



Asian Breast Cancer Support Group

The Nightingale Centre Wythenshawe Hospital
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Symposium on Patient Engagement & Empowerment

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

Theme 3: Patient Empowerment

Introduction by Catherine Thompson and Campbell McNeill followed by group work

1. Are patients given enough opportunity to make informed decisions?
 - Sense check – depends/ Yes/ No
 - Offered sufficient information but many always events don't happen particularly in the Cancer services – patients not involved in key healthcare decisions about services – mental health patients are involved from the start
 - Good opportunity to ask about treatment but also need to know about after care and support, being supported and sign posted. Sometimes being given a leaflet needs more explanation and context.
 - Sometimes the emotional impact and mental impact can be hard and other people family may not be able to help so very important to have community support and signpost to people.
 - People can slip through so whole there in excellent care and support but some do slip through and need to make sure don't feel alone. (not everyone has social media etc) Understand treatment and timescales and what will happen, importance of such group as 'moving forward but needs to be open for everyone. Having support in central places. Working lives making 'good employees' . Importance of learning from experience.

2. Do patients feel empowered to ask questions surrounding their health and treatment?
Possible solutions on how to empower patients, eg Are they provided with enough digestible information.
 - Patients don't always feel empowered
 - It would be great for HCPs to ask the patients understanding before they start giving further information surrounding their condition
 - Ask patients what they want to gain from the consultation – if the HCP can't address certain confirms they need to be aware of options to signpost the patient to the appropriate source to get answers.
 - Enhanced Recovery Pathway- Example told about Bowel School – 'a social movement' (pun intended)
 - Touchy feely experience to show what would happen when the patient underwent surgery. This could be an option which gives patients informed decision making options and could provide comfort to some patients.

3. Are patients provided with the right tools in order to empower them to make decisions about their health and treatment?
 - Culture change
 - Improve SDM
 - Fluid guidelines - adaptable
 - Patients not provided tools to be empowered



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- Power imbalance
 - Lack of data/research
 - Lack of trust but a blind trust
 - Ask patient what tools they need
 - Holistic needs assessment – patient information has suggested questions tailored solutions – not 'one size fits all'. Cultural champions, person centred approach.
 - Patient advocate
 - Website, social media, leaflets, specialist website, face to face,
 - Decisions made without patient knowledge
 - Solutions: treatment plan – a written summary at diagnosis
 - Solutions – hand held notes
 - Access to a Specialist Nurses
 - End of life care plans
 - Communication is key
 - Solution - A buddy system?
 - Access to a Specialist Nurses
 - End of life care plans
 - Communication is key
 - Solution - A buddy system?
 - Explanations from consultants, nurses and admin – videos, leaflets and talking
 - People should know what to expect from their screening
 - Make questionnaires simple to read, open and not too long
 - Ask in what format do they want the information ie videos, shorter leaflets, websites
 - Sometimes sufficient information and sometimes not enough
 - Signposting is important
 - Tools – mammography to show the discomfort in the visual aid
 - Waiting area provide visual aids before appointment to put some fears at ease and have an idea of what to expect ie mammogram
 - Explanations to be made aware
 - People can slip through so whole there in excellent care and support but some do slip through and need to make sure don't feel alone. (not everyone has social media etc) Understand treatment and timescales and what will happen, importance of such group as 'moving forward but needs to be open for everyone. Having support in central places. Working lives making 'good employees'. Importance of learning from experience.
 - Introduce buddy system – patient advocates
 - Share experiences
 - End of life care plans – why don't we have them
 - Assurance – understanding about creating a care plan
 - Tools – patients should be given a choice and supported
4. Are patients given the chance to report their experience of care? Do services listen to what patients say and how does this affect policy.
- Variable of patient input
 - Not involved in strategy or planning
 - Tokenistic input
 - Within CLAHRC
 - Literacy levels – How easy are methods? Methods of engagement - needs to be inclusive. Do people listen.
 - Some people reluctant to provide feedback because fear of impact on care/ treatment
 - Solution: breakdown to 10% that are not happy



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- Worry about complaints – impact on care
- Might have positive outcome but a negative experience
- PALS service
- PALS – is it properly promoted?
- Are patients given a choice – friends + family + text messages
- Possibly need different mediums to report the experience of their care
- Patients not involved in strategic planning - no patient inputs into policy changes
- Sharing experiences may be different for different cultures, create spaces in places of work and communities. Public sector employers supportive of people going through cancer that doesn't have to be clinical.