

Patient questions on follow-up after Upper Gastro-intestinal Surgery (part of the RESTORE study)

Thank you for taking the time to answer the questions below. We are trying to understand the common symptoms people experience after major surgery to the oesophagus and stomach and also their perspectives on follow-up after surgery. Your participation is greatly appreciated.

Please circle appropriate answers (all answers will be treated confidentially)

Initials (optional):

Date of surgery (Month/year rather than exact date) :

Hospital where surgery took place ?

Chemotherapy in addition to surgery ? Y / N

Radiotherapy in addition to surgery ? Y / N

How long were you followed-up for at the hospital where you had your surgery ?

1month 6months 12 months 2 years 5years longer

If you were followed-up at another hospital from where you had your surgery, for how long ?

6months 12 months 2 years 5years longer

Who conducted the follow-up mainly ?

Surgeon Oncologist Gastroenterologist Dietitian Nurse (CNS) Other

Did you see a dietitian routinely as part of follow-up beyond the first post-op appointment ? Y / N

Did you have any additional follow-up apart from that with your GP ?

Telephone consultations Email follow-up Other

How happy were you with the Follow-up you received (please circle) ?

1.....2.....3.....4.....5.....6.....7.....8.....9.....10

Very unhappy

Extremely happy

Ideally, how long would you choose to be followed up after surgery?

1month 6months 12 months 2 years 5years longer

Apart from the treatment you were receiving (e.g seeing Oncology for post-operative chemotherapy) would you have any preference for who conducted your routine follow-up ?

Surgeon Oncologist Nurse / Dietitian Other

We are interested in studying the following symptoms that commonly occur after oesophagectomy or gastrectomy. Please indicate whether you believe the symptom is important (Y/N) and whether any additional symptoms should be included. You do NOT need to have experienced the symptom itself to judge it to be important and are welcome to select all of them if you wish. Please place a "X" in the appropriate box

Symptom	Important Y/N ?		Symptom	Important Y/N ?	
	Yes	No		Yes	No
Experienced change in smell	<input type="checkbox"/>	<input type="checkbox"/>	Pain around your bottom	<input type="checkbox"/>	<input type="checkbox"/>
Experienced change in taste	<input type="checkbox"/>	<input type="checkbox"/>	Abdominal bloating/distension	<input type="checkbox"/>	<input type="checkbox"/>
Bad breath/halitosis	<input type="checkbox"/>	<input type="checkbox"/>	Excessive passing of wind from your bottom	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty swallowing liquids	<input type="checkbox"/>	<input type="checkbox"/>	Stomach/abdominal gurgling	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty swallowing solids	<input type="checkbox"/>	<input type="checkbox"/>	Need to rush to open bowels	<input type="checkbox"/>	<input type="checkbox"/>
Belching or burping	<input type="checkbox"/>	<input type="checkbox"/>	Feeling that you have not emptied your bowel properly	<input type="checkbox"/>	<input type="checkbox"/>
Heartburn or acid regurgitation	<input type="checkbox"/>	<input type="checkbox"/>	Leakage/ soiling or lack of control of the bowel	<input type="checkbox"/>	<input type="checkbox"/>
Feeling full after small amount of food	<input type="checkbox"/>	<input type="checkbox"/>	Mucus in the stool	<input type="checkbox"/>	<input type="checkbox"/>
Reduced appetite	<input type="checkbox"/>	<input type="checkbox"/>	Greasy, pale or oily stool	<input type="checkbox"/>	<input type="checkbox"/>
Hiccups	<input type="checkbox"/>	<input type="checkbox"/>	Bleeding from your bottom	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/feeling sick	<input type="checkbox"/>	<input type="checkbox"/>	Itchiness around the bottom	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting/being sick/retching	<input type="checkbox"/>	<input type="checkbox"/>	Woken from sleep to have bowels open	<input type="checkbox"/>	<input type="checkbox"/>
Abdominal cramps/trapped wind	<input type="checkbox"/>	<input type="checkbox"/>	Tiredness/lethargy	<input type="checkbox"/>	<input type="checkbox"/>
Upper abdominal pain/discomfort	<input type="checkbox"/>	<input type="checkbox"/>	Dizzy / light headed after meals	<input type="checkbox"/>	<input type="checkbox"/>
Lower abdominal pain/discomfort	<input type="checkbox"/>	<input type="checkbox"/>	Bowel frequency / consistency	<input type="checkbox"/>	<input type="checkbox"/>
Weight loss	<input type="checkbox"/>	<input type="checkbox"/>			
Any other symptoms you feel are important ?					

Thank you for your time. Please send your reply either by email (a scanned document or this word file) to Andrew.davies1@gstt.nhs.uk or by post to Andrew Davies, Consultant Surgeon, Dept of General surgery, East Wing link corridor, St Thomas hospital, London, SE1 7EH

Thank you for your time