Gynaecology and Breast Combined Research Day

A One Stop Clinic for BRCA Carriers

Dr Louise Izatt
Consultant in Clinical Genetics
BRCA Family Service Lead
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Our patients are becoming much more aware - driving change and increasing demand

1994- BRCA1
1995- BRCA2
2004- NICE Guideline
2006- NICE guideline for MRI
2006-fully comprehensive testing of both genes>20% risk
2013-NICE gene testing threshold lowered to 10% risk BRCA1/2

CG164 Familial breast cancer (CG164)
Co-ordinated BRCA Family Service for carriers

• One-stop multidisciplinary BRCA clinic
  » Genetics
  » Breast care and plastics
  » Gynae-oncology
  » Oncology
  » Clinical psychology
  » Research

• Access to professional and peer support
• 6-monthly patient update meetings and patient newsletter
• Opportunities to take part in research
• Follow up at key time points
• Open door policy for contact with Genetics
Routes into the BRCA clinic

Genetics

Mutation search test, affected individual

Mutation search test, unaffected individual

Predictive test

BRCA Mutation identified

~50

BRCA Family Service

BRCA Mutation Positive

~100

BRCA Register
80 in 2003
278 in 2006
401 in 2008
1233 in 2014

Patients referred at various stages

Diagnosis → Primary treatment → Remission → Relapse → Secondary treatment → Remission

GSTT BRCA Family Service Team

Consultant Genetics Doctors
- Louise Izatt
- Anjana Kulkarni

Genetic Counsellors
- Sarah Rose
- Cecilia Compton

Gynae-Oncologist
- Gautam Mehra

Breast Surgeons
- Hisham Hamed

Plastic Surgeons
- Jian Farhadi

Oncologist
- Andrew Tutt

Clinical Psychologist
- Clare Firth

Genetics Research team
- Michelle West

Administrator
- Stephanie Wells
Role of the Genetics team before BRCA clinic

- One or more genetic counselling appointments prior to testing
- Pre-test counselling includes:
  - Likelihood of genetic susceptibility in the family
  - Risks associated with BRCA genes
  - Options for risk reducing surgery and surveillance
  - Risk to children and other relatives
  - Insurance
  - Feelings about positive/negative result
  - Family/bereavement/other issues
  - Assistance with decision-making
- Results appointment or telephone follow-up
- Update pedigree
- Discuss and enable cascading information amongst family
- Refer to Higher Risk breast screening programme if eligible
- Ensure capture of data for accessing records of any prior cancer treatment ahead of BRCA clinic
- Refer for RRSO if > 50 and keen to proceed ASAP
Risk management options for women at high risk of breast cancer

- Breast surveillance (NHSBSP Higher risk programme)
- Risk reducing bilateral salpingo-oophorectomy
- Risk reducing bilateral/contralateral mastectomy with/without reconstruction
- Chemoprevention

Breast Screening- local access
2013 NICE guidelines and referral to Higher Risk screening programme in NHSBSP
BRCA Clinic

- All patients see one of the genetics consultant team
- All patients are seen by research team if eligible
- They choose whether they would like to see the clinical psychologist, breast team (surgeon/plastics/breast care nurse), gynae-oncologist and oncologist for patients with current cancer
- Consecutive appts (n=2-6), own room, expect to be in Guy’s for half a day
- Partners or a supportive friend encouraged to attend
- MDT in middle of clinic- unaffected patients or less complex cases in the morning
- Appt is for a single family member
- Some flexibility to see another clinician if needs have changed

Individuals seen in Multidisciplinary Clinic
February 2006 – February 2008
Specialist appointments at Multidisciplinary Clinic  
February 2006 – February 2008

N=170 attendances over 24 months  
Now ~120 appts per annum

Role of the genetics team in the clinic

- Discuss issues raised by the patient e.g. surveillance, reproductive issues etc.
- Support cascading information to the family
- Discuss chemoprevention
- Help identify key issues to be discussed with members of MDT
- Liaise between other members of the team
- Co-ordinate patient’s management
- Encourage participation in research studies
The first baby in the UK tested before conception for a genetic form of breast cancer has been born. BBC News 1/2009

Offered at GSTT - Strict entry criteria for funding
• Revised techniques are improving success
• For some couples this is the only way they would want a family of their own

Some couples have elected for PND- ffDNA-
If female fetus, proceeding to CVS and opting for TOP if affected

Others have sought egg preservation, with a view to PGD later

BRCA family service- RRM

• RRM reduces brca risk by >90% (Rebbeck 2004)
• >60% opt to see the breast and plastics team
• 159 women chose BRRM before any cancer diagnosis
• Others have opted for RRM at cancer diagnosis/or chosen CRRM at a later date
• Age range 23-65
• Majority 35-49
• ~25% at earliest opportunity, rising to 55% with time
Uptake of RRSO

- RRBSO (before menopause) reduces breast cancer risk by 50%, ovca risk by >80% with a 77% overall reduction in mortality (Finch et al, 2013)
- Majority 40-59. (Range 29-77)
- Uptake >85% in non cancer patients

Current recommendation
- Consider RRSO in BRCA1 from 35
- Consider RRSO in BRCA2 from 45
- RRSO as a separate operation to RRM
- Autologous breast reconstruction not compromised by RRSO
- TAH not required unless separate gynae problems
- Add back HRT in non cancer patients until 51- Mirena coil and oestrogen patch
- Consider RRSO on a case by case basis in patients with current/recent breast cancer due to competing risks

Risk management options for women at high risk of breast cancer

Breast surveillance

Risk reducing bilateral salpingo-oophorectomy

Risk reducing bilateral/contralateral mastectomy with/without reconstruction

Chemoprevention
Chemoprevention options

• Breast cancer risk reduction over 10 years: 38% for Tamoxifen and 23% for Raloxifene \(^1\)

• Risks include menopausal symptoms, reduced bone density, endometrial cancer

• Offered to women at high risk of breast cancer - NICE, 2013

• Estimate 25% uptake- in our clinic only one person has opted to take this option, most are seeking RRM or screening only whilst completing their families


Managing Health in the Context of Chemoprevention

Multi-disciplinary approach
Individualised risk / benefit assessment
Baseline assessment of;
• Breast cancer risk
• Cardiovascular risk
• Metabolic syndrome
• Quality of life
• Bone health
• Illness perception
• Attitude about medicines

Impact of chemoprevention on individual cancer and non-cancer outcomes
Plan appropriate individualised surveillance and monitoring

Patient centred
Who should do it?
Cancer genetics?
Breast clinics?
Gyna-endocrine?
Primary care?

Cancer surveillance
Cardio-vascular disease
Vaginal dryness
Metabolic syndrome
Bone Health
Weight / obesity
Uptake and adherence
Psychological support

Courtesy of Jo Marsden, KCH
Psychology Input - Measures

- Distress Thermometer Akizuki et al, 2003 (since Feb 08)
- 1-10 and physical and emotional symptoms
- Sent back with appts form, copied to clinicians (geneticist and psychologist) on clinic day
- Patients with high distress (8-10) offered appt or write to GP
- 54 appts in BRCA clinic 2014 - mean DT 5.54 cf. 3.65 for carriers not opting to see psychologist
- All pts undergoing RRM are seen by psychologist pre-op- either in BRCA clinic or before RRM surgery date

Main themes discussed with psychologist

- RR Surgery- decision, weight loss, body image, impact of surgery, operation anxiety
- Bereavement
- Cancer anxiety
- Cancer experiences
- Guilt about passing gene on
- How to tell the family about the result
- Self esteem/assertiveness
- Contact with family
- Discovering ancestry
- Informing children about cancer
- Telling children about a BRCA gene result
- History of depression (fertility)
- Relationship issues
Interventions (Brief)

• Space to talk and reflect
• Review situation
• Discover resources, external and internal
• Brief CBT, e.g., panic cycle, negative thoughts around guilt etc.
• Identify ways of coping
• Brief Couple work
• Help with making Decisions
• Providing info on research (i.e., for psychosocial impact of surgery, helping them to prepare)
• Onward referral (Breast Unit Psychology, breast cancer support group)

Satisfaction survey of BRCA Clinic 2014

• 14 item questionnaire handed out in clinic
• 92% returned (35/38) (Feb-April 2014),
• Improved ratings compared to 2013, despite increased numbers seen in clinic

“I found this so helpful. Everyone was really professional but also warm and compassionate & client/patient focussed. I know where I am heading now. It’s given me back a much-needed sense of control. Thanks so much.”
BRCA Family Service

- Successful monthly clinic running monthly since 2006, helping BRCA carriers make informed decisions about reducing ca risk
- Over 800 BRCA carriers seen in the clinic (>1200 on register)
- Comprehensive care pathways with multiple specialists in a one-stop clinic, following national or local protocols to offer consistent, timely, evidence-based care
- Psychology input is an important component to its success
- High satisfaction with clinic model
- Recall to consider RRSO
- Open door access to ensure management options are explored at earliest opportunities
- Opportunities for update days to explain new developments, meet other BRCA carriers and question the team on any relevant topic
- BRCA support groups in four locations in the region - a model of patient involvement and partnership
- The BRCA Family service can adapt equably as new guidance and opportunities emerge (e.g. translational studies)
- The clinic model that has been adopted for other genetic diseases

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Refs:

Contact : louise.izatt@gstt.nhs.uk