



Asian Breast Cancer Support Group

The Nightingale Centre and Wythenshawe Hospital
Southmoor Road, Manchester M23 9LT

Email: asianbreastcancersg2011@gmail.com
Twitter: Asian Breast Cancer @BME_CANCER
www.asianbreastcancersg.org

ASIAN BREAST CANCER SUPPORT GROUP MEETING

Friday 31st March 2017, The Nightingale Centre and Genesis Prevention Centre

FEEDBACK AND EVALUATION FORM

It would be helpful to us in planning future events if you would please complete this form.

1. What were you expecting to gain from today?

Insight into the work of Support group
Experience of patient engagement / involvement and relates to cancer treatment + care
Ideas of how to involve patients in research – what patients feel we as clinicians can do to involve them more
Learning & understanding
Look forward to some place
Positive steps taken by health professional to improve patient care
Experience of patients around engagement & empowerment and suggestions on how to improve
Knowledge + understanding of patient engagement – Networking
Increase knowledge around patient experience
Meeting people, talking about cancer in the BME community
Knowledge
To meet / network with other providers and gather information about specific piece of work that have been carried out around reducing inequalities and engaging Asian population in breast screening programmes
Hear from patients themselves to inform practice
An opportunity to speak your mind and listen
To know more about patient engagement & empowerment
Networking – Insight into other cultures and beliefs
Insight in what has changed and people's views about the way things have moved forward
Information on how patient can change the NHS
Have been coming to these meetings and each time go with more understanding on this important issues
More information around barriers to engagement amongst BME communities
Patient Experience in cancer, what's happening nationally
How I can help any local community in Altrincham. Come from a Muslim background and hope to hold talks in my local mosque in Altrincham.
Sharing of ideas – Understanding
Learn from best practice
Tangible outcome to improve care
Networking + learning more about patient engagement
Information of services - Signposting – Greater understanding of the procedures involved



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To find out if things are changing & if so is it better, Is there more to be done

Gain a better understanding of terms of patient empowerment & motivation and the barriers to this. Also understanding patient perspective & networking with other professionals ideas to change practice and respect.

& professionals.

An understanding of problems (Asian B/C) face, and how to overcome.

More awareness on issues BME communities face and how to address them.

Current practice in UK related to breast cancer in UK

How the south Asian patients experiencing in UK after they have been diagnosed with cancer.

Research ongoing in the area of breast cancer.

Patient motivation/engagement/involvement.

Understanding and insight.

Networking opportunity, knowledge/understanding experiences of others. Skills and notes on how to engage patients.

Greater connections with others to encourage reflection & insight about difference/diversity/commodities

Meet the group & learn from them & connect with people with similar experiences.

I didn't really know what to expect – I thought it would be more of a support group for women affected by breast cancer. I was surprised to see so many professionals.

BME knowledge and methods to improve.

I would like to have something to take back to my unit. A tool to measure

Open mindedbut wanted to hear patients and NHS England.



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2. Did the event meet your expectations?

Yes (15)

Yes. If the programme /project outcome implemented in the work place

No- felt more focused on HCP'S and their views on it. I thought it would be largely patients

Fully

Exceeded – best yet

yes it did to most extent

Yes, it was very good informative

In part

Very interesting

In part (would have liked more case studies to highlight good work + outcomes

Lots of information needed to be more focus on outcomes to improve care

Yes the survivors stories were very powerful and having patients here along professionals really opens up the conversation

Yes, in general

Yes definitely

Yes

Yes lots of interesting ideas

Exceeded them - my first time there so not sure what to expect.

Yes, but in different aspect which was whether to attend. The experienced breast cancer survivors empowered, even to think they are the real ambassadors to convey their experience and empower the patients.

Yes this event has met my expectations.

Yes

Yes

Yes, Thank you!

Yes

Yes

Didn't know what to expect thought it would be more of a support group for women affected by breast cancer. Surprised to see so many professionals.

Not as focused on BME as I had expected.

Not really today, thought networking was good.

Yes very interesting



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3. What all new information did you learn today?

Work of NHS England patient experience
Potentially the Cultural Humility approved /aspect
Groups available for patients – Patients Ideas
Understanding of the different issues around BME & Cultural differences
How then resolve problems
Some organisation should be held in the area
Neil's lecture on future improvement
Cancer Dashboard had never heard of this before/ good to learn what it is and the stats around this
I had very little experience around patients, so it has been invaluable
Patient stories
Changes are being implemented or planned to improve patient/healthcare professionals relationship
Meeting new groups + Patients NHS England involvement in patient empowerment & involvement
I learnt about the concerns of medical profession that they want to know about the barriers and want to overcome
More on Cultural Humility
Information about new initiatives by government / Health authorities
Info from a medical perspective
Need of patient understanding of problem / communication
Diverse attendance
Good networking /new contacts which will be followed up
National work / Barriers & experience / engagement
Cultural humility is a new concept
Patient's experience have an impact on everyone's care
Understanding the work of Asian Breast Cancer Support Group
Models / information patient experience + dashboard information
Patients being empowered to drive change
Designing patient pathway maps that mirror patient experiences from other countries
Cultural Information
That services operate independently from each other and that a patient care is not just managed by one team and thus can leave some patients lacking aftercare
Change in teaching medical students

Patient perspective:

- How to make them feel more empowered
 - How to address cultural attitude
 - How to overcome barriers in patient empowerment.
- Cultural humility model always evident



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Care plans, charities and improvement of care for the future.

Patient's stories & perspectives

Appreciating things from a different point of view (patients and clinicians)

Power imbalance and how this influences patients and clinicians.

Patient experience is the major contributing factor for proper clinical outcome.

Definitions – Power imbalance

Cultural humility

Importance of engagement/movement/ participating in the decision making process

Motivation

Cultural issues & barriers

The different stories, people's insight & experiences.

Cultural humility

Wider NHS experience

Group work

Useful discussions

Enjoyed connecting & presentation on cultural humility

I learnt most from women talking about their experiences rather than the "theory" of patient experience.

Enhanced recovery.

Patient experience will be put on a par with clinical outcomes

Confirms that patient engagement needs to happen

Some of the NHS England directors and jargon e.g. Always events....hearing women affected by breast cancer

4. Do you think the event has been useful?

Yes, to hear peoples different views particularly patients

yes, very

yes, extremely

yes, the way workshop was facilitated was good & informative

Yes, in that it helped gain an understanding of HCPs and there still need to be more on PPI

Yes, Hugely

Very useful

Very and has provided some fantastic networking opportunities

Yes it was very useful and informative

Yes, very much

Yes very much. Well done!

Yes (5)

Not sure

Yes, Good networking, sharing of ideas

Good for networking

Yes (2)

Yes, it has crossed services and helped create a support network

Yes

Yes (11)

Yes – engaging

Breakout sessions (decision making)



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5. Which areas were most useful?

Listening to patients experience, their own stories and learning from that

Hearing patient views

The actual discussions between patients, other healthcare professionals & other professionals & listening to other people's view – very insightful

Patient empowerment (2)

The discussion around cultural humility

The breadth of knowledge + experience of people talking & contributing

Conversations

All areas had significance

Networking – Patient experience update – Listening to experiences of people with Cancer

All of the presentations + group talk with feedback

Patient's experience

Patient engagement and on Barriers

Group work – Moving services forward

The speech by Neil Churchill was very good and informative

Patient Empowerment + Discussions

Everything

All

Networking – Neil Churchill intro

Life experience – National Picture

Group Discussions – Talks all useful / interesting

NHS England – how they are using the information

NHS England presentation

Discussion in groups

Networking

Hearing from the Champion and amazing organisations setup by survivors

Self-care ideas

Understanding

Very useful to be aware of patient perspective directly and h/how to change my practice in future particularly among ethnic minorities. Good reflection on my 4 months on breast rotation.

How to motivate patients.

Group work was great. Really had me engaged and made me reflect.

Cultural humility and bridging the power balance and the patient empowerment.

Theme 1, 2, 3.

Cancer patient experience / empowerment.

Cultural humility barriers.

Group involvement and discussions.

Connecting across all levels of experience

Great levelling event everyone is equal.

Patient stories

Networking and sharing ideas

Women talking about their experiences, rather than the "theory" of patient experience.

Sharing of ideas to improve patient pathway

Always meeting people who care so much and want to improve women's experiences.



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6. Any suggestions for future events please e.g. any particular topics you want more or less emphasis?

Just a larger room!

How do you involve people in self-care + preventative behaviours

More patient speakers for clinicians to understand

We should get more information about cancer, Doctors should explain to the patients properly

Should get together once a month for talk, what patient feel and needy especially people live alone

If you are doing an event about patient engagement & empowerment include more patients; find out what patients want not what HCPs think. Also suggest training facilitators

More – mine were too leading or answering from their point of view rather than facilitating & encouraging the participants on the table.

Having a focused topic was really good – can we work towards co-production for future research project – Research focused meeting – how to be involved in research – Ideas for research

More events like this should happen with more involvement from people who are affected by the cancer

Some lectures would be better instead of table work completely

Where involvements have been made – where changes can be made - What lies in the future – more interactive events involving patients, health professionals of the future

Keep it up

Lots of background news – sat at the back - Door noise

Thank you – Great event

Looking more at a GM approach – Profile of lots of good, smaller projects

Link with Acute / community – voluntary

Equality monitor feedback forms including demographics – focus on the ‘so what’ principle

Community self-care events, outreach into closed communities

Peer topic support signposting

Explain activities – how you want info presented clearly. Also event goes on too late especially for a Friday afternoon.

More time in groups to discuss thoughts. Felt they were cut short a little. Loads of questions and experiences – get more patients involved in this group (ironic I know)

More research outcomes done among the:-

a) Breast cancer sessions

b) Clinicians self-reflections on delivering treatment.

Some topics took time to discuss, maybe make them simple, helpful tips to promote discussions between strangers.

More personal stories! (Staff & patient) so powerful.

Same + more!

How practitioners have a direct impact on patient population experience.

What they could do in their practice

How the ABC group has been successful clear examples that are in clinical practice (Drs & Nurses etc.)

More Asian speaking and reading.



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