

# COLORECTAL CANCER SCREENING PILOT PROGRAMME



## PARTICIPANT CONSENT FORM Undertaking and Declarations

1. I understand that the Colorectal Cancer Screening Pilot Programme ("Pilot Programme") will commence on a date to be specified by the Government and run for a period of thirty- six (36) months or such other period as may be specified by the Government.

#### 2. Under the Pilot Programme, I understand that:-

- a. clinical care will be provided by Primary Care Doctors ("Enrolled PCD") and Colonoscopy Specialists ("Enrolled CS") enrolled in the Pilot Programme (collectively, "Service Providers");
- b. the Service Providers shall be professionally accountable for all related clinical care and management. The Government bears no responsibilities and obligations in this context;
- c. I will receive Government subsidy for the following services:
  - i. the faecal occult blood test in the form of Faecal Immunochemical Test ("FIT"). The Enrolled PCD will issue FIT tubes to me for collecting stool specimen, which will be sent to a designated laboratory for analysis;
  - ii. the standard package of colonoscopy service (if my FIT result is positive) which includes
    - one pre-procedural consultation,
    - colonoscopy examination, and
    - post-procedural consultation (optional).

The Enrolled PCD may refer me to the Enrolled CS for the standard package of colonoscopy service to rule out colorectal cancer or other possible lesions.

#### 3. Considering workflow pertaining to the Enrolled PCD, I understand that,

- a. before specimen collection, I will be given by the Enrolled PCD two FIT tubes to collect stool specimen within eight weeks of issue for colorectal cancer screening, and another two FIT tubes in case both of the original FIT tubes are spoilt, lost, damaged, or rejected by laboratory;
- b. after specimen collection, I will return the FIT tube(s) together with the laboratory request form to designated FIT specimen collection points within four days of the first specimen collection with date of collection written on the FIT tubes;
- c. the authority who has the responsibility to inform me the FIT results and discuss with me the subsequent management shall be the Enrolled PCD but not the Government;
- d. no screening test, including the FIT adopted in the Pilot Programme, is 100% correct.
  - i. I may suffer from colorectal cancer even if the FIT result is negative. Hence, I should still be aware of symptoms of colorectal cancer and seek prompt medical advice accordingly, and that repeated screening at regular intervals is important;
  - ii. I may not suffer from colorectal cancer even if the FIT result is positive. I understand that the Enrolled PCD will call me for Second Consultation if the FIT result is positive to explain its implication, discuss and refer for colonoscopy.

#### 4. Considering workflow pertaining to the Enrolled CS, I understand that,

- a. colonoscopy is an invasive diagnostic investigation with associated risks and these risks will be explained to me in detail by the Enrolled CS before the procedure;
- b. in circumstances where the first colonoscopy has failed, the Enrolled CS will discuss with me for repeating the colonoscopy or referral to receive Computed Tomography Colonography which its charges will be fully paid by the Government;
- c. where colorectal cancer or other lesion is detected after colonoscopy, I will be referred by the Enrolled CS for further management under the usual care pathway outside the Pilot Programme, for instance clinical care received in institutes under the Hospital Authority or in the private sector, which will not be subsidised under the Pilot Programme.
- 5. Depending on my choice of Service Providers, I may need to pay a co-payment fee as published on the Prevent Colorectal Cancer website (www.ColonScreen.gov.hk) and the mini-poster at the Health Care Institution, even though the Government has provided a subsidy for the FIT and colonoscopy examination under the Pilot Programme.
- 6. I understand that if I withdraw from or exit the Pilot Programme, or withdraw from eHRSS, Service Providers will no longer be able to access to and have no further obligation to inform me of my screening results. Thus, I will be at risk of missing significant screening results.

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- 7. I hereby agree to transfer and release to the Government, its agents, or other persons authorised by the Government (a) my personal data, (b) my correspondence address, (c) my contact telephone number and (d) any information (including but not limited to the clinical information) related to the Pilot Programme for the use by the Government for the purposes as set out in the "Statement of Purpose". My personal data includes:-
  - In the case of HKIC holder, my HKIC number, name (in English and Chinese), sex, date of birth, date of issue of HKIC;
  - In the case of Certificate of Exemption holder, my HKIC number, name (in English and Chinese), sex, date of birth, Serial number, Reference number, issue date as shown on the Certificate of Exemption.

My correspondence address and contact telephone number refer to those captured under the eHRSS.

- 8. I note that the Government may contact me by calling my contact telephone number or/and sending correspondence to my correspondence address for the purposes as set out in the "Statement of Purpose".
- 9. I agree to authorise the Service Providers to read my name (in English and Chinese), sex, HKIC number, date of birth and date of issue stored in the chip embodied in the HKIC for the purposes as set out in the "Statement of Purpose".
- 10. I agree that my personal data and any information collected and stored in the Colorectal Cancer Information Technology System under the Pilot Programme will be transferred onto the eHRSS for access by healthcare providers whom I have given consent under the eHRSS.
- 11. I understand this consent (including these Undertaking and Declarations) shall be governed by and construed in accordance with the laws of Hong Kong Special Administrative Region and I, and the Government shall irrevocably submit to the exclusive jurisdiction of the Hong Kong Special Administrative Region.
- 12. I have read this consent (including these Undertaking and Declarations) carefully and fully understood my obligations and liability under these Undertaking and Declarations.

(For illiterate participant: This consent including these Undertaking and Declarations has been read over and explained to me and I fully understand my obligations and liability.)

- 13. I declare that the information provided in this Consent Form is factually correct.
- 14. I understand that I should observe the Prevention of Bribery Ordinance (Cap. 201) and should not offer to, solicit or accept from any person any advantage as defined in the Ordinance.
- 15. I consent to and authorise the Government to (i) obtain from the Hospital Authority clinical information related to the diagnosis and management of my colorectal condition and (ii) use such information for the purpose of evaluating the Pilot Programme. My consent given under this paragraph shall survive the expiration of the term of the Pilot Programme.

## **Statement of Purpose**

#### **Purpose of Data Collection**

Any information, including the personal and clinical data as well as contact details provided under the Pilot Programme will be used by the Government for one or more of the following purposes:

- a. Processing the enrollment of participant into the Pilot Programme including but not limited to a verification procedure with the data kept by the Immigration Department;
- b. Administration, monitoring, auditing and evaluation of the Pilot Programme including but not limited to processing subsidy payment, providing necessary health care service and continuity of care to participant, sending reminder(s) for colorectal cancer screening, and investigation of incidents and complaints;
- c. Statistical, programme monitoring, evaluation and research purposes; and
- d. Any other legitimate purposes as may be required, authorised or permitted by law.

The provision of any information, including the personal data is voluntary. However, if insufficient information is provided, you may not be able to participate in the Pilot Programme.

#### **Classes of Transferees**

The personal data you provided are mainly for use within the Government but they may also be disclosed by the Government to other persons, organisations, and third parties for any of the purposes stated in paragraphs (a) to (d) above, if required.

#### **Access to Personal Data**

You have a right to request access to and correction of your personal data under sections 18 and 22 and Data Protection Principle 6, Schedule 1 of the Personal Data (Privacy) Ordinance (Cap. 486). The Department of Health may impose a fee for complying with a data access request. Request for access to or correction of the personal data should be made in writing to:

Programme Office, CRC Screening Pilot Programme, Department of Health

Room 1301, 13/F, Guardian House, 32 Oi Kwan Road, Wan Chai, Hong Kong

Tel no.: 3565 6288

### **Enquiries**

Enquiries regarding the personal data provided, including the making of access and corrections, should be addressed to

Programme Office, CRC Screening Pilot Programme, Department of Health

Room 1301, 13/F, Guardian House, 32 Oi Kwan Road, Wan Chai, Hong Kong

Tel no.: 3565 6288

2 June 2016

# COLORECTAL CANCER SCREENING PILOT PROGRAMME

### **Background**

The Government announced in the 2014 Policy Address the planning and implementation of a pilot programme that subsidises colorectal cancer screening for specific age groups.

The Pilot Programme will commence on a date to be specified by the Government and run for a period of thirty-six (36) months or such other period as may be specified by the Government.

## Who may enrol

To enrol in the Pilot Programme, participants should:

- Be born in the years 1946 to 1955;
- Hold a Hong Kong Identity Card or Certificate of Exemption; and
- Have already registered in the Electronic Health Record Sharing System (eHRSS).

## Participants will receive screening in phases

Participants will receive screening in phases based on their year of birth

PHASE 1 Individuals born in the years 1946 to 1948

PHASE 2 Individuals born in the years 1946 to 1951

PHASE 3 Individuals born in the years 1946 to 1955

### **About Screening**

- Screening refers to the carrying out of tests on people without symptoms in order to detect disease or identify people at increased risk of the disease. This will allow prompt treatment and improve treatment outcome.
- Colorectal cancer is usually developed from polyps. This process may take up to 10 years. People suffering from early stage of the disease may not notice any symptom even though blood is present in stool.
- The Pilot Programme adopts faecal immunochemical test (an improved version of FOBT) as the screening test to detect small amounts of blood in stool, which is invisible to the naked eye. Participants collect FOBT specimen at home. The procedure is easy, hygienic and safe.
- If the FOBT result is **negative**, participants should repeat screening every two years. Participants should also continue to watch out for symptoms of colorectal cancer, such as a change in bowel habit, blood or large amounts of mucus in stool, persistent urge after passing stool, etc. Seek advice from a doctor if there is any concern.
- If the FOBT result is **positive**, the doctor will refer participants for colonoscopy. This examination is done by passing through the anus a thin flexible tube with a small camera at its end to visualise and detect any abnormality on the inner wall of the large bowel. When required, the doctor can remove polyps or obtain tissue samples for laboratory examination.

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# COLORECTAL CANCER SCREENING PILOT PROGRAMME

## The Primary Care Doctor will check if you are fit for joining the Pilot Programme

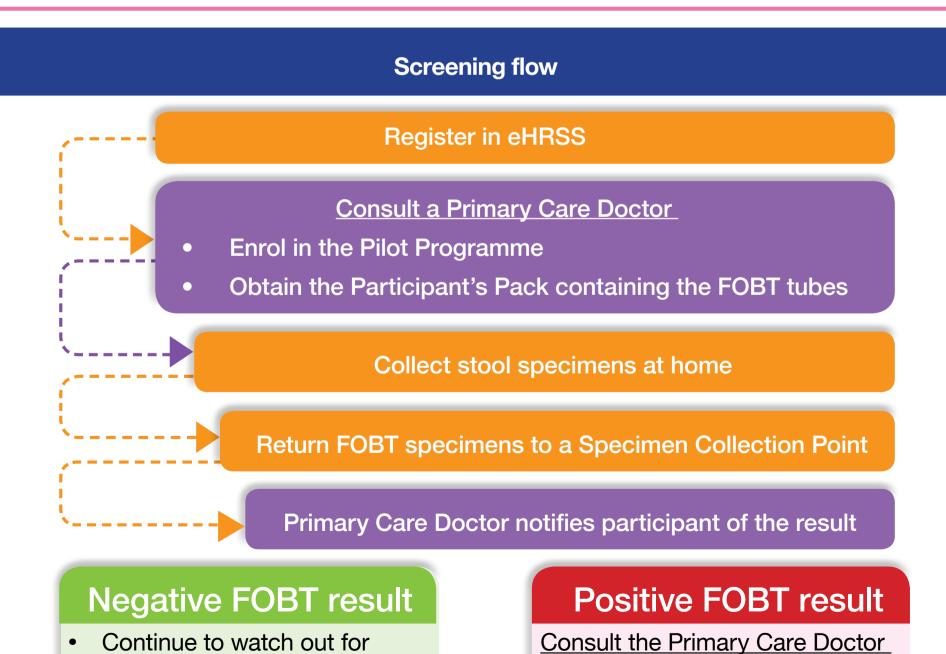
You should inform the PCD if you have any of the following:

- History of colorectal cancer.
- History of chronic inflammation of the bowel, e.g. ulcerative colitis.
- Diagnosis of hereditary colorectal cancer syndrome, or have first-degree relative diagnosed with such syndrome.
- Have two or more first-degree relatives diagnosed with colorectal cancer.
- History of colorectal polyp.

colorectal cancer symptoms

Repeat FOBT every 2 years

- Symptoms of colorectal cancer, such as blood or large amounts of mucus in the stool, change in bowel habit with unknown reason and lasting for more than 2 weeks or abdominal discomfort.
- Previously been advised against receiving colonoscopy by a doctor.
- Record of receiving colonoscopy within the past 10 years.
- Record of receiving flexible sigmoidoscopy within the past 5 years.
- Record of receiving FOBT within the past 2 years (irrespective of results).



#### June 2016

for follow up

result

Receive explanation on FOBT

Receive referral for colonoscopy