

CIPHER Newsletter

STUDY

Issue 1, March 2020

Thank you

for taking part in the CIPHER study!



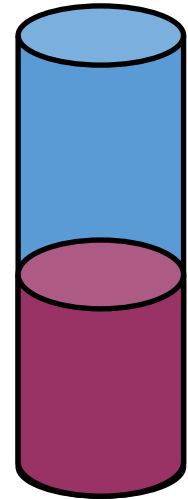
The CIPHER study has now been running for two years. Thanks to your contributions to the study, we now have detailed information on the largest ever group of patients who are living with a stoma.

We currently have 78 NHS hospitals across the UK working hard to recruit patients into the study. This includes hospitals in England, Scotland and Wales!

← Here is the location of all of our hospitals.

How are we doing?

1955 participants recruited out of a target number of 4000!



Why are the study questionnaires important?

We have been sending you questionnaires to complete for the study. You will have received a questionnaire six weeks after your surgery to form a stoma and then every six months. We are very grateful to you for completing these questionnaires so far. These questionnaires are very important to help us understand how you are recovering from your surgery and to help us identify if you have a parastomal hernia based on the symptoms you may be experiencing.

Please continue to complete the questionnaires, your answers are very important to the study!

Number of questionnaires completed in the study so far:

1309 6-week questionnaires

842 6-month questionnaires

334 12-month questionnaires

82 18-month questionnaires

[Data as of 26/02/20]

What's new?

When you agreed to take part in the CIPHER study, you were asked to choose your preferred method of completing questionnaires: online or by post. Up until now, you will have received all the questionnaires by post, even if you selected the online option. The online questionnaires are now available! When your next questionnaire is due, if you selected the online method as your preferred option, you should receive an email to the email address that you provided with a web-link to complete the questionnaires.

If you consented to text messages, we will also start sending you text message reminders. We hope you find these helpful. **Please let us know if your email address or mobile number has changed since you were enrolled into the study.**

CONTACT THE CIPHER TEAM!

Email: cipher-study@bristol.ac.uk | Tel: 0117 342 2526 | Twitter: @TheCIPHERStudy

Frequently Asked Questions

How should I answer the questions about how I feel if I have other health conditions?

1

We appreciate that a lot of CIPHER participants are living with other health conditions besides their stoma. The questionnaires in the booklet are intended to collect information on your overall health. Please complete the questionnaires based on how you feel overall—don't try to answer the questions specifically for your stoma. We will take other health conditions into account when we analyse all the information at the end of the study.

I have already completed my questionnaire but I have received a reminder. What should I do?

2

It is possible that your completed questionnaire and the reminder letter have crossed in the post. If you're sure you completed the questionnaire, you do NOT need to complete the one enclosed with the reminder. If you're unsure whether you completed the questionnaire or want to double check we've received it, please feel free to contact us.

Does it matter if I miss one questionnaire?

3

We encourage all patients to complete all questionnaires. However, we know life and sometimes health can get in the way. Please let us know if you're not feeling able to complete your questionnaire booklet and we will make sure to not send further reminders. However, we hope you will be able to fill in the next booklet in 6-months' time.

What should I do if I move house?

4

Please let your local CIPHER team know or alternatively, call us on 0117 342 2526 and we will update your records.

What if I no longer have my stoma?

5

We are still interested in your progress even if you have had your stoma reversed. We would be grateful if you could continue to complete the follow up questionnaires. However, if you have had your stoma closed, there are a couple of questionnaires in the booklet that you will not need to complete.

Meet the Team!

In September 2019, we had a meeting to bring together the CIPHER study teams from hospitals all over the UK. It was great to see consultants, stoma care nurses, research nurses and study coordinators in the same room, exchanging experiences of working on the study. We also had the chance to hear some amazing patient stories about what it is like to live with a stoma. There were so many of us, we didn't fit in the photo!

