



## **UK PSC STUDY - APPENDIX E**

### **DATA TO BE SOURCED FROM ELECTRONIC MEDICAL RECORDS (EMR)**

#### **1. Laboratory investigations**

Please note the following:

- Laboratory investigations from EMR are only required if they are not available from central data repositories;
- If laboratory investigations are obtained from EMR, the date of the investigation, result and reference range (if appropriate) should be provided.

#### **a. Biochemistry**

##### **i. Renal biochemistry**

- Sodium (Na)
- Potassium (K)
- Urea
- Creatinine
- CA19.9

##### **ii. Liver biochemistry**

- Total bilirubin
- Alanine transaminase (ALT)
- Aspartate transaminase (AST)
- Alkaline phosphatase (ALP)
- Gamma glutamyl transferase (GGT)
- Albumin

##### **iii. Bone biochemistry**

- Calcium (Ca)
- Corrected calcium
- Phosphate

##### **iv. Vitamin D profile**

- 25-hydroxy-vitamin D (Calcidiol)
- 1,25 dihydroxy-vitamin D (Calcitriol)

##### **v. Lipid profile**

- Total cholesterol
- HDL-cholesterol
- LDL-cholesterol
- Total cholesterol : HDL ratio
- Triglycerides

##### **vi. Glucose**

##### **vii. HbA1c**

##### **viii. Serum immunoglobulins**

- Immunoglobulin G (IgG)
- Immunoglobulin A (IgA)

- Immunoglobulin M (IgM)  
Immunoglobulin G4 (IgG4)

## **b. Haematology**

### **i. Full blood count**

- Haemoglobin (Hb)
- White cell count (WCC)
- Platelet count

### **ii. Coagulation**

- Prothrombin time (PT)
- Activated partial thromboplastin time (APTT)
- International normalised ratio (INR)

## **c. Immunology**

### **i.**

- Anti-nuclear antibodies (ANA)
- Anti-centromere antibodies (ACA)
- Anti-gp210 antibodies
- Anti-sp100 antibodies
- Other ANA, unspecified incl ANCA

### **ii. Anti-mitochondrial antibodies**

- M2 antibodies
- Anti-PDC antibodies

### **iii. Anti-smooth muscle antibodies**

## **d. Histopathology**

### **i. Liver biopsy**

### **ii. Liver explant**

### **iii. Gastrointestinal biopsy**

## **2. Imaging investigations**

### **i. Ultrasound scans (USS)**

- USS liver
- USS abdomen
- Fibroscan

### **ii. Computerised tomography (CT)**

- CT liver
- CT abdomen
- CT abdomen and pelvis
- CT thorax, abdomen and pelvis

### **iii. Magnetic resonance imaging (MRI)**

- MRI liver
- MRI abdomen
- MRI cholangio-pancreatogram (MRCP)

## **3. Endoscopic investigations**

### **i. Upper gastrointestinal endoscopy/oesophago-gastro-duodenoscopy (OGD)**

### **ii. Colonoscopy/Flexible sigmoidoscopy**

iii. Cholangiographic studies including ERCP and Endoscopic Ultrasound

## **DATA FROM CENTRALISED DATA REPOSITORIES**

If laboratory investigations are obtained from centralised data repositories, the date of the investigation, result and reference range (if appropriate) should be provided.

### **4. Biochemistry**

i. Renal biochemistry

- Sodium (Na)
- Potassium (K)
- Urea
- Creatinine
- CA19.9

ii. Liver biochemistry

- Total bilirubin
- Alanine transaminase (ALT)
- Aspartate transaminase (AST)
- Alkaline phosphatase (ALP)
- Gamma glutamyl transferase (GGT)
- Albumin

iii. Bone biochemistry

- Calcium (Ca)
- Corrected calcium
- Phosphate

iv. Vitamin D profile

- 25-hydroxy-vitamin D (Calcidiol)
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v. Lipid profile

- Total cholesterol
- HDL-cholesterol
- LDL-cholesterol
- Total cholesterol : HDL ratio
- Triglycerides

vi. Glucose

vii. HbA1c

viii. Serum immunoglobulins

- Immunoglobulin G (IgG)
- Immunoglobulin A (IgA)
- Immunoglobulin M (IgM)
- Immunoglobulin G4 (IgG4)

### **5. Haematology**

i. Full blood count

- Haemoglobin (Hb)

- White cell count (WCC)
- Platelet count

ii. Coagulation

- Prothrombin time (PT)
- Activated partial thromboplastin time (APTT)
- International normalised ratio (INR)

## **6. Immunology**

i. Anti-nuclear antibodies (ANA)

- Anti-centromere antibodies (ACA)
- Anti-gp210 antibodies
- Anti-sp100 antibodies
- Other ANA, unspecified

ii. Anti-mitochondrial antibodies

- M2 antibodies
- Anti-PDC antibodies

iii. Anti-smooth muscle antibodies

## **DATA FROM NHS DATA CENTRES**

### **7. NHS Digital (for England)**

Data from the following datasets will be requested from NHS Digital:

Hospital Episodes Statistics (HES)

- Inpatient episodes: all admissions to hospital since the diagnosis of PSC, including the diagnoses, investigations, procedures and treatments linked to these admissions;
- Outpatient appointments: all outpatient visits since the diagnosis of PSC, including the diagnoses, investigations, procedures and treatments linked to these visits;
- Accident and Emergency attendances: all visits to A&E since the diagnosis of PSC, including the diagnoses, investigations and treatments linked to these visits;
- Diagnostic Imaging Dataset
- Cancer data from the Office for National Statistics (for England and Wales).
- Mortality data from the Office for National Statistics (for England and Wales).
- Primary care data (GPES)

### **8. Scottish Health Information Service (SHIS), for Scotland**

Data from the following datasets will be requested from the SHIS:

SMR01 – General / Acute Inpatient and Day Case dataset

- Inpatient episodes: all admissions to hospital since the diagnosis of PSC, including the diagnoses, investigations, procedures and treatments linked to these admissions;
- SMR00 – Outpatient Attendance dataset
- Outpatient appointments: all outpatient visits since the diagnosis of PSC, including the diagnoses, investigations, procedures and treatments linked to these visits;

A&E2- Accident and Emergency Datamart (limited)

- Accident and Emergency attendances: all visits to A&E since the diagnosis of PSC, including investigations and treatments linked to these visits;

SMR06 – Scottish Cancer Registry

- Cancer data (Socrates)

National Records of Scotland Death Records

- Mortality data (previous GRO)

**9. NHS Wales Informatics Service, for Wales**

Data from the following datasets will be requested from the NHS Wales Informatics Service:

Patient Episode Database for Wales (PEDW)

- Inpatient episodes: all admissions to hospital since the diagnosis of PSC, including the diagnoses, investigations, procedures and treatments linked to these admissions;
- Outpatient appointments: all outpatient visits since the diagnosis of PSC, including the diagnoses, investigations, procedures and treatments linked to these visits;
- Accident and Emergency attendances: all visits to A&E since the diagnosis of PSC, including the diagnoses, investigations and treatments linked to these visits;