

All Party Parliamentary Group on Pancreatic Cancer: Terms of reference for early diagnosis inquiry

Introduction

The All Party Parliamentary Group on Pancreatic Cancer is launching a special inquiry into early diagnosis. The inquiry will build upon our prior reports, [Pancreatic Cancer Research: A roadmap to change](#) and [Time to Change the Story: A plan of action for pancreatic cancer](#).

Questions for Stakeholders

The APPG on Pancreatic Cancer is particularly interested in hearing evidence from stakeholders responding to the following questions:

- How much progress has been made on improving the early diagnosis of pancreatic cancer since 2013 and the past APPG on Pancreatic Cancer inquiries? The inquiry reports, [Pancreatic Cancer Research: A roadmap to change](#) and [Time to Change the Story: A plan of action](#), include a number of early diagnosis recommendations. The following is a brief overview of these recommendations (Please see the reports for the full text):
 - **Decision Aid Tool** - Department of Health and professional body action to ensure increased GP use of the Decision Aid Tool;
 - **Educational Tools and Curriculum** - Professional body support for increased use of pancreatic educational tools by clinicians and a review of the medical training curriculum;
 - **Symptom Awareness Campaign** - Consideration of a pancreatic cancer specific symptom awareness campaign pilot under the National Awareness and Early Detection Initiative (NAEDI) in a region where decision aid tools are used;
 - **Pathways** - A review of pathways between primary and secondary care for referral and investigation of pancreatic cancer patients;
 - **Coordinated approach to new models** - A coordinated approach supported by the Department of Health and NHS England (NHSE) to piloting and evaluating new models (i.e., direct access to CT scans, named diagnostic specialists, specialist diagnostic centres and rapid access clinics);
 - **Emergency Admission Audit** - An audit of pancreatic cancer patient deaths diagnosed via emergency admissions;
 - **Less Common Cancer Audit** - GP audits of diagnosis of less common cancers as part of their annual appraisal process and the use of these audits during revalidation;
 - **Suspected Cancer Guidelines** - NICE consideration of the APPG on Pancreatic Cancer's first inquiry when it reviews the referral for suspected cancer guidelines;
 - **Carcinoma of unknown primary guidelines** - NICE review of the 'carcinoma of unknown primary' guidelines to ensure clarity about its application;
 - **Monitoring and Surveillance** - Public Health England's consideration of monitoring and surveillance for patient groups at increased risk of pancreatic cancer, as well as, changes to the patient group guidelines so they reflect this risk and the need for surveillance; and

- **Research** - More pancreatic cancer research focusing on early diagnosis, including research that may lead to screening tools. (Please see the reports for the full text.)

Explain the progress made toward each one of these objectives. If none, why is this?

- What are the main barriers to the early diagnosis of pancreatic cancer?
- Will pancreatic cancer benefit from earlier diagnosis initiatives undertaken by NHSE as part of the Cancer Strategy 2015-2020? Some of the most notable NHSE initiatives include the following:
 - The 28 day GP referral objective;
 - Increases in diagnostic capacity; and
 - Multi Diagnostic Centres (MDCs) for Vague Symptoms.
- How can Cancer Alliances support the earlier diagnosis of hard-to-diagnose cancers, such as pancreatic cancer?
- How should we measure progress on improving the early diagnosis of pancreatic cancer patients? What data should be collected? How often? In what format?
- What are the most promising developments for ensuring that pancreatic cancer will be detected earlier - now and in the future?
- What do we need to do to ensure that promising initiatives come to fruition?
- What one thing do you think we should focus attention and investment on for early detection and pancreatic cancer?
- What can parliamentarians do to ensure pancreatic cancer is diagnosed sooner?

The inquiry is calling for written and oral evidence from a range of stakeholders including patients, carers, family members, clinicians, researchers, charities, policy makers and others.

Terms of reference

This is the first APPG inquiry to focus solely on early diagnosis, but it has been at the forefront of its efforts for many years. Many of the APPG's recommendations in a [Time to Change the Story: A plan of action for pancreatic cancer 2013](#) and at least one recommendation from [Pancreatic Cancer Research - A roadmap to change](#) analyse various early diagnosis measures. "[Achieving world class outcomes](#)" [A Strategy for England 2015-2020](#) also recognises the important role early diagnosis plays in increasing survival rates for cancer patients.

In response to the Cancer Strategy for England, NHSE has adopted various initiatives and targets (including MDCs for vague symptoms under the Accelerate, Coordinate, Evaluate [ACE] programme) to ensure cancer is diagnosed sooner. The charity sector has also developed and/or funded a number of early diagnosis projects. Finally, the National Awareness and Early Diagnosis Initiative (NAEDI), is

noted for its coordinated approach to investment, research analysis, policy activity and a range of interventions.

Research is fundamental to making breakthroughs we need for earlier diagnosis. Cancer Research UK, Pancreatic Cancer UK, Pancreatic Cancer Action, and Pancreatic Cancer Research Fund have funded a large number of research projects related to the diagnosis of pancreatic cancer.

Given the previous APPG inquiries, the Cancer Strategy, the research environment, and the initiatives by NHSE, charities and other entities, the APPG inquiry will aim to:

- Assess the progress made against existing APPG recommendations on early diagnosis;
- Analyse the early diagnosis developments made in the last few years (since the APPG's previous inquiries), specifically any relevant successes and failures;
- Identify the most promising initiatives;
- Assess to what degree early diagnosis initiatives taken forward by NHSE and possibly other NHS entities in the UK will benefit pancreatic cancer patients; and
- Make recommendations for early diagnosis and pancreatic cancer in the future.

Submission guidelines

We would appreciate it if the submissions addressing the [Questions for Stakeholders](#) followed these guidelines:

- be in Word format;
- state clearly who the submission is from, and whether it is sent in a personal capacity or on behalf of an organisation;
- be no more than 2,500 words in length;
- comprise a single document attachment to the email;
- begin with a short summary in bullet point form;
- have numbered paragraphs; and
- use footnotes rather than endnotes.

A copy of the submission should be sent by e-mail with the subject "Pancreatic Cancer APPG Early Diagnosis Inquiry" to appgpc@pancreaticcancer.org.uk.

Much of the evidence we receive will be made public either as part of oral evidence submissions or in our final written report. If you wish for your submission or parts of your submission to remain private then please note this in the submission, or contact us to discuss this prior to submission.