

The ROMIO Study Newsletter



Welcome to the winter edition of our patient newsletter for ROMIO. We hope you find it interesting and informative.

Please let us know if you have any suggestions for future newsletters.

Thank You for your Participation in ROMIO!

We hope you are all well and managing life in this unusual and difficult time.

Thank you for staying in touch with us and completing your questionnaires.

ROMIO has been running since 2016 and many of you will soon have your last set of ROMIO questionnaires and phone calls. It's brilliant if you can return these after completing them because your views on how you feel now are important to the research and future patients. We are pleased so many of you have continued to complete the questionnaires and are grateful to you for taking the time to do this and speak to us on the telephone. Thank you so much for sticking with us - this is not a good-bye yet.



Sharing the Study Findings

The ROMIO first findings will soon be ready!

We plan to share the first findings of the study with you in a leaflet in Spring 2021. The leaflet will be sent to you in the post. It will describe whether we saw any differences in recovery after surgery between the different types of surgery. It will also include some other findings that our patient and public advisory group have told us you may be interested to hear about. We are working to make sure we have all the information we need to finish this analysis. This includes making sure our data is complete and accurate before we complete the analysis. We hope the enclosed leaflet explains why there is a delay before we can share the findings. It also describes what is happening at the moment, and after your participation finishes.



If you have any comments about this newsletter, you can contact the main ROMIO study team using these details:



romio-study@bristol.ac.uk



@ROMIOStudy

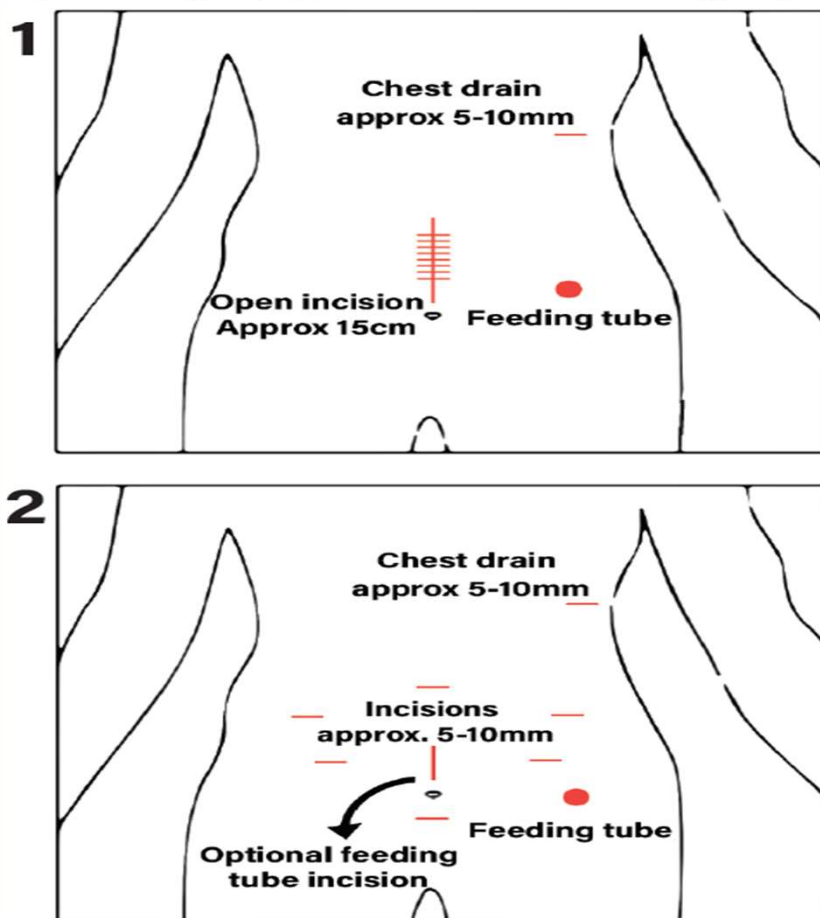
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Patient and Participant Involvement

We invited some of our ROMIO study participants to attend a meeting at our Nottingham site in January 2020. Here are some of the things our patients wanted to see from us:

You asked for examples of 'big cuts' (open oesophagectomy) vs 'little cuts' (minimally invasive/keyhole oesophagectomy): [see images below].

Open Surgery (1) and Combined Surgery (2)



We also talked about sharing more detailed information on both our ROMIO study website and websites for other organisations, such as Macmillan Cancer Support and Cancer Research UK.

Other ideas included providing brief summaries of our findings through short videos and pictures/graphs on these websites. We plan to do this.

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Patient Support Groups

Bristol & Bath	Gastro Oesophageal Support & Help Group (GOSH), Bristol	Jackie Elliott: 0117 983 9906
Plymouth	Exeter Support Group (open to all patients in the South West Peninsular)	Brian Kohl: 07745 577225
Southampton	Heartburn Cancer UK (HCUK) Support for People Impacted by Cancer of the Oesophagus and Stomach (SPICOS)	HCUK: 01256338668 SPICOS: SPICOS01@gmail.com / 01794512718
Edinburgh	ICUsteps	Voicemail number: 0300 30 20 121
Leicester	Oesophagus Support Group	Cathy Thompson: 0116 258 5809 Cathy.Thompson@uhl-tr.nhs.uk
Preston	Gullet and Stomach Cancer Support Group (GASSUP)	David Critchley: 01257452384
Salford	Macmillan Upper GI Cancer Support Group	0161 206 5062
Nottingham	Maggie's Nottingham Cancer Support Service	0115 924 6210 (drop-in clinic available)

The Oesophageal Patients Association website details all groups meeting in the UK – www.opa.org.uk // 0121 704 9860

What happens when my participation in the ROMIO study ends?

It can take a long time between the end of your study participation and the study results becoming available. This infographic explains what happens behind the scenes after your participation ends.

