United Kingdom Familial Ovarian Cancer Screening Study: an update

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Background


• Phase 2: study gynaecologist Mr K. Luthchman-Singh. Consultant Geneticist Dr. A. Murray. Genetic Counsellor, Mrs Liwsi-Kim Protheroe Davies.

• Swansea : +/- 120 volunteers, from S.W.Wales and Mid Wales. Cover part Bridgend, Neath Port Talbot, Swansea, Llanelli, Carmarthen, Haverfordwest, Aberystwyth.

• Study finishes completely in June 2011
Who

- Women > 35 assessed at increased risk of ovarian cancer by the Cancer Genetics Service
- Met study eligibility criteria from their family history
- Carriers of BRCA1 or 2 gene alteration – at risk of ovarian, fallopian tube and primary peritoneal cancer.
- Carriers of Lynch Syndrome gene alteration (HNPCC)—at risk of ovarian and endometrial cancer
How

- Phase 2 informed from phase 1 co-ordinated in London
- 4 monthly CA125s, bloods posted to UCL
- Results processed by the ROCA computer algorithm, stratifies women according to their CA125 pattern over time
- Annual TVS in Singleton, reports sent to UCL
- If ROCA raised: repeat blood or scan as indicated, or rapid access appointment with KLS.
- Outcome, high alert screening or
- Surgery.
Suggested by UKFOCSS
end of study winding up

Last Screen result (end June 2011)

• 1. Normal (83%): write to volunteer, give symptom information, need to d/w Genetics re risk, gynaecologist if requesting RRSO

• 2. Intermediate results or abnormal scan (est 15%): need to repeat investigations - hand over to named gynaecologist (KLS): write to volunteer re transfer of care

• 3. Needs or already referred (est 2%): write to volunteer re handover and need to continue care.
What then?

- No set strategy, each centre to decide what they can offer
- 12 centres responded to UKFOCSS query as to what they will do. 50:50 will/will not continue to offer screening despite being unproven. (Certain centres offered before UKFOCSS)
- Possibly 2015 before clear direction
UCLH post UKFOCSS Mx

- Family Cancer Clinic: baseline assessment (CA125 TVS)
- G.P. if symptoms, refer, investigations
- 41% volunteers are >50
- UCL focus group.
- Women like screening, faith, "reassuring" attach psychological benefit
Groups to consider

- Existing volunteers
- New women identified at risk
- Mutation carriers who are the highest risk
• Cancer Genetics will continue to counsel regarding risk and options
• We anticipate there will be an increased number seeking referral to a local gynaecologist for ovarian risk management / consideration of risk reducing surgery
• Approx estimate 15 women at risk are from each hospital catchment
Protocols and Information Sheets
copies available

• Stand alone protocol produced by UKFOCSS for surgeons and pathologists

• Peritoneal washings (PPC and staging)

• Informing lab on request form from theatre

• Pathology procedure (small sectioning and exam of entire ovary and both fallopian tubes in case of small micro cancers)

• Patient information sheets – cover for eg not essential for risk reduction to include hysterectomy (except in Lynch syndrome). Each case d/w gynaecologist. Also when necessary to address osteoporosis prophylaxis.