please describe link:	Relationship:	DOB:	
	Name:	Main Study ID:	

CLINICAL DIAGNOSIS:	Date of formal diagnosis / /
Small vessel vasculitis (ANCA associated)	
Microscopic polyangiitis (including renal limited vasculitis)	
Granulomatosis with polyangiitis (Wegener)	
Eosinophilic granulomatosis with polyangiitis (Churg Strauss)	
ANCA vasculitis unclassified	
Small vessel vasculitis (Immune complex)	
anti-GBM disease	
Cryoglobulinemic vasculitis	
IgA vasculitis (Henoch-Schonlein)	
Medium vessel vasculitis	
Classical PAN	
Kawasaki disease	
Other	
Other	
Large vessel vasculitis	
Giant cell arteritis	
Takayasu's arteritis	
Variable vessel vasculitis	
Behcet's disease	
Cogan's syndrome	
Single organ vasculitis	
Isolated aortitis	
Primary cerebral angitis	
Secondary vasculitis	
Drug related vasculitis	
Infection related vasculitis	
Other	
Unclassified vasculitis	

PART C: RKD - Visit Document

Please fill in the following fields for each visit over: DATE OF VISIT:.....

CLINICAL SAMPLES OBTAINED	Leukocytes	<input type="checkbox"/>	Urine	<input type="checkbox"/>
	Leukocytes (for RNA)	<input type="checkbox"/>	Serum	<input type="checkbox"/>
	Saliva (no DNA extracted)	<input type="checkbox"/>	Plasma	<input type="checkbox"/>
	Proteomic	<input type="checkbox"/>	Tissue	<input type="checkbox"/>
	None	<input type="checkbox"/>	DNA	<input type="checkbox"/>

Disease Assessment		Renal Assessment	
Disease Activity since last return:	Remission	<input type="checkbox"/>	ESRD Yes/No
	Active	<input type="checkbox"/>	Transplanted Yes/No
	Low Disease Activity	<input type="checkbox"/>	Dialysis Dependent Yes/No
			Date of Dialysis Start:.....Stop:.....
			Weight:.....kg

Diagnosis Confidence (initial assessment) Matrix for ANCA related Disease (please circle)

Diagnosis Confidence	Definite	Probable	Possible
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Investigations (Please indicate results of investigations specific to the visit. Please Circle Abnormal/Normal/Not Performed)

ANCA IF PATTERN (specific to visit date)	C	<input type="checkbox"/>	Positive	<input type="checkbox"/>
	P	<input type="checkbox"/>	Negative	<input type="checkbox"/>
	Not tested	<input type="checkbox"/>		

Anti-PR3 Level	Abnormal/Normal/Not performed	Level:.....	CRP:	Abnormal/Normal/Not performed	Level:.....
Anti-MPO Level	Abnormal/Normal/Not performed	Level:.....	Creatinine:	Abnormal/Normal/Not performed	Level:.....
EGFR	Abnormal/Normal/Not performed	Level:.....	IgG:	Abnormal/Normal/Not performed	Level:.....
Hb	Abnormal/Normal/Not performed	Level:.....	Lymphocyte:	Abnormal/Normal/Not performed	Level:.....
WCC	Abnormal/Normal/Not performed	Level:.....			

Treatment (please tick if patient is receiving any of the following medication)

Corticosteroids (please circle)	Yes/No	<input type="checkbox"/>	Pulsed IV Steroids (please circle)	Yes/No	<input type="checkbox"/>
Immunosuppressive Medication:	Daily oral cyclophosphamide	<input type="checkbox"/>	Methotrexate	<input type="checkbox"/>	
	Azathioprine	<input type="checkbox"/>	Leflunomide	<input type="checkbox"/>	
	Pulsed cyclophosphamide	<input type="checkbox"/>	None	<input type="checkbox"/>	
	MMF	<input type="checkbox"/>			
Rituximab	(i.e. currently under the influence of Rituximab).		Yes/No	<input type="checkbox"/>	

Current Steroid Dose (mg/daygoing forward) _____

Dose of other Immunsupressants (total daily dose going forward ,weekly in case of MTX) _____

Prophylaxis	Co-trimoxazole	<input type="checkbox"/>	Calcium + Vitamin D	<input type="checkbox"/>
	Pentamidine	<input type="checkbox"/>	Bisphosphonate	<input type="checkbox"/>
	Calcium	<input type="checkbox"/>	Antifungal	<input type="checkbox"/>

Plasma exchange (going forward):

Current Complications (Please see Current Complications in Clinical Data Entry SOP)

Complication of Therapy	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Infection, Diagnosis/Organism if known:			Infection Severity (1-5):	_____
			Date of event:	___/___/_____
Leukopenia:	Yes	<input type="checkbox"/>	Leukopenia Severity (1-5):	_____
	No	<input type="checkbox"/>	Date of event:	___/___/_____
Other ADR/Disease Complications:	Yes	<input type="checkbox"/>	Other Complication Score (1-5):	_____
	No	<input type="checkbox"/>	Date of event:	___/___/_____

PART D: Patient Registration		SAMPLE DETAILS		Date of Visit:.....
UK VAS ID		PAXgene tube	Time of Collection:	
Main Study I.D.			Time of Freezing:	
Collected by:		BDP100 Proteomics	Time of Collection:	
Processed by:			Time of Freezing:	
Date:				
URINE DETAILS	TIME OF VOIDING:			
TRANSPORT TEMPERATURE	ICE / 4°	ICE / 4°	ROOM TEMPERATURE	
Urine Sample type:	Proteomics	Metabolomics	Exosome	
TIME OF PROCESSING				
TIME OF FREEZING				
Total Volume (ml):				
No. of 5ml (50ml for Exosome) tubes frozen:				
Volume of each 5ml (or 50ml) tube:				
Number of 2ml cryovials frozen:				
Volume in each cryovial:				
Protease Inhibitor tablet added				
SERUM DETAILS		PLASMA DETAILS		
TIME OF COLLECTION:		TIME OF EDTA TUBE COLLECTION:		
TIME OF SPINNING:		TIME OF SPINNING:		
TIME OF FREEZING:		TIME OF FREEZING:		
Number of 2ml cryovials frozen:		Number of 2ml cryovials frozen:		
Volume stored in each cryovial:		Volume stored in each cryovial:		
		Protease Inhibitor added:		
DNA DETAILS		ACD TUBE PBMC- PREP DETAILS		
Time of Blood EDTA Collection:		Time of Blood ACD Collection:		
Time of Freezing:		Date of Processing:		
Date of Processing:		Time of Processing:		
Processed by:		Processed by:		
DNA concentration after extraction:		Cell concentration:		
Normalised to:		Number of cryovials frozen:		
Number of normalised vials frozen:		Volume per cryovial:		
Volume in normalised vials frozen:				

Note: If the integrity of the sample container is compromised,
 or the proper amount of sample is not present,
 or the sample containers/labelling is not adequate,
 or the blood samples appear hemolysed
 or there was any problem with processing

To be filled in by Research Nurse

To be filled in by biobank technician.

To be filled in by whomever is processing the sample.