



Asian Breast Cancer Support Group

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

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Twitter: Asian Breast Cancer @BME_CANCER

Symposium on Patient Engagement & Empowerment

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

Theme 1: Motivating and engaging patients

Introduction by Jo Taylor and Anneela Saleem, GP followed by group work

1. What are the likely barriers to effective motivation and engagement of patients?
 - Language barriers
 - Knowledge interpreters and how to access those routes
 - Ensuring patients have understood – two way conversation
 - Patients not listened to – expert on their own body
 - Focus only on the physical cancer and not on the depression and isolation that can result
 - Health literacy
 - Lack of awareness
 - Wrong assumptions
 - Staff experience and engagement
 - Being aware of own body issues and being confident to speak – even to family let alone professionals
 - Lack of support from various people (staff, home) – being isolated as off work and sometimes that can be the main place where people interact.
 - Peer support
 - Not knowing about services and signposting
 - Time from nurses/GP
 - Treatment is good but access and aftercare is poor
 - Sometimes for BME people – the focus is on the cancer only not the wider things like depression, isolation etc.
 - System issues rather than engagement?
 - Stigma and confidentiality
 - No point – nothing will happen with their views
 - Vocabulary – medical jargon/ scientific terms
 - Not wanting to look stupid
 - Fear/ worried about being too emotional
 - Consultant not always ensuring that the patients have understood – too much information all at once/ takes time to absorb and digest
 - Patient support network
 - Culture/ religion/ language (and not making judgements) community/ education.



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- Family members acting as interpreters sometimes not delivering the full message
- GP/ receptionist - receptionists need to be friendly – 1st port of call
- Communication of what to expect
- Previous experiences of healthcare – experience of health care in a different country
- Low numbers of interpreters – access and telephone services
- HCP education/ cultural awareness
- Knowledge of the pathway
- The first point of contact should know about language barriers
- Communication pathway
- Patient journey
- Ideas, concerns, expectation differences
- Stereotyping
- Overcoming barriers to speak
- Patient reluctance – more in Asians
- Previous negative experiences with HCP
- Age related differences
- Fear of the unknown
- Not listening to patients as clinicians
- Socioeconomic background age etc
- Lack of knowledge to inform decisions
- Perceptions of the clinician – ‘always knows best’
- Clinicians approach – unaware of the prognosis
- Language at initial diagnosis
- Local community – religious centres – break the barrier
- Language barriers don’t tend to engage if lack of understanding
- Attitude
- Staff ‘listening’, not looking too busy
- Confidentiality

2. What are the benefits of effective motivation and engagement of patients?

- Recovery time – may be reduced as a result of knowing information
- Compliance with treatment if health benefits are outlined properly
- Better patients – save money
- Empower others – patients or community
- Enough information can help the patients’ mental state
- Engage/ support can be simple by understanding patient needs
- Engaging trust and putting people at the centre makes them able to follow/ engage treatment
- Co-production/ co-design
- Being listened to and respected
- Offering support in ways that are simple



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- People from BME backgrounds may have different engagement and motivation which current systems may not know how to respond to – need to ask right questions.
- Positive outcomes
- Patient based, individual info – everyone's different
- Empower other patients
- Shared experience/ support
- Control from the patient perspective
- Improvement of their health
- Patient at the heart
- Can give feedback to improve health services
- Adherence to their drug regime
- Increase in screening uptake
- Empowered self-knowledge
- Positive outcome in their hands
- Money savings for NHS
- Better patient outcomes
- Reduced cost of wasted medicines
- More information improved mental state
- Make informed decisions
- Confidence in discussing their illness
- Family involvement – who can you share with, burden to your family
- 'I am an expert on me'
- Building trust – approach and attitude of the clinicians
- Equal engagement
- Motivates an individual
- Medical and physical process
- Better uptake
- Control
- Trust
- Allows signposting

3. How we can meet patient's emotional needs and allay their fears and anxiety?

- Break down info into simple info – not the same to everyone, some people may need more reassurance than others
- Deep listening - 'HCP didn't say anything' – HCP should take a step back
- Use of photos of staff (on letters, in waiting rooms) to put people at ease.
- Understanding not making assumptions
- Need to have open practitioners to ensure patients are honest about their symptoms to receive the right treatment
- Understanding what engages and motivates BME women – openness and the right questions.
- Having champions/ ambassadors who people trust to speak to
- Sharing stories and experiences



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- Finding out about the things that are working for people – not just NHS support
- Ensure system can respond to the needs of people
- Providing support for things outside the cancer diagnosis
- Trust in staff who are knowledgeable
- Understanding but not assuming
- No right or wrong response/ reaction to feelings
- Signposting/ choices
- Taking account of individual personality
- Engaged and motivated as much as suits the individual
- Meeting emotional needs and anxiety
- Past experiences creates anxiety
- Respect all patients
- Give treatment plan early
- Inclusive image
- Put yourself in others shoes
- Expectations of different groups
- Guidance through the system
- Emotional needs not met
- Individuals emotional needs should be met
- Initial shock – how much can you absorb
- Positive – disease not the end of life – very important
- Emotional element – support from a professional
- Clinicians approach can affect the way you take information
- Acknowledge it is new for you

4. Possible solutions on how to motivate and engage patients.

- Free education workshops about general illness; give them information about potential questions to empower the patient to ask the GP.
- Fear of the word cancer – Educate the males too. Potentially school education system.
- Confidentiality – if patients have not met anyone else in the same position as them it could make them feel isolated – have quarterly meetings with other patients through email, face to face and social media – gives people to talk to for support.
- Collective projects
- Plain language and communication
- Access to navigators/ and organisations like patient voices to be heard – ensure people are in touch with each other if they express an interest to do so.
- Ensure there is a safe place to share stories and relate to each other. E.g. ensure ages and groups are taken into consideration - more powerful.
- Creating condition to be open and safe
- Asking questions
- Bridging gaps in understanding



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- Easy/ simple messages
- Plain language/ communication/open and honest
- Listening – treat as an individual
- Listening to the stories of others
- Devolution Manchester – collective projects
- Effective tools for engagement
- Celebrate success
- Photos of all staff on the walls
- Outreach projects
- Routes to cascade info into the community
- Look at best practice – what works
- Always events – for BME Communities
- Reflective practice
- Sharing of best practice
- Map of healthcare differences
- Improving communication between patients and HCP
- Expert by experience not necessarily by clinician
- Education Knowledge Information
- Going to communities for screening
- Information at an early stage
- Being honest about risks and outcomes and choice
- Patient group meetings
- 'Navigators' being available
- Existence of 'HealthWatch' – Patient Voice
- Access to support groups for similar patients
- Patients may feel less scared if they talk to other patients
- Educate Males – head of the family
- Listen to patients
- Take fear away from Cancer
- Support groups in the community
- Provide info in a way people understand
- Male participation
- Women support groups, activities e.g. art, therapy
- Good access to Breast Cancer Nurse
- College level education
- Cultural Centre – socialising centre
- Ask patient what she wants and who she wants to be involved
- Family lead – male educated at the same time – if patient is in shock may not remember
- Find out what motivates patients
- Looking at body language
- 'Correct less and connect more' as professionals
- Trying different approaches – have groups
- Communication – Training
- Time
- 'What matters to you' instead of 'what's the matter'



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- Approach of consultants – open questions
- Correct less – connect more