

FINAL

NATIONAL BOWEL CANCER SCREENING PROGRAM

PHASE 2

**PARTICIPANT FOLLOW-UP FUNCTION:
SCOPE AND MINIMUM GUIDELINES**

DECEMBER 2008

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1. Introduction

This document outlines the scope and minimum guidelines to implement the 2008/09 Australian Government Budget initiative to support care coordination at a local level for the National Bowel Cancer Screening Program (the Program). The function is referred to herein as the "Participant Follow-up Function". The document was developed in consultation between State and Territory health departments, Medicare Australia and the Australian Government Department of Health and Ageing (DoHA).

The Participant Follow-up Function is to encourage Program participants (herein referred to as participants) to progress through the screening pathway where they have received a positive Faecal Occult Blood Test (FOBT) result and are not recorded on the Program Register as having attended the necessary follow-up including:

- general practitioner (GP) / primary health care provider (PHCP) appointment, or
- an assessment colonoscopy or other clinically relevant assessment.

It is acknowledged that State and Territory health departments have varying degrees of infrastructure in place to support the Program.

2. Purpose of the document

The purpose of this document is to outline the agreed:

- nationally consistent minimum guidelines and follow-up protocols that will be used for the Participant Follow-up Function
- roles and responsibilities of DoHA, the Register (currently operated by Medicare Australia) and State and Territory health departments in regard to the Participant Follow-up Function.

3. Background

In the 2008/09 Federal Budget the Australian Government announced the expansion of the Program to include men and women turning 50, 55 and 65 years of age from 1 January 2008 to 31 December 2010. The Federal Budget comprised a commitment of \$87.4 million over three years to deliver a national framework that includes workforce planning, training and support, and to ensure quality assurance mechanisms are in place.

In May 2008, the Federal Health Minister in a letter to health departments outlined a commitment of \$6 million, over three years, to be allocated to State and Territory health departments to support care coordinators (now known as the Participant Follow-up Function) at a local level in Phase 2 of the Program.

It was the intention of DoHA that State and Territory health departments implement the Participant Follow-up Function and that the Program Information Manager function, with Medicare Australia, would cease.

In June 2008, at the national Program Managers' meeting held in Melbourne, it was agreed that a small working group be established to develop the Participant Follow-up Function, including the scope of the function and minimum guidelines for national consistency. A working group was subsequently established and consisted of representatives from Queensland, Victoria and the Northern Territory, Medicare Australia and DoHA.

The Participant Follow-up Function differs from that of the Program Information Manager positions whose role during Phase 1 and the first 8 months of Phase 2, focused on following-up participants, forms and data for the Register, as well as undertaking health practitioner education activities. The Participant Follow-up Function transfers the participant follow-up role of the Program Information Managers to participating States and Territory health departments who have entered into a Funding Agreement with the Commonwealth from 2 February 2009 for the duration of Phase 2, ending on 30 June 2011¹. The Program Information Manager positions will continue until 30 June 2009 to facilitate training of the Participant Follow-up Function with the Register and follow-up activities.

4. Purpose and scope of the Participant Follow-up Function

The purpose of the Participant Follow-up Function is to encourage participants to progress through the screening pathway where they have received a positive FOBT result and are not recorded on the Program Register as having attended the necessary follow-up.

The Participant Follow-up Function will:

- commence when notification from Medicare Australia is received of identified participants who may require follow-up (herein referred to as the Follow-up Report (refer to Appendix 1) at established points in the screening pathway; and
- cease when:
 - contact has been made with identified participants or their nominated GP/PHCP and the outcome on the interaction has been notified to the Register via an agreed data report (Refer to Table 4 in Section 7 for the data items. Refer to Appendix 2 for the Register Update Form); or
 - a colonoscopy is recorded as having occurred in the Register; or
 - a participant has chosen to suspend or opt off the Program.

¹ Invitations for Phase 2 of the Program conclude on 31 December 2010.

To meet this purpose, in accordance with the Guidelines at Section 7 of this document the Participant Follow-Up Function of the State and Territory health departments will:

1. receive weekly Follow-Up Reports that identify participants who four weeks prior were issued with a Program reminder letter (C061, C071, C081 and C091) from Medicare Australia;
2. using information in the Follow-up Report from Medicare Australia, access the Register to view the participant's record and determine whether a follow-up telephone call is required (refer to Appendix 3 for the Diagrams of follow-up of the screening pathway);
 - o if necessary, contact (refer to Table 1 for definition) the participant to determine if subsequent to receiving Program reminder letters, they have or encourage them to:
 - i. attend an appointment with their GP/PHCP; or
 - ii. attend a specialist appointment and/or colonoscopy (or other clinically relevant procedure).
 - o if contact is unable to be made with the participant, contact the participant's GP/PHCP to determine the participant's status on the screening pathway.
3. follow their jurisdictional protocol regarding wait list issues for colonoscopy procedures;
4. liaise with others undertaking the Participant Follow-up Function within and across States and Territories borders to assist with the progression of the participant through the screening pathway where they reside in one state and are serviced in another, as appropriate;
5. respond to queries from State and Territory health departments or health professionals to identify if individuals are participants of the Program; and,
6. provide information to the Register to update the participant's status on the screening pathway (refer to Table 4 in section 7).

Access to the Follow-up Report and Register will be provided to the Participant Follow-up Function in two distinct stages as outlined in the Roles and Responsibilities section (refer to section 5.2).

At times when the Participant Follow-up Function is not operational in jurisdictions the primary follow-up of participants will occur by the Register reminder letters.

It is acknowledged that the Participant Follow-up Function will not:

- provide clinical advice to participants;
- arrange individual appointments for participants;
- provide clinical data to the Register; or,
- follow-up missing data and Program forms from health professionals.

4.1 Limitations of the Participant Follow-up Function

While the Participant Follow-up Function aims to assist with the follow-up of participants who either fail to go to a GP/PHCP or undertake an assessment colonoscopy following a positive FOBT result, it does not include the provision of care coordination to the point of histopathological diagnosis of polyps, adenomas (pre-cancerous lesions) or cancer, or re-entry into the screening pathway.

The Participant Follow-up Function is intended to assist with the follow up of participants in conjunction with the Register's safety net follow-up activities, rather than to replace any existing reminder system implemented by the Program or medical practitioners.

There are a number of limitations to the Participant Follow-up Function including but not limited to:

- no access to GP/PHCP information, so can not book appointment times for people who have special needs or who are unable to access a GP/PHCP in their local area;
- no access to public sector colonoscopy information to confirm that the participant has had their scheduled procedure (MBS items will confirm private sector colonoscopy);
- being limited to following up participants within a narrowly defined band on the screening pathway meaning that coordination will not follow participants' to definitive diagnosis; and,
- facilitating the return of data to the Register by health practitioners, including GP/PHCP, colonoscopists and pathologists; this function continues to be a function of Medicare Australia.

5. Roles and responsibilities

The roles and responsibilities included in this document are specific to the Participant Follow-Up Function. Additional roles and responsibilities of DoHA, Medicare Australia and State and Territory health departments can be found in the Phase 2 National Bowel Cancer Screening Program Policy Framework document.

5.1 Department of Health and Ageing

In relation to the Participant Follow-up Function, DoHA will:

- provide State and Territory health departments with funding to implement the Participant Follow-up Function in that jurisdiction;
- work with Medicare Australia to:
 - ensure training for the Participant Follow-up Function is provided;
 - ensure the Participant Follow-up Function receives weekly Follow-Up Reports;
 - establish real-time access to the Participant Follow-up Function on the Register;
 - ensure processes are in place for interaction between the Program Register (including Information Line operators) and the Participant Follow-up Function.

5.2 Medicare Australia

In relation to the Participant Follow-up Function, Medicare Australia will:

Stage 1 – From 1 January 2009

- provide the Participant Follow-up Function with a Follow-up Report identifying participants who four weeks prior were issued with a Program reminder letter (C061, C071, C081 and C091), relevant to their State or Territory. The format of the report will be an Excel spreadsheet that can easily be manipulated by sorting or adding other information or notations, printed and saved to a computer;
- provide the Participant Follow-up Function with secure online “Enquiry Only” access to the Register to view specified data relating to participants identified in the weekly Follow-up Reports;
- have the capacity to receive and record information contained in the Register Update Form on the Register.

Stage 2 – From no later than 1 June 2009

- provide the Participant Follow-up Function with:
 - online access (via a secure process) to the Follow Up Report provided in Stage 1;
 - the ability to transfer information contained in the Register Update Form, via a secure online access, to immediately update the Register.

Training and support

- provide Register training to the Participant Follow-up Function (when and how this occurs will need to be determined);
- provide ‘help desk’ support to the Participant Follow-up Function for the transition period 1 January 2009 to 30 June 2009;
- work with DoHA to ensure processes are in place for interaction between the Program Register (including Information Line operators) and the Participant Follow-up Function
- work with DoHA to develop and provide a Participant Follow-up Function Manual for the Participant Follow-up Function Working Group, including scripts by the end of November 2008.

5.3 State and Territory Health Departments

In relation to the Participant Follow-up Function, State and Territory health departments will:

- implement the Participant Follow-up Function to follow-up participants four weeks after being issued with a Program reminder letter (C061, C071, C081 and C091);
- maintain the Participant Follow-up Function in line with the intent of this document until the expiration of the Funding Agreement on 30 June 2011;

- ensure that the Participant Follow-up Function complies with national minimum guidelines and duty to follow-up participants, quality management systems will be put in place;
- be responsible for determining the qualifications and eligibility criteria for the employees or agents engaged to carry out the Participant Follow-up Function. The following attributes may be desirable:
 - high level communication skills;
 - population screening/health background and understanding of health services; and,
 - information technology/systems skills.

5.4 Joint responsibilities

The following are the responsibility of DoHA, Medicare Australia and State and Territory health departments to work in collaboration to develop an agreed:

- set of consistent messages regarding the Participant Follow-up Function;
- Register Update Form;
- nationally consistent guidelines on the interaction between the Program Register (including Information Line operators) and the Participant Follow-up Function.

The Participant Follow-up Function will be a standing item at the Program Manager's bimonthly teleconference where successes and challenges can be discussed and documented in the meeting minutes. Capturing this information will be important to informing the project evaluation towards the end of June 2011.

6. Duty of Care

The Department of Health and Ageing has provided the following information in relation to the Duty of Care:

"The Department does not seek to impose any additional duty of care upon States and Territories by virtue of their involvement in the Participant Follow-up Function. The Commonwealth doesn't intend to delegate its duty of care to participants to the States and Territories.

Once the guidelines for the Participant Follow-up Function have been finalised, States and Territories may wish to seek their own legal advice as to the possibility that a duty of care to participants may be imposed on them, in certain circumstances, in relation to their responsibilities as the Participant Follow-up Function, depending up on the action of State/Territory officers. That said, assuming State/Territory officers act within the boundaries of the Participant Follow-up Function; such officers will only be assisting in the follow-up of participants, the ultimate responsibility for which will rest with the Commonwealth and participant's doctors acting in accordance with their duty of care."

7. Minimum guidelines for the Participant Follow-up Function

The following section outlines the minimum guidelines for the Participant Follow-up Function.

Diagram 1 demonstrates the follow-up system for the Program during Phase 1 and 2. The system uses both letter follow-up and telephone contact with the participant, and where required the GP/PHCP. The main differences between Phase 1 and 2 are:

- Telephone contact is transferred from the Program Information Managers to the Participant Follow-up Function;
- Telephone contact is initiated at points 3, 5 and 7 months during Phase 2, which is one week later than Phase 1;
- The reminder letters and request for colonoscopy reports are sent by the Register and are unchanged from Phase 1, with the exception of the 6 month and new 10 month final reminder letters to participants and GPs/PHCPs; and,
- The new 10 month final letters will be sent by Registered Post to provide formal closure of the screening episode after the 7 month telephone follow-up.

During Phase 1 of the Program it was noted by Information Managers that there were a number of participants requiring follow-up following the 6 month reminder letter. The DoHA in consultation with Medicare Australia responded by implementing a 7 month follow-up phone call to participants. Anecdotal evidence from Information Managers during Phase 1 suggested that participants were more likely to progress through the screening pathway after talking with an Information Manager, rather than only receiving written correspondence. The timing of the new 10 month letter will provide participants with a 3 month interval following the 7 month follow-up phone call to undertake an assessment colonoscopy prior to formal closure of the screening episode.

The table on the following page demonstrates a decrease in the number of participants requiring follow-up nationally at the 6 month reminder point in comparison with the 2 and 4 month reminder points during Phase 1. It also shows that there are a number of participants requiring follow-up after the 6 month reminder letter.

Number and percentage of Phase 1 participants requiring follow-up nationally at the 6 month reminder point in comparison with the 2 and 4 month reminder points¹.

Date of FOBT result	No. of positive FOBT results	No. of C061 ² letters (8 weeks post positive FOBT result)		No. of C071 ³ letters (6 months post positive FOBT result)		No. of C081 ⁴ letters (4 months post positive FOBT result)		No. of C091 ⁵ letters (6 months post positive FOBT result)	
		No.	%	No.	%	No.	%	No.	%
June 2007	1742	1258	72.22	288	16.53	230	13.20	36	2.07
July 2007	2104	1490	70.82	234	11.12	209	9.93	61	2.90
August 2007	2583	1793	69.42	228	8.827	288	11.15	66	2.56
Sept 2007	2751	1440	52.34	307	11.16	263	9.56	101	3.67
Oct 2007	2207	1542	69.87	190	8.61	234	10.60	67	3.04
Nov 2007	1811	1204	66.48	187	10.33	350	19.33	86	4.75
Dec 2007	1240	733	59.11	158	12.74	188	15.16	84	6.77
Jan 2008	818	641	78.36	101	12.35	109	13.33	45	5.50
Feb 2008	1334	901	67.54	161	12.07	221	16.57	50	3.75
Mar 2008	1363	962	70.58			178	13.06		
Apr 2008	1773	1178	66.44			158	8.91		
May 2008	1631	845	51.81						
June 2008	1569	804	51.24						
TOTAL	25142	14791		1854		2428		596	

¹ Data provided in monthly report provided to Program Managers.

² C061 – no GP visit – 8 week reminder letter

³ C071 – no GP visit – 6 month reminder letter

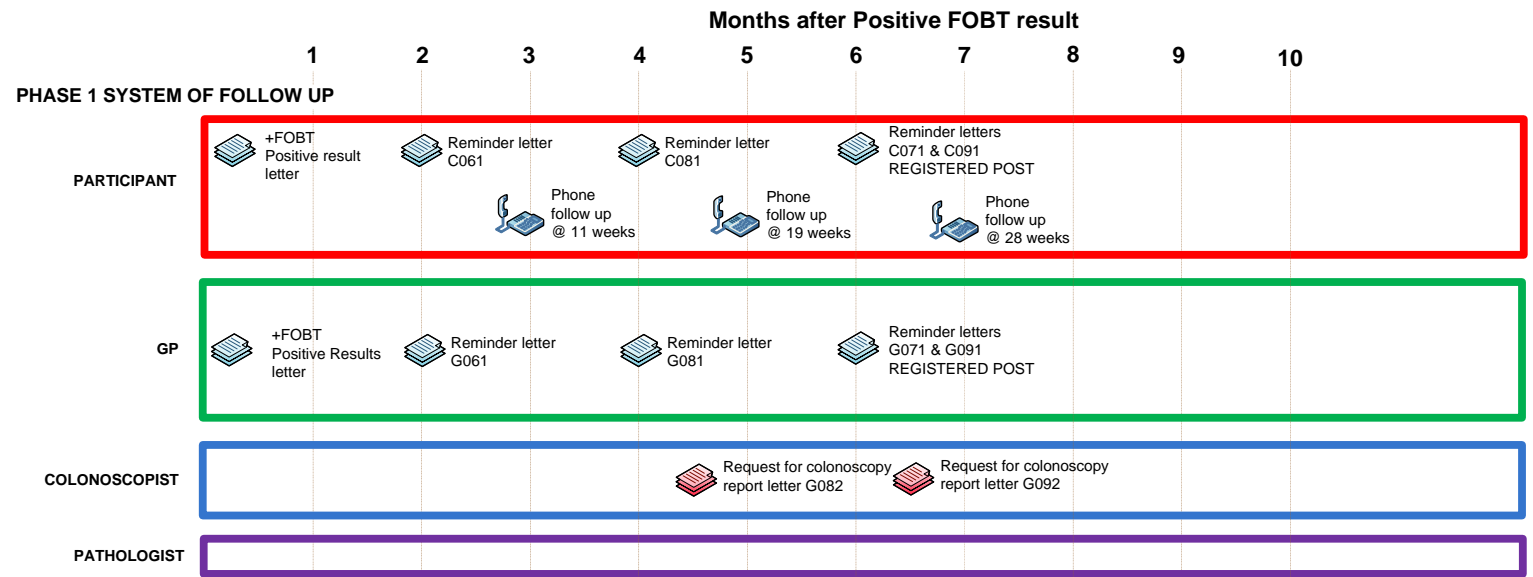
⁴ C081 – no colonoscopy – 4 month reminder letter


⁵ C091 – no colonoscopy – 6 month reminder letter

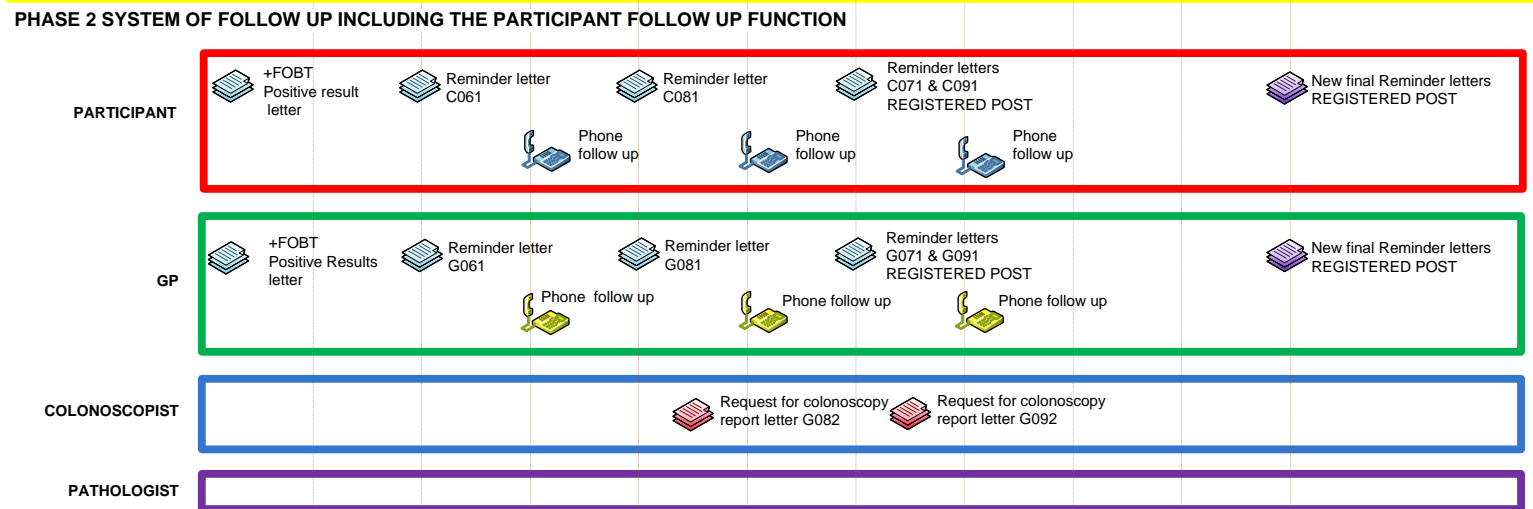
The reminder letters are triggered at defined time intervals after a participant received a positive FOBT result. The time intervals are; 2, 4, 6 and 10 months. A specific letter is triggered to be sent depending on the progress of a participant along the pathway as recorded by the Register. Appendix 4 illustrates the circumstances under which the 2, 4, 6 and 10 month letters are triggered and then sent to participants.

Prior to the 4 and 6 month reminder letters, the MBS claims data is checked for claims for items 32090 & 32093 (32090 - fiberoptic colonoscopy examination of colon beyond the hepatic flexure with or without biopsy; 32093 - fiberoptic colonoscopy examination of colon beyond the hepatic flexure with removal of 1 or more polyps).

If a claim has been recorded, those participants *are excluded from the reminder letters* and a request for a Program Colonoscopy Report is sent to the relevant specialists 2 weeks after the recorded date of colonoscopy.



- Legend**
-  Telephone contact with participant
 -  Telephone follow up with GP/PHCP if contact cannot be made with participant
 -  Reminder & Final letter sent by Register
 -  If MBS claims identified request for colonoscopy report letter G082
 -  New final Reminder letters REGISTERED POST



The following tables outline the minimum guidelines for the Participant Follow-up Function for:

1. Telephone contact with the participant and nominated GP/PHCP.
2. Follow-up points for the follow-up of participants with a positive FOBT result.
3. Management of situations that may be encountered during follow-up.
4. Data exchange between the Register and the Participant Follow-up Function.

Table 1. Guidelines for telephone contact with the participant and nominated GP/PHCP

Type of contact	Action
Contacting the participant	<p>a) A minimum of three (3) attempts will be made to contact the participant via telephone to encourage them to make and attend an appointment with their GP/PHCP</p> <ul style="list-style-type: none"> o In the first instance during business hours; o If telephone contact is unable to be made during business hours, contact should be attempted outside of business hours (9am – 7pm).
Transfer to message service	<p>If a call is transferred to a message service during an attempt, do not leave a message. This includes personal mobile phone services. This is to protect the participant’s privacy and confidentiality.</p>
Contact with participant is not achieved – contact with nominated GP/PHCP	<p>b) A minimum of one (1) attempt will be made to contact a participant’s nominated GP/PHCP to establish:</p> <ul style="list-style-type: none"> o if an appointment has been made and/or attended; or, o if no appointment, advise the GP/PHCP that a reminder letter advising them of the importance of seeing the GP/PHCP has been sent to the participant. <p>c) If contact is unable to be made with the GP/PHCP, speak to the practice staff to ascertain if the participant is a patient at that practice and if so:</p> <ul style="list-style-type: none"> o inform them that the person is a NBCSP participant and has a positive FOBT but that the Register has no record of a GP/PHCP attendance o ascertain if an appointment has been made and/or attended o ascertain if contact details vary from that on the Register

Type of contact	Action
	<ul style="list-style-type: none"> o request that the GP/PHCP is made aware of the situation.

Table 2: Follow-up points and guidelines for follow-up of participants with a positive FOBT result

Timeframe	Progress along screening pathway	Follow up	Who	Timing
2 months after positive FOBT	No record of GP Assessment form on Register	CO61 and G061 reminder letters are sent to participant and nominated GP/PHCP	Register	2 months after positive FOBT result date
		Local participant Follow-up Report generated	Register	1 month after CO61 reminder letter sent
		Status of participants on Follow-up Report checked	Participant Follow-up Function	1 month after CO61 reminder letter sent
		Contact participant as per telephone contact guidelines (refer to Table 1)	Participant Follow-up Function	Up to 1 month after receipt of Follow-up Report

Timeframe	Progress along screening pathway	Follow up	Who	Timing
4 months after positive FOBT	GP Assessment From recorded on Register No record of Colonoscopy form on Register	<p>MBS claims checked to identify those participants who have claimed items 32090 & 32093</p> <p>If MBS claims identified, GO82 request letter sent to specialist for completion of colonoscopy report</p> <p>If no MBS claims, CO81 and GO81 reminder letters are sent to participant and nominated GP/PHCP</p>	Register	4 months after positive FOBT result date
		Local participant Follow-up Report generated	Register	1 month after CO81 reminder letter sent
		Status of participants on Follow-up Report checked	Participant Follow-up Function	1 month after CO81 reminder letter sent
		Contact participant as per telephone contact guidelines (refer to Table 1)	Participant Follow-up Function	Up to 1 month after receipt of Follow-up Report

Timeframe	Progress along screening pathway	Follow up	Who	Timing
6 months after positive FOBT	<p>No record of GP Assessment form</p> <p>AND</p> <p>No record of Colonoscopy form recorded on Register</p>	<p>MBS claims checked to identify those participants who have claimed items 32090 & 32093</p> <p>If MBS claims identified, GO82 request letter sent to specialist for colonoscopy report</p> <p>If no MBS claims, C081 and GO81 reminder letters are sent to participant and nominated GP/PHCP via REGISTERED POST</p>	Register	6 months after positive FOBT result date
	<p>Record of GP Assessment form</p> <p>AND</p> <p>No record of Colonoscopy form</p>	<p>MBS claims checked to identify those participants who have claimed items 32090 & 32093</p> <p>If MBS claims identified, GO82 request letter sent to specialist for colonoscopy report</p>	Register	6 months after positive FOBT result date
		<p>If no MBS claims identified, C091 and G091 reminder letters sent to participant and nominated GP/PHCP via REGISTERED POST</p>	Register	6 months after positive FOBT result date

Timeframe	Progress along screening pathway	Follow up	Who	Timing
		Local participant Follow-up Report generated	Register	1 month after CO81 and C091 reminder letters sent
		Status of participants on Follow-up Report checked	Participant Follow-up Function	1 month after CO81 and C091 reminder letters sent
		Contact participant as per telephone contact guidelines (refer to Table 1)	Participant Follow-up Function	Within 1 month of receiving Follow-up Report
10 months after positive FOBT	No record of GP Assessment form OR No record of Colonoscopy from	New 10 month final follow-up letter sent to participant and nominated GP/PHCP via REGISTERED POST (TO BE DEVELOPED)	Register	10 months after positive FOBT

Table 3: Guidelines to manage scenarios that may be encountered during participant follow-up

Situation	Management by the Participant Follow-up Function
Successful contact with participant but no GP/PHCP	<p>Refer to jurisdictional protocols regarding issue of participant not having a GP/PHCP</p> <p>Update Register with completed follow-up details.</p>
Participant does not wish to make a GP/PHCP appointment	<p>Refer to script (to be developed)</p>
Informed that the participant is deceased	<p>Update Register with completed follow-up details.</p>
Participant does not want to have a colonoscopy	<p>Refer to script (to be developed).</p>
Participant has an appointment for colonoscopy but it is more than 30 days time	<p>Refer to jurisdiction protocols regarding wait times.</p>
Participant has had a colonoscopy but need to have a repeat colonoscopy	<p>Update Register with completed follow-up details.</p>
Participant has had a colonoscopy in another State or Territory	<p>Update Register with completed follow-up details.</p>
Participant is on a waitlist of over 30 days in another State or Territory	<p>Refer to jurisdictional protocols.</p> <p>Update Register with completed follow-up details.</p>

Situation	Management by the Participant Follow-up Function
Participant wishes to opt off or suspend from the Program	<p>Advise the participant of the consequences of suspending or opting off (script to be developed).</p> <p>Update Register with completed follow-up details.</p>
Participant's GP/PHCP has repeated the FOBT (non-program FOBT kit)	<p>Refer to script (to be developed)</p>
Participant has regular colonoscopies due to previous specialist recommendation	<p>Update Register with completed follow-up details.</p>
Participant advises that they have had a colonoscopy just prior to completing NBCSP FOBT	<p>Update Register with completed follow-up details.</p>
Participant has new personal details such as: name, DOB, gender, contact details/address	<p>Advise participant to contact Medicare Australia by telephone on 13 20 11 or on-line at www.medicareaustralia.gov.au (if registered for on-line services)</p>

Table 4: Guidelines for data exchange between the Register and the Participant Follow-up Function

Data/report	Requirement	Who	Timeframe
Participant Follow-up Report	<ul style="list-style-type: none"> • Interaction – reminder letter • Participant ID number • Date +FOBT • Mail date • State • Postcode • Family name • First name 	Register	At four weeks after reminder letter
Updating participant record after follow-up	<ul style="list-style-type: none"> • State/Territory • Participant ID number • Family name • First name • Contact with <ul style="list-style-type: none"> ○ Participant ○ Health professional/staff • GP/PHCP <ul style="list-style-type: none"> No GP/PHCP <ul style="list-style-type: none"> ○ No GP/PHCP visit scheduled ○ GP/PHCP visit scheduled <ul style="list-style-type: none"> ○ Date ○ GP/practice name ○ GP/practice address ○ GP/PHCP visit completed <ul style="list-style-type: none"> ○ Date ○ GP/PHCP/ practice name ○ GP/PHCP/ practice address ○ Referred for Colonoscopy ○ Not referred for colonoscopy ○ Referral status unknown ○ Referred for other 	Participant Follow up Function	Within 24 hours of completion of contact

Data/report	Requirement	Who	Timeframe
	<p style="text-align: center;">procedure</p> <ul style="list-style-type: none"> • Colonoscopy referrals <ul style="list-style-type: none"> ○ Has not made appointment ○ Is waiting to see specialists ○ Other ○ Has seen specialist or attended outpatient appointment <ul style="list-style-type: none"> ○ Date ○ Specialist / Facility ○ Waiting for colonoscopy date ○ Advised not proceeding to colonoscopy • Opt off <ul style="list-style-type: none"> ○ Already under cancer care ○ Not interested ○ Uncomfortable with process ○ Medical advice not to participate ○ No reason given ○ Privacy concerns ○ Other • Suspend <ul style="list-style-type: none"> ○ GP advice ○ Illness ○ Travelling ○ No reason given ○ Not eligible ○ NT rural/Indigenous metro ○ Other ○ Date to recommence • Free text field to report on specific situations relevant to follow-up 		
Confirmation of opt	Letter confirming same sent	Register	Within 1 week of

Data/report	Requirement	Who	Timeframe
off / suspend	to participant		update

8. Privacy and confidentiality for the Participant Follow-up Function

The following information has been provided by Medicare Australia:

"Invitations sent to participants to take part in the Program are selected from either the Medicare enrolment records held by Medicare Australia or the enrolment file held by the Department of Veteran Affairs. When releasing information Medicare Australia must consider both the Privacy Act 1988 and the Secrecy Provisions within the Health Insurance Act 1974. The Privacy Act is relevant to all data in the possession of Medicare Australia (as data manager) and the Secrecy Provisions are relative to personal information captured and stored for the purpose of administering Medicare.

As personal and confidential information is contained within the Program Register, Medicare Australia requires each person performing the Participant Follow-up Function to sign a confidentiality deed that obligates them to keep the confidential information confidential. The Deed of Confidentiality covers 'Confidential Information' (information covered by the common law duty of confidentiality) as well as 'Personal Information' (as defined in the Privacy Act 1988 Cwlth)."

The following pages contain the *Nomination Form* and *Deed of Undertaking* for the Participant Follow-up Function as provided by Medicare Australia.

**Nomination Form For
Authorised Participant Follow-up Function
Access to the National Bowel Cancer Screening Register**

Please complete the Personal Details and return form as soon as possible to:

The Manager
National Bowel Cancer Screening Program
National Office - Comms M-G
PO Box 1001
TUGGERANONG DC ACT 2901.

Should you wish to discuss any details on this form, please do not hesitate to call 02 6124 7174.

Participant Follow-up Function Personal Details:

Title:..... First Name:.....

Surname:.....

Business Name:.....

Business Address:.....

..... P/C:.....

Postal Address:.....

..... P/C:.....

Email Address:.....

Fax Number:.....

Telephone Number:.....

Pass Phrase: _ _ _ _ _

(Pass Phrase can be alpha or numeric or alpha/numeric with a minimum of four and maximum of eight characters.)

.....
State / Territory Health Department Name

.....
State / Territory Health Department Manager's Name

.....

State / Territory Health Department Manager's Signature
Date

THIS CONFIDENTIALITY DEED POLL is dated the _____ day of 2008

for the benefit of the Commonwealth of Australia as represented by the Chief Executive Officer of Medicare Australia, with its head office at 134 Reed Street North, Greenway in the Australian Capital Territory ABN 75 174 030 967 (**Medicare Australia**)

By

[insert name of the Authorised Participant Follow-up Function Officer] of

[insert work address of the Authorised Participant Follow-up Function]

(the **Authorised Participant Follow-up Function**)

Purpose

The purpose of this Deed Poll is to protect from disclosure, the Confidential Information and Personal Information of participants registered on the National Bowel Cancer Screening Register ("**NBCSR**") administered by Medicare Australia ("**Medicare Australia**").

Medicare Australia will make information recorded on the NBCSR available to the Authorised Participant Follow-up Function (**APFF**) via a secure internet site. APFFs are selected employees of State and Territory Health Departments (**Agency**).

I, irrevocably agree that:

1. I understand that in the course of accessing the NBCSR I will have access to Confidential Information as defined in this Deed Poll.
- 1A. I will only access the NBCSR in the course of, and for the purpose of, fulfilling my duties as an APFF.
2. I agree that Confidential Information means information of or in the possession of Medicare Australia that is obtained by myself with restricted access to the NBCSR; or
 - (i) is by its nature confidential;
 - (ii) is designated by Medicare Australia as confidential;
 - (iii) is obtained by myself in circumstances inferring confidentiality; or
 - (iv) I know or ought to know is confidential; and

includes any notes or copies based on or derived from such information.

3. I acknowledge and agree that:

- (i) I will use Confidential Information only for:
 - **the primary purpose of ascertaining the screening pathway status for participants in the National Bowel Cancer Screening Program (NBCSP); and**
 - **any purpose incidental to the primary purpose.**
- (ii) apart from any authorised disclosure under Clause 3(I), I must not disclose, other than to Medicare Australia, any Confidential Information without the written authority of Medicare Australia, which may be given subject to reasonable conditions;

- (iii) I must take all reasonable measures to ensure that Confidential Information in my possession or control is protected against loss, and against unauthorised access, use, modification, disclosure or other misuse, and that only myself and others authorised by Medicare Australia under clause 3(ii) have access to it;
 - (iv) apart from making authorised copies under Clause 3(i), I must not without the prior written authority of Medicare Australia, which may be given subject to reasonable conditions, make any copies of or otherwise duplicate any Confidential Information;
 - (v) I must, when I cease to be an APFF, or earlier if Medicare Australia requests it, return all Confidential Information in my possession to Medicare Australia and not retain Confidential Information in any form whatsoever; and
 - (vi) I must not transfer Confidential Information outside Australia, or allow parties outside Australia to have access to it, without the prior written authority of Medicare Australia.
4. I agree that I must immediately notify Medicare Australia where I become aware of a breach of clause 3 or where a disclosure of Confidential Information may be required by law.
5. I understand that the obligations of clause 3 will not be taken to have been breached where Confidential Information:
- (i) is or becomes public knowledge other than by breach of this Deed Poll or by any other unlawful means;
 - (ii) is in my possession without restriction in relation to disclosure before the date I receive it from Medicare Australia;
 - (iii) is legally required to be disclosed; or
 - (iv) has been independently developed or acquired by myself or the Agency.
6. I agree that Personal Information means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about a natural person whose identity is apparent, or can reasonably be ascertained, from the information or opinion, being information or an opinion obtained in connection with any dealings with Medicare Australia.
7. I acknowledge and agree that:
- (i) I must use Personal Information only for:
 - **the primary purpose of ascertaining the screening pathway status of identifiable individuals; and**
 - **any purpose incidental to the primary purpose.**
 - (ii) Apart from any authorised disclosure under Clause 7(i), I must not disclose, other than to Medicare Australia, any Personal Information without the written authority of Medicare Australia, which may be given subject to reasonable conditions;
 - (iii) I must take all reasonable measures to ensure that Personal Information in my possession or control is protected against loss, and against unauthorised access, use, modification, disclosure or other misuse, and that only myself and those authorised by Medicare Australia under clause 7(ii) have access to it;
 - (iv) Apart from making authorised copies under Clause 7(i), I must not without the prior written authority of Medicare Australia, which may be given subject to reasonable conditions, make any copies of or otherwise duplicate any Personal Information;

- (v) I must, when I cease to be registered as an APFF or earlier if requested by Medicare Australia, return all Personal Information in my possession and not retain Personal Information in any form whatsoever; and
 - (vi) I must not transfer Personal Information outside Australia, or allow parties outside Australia to have access to it, without the prior written authority of Medicare Australia.
8. I agree that I must immediately notify Medicare Australia where I become aware of a breach of clause 7 or where a disclosure of Personal Information may be required by law.

I acknowledge that:

- (i) any unauthorised and intentional use, access, destruction, alteration, addition or impediment to access or usefulness of Personal Information stored in any Medicare Australia or other Commonwealth computer may be an offence under Part VIA of the Crimes Act 1914 for which there are a range of penalties, including a maximum of ten years imprisonment;
 - (ii) the publication or communication of any fact or document by a person which has come to their knowledge or into their possession or custody by virtue of that person's appointment or engagement with the Commonwealth or Medicare Australia (other than to a person to whom the person is authorised to publish or disclose the fact or document) may be an offence under section 70 of the Crimes Act 1914, the maximum penalty for which is two years imprisonment; and
 - (iii) Personal Information may be protected by section 130 of the Health Insurance Act 1973, section 135A of the National Health Act 1953 and by the Privacy Act 1988.
9. I acknowledge and agree that I must cooperate with any reasonable requests or directions of the Chief Executive Officer of Medicare Australia or his or her delegate in respect of Personal Information, arising directly from, or in connection with the exercise of, the functions of the Privacy Commissioner under the Privacy Act 1988 or otherwise, including, but not limited to, the issuing of any guideline concerning the handling of Personal Information.

I agree that if I am uncertain as to whether any information is Personal Information or Confidential Information, I will treat the information as if it were Personal Information or Confidential Information and as not being in the public domain unless and until Medicare Australia agrees otherwise in writing.

I acknowledge and agree that the obligations in this Deed Poll continue to apply after I cease to be an APFF.

I acknowledge and agree that this Deed Poll will be governed by, and construed in accordance with, the law for the time being in force in the Australian Capital Territory and that the Courts of that Territory shall have jurisdiction to entertain any action in respect of, or arising out of, this Deed Poll.

Executed as a Deed Poll

Date:

SIGNED SEALED AND DELIVERED by the
Authorised Participant Follow-up Function in the
presence of:

)
).....

.....
(Signature of Authorised Participant Follow-up
Function)

.....
(Signature of Witness)

.....
(Name of Authorised Participant Follow-up
Function)

.....
(Name of Witness)

APPENDIX 1 – Example of a Follow-up Report

INTERACTION - REMINDER LETTER	ID number	Date + FOBT	Mail date	State	Postcode	Surname	Firstname
C061 - 8 WEEK GP VISIT	2561482051	20/06/2008	25/08/2008	ACT	2617	DOOR	MARY
C061 - 8 WEEK GP VISIT	2018312951	20/06/2008	25/08/2008	ACT	2906	ROOM	DAVID
C071 - 6 MONTH GP VISIT	2088161140	19/02/2008	25/08/2008	ACT	2912	HAMPER	JOSEPH
C081 - 4 MONTH COLONOSCOPY	2288180000	24/04/2008	25/08/2008	ACT	2604	MILLIEC	ADAM
C091 - 6 MONTH COLONOSCOPY	2444529260	15/02/2008	25/08/2008	ACT	2600	JONES	BRUCE

APPENDIX 2 – REGISTER UPDATE FORM

State or territory Participant ID
Participant Name

Successful contact made with participant/health professional/practice staff

Participant Health Professional/Practice Staff Date

GP visit scheduled/completed Date

GP or Practice Name

Location

No current GP **No GP visit scheduled at this stage**

Referred for colonoscopy Appointment date Colonoscopy date

- | | |
|---------------------------------------------------------------------------|--------------------------------------------------------------------|
| <input type="checkbox"/> Has seen specialist/outpatient appointment | <input type="checkbox"/> Is waiting to see specialist |
| <input type="checkbox"/> Is on waiting list for colonoscopy | <input type="checkbox"/> Has not made appointment with specialist |
| <input type="checkbox"/> Specialist advised not proceeding to colonoscopy | <input type="checkbox"/> Appointment for colonoscopy has been made |
| <input type="checkbox"/> Has had colonoscopy | <input type="checkbox"/> Other <input type="text"/> |

Specialist and/or Facility (if known)

Referred for other examination

Not referred for colonoscopy or other procedure GP Specialist

Opt off

- Already under cancer care
- Not interested
- Uncomfortable with process
- Medical advice not to participate
- No reason given
- Privacy concerns
- Other reasons

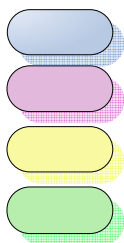
Suspend

- GP advice
- Illness
- Travelling
- No reason given
- Not eligible
- NT/rural Indigenous metro
- Other reasons

Date to recommence

Other comments

APPENDIX 3 – DIAGRAMS OF HOW FOLLOW-UP OCCURS ALONG THE SCREENING PATHWAY



Legend for diagrams

Register activity

Participant Follow up Function

Temporary end of participant pathway

End of participant pathway

Diagram 1 – Common participant actions 2 months following positive FOBT result (C061 reminder letter)

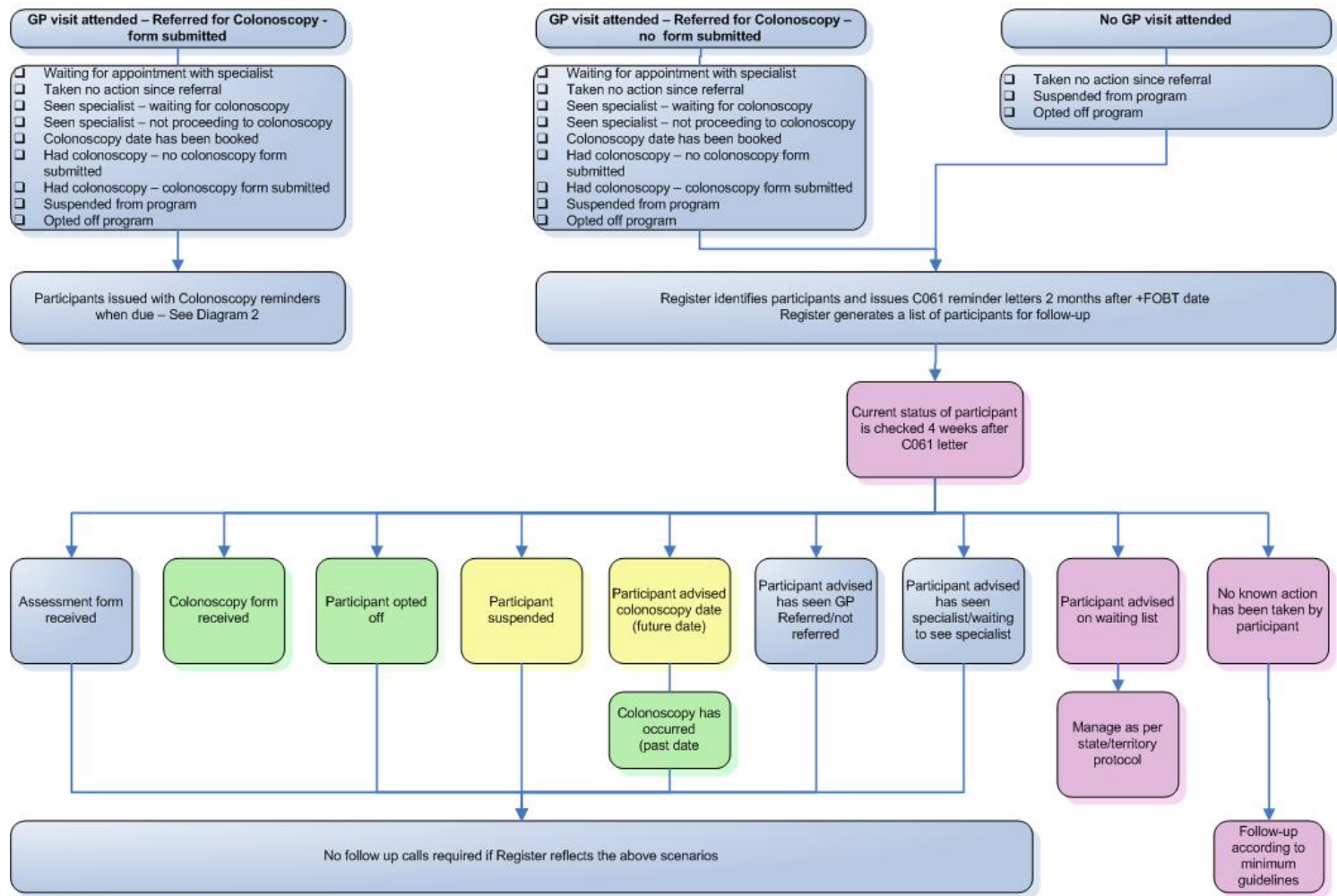


Diagram 2 – Common participant actions 4 months following positive FOBT result – Assessment form received – Referred for colonoscopy (C081 reminder letter)

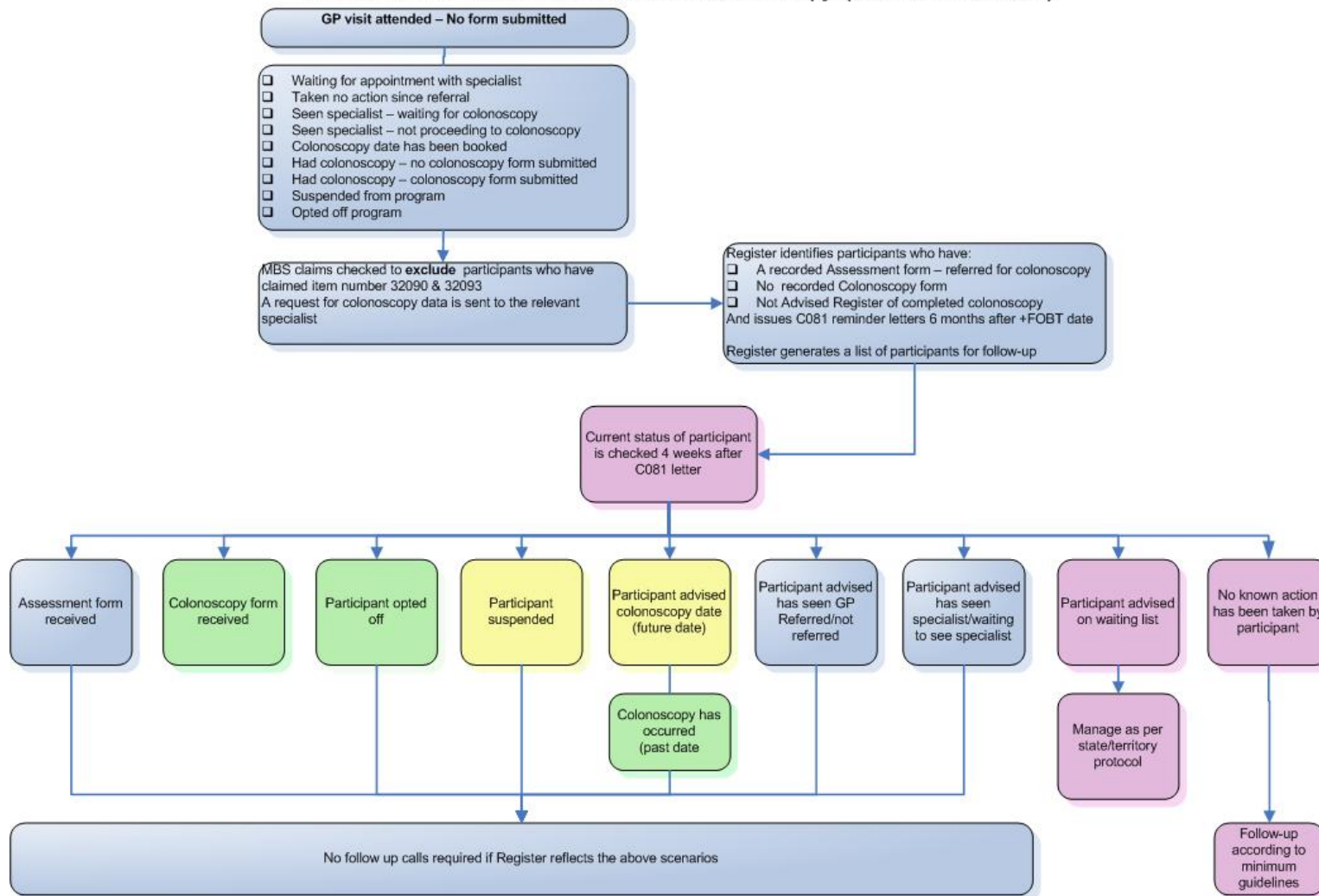


Diagram 3 – Common participant actions 6 months following positive FOBT result – No GP visit (C071 reminder letter)

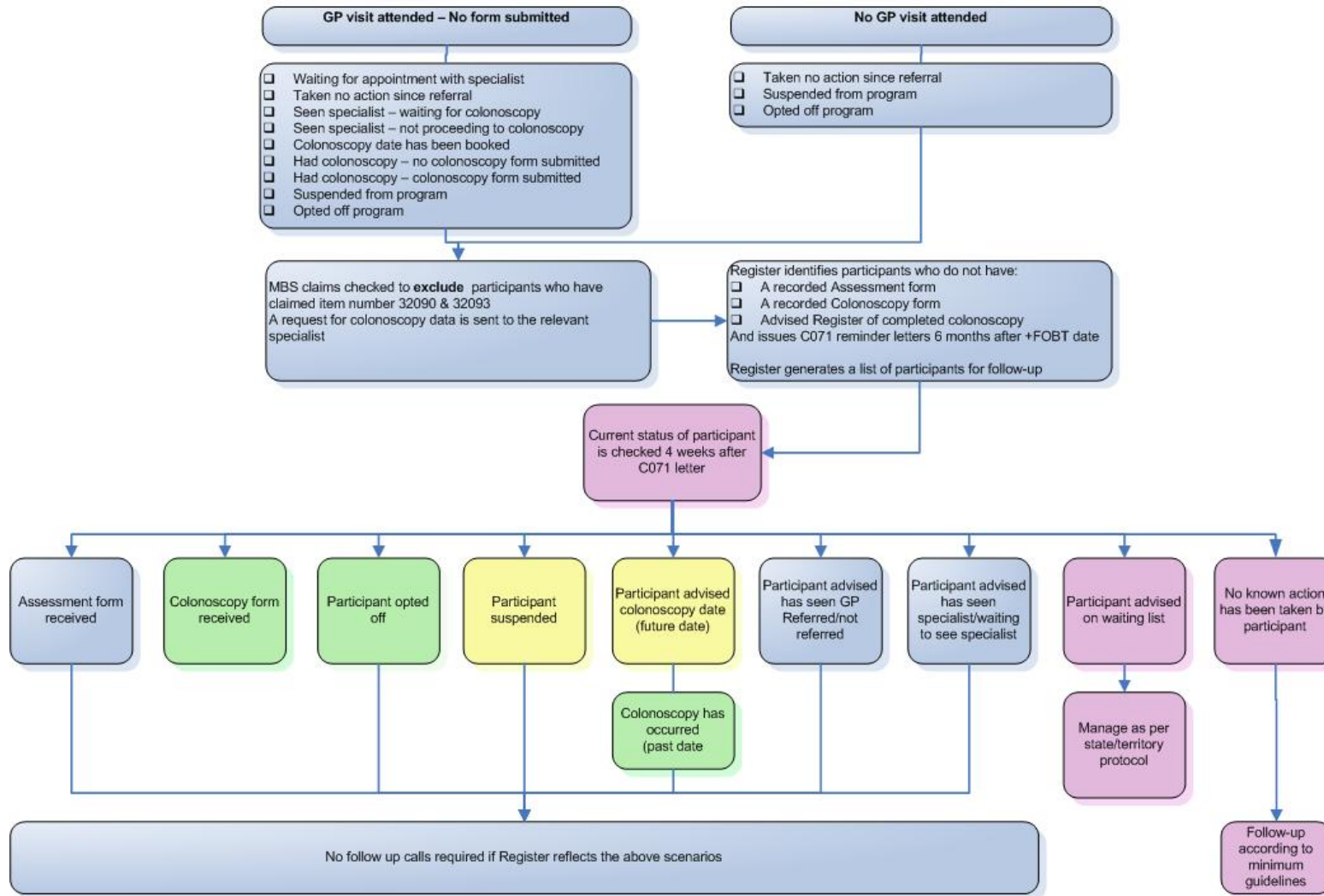


Diagram 4 – Common participant actions 6 months following positive FOBT result – Assessment form received – Referred for colonoscopy (C091 reminder letter)

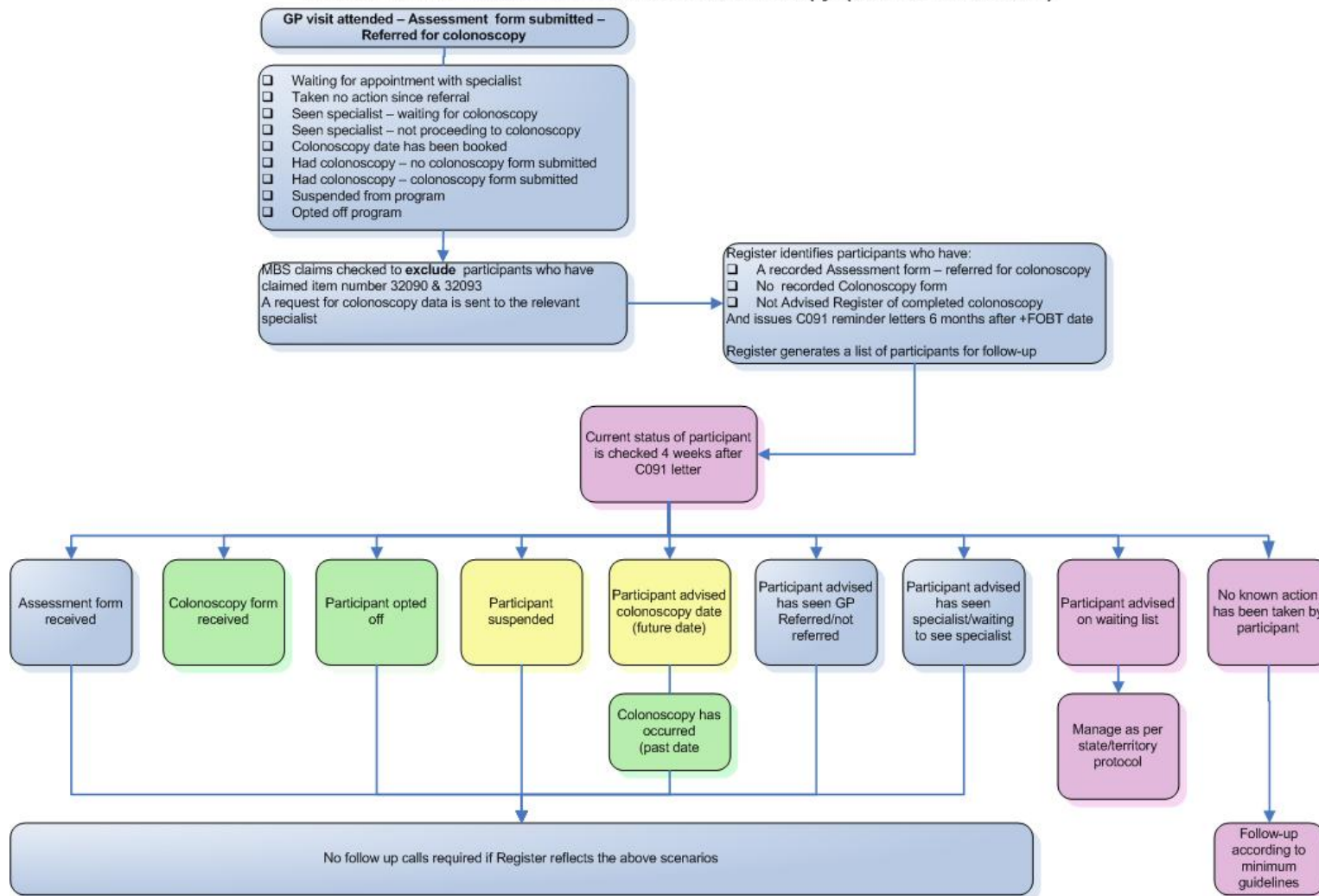


Diagram 5 – Common participant actions 10 months following positive FOBT result (10 month final reminder letter)

