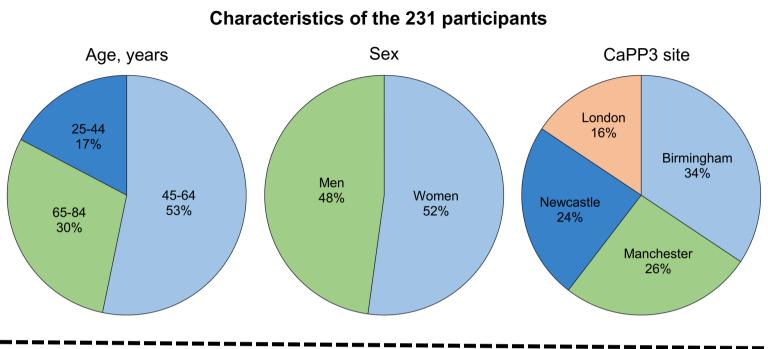
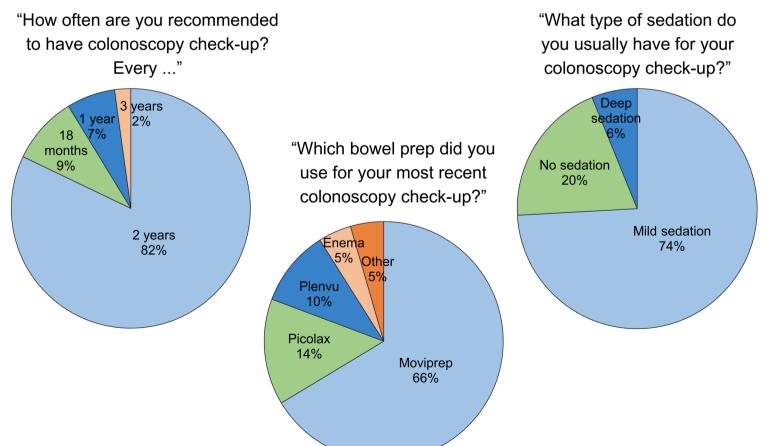
The 'Views, experiences, and challenges of having colonoscopy check-up questionnaire': Summary of results



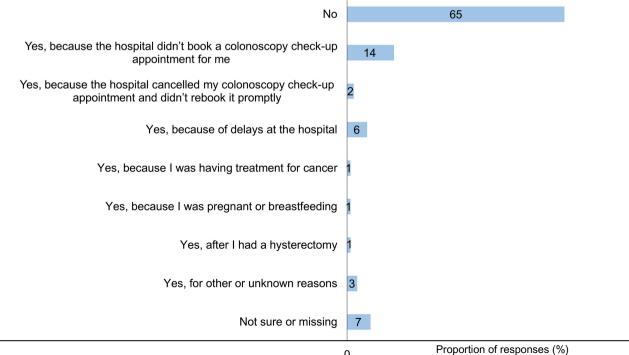
Colonoscopy check-up characteristics



"What happened to your colonoscopy check-up during the COVID-19 pandemic?"

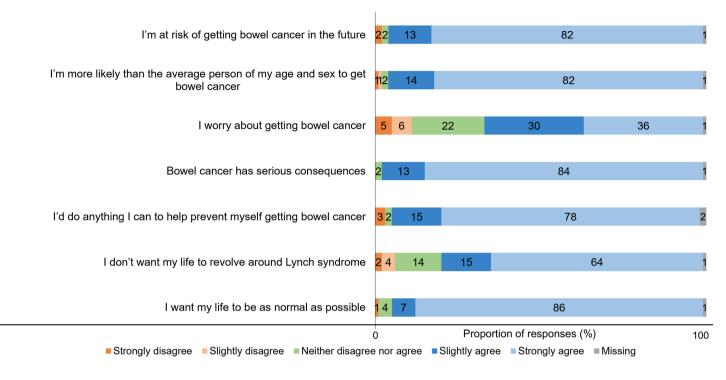
	0	Proportion of r	esponses (%)	100
Other, not sure, or missing	3			
I attended a colonoscopy check-up appointment and was offered a FIT	4			
My colonoscopy check-up wasn't due during this time	10			
I was invited to do a FIT as an alternative to colonoscopy	6			
I initially wasn't given a colonoscopy check-up appointment but I got one after chasing up with the hospital	16			
I was given a colonoscopy check-up appointment which I cancelled, postponed, or did not attend	1			
I was given a colonoscopy check-up appointment which I attended		17		
I was told that my colonoscopy check-up was cancelled or postponed	7			
My colonoscopy check-up was due during this time, but I didn't receive a notification telling me when it would be or if it was cancelled or postponed	7			

"Has your colonoscopy check-up ever been delayed by over 6 months for reasons not related to the COVID-19 pandemic?"

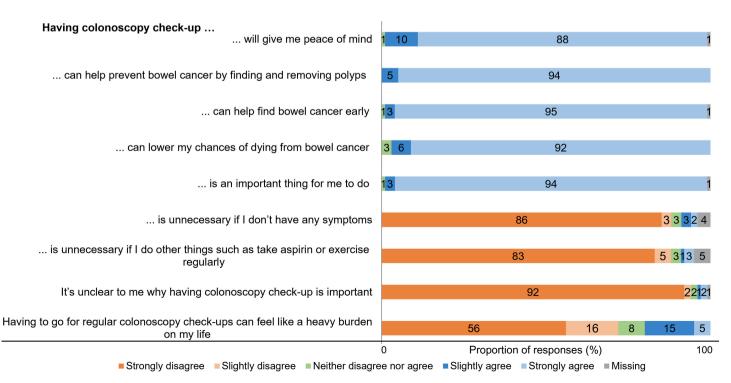


"Please indicate how much you disagree or agree with each statement below."

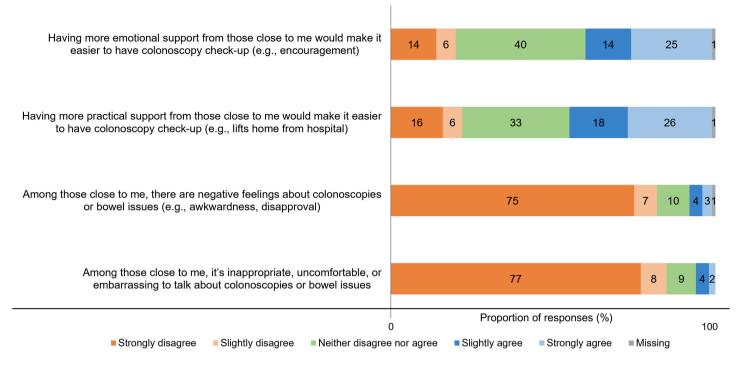
Thoughts / feelings about bowel cancer and living with Lynch syndrome



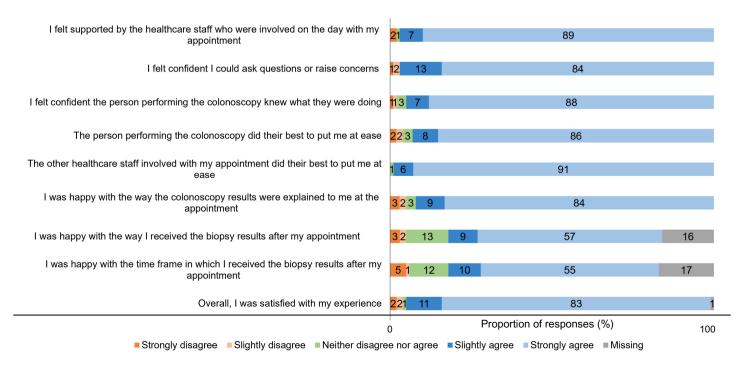
The need for and benefit of colonoscopy check-up



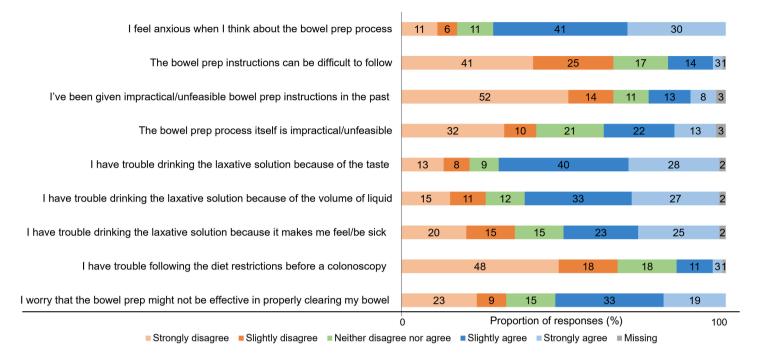
Support from loved ones and their attitudes towards colonoscopies / bowel issues



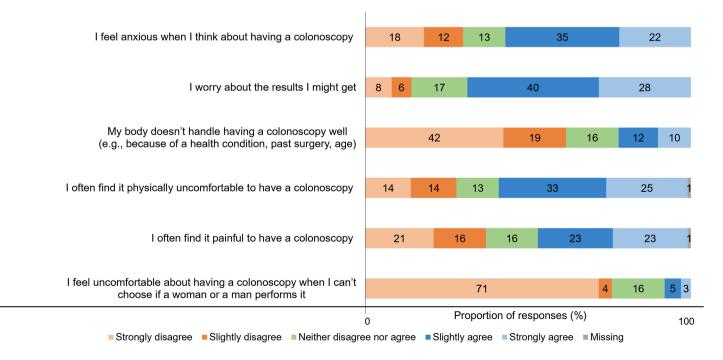
Experience at most recent colonoscopy check-up appointment



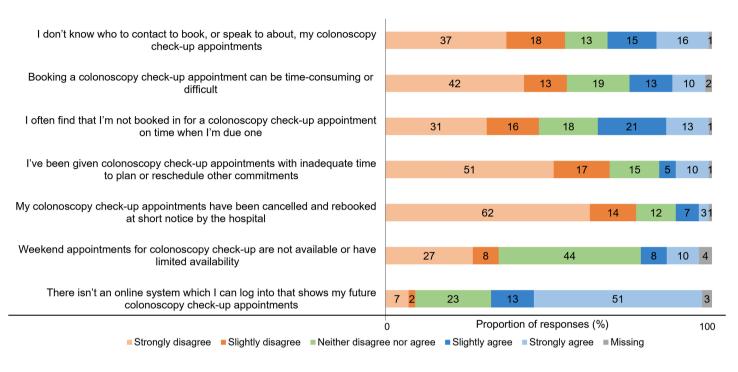
The bowel prep process



The colonoscopy procedure and results



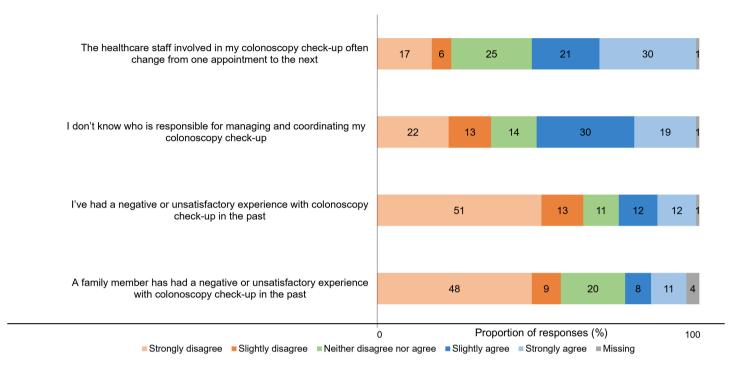
Colonoscopy check-up appointments



Travel, time, and costs associated with having colonoscopy check-up

Getting to and from a hospital for a colonoscopy takes a long time or requires travelling a long way	53		12	12	12	9 1
or requires travening a long way						
Getting to and from a hospital for a colonoscopy is challenging because of limited public transport	46	8		25	5 7	9
Cotting to and from a boanital for a colonoccony is aballonging						
Getting to and from a hospital for a colonoscopy is challenging because it can be difficult to find someone to give me a lift	55		10	15	11	6 4
It's difficult for me to take time away from work for the bowel prep	50		13	18	12	3 3
and colonoscopy			10	10	12	00
It's difficult for me to take time away from caring responsibilities for the bowel prep and colonoscopy	55		10	17	53	10
It's financially difficult for me to have colonoscopy check-up (e.g., time not working, hospital travel costs)	65			9	16	<mark>3</mark> 24
	0 Proportio	n of respo	onses (°	%)		100
Strongly disagree Slightly disagree Neither disagree nor agree Slightly agree Strongly agree Missing						

Coordination of colonoscopy check-up and past experiences



Overall care

I haven't been given the name of a healthcare professional who looks after my overall care needs	27	11	10 19		32 1
Overall, there's a lack of effective communication between different healthcare staff involved in my care	29	11	19	20	20 1
I haven't received enough information or advice related to my Lynch syndrome diagnosis	5	3	16	10	15 5
Different healthcare staff give me different information or advice related to my Lynch syndrome diagnosis	46		17	21	961
Overall, I don't receive enough support from healthcare staff	48		18	17	10 4 1
Overall, the healthcare staff involved in my care don't know enough about Lynch syndrome	33	14	13	26	13
I don't have enough opportunities to hear from or talk to other people living with Lynch syndrome	26	12	26	23	11 1
	0	•	on of responses	()	100
Strongly disagree Slightly disagree Neither disagree	e nor agree 🛛 = Slightl	y agree 🛛 🔳	Strongly agree	Missing	

"Which of the statements (shown on pages 3-7 of this summary) represent the biggest challenges for you in having colonoscopy check-up? Please choose a maximum of 4."

1. I have trouble drinking the laxative solution because of the taste 56 =2. I worry about the results I might get 45 =2. I have trouble drinking the laxative solution because of the volume of 45 liquid 3. I feel anxious when I think about having a colonoscopy 4. I feel anxious when I think about the bowel prep process 33 5. I often find it painful to have a colonoscopy 32 6. I worry that the bowel prep might not be effective in properly clearing my 30 howel 7. There isn't an online system which I can log into that shows my future 29 colonoscopy check-up appointments 8. I have trouble drinking the laxative solution because it makes me feel/be 24 sick 9. I don't know who to contact to book, or speak to about, my colonoscopy = bowel prep 23 check-up appointments = results = colonoscopy =10. I often find it physically uncomfortable to have a colonoscopy 22 = appointments =10. I often find that I'm not booked in for a colonoscopy check-up 22 appointment on time when I'm due one Number of times the 0 60 statement was selected*

*Two statements were both ranked as the second biggest challenge because they both had 45 selections. Two statements were both ranked as the tenth biggest challenge because they both had 22 selections.

The 10 biggest challenges

When we looked at all questionnaire responses together, the following key areas for improvement and further research stood out:

 Make bowel prep more tolerable Better tasting, smaller volume of liquid Allow individuals to choose the brand of bowel prep that works best for them? 	 Support with managing appointments Online system showing appointments Clear point of contact 			
 Minimise pain, discomfort, and anxiety of having a colonoscopy Careful consideration of individuals' characteristics, past experiences, and preferences Supportive and empathetic bedside manner Colonoscopy performed with care 	 Worry about results Investigate ways to support individuals who are experiencing worry about their results, or who might avoid getting a colonoscopy because of this worry 			
	There is a need for a nationwide study of the views and experiences of having colonoscopy check-up under the Lynch syndrome-Bowel Cancer Screening Programme, involving individuals from across the UK			

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