

# Connecting with Black Communities

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Clear Solutions for engaging  
black people in Crohn's and  
Colitis research



CLEARVIEW  
RESEARCH

**CROHN'S &  
COLITIS UK**



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## About Us

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**ClearView Research** (ClearView/CVR) is an audience insight and strategy agency. We are specialists in working on research, evaluation and engagement projects with young people, minority ethnic groups, culturally diverse communities, people with protected characteristics and those who often go unheard. We are committed to ensuring that our work is always inclusive and equitable. We strive to ensure that all of our participants enjoy the research process and find it accessible, engaging, and empowering. We ensure that their voices are central in the materials (e.g., reports and frameworks) that we produce. We work best with organisations who give a damn and want to make a genuine impact.

We are proud to be a:

- **MRS company partner** that upholds and acts in a manner compliant with the strict ethical and rigorous rules contained in the MRS Code of Conduct.
- **Certified B Corporation**, which is a certification only awarded to organisations who exemplify the highest standards of social corporate responsibility, transparency, and accountability. Our Impact Business Model is recognised for its intended design to create positive outcomes for all our stakeholders and address community-oriented challenges. Our standards and values serve as a foundation for social, economic, environmental and governance best practices for businesses. We exist not just for profit but to benefit all people, communities, and the planet.

Find out more at: [www.clearviewresearch.co.uk](http://www.clearviewresearch.co.uk)

## About Crohn's & Colitis UK

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Crohn's & Colitis UK are the UK's leading charity for people affected by Crohn's and Colitis.

Every day, people are diagnosed with Crohn's or Colitis, the two main forms of Inflammatory Bowel Disease. They could be any age, rich or poor, of any faith or none, of any ethnicity, sexuality, or gender. They could be anyone walking down any UK street. Whoever they are, a diagnosis of Crohn's or Colitis will be life changing.

Right now, over 500,000 people in the UK are living with this lifelong disease that many people have never heard of. Because of the stigma and misunderstanding that surrounds these diseases, thousands of people are suffering in silence. But they're not alone. Crohn's & Colitis UK are here for everyone affected by Crohn's and Colitis.

Crohn's & Colitis UK's campaigns break the silence – changing perspectives, policies, and lives. Their work with healthcare professionals helps improve diagnosis, treatment, and management of the diseases. Their brilliant team of staff and volunteers give people essential information when they need it – and bring them together to find strength and support in one another. And their vital research grants drive pioneering research to discover better ways of managing the diseases and, one day, a cure. They are here to give people affected by Crohn's and Colitis hope, comfort, and confidence. To make sure their voices are heard and help them live freer, fuller lives.

Crohn's & Colitis UK hear from thousands of people every day so they know they can tell powerful stories about people's lives and what needs to change, backed by facts and statistics. But they also know that they are not reaching every part of the Crohn's and Colitis community. Crohn's & Colitis UK want to understand the diversity of the Crohn's and Colitis experience, so they can speak up on everyone's behalf and support the entire Crohn's and Colitis community.

Find out more at: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

## Executive Summary

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**Crohn's & Colitis UK commissioned ClearView Research to carry out a research project to gain insights into why people from black communities do not engage in Crohn's and Colitis research. The project also aimed to identify clear recommendations that would promote increased engagement with these communities.**

The research project was carried out over a seven-month period from March 2022 to September 2022. In this time, the ClearView team delivered two exploration labs, seven interviews, and one full-day ClearSprint workshop.

ClearView Research worked with a co-creation group to design the discussion guides and recruitment strategy for the interviews and exploration labs. The findings from this research were thematically analysed and arranged under the ClearView Four Pillars of Engagement.

### **Finding 1: Trust**

***Build a trusted relationship with participants through engagement, branding or reputation.***

People in black communities do not always feel comfortable divulging information about their medical diagnoses. Many of the opportunities to participate in research are promoted on social media and people from black communities with Crohn's and Colitis revealed that they are particularly unwilling to disclose their information online as they do not feel confident that it will be kept safe. Participants in our research told us that they would be willing to participate in research if the opportunities were offered by a trusted source. Organisations that are looking to engage people from black communities in Crohn's and Colitis research, where possible, should be building a trusted reputation within these communities, or working in partnership with community figures and representatives that already have established trust within black communities.

### **Finding 2: Reach**

***Meet people where they are and don't expect them to find you***

We found that black people with Crohn's and Colitis are mostly not aware of opportunities to participate in research. Many of the people that we spoke to expressed that they would be interested to participate in research but that they had just not heard about the opportunities. People mentioned an expectation that they would be invited by their healthcare professionals to join research. However, they also said that their contact time with healthcare professionals is very limited, and they will always prioritise treatment and care above conversations about participating in research.

Organisations that are looking to engage people from black communities in research should be advertising these opportunities in spaces where black communities are already engaged. One option is to work in partnership with healthcare professionals and other community representatives that are known and respected within black communities.

### **Finding 3: Interest**

***Make sure what you are asking is of interest to people and you know what interests them***

If people from black communities were able to see statistics and stories about Crohn's and Colitis that specifically related to them then they would be more likely to want to participate in research. The participants in this research reported that majority of the materials that are available do not feature people from black communities and do not include components of their cultures, specifically food. Participants in our research told us that they are sensitive to the use of stock images that feature people from black communities, so it is important that any inclusion of people from black communities comes from an authentic place. Organisations that want to attract people from black communities to participate in Crohn's and Colitis research can do so by featuring statistics and stories that are generated through authentic engagement.

### **Finding 4: Motivation**

***Incentivise participation through payment and by providing an experience that brings about feelings of pride and accomplishment.***

People in black communities, living with Crohn's and Colitis face a number of challenges around managing their healthcare. It is important that any engagement that they do in research is offered to them in a way that provides value to them and is not disruptive or extractive. Participants in our research told us that they experience challenges navigating their employment and some social commitments due to their diagnosis of Crohn's and Colitis. Any organisation that is seeking to engage black communities in Crohn's and Colitis research should ensure they are doing it on the terms that are convenient and agreeable to the people in the black communities.

## **Clear Recommendations**

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The findings detailed above that were collected from the first phase of the research, the exploration labs and interviews, were then presented to a group of participants at a ClearSprint workshop. ClearSprint participants included key stakeholders from Crohn's & Colitis UK and people from black communities with lived experience of Crohn's and Colitis. The findings from the exploration labs and interviews formed the basis of a discussion in the ClearSprint around the barriers that black people with Crohn's and Colitis experience when it comes to participating in research. These barriers were then reframed into problem statements and the participants worked individually and collectively to come up with ideas that can help to overcome these barriers.

During the ClearSprint workshop the main opportunities that were raised in terms of creating solutions for overcoming the barriers for black people with Crohn's and Colitis participating in research were:

- 1. Destigmatising the research process**
- 2. Partnerships with trusted members of black communities**
- 3. Disseminating stories widely**
- 4. An aspect of social media presence**

Participants at the ClearSprint incorporated these criteria into their prototypes that they presented to overcome the barriers that people in black communities have towards research opportunities. There were three prototypes created by the participants at the ClearSprint, featuring components of co-creation, community building and innovative ways of collecting research data that put the control of both the method and content of what was collected into the hands of the people with lived experience. These prototypes are described in more detail at the end of this report.

## Purpose of Project:

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Crohn's & Colitis UK recognises the importance of reaching ethnically diverse communities (and in particular, black people) with culturally appropriate support and engaging them in research.

However, Crohn's & Colitis UK have identified that currently there is a lack of representation of people from the black community in research related to inflammatory bowel disease. The charity aspires to drive world class research, to support population-wide understanding of Crohn's and Colitis, and to ensure high quality, sustainable clinical care for everyone. In order to do this, they are aware they need to engage more people from black communities in research to better understand their needs and how they can support them.

This research sets out to better understand the reasons why fewer black people with Crohn's and Colitis engage in research and what Crohn's & Colitis UK can do to promote more representative research.

We are aware that this project will be part of a wider programme of work taking place at Crohn's & Colitis UK to help the charity understand more about everyone with Crohn's and Colitis, which in turn will inform the aims and priorities of the charity in future. In this context, this project is a unique opportunity to build on existing evidence in this space and provide clear findings and recommendations for improving the engagement and representation of black people with Crohn's and Colitis in research.

**Crohn's & Colitis UK commissioned ClearView to conduct a study to achieve multiple objectives. The objectives of the project were the following:**

- 1. Understand the reasons why fewer black people with Crohn's and Colitis engage in research.**
- 2. Provide clear findings and recommendations for improving the engagement and participation of black people with Crohn's and Colitis in research.**
- 3. Help the charity understand more about everyone with Crohn's and Colitis, which in turn will inform the aims and priorities of the charity in future.**

## Rapid literature review

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The research team conducted a rapid literature review that covered the following.

- Barriers and challenges to research participation.
- Specific barriers and challenges to research participation for people from non-white, or ethnic minority communities, including language, communication, trust, stigma, engagement, etc.
- Facilitators to research participation, specifically for those communities who are less represented in research, e.g., black communities.
- Interventions to improve diverse communities' engagement in research.

## Specific barriers and challenges to research participation

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### Language

For some groups within black communities, there can be several language barriers that prevent black people from participating in the research. For those who do not speak English as a first language, it can be difficult to understand the research process and consent forms. Additionally, there may be a lack of culturally-appropriate information about the research, making it difficult for black people to engage in the process.<sup>1</sup>

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<sup>1</sup>Mukherjee SKM, Beresford BA, Sebastian S, Atkin KM. Living with inflammatory bowel disease: the experiences of adults of South Asian origin. Social Policy Unit, University of York. 2015

## Communication

It is essential to ensure effective communication between patients and healthcare professionals to remove any barriers that may prevent participation in research. The use of interpreters may be required for some black people with Crohn's and Colitis to ensure that they understand the research process and can ask any questions they may have. Healthcare professionals must also be aware of the different cultural beliefs and attitudes that black people with Crohn's and Colitis may hold about research to dispel any myths or misconceptions.

## Trust

There can be issues of trust amongst black communities for the healthcare system, making many hesitant to engage in the research process. The reasons behind a lack of trust for the healthcare system are complex. Historically, there have been issues within the black community of exploitation by the healthcare system, which has led to a mistrust of research. For example, the Tuskegee Syphilis Experiment was a study conducted on black men in which they were not given treatment for syphilis even after it was proven to be effective.<sup>2</sup> This experiment led to the death of many black men and caused great harm to black communities. Hesitancy of black communities to engage with healthcare is not just historic and can be linked to ongoing experiences of microaggressions and outright discrimination faced by themselves or people they know. By not fostering a relationship of trust with black communities, some black people may fear ongoing discrimination and therefore, may not engage in treatment or research.

## Stigma

There is often a stigma associated with Crohn's and Colitis, making black people less likely to participate in research. Crohn's and Colitis are often seen as taboo subjects because of the intimate area concerned and black people may feel embarrassed or ashamed to talk about their experiences with the condition.

## Engagement

In terms of engagement, many black people are approached by healthcare professionals or researchers who may not understand the specific cultural issues that black people with Crohn's and Colitis face.<sup>3</sup> This can act as a barrier to participation. This can cause black people with Crohn's and Colitis to feel disengaged and singled out from the research process.

## Awareness

It is thought that some black communities are less equipped with the knowledge and understanding of Crohn's and Colitis, their causes, symptoms and treatments.<sup>4</sup> This may be for a variety of reasons, but could be largely linked to the forms of communications and awareness campaigns that are circulated to ensure people with a variety of needs feel confident when making decisions about their care. Although this needs further investigation, a lack of awareness and understanding can

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<sup>2</sup> <https://www.cdc.gov/tuskegee/timeline.htm>

<sup>3</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3170037/>

<sup>4</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0002927099005900>

mean that many black people are unaware of the condition and therefore may not see the need to participate in research.

## Facilitators to research participation

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There are several things that facilitators can do to encourage black people to participate in research. These include:

1. Providing culturally-appropriate information about the research process. This can help ensure that black people have a better understanding of what is involved in the research process and can help build trust and confidence in the research.
2. Working with trusted community leaders and organisations to promote and explain the research. This can help increase awareness of the research as well as demonstrating its reliability or credibility.
3. Ensuring that the research is designed with the needs of black people in mind. This can help to ensure that black people feel that the research is relevant to their lives and that their needs are being considered.
4. Working with black-led organisations to develop and deliver the research. This can help to ensure that black people feel ownership of the research process and that their needs are being considered.
5. Ensuring that all communications about the research are culturally appropriate and sensitive to the needs of black people. This can help ensure that black people feel comfortable and represented, as well as trust the research process.

## Conclusion

To conclude, black people with Crohn's and Colitis face many barriers that may prevent them from fully engaging in research. These include a lack of trust, lack of appropriate information, and a lack of culturally-sensitive materials or approach. There is a need for more awareness of Crohn's and Colitis, the importance of research in these communities, and more interventions to improve communication and involvement in research. By implementing the recommendations in this literature review, we can help improve and strengthen the engagement of black people with Crohn's and Colitis in research and ultimately improve the care and support they receive. This will in turn inform the aims and priorities of the charity in future to better support everyone with Crohn's and Colitis.

## Methodology and Approach

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### Approach

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Our approach to completing this project has been collaborative, working with the Crohn's & Colitis UK team to ensure the project meets its desired objectives. As leaders in peer and community-led research, we have focussed our approach on developing a community-centred approach where we have engaged with the black community in a sensitive, equitable and culturally appropriate manner.

ClearView co-created our approach to designing the project with a group of people from black communities with Crohn's and Colitis. The members of the group were recruited through our social media channels and extensive networks. They were involved at every step of the project process from design to delivery to evaluation. Co-creation groups are a crucial part of ClearView's approach to making sure that the right questions are being asked, to the right people, using the right language. Co-creation groups also help us to validate the findings towards the end of the project.

ClearView sought to engage a range of people from black communities across the UK to discuss their everyday lives with Crohn's and Colitis and any experience they have had accessing opportunities to participate in social or clinical research. This was done through exploration labs and interviews, facilitated by ClearView, both of which are methods developed by ClearView as participatory ways

of engaging people in research. The exploration labs and interviews were conducted using a discussion guide with structured questions whilst also allowing spaces for participants to take the lead in navigating the discussion into alternative directions.

Crohn's & Colitis UK asked for this research project to provide clear recommendations for engaging people from black communities in research. Our approach to generating these recommendations was to use a ClearSprint. This is a methodology developed at ClearView that engages participants with lived experience, alongside stakeholders at our partner organisation and facilitated by the ClearView team to navigate a five-step process that takes a problem or challenge and finds solutions that are tested for feasibility. The ClearSprint is a proven method that allows participants to work independently and collaboratively to generate options for solutions to problems. The ClearSprint provides clear recommendations in terms of the key aspects that any solutions should incorporate.

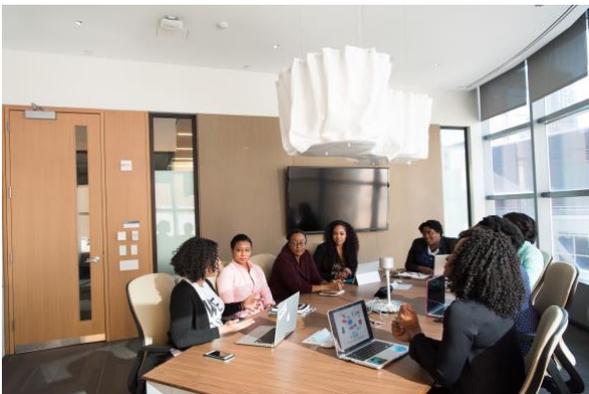
### Co-creation group

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Working with a co-creation group is a standard practice at ClearView. We recognise that it is important that research is focussed on the concerns of people with lived experience, that is why we engage with a co-creation group at the outset of the project. We recruited four

members to our co-creation group, with diagnoses of Crohn's and Colitis, from black communities.

The co-creation group met at key stages of the project, where they worked in partnership with researchers at ClearView to design the discussion guides for exploration labs and interviews, and to establish the selection criteria for the recruitment for the labs and interviews. After the ClearView team had collected the responses from the interviews and exploration labs, the interim findings were shared with the co-creation group for sense-checking and validation of expectations. The co-creation group were invited to participate in the ClearSprint and following the completion of the Sprint, there was a findings session where the outcomes from the Sprint were presented to the co-creation group, and they were able to give feedback on the solutions and offer a further level of validation to the findings.



## Exploration labs

ClearView engaged with 12 people across two exploration labs. Exploration labs are similar to focus groups, allowing participants to share their experiences, views, and ideas.

Participants were recruited through our social media channels. They were all from black African and black Caribbean communities with diagnoses of Crohn's and Colitis. We had a mix

of gender/ age groups/ geographic location in the UK and people who had and hadn't participated in research in the past.

Exploration labs lasted approximately 90 minutes and were led by one member of the ClearView team, while another member of the ClearView team took notes. Participants were made aware of the nature of the project, its purpose and how it fitted into Crohn's & Colitis UK's broader programme of work. A set of structured and unstructured questions were then asked (please see Appendix A) and participants were also told that they could contact a member of the ClearView team if they had any specific questions about the management of their information.

The exploration lab began with providing context on the aims of the project for participants, particularly revealing that this project is about the reasons why fewer black people with Crohn's and Colitis engage in research. Participants were asked to share how they had heard about the project, their expectations and why they wanted to get involved. They were also asked if they wanted to share their experiences of living with Crohn's and Colitis, and the impact they hoped that they could have by sharing this experience.

## Interviews

We engaged with seven people who have lived experience of being carers for people from black communities with diagnoses of Crohn's and Colitis. The people who participated in the interviews had experience of living with either a partner, parent, child, or a close friend with diagnoses of Crohn's and Colitis.

We decided to conduct interviews with carers, as we were keen to hear about the day-to-day perspective of living with someone from black

communities who has a diagnosis of Crohn's and Colitis.

Similar to the exploration labs, the interviews began by providing context on the aims of the project for the interviewee, particularly revealing that this project is about the reasons why fewer black people with Crohn's and Colitis engage in research. Interviewees were invited to ask any questions they had about the project before proceeding with the questions from the discussion guide.

The interviews were conducted by a member of the ClearView team, using the same discussion guide as the exploration labs. The decision to use this guide was made with the co-creation group. Using the same guide enabled us to compare the responses that carers and people with diagnoses of Crohn's and Colitis made to the same questions.

## Thematic Analysis

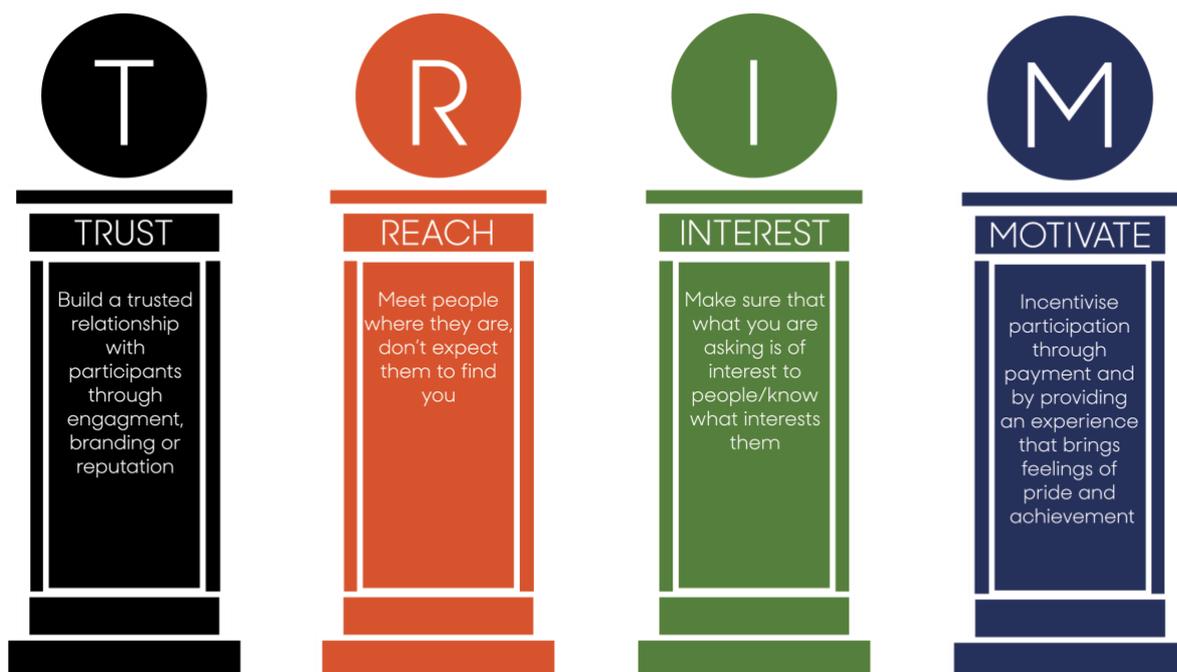
The findings from the interviews and exploration labs were analysed to understand why few black people engage in research. The ClearView team found that the responses from the participants aligned very closely with the ClearView Four Pillars of Engagement:

**Trust:** build a trusted relationship with participants through engagement, branding, or reputation.

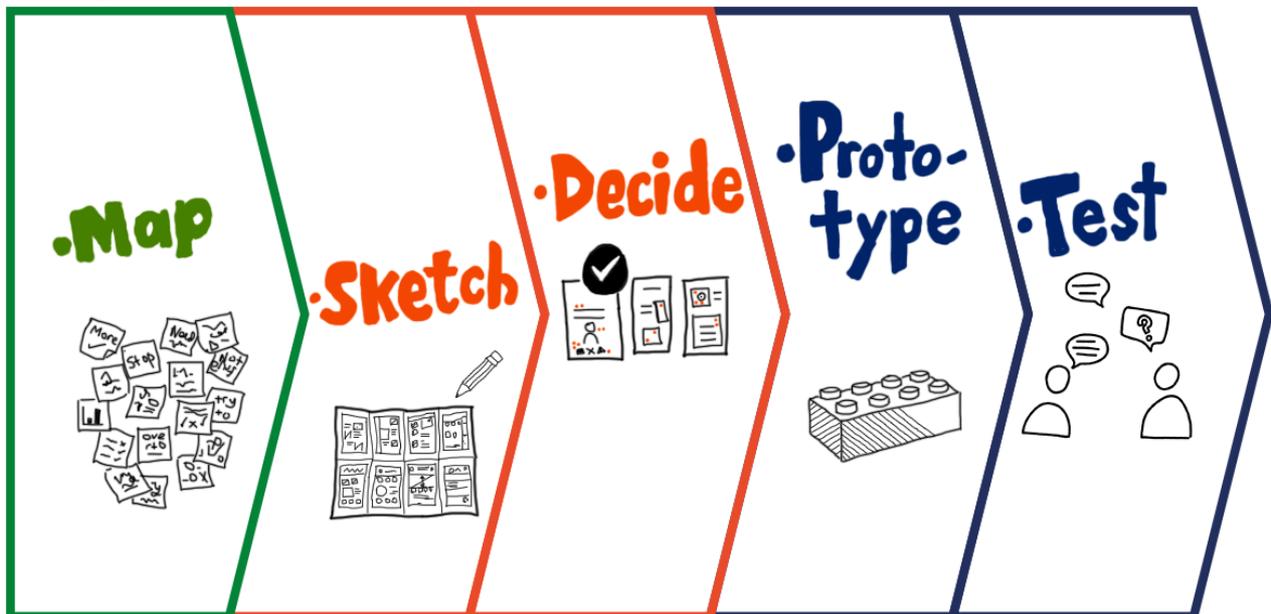
**Reach:** meet people where they are and don't expect them to find you.

**Interest:** make sure that what you are asking is of interest to people and you know what interests them.

**Motivate:** incentivise participation through payment and by providing an experience that brings feelings of pride and accomplishment.



## ClearSprint



A ClearSprint is a proven design thinking methodology that allows participants to work independently and collaboratively to generate options for solutions to problems. It is a 5-step process, using design thinking methodologies that enables us to test Big Ideas in order to make strategic decisions about where to invest more time and money to pursue concepts and ideas.

A ClearSprint is a five-step process incorporating the following:

**Map** – where all the information relating to the topic or problem is brought together and put on the table for consideration. During the mapping phase the group considers what are the most pressing or priority aspects of the challenge and focus in on those to establish where to pay most attention for the next phase.

During our ClearSprint, we began with a presentation of the findings from the Interviews and Exploration Labs. This informed the workshop participants of the reasons why fewer black people engage in research opportunities. Participants then mapped out a list of all the factors that are currently working in the favour of bringing more black people towards research opportunities, followed by a list of all the factors that are holding black people back from participating in research. The list of factors holding people back were mapped out and participants voted on the most priority of these to reframe into 'How Might We' statements to consider how to resolve them as problems. The problem resolution came in the next phase:

**Sketch** – during the sketching phase, all participants are tasked with sketching and drawing and taking notes in reflection of what has been discussed in the mapping phase. Each participant then sketches out a proposed solution to the highest priority problem that was identified in the mapping phase.

For the ideation phase, participants were asked to write down all their reflections from the introductory segments. They then sketched out solutions in response to the problem that had been framed in the mapping phase.

**Decide** – in this phase, the group looks at each of the solution sketches that have been presented in the second phase and they identify the aspects of the individual sketches that they like the most. All the Solution Sketches were put up in the workshop and in the virtual space where participants voted on the most popular and priority aspects that should be taken forward to the prototyping phase.

**Prototype** – here the participants form groups that work on developing a solution that incorporates each of the criteria that were set out in the previous phase. The principles for producing the prototypes are that they should appear real and convey the main ideas of the prototype, but that finer details shouldn't necessarily be included and that the prototype can expect to be disposed after the Sprint. During the prototyping phase, participants formed groups and produced prototypes that responded to the key criteria that were established in the voting phase.

**Test** – this is an opportunity for the participants to present their solution and to capture feedback from key stakeholders. Three prototypes were created and these were pitched to the whole group who provided feedback on the solutions and recommendations for taking forward to real world events.

The Sprint approach enabled us to co-create ideas for engaging black people in the research process and capture feedback on the solutions. The advantage of the Sprint methodology is that it gets everyone - those with lived experience and those from the organisation - mapping out the problem based on their expertise. From these problems, they then generate ideas to solve the problem and create rapid prototypes all in one day. This enables the group to assess what the best avenues are for pursuing future engagement and investment. This beats conventional approaches where teams can often spend months coming up with ideas that ultimately are rejected by the target group who deem the initiatives to be unsuitable.

### **Reporting and next steps**

After the Sprint was completed, the findings were organised by the ClearView team to feed into the final report. The prototypes were shared with members of the co-creation group who were unable to participate during the Sprint and they gave their feedback on the prototype solutions.

The ClearView team organised the findings from the Sprint alongside the analysis from the exploration labs and interviews to produce a set of recommendations. The recommendations offered cover both short and long term actions that can be addressed by both Crohn's and Colitis UK and the wider research community.

## Key Findings

### T.R.I.M.

The ClearView Four Pillars of Engagement is a framework for engaging with people from communities that are underrepresented in research. It is unsurprising, therefore, that through the interviews and exploration labs, these four pillars also emerged as enablers to engaging in research for people from black backgrounds with diagnoses of Crohn's and Colitis. We have organised the findings from our exploration labs and interviews during the Crohn's & Colitis UK research under these headings of the ClearView Four Pillars of Engagement to produce an actionable framework that includes specifics to engage people from black communities who have Crohn's and Colitis.

For each of the ClearView Four Pillars of Engagement we will identify responses from the exploration labs and interviews that reveal insights around why fewer black people engage in research with Crohn's & Colitis UK.

### Trust

**When appropriate measures are not taken to build trusted relationships with people from black communities who have Crohn's or Colitis this creates a barrier to engagement.**

The people we spoke with during our research, people from black communities with Crohn's and Colitis and their carers, spoke about a long history of mistrust towards the medical professions by black communities in

the UK. They said that this is built on personal and passed down stories of experiences of black people being treated unfairly in healthcare settings. They felt that this leaves many black people believing that they will not be treated fairly when they attend medical appointments.

**“It helps to have someone you can relate to going through these kinds of things and also reduce the suspicion because I think black people in general are quite suspicious of the medical profession in general. Like, I mean, the whole COVID situation is a prime example. I know a lot of black people, especially within the community, say that we're convinced that vaccines will be different and that we try and do experiments, handoffs and stuff like that. And you know, it sounds really silly, but historically, the medical profession doesn't have a very good reputation for treating black people very well. And some people, as I said, especially the older ones, still hold those views. And it doesn't help when you went in to get medical treatment and then you actually go to a doctor or**

**a hospital and then you aren't necessarily treated the way you'd like to be treated.”**

*(Jill, female, East Midlands, Black Caribbean English, 35-44, Carer for someone with Crohn's/Colitis.)*

**Fears about their personal information not being protected also prevents people from black communities with Crohn's and Colitis from engaging with research. This is especially the case when registration forms or engagement is online.**

Many of our participants told us that they are hesitant to share their personal information and their medical diagnosis on the internet, especially when links appear across social media platforms, as they do not trust that the information will be kept securely. People said that they found that the opportunities to participate in research would usually begin with a form to fill out that asked for a comprehensive list of personal information. Many were put off by needing to share this level of detail for fear it would get leaked or exposed. This prevents them from registering their interest and joining the research.

**“I think we would want to engage in stuff like that more if we are assured of the anonymity and we aren't going to be exposed, so you know social media is like a place everyone is afraid of their privacy and security ... we just want to be assured that we are going to stay anonymous and that none of our data is going to be exposed to the public.”**

*(Kelly, female, SE England, Black African English, 18-24, Crohn's)*

**“The ability to be confidential goes a long way. There's definitely a culture of keeping yourself to yourself, mind your business, so on and so forth ... knowing that they're not required to provide a lot of personal details might go a long way ... removing some of those barriers of details you don't need to provide and just have details you do need.”**

*(Simon, male, West Midlands, Black Caribbean British, 25-34, carer for someone with Crohn's/Colitis)*

It may be that if organisations have better trusted relationships with people from black communities then inputting this level of personal information may be less of a barrier. However, it also is worth research organisations reflecting on how much information they need upfront on engaging research participants as to not extract unnecessary information.

## Reach

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However, trust alone is not enough, if potential research participants are not aware of the opportunities that exist then no matter how much they trust the organisation offering the opportunity they will not have the opportunity to participate.

**We found that there is a serious lack of awareness about research opportunities amongst black people who have Crohn's and Colitis.**

Many of the people that we spoke to explained to us that it is not necessarily that they are not interested or willing to participate, but that they had not heard about or seen any of these opportunities for participating in research.

**“I guess all I can say is that it's just really not seen, and it's not that we see opportunities and are thinking that doesn't really appeal to us. It is just full stop we just do not see any opportunities.”**

*(Mario, male, South East England, White/Asian British, 25-34, carer for someone with Crohn's/Colitis)*

Organisations need to do sufficient outreach to make sure that people are being reached with the opportunities to participate in research. This may involve building links with community leaders or thinking differently about communications and awareness raising campaigns.

**When people do see opportunities there is often a lack of understanding around the type of research opportunities that are available to black people who have Crohn's and Colitis**

Of the people who had done some research around the opportunities to participate in research, there was some confusion about what sort of engagement the research opportunities were offering. Some participants spoke about the expectation that engaging in research would entail visits to laboratories and contact with people in 'white coats.' Participants expressed hesitancy at the idea of being tested on or visiting laboratories and therefore did not pursue these opportunities, even though this is not what was on offer.

**“You have to come to the lab like you have to come to a visit and you know. If the person is not my doctor or my health practitioner, talking about my illness like one on one to the person, I'll kind of feel uncomfortable and it will feel like I'm exposing myself.”**

*Cindy, female, London, Black African English, 25-34, ulcerative colitis*

Crohn's & Colitis UK needs to work on their messaging to ensure that people understand the purpose of the research opportunities they are offering. Crohn's & Colitis UK can also support their partners to produce clearer messaging when offering opportunities to participate in research.

**There is an expectation that opportunities to participate in research would be made available to people during their contact time with healthcare professionals.**

The majority of participants expressed that they had not heard about these opportunities through their healthcare provider. They said they would be keen to get involved in research opportunities if they came from healthcare providers who are considered a trusted source of information. Participants felt that this was an untapped way into research, as they are regularly in contact with their healthcare providers and could use that space to ask more questions about the research itself.

**“I think with my specific care I am I'm seen at a hospital every say three to six months. So I go, I have a blood test or speak with the consultant there and the Crohn's**

nurse and, to be honest, I think that to me, is my most you know, like authoritative source of information and they've never told, let me know about any Crohn's research or anything like that I don't know if that's something that happens, through hospitals, because I've been seeing them for a few years and then never told me of anything.

*(Kristen, female, London, Black Caribbean British, 25-34, Crohn's)*

By linking in with healthcare providers and providing them with information resources about upcoming research opportunities, Crohn's & Colitis UK may be able to better reach a diverse population of research participants.

**Contact time with healthcare professionals is precious so people prioritise discussing their treatment options over and above potential opportunities to participate in research opportunities. Although healthcare professionals could act as a good way into research, Crohn's & Colitis UK need to be wary of not taking over that space.**

Typically, participants were interested in using the space they have with their healthcare provider to ask questions about research opportunities. However, they found these appointments were too short and filled with other priorities around managing symptoms and treatments. This is unfortunate because there is a motivation to participate in opportunities, but people feel they are not able to explore the options in more depth with their trusted medical professional.

**"I don't know if it's more specific to our area because it's so busy or if it's just a general problem as a whole. But what obviously tends to happen is when you do get an appointment, it's like gold dust and you really get the sense that they need you in and out as quick as possible. And so obviously, when you go in and because of time related issues, your focus is you need to get as much info as you can to do with how to deal with what's going on. It's not going to be on your mind to ask them, do you have any research opportunities as well?"**

*Mario, male, South East England, White/Asian British, 25-34, carer for someone with Crohn's/Colitis*

Currently, Crohn's & Colitis UK do have healthcare professionals they work closely with. This research shows that healthcare professionals are a key group that could be used to increase engagement with Crohn's and Colitis patients. This points to a key opportunity to engage these healthcare professionals in providing information and signposting to research opportunities if they have the time to do so.

## Interest

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**Stories and statistics that specifically relate to people from black communities will encourage people to engage in future research.**

We were told that black people did not see themselves represented in the statistics and stories associated with Crohn's and Colitis. This made some people feel like there was a narrative that black people don't get Crohn's and Colitis. As a result, this made some people feel hesitant to participate in research opportunities for fear of standing out or not being understood.

**“I think it definitely would draw my attention more ... I'm looking at these advertising materials and it's an only Afro-Caribbean people. If it was just a broad, the range of representation across the board, white people , Asian people , black people . But as I said, a lot of things in adverts, you say it's very much white people unless specific conditions that target ethnic minority communities such as diabetes and high blood pressure. We've got certain things that are specifically targeted for us, and it kind of distracts from the fact that actually we do have other health conditions and we don't specifically have these two things that just target our community. Like I think across the board, advertising and representation could be a lot better than what it is.”**

*Jill, female, East Midlands, Black Caribbean English, 35-44, Carer for someone with Crohn's/Colitis.*

Crohn's & Colitis UK should be doing more work with people from black communities to share stories that help people feel included.

**It is essential that content is authentic. Using stock imagery of black people to tell stories that lack this authenticity will not promote engagement from people from black communities.**

People told us that although they were keen to see representation of black people in Crohn's & Colitis media, they were clear that these statistics and stories must be accurate and authentic portrayals. People told us that they are sensitive to instances where stock images of black people are used in media that are not accurate or authentic portrayals of real people used in media that are not accurate or authentic portrayals of real people.

**“Honest visuals , yeah , you want people that look like you ‘ordinary’ ... but we're in a generation where it's the norm to find stock footage of what you're looking for. If you could get somebody to actually participate, taking direct quotes as well might go a long way. I imagine that people from those backgrounds will say exactly what they would need to hear.”**

*(Simon, male, West Midlands, Black Caribbean British, 25-34, carer for someone with Crohn's/Colitis)*

Crohn's & Colitis UK should be taking the time to speak directly to people from black communities who have lived experience of Crohn's and Colitis, and platforming their stories so that other people can see people

who are like themselves, sharing stories similar to theirs.

## Motivate

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**People with Crohn's and Colitis who show willingness to support others should be supported to do this in a way that doesn't cause a detriment to the management of their own care.**

Many people living with Crohn's and Colitis told us that they felt an overwhelming sense of obligation to offer their support to people who are newly diagnosed or awaiting a diagnosis. However, people living with Crohn's and Colitis are dealing with their own challenges around managing their health. Any involvement in research needs to be accessible, compensated and non-extractive.

**“People really don't understand how it impacts everything, even mentally, how my wife feels from day-to-day fatigue, all sorts. And then on top then it can be a vicious cycle because stress and worry and whatnot can make the symptoms flare up that often causes stress like will I lose my job? Will my boss not understand? I've had to keep going to the toilet all throughout the day, are they going to think I'm just not trying at work?”**

*(Mario, male, South East England, White/Asian British, 25-34, carer for someone with Crohn's/Colitis)*

**“What I'm trying to say ... I feel like anyone who is just recently**

**diagnosed with this deserves to be you know, really, really pampered and just taken care of. And I don't know I just feel I know what I went through when I got diagnosed ... I felt like I had an obligation to participate in this research study to give my opinion.”**

*(Kelly, female, SE England, Black African English, 18-24, Crohn's)*

## ClearSprint Solutions

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### Setting the tone:

The Sprint began with a presentation of the findings from the interviews and exploration labs with a focus on the ClearView Four Pillars of Engagement. After each pillar was presented, we opened up discussion to people in the room and in the virtual space. This discussion provided solidification of the findings, as participants in the room backed up the points with further evidence and explanation towards the points.

### Sailboat Exercise:

Participants were asked to contribute as many challenges or problems that prevent black people from engaging in research.

**During this exercise, the key problems that both groups chose to focus on were related to aspects of community and a sense of belonging.**

People felt that there was a lack of connection between the community of Crohn's & Colitis UK and communities of black people who have Crohn's and Colitis.

Some of the suggested 'barriers to engagement' included:

**“People don’t feel represented or don’t see themselves in our work”**

**“Cultural barriers – cultural representation and language”**

**“Lack of trust”**

**“A genuine heartfelt care towards the intent of including black people”**

In order for Crohn's & Colitis UK to make research opportunities more inviting for people from black communities, they need to focus on three of the four pillars from the ClearView Four Pillars of Engagement, namely trust, reach, and interest. By understanding what interests this community and knowing how and where to reach them, Crohn's & Colitis UK can start building trust and connection. This will in turn improve overall engagement with these communities.

**The ClearSprint also identified that the research opportunities that Crohn's & Colitis UK are presenting do not attract people from black communities because of cultural and language barriers.**

The points that were raised in the Sailboat Exercise were discussed and consolidated into a series of 'How Might We' statements that captured the main aspects that needed to be addressed. The online group and the in-person group each discussed and agreed on the 'How Might We' to carry forward to the ideation phase. The barriers identified to be taken forward were:

**‘How might we remove barriers, including cultural and language barriers, for black people in order to make getting involved in research more appealing?’**

*From the in-person group.*

**‘How might we use a trusted group to make sure people are involved and not extracted from?’**

*From the online group.*

It was recognised that the current methods that Crohn's & Colitis UK use to advertise opportunities are not generating reach or interest for people from black communities. It was agreed that Crohn's & Colitis UK can address this by improving the language and cultural representation on their platforms. This is a key engagement opportunity that is currently being missed.

### **Sticky Decisions**

During the final sketching activity, participants developed proposals for solutions to the 'How Might We' exercise. These proposals were stuck up around the room and in the next phase they voted on the aspects that would be carried forward to prototyping. The key aspects that people voted on reflect the priority areas that Crohn's & Colitis UK should focus on to begin building better engagement with people from black communities.

**Dismantling barriers for engagement in research opportunities for people from black communities needs to be done in partnership with community leaders who are trusted. By building solutions in partnership with black communities, the solutions will**

### **align with how people from black communities choose to participate.**

Participants felt that promoting a sense of community and belonging was key for dismantling barriers to research engagement. These criteria demonstrate the importance of working in partnership with people and communities in order to make them feel comfortable and inclined to participate in research.

The items that were included in these sketches included:

**“An aspect of social media presence”**

**“Sharing stories widely”**

**“Destigmatising research”**

**“Partnerships with trusted members of black community”**

**“As more people assist with research, feedback should include FAQs that cover common issues that are brought up and how they can be addressed.”**

**“Equal partnership and codesigned with equal status”**

**“Once we have achieved more roll out – cultural competence training for staff delivered by black people”**

Crohn’s & Colitis UK should be considering each of these aspects when they are looking to promote opportunities for more black people to participate in social research.

## **Prototypes**

### **Equal Partnership:**

The Equal Partnership project was developed by the participants who joined the ClearSprint virtually. The group designed an outline for the formation of a co-creation group made up of people from black communities with diagnoses of Crohn’s and Colitis. The co-creation group would set the agenda for how to reach audiences and ask the right questions in order to establish ways to promote better participation for black people in research.

This project tells us that there is a strong sense of trust in the ability of people with lived experience to identify and capture the solutions that Crohn’s & Colitis UK are seeking. Therefore, it is crucial that Crohn’s & Colitis UK are committed to co-creation in any community engagement work they do.

### **#CrohnsandColitisonCam**

The #CrohnsandColitisonCam project was developed by one of the groups in the workshop room. It is a photo ethnography project that puts the research into the hands of people who have lived experience of Crohn’s and Colitis and are from black communities.



This project showed us that participating in research can be framed in a way that is fun

and creative and will bring an understanding around the everyday lives of people who have Crohn's and Colitis without being invasive or extractive. Crohn's & Colitis UK should be working with people in black communities to identify options for engaging in research that allow them to be in control of the information that they share and also to ensure that the participation is something they enjoy and allows them to express themselves creatively.

### **Building a Community:**

The 'Building a Community' proposal was developed by a group in the workshop space. The objectives for the project were to generate access into research by creating a community that was inclusive for black people with Crohn's and Colitis.

**Proposal:** 6 x virtual events per year co-designed by the co-creation group and Crohn's & Colitis UK

### **Why?**

- Building Trust
- Sharing Experiences
- Sharing Stories
- Building a Community
- Destigmatise Research

### **How:**

- Build awareness through social media, blogs, direct marketing, trusted leaders
- Q&A sharing including offline (mag)
- My Journey videos
- Remunerate co-creators

The 'Building a Community' project reiterated the importance of producing initiatives for engagement in partnership with the people who will be using them. By having a space to allow black people with Crohn's and Colitis to share their experiences and stories, this creates a community that is built on trust and shared experiences. Crohn's & Colitis UK should be seeking to work alongside communities to support the facilitation of creating spaces where people from specific communities, in particular black communities, can access opportunities to meet other people like them and share their experiences.



### **Conclusion from ClearSprint:**

- Important that there is a drive and interest at Crohn's & Colitis UK to make the change happen – it is evident from the participants in the workshop that the drive exists, which is a huge advantage for taking the ideas forward.
- Progress towards building trust and engaging black people in research cannot be done without the involvement of people with lived experience. It is crucial that this is authentic involvement and co-created.

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## Conclusions

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### The Conclusions are the following:

1. **Application of the ClearView Four Pillars of Engagement is essential for the effective engagement of people from underrepresented groups in research.** In order to engage any group in the future, Crohn's & Colitis UK or any other organisation will have to consider how the ClearView Four Pillars of Engagement apply to the group they are trying to engage. This is strongly supported by the findings from the interviews, exploration labs and ClearSprint. Crohn's & Colitis UK should be making the application of the ClearView Four Pillars of Engagement a priority for any future engagement work with diverse groups of people.
2. **It is important to think of the particular group you are trying to engage for the ClearView Four Pillars of Engagement to be effective.** This research showed how this tool can be applied to people from black communities, but it is crucial to not

think of black communities as a homogenous group. For example, the discussions that we had during this research showed that people from varying age groups will interpret trust differently.

3. **An engagement process that is culturally sensitive and inclusive will attract more people from black communities to participate in research opportunities.** People from black communities are looking to engage with organisations that have welcoming and inclusive pathways to participate in research opportunities. They are particularly keen to engage if organisations and healthcare providers understand their particular needs and how to engage with them appropriately.

Organisations that are interested in engaging people from black communities in Crohn's and Colitis research should develop pathways that are culturally sensitive and

inclusive. This is particularly important for early diagnosis initiatives.

Using the CVR Four Pillars of Engagement Framework, and the insights particular to each pillar as presented in this report, organisations can build engagement strategies that will support more positive engagement with people from black communities who have a diagnosis of Crohn's and Colitis. (please see example engagement plan in appendix)

- 4. More people from black communities would be encouraged to participate in research if the process appealed to their particular interests.** People are not keen to give up their time to participate in research processes that are tedious and extractive. People are also put off by the term 'research' and feel that it treats them as subjects to be studied. Participants in our research told us that their time is precious, and they are not willing to engage in research methodologies that do not meet their interests or enjoyment.

There should be a variety of ways for people to get involved in research,

including ways that put them in control of what data is collected and enable them to choose how their stories are shared.

The use of the term 'research' should also be reconsidered. Alternatives could include 'gathering insights', 'experiences', 'perspectives', etc. It is often useful to engage a co-creation group at the beginning of any research study to help you design the research and how you speak about it.

- 5. Any work that features stories and statistics about people from black communities needs to be told using honest visuals and language.** People from black communities are sensitive to the use of stock imagery and they are able to see whether the accounts and stories that are being told are coming from a place of authenticity. In our research, we were told by some people that when they see statistics and stories featuring people from black communities, they will look at the source of who is telling the story and question its authenticity.

It is important that when organisations are platforming the stories of people from black communities, that these stories are told in partnership with people from black communities, so that authentic stories can be told.

- 6. It is essential that co-creation is embedded at every stage of the approach to designing, delivering, and evaluating research initiatives.** Co-creation is important to ensure that the people who are going to be using services have control over how these services are created and that they reflect the needs and desires of these users. Throughout this research project, ClearView has engaged a co-creation group of people from black

communities with lived experience of Crohn's and Colitis.

This group has produced a series of recommendations that can help Crohn's & Colitis UK better understand how to engage people from black communities in research opportunities.

Crohn's & Colitis UK, and other organisations that want to engage people from black communities in Crohn's and Colitis research, should always engage with people with lived experience to ensure the research opportunities are inclusive and reach a more diverse audience.

## Recommendations

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Throughout the engagements, it was clear that participants wanted to be involved in decisions that were being made about them. To ensure outreach, engagement and research studies themselves are empowering and non-extractive for people from black communities with diagnoses of Crohn's and Colitis, Crohn's & Colitis UK should consistently engage a co-creation group. This should be made up of people from black communities who have lived experience of Crohn's and Colitis. The following recommendations should be read with this level of collaboration in mind.

### The recommendations for Crohn's & Colitis UK are the following:

- 1. All of the materials that Crohn's & Colitis UK produce should be created in partnership with a diverse co-creation group to ensure that the content and the messaging is relevant, informative and appealing to diverse audiences.** Crohn's & Colitis UK should be having regular meetings with diverse groups of people who have lived experience of Crohn's and Colitis to give them the opportunity to talk about their specific needs and what matters to them. Our participants told us that language and messaging are key to attracting black people to engagement opportunities. It is crucial that Crohn's & Colitis UK are working in partnership with diverse communities to ensure their engagement opportunities are landing with and appealing to the people they want to reach.
- 2. Crohn's & Colitis UK should take forward at least one of the prototypes that was generated during the ClearSprint.** The three prototypes that were presented during the ClearSprint each represent an opportunity to engage black communities in research at Crohn's & Colitis UK. The team at Crohn's & Colitis UK should maintain some of the momentum generated at the ClearSprint and carry forward at least one of the prototypes to completion. The groups at the ClearSprint demonstrated several ways of engaging black communities in research and these concepts should be embraced by Crohn's & Colitis UK. The team at Crohn's & Colitis UK must ensure that the concept they proceed with is built in direct partnership with members of black communities.
- 3. Crohn's & Colitis UK, having already stepped forward and taken a positive step in this space, should see themselves as ambassadors in diversity and representation in research**

**and continue to grow their advocacy in this space.** As the leading charity for Crohn's and Colitis in the UK, Crohn's & Colitis UK holds a position of influence and can make a real difference by advocating for diversity and representation in research. During the ClearSprint, members of the Crohn's & Colitis UK team demonstrated cultural competence working alongside members of black communities to develop clear recommendations for engaging people from black communities in research. Crohn's & Colitis UK should be building on this experience by creating opportunities for people across the organisation to work together with people from diverse communities to create solutions for engagement in research. These experiences should be talked about and shared widely, especially in the Connect magazine produced at Crohn's & Colitis UK.

### The recommendations for the wider audience are the following:

- 4. The ClearView Four Pillars of Engagement should be applied to all engagement activities, considering each different group that will be engaged and making a plan that is specific for each one.** The ClearView Four Pillars of Engagement are a proven tool for engaging diverse communities. This research project shows that the audience Crohn's & Colitis UK are seeking to reach are interested in engaging with organisations that understand their culture and their needs. It should be noted that within black communities there is a significant diversity in cultural attitudes and lifestyles. An approach that suits people from black African communities may not meet the interests or preferences of members of the black Caribbean communities. Organisations will need to be adaptive with their application of the ClearView Four Pills of Engagement, by working in partnership with diverse communities to establish the most appropriate engagement strategies to meet the specific needs of the people they are trying to reach. (please see example engagement plan in appendix)
- 5. Organisations looking to engage diverse audiences in research should use the barriers identified by participants as the basis for programmes of work to address gaps, going forward.** During the ClearSprint mapping, a total of 78 barriers were identified by participants in the workshop as barriers that prevent black people from engaging in research. These barriers have been organised and included in the appendix in this report.

These barriers should be explored further and a programme to address them put in place to better engage people from black communities and improve diversity in research.

## Appendix

### A. Interview and Exploration Lab Discussion Guide

Q1. What preferred mediums/channels would encourage engagement and participation in Crohn's and Colitis research? and why?

Q2. How, if at all, does the area you live in affect your access and awareness to participating in social research?

Q3. Would statistics and stories specifically related to people with Crohn's & Colitis from Black communities help you engage with future research?

Q4. Has lack of cultural awareness around diagnosis and managing the disease within the healthcare service/wider community during your Crohn's and Colitis diagnosis affected your decision to engage, participate and/or seek research?

Q5. What have been your experiences since being diagnosed with Crohn's or Colitis? And has that impacted your decision to participate in research?

Finally, if we could give you a magic wand, what would you do to make participating in Crohn's and Colitis research better for Black communities?

Is there anything else you would like to know or learn about Crohn's and Colitis?

### B. List of barriers

MEDICAL COMMUNITY	Crohn's & Colitis UK	UNMET NEED IN BLACK COMMUNITIES	REACH
Lack of perceived care/ compassion	lack of awareness as to who Crohn's &	taboo topic	not reaching people where they are

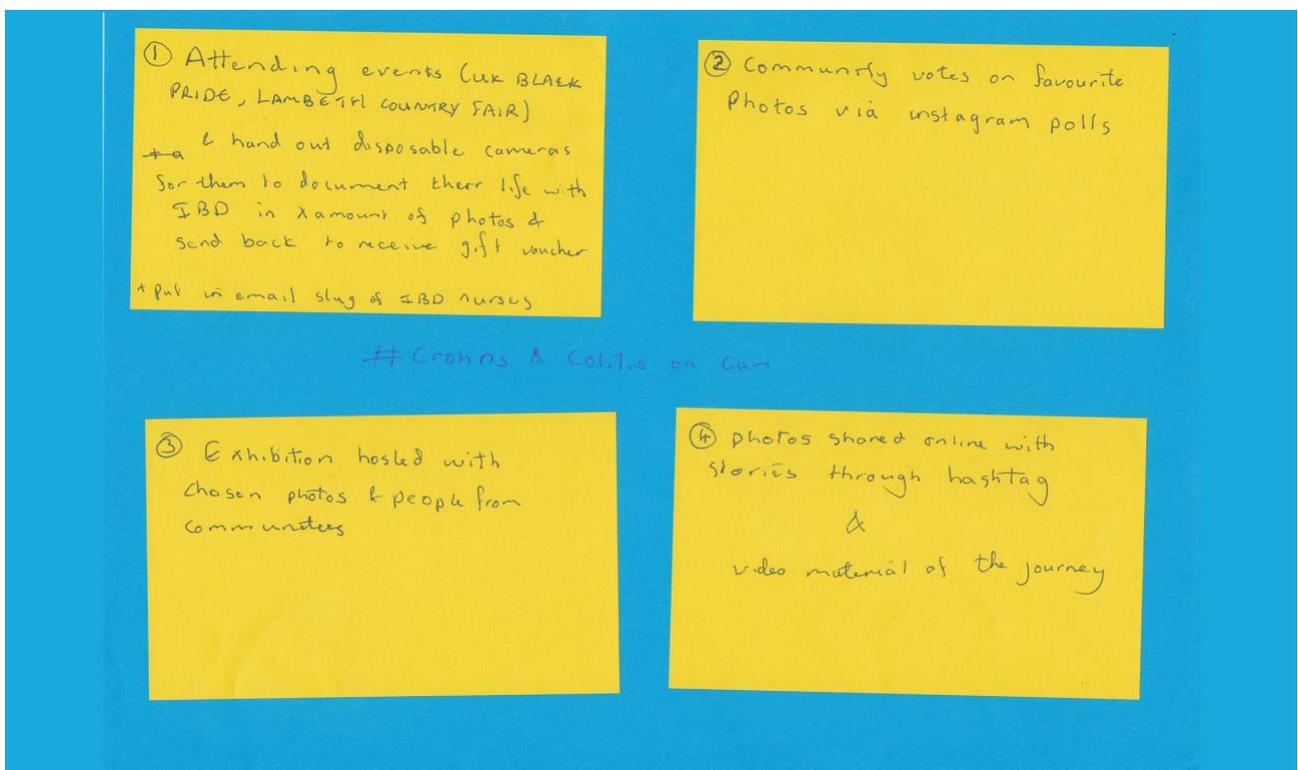
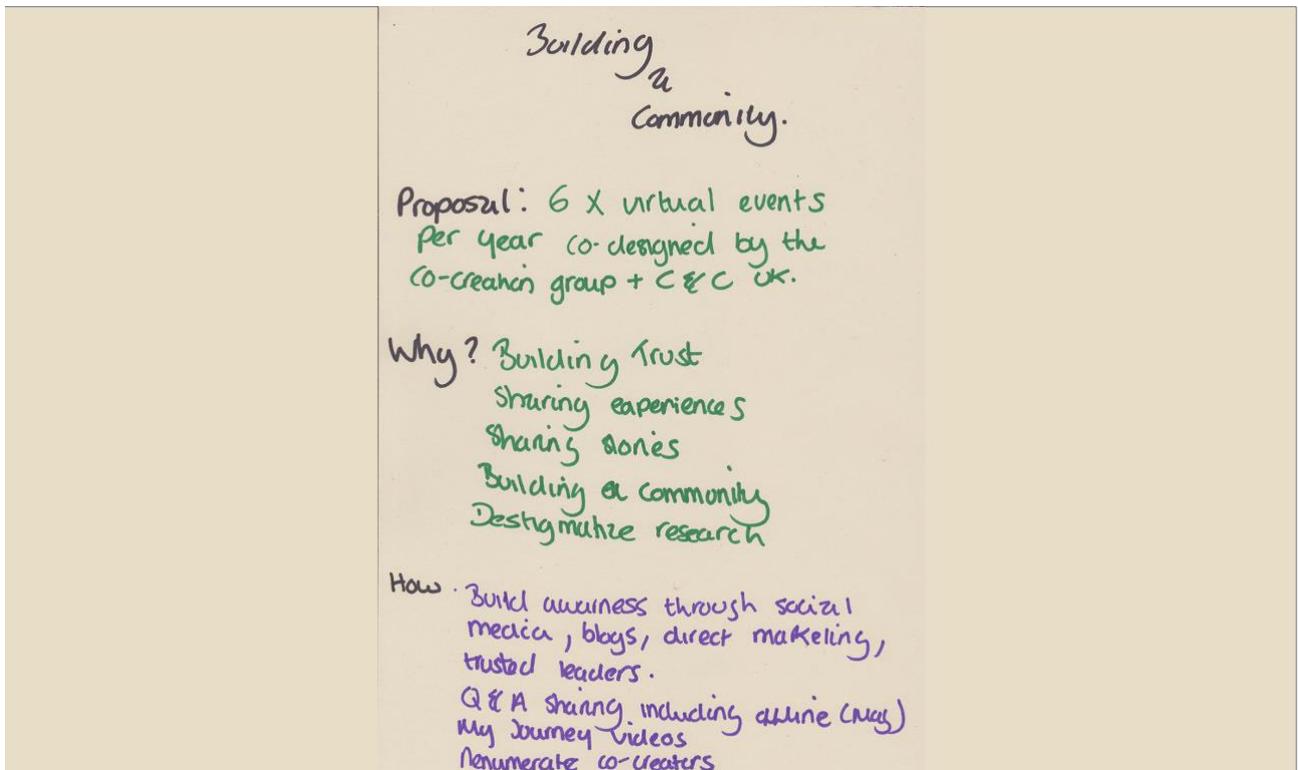
from medical practitioners	Colitis UK are and the aims of the charity		
Fear of medical profession	mistrust	mistrust of word research: loaded term	We need to look into how we go to where people are
people from black communities do not trust medical professionals to treat them equally	representation of black people in the charity needs to improve	trust	misunderstanding amongst peers
raising awareness of support and help available at hospitals when diagnosed or via IBD nurses	not enough authentic representation in comms from charity	the perception that Crohn's and Colitis is a European disease	Broker conversations through existing trusted relationships
fear of doctors/medical profession	finding people to share their experiences and encouraging others to get involved in research	adapting language, e.g. from research to insights	Targeted media/engagement that works with black communities
healthcare professionals lack of time	finding people to share their stories and experiences	knowing the right language to use	Knowing who the key community/faith leaders are to engage
black people employed to help deliver the work	Limited understanding of what needs to change across our entire organisation	minority means smaller voices	improving knowledge and information provided through cultural sensitivity e.g. food advice
staying mindful of patient journey	not enough success stories/ happy testimonials of previous survey experiences etc	cultural taboo in discussing the disease and its impact	building a genuine connection through help and support

targeted medical engagement that works with the community	Not enough representation of cultural diversity among the team conducting	language and cultural barriers - known and unknown	minimise the personal information required to participate in research
medical appointments are rushed so there is no chance to discuss research opportunities	lack of awareness as to the black culture	worry about public perception	one size fits all
	working with black people to better understand/address how we can gain their trust	poor health - lack of energy to do anything other than survive when in a flare	asking people at the wrong time
	limited time and resource with lots we could focus on	fear of exposure/anonymity - being made into a case study	lack of opportunity for black people only
	not getting opportunities in front of people and at the right time	presenting the story - the reason why I should be involved	painting everyone with the same brush
	a lack of understanding of effective comms channels	not wanting to be used as a tickbox	a lack of understanding of the diverse cultures within black communities
	go beyond a strategic aim 'conviction'	previous negative experiences	Genuine heart care
	people don't feel represented and don't see themselves in our work	cultural attitudes towards cleanliness and ill health	knowing who to ask to participate

	funding	fatigue of being asked to be involved in things due to background	robust qualitative and quantitative research
	people don't see themselves in our materials	Lack of trust in organisation/ researchers	word of mouth or social media groups with a large concentration of black individuals
	lack of stories and quotes from black people who have been involved in research		language around research
	lack of representation leads to lack of involvement, so we need to start somewhere		people don't know about opportunities to engage in research - lack of reach
			avoiding tokenistic involvement and making it meaningful
			trust
			language barriers
			unfriendly language
			cultural barriers (example of food given previously)
			Facebook page that invites people of colour to participate in research



D. Images of Proposals from Sprint



# ALL STAR ACTION PLAN



- ① FOCUSED ON THE END GOAL OF IMPROVING LIVES, CARE & SUPPORT, CLEAR ACTIONS DEVELOPED ACROSS CROHN'S & COLITIS UK THAT BUILD TRUST, REACH, INTENT & MOTIVATION

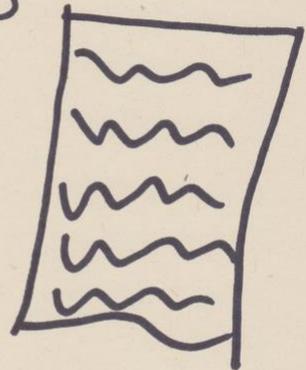
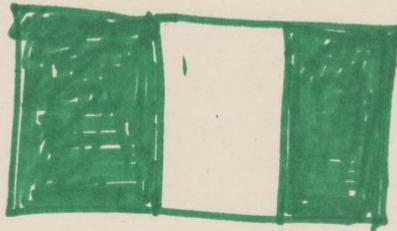
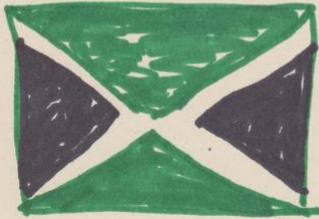


- ② LANGUAGE GUIDE - WHAT LANGUAGE SHOULD & SHOULDN'T BE USED. CULTURAL GUIDE DEVELOPED TO BOTH SUPPORT STAFF.

- ③ PROJECTS ACROSS THE UK TO USE & TEST LEARNING, E.G. WORKING WITH IBD TEAMS TO PROMOTE RESEARCH AT THE RIGHT TIME.

- ④ SHARE STORIES WIDELY!!

# Breaking Bread

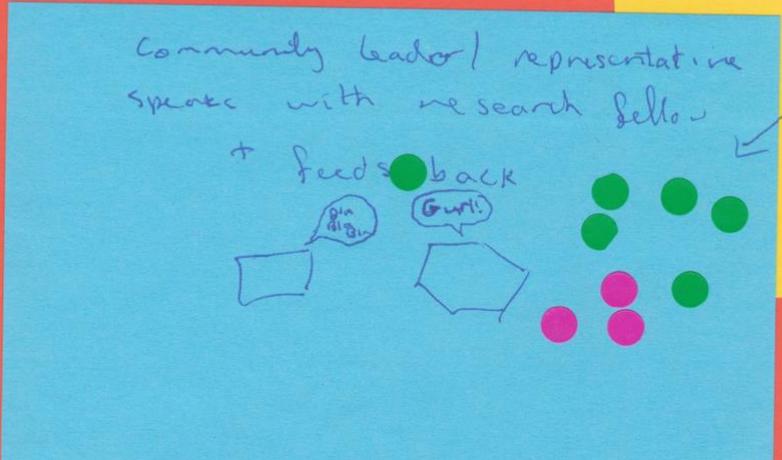
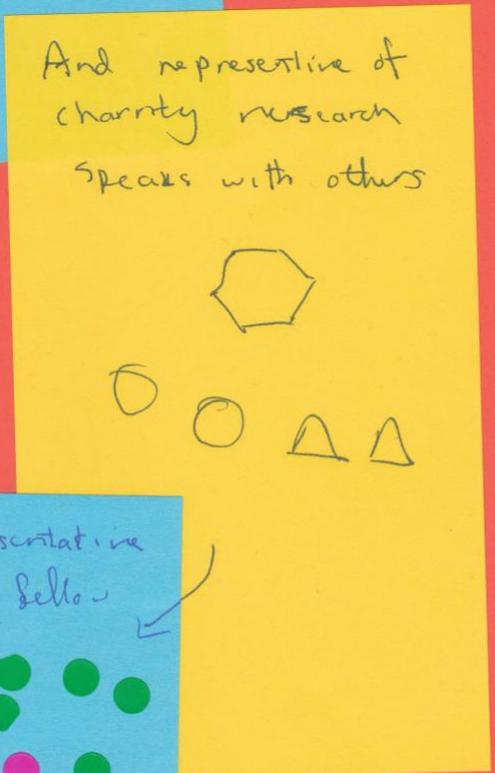
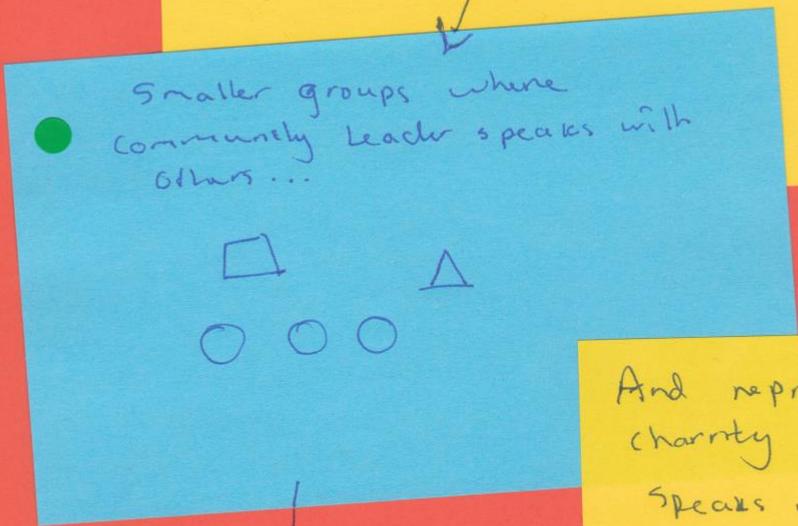


Engaging communities through food.  
 Producing a list of safe foods using  
 tools & spices traditional found in  
 black dishes.

Partnering with chefs to produce recipes/  
 look along so those suffering from +  
 newly diagnosed can still enjoy cultural  
 foods.



••••• Owambb (Nigerian term for a PARTY!)  
WHO DOESN'T LOVE FREE FOOD & MUSIC!!



# STRONGER TOGETHER



VIDEOS

IMAGES/  
POSTERS

SOCIAL  
MEDIA

LISTEN



PLAN



REVIEW

EVENTS



Destigmatise  
"Research"

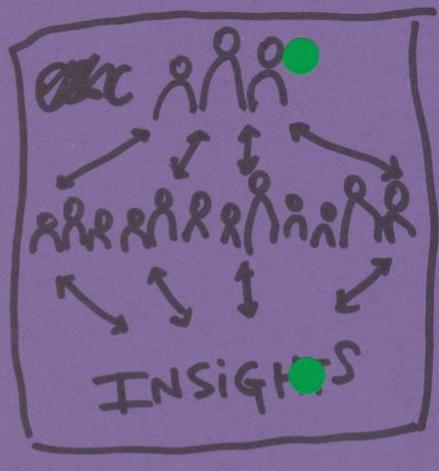
Promote  
positive,  
but honest  
& authentic  
experiences



1. Establish relationship with a specialist organisation that recruits participant group together insights around priorities for overcoming cultural barriers.



2. Recruit and train a team of community researchers to dive deep into understanding the barriers and build a knowledge base around this



3. Become thought Leaders on the topic, sharing insights within the medical and wider research community



## E. How to build a ClearView Four Pillars of Engagement Strategy



## Build a ClearView Four Pillars of Engagement Strategy

### Trust

#### Build a reputation

[This is an ongoing and non-project specific requirement. Many people will question the reputability of an organisation and will only engage with those where they already have trust and confidence. This reputation needs to be built over time, but in building this reputation the other elements of this engagement strategies should be considered to ensure that you reach diverse audiences.]

We will use our established reputation within black communities in the UK and those who have had positive experiences working with us in the past to help us distribute our announcements and support recruitment for this project.

We will reach out to our partners in the health industry who are already trusted by people from black communities with Crohn's and Colitis and who can share this information on our behalf.

#### Immediate/project specific

[Provide clear, accessible, and transparent information about what you wish to engage people in, why and how they can participate.]

Develop communications materials for multiple media channels that clearly describe what this research is about and what type of commitment we need from participants, including what they will get in return. Be clear that we are working with Crohn's & Colitis UK and that we will be sharing the final insights with them, but any individual responses will be kept anonymous. Also, specify that this work will help open research opportunities up to people from black communities.

### Reach

#### Who do you want to engage?

[Who exactly do you want to involve in this project? For example, include their ethnicity, age, gender, location. Be as specific as possible – Ethnic minority, black people, etc are all vague terms. Black African is less vague, and black African Ghanaian men, aged 18-25 years who are second generation migrants is best.]

People from black communities who either have a diagnosis of Crohn's and Colitis or are carers for people from black communities with a diagnosis of Crohn's and Colitis. Within this group we will engage a diverse audience of gender; rural/urban locations; age groups; level of formal education; people who had/had not participated in research in the past; religion or beliefs.

#### What do you know about these people?

[Have or seek out sound knowledge yourself about the different groups that exist within the participant profile(s) and the cultural backgrounds.]

Different age groups will be present on different platforms/spaces. To engage older people, we can target younger members of their family/friends' network and offer referral incentives.

Because people with Crohn's and Colitis are likely to know and engage with other people with Crohn's and Colitis we will reach out to people within our networks who have a diagnosis or know someone who does and use a snowballing approach.



We will develop a database of contacts for community groups, faith groups, Crohn’s and Colitis groups and other groups that already engage with people from black communities. We will send them communication materials to share with their groups.

We will look for groups online that engage people from black communities with Crohn’s and Colitis and ask them to share our communications materials.

If we struggle to engage enough people, we can look at advertising in GP offices or contacting our network of health professionals to explore referral possibilities.

Where do you need to be to reach these people?

[If you are looking to engage digitally excluded people you would not advertise your opportunity online. Consider the specifics of the group that you wish to engage, where do they already spend their time? What mediums of communication do they already engage with and who do they already speak or listen to?]

Where are these people?

Establish this with the co-creation group. Are people expected to engage online/ in their local community/ with healthcare providers? This might be different for people who come from rural/urban backgrounds in terms of the places they access outside of the internet.

What other stakeholders already engage these people?

Local community leaders and groups. These can be accessed through our established network and by the Community Engagement Executive exploring relevant groups on Facebook and other social media platforms.

Healthcare professionals

Online sources of trusted information, such as Crohn’s and Colitis UK.

## Interest

What type of information will these people engage with?

[What topics or information sources do these groups of people already engage with? What interests them? What will stop them in their tracks and grab their attention? Often a co-creation group is really helpful to support with this section of the engagement strategy.]

Information that is specifically relevant to them, in social media comms ask questions that will help them to self-identify.

What type of information is of interest to these communities – helpful tips to manage their disease, advice from a black doctor/dietician.

What other tricks can you use to capture people’s interest?

[Try to put yourself in your target audience’s shoes and consider what would capture your interest and cause you to take a pause in your day to engage with, e.g., videos, images, events].

Engagement strategy online across social media platforms including Twitter and Instagram. Referrals process for people to share the opportunity with people they know within their community who are affected by Crohn’s and Colitis.

Any engagement materials led by someone from a black community



## Motivation

### Extrinsic

[What reward are you trading for the time that participants commit to the project?]

All participants will be paid for their time and any additional expenses that are incurred, such as travel costs to attend in-person ClearSprint. Paying people who refer their friends/family towards research opportunity.

### Intrinsic

[Be clear from the outset on the value of their contribution and who will benefit from it. Have a clear plan from how you will continue to inform them of the progress of this contribution such as sharing the report and the findings. This is key also to ensure positive ongoing relationship and future engagement.]

The co-creation group will be involved at every step of the design process for the research project. The findings will be run past the co-creation group to check that they measure up with expectations. Where possible, co-creation group participants will be invited to participate in the presentation of findings to the client.

The final report and next steps for the client will be shared with the co-creation group and all participants, to close the feedback loop.