

Testing public perceptions about endoscopies

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Background and context

The Kent & Medway Cancer Alliance (KMCA) wanted to understand people's attitude and experience of diagnostic tests such as an endoscopy used in identifying health problems such as cancer, and what barriers there might be which stop people attending, or delay attendance at diagnostic appointments? KMCA also wanted to understand any barriers that may reduce or stop people attending cancer screening appointments. KMCA also wanted to understand whether people had experience of the shift in healthcare appointments to technology via phone or online and their thoughts on this.

Primarily the research was to understand attitudes and experience of diagnostic tests and any barriers people spoke of, so that KMCA could consider what changes might be made to increase the take up of diagnostic tests focusing particularly on endoscopies. As NHS staff in hospital trusts have reported an increase in the numbers of people failing to attend for diagnostic tests during covid, and they have historically observed a reluctance particularly among men in take up for these tests.

The focus of this report is therefore on exploring the perceptions of endoscopies with some target audiences, including men and those living in neighbourhoods with high indices of deprivation. In their 2018 report on Cancer, the Kent Public Health Observatory team reported 9,000 new cases of cancer between 2012-2016. This equates to an annual average of 2,225 new cancer patients every year in Kent. Of these cases 12% were colorectal cancer, the equivalent of 267 people. The report also noted that people living in areas of deprivation in Kent were less likely to be screened than the national average (51% in Kent compared to 61% nationally). The report highlighted that Kent residents have a higher overall uptake of cancer screening than the national average but that there is large regional variation based on where people live.

Aims of the research

Whilst the research involved a range of people living across Kent & Medway, the focus was to hear feedback from men and people who live in neighbourhoods of Kent ranked with a high value in the Indices of Deprivation 2019.

The Indices of Deprivation 2019 (IoD2019) is produced by the Ministry of Housing, Communities and Local Government (MHCLG) and provides a set of relative measures of deprivation for neighbourhoods. The IoD2019 is based on 39 separate indicators, organised across seven distinct domains and 4 sub-domains of deprivation. These are combined and weighted to calculate the overall Index of Multiple Deprivation 2019 (IMD2019).

The aims of our research was:

- To ensure feedback from a diverse group of people, including the target cohorts.
- To gather qualitative feedback about concerns people may have about endoscopy testing.
- To explore with the people any suggestions for increasing the uptake of endoscopy testing.
- To explore with people what they value most in a cancer screening service.

Summary of findings

76 participants took part, 58% of which were male. Participants were targeted from 5 cohorts:

- Men
- People living in areas with high indices of deprivation
- People from BAME communities
- People living with a disability
- People identifying as part of the LGBTQIA+ community

91% of participants reported that they knew about cancer screening, with the highest concentration of those who did not know about screening being people living within areas of deprivation.

88% of participants reported they would attend cancer screening, with people within disability and LGBTQIA+ communities having the highest levels of refusal.

When asked about attending an endoscopy appointment, 92% of participants said they would attend saying 'if the need was greater than the fear, then I'd go'.

Peoples' concerns around endoscopies include:

- A previous negative experience, either personally or having heard from a close friend / relative
- Concerns about discomfort, pain, and embarrassment
- A fear of the unknown

Participants were able to identify a number of suggestions as to how to overcome these concerns.

The LGBTQIA+ cohort identified some unique barriers to screening services:

- Transgender men and women not being offered the correct screening
- Language and forms not reflecting those with 'mixed biology'

The research also looked at accessing NHS appointments via phone or online systems.

91% of participants said they had accessed the NHS in this way. Of those that had not accessed appointments using phone or online systems, 12% were residents in areas with high indices of deprivation.

- 61% of people had accessed appointments over the phone but only 19% used online systems.
- 20% of people said they did not have access to online systems, 16% of this group being residents in areas with high indices of deprivation

Methodology

Our approach was underpinned by 'assertive outreach' engagement methodologies, reaching into communities to engage with them in their daily lives.

This included:

- Working with organisations who already have a trusted relationship with the target communities, including community groups and foodbanks
- Working with local employers in targeted trades to engage their workforce.
- Street surveys
- Online focus groups
- Drawing on our own Public Panel

Using the statistics from Kent Public Health Observatory report 2018, we identified the research would benefit from a sample size of 70 people. This would give a confidence level of 95% with a 10% margin of error.

Our researchers secured informed consent from all our participants and worked from an agreed set of questions, that were formulated alongside the Kent & Medway Cancer Alliance. Consent was recorded in a database against each participant's responses.

Researchers captured the demographics of each participant which was entered straight into a database.

As a 'thank-you' participants were offered a £15 voucher.

Engagement methods

Outreach via Organisations

By working with trusted organisations, our researchers met face to face with groups of participants. Some of these engagements required one to one interviews and some were structured as a group discussion. In both situations the same semi structured interview was used to underpin the engagement discussion.

This methodology reached 38 participants

Online Focus Groups

We facilitated two online focus groups, one was populated by participants from a single community group and the other was populated by people who responded to social media advertising for participants.

This methodology engaged 10 participants

Engagement via local employers

Working with local employers in construction and haulage we were able to interview men whilst at work, either individually or in small groups.

This methodology engaged 16 participants

Street engagement

A researcher undertook interviews with people walking in a defined area on a particular day. Participants in this group were therefore a random sample of local residents from a neighbourhood chosen because of its high indices of deprivation.

This methodology engaged 10 participants

Reaching into our Public Panel

We have a database of members of the public we have worked with previously, and we promoted the opportunity to them. People were able to put themselves forward based on the criteria.

This methodology reached 2 people

Research methods

A semi structured interview was designed to elicit both quantitative and qualitative text data for later analysis.

Time was spent with each participant before starting the interview, ensuring they felt comfortable and fully understood the purpose of the insight gathering and the permissions they were giving.

Interviews were undertaken face to face, either individually or within groups depending upon the engagement methodology utilised.

Our interviews with participants ranged from 10-20 minutes in duration.

Responses from the interviews were entered as text data into a database and then using a form of thematic content analysis, the data was reviewed, identifying themes within the data, and reported using examples from within the text.

The data was first themed as a whole data set and then reviewed by target groups identified in Table 1 to identify any commonalities or variances within different target cohorts responses.

Target cohort		Data set for secondary analysis
Men		22
Male	22	
Residents in areas of Deprivation		34
Male	19	
Female	14	
Other	1	
BAME		9
Male	0	
Female	9	
Other	0	
Disability		6
Male	2	
Female	4	
Other	0	
LGBTQIA+		5
Male	1	
Female	4	
Other	0	

Table 1.
Grouping of interviews to form data sets for secondary thematic analysis

Findings

A total of 76 participants (see Appendix 1), from all over Kent and Medway were engaged in this research (see Table 2).

58% (44) were male and 42% (31) female with one person not identifying their gender.

92% (70) of participants identified as heterosexual, with three people identifying as gay/ lesbian and two people identifying as pan sexual. One person preferred not to say.

16% (12) identified themselves as being a Carer for a dependant.

38% (29) identified themselves as having a disability, 17% (13) identified a physical disability, 17% (13) a mental health issue. 8% (6) identified as having a long-term health condition and 5% (4) a learning disability.

<i>Participant's postcode</i>		
Ashford	TN23	1
	TN24	1
Canterbury	CT1	4
	CT4	1
Dartford	DA1	7
	DA8	1
Dover	CT14	1
	CT16	5
Maidstone	ME14	4
	ME15	5
	ME16	1
	ME20	1
	ME9	2
Medway	ME1	3
	ME2	8
	ME4	3
	ME5	1
	ME7	3
	ME8	2
Swale	ME10	2
	ME12	6
Thanet	CT11	1
Tonbridge and Malling	ME6	1
	TN12	6
Tunbridge Wells	TN17	1
	TN4	1
	TN5	2
not stated		2
	Grand Total	76

Table 2. Participant's postcode

Awareness and attitudes to screening procedures.

Participants were asked if they knew about cancer screening. Across the whole sample, 91% (69) said that they did.

Target cohort			
Men (22)		Aware	Not aware
Male		21 (95%)	1 (5%)
Residents in areas of Deprivation (34)		28 (82%)	6 (18%)
Male	19	16	3
Female	14	12	2
Other	1	0	1
BAME (9)		8 (89%)	1 (11%)
Male	0	0	0
Female	9	8	1
Other	0	0	0
Disability (6)		5 (83%)	1 (17%)
Male	2	2	0
Female	4	3	1
Other	0	0	0
LGBTQIA+ (5)		5 (100%)	0
Male	1	1	0
Female	4	4	0
Other	0	0	0

Table 3. Participants awareness of cancer screening

This can be further broken down into the target cohorts, which identifies that those living in areas of deprivation seem to have the highest number (18%) of participants who felt they were not aware of cancer screening. Of these six participants, three were Male.

When participants were asked if they would go for cancer screening, such as bowel screening, smear test or a mammogram, when invited, 88% (67) said that they would. This can be further broken down into the target cohorts, which indicates that those who identified as having a disability or as LGBTQIA+ had the highest percentage of participants who felt they would not attend a cancer screening appointment, 33% (2) with a disability and 20% (1) of participants who identified as LGBTQIA+. Of the seven people who said they would not attend, four were female.

Target cohort		Would attend	Would not attend
Men (22)			
Male		20 (90%)	2 (10%)
Residents in areas of Deprivation (34)		30 (88%)	4 (12%)
Male	19	17	2
Female	14	13	1
Other	1	0	1
BAME (9)		9 (100%)	0
Male	0	0	0
Female	9	9	0
Other	0	0	0
Disability (6)		4 (67%)	2 (33%)
Male	2	2	0
Female	4	2	2
Other	0	0	0
LGBTQIA+ (5)		4 (80%)	1 (20%)
Male	1	1	0
Female	4	2	2
Other	0	0	0

Table 4. Participants intention to attend cancer screening

General cancer screening

When participants were asked why they would not attend cancer screening they gave a variety of reasons:

- ‘No for bowel screening – due to experience of seeing a close relative go through this and the embarrassment aspect.’ (Male)
- ‘No for mammogram – due to being exposed to intensive rays & also due to it being taking place in a unit parked in local supermarket car park’. (Female)
- ‘Not a smear test – too painful and invasive. I don't go for smear tests; I just can't have it. I'll take the risk thank you. Of everything I've had, I've come out the other side of, so I'll take the risk with the smear because I am treated like a slab of meat and it's too painful. It's a bloody Victorian thing. If men had to have this, they would find a treatment that doesn't involve sticking a Victorian contraption up you. I mean how dare they?! Men have a blood test for prostate cancer now. Why can't they do that for cervical cancer? No, it's because it's for women and I would be very grateful if you could feed that back because I feel very strongly about it!’ (Female)
- ‘Because I'm 75. If I had anything, I couldn't go through what my daughter in law is going through. She's in her 40's. I'd just rather not know until it was the end’. (Female)
- ‘We do know a lot of people that have gone through treatment, and they say it's just about quality of life. If I was in my 40's and had young kids maybe I would’. (Female)

Endoscopy appointments

When participants were asked if they would attend an endoscopy appointment, 92% said that they would if they had too, but it would be something they were nervous about.

One person summed up the comments of many others in saying ‘If needed, I'd suck it up and have it’.

Other comments included:

- ‘As long as I knew what it was for, where the camera is going, I can psyche myself up for it’ (Male)
- ‘I have all sorts of stuff in my life, I’ll be ok with this if I needed to have one’ (Female)
- ‘I would need to be really suffering and if it was the only way to do any further tests then yes, I would go’ (Male)
- ‘I would need to be ill or in pain to go, not just invited as a massive screening thing’ (Male)
- ‘I have had endoscopies before and would have again if needed, they’re horrendous but it wouldn’t put me off’ (Female)
- ‘If the need was greater than the fear then I’d go’. (Male)
- ‘If I had to have one, otherwise I'm not going. I am not going to voluntarily have something go in a no entry zone!’ (Male)
- ‘If you wanna face tomorrow, you got to face today. I do it for my grandchildren. I want to be around them when they grow up’. (Male)
- ‘It is always better to just go and get it checked out than leave it until it is too late. You hear those stories a lot’. (Male)

Target cohort		Would attend	Would not attend
Men (22)		22 (100%)	0
Male		22 (100%)	0
Residents in areas of Deprivation (34)		30 (88%)	3 (12%)
Male	19	18	1
Female	14	12	2
Other	1	1	0
BAME (9)		9 (100%)	0
Male	0	0	0
Female	9	9	0
Other	0	0	0
Disability (6)		4 (67%)	2 (33%)
Male	2	2	0
Female	4	2	2
Other	0	0	0
LGBTQIA+ (5)		5 (100%)	0
Male	1	1	0
Female	4	4	0
Other	0	0	0

Table 5. Participants intention to attend an Endoscopy appointment

Concerns and fears around endoscopy procedures

Given that the majority (92%) of participants said they would have an endoscopy if needed, but they would be concerned about it, the research explored further what aspects of an endoscopy screening procedure creates the most concern or worry. There were no significant variations between the cohorts.

These have been grouped into key themes, listed in order of frequency of mention.

Previous negative experience

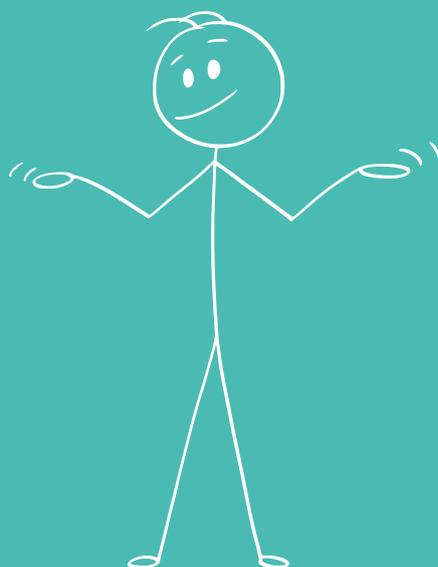
The most frequently mentioned area of concern was having had a previous negative experience, or having heard about an experience from a friend or relative. 26% (20) people talked about negative experiences whilst 19% (14) people talked about positive experiences.

- 'I think its experience based. For the first time you pluck the courage, and you go but if it's a bad experience, you will be put off and not want to go again'. (Female)
- 'I went before and stopped it as I didn't like it. I will never try again'. (Female)
- 'I'd be thinking about my past experience, I'd be a nervous wreck if you phoned me up for another appointment' (Male)
- 'A close relative had that procedure and the lack of information and seeing the recovery back on the ward wasn't nice, I wouldn't do it'. (Female)
- 'I have had an endoscopy and it was not a pleasant experience. It was in my mouth to look at my hernia. I would have liked to have been sedated in all honesty, it was horrendous.' (Male)
- 'I've had a camera down the throat and the sedation didn't quite kick in quick enough and that was really horrid. And I couldn't understand why they had these two burley nurses with them... of course, they hold you down! It was really most unpleasant but the before and after care was truly fabulous' (Female)
- 'I'm concerned about attending another endoscopy as the last time I had one done I went home, and the toilet was full of blood, I couldn't stop bleeding, I called 111 and the ambulance came. I showed him the toilet and they took me to hospital; it took time and two blood transfusions to be better!' (Male)

- 'I had one (an endoscopy) and it is a horrendous experience, and it is purely because I have been abused, so there are issues around that. I spoke to the nurse as my anxieties were through the roof, they said they were going to give me a stronger sedative – they could not do it as I couldn't relax'. (Female)
- 'I've had three down my throat and four in the rear end. A student done one of them and apparently, as the camera was going through, somewhere had collapsed and like stuck itself together. And they blast a jet of air to open it up. He pressed the button to open it up and carried on but kept his finger on the button. It was really painful, my stomach was actually getting bigger, and he filled my stomach up with air. And when they took it out, I said 'I gotta go to the loo, I've gotta go now!' and I got in the gents, and I let go the loudest, longest parp you've ever heard. But it was all this gas, and I could feel my stomach going down. You've gotta see the funny side of it!' (Male)
- 'I've had a very painful one up the bum, Jesus Christ! They squirt a load of gel up there and when it goes into the bladder – Jesus Christ!' (Male)

Positive experiences:

- 'I have bowel cancer screening every two years. The first one I had was a bit strange because there were about seven people! I found it quite funny in the end and the surgeon was fantastic, so they put you all at ease that wasn't a problem' (Male)
- 'I have had an endoscopy; it wasn't the most pleasant thing ever I have to say. I wouldn't be worried about going again though, now I have had one I know what to expect and the staff were so informative when I got there. They explained everything to me.' (Male)



Discomfort and embarrassment

25% (19) of people said that their fear of pain and discomfort would be a barrier to their attending an endoscopy.

- 'I might need a drink before it though - or after - both! Is it uncomfortable?' (Male)
- 'I would be hesitant. I don't like the idea of it but if I had to go I would do it. Being intrusive worries me as I don't like being touched by people let alone have them shove something in me, but I understand the reason, but it does bother me all those people being so close and even touching me'. (Male)
- 'I wouldn't fancy anything down my throat, I'd be gagging. I've had something up my nose and I was sick. If it would be something through the skin, I would be ok but not otherwise...I'd have it if I was sedated.' (Male)
- 'I would worry about the operation beforehand, but once it's done it's done. If it is a bowel one it's the stuff you have to eat that puts me off, I wish there was a better way to clear you - that would be good. (Female)

Of this group, four people (2 female and 2 male) talked about being embarrassed,

- 'I guess it is, having something go down your throat would make me want to gag - I'd want to sneeze if it's going up my nose and as for the bottom - what if I break wind? They're probably used to that though'. (Male)
- 'With men, it can be a bit embarrassing. It's probably the same with women for certain things as well, like smear tests and that sort of thing. It's invasive, isn't it? (Male)
- 'I'm invited every 3 years. It's just embarrassing because it's a private part of the body. It's embarrassment mainly' (Female)
- "I think one of the things which probably holds men back is you have to give up your masculinity perhaps for a minute or two. And yeah, I think that that is an issue. My father, when he was about 70, he was working at B&Q, he had to ask for time out for an endoscopy and his boss said, why do you want some time off. He explained to his boss, and his boss said, 'well there a couple of people here who would like things stuck up their bottom'. But that's because he felt uncomfortable, I think, he didn't know how to respond (Female)

Fear of the unknown

24% (18) of people said that not knowing about the detail of the endoscopy process itself, and the outcome of the procedure would create anxiety and be a barrier.

- 'I suppose anything like that is gonna worry you. The camera thing going inside you, they wouldn't put you right out, they would give you some sedation, and I don't know, things like that are naturally worrying for people.' (Female)
- 'Do you have to have anything to flush your system out if it's going up your bottom? I'd want to know that'. (Male)
- 'I guess it's not nice, especially down the throat or up your nose. Can you get knocked out for it?' (Male)
- 'I think my main concern would be about the unknown, is it going to be uncomfortable?' (Male)
- 'Do they use the same camera up your bum and in your mouth? What about cleaning it? It's bad enough it's going in a one-way street but if it's then going into a mouth or up someone's nose, how do they clean stuff - yeah, I'd be worried about catching something. I would need to know how clean the stuff is'. (Male)
- 'I've known people who have had them, and they say it is pretty unpleasant. For me it is the not knowing that bothers me'. (Male)
- 'I would worry it was something cancerous'. (Female)
- 'If I had short notice, I would worry a lot because I wouldn't have time to prepare properly, mentally and logistically' (Male)
- 'I think if you live on your own like I do, it is a bit of an unknown quantity. You become a bit apprehensive about all those procedures because you really don't know what's going to happen. Before I go, I find it very daunting and I get very uptight.' (Female)

Other perceived barriers

People mentioned a number of barriers to attending a hospital appointment that are not directly related to the endoscopy procedure itself.

Logistics of attending a hospital appointment

59% (45) of participants said that issues around the logistics of getting to a hospital appointment could be a barrier. This included accessibility of the hospital if they were unable to drive, and for a few people it included arranging carers to look after someone, or working around childcare responsibilities to enable them to attend a hospital appointment.

Most participants didn't feel that getting time off work would be a barrier but one or two commented that they lost earnings if they didn't work.

- 'My main concern would be taking time off of work. But also, I would worry about getting home safely, I know that sometimes you have to be sedated and then I wouldn't be able to drive home. It would be ok if I could drive home' (Male)
- 'Where it is would concern me and it's always the fear of them telling you something you don't want to know. They always send you to the most inconvenient place at the most inconvenient time. We live near the Maidstone hospital, but they send you to Tunbridge Wells!' (Male)
- 'I would drive so I have no concerns about getting there. If I couldn't drive that would be a serious problem. I couldn't go by bus because of this (pointed at his wheelchair).' (Male)
- 'I would go by bus, but I would have to take my baby' (Female)

Covid

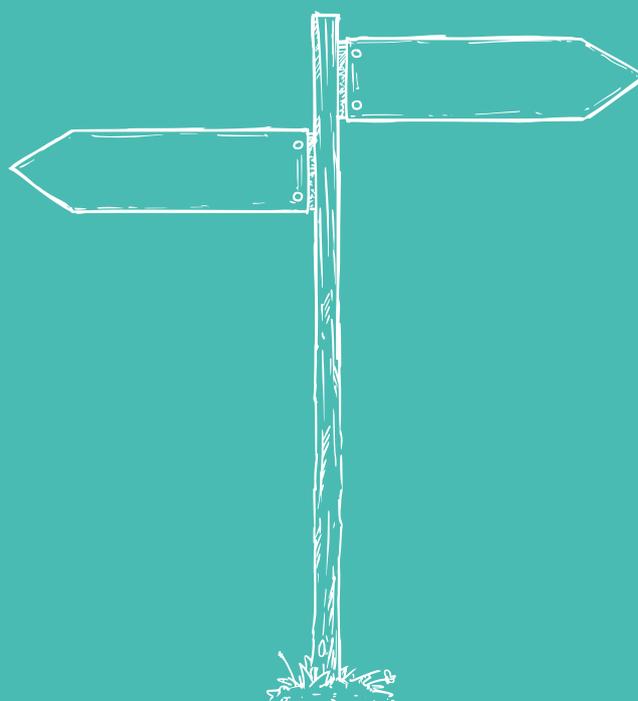
28% (21) of participants said that concern about catching Covid would not be barrier, whilst 13% (10) of participants said it could be a barrier to their attending a hospital appointment.

- 'I have had both jabs for Covid and test twice weekly for work. Hospitals are clean, so I'm not overly concerned about getting Covid from that appointment.'
- 'Covid was a concern but not now there is good protection with face mask and handwashing' (Female)
- 'You can get Covid anywhere so going to hospital doesn't make it worse, I just wear my mask and treat the hospital staff and rules with respect' (Female)
- 'I am very wary of going in now [hospital] as my friend went in there with a heart condition and came out in a box after Covid'. (Male)
- 'Covid is a slight worry for me, going into hospital for an endoscopy although we are getting used to Covid and have been double vaccinated so that helps. (Female)
- 'I'm still concerned about Covid because hospitals are the place that everybody goes when they are ill, so I think there is more possibility of catching something and in the waiting rooms you could catch something. I've still got a fear and unless I was almost dying, I wouldn't want to go'. (Female)

Transgender Concerns

The LGBTQIA+ cohort identified some systemic barriers that would impact on their experience of taking up an endoscopy appointment.

- 'For my son who is trans male he probably would not want to go to a smear test as it is all a bit gross. But if he was worried about a lump he would probably go. He would probably go for a non-routine test rather than a routine one.' (Female)
- 'There are issues around barriers about accessing the service, form filling, language etc. And people being aware of the difference in biology between trans men and trans women'. (Female)
- 'From a community perspective it starts from are you even going to be asked to have test? Obviously with mixed biology, there are stories of not being asked for tests, like a trans woman needing a prostate check. Trans women would get cervical smear and mammogram reminders but not prostate ones. I know from the incidents of prostate cancers in trans women there are not many cases, so they are not really worried about it.' (Female)



Overcoming people's concerns and worries about endoscopy

Information

Although 91% (69) people said they were aware of endoscopies, 62% of participants (47) felt that information about the detail of the procedure could help them overcome their concerns about attending an endoscopy appointment.

Alternatives to written information

- 'A video or a leaflet explaining what will happen at the appointment, directions, how long the appointment will take'. (Male)
- 'Visual information helps me, as the words don't always mean much (I'm dyslexic), it is also important to let the nursing staff know I need extra help' (Female)
- 'I tend to like visual things, if there was a video of what to expect and how the tests are carried out. Some might not like it but for others it would make them less worried'. (Female)
- 'I know with the sexual health clinic they produced a walk-through video, for example "this is reception, you will go through here" – explaining what is going on and allay fears about what is going on.' (Female)
- 'Visual information. Not just words. Maybe we could watch a video of a real person who has had it done and they could ask the patient how it feels and how they felt it'
- 'Need to think about plain English, people don't realise the complicated language they use. Use easy read with pictures' (Female)

Step by step guide from screening to results

- 'Knowing what's going to happen when you're there, having someone explain it to you in non-medicalised language. Every step explained from the GP, the surgery nurse to the results after' (Female)
- 'Information to tell us how they clean the camera...' (Male)
- 'For me I think having a chat with a specialist or someone who is going to carry out the procedure would reassure me. I would like to know what is going to happen and have very clear information' (Male)
- 'I would like information and the reasons for doing it along with what the outcome possibly would be - operation etc. I need a lot of information before so I can read it all and understand my options'. (Male)
- 'Lots of information so you understand that it's not a huge camera - it is in fact quite small. What happens at the appointment, what clothing to wear so you're comfortable, that kind of thing. I wore joggers - easy to get on and off. Stuff for your family as well, my mum was really worried, but after the endoscopy that's what gave me my full diagnosis (Male)
- 'They have these fabulous disposable pants you can get. Maybe this could be included in information packs, or clinicians could suggest people take a couple of pairs of them in case they get cut short. I didn't realise the prep needed for the ones up your bum! And afterwards you might be worried about pooing your pants so wearing these things can help.' (Female)

Personal stories

- 'I would like to speak to someone that's had the procedure - do they have videos of people that have had it done? That would be good, hearing from people that have had it, what to expect, any issues that kind of thing. Do the Hospitals have anything like that?' (Male)
- 'I think hearing other people's stories who have been through it (both good and bad) so I can make a decision as to whether I want the procedure'. (Female)
- 'It would help to have someone with experience of having it done talking to me and telling me what it was really like and realistically what to expect, you know the number of people. How much they touch you. What it feels like etc. (Male)
- 'I would find it helpful to know both good and bad stories about how people have found it, what it is actually like. It visually puts something in my head. "That person has had it done and it was alright"' (Female)

Education and addressing the taboo

- ‘They could inform us with adverts on TV. Billboards and on buses. Any advertising really. I suppose what I am saying is the more I see it as something a lot of people do the less anxious, I will be if I have to go and have it done’. (Male)
- ‘Make cancer screening adverts on TV more light-hearted. The more they talk about it, the more normal it becomes so people feel better about it because they think everybody does it’. (Female)
- ‘What you used to see on the better construction sites is a lot of information about why it is good to attend things like prostate tests. I think it’s important to get positive messages out there’. (Male)
- ‘In construction you get a lot of asbestos information up on the walls. The fact you have to explain what an endoscopy is at the beginning says everything, I think education is key’. (Male)
- ‘We had a GP come and talk to us about men’s health issues. It was good to know you’re not alone about somethings’. (Male)

Accessibility

26% (20) of participants felt that addressing practical issues around accessing an appointment would reduce their concern around attending an Endoscopy appointment

- ‘I would go on my own, evening would be better as I could go after work and not lose money - 9-5 appointments do not suit everyone, what about shift workers? It's not always easy to get time off work’. (Male)
- ‘Closeness to home is important, I don’t want to go on a bus, I need to go with my husband’. (Female)
- ‘Having at least 2 weeks’ notice ... so that I am able to plan my transportation so somebody else can take me on the day and letting my employer know in advance so they can find someone to cover my shift’. (Female)
- ‘If the hospital can make it clear how to get there, it will make it easier for me and anyone who might have to take me or pick me up’ (Female)

Family support

24% (18) of participants felt that making it easier for friends and/ or family to accompany them would reduce their concerns around attending an endoscopy appointment.

- ‘Having someone with me would help. If I have to have a test, then crack on but I would like it if someone could come along’. (Male)
- ‘Having someone (friend/family) waiting outside the theatre would help me, not inside the theatre!’ (Female)

Staff communication

22% (17) of participants suggested that GPs, nursing staff and consultants could improve their support and communication with patients and help reduced concerns that people feel around endoscopy appointments and procedures.

- 'I think it's about having staff trained in how to communicate and deal with people who need additional support (e.g. individuals with autism, learning difficulties or mental health conditions such as anxiety). It is important that the staff are aware of these conditions'. (Female)
- 'Having the same staff member for the whole process would help me' (Male)
- 'Staff treating you with compassion, respect and dignity and being gentle. Perhaps they should have the procedure themselves, so they know what it is like!' (Female)
- 'If they was more caring in the way they spoke to you. Make it simple. Latin words are scary' (Male)
- 'GPs to be more empathetic and explain to patients what to expect.' (Male)
- 'For me just getting friendly staff who explain things step by step would really help'. (Male)
- 'I don't want the information all in one go by the consultant as they go too fast, but slowly and step by step' (Male)

Highlighting consequences

16% (12) of participants suggested that spelling out the consequences of not attending an endoscopy appointment might be a way of helping people prioritise attendance.

- 'I just knew I had to have it and so I just knew that I was gonna have to go for it. It's better to know then to not know. Not stiff upper lip but, yeah, you gotta go.' (Male)
- 'If I was in a lot of pain or was told it's the only option for me then I would go, I wouldn't need any further support or encouragement.' (Male)
- 'Try scare tactics and considering the consequences of not having the endoscopy'
- 'I think just the fact that you could die of cancer is enough to encourage me to attend.' (Female)
- 'Well, you could die a painful death a bit quicker if you don't go!' (Female)

Efficient testing and results

8% (6) of participants focused on the whole process and felt they would be encouraged to attend an endoscopy if they were assured of quick results and a clear explanation of what would or could happen next.

- 'I think getting clear results would be important to me, I want to know is it nothing? Something? Have they got a plan? My dad had an endoscopy recently and he got his results straight after. I would like to know what it means for me going forward. Sometimes test results get sent to the doctors and then you don't hear anything. I would like nice clear results. ...So good communication is important, especially between the hospital and the GP. Ideally you would have it all dealt with in one place including going to the hospital pharmacy, all there together.' (Male)
- 'Having an idea about after; time scales about what support is there when you get the results; how that is delivered, that sort of thing!' (Female)
- 'Getting results straight away, being told there and then. That happened to me. They removed the polyps straight away, as for the cancer it got sent off and they told me there was not a high chance it was cancer. It is reassuring to be told straight away it was going to be 2 weeks, but I was told, and I was assured' (Female)
- 'Quicker results would help with anxiety of waiting.' (Female)
- 'Clinicians should be clear on waiting times for results and in what format we are going to get results (e.g., phone/email/letter in post)'. (Male)

Distraction

7% (5) of participants mentioned that being distracted whilst undertaking the procedure would encourage them to attend.

- 'I think it would help me to listen to my own music for distraction.' (Female)
- 'I would like to see the screens showing what was going on to give me something else to think about and focus on something.' (Male)

LGBTQIA+

The LGBTQIA+ cohort identified some specific improvements for trans men and women, to reduce concerns around endoscopy appointments.

- 'Ensuring that records enable people to get called for tests that are relevant'. (Female)
- 'It is how they talk, the language – there is a sensitivity about how staff need to talk about peoples bodies'. (Female)
- 'The most basic thing is the forms. I've don't a lot of work with sexual health services who even had blue or pink forms! Why aren't they all on one for? Is it gendered language?' (Female)
- 'I think at the initial meeting before you have the procedure, just to listen to us. That's it. The clinician needs to give the patient of the choice of whether they want to be taken through it step by step. Because quite frankly, it's got to be done'. (Female)

Accessing an NHS appointment by phone or online

91% (69) said that they had accessed an appointment on the phone or online with many people talking about their experiences of accessing their GP via phone or ordering repeat prescriptions online. Of the 7 people that said no, 4 of them were in the cohort identified as residents living in areas of high indices of deprivation. This represents 12% of that cohort. Broken down, this equates to 61% (46) of the participants accessing an appointment via the phone but only 19% (14) accessing an appointment using an online booking system. The remaining 20% (16) reported that they had not got access to online facilities, with 16% (12) of these being within the 'area of deprivation' cohort.

- 'I can manage on the phone, but I can't use the internet.'
- 'Sorry I don't understand that online stuff. I don't do anything online. I don't have a computer to start with'

Positive phone experiences

25% (19) of participants reported a positive experiences of booking or attending a phone appointment.

- 'I have been fine with it. At the moment I think it is better than going in for an appointment.' (Male)
- 'I have regular appointments on the phone with my Mental Health nurse, it's always at a mutually convenient time and I have never had any issues with doing appointments this way' (Male)
- 'It was quite strange 'cos my surgery contacted me 'cos I asked for an appointment, and they said it would be telephone. Then I got a message saying it would be at the surgery, so I went actually down to the surgery on the time, and I wasn't allowed in, and I was sitting outside on the bench with the doctor talking to me from inside on the telephone!' (Male)
- 'Our GP is really good, when it was needed he did see us but for discussing a blood test you can do that over the phone.' (Female)
- 'Phone calls are better protection for everyone including the GP - they are not immune to covid! It works both ways. People just want to have treatment face to face but phone calls are adequate a lot of the time' (Female)
- 'I found the phone system of appointments with the NHS very successful and helpful' (Male)

Choice

15% (11) participants said that they would like a choice as to whether an appointment was on the phone / online or in person.

- 'It would depend on if it wasn't too bad, I could do phone but if it was more serious, I would want to go in.' (Male)
- 'Phone would be ok, I don't have email, I have a smart phone, but I hate using the stuff on there - I can do WhatsApp, text and phone, that's all I need. The doctor knows I need face to face, touchwood I haven't needed to go'. (Male)
- 'No problem with either, but I prefer to go in rather than speak on the phone.' (Male)
- 'By phone yes but not online. I'm not very good online. I like to have a choice. I'm a little bit annoyed by so many things being pushed online because our generation especially are not online savvy' (Female)
- 'I have had a phone call with the doctor and that was fine, but I'd rather see someone face to face' (Male)

Negative phone appointments

9% (7) participants said that they had experienced negative phone appointments

- 'It's gotta be on the phone - I don't do online. I've had a phone appointment, but it wasn't a good experience. The last one was in July 'cos I needed another OT. I spoke to the doctor, and he was useless. It just seems like a waste of time. It's just like you're being ignored. And 'cos I can't describe what it is or where it is, how do they know what the problem is?' (Female)
- 'The wife had one and she was still prescribed pills she was allergic to. It was awful.' (Male)
- 'They can go wrong. I had a phone appointment, but it didn't help me. At the end of it, I was like 'so what do I do about this rash' and he hadn't seen it, so he didn't know'. (Male)
- 'You judge people when you speak to them and see them, you need to see them face to face to be able to give them the right treatment. I don't like this phone business' (Male)

Positive online appointments

8% (6) of participants said that they had a positive experience of online appointment booking and attending appointments. This is 43% of the total number of people who identified using online systems.

- 'It's not too bad. Providing they send the information about where you need to go. They give you some weird password like ""pudding"" but its ok' (Male)
- 'I use the app for appointments and prescriptions and it's easy to use' (Female)
- 'I get my medication online. GP appointments online. It's all very easy and I always do it'. (Male)
- 'I don't have problems accessing either by phone or online but at the moment, online is much better than the phone for booking appointments because the phone was taking forever... you were in the queue for ages. It's frustrating on the phone and you just give up because it makes you late for work and stuff' (Female)
- 'Yes, I can, and I have done it. It was passable. I have done face to face appointments. I did one about two and a half weeks ago with the metal health team. That went very well. First time I did it, it was a total disaster; the person didn't even turn up. I'd rather be face to face to be honest.' (Male)

Appendix 1 Demographic profile of Participants

		Male		Female	
Men (working in construction or associated Trades)	22	16-24 yrs	1	16-24 yrs	0
		25-34 yrs	3	25-34 yrs	0
		35-44 yrs	5	35-44 yrs	0
		45-54 yrs	4	45-54 yrs	0
		55-64 yrs	3	55-64 yrs	0
		65-74 yrs	4	65-74 yrs	0
		75-84 yrs	1	75-84 yrs	0
		85-94yrs	1	85-94yrs	0
	22				
Residents in areas with high indices of deprivation 1 person not identify gender (aged 55-64yrs)	33	16-24 yrs	3	16-24 yrs	0
		25-34 yrs	2	25-34 yrs	2
		35-44 yrs	0	35-44 yrs	2
		45-54 yrs	1	45-54 yrs	2
		55-64 yrs	4	55-64 yrs	2
		65-74 yrs	4	65-74 yrs	1
		75-84 yrs	4	75-84 yrs	3
		85-94yrs	1	85-94yrs	1
	19		13		
People from BAME background	9	16-24 yrs		16-24 yrs	
		25-34 yrs		25-34 yrs	
		35-44 yrs		35-44 yrs	6
		45-54 yrs		45-54 yrs	2
		55-64 yrs		55-64 yrs	1
		65-74 yrs		65-74 yrs	
			9		
People identifying with a Disability	6	16-24 yrs		16-24 yrs	
		25-34 yrs		25-34 yrs	
		35-44 yrs		35-44 yrs	
		45-54 yrs		45-54 yrs	
		55-64 yrs	1	55-64 yrs	2
		65-74 yrs	1	65-74 yrs	1
		75-84 yrs		75-84 yrs	1
	2		4		
People identifying as LGBTQIA+	5	16-24 yrs		16-24 yrs	
		25-34 yrs	1	25-34 yrs	
		35-44 yrs		35-44 yrs	
		45-54 yrs		45-54 yrs	2
		55-64 yrs		55-64 yrs	1
		65-74 yrs		65-74 yrs	1
	1		4		

Ethnicity	Number of participants
English/Welsh/Scottish/Northern Irish/British	62
African	9
Nepalese	1
Any other Mixed / Multiple ethnic background	1
Polish	1
Chinese	1
Not say	1

Appendix 2 Questionnaire

Screening & Endoscopy Questions

EK360 is working with Kent and Medway Cancer Alliance to research people's views about cancer screening and testing, in particular endoscopy tests. We'd really like to hear your thoughts about endoscopies, even if you haven't had one before. Your feedback will help us understand how best to encourage people to attend an appointment. Everything you say will be anonymous. Are you happy for us to ask you some questions and for us to record and share your feedback with the cancer alliance? Yes/No.

Have you heard about endoscopies?

An endoscopy is a test that looks inside your body using an instrument called an endoscope. An endoscope is a thin, flexible tube. The tube has a light and a camera at the end and is passed into your body through your mouth, nose or bottom and sometimes through a small cut in the skin when keyhole surgery is being done. An endoscope helps doctors see inside your body. Endoscopy tests can be used to help diagnose cancer. An endoscopy may be used to remove a small sample of tissue from inside the body. This is called a biopsy. When the tissue sample is seen under a microscope, abnormal cells may be identified, which can help diagnose a specific condition. If a condition is already diagnosed, it can help to assess its severity and grade. Which can also then help with decide on the most appropriate treatment.

- 1) Do you know about cancer screening? If you were invited for cancer screening, such as bowel screening, smear test or a mammogram, would you go? (Yes/No, if not why not?)
- 2) Would you attend an endoscopy appointment if you needed one? (Yes/no, If no why not?)
- 3) worries would you have about attending an endoscopy? (prompts: Are there any practical issues like how you travel to get the test, where the test takes place, taking the time off work/study, running the risk of catching covid, or not quite knowing what the test is for? How uncomfortable it might be?)
- 4) What would help you overcome your concerns and fears? (Prompts, attending with someone, clear information in advance, closeness to home, directions to the testing centre)
- 5) What would be the best way to encourage and support you to attend an endoscopy?
- 6) Would you be able to access an NHS appointment by phone or online if needed? (Yes/No) If you have What's your experience of NHS appointments online or on the phone? Have you had any issues?
- 7) Is there anything else that you would like add?

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A large, dark grey speech bubble with a tail pointing towards the bottom right, containing white text.

We engage
We reflect
We improve peoples
lives