

# Questionnaires sent to participants and their GPs and methods of reconciling multiple responses

## Table of Contents

1: Questionnaire sent to all participants two days after their imaging visit to assess their understanding of the consent they had given .....	2
2: Six-week questionnaire sent to participants who received feedback of a possible abnormality on their scans (web-based) .....	6
3: Six-month questionnaire sent to participants who received feedback of a possible abnormality on their scans (web-based) .....	11
4: Six-month questionnaire sent to the GPs of participants who received feedback of a possible abnormality on their scans (sent on paper) .....	20
5: Methods used to reconcile multiple responses on similar items across three questionnaires .....	26

**1: Questionnaire sent to all participants two days after their imaging visit to assess their understanding of the consent they had given**

<p>1. Did you read the participant information leaflet?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes, in detail <input type="checkbox"/></p> <p>Yes, had a quick look <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>
<p>2.1 Was the participant information leaflet length...</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Much too short <input type="checkbox"/></p> <p>A little short <input type="checkbox"/></p> <p>Just right <input type="checkbox"/></p> <p>A little long <input type="checkbox"/></p> <p>Much too long <input type="checkbox"/></p>
<p>2.2 Was the participant information leaflet content...</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Much too simple <input type="checkbox"/></p> <p>A little simple <input type="checkbox"/></p> <p>Just right <input type="checkbox"/></p> <p>A little complicated <input type="checkbox"/></p> <p>Much too complicated <input type="checkbox"/></p>
<p>2.3 Did the participant information leaflet answer all of your questions?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>If no, what would you have liked it to tell you?</p>
<p>3. Please use this space to write any comments you have on the email invitation and participant information leaflet that you received before your visit:</p>	

<p>4. Were you aware beforehand that you would have to answer questions about yourself for us to check that you were eligible for the imaging study?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Can't remember <input type="checkbox"/></p>
<p>5. Was the telephone interview about your eligibility...</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Much too short <input type="checkbox"/></p> <p>A little short <input type="checkbox"/></p> <p>Just right <input type="checkbox"/></p> <p>A little long <input type="checkbox"/></p> <p>Much too long <input type="checkbox"/></p>
<p>6. Were the staff able to answer any questions or concerns you had</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Can't remember <input type="checkbox"/></p>
<p>7. Did another member of staff have to call you back because the person you spoke to was not sure about your eligibility?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Can't remember <input type="checkbox"/></p>
<p>8. Your visit started with you being asked to give your agreement (consent) to participate. Did you find this...</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Much too simple <input type="checkbox"/></p> <p>A little simple <input type="checkbox"/></p> <p>Just right <input type="checkbox"/></p> <p>A little complicated <input type="checkbox"/></p> <p>Much too complicated <input type="checkbox"/></p>

<p>9. Did you have any questions during the consent process?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Can't remember <input type="checkbox"/></p>																																
<p>10. If you answered 'Yes' to question 9, to what extent were your questions answered?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Fully answered <input type="checkbox"/></p> <p>Most answered <input type="checkbox"/></p> <p>Some answered <input type="checkbox"/></p> <p>None answered <input type="checkbox"/></p>																																
<p>11. As far as you are concerned, when you consented to participate, which of the following did you agree to?</p>	<p><i>(Please answer <b>ONE</b> box only for each item)</i></p> <table border="0"> <thead> <tr> <th></th> <th style="text-align: center;">Yes</th> <th style="text-align: center;">No</th> <th style="text-align: center;">Don't know</th> </tr> </thead> <tbody> <tr> <td>My imaging scans and results would be given to me at the end of the visit</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td colspan="4" style="text-align: center;"><b><i>In the event a potentially serious finding was identified on a scan:</i></b></td> </tr> <tr> <td>I could choose whether my GP and I would be informed</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>Both my GP and I would automatically be contacted</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>I would be told about this finding during the assessment visit</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>I would be told about this finding after the assessment visit</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>Other (please write below):</td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		Yes	No	Don't know	My imaging scans and results would be given to me at the end of the visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<b><i>In the event a potentially serious finding was identified on a scan:</i></b>				I could choose whether my GP and I would be informed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Both my GP and I would automatically be contacted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I would be told about this finding during the assessment visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I would be told about this finding after the assessment visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other (please write below):			
	Yes	No	Don't know																														
My imaging scans and results would be given to me at the end of the visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																														
<b><i>In the event a potentially serious finding was identified on a scan:</i></b>																																	
I could choose whether my GP and I would be informed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																														
Both my GP and I would automatically be contacted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																														
I would be told about this finding during the assessment visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																														
I would be told about this finding after the assessment visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																														
Other (please write below):																																	

<p>12. When you joined UK Biobank, you gave consent for us to access your medical and other health-related records. Which of the following do you think this includes?</p>	<p><i>(Please answer <b>ONE</b> box only for each item)</i></p>			
		Yes	No	Don't know
	Electronic medical records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Written notes and letters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	X-rays and photographs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Imaging scans (done as part of a clinical investigation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Tissue samples (e.g. biopsy specimens)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>13. Please write below any comments or thoughts you might have to help us improve the imaging assessment visit:</p>				

**2: Six-week questionnaire sent to participants who received feedback of a possible abnormality on their scans (web-based)**

Thank you very much for taking part in the UK Biobank Imaging Assessment Visit. Following the visit, we wrote to inform you that a possible abnormality had been identified on one of your scans. In that letter, we suggested that you visit your GP, who may wish to investigate this further. This is the first of two surveys to help us understand the impact that receiving this information has on research participants. Your answers will be treated in the strictest confidence and will be used to improve our policies for the future and to help others doing similar research projects. We are very grateful to you for your support of this study.

**How to complete this questionnaire:** Please tick the box next to the answer you want, like this

<p>1. Did you receive a letter from us informing you that a possible abnormality had been found on one of your scans?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>If no, there is no need to answer any more questions but please contact us on the telephone number provided at the end of the form</p>
<p>2. When did you receive this letter?</p>	<p>Less than a week after the imaging visit <input type="checkbox"/></p> <p>Between 1 and 2 weeks after the imaging visit <input type="checkbox"/></p> <p>More than 2 weeks after the imaging visit <input type="checkbox"/></p> <p>More than 1 month after the imaging visit <input type="checkbox"/></p> <p>Can't remember <input type="checkbox"/></p>
<p>3. Was the content of the letter clear?</p>	<p>Very clear <input type="checkbox"/></p> <p>Mostly clear <input type="checkbox"/></p> <p>Mostly unclear <input type="checkbox"/></p> <p>Very unclear <input type="checkbox"/></p> <p>No opinion <input type="checkbox"/></p> <p>Can't remember <input type="checkbox"/></p> <p>If you wish to make comment, please do so here:</p>

<p>4. When you received the letter about this possible abnormality, did you go and see your GP about it?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes, I have seen a GP <input type="checkbox"/></p> <p>No, I made an appointment but it hasn't happened yet <input type="checkbox"/></p> <p>No, I haven't got round to making an appointment yet <input type="checkbox"/></p> <p>No, I didn't think it was important <input type="checkbox"/></p> <p>No, I didn't want to follow it up <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p> <p>Other (please state below):</p>
--	---

If you have seen a GP about the possible abnormality, please answer the following questions.

<p>5. Who arranged the appointment?</p>	<p>I arranged to see my GP <input type="checkbox"/></p> <p>My GP contacted me <input type="checkbox"/></p>
<p>6. When did you first see a GP at your GP practice about the possible abnormality?</p>	<p style="text-align: center;">D    D                    M    M                    Y    Y</p> <p style="text-align: center;"> <input type="text"/> <input type="text"/>                    <input type="text"/> <input type="text"/>                    <input type="text"/> <input type="text"/> </p> <p><i>If you can't remember the exact date, please guess as closely as you can</i></p>

<p>7. Did the GP that you saw about the possible abnormality take any of the following actions?</p>	<p><i>(Please answer yes, no or don't know for each)</i></p> <table border="1"> <thead> <tr> <th></th> <th>Yes</th> <th>No</th> <th>Don't know</th> </tr> </thead> <tbody> <tr> <td>Ordered blood tests</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Ordered another scan</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Ordered a different type of scan (e.g. ultrasound, CT)</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Referred me to a specialist</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Other (please state below)</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </tbody> </table>		Yes	No	Don't know	Ordered blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Ordered another scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Ordered a different type of scan (e.g. ultrasound, CT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Referred me to a specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other (please state below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Yes	No	Don't know																						
Ordered blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Ordered another scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Ordered a different type of scan (e.g. ultrasound, CT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Referred me to a specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Other (please state below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
<p>8. Do you think the GP took this letter about the possible abnormality seriously?</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Not sure <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>																								
<p>9. Has a doctor explained to you what this possible abnormality is or might be?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes, I have been given a <u>definite</u> diagnosis <input type="checkbox"/></p> <p>If yes, please write below what the diagnosis was:</p> <p>Yes, I have been given a <u>possible</u> diagnosis <input type="checkbox"/></p> <p>If yes, please write below what the possible diagnosis was:</p> <p>Yes, I have been told that there is no abnormality <input type="checkbox"/></p> <p>No, I have not had any explanation <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p>																								



Whether or not you have seen a GP about the possible abnormality, please complete the following questions:

<p>10. Looking back on your experience, since you received our letter about the possible abnormality, which of these statements best describes how you feel?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>I would rather UK Biobank had not told me about the possible abnormality <input type="checkbox"/></p> <p>I am glad UK Biobank told me about the possible abnormality <input type="checkbox"/></p> <p>I don't have an opinion one way or the other <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p> <p>Please tell us the reasons for your answer:</p>
<p>11. When signing up for a study like UK Biobank, which of the following options should apply?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Participants should always be told about potentially serious findings <input type="checkbox"/></p> <p>Participants should be able to choose whether or not they would like to be told about potentially serious findings <input type="checkbox"/></p> <p>No opinion <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p>
<p>12. On balance, knowing what you know now, how do you feel about taking part in the UK Biobank imaging study?</p>	<p>I am glad that I took part <input type="checkbox"/></p> <p>I wish I hadn't taken part <input type="checkbox"/></p> <p>No opinion <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p>

<p>13. Would you be willing for us to telephone you if we thought we needed to understand more about your experience of receiving this feedback?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please provide below the best number or numbers for us to contact you on:</p> <p>No <input type="checkbox"/></p>
--	--

Please write any further comments you would like to make in the box below:

**THANK YOU FOR COMPLETING THIS SURVEY**

**We will send you another survey in a few months' time to find out about the longer-term impact this information has had on you.**

**If you have any questions:** If you have any questions about how best to complete this survey, please telephone the Participant Resource Centre on 0800-0-276-276 (free from BT landlines) or 0292-0-765-597 (Mon-Sat; 8:00am to 7:00pm).

Email: [ukbiobank@ukbiobank.ac.uk](mailto:ukbiobank@ukbiobank.ac.uk)

Website: [www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk)

**3: Six-month questionnaire sent to participants who received feedback of a possible abnormality on their scans (web-based)**

Thank you very much for taking part in the UK Biobank Imaging Assessment Visit. Following the visit, we wrote to inform you that a possible abnormality had been identified on one of your scans. In that letter, we suggested that you visit your GP, who may wish to investigate this further. This is the first of two surveys to help us understand the impact that receiving this information has on research participants. Your answers will be treated in the strictest confidence and will be used to improve our policies for the future and to help others doing similar research projects. We are very grateful to you for your support of this study.

You may have already answered some of these questions on the first questionnaire that we sent to you a few months ago. We are asking them again as your views on the impact this information has had on you may have changed over time

**How to complete this questionnaire:** Please tick one box only for each question next to the answer you want, like this , unless otherwise stated

<p>1. Did you receive a letter from us informing you that a possible abnormality had been found on one of your scans?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>If no, there is no need to answer any more questions but please contact us on the telephone number provided at the end of the form</p>
<p>2. When you received the letter about this possible abnormality, did you go and see your GP about it?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes, I have seen a GP <input type="checkbox"/></p> <p>No, I made an appointment but it hasn't happened yet <input type="checkbox"/></p> <p>No, I haven't got round to making an appointment yet <input type="checkbox"/></p> <p>No, I didn't think it was important <input type="checkbox"/></p> <p>No, I didn't want to follow it up <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p> <p>Other (please state below):</p>

If you have seen a GP about the possible abnormality, please answer the following questions.

<p>3. Who arranged the appointment?</p>	<p>I arranged to see my GP <input type="checkbox"/></p> <p>My GP arranged to see me <input type="checkbox"/></p>																								
<p>4. When did you first see a GP at your GP practice about the possible abnormality?</p>	<p style="text-align: center;">D    D                    M    M                    Y    Y</p> <p style="text-align: center;"> <input type="text"/> <input type="text"/>                    <input type="text"/> <input type="text"/>                    <input type="text"/> <input type="text"/> </p> <p><i>If you can't remember the exact date, please guess as closely as you can</i></p>																								
<p>5. Did the GP that you saw about the possible abnormality take any of the following actions?</p>	<p><i>(Please answer <b>ONE</b> box only for each item)</i></p> <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 70%;"></th> <th style="width: 10%; text-align: center;">Yes</th> <th style="width: 10%; text-align: center;">No</th> <th style="width: 10%; text-align: center;">Don't know</th> </tr> </thead> <tbody> <tr> <td>Ordered blood tests</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>Ordered another scan</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>Ordered a different type of scan (e.g. ultrasound, CT)</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>Referred me to a specialist</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>Other (please state below)</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </tbody> </table>		Yes	No	Don't know	Ordered blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Ordered another scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Ordered a different type of scan (e.g. ultrasound, CT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Referred me to a specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other (please state below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Yes	No	Don't know																						
Ordered blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Ordered another scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Ordered a different type of scan (e.g. ultrasound, CT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Referred me to a specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
Other (please state below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
<p>6. Do you think the GP took this letter about the possible abnormality seriously?</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Not sure <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>																								

<p>7. Has a doctor explained to you what this possible abnormality is or might be?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes, I have been given a <u>definite</u> diagnosis <input type="checkbox"/></p> <p>If yes, please write below what the diagnosis was:</p> <p>Yes, I have been given a <u>possible</u> diagnosis <input type="checkbox"/></p> <p>If yes, please write below what the possible diagnosis was:</p> <p>Yes, I have been told that there is no abnormality <input type="checkbox"/></p> <p>Still under investigation <input type="checkbox"/></p> <p>No, I have not had any explanation <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p>
<p>8. Has seeing a GP or other doctors about the possible abnormality led to any change in your medication (i.e., started new medication or changed existing medication)?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please provide details:</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>

<p>9. Has seeing a GP or other doctors about the possible abnormality led to you having a procedure or an operation performed?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please tell us what procedure(s) or operation(s) you had and date(s), if possible:</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>
<p>10. Has the information about this imaging finding led to any other treatment(s) or intervention(s)?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please provide details:</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>
<p>11. Approximately how many times have you seen your GP about or because of the imaging scan result?</p>	<p>Number:</p>
<p>12. Have health and social care professionals been involved in your care as a result of the imaging finding (e.g., for personal/physical care, household duties, etc.)?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe the help:</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>

Whether or not you have seen a GP about the possible abnormality, please complete the following questions:

<p>13. Have any of the following aspects of your life been affected as a result of this information?  <i>(Please tick <b>ONE</b> box only for each item)</i></p>	
<p>a. Your need to take time off work?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p>
	<p>No <input type="checkbox"/></p>
	<p>Prefer not to answer <input type="checkbox"/></p>
<p>b. Your need to change job or retire?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p>
	<p>No <input type="checkbox"/></p>
	<p>Prefer not to answer <input type="checkbox"/></p>
<p>c. Your need for help in activities of daily living?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p>
	<p>No <input type="checkbox"/></p>
	<p>Prefer not to answer <input type="checkbox"/></p>
<p>d. Your ability to get travel insurance or its cost?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p>
	<p>No <input type="checkbox"/></p>
	<p>Prefer not to answer <input type="checkbox"/></p>

<p>e. Your ability to get health insurance or its cost?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p> <p>No <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>
<p>f. Your ability to get life insurance or its cost?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p> <p>No <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>
<p>g. Your overall financial situation?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p> <p>No <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>
<p>14. Has this information led to changes in the following emotional aspects of your life? <i>(Please tick <b>ONE</b> box only for each item)</i></p>	
<p>a. Your overall emotional wellbeing?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p> <p>No <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>



<p>b. Your family life?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p> <p>No <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>										
<p>c. Your family's emotional wellbeing?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p> <p>No <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>										
<p>d. Your close friends' emotional wellbeing?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please describe in more detail:</p> <p>No <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p>										
<p>15. Compared to before the imaging assessment visit, how would you rate your health in general now?</p>	<table data-bbox="606 1227 1372 1366"> <tr> <td>Much better</td> <td>A little better</td> <td>The same</td> <td>A little worse</td> <td>Much worse</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table> <p>If you would like to add further information, please do so here:</p>	Much better	A little better	The same	A little worse	Much worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Much better	A little better	The same	A little worse	Much worse							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

<p>16. Looking back on your experience, since you received our letter about the possible abnormality, which of these statements best describes how you feel?</p>	<p>I would rather UK Biobank had not told me about the possible abnormality <input type="checkbox"/></p> <p>I am glad UK Biobank told me about the possible abnormality <input type="checkbox"/></p> <p>I don't have an opinion one way or the other <input type="checkbox"/></p> <p>Prefer not to answer <input type="checkbox"/></p> <p>Please tell us the reasons for your answer:</p>
<p>17. When signing up for a study like UK Biobank, which of the following options should apply?</p>	<p>Participants should always be told about potentially serious findings <input type="checkbox"/></p> <p>Participants should be able to choose whether or not they would like to be told about potentially serious findings <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p> <p>No opinion <input type="checkbox"/></p>
<p>18. On balance, knowing what you know now, how do you feel about taking part in the UK Biobank imaging study?</p>	<p>I am glad that I took part <input type="checkbox"/></p> <p>I wish I hadn't taken part <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p>
<p>19. Would you be willing for us to telephone you if we thought we needed to understand more about your experience of receiving this feedback?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please provide below the best number or numbers for us to contact you on:</p> <p>No <input type="checkbox"/></p>

Please write any further comments you would like to make in the box below:

**THANK YOU FOR COMPLETING THIS SURVEY**

**If you have any questions:** If you have any questions about how best to complete this survey, please telephone the Participant Resource Centre on 0800-0-276-276 (free from BT landlines) or 0292-0-765-597 (Mon-Sat; 8:00am to 7:00pm).

Email: [ukbiobank@ukbiobank.ac.uk](mailto:ukbiobank@ukbiobank.ac.uk)

Website: [www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk)

**4: Six-month questionnaire sent to the GPs of participants who received feedback of a possible abnormality on their scans (sent on paper)**

You were recently contacted by UK Biobank to inform you that one of your patients, who participated in the UK Biobank Imaging Assessment visit, had an incidental finding identified on one of their scans that we thought might be serious (that is, indicating the possibility of a condition which, if confirmed, would carry a real prospect of significantly threatening lifespan, or of having a substantial impact on major body functions or quality of life). There is little consensus in the UK (or elsewhere) on the balance of benefit versus harm in telling research participants about these so-called ‘incidental findings’. In order to improve our procedures and those of other research projects in the future, we would be most grateful if you could answer a few questions about the impact of this information on the health service and the outcome of any investigations that were made.

All UK Biobank participants have provided their consent for us to access their medical and other health-related records for health-related research purposes (even after their incapacity or death).

Patient name:	«Title» «First_name» «Surname»
Date of birth:	«Date_of_birth»
NHS number:	«NHS_number»

Several parts of this questionnaire could be completed by your practice manager or other practice administrative staff.

**How to complete this questionnaire:** Please tick the box next to the answer you want, like this

1. Did you receive a letter from us informing you that, during the imaging assessment visit, a potentially serious incidental finding has been found on this patient’s scan?	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>If no, please contact us on the telephone number provided at the end of the form</p>
2. If yes, who arranged the appointment?	<p>The patient arranged to see me <input type="checkbox"/></p> <p>I contacted the patient <input type="checkbox"/></p>

<p>3. Did the patient come and see you about the imaging scan result?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>
<p>4. What was the date of the first appointment at which they consulted about this imaging finding?</p>	<p><input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p>
<p>5. Did you request a copy of the UK Biobank scan(s)?</p>	<p>Yes <input type="checkbox"/></p> <p style="padding-left: 40px;">If yes, did you receive a copy? <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Still under investigation <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>
<p>6. What further action was taken about this imaging finding?</p>	<p><i>(Please tick as many boxes as you wish and provide copies of any relevant documentation, if available)</i></p> <p>No further action was required <input type="checkbox"/></p> <p>Blood tests ordered <input type="checkbox"/></p> <p>Other investigation(s) carried out <input type="checkbox"/></p> <p>Referral to a specialist <input type="checkbox"/></p> <p>Other (please state below) <input type="checkbox"/></p> <p>.....</p> <p>.....</p>

<p>7. Was a clinical diagnosis of the imaging finding made?</p>	<p><i>(Please tick <b>ONE</b> box only and provide copies of the results of any tests or investigations and relevant notes or correspondence)</i></p> <p>Yes <input type="checkbox"/></p> <p>If yes, please provide details of clinical diagnosis and approximate date:</p> <p>.....</p> <p>.....</p> <p>No <input type="checkbox"/></p> <p>Still under investigation <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>
<p>8. Has the information about this imaging finding led to the change of medication?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>If yes, please provide details:</p> <p>.....</p> <p>.....</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>

<p>9. Has the information about this imaging finding led to any operations or procedures?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>If yes, please provide details of operations or procedures and date(s):</p> <p>.....</p> <p>.....</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>
<p>10. Has the information about this imaging finding led to any other treatment(s) or intervention(s)?</p>	<p>Yes <input type="checkbox"/></p> <p>If yes, please provide details:</p> <p>.....</p> <p>.....</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>
<p>11. Have other health and social care professionals been involved in this patient's care as a result of the imaging finding?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes <input type="checkbox"/></p> <p>If yes, please provide details:</p> <p>.....</p> <p>.....</p> <p>No <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>

<p>12. Approximately how many consultations have you had with the patient about or because of the imaging scan result?</p>	<p>Number:</p>
<p>13. In your opinion, what impact has this information about the incidental finding had on the patient's emotional well-being?</p>	<p>Very positive   Positive   No impact   Negative   Very negative   N/A</p> <p><input type="checkbox"/>   <input type="checkbox"/>   <input type="checkbox"/>   <input type="checkbox"/>   <input type="checkbox"/>   <input type="checkbox"/></p>
<p>14. In your opinion, has this information been of net benefit or harm to the patient?</p>	<p>Net benefit <input type="checkbox"/></p> <p><i>Please write your comments here:</i></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>Net harm <input type="checkbox"/></p> <p><i>Please write your comments here:</i></p> <p>.....</p> <p>.....</p> <p>.....</p>



<p>15. Do you think participants should have a choice to opt out of having any feedback of potentially serious findings, if they so wish?</p>	<p><i>(Please tick <b>ONE</b> box only)</i></p> <p>Yes, participants should be able to opt out of feedback <input type="checkbox"/></p> <p>No, all participants should be told this information <input type="checkbox"/></p> <p>No opinion <input type="checkbox"/></p> <p>If you would like to add further information, please do so here:</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
---	---

Please write any further comments you would like to make in the box below:

**THANK YOU FOR COMPLETING THIS SURVEY**

Please return in the enclosed envelope provided or to:

UK Biobank,  
 Freepost RRKZ-UAXH-ZYSR,  
 Units 1-2 Spectrum Way,  
 Stockport  
 SK3 0SA

**If you have any questions:** If you have any questions about how best to complete this survey, please telephone Vikki Arrundale on 0161 475 5360, Mon-Fri, 9:00am to 5:00pm or send an email to [vikki.arrundale@ukbiobank.ac.uk](mailto:vikki.arrundale@ukbiobank.ac.uk).

Alternatively, you can call the Participant Resource Centre on 0800-0-276-276 (free from BT landlines) or 0292-0-765-597 (Mon-Sat; 8:00am to 7:00pm).

Email: [ukbiobank@ukbiobank.ac.uk](mailto:ukbiobank@ukbiobank.ac.uk)

Website: [www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk)

### **5: Methods used to reconcile multiple responses on similar items across three questionnaires**

The two web-based questionnaires sent to participants who received feedback of a possible abnormality on their scans (Sections 2 and 3 of this document), and the questionnaire sent to their general practitioners (Section 4) asked similar questions on some topics related to the follow-up and impacts of feedback of abnormalities. As such there are multiple responses related to these topics.

For example, each of these three questionnaires asked whether or not the participants had been referred to a specialist. The participant questionnaires have tick-box response options of 'yes,' 'no' and 'don't know.' The GP questionnaire is different, and asks the GP to tick a box if that action has been taken. As such, a lack of response by the GP (i.e. no tick) may represent 'no' or 'don't know'. In addition, there are multiple free text fields available on all three questionnaires. Therefore, multiple responses may be available about a topic such as specialist referrals, depending on the return of the questionnaires, and the completion of tick boxes and free text fields.

In order to analyse these questionnaire data, UK Biobank decided to reconcile these multiple responses by prioritising 'yes responses,' in order to generate a maximum count. For example, if a participant responded that they did not know if they had been referred to a specialist, but their GP ticked that they had been referred, UK Biobank prioritized the 'yes' response of the GP, and coded the participant as being referred to a specialist. Similarly, if a participant indicated on their six-month questionnaire that 'no,' they had not been referred to a specialist, but had previously indicated 'yes,' they had been referred on their six-week questionnaire (either by ticking the box, or mentioning a specialist appointment in free text, or both), UK Biobank coded the participant as having been referred to a specialist.

This methodology maximizes the counts of types of follow-up and the impacts of feedback of abnormalities, and makes use of the maximum amount of available data.