

Community Cancer Support End of Engagement Summary

Overview & Background of Community Cancer Support (CCS):

We know that life for those affected by cancer can be challenging. We also know that more and more people are now living longer with cancer; in Leeds there are over 25,000 people currently living with or beyond a cancer diagnosis.

It is not uncommon for people to feel lost and struggle to come to terms with living with cancer, or going back to 'normal life' after cancer treatment has been completed. We want to help people affected by cancer find help in their local community easily, as and when they need it.

The aim of this engagement was to find out what sort of things people who have a diagnosis of cancer (or their carers) would want help with, and how it would be best for them to access it. The feedback was wanted to develop a useful and accessible support service for people affected by cancer.

This project is subject will be based in the following areas (due to allocation of funding):

- Aire Valley
- Harehills, Richmond Hill & Burmantofts
- Beeston & Middleton
- Wetherby

We know that some of the geographical areas this service will cover have high percentages of people from seldom heard communities. Therefore we wanted to make sure that we engaged with these communities to make sure we take into account their needs when developing this service. As such we engaged Voluntary Action Leeds (VAL) to host focus groups with specific groups to enable us to gather their views. In total 68 people from seldom heard communities gave their feedback. These communities particularly included:

- South Asian elder population
- Gypsy & Roma Travellers
- Refugees & Asylum Seekers
- Black men & women
- Eastern European migrants/economic migrants.

Overview of learning from this engagement process:

- All GP's Practices in the Pilot areas were contacted asking them to promote this survey to current/previous cancer patients and their carers. Uptake in some practices was excellent, however some practices did not engage at all.
- As the engagement took place over the summer period there was a concern that this may negatively impact on the volume of people who may want to take part. As such, the engagement was extended beyond the summer holiday period, into the first half of September.
- In total there were 202 responses from patients/carers/public/seldom heard communities
- We asked staff and stakeholders, who may come across people with cancer as part of their day to day role their thoughts on what a Community Cancer Support service may look like.

We had 17 responses in total from people in varying roles, from GP's to Pharmacists, Physio's and non-specified community support roles.

- 88% of staff felt there was a need for a service like Community Cancer Support
- 94% of staff said they would refer people who had been affected by cancer to a service like Community Cancer Support

Key themes on CCS from Patient feedback (people contacted by Practices to take part):

- 75% of respondents were female, with the majority of respondents also describing themselves as White British.
- Most respondents were aged between 56-65, closely followed by people aged 66-75yrs
- 44% of respondents were retired, with 29% of people working full time.
- Less than 3% had a child under 5yrs, and 12% of people said they identified themselves as a carer.
- 56% of respondents were former cancer patients, whilst 35% of people said they currently had cancer. 38% of people said they were a relative/friend/carer of someone who has cancer
- Overwhelmingly 86% of people said they would use a service like Community Cancer Support
- 45% of people said they felt that accessing the service would best for them if it was based at the GP practice, with 29% of people saying they would prefer the service to provide home visits. A number of people said they would like contact with the service via email/phone/letter.
- The biggest barriers to accessing Community Cancer Support (for the general population) would be the time the service was available (45%), Work (19%, Transport issues (17%) followed by health issues (13%)

Recommendations:

Based on this learning we know that the majority of people would want to access this service. However, to do so the service would need to be:

- **Flexible:** To enable access the service needs to offer flexibility in the times it is available – to take into account those people who may work or have family commitments. Flexibility is also needed as people have commented that their general health may cause problems for them when trying to access support. People may want to access the facility in a mixture of places to suit their needs at the time.
- **Accessible & Local:** The service needs to be in easily accessible locations for people, as transport has been highlighted as a barrier for people. In some instances it may be most appropriate to offer this support at home for people who need this.

Key themes from Seldom heard communities:

- **Fear:** All the groups highlighted fear as a key theme when thinking about Cancer. Many of people automatically associated it with dying. It was described as scary, an automatic death sentence. In some cultures it was believed that cancer was inevitable, *'every person I know that got it is dead'*. There were very low expectations around surviving cancer, and some groups mentioned that symptoms have been disregarded by people as it's something to be expected.
- **Language:** The word 'Cancer' is very much disliked in a number of these communities, with some communities avoiding the term completely. Interestingly, it is also a word that is instantly recognisable as it is the same word in many languages. The word itself generates fear, is seen as 'unlucky' and in some groups it was even suggested that just by saying the

word you could 'catch it'. As such it is not mentioned. People are 'poorly, or have 'that bad complaint', 'that big disease' or simply do not mention it at all. The word itself is taboo.

- **Lack of understanding of signs & symptoms:** Each one of the groups highlighted a lack of understanding about cancer, specifically about the different types and common signs and symptoms. One group highlighted a desire for healthy lifestyle advice in how to make better choices to help avoid cancer, but said they wouldn't know where to access this. One community highlighted that in recent times that awareness and openness had improved, but it was still not discussed by the older generation. There were comments about literature needing to be available in different languages:

"Support groups can and do sometimes go to temples and then say we'll leave leaflets and information on noticeboards, but the leaflets are in English"

Another suggestion being using short video or audio clips to share important health messages for those who have literacy issues. It was also mentioned that whilst literature was available it was confusing to know what to trust (as in general lots of leaflets are left at community groups).

- **Faith & religion:** Some groups highlighted that there were perceptions that by having cancer a person or their family could be ostracised by the community; that cancer was a punishment for past sins, or a way of being 'washed clean' of past sins. It was mentioned in some groups that the process of even seeking medical treatment showed a lack of faith meaning people are reluctant to seek help.
- **Stigma:** People discussed varying stigmas associated with cancer; from being able to 'catch it' by saying the word, to seeing it as a form of punishment for something, to questioning a person's faith if they seek help.
- **Language Barriers:** Language was cited time and again as being a huge barrier to accessing services. In communities that already have to overcome stigma's associated with cancer, not being able to understand the information around cancer compounds issues further.
- **Gender:** It is clear that in a number of the groups we spoke to, men and women's needs were different when it came to accessing health related support. In a number of the groups it was suggested that men wouldn't willing come forward and ask for help and information; however women were viewed as key players in disseminating important messages to the men in their life. Some groups highlighted that men don't seek medical advice/go to the GP because it is 'shameful' and embarrassing.
- **Mistrust of Health Services:** It was mentioned a number of times that some cultures would prefer (and do) seek holistic treatments over medical ones:
"Why is there a lack of information about how to prevent cancer, and holistic ways of treating it as opposed to the one method given by doctors?" A number of people in the various groups said they would prefer to seek treatment in the form of Prayer, herbalism and in some cases, witchcraft. One person mentioned that they would want the views of at least 4 or 5 medical professionals before they accepted their diagnosis.

Recommendations:

- **Translation Services** – Each group where English was not as a first language (or not spoken at all) it was highlighted that appropriate translations services were essential (This is being done with success at Bellbrooke surgery). This to help improve access, accurate understanding and also to privacy. Many people said they were reliant on family translating for them, and given the issues/stigma regarding cancer this was not always appropriate. It was highlighted that there had been cases of this where family members had not passed on the information a medical professionals was saying, being selective in what they were telling the patient.
- **Clarity & Access** - People want simple, clear advice on signs, symptoms, what to expect. Information on posters would benefit from being more visual (less text) and more

representative of communities. Think about the use of Video Clips/Audio to help reach people who cannot read. A number of the groups said they had limited access to online information due to a lack of technical skills.

- **Outreach** – The groups highlighted a need for the service to build and make strong links within the different communities and key players in the community. To take the service to the community. Making contacts with organisations that were well used and respected in the community was essential to its success. Especially regarding key messages, and may even be a location to base services from. Groups were keen to want to share their cultural information with professionals to help build mutual understanding.
- **Cultural Sensitivity & Awareness** – It was felt that there was a lack of understanding by some medical/NHS professionals regarding culture and some of the sensitivities around this. It is recommended that staff are aware of the needs of different cultures, and take into account what is important to these cultures when giving advice/information. It's also important that people's faith plays a key part in some of their decisions around seeking help (or not) and therefore needs to be an awareness of this fact and approached sensitively.
- **Gender** – Consideration to be given to the fact that in some cultures it is can be difficult for men to speak to women and vice versa. Therefore a mixture of genders of the staff delivering the service should be considered. The locations where they would access help may also be different (for example, some places are men only, or seen as inappropriate for women to attend) Discretion is essential to encourage people to access support.
- **Lived Experience** - Involve people with lived experience of cancer in breaking down barriers: A number of groups mentioned that it would be helpful to meet people from their own faith/culture who had had cancer and were well. They felt that this would be a great way to open up discussion and show people that cancer can be treated (instead of simply associating it with death). There is an opportunity to recruit volunteer's/paid staff from these communities to fulfil this role.
- **Empowering communities** – There is an opportunity to work closely with communities to empower people within them to share key messages regarding cancer.
- **Settings** – People mentioned that some clinic settings can feel intimidating. Therefore if the sessions could be held in places that are welcoming (wherever this happens to be).

Key themes on CCS by Support Staff & Stakeholders:

- **Lack of clarity:** There is lots of support on offer, but often people and professionals are not aware of it. Some staff mentioned that they had a lack of clarity about the best place to signpost someone with cancer for support. There was also mention that some patients/carers who would benefit from Hospice support, don't live in an area where they could easily access it. Only one person felt that: *"There is a well-coordinated approach to care in the community...with shared I.T provision it makes the service provision quite streamlined and patient centred"*
- **Support outside clinical need:** It was discussed that people's clinical needs were met, however there was less easily accessible support to help people deal with feeling 'Isolated, demoralised, loneliness'. A number of professionals highlighted that there was 'huge involvement' following diagnosis, but that 'the level of support drops' after treatment. It was also discussed that some patients decline care that is on offer – especially if it is from Hospice nurses. The result then being people seems to have more 'fragmented care'. One person mentioned that there needs to be a 'custom approach' to service delivery, implying that people's cancer journeys are not one size fits all. There was also feedback that there was a lack of funding for people who wanted to access such as exercise simply for fun. One professional highlighted that it is even harder for marginalised people to access provisions in the community

- **Psychological & emotional support needed:** Many of the staff mentioned the importance of access to psychological and emotional support – not only for the patient but for carers. They discussed how a diagnosis can be very hard to come to terms with, and quite often people can feel lonely and isolated: *“Psychological support could be improved in the community. In hospital patients have lots of support and people to speak with. This can often be lost when at home.”*

Recommendations:

- 88% of staff felt there was a need for a service like Community Cancer Support
- 94% of staff said they would refer people who had been affected by cancer to a service like Community Cancer Support
- 52% of staff would refer by SystemOne/Emis, closely followed by Email (29%) then phone (18%). Therefore a combination of all these methods would make the service accessible for professionals to refer.
- The service needs to be bespoke to the patient need – not one size fits all. The CCS offers an opportunity to coordinate support for patients/carers in a way that prevents people from feeling overwhelmed or lost

Next Steps:

These findings have now been shared with the Community Cancer Support steering group to plan next steps, and incorporate key recommendations into the service models for each area. The initial focus of the CCS service in the areas where many of the seldom heard groups live will be to spend time engaging with the local community and building relationships with community leaders and groups before the service is established in order to ensure it is accessible as possible for all people living within the local area.