APPENDIX 1 (Web Only File)

Interview topic guide: IPCARD Symptoms Study

I. +II. Unstructured and Semi-structured interview:
- Record patient’s health and illness experiences
- Focussing on the period leading up to their referral for LC Investigation and all experiences of health and illness during the last 2 years, explore:
  - participants’ interpretations of and explanations for symptoms
  - Impact of ill health/symptoms

III. Structured interview:
- Explore list of specific symptom presentations and health changes (attached).

IV. Further semi-structured interview questions: Help-seeking behaviour and use of health services (These questions are to follow accounts of symptoms elicited in sections I, II and III):
- What did you do about [symptom/health change]?
  - any health care, treatments, information or advice received
  - reasons for seeking or not seeking medical help.

Introduction

“Thank you for agreeing to this interview. It should take about 60-90 minutes to complete. If at any time, you wish to stop or have a break, please let me know. If you want any questions repeated or clarified, please ask. I would like to build up a detailed picture of your experiences of health and illness. I am interested in anything that you noticed about your health even if you thought it was minor or not connected to your recent visit to [hospital/clinic]. I will then be asking you to talk in more detail about your experiences of health from when you first noticed a change in your health up to the time when you were referred to the [clinic] and about all aspects of your health in the last 2 years.”

Section I
The topic guide provides a number of questions which the interviewer might use to initiate discussion about a particular topic. However, the interviewer might revise the questions, or alter their order, in light of the interviewee’s response to earlier questions.

Part 1: Exploration of health and illness

Purpose: To explore the participant’s experiences of health and illness over their lifetime including any symptoms/problems/changes in health that they have noticed in the last 2 years.

- Could you tell me how you came to be in Dr [ ]’s clinic/ came to be seeing Dr X
• Please tell me about your health and any illnesses that you have experienced
• How has your health changed (are there any changes that you noticed)?

**Section II**
• When did you first notice something was wrong, or a there had been a change in your health?
• Have you experienced any other changes in your health during the last 2 years?

Prompts: use following prompts to aid recall of dates:
- What year was this?
- What month was this?
- What season was this?
- What it close to an event in the year, such as Christmas or Easter?
- Was this at the same time as any other event in your life?
- Was this at the same time as any family/social event?
- What else was going on in your life at the time?
• Has there been anything else that you have visited your doctor about during the last 2 years?
• Has there been anything else at all relating to your health that you have noticed during the last 2 years even if minor?

Probes: for all illnesses explore:
- Severity
- Duration
- Change over time/how/when (use same probes as for Part 1)
- Impact (social/lifestyle/family/psychological/what did the participant think about their symptom)
- Participant's explanations for illness/associated with?/causes

**Section III**
“I have a list of things that some people notice before they are told that they have a chest problem. I am going to ask you if you experienced each of these things. I will then ask you about each health change that you experienced in more detail.”

01. Cough
02. Coughing up blood
03. Breathlessness or panic attacks
04. Changes in eating, appetite, taste or weight
05. Pain
06. Discomfort or strange sensations
07. Aches or pain in chest, back, shoulders or joints
(if not mentioned in response to 5 and 6)
08. Skin changes

YES NO (see structured guide - cough)
YES NO (see structured guide - haemoptysis)
YES NO (see structured guide - breathlessness)
YES NO (see structured guide – eating/weight)
YES NO (see structured guide – pain)
YES NO (see structured guide – discomfort)
YES NO (see structured guide – specific aches)
YES NO (see structured guide – skin)
09. Lots of infections  YES NO (see structured guide - infections)
10. Tiredness  YES NO (see structured guide – tiredness)
11. Feeling generally unwell  YES NO (see structured guide – unwell)
12. Hot or cold sweats  YES NO (see structured guide – sweats)
13. Voice changes or hoarseness  YES NO (see structured guide – voice changes)
14. Other (DESCRIBE)  ____________ YES NO (see generic guide – other)

Information: Turn to relevant problems identified by participant. Only sections relating to the problems/changes identified by the should be completed

Section IV

Semi-structured interview: Help-seeking behaviour and use of health services (These questions follow accounts of symptoms elicited in sections I, II and III, and do not necessarily come at the end of the interview):

- What did you do about the symptom?

  **Prompts**
  o Confided in close family member/friend – who did you talk to first?/who else did you speak to
  o Found information (Read health related article in magazine or book, Consulted a medical dictionary/encyclopaedia, watched a health related TV/Video, Undertook an internet search),
  o Sought advice (e.g. Sought advice from NHS direct/ walk-in centre, Spoke to practice nurse/other health professional, Spoke to your GP/made appointment to see GP)
  o Treatment (other than GP advised) Took over the counter medication (self-prescribed or pharmacist consulted), Took complementary medicine/ therapy

- Why was that, what was it about your [symptom] that made you do /see X/not seek help?

- What happened when you did X?

- Have you done anything further about/received any further medical care /help with [symptom] since X?
  o If further help was sought - what made you seek this help?

- Please describe any changes in the way you manage or live with the [symptom] since X

Relationship with GP and barriers to use of primary care services
• Have there been any circumstances in which you were unsure about whether to seek help from your GP?
• What things have made you decide against visiting your GP/practice nurse?
• Have there been any other circumstances in which attending your GP would have been difficult?
  o What were these?