

Spring 2012

Patient Experience Team Newsletter

Welcome

Hello and welcome to the first edition of our newsletter.

Page 2

Cancer Does Not Discriminate Launch

Find out about our exciting trip to the House of Commons to launch the Cancer Does Not Discriminate Campaign.

Page 3

Update on current projects

Find out what we are doing at the moment.

Page 4

Great Lengths

Find out about our latest work with an innovative hair loss project.

Page 5

NCAT Community Ambassadors

Find out about our community ambassadors scheme and our cancer awareness broadcasts.

Page 6

Cancer and Ethnicity Research Portal (CERP)

What is CERP? How do you use it? And why you should!

Page 7

Welcome to the newsletter

Welcome to the first edition of the Patient Experience Team newsletter. This newsletter has been written to provide you with an update on the projects we are currently working on and also to give you a chance to input into the work and get involved.

Hopefully by the time this reaches your inbox we will be well on the way to spring and we will all be feeling the joys of it!

Editorial

2011 was a very busy year for the Patient Experience Team. We worked on a number of very exciting projects. In 2012 we will be continuing to move forward with the same enthusiasm.

In December 2011 we launched the Cancer Does Not Discriminate Campaign at the House of Commons. This saw the culmination of many months of planning and preparation. However, it was just the start! The projects and initiatives highlighted at the launch will continue over the next 12 months and in some cases beyond.

We started 2012 as we mean to go on. We're working on raising cancer awareness in Black and Ethnic Minority communities with a series of radio shows. These shows are broadcast every two weeks. Work is also nearing completion on an Asian health supplement. This follows the well received publication of the health supplements created specially for the African and African Caribbean communities, and the Irish community.

We will also continue to work in other areas where cancer patient experience has been identified as poor. We will be working to support healthcare professionals with tools and resources to help improve the experience of cancer patients.

Meet the team

We are a small team within the National Cancer Action Team. Our work focuses on improving the experiences of all cancer patients. We also help trusts, teams and individual health care professionals to ensure quality and equality of experience.

The team is led by Associate Director for Patient Experience Paula Lloyd Knight.

Paula is assisted by her PA Dennise Friday. However, this role is currently being filled temporarily by Stefenie Milosz.

The team also has two project managers, Suzi Chung and Claire Elshaw. Suzi's work focuses on equality whilst Claire's work focuses on communications.

Fiona Barlow is also currently working with the team as a research fellow.

The team works with a number of partners on its projects. This working partnership is vital to the success of the projects and we would like to thank everyone who is involved in the projects for their hard work so far and continued support.

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Unless otherwise stated photography is by Claire Elshaw for the National Cancer Action Team.

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claire.elshaw@ncat.nhs.uk

Cancer Does Not Discriminate Campaign Launch

On Wednesday 7th December NCAT was very pleased to launch its 'Cancer Does Not Discriminate' campaign.

The campaign brings together several of NCAT's projects on raising awareness of cancer in Black and Minority Ethnic (BME) communities. The launch was held at the House of Commons and was hosted by David Lammy, MP for Tottenham. Mr Lammy welcomed the guests and spoke about his own personal reasons for supporting this important campaign, as well as its importance to the wider BME communities.

'I am proud to be hosting the launch for the Cancer Does Not Discriminate Campaign. Cancer can affect anyone, from any background, at any time. Being aware of the early signs and symptoms, attending screening, and being proactive about your health are very important. We all need to take the time to look after ourselves and each other, and to be able to discuss issues which affect us and our communities.'

David Lammy, MP for Tottenham

'NCAT is pleased to have developed this very important campaign to raise the levels of awareness of cancer in BME communities. By working with all diverse communities, through local community groups, support groups, and third sector organisations, we will be able to work in a more effective way, which will reach people, whose awareness and knowledge of cancer may be low. By doing this we will ensure that more people go on to use the national cancer screening programmes, and visit their GPs earlier'.

Professor Sir Mike Richards, National Clinical Director for Cancer and End of Life Care.



Professor Sir Mike Richards, speaking at the event

The event was also attended by members of National BME Cancer Voice; representatives of leading cancer charities and our project partners including The Spectrum Radio Network.

The campaign will initially be targeted in the following areas: London; Leeds; Leicester; Birmingham; Nottingham.



Attendees at the event all wearing the campaign shirts, including David Lammy, MP and Anjula Mutanda

Other speakers at the event included Diane Abbot, MP for Hackney North and Stoke Newington; Anjula Mutanda, celebrity psychologist and Prof. Sir Mike Richards.



We'd like you to show your support for the Cancer Does Not Discriminate campaign by putting our badge on your website.

Please contact Claire Elshaw for details
claire.elshaw@ncat.nhs.uk

Current Projects Update

National BME Cancer Voice

NCAT is working to help give a voice to those from BME backgrounds affected by cancer. The National BME Cancer Voice, which includes Asian Cancer Voice and Black Cancer Voice, has been set up to encourage people from all BME backgrounds to share their experiences of cancer care and work towards improving NHS cancer services.

NCAT is working with several recruitment stakeholders to encourage participation from cancer patients and carers. We would really appreciate your help in recruiting members. For more details visit:

www.bmecancervoice.co.uk or email Suzi at: suzi.chung@ncat.nhs.uk



BME Cancer Voice members at the Cancer Does Not Discriminate Launch

You can help us by displaying posters and leaflets in your locality. Order resources from www.bmecancervoice.co.uk/index.php/getting-involved/order-materials

Libraries Project

NCAT is taking to the road with its Libraries Roadshow. The roadshow targets our key areas of London, Leeds, Leicester, Birmingham and Nottingham. Each event will

last up to three weeks and will feature a combination of information stalls, banners, awareness talks and drop-in sessions.

The stall hosts a variety of information on the most common forms of cancer including: breast, bowel and prostate cancer; information on the national screening programmes; information on cancer in a range of languages spoken by local residents and information on NCAT BME Cancer Voice which gives those from BME backgrounds a chance to share their experiences of cancer.



Our stall at the Brixton Library in November 2011

If you would like to volunteer to give an awareness talk or host a drop in session at a local library event please contact Claire Elshaw on: claire.elshaw@ncat.nhs.uk

Culturally Sensitive Audit

In 2009 a baseline audit of trusts and their capacity to deliver culturally sensitive cancer services was conducted by the National Cancer Action Team. A self assessed audit was completed by 111 trusts. The baseline audit can be downloaded from www.cancerinfo.nhs.uk.

In 2012 a qualitative follow up was undertaken to ascertain best practice and key principles. This work was done in partnership with Breast Cancer Care.

A support tool for commissioners will be published late spring.

Patient Experience Survey

A stand alone survey regarding the provision of patient information will be sent out to over 1000 BME patients, who originally responded to the 2010 National Cancer Patient Experience survey.

This survey is to drill down deeper into some of the issues that have been highlighted by the original survey. The survey will go out to the patients during Spring 2012.

Patient Partnership Forum

The NCAT Patient Experience Team are pleased to be working with the Patient Partnership Forum. We are happy to be working with them to help improve the experiences of all cancer patients across England.

Great Lengths

Many people experience hair loss during their treatment for cancer. Across the country there is variation in the type and level of services offered to people. These range from being given access to a wig after the first or second course of chemotherapy, to access to a voucher or home wig service. In most cases issues around hair loss, although explained within the consultation setting, do not go into detail about the process, pain, or options available at a time before hair loss is well on its way. 'Great Lengths' has been set up by a patient and her husband after treatment for cancer, which resulted in hair loss, to provide timely advice and information on hair loss. The courses will be free to both patients and trusts, and will work alongside existing wig provision.

Workshops are there to enhance the information and advice that patients get about the process of hair loss and the choices they have with regards to wigs and hair coverings



Photographs in this article provided by Great Lengths.

Great Lengths have developed a model based on a similar concept to 'Look Good Feel Better'. It sees patients having free access to a workshop which takes them through the stages of hair loss, what to do, and how to style wigs and apply false eyebrows and eye lashes.

NCAT is supporting Great Lengths to pilot the hair workshops in Leeds, Bristol and Oxford.

The pilot aims to:

- assess if the concept of free workshops on hair loss appeal to patients
- ascertain the correct point in the patient journey that a workshop should be made available to patients
- understand the experiences of the patients taking part in the workshops
- understand the trusts view of the workshops and whether they see this as beneficial to patients.

The pilot will take commence in March and a report will be available by Summer 2012.

We would like to hear your views and comments on this project, please email:
Patient.Experience@london.nhs.uk

NCAT Community Ambassadors

NCAT is currently three months into a 12 month community ambassadors pilot in partnership with the Spectrum Radio Network. This pilot is aimed at raising cancer awareness levels in two target BME communities through radio shows and awareness events.

In 2011 two NCAT Community Ambassadors were appointed as high profile representatives of their communities. These ambassadors are: Mugabe Maase, a well establish Morning Radio show presenter and now NCAT Ambassador for the Ghanaian community; Misbah Jamal presenter of the London Bangla Show and NCAT Ambassador for the Bangladeshi community.



Misbah Jamal interviewing Jusna, a hospital Imam, about cancer treatment and Ramadan

The ambassadors have already interviewed knowledgeable guests around several tumour types in a series of engaging and informative shows. Clinical Nurse Specialists, Consultants, Charity Health Promoters and even patients have shared their experience and knowledge on breast, bowel, prostate and mouth cancer. The shows have highlighted signs and symptoms, discussed what to do if you have any worries, encouraged people to talk about problems and visit their GPs with any concerns.

We have had guests from The Prostate Cancer Charity, The Mouth Cancer Foundation, Breast Cancer Care and Bowel Cancer UK.



Mugabe Maase, NCAT Community Ambassador for the Ghanaian Community on the airwaves.

As well as the radio shows, our NCAT Community Ambassadors are attending leading cultural community events and hosting their own events. At these events they talk about their role and discuss issues around cancer in their own communities on a face to face and individual basis. At these events they are encouraging more proactive community engagement in cancer awareness, more open discussions around signs and symptoms and helping to signpost people to further information.

NCAT hopes that this pilot will prove to be an effective way to communicate with communities about cancer. Over the next few months we will continue to attend events and will have more radio shows on specific tumour types and general issues around cancer awareness. To find out more about the presenters and listen to previous shows head over to:

www.spectrumradio.net/ncat

If you would like to be considered as a guest for a radio show or a speaker at a community event, please contact Claire Elshaw on:

claire.elshaw@ncat.nhs.uk

Cancer and Ethnicity Research Portal (CERP)

What is CERP?

The Cancer and Ethnicity Research Portal (CERP) is a resource for the sharing of information. It is a website containing a collection of grey literature specific to cancer and ethnicity.

CERP's aim is to provide a facility which allows these resources to be made more widely available. The reasons for this are to:

- help fill gaps in knowledge around cancer and ethnicity
- enable the spread of information about potentially innovated and informative practices
- share best practice and learning experiences
- share care practices for BME patients that are appropriate and sensitive to their individual and cultural needs.

CERP contains material that is uploaded by users who want to share their work and findings with others. These materials include reports; research papers; project outlines; Masters Dissertations and PhD theses; conference abstracts, posters and presentations and links to useful sites providing additional resources.

Where is CERP?

CERP is open access. It can be accessed via www.cancerinfo.nhs.uk/cerp

Go take a look at the material already there, browse around to find things that might help you in your daily practices.

Can I contribute?

Do you have a paper you think should be on the portal? Do you want to share your good work with colleagues? You can become a contributor and submit your material to be included on CERP. This material will be considered by an editor to make sure it is appropriate for the portal.

To check out the content head over to
www.cancerinfo.nhs.uk/cerp

If you have any projects, research papers etc that you'd like to upload we'd be happy to receive them.

Thanks for reading

We hope you enjoyed reading this newsletter. Please feel free to pass it onto your colleagues.

Keep an eye out for the next edition, due out summer 2012.

Please direct any general comments or enquiries you have regarding this newsletter or the team's work to:

Patient.Experience@london.nhs.uk



Check it out!

Future Projects:

More information will be available in future issues of this newsletter on our future projects including:

- Children's and Young People's survey
- Community Pharmacists project
- Prosthesis project
- Champions for Change
- Patient Experience interviews.

On the web!

You can find more information on our projects at our website:

www.cancerinfo.nhs.uk

The work on Cancer Does Not Discriminate and BME Cancer Voice can be found here:

www.bmecancervoice.co.uk



See you again in the summer!



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