



Macmillan Cancer & Healthwatch On Tour

Understanding Views & Raising Awareness on Cancer & Cancer Services from Young BAME Residents in Blackburn with Darwen

May 2016

Acknowledgments

SLYNCS, Strengthening Links Between The Youth And Networks, Communities And Specialists

Healthwatch Blackburn with Darwen Volunteers

Macmillan Cancer Support Staff & Volunteers

Introduction

Healthwatch Blackburn with Darwen worked in partnership with Healthwatch Blackpool, Healthwatch Lancashire & Macmillan Cancer Support to deliver a series of interactive events to seldom heard groups across Lancashire, allowing them the opportunity to share their views on Cancer & Cancer Services.

More than 1 in 3 people will develop Cancer at some point in their lifetime

The project also allowed both local Healthwatch & Macmillan Cancer Support to raise awareness on their roles and what part they can play in the Cancer journey.

Why BAME(Black, Asian & Minority Ethnic)?

One of the core principles underpinning the health and social care system in the UK is that access to - and appropriate delivery of - the best quality care services is available to everyone. This applies irrespective of race, age, sexual orientation, gender or gender identity, income, disability or religion.

However, health consistently remains one of the great focal points of inequality - especially when it comes to cancer.

Macmillan Cancer Support is working hard to understand the complex issues driving these inequalities, and identify hidden needs, by engaging with seldom-heard-from groups. By working with these groups and our partners, including community partners, service providers and policy makers, we aim to understand specific needs, and co-design solutions that work, so we can help shape the future of cancer care - and ensure no-one faces cancer alone.

Method

A 90 minute workshop was delivered by AFTA Thought, a drama based training company. They encouraged the group to share their views & experiences on Cancer & Cancer Services in an informal & interactive way.

Healthwatch & Macmillan staff and volunteers facilitated group discussions amongst small groups within the audience throughout in order to record the discussions being had.

15 young people participated in the event

Findings & Key Themes

Barriers to accessing Services & Support

Age Discrimination

Participants spoke about how often they weren't taken seriously by services which had an impact on their decision to access again in the future. Almost all participants agreed young people were treated differently by Health Professionals.

'Typical Teenagers'

'First time laughed at'

Communication

The way in which health professionals communicated with clients had a significant impact, participants spoke about how they wouldn't access services again if the communication hadn't been effective e.g. 'tonnes of questions', face to face communication

Seeing the same GP

Seeing the same GP gave young people more confidence in accessing services; regularly seeing different people or changing with short notice created frustration & lack of trust. One participant spoke of how they would cancel their appointment if the doctor was changed at the last minute. It was also important to see the preferred gender of professional, again if this was changed it had a negative impact on accessing services & support.

Timescale

Having to wait a long time to see a health professional put young people off accessing services or talking about their issues. Once services were accessed participants talked of the lengthy process in getting a diagnosis or treatment.

Misdiagnosis

Two participants (13.3%) spoke of being misdiagnosed, one ended up in hospital for eight weeks with Immune System & Heart problems. Initially he had been laughed at and it was only when symptoms got significantly worse he was taken seriously.

Stigma

All participants spoke of the stigma relating to Cancer (Mental Health & Dementia) within the Asian Community. Young people said it was within their culture that nobody talks about it. A number said they may speak to their close friends but it was unlikely they

would open up to family or the wider community.

'Put up & keep it to yourself'

'What you don't know can't hurt you'

'Paracetamol cures all'

Q. Do you feel listened to if you go to the doctor or health centre?

Participant's Positive Experiences

One participant spoke of how their family was accident prone, they spoke of how medical professionals had taken care, paying attention to what they said and the importance of eye contact during the conversation to show an interest in the patient.

Another participant went on to say how they *'always give respect to doctor because of their position'*.

'Yes I feel listened to at my local GP'

Participant's Negative Experiences

One participant spoke of how he had attended hospital with a broken arm, initially doctor told him to 'rub arm' and it would be okay, it was only when a nurse followed up and an X-ray was carried out that the broken arm was identified.

Another spoke of how they felt doctors rushed through patients. This was a particular problem when they were translating for an older member of their family.

A number of participants spoke about how they felt doctors didn't take them seriously and how if they weren't approachable, friendly & helpful they wouldn't return.

'They do not know what they are talking about'

Q. Why might young people & the BAME Community not talk about Cancer?

Many spoke & felt that people did not talk about cancer within their community because it's a taboo subject.

Participants said often they didn't want to worry their family so would rather keep things to themselves rather than sharing.

One participant spoke about not wanting to be 'centre of attention'.

A fear of people talking about them within their family & community was also mentioned.

Q. How can Macmillan Cancer Support reach more people in the BAME Community?

Locations

The locations in which Macmillan Cancer Support promote their services was spoken about, young people were keen to have improved accessibility, being based in mosques, halls of residence, schools, colleges & university.

Communication Method

Young people said how they didn't read leaflets and would be far more likely to engage online, via Facebook, chat rooms, YouTube & Twitter. The communication method needed to be targeted at young people; advertisements on YouTube and Mascots were also mentioned.

Language

Young people thought Macmillan Cancer Support could use community languages to engage with those hardest to reach in the BAME Community. It was suggested professionals may learn some basic words/greetings in different languages to break down the barriers in engagement.

Challenge Stigma

Engaging with people from a young age within schools would help to challenge stigma, young people could then act as the link between the older generations.

Q. How can Healthwatch support people to have their say?

'highlight the negative consequences of not talking.'

Locations

Healthwatch representatives to be based in local GP surgeries so people can talk whilst waiting, participants also mentioned events & music festivals.

More workshops & get togethers at Community Centres, Children's Centres, Colleges, women's groups & gyms.

Increased Awareness

'no knowledge of what Healthwatch do'

Participants Feedback

'Eye opening'

'A very different approach to a serious topic'

'A very good presentation, did find out a lot of things about Cancer I didn't know'

Conclusion

Young people felt they were discriminated against because of their age, not being taken seriously by health professionals.

When young people couldn't see the same GP this decreased their confidence in accessing services and had an impact on future engagement.

Waiting times put young people off accessing services & the time spent for referrals was a frustration to allow for diagnosis and/or treatment.

Misdiagnosis was spoken of by two participants, this had an effect not only on their confidence but that of their peers when they heard about the experience.

The stigma within the Asian community around Cancer, Mental Health & Dementia was a key concern for the young people involved, this impacted awareness within the community and also likelihood of accessing services along with preventative measures.

Recommendations

Young people need to be treated as individuals, with their knowledge & understanding of their own health taken seriously by professionals. (In line with NICE guideline C9138 1.1.1)

Young people should be able to see the same GP if requested, if changes are made they should be kept informed at all times.

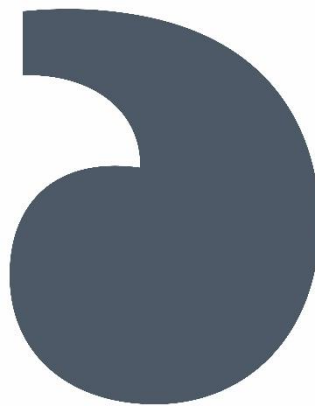
Misdiagnosis needs to be taken seriously, young people need to be listened to and sufficient time should be spent with individuals to correctly diagnose.

Stigma needs to be challenged within the Asian Community, this can be done by raised awareness & empowering individuals who are happy to talk about possibly sensitive issues. (In line with NICE guideline C9138 1.1.4)

NICE Guidelines

1.1.1 Develop an understanding of the patient as an individual, including how the condition affects the person, and how the person's circumstances and experiences affect their condition and treatment.

1.1.4 Listen to and address any health beliefs, concerns and preferences that the patient has, and be aware that these affect how and whether they engage with treatment. Respect their views and offer support if needed to help them engage effectively with healthcare services and participate in self-management as appropriate.



If you would like more information about Healthwatch Blackburn with Darwen, a hard copy of this report or to find out how you can get involved in future projects please get in touch:

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