



Finding Cancer stories in London using Ethnography

Project Findings - January 2020



Funded by

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CANCER SUPPORT

Executive Summary

Wilding Health Ltd was commissioned by the Macmillan London Engagement team to collaboratively develop a community engagement, training, insight and associated film over the course of a 6-month period in 2019.

The project was designed to respond to the challenges and problems set out in the Mind the Gap report in 2018 by engaging with seldom heard communities, to empower communities to collect stories from their own networks and to share the findings with the health system in London to co-design solutions.

Findings are intended to provide information and recommendations for anyone working in cancer services generally, and broadly in health and wellness in London. Its purpose is to enable greater inclusion of people affected by cancer (PABC) in these processes.

The three broad thematic findings were:



Navigating the system

PABC spoke a lot about confusion, feeling lost, not knowing what to do. People also said they would have liked support to understand options, support available to them and that support/ community groups who did this really helped.



Emotional support

Many respondents spoke about their emotional journey being one of the most impacting factors of being diagnosed with and living with cancer. PABC either had supportive family and friends and others had few people to help. In some cases, even where PABC had support, they still felt like they needed more emotional support, even in the cases where people didn't realise this until later on in their journey.



Language barriers

Some community groups reported that not speaking English as a first language had meant that navigation of the healthcare system was harder, and they required additional support. Furthermore, respondents reported that the language in which their diagnosis, and later their treatment options were delivered had caused confusion.

Five key recommendations are suggested to tackle the issues raised in the story gathering and is also based on the suggestions made at the Macmillan Mind the Gap Conference co-design hack at London City Hall in December 2019.

- ① Conduct research into the experience of carers in London**
- ② Continue to have co-design sessions to identify solutions and people to take them forward with funding**
- ③ Support community partners to co-produce solutions required to solve the problems identified in this work**
- ④ Use Macmillan strategy and advertising to reduce stigma, improve awareness and ensure the message that Macmillan is there for everyone is delivered to BAME communities**
- ⑤ Continue to be pro-active in identifying and working with seldom heard groups, providing training using the tool of story gathering to share experiences and find solutions**

Background

Wilding Health Ltd was commissioned by the Macmillan London Engagement team to collaboratively develop a community engagement, training, insight and associated film over the course of a 6-month period in 2019.

The project was designed to respond to the challenges and problems set out in the Mind the Gap report in 2018 by engaging with communities that would normally not have engaged with Macmillan, to empower communities to collect stories from their own networks and to share the findings with the health system in London to co-design solutions.

This project is intended to provide information and recommendations for anyone working in cancer services, and health and wellness in London.

Project overview

The project was not research, rather it was a community story gathering project that enabled us to reach communities and seldom heard people including those with language barriers by training active community members in ethnographic story collection methods.

Ethnography is the study of cultures and groups of people who live within select communities. Ethnography illuminates social life and culture in a social system drawing from observations and inquiry into peoples lived experiences.*

Ethnography is suitable if the needs are to describe how a cultural group works and to explore their beliefs, language, behaviours and also issues faced by the group, such as power, resistance, and dominance.



In this case, the story gatherers were trained in ethnographic methods in order to enrich the stories they collected and to inform the results more deeply. By working with people from communities that they belong to, we further expected there to be an even deeper level of insight gleaned from the stories they collected.

*Cresswell, J. (2007) Qualitative Inquiry and Research Design: Choosing Among Five Approaches, SAGE, London

The project was delivered in five key stages:



Training

79 Participants were trained in ethnographic story collecting in eight organisations:

- London Pathway Partnership HUB, in partnership with National Probation Service London (NPS London)
- Harrow Carers
- Community African Network
- Croydon Social P
- The Selby Trust
- One of London's biggest employer
- Asian Women's Cancer Group
- Chinese Association for Cancer Care (CACACA)



Collecting Stories

Participants collected stories from their communities and fed them back to us, via Macmillan Engagement Leads.

The questions people asked related to diagnosis, treatment, interface and experiences of primary care, who they spoke to about their care, and what they would have improved. Wilding synthesised the stories into themes.



Co-design Hack

The co-design Hack was designed to be a participatory session to identify solutions, leaders for change, and plans to improve the future of cancer services in London for people traditionally without a voice or from seldom heard groups. The session was delivered as part of the Macmillan Minding the Gap City Hall Conference.



Film

The project was documented as a snapshot in time to showcase the methodology we employed, as well as reflecting experiences of people's cancer journey.

Themes

The stories were gathered by the community organisations worked with over a two-month period. 25 stories were submitted from the following organisations:

CACACA **x8**

A large London employer **x5**

Selby Trust **x3**

Asian Women's Cancer Group **x5**

Probation service **x3**

BME Forum **x1**



The stories were analysed and ordered into themes and the top line themes fall into three broad **categories**:

01

Issues encountered on the cancer journey

02

Things that helped

03

Things that would have helped

01

Issues encountered on the cancer journey

- Support needed to navigate the system
- Needing emotional support
- Needing to know more about the side effects of treatment
- Language barriers
- Issues to do with primary care:
 - Booking appointments
 - GPs not having enough time

The themes in the Issues above were summarised in three broad categories, and were discussed in the Hack session to identify potential solutions with community organisations and people from BAME groups alongside health professionals:

1 Navigation

PABC spoke a lot about confusion, feeling lost, not knowing what to do. People also said they would have liked support to understand options, support available to them and that support/ community groups who did this really helped.



“At the cancer group I have made friends who’ve gone through the same journey. We do things on a regular basis to enjoy life...so I think all of that has got me out of my depression, and it has made me stronger. And, I’ve managed to get a lot of information about wellness courses and things like that.”

A 31-year-old woman reported that her diagnosis was a shock and felt overwhelming at the time:



“And at that time being told I had cancer, obviously, was the biggest shock that you could hear as a 31-year-old. And it wasn't the news I wanted to hear. And I was slightly in denial I thought that it was a mistake. I didn't realise that it was me being told I had cancer. Really like an out of body experience if you like. I kept questioning the nurse about death. And, you know, just my association with cancer at the time, was death, and you're gonna have chemo, you're gonna die. it was just, you know, I didn't want to die. I didn't want to be told that I had to have chemo, but that's what they said.

With regards to the information I was given. I was just bombarded with paperwork. I mean, it was great, the amount of materials that were available but just at the time it was just not what I needed. I didn't need someone to say, here's a booklet. Here's another booklet out here is about information about your surgery, so I've just been told I had cancer.

I didn't know what was happening to me I didn't know what I wanted to happen to me, except for I just didn't want to die from it. And Macmillan was actually fantastic when it came to the level of support for the area that I'm from, in particular, there's not a lot going on in Haringey.”

2 Emotional support

Many respondents spoke about their emotional journey being one of the most impacting factors of being diagnosed with and living with cancer. PABC either had supportive family and friends and others had few people to help. In some cases, even where PABC had support, they still felt like they needed more emotional support, even in the cases where PABC didn't realise this until later on in their journey.

A member of the AWCG spoke in detail about her needs:

“

“...it was after my treatment, when I [realised] that I wasn't supported. I felt emotional that I didn't get the support that I needed... I think I needed emotional support as I was going through my treatment. I didn't have time to think about my emotions, I had to remain positive, while I was going through my treatment; it was just one thing after another.”

A member of the AWCG spoke in detail about her needs:

“

“And when I rang up the [Macmillan] helpline and this lady on the other line bless her, she just listened for 45 minutes. The only words she said to me was Hello, welcome to Macmillan, thank you for calling me, or something like that. And that was it. She just listened as I ranted and raved. I cried. I swore. I told her how shit the world was how angry I was at the world. She just listened and genuinely for 45 minutes I just cried and shouted and screamed for 45 minutes, and I felt better. I really felt better. Because I just got to offload everything that I needed to offload. I didn't want to burden my family.”

③ Language

Some community groups reported that not speaking English as a first language had meant that navigation of the healthcare system was harder, and they required additional support. Furthermore, respondents reported that the language used to explain their diagnosis and treatment had caused confusion.

a. English as a second language

Some respondents spoke English as a second language and had issues understanding medical advice, making appointments or understanding treatment option.

A member of CACACA described her experience as:

“

“If I had regular cervical screening, I would have an early diagnosis. Due to my language barrier, GP reception did not give me a timely appointment, and I missed the chance to remove the tumour”

The founder of CACACA describes her reasons for founding the organisation as:

“

“In 2010, I had breast cancer. Since then, I've figured out that Chinese people need a lot of support, especially for language barrier. So, in 2013 five Chinese including me set up Chinese Association for cancer care. The support in, including an interpretation home visit, and also monthly Cancer Support Group.”

b. Clinical language and information

A Woman who worked at a Large London Employer was asked: What would have made a difference to you and your care? responded that she would have like to have had a “[better understanding] of where chemo was available...it would have been better to have a clearer understanding around my fertility treatment”

02

Things that helped

PABC were asked by their community story gatherers what had helped them in their journey. The findings are summarised as themes below:

- Overwhelmingly PABC were happy with the NHS treatment they received
- Peer Support and Support groups such as Asian Women's Cancer Group, Chinese Association for Cancer Care, Maggie's
- Macmillan cited as helpful, but this was only mentioned a few times
- Complementary therapies
- Local Area Coordinators (Selby)

03

Things that would have helped

PABC were asked, and the synthesis of the stories findings identified what would have helped them during their cancer journey. The findings are summarised below as:

- Emotional support
- Exercise
- Help to navigate the health system
- Translation
- Knowing more about side effects of treatment
- More information on treatment options



Hack session – thematic actions

The session was co-curated and led by Macmillan, Wilding Health Ltd and Be More Pirate and was designed to enable participants (a mixture of PLWC and PABC, healthcare commissioners, professionals and third sector organisations) to co-design creative solutions to the problems, issues and themes identified in the story gathering. The attendees for the day came from various organizations and are listed in the back of this document.

Although Macmillan convened and facilitated the session, they did not position themselves to take responsibility for all of the recommendations and solutions suggested. The invitation to participants was to be creative, bold and daring in their solution suggestions, with each individual being responsible for taking ideas forward.

Perhaps unsurprisingly several of the suggestions reflect the stories gathered from communities.

As the Hack session was designed to identify solutions, this document has been summarised thematically below to set out what was suggested by participants of the hack session:

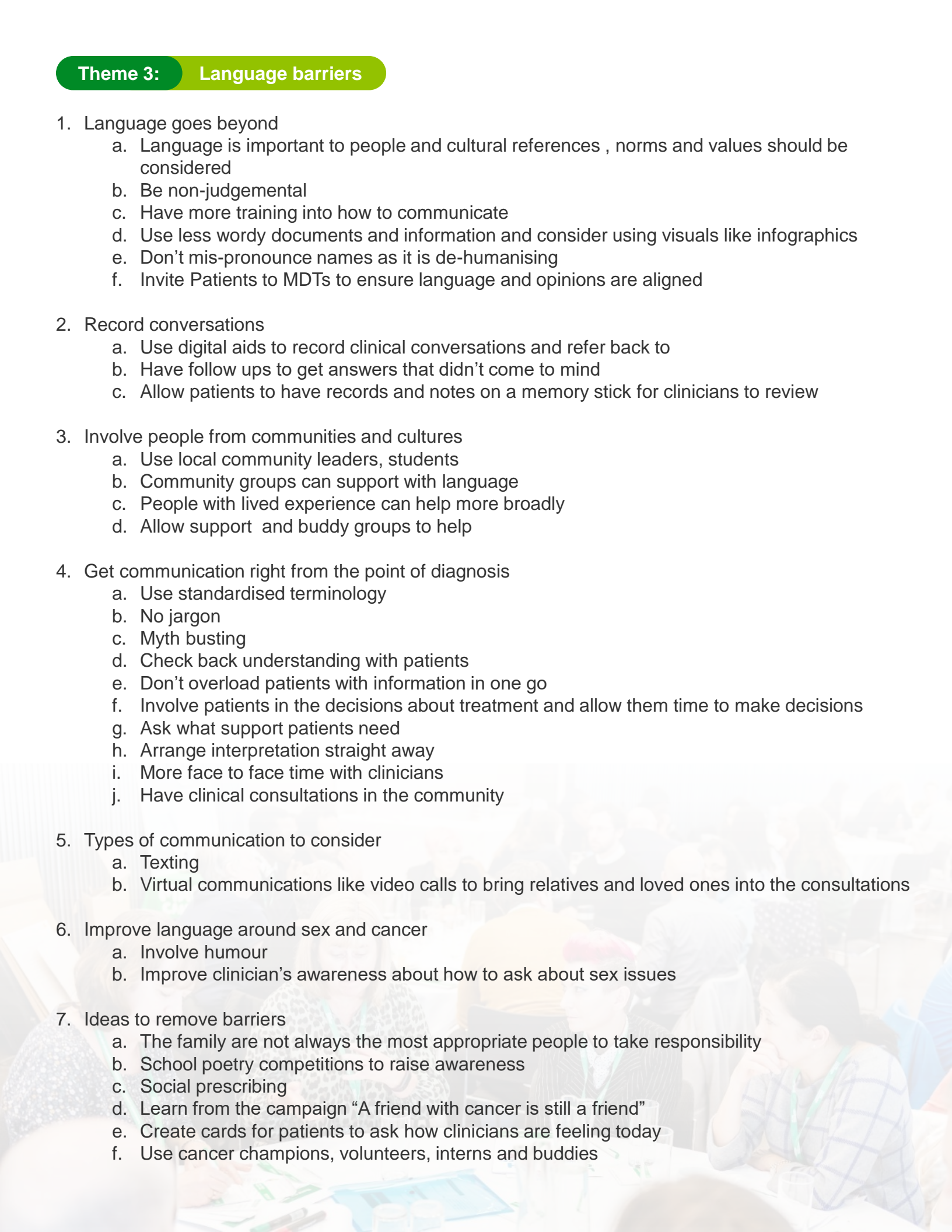
Theme 1: Emotional Support

1. Networks of support
 - a. Peer support for people navigating care
 - b. Peer/ buddy support in hospital
 - c. Train people with lived experience
2. Less hierarchy, more patient involvement
3. Community led involvement
 - a. WhatsApp groups for people with cancer
 - b. Use community venues
 - c. Schools to educate children about cancer experiences
 - d. Training for grandparents
 - e. Advertisements need to show a more diverse and representative sample
 - f. Support groups should represent their audience
 - g. Invite responsibility of corporate organisations to support
 - h. Share personal experiences to promote the Macmillan help line
 - i. Greater use of social media to share knowledge and understanding of cancer
 - j. Promote doing things for yourself like creative groups
4. HCP training
 - a. Using a holistic approach to treat PABC
 - b. Understanding cultural and identity needs
 - c. Understanding body language
 - d. Emotional support difficult conversations training
 - e. Signposting
 - f. Using experiences to help work with PABC
 - g. Humanising and non-medical approaches
5. Making the journey easier to understand
 - a. Clear language, no jargon, plain English
 - b. HCPs to be aware that the PABC is in shock and unlikely to retain all information
 - c. Improve environments
 - d. Mindfulness of the timing in which the information is shared with the patient
6. Emotional Support as part of the cancer journey
 - a. Being contacted directly at the start of the journey
 - b. Not self-referring
 - c. Inform people on range of choices
 - d. HCPs to make time to discuss emotional support
 - e. MDT approach to emotional support

Theme 2: Navigating the system

1. Empower people to navigate the system
 - a. Clear information on pathways (delivered at the point of diagnosis)
 - b. Advanced warning of appointments
 - c. Create guides/ FAQs/ online Wikis/ directory of services
 - d. Harness the community to give support and guidance
 - e. Use share and learn from best practice
 - f. Patient Advisory Groups
2. Train HCPs
 - a. Train primary Care on Social Prescribing, and awareness raising
 - b. Hospitals to be equipped to signpost
 - c. Primary Care awareness raising in community settings
 - d. Closer links to community and collaboration on solutions
 - e. Offer Advanced Care Plans
 - f. NHS Commissioned Health Unblocked
 - g. GPs and Primary Care to train people on how best to use their time
 - h. Incorporate compassionate care into clinical practice
3. Involve family and friends more
4. Plan from the start to make navigation easier
5. Macmillan to do more
 - a. Have Macmillan Community Ambassadors to help navigate locally
 - b. More Macmillan Cancer Nurses
 - c. More Hubs and information centers
 - d. Best practice sharing events
6. Community and additional suggestions
 - a. Use more community settings e.g. cancer cafes
 - b. Have a "Huge advertising campaign" to raise awareness
 - c. Sharing medical and emotional needs with managers (see Met Police 'Disability Passport' example)
 - d. Support groups and online forums for specific communities
 - e. Patient navigator roles
 - f. Training peers in how to support
 - g. Community outreach
 - h. Supermarket pop-ups
 - i. Have more advertising and campaigns
 - j. Empower people to know their rights
 - k. Taboo and myth busting work
 - l. Consider culture when working with key groups

Theme 3: Language barriers

1. Language goes beyond
 - a. Language is important to people and cultural references , norms and values should be considered
 - b. Be non-judgemental
 - c. Have more training into how to communicate
 - d. Use less wordy documents and information and consider using visuals like infographics
 - e. Don't mis-pronounce names as it is de-humanising
 - f. Invite Patients to MDTs to ensure language and opinions are aligned
 2. Record conversations
 - a. Use digital aids to record clinical conversations and refer back to
 - b. Have follow ups to get answers that didn't come to mind
 - c. Allow patients to have records and notes on a memory stick for clinicians to review
 3. Involve people from communities and cultures
 - a. Use local community leaders, students
 - b. Community groups can support with language
 - c. People with lived experience can help more broadly
 - d. Allow support and buddy groups to help
 4. Get communication right from the point of diagnosis
 - a. Use standardised terminology
 - b. No jargon
 - c. Myth busting
 - d. Check back understanding with patients
 - e. Don't overload patients with information in one go
 - f. Involve patients in the decisions about treatment and allow them time to make decisions
 - g. Ask what support patients need
 - h. Arrange interpretation straight away
 - i. More face to face time with clinicians
 - j. Have clinical consultations in the community
 5. Types of communication to consider
 - a. Texting
 - b. Virtual communications like video calls to bring relatives and loved ones into the consultations
 6. Improve language around sex and cancer
 - a. Involve humour
 - b. Improve clinician's awareness about how to ask about sex issues
 7. Ideas to remove barriers
 - a. The family are not always the most appropriate people to take responsibility
 - b. School poetry competitions to raise awareness
 - c. Social prescribing
 - d. Learn from the campaign "A friend with cancer is still a friend"
 - e. Create cards for patients to ask how clinicians are feeling today
 - f. Use cancer champions, volunteers, interns and buddies
- 

Alex Barker from Be More Pirate summarised the session along the following lines:

Better signposting

- People need information from the very beginning - before diagnosis or immediately after, so they know what to expect, how many appointments etc, and what to ask for
- A Money Saving Expert style site for cancer - with hints, tips, templates or a wiki style map of what's available to me in my area, could be valuable
- Encourage PLWC to build own personal support toolkit, bespoke to their needs
- However, must recognise that entry point into emotional support journey is usually via a direct personal interaction, so this part can't be replaced by technology

Re-humanise the interactions

- Change interaction with clinicians so they are more human centred (less clinical), offer training on what a more holistic approach looks like e.g. asking how patients are first, thinking about body language, when, where and how difficult information is delivered.
- Need to decode medical language around diagnosis - e.g. 'stage', 'grade' and get to the point quicker
- Using spaces to connect - **missed** opportunity to encourage open conversations in waiting rooms / or create more space for connection in hospitals or via on site 'friendship groups or 'cancer cafes'
- Recording conversations with consultant at point of diagnosis so that it's easier to remember all the information / use of memory sticks, at a point when it might not sink in


Community support

- Peer to peer support first - create a community buddy system before and after appointments, make use of PLWC, and volunteers - recognise that helping others is part of the healing process. How could we support and scale this?
- Training up family/friends or key people in the community so that they know how to talk about cancer and have a better understanding of the journey.
- Creative groups to express emotions around cancer - poetry, music, sharing groups. More diversity in support groups - where they happen and who is involved e.g. barber shops, cafes, job centres, who and where else could people be educated to provide emotional support?
- Interpreters for non-English speakers - need for more interpreters who understand cancer terminology - make use of students or refugees/asylum seekers with medical background
- Peer led groups to tackle the taboo areas of cancer, e.g. sex and cancer

Changing the story

- Podcasts /YouTube films in different languages to help people understand what they're going through and normalise the conversation
- Shift language away from fear, 'fighting', 'struggle' to more positive based narratives about living well with cancer.
- More humour! Ad campaigns are too sombre, cancer doesn't always equal death
- Other ways of sharing the stories of experience that are human, anecdotal, and use ordinary language and humour

Observations



In carrying out this project several reflections were made, and the author would like to draw attention to several key observations

Although this project has highlighted active members of the community in the case studies sections of these findings, there are also those who are unable, unlikely or do not want to directly participate. It is essential that measures are put in place to enable the inclusion of the voices of community members who are less likely to engage and get involved.

- Listening to the doctor without feeling able to have an opinion is strong (paternalism)
- Diagnosis is an extremely challenging time for everyone and is often followed with a period of shock around the time of diagnosis
- Support is the one thing that PABC need the most through connection with people
- Faith plays a part in living with and beyond cancer
- Carers may not be supported well enough and are the least understood part of the BAME communities to date (not enough info or respondents) and should be researched to identify key unmet needs
- Targeted and relevant information about treatment, side effects, local events, support and guidance should be given to people at the right time, and in the right format
- People remained remarkably positive throughout their journey and these stories should be shared with people through targeted advertising and online
- Self-organized groups like AWCG and CACACA often filled the gap in support
- In training and empowering more active members of the community to collect stories using ethnography, we ensured that we heard from less active or more passive members of the community which is essential in the drive towards health equalities and community led health

Recommendations

- Conduct research into the experience of carers in London
- Continue to have co-design sessions to identify solutions and people to take them forward with funding
- Support community partners to co-produce solutions required to solve the problems identified in this work
- Use Macmillan strategy and advertising to reduce stigma, improve awareness and ensure the message that Macmillan is there for everyone is delivered to BAME communities
- Continue to be pro-active in identifying and working with seldom heard groups, providing training using the tool of story gathering to share experiences and find solutions
- Self-organized groups like AWCG and CACACA often filled the gap in support, and should be funded to do so in the future



Thank you

For attending the Macmillan conference and contributing to finding solutions:

Community	NHS/other organisations	Macmillan
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Thank you

Macmillan Engagement Leads:

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Organisations involved:

- London Pathway Partnership HUB, in partnership with National Probation Service London (NPS London)
- Harrow Carers
- Community African Network
- Croydon Social P
- The Selby Trust
- One of London's biggest employer
- Asian Women's Cancer Group
- Chinese Association for Cancer Care (CACACA)

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