



# Asian Breast Cancer Support Group

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

Email: [asianbreastcancersg2011@gmail.com](mailto:asianbreastcancersg2011@gmail.com)  
Twitter: Asian Breast Cancer @BME\_CANCER  
[www.asianbreastcancersg.org](http://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

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



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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 minded .....but 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)



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Yes – engaging

Breakout sessions (decision making)

## 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/ow to change my practice in future particularly among ethnic minorities. Goof 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.



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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.

## 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 need 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:-



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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.

***Thank you for taking the time to complete this form.***