JEWISH MEDICAL ASSOCIATION UK

JEWISH POPULATION BASED BRCA TESTING

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Disclosures

Research Funding

Pop Testing

the eve appeal
fighting women's cancers

TheAHSNNetwork NHS England
NHS Innovation Accelerator

NHS CANCER PROGRAMME

Yorkshire Cancer Research

CANCER RESEARCH UK

Other

gsk GlaxoSmithKline

b+tlc BARTS CHARITY

Rosetrees Trust
Supporting the best in medical research

BRITISH GYNAECOLOGICAL CANCER SOCIETY

NHS North East London Cancer Alliance

NHS North Central London Cancer Alliance

Other Disclosures- Honorarium – MSD, Astrazeneca, GSK, EGL, Israel National Institute for Health Policy Research

COMMUNITY SUPPORT

the eve appeal
fighting women's cancers

The movement for REFORM JUDAISM

Boots

JEWISH CARE

NORWOOD
CHILDREN & FAMILIES FIRST

Agudas IHA

ovacome
the ovarian cancer support network

THE ASHKENAZI STUDY GROUP ISRAEL AND THE MIDDLE EAST

liberal judaism

oneinforty
BRCA awareness, education and support

PREVENT HEREDITARY CANCER COALITION

Jnetics

Kisharon

TheAHSNNetwork NHS England
NHS Innovation Accelerator

NIA Fellowship

chai cancer care
together we can cope

BRCAUmbrella
Support when you need it...

OVARCOME
OVERCOMING CANCER CELEBRATING LIFE!

TARGET OVARIAN CANCER

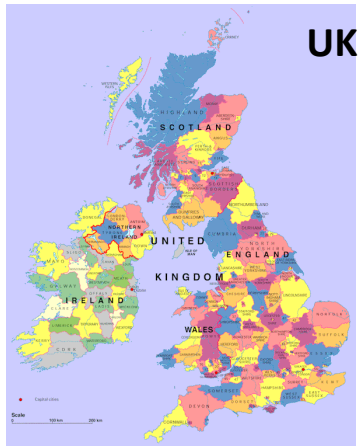
ovarian cancer action

gogirls
SUPPORTING YOUR CANCER JOURNEY

Multiple other Stakeholders

- BACKGROUND
- THE JEWISH POPULATION MODEL
- NHS BRCA TESTING PROGRAMME
- GENERAL POPULATION TESTING

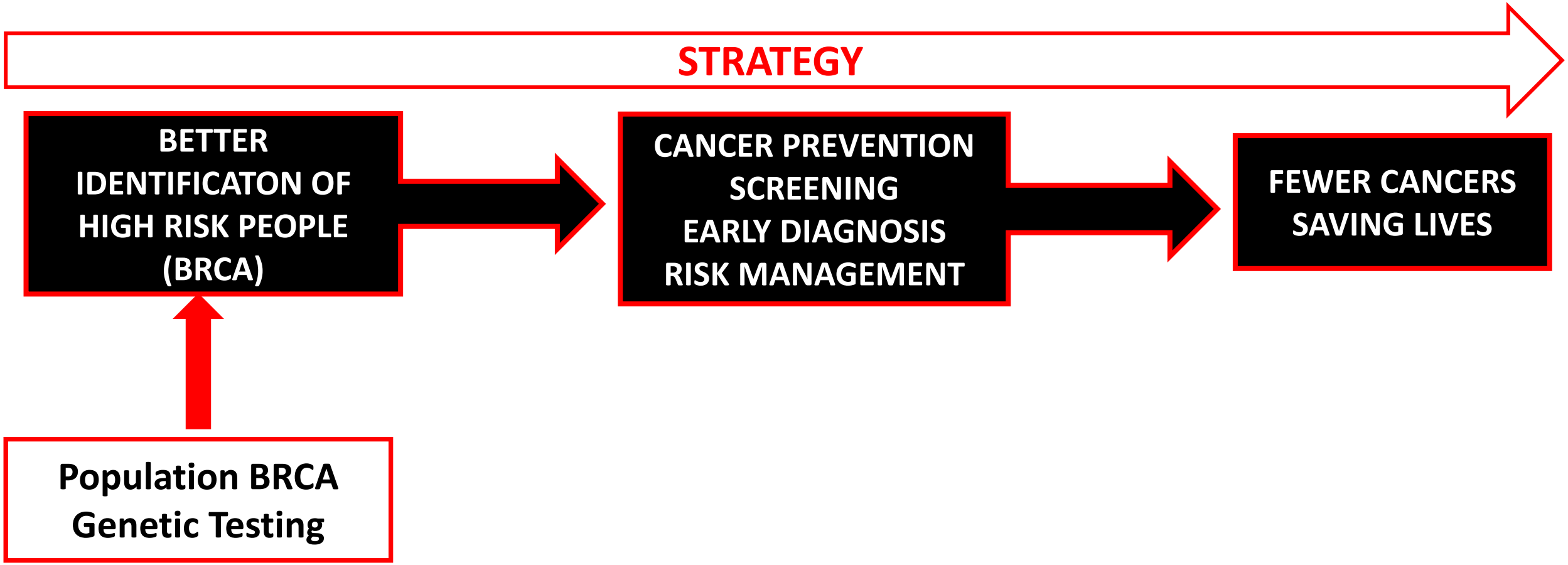
Predicted Rise in Breast and Ovarian Cancer Cases by 2040



Cases: 20-26%
Deaths: 36%

Cases: 31-37-%
Deaths: 49-53%

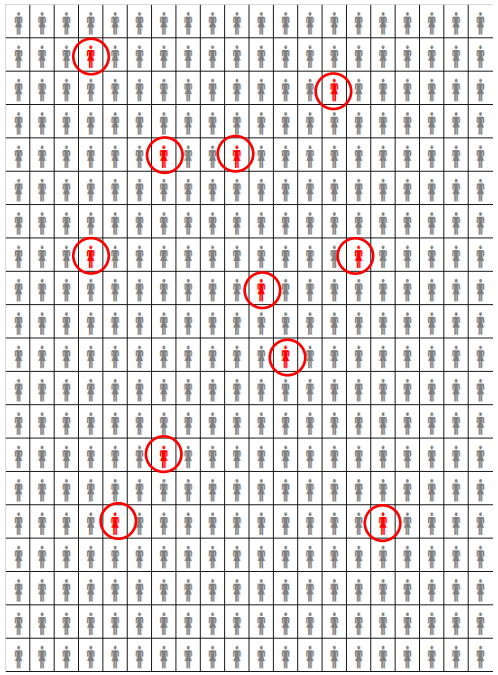
BRCA: Jewish Population
30-40% Ovarian Cancers
10% Breast Cancers


STRATEGY
BETTER IDENTIFICATON OF HIGH RISK PEOPLE (BRCA)
CANCER PREVENTION
SCREENING
EARLY DIAGNOSIS
RISK MANAGEMENT
FEWER CANCERS SAVING LIVES
Population BRCA Genetic Testing

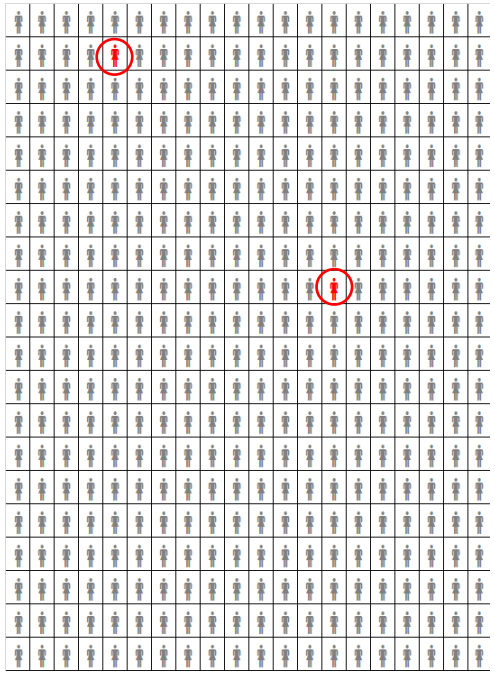
Jewish Population & BRCA

3 common alterations:
Founder mutations

185delAG (c.68_69delAG)
5382insC (c.5266dupC)
6174delT (c.5946delT)

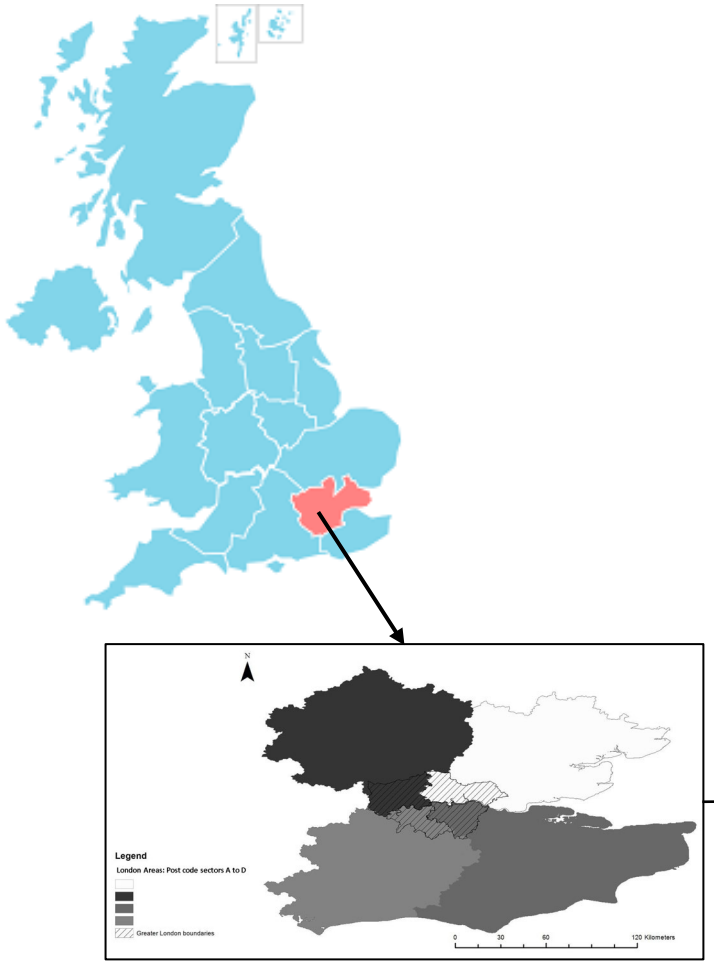


1:40 BRCA



1:200 BRCA

40% Ovarian Cancers
10% Breast Cancers



Jewish Population	BRCA
330,000	8458
270,000	6920

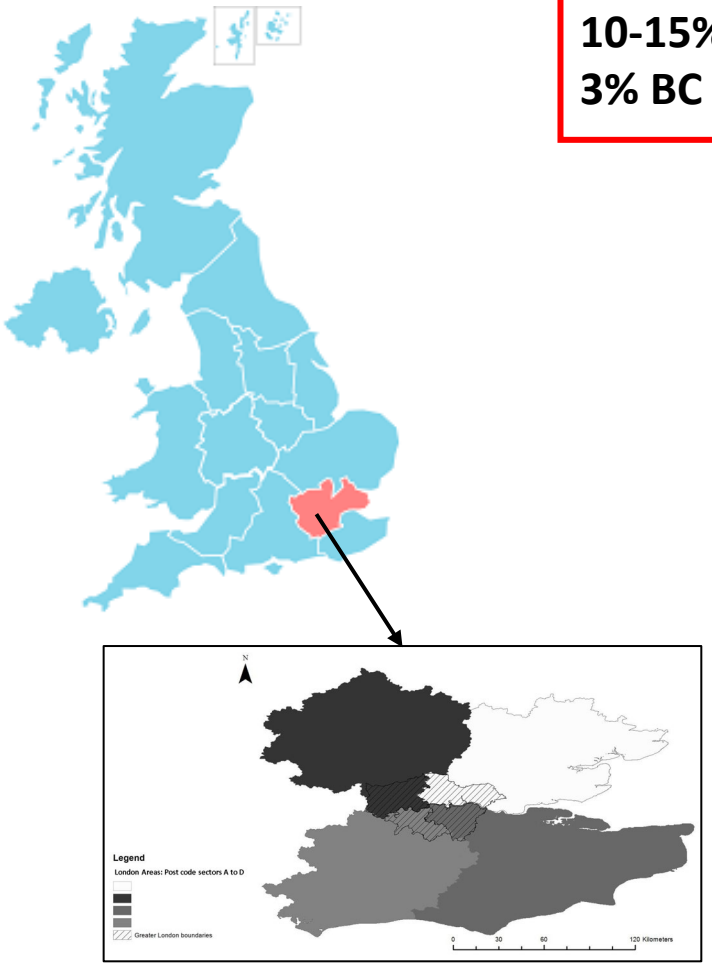
>90% Don't know about it (undetected)

Current detection rates and time-to-detection of all identifiable *BRCA* carriers in the Greater London population

Ranjit Manchanda,[1,2,3] Oleg Blyuss,[4,5] Faiza Gaba,[1,2] Vladimir Sergeevich Gordeev,[6] Chris Jacobs,[7,8] Matthew Burnell,[4] Carmen Gan,[2] Rohan Taylor,[9] Clare Turnbull,[1] Rosa Legood,[10] Alexey Zaikin,[4] Antonis C Antoniou,[11] Usha Menon,[3] Ian Jacobs[12]

Manchanda 2018 J Med Genet

67.3M pop



10-15% OC
3% BC

Estimated >335,000 BRCA carriers in the UK general population

97% BRCA carriers Don't know about it (undetected)

Manchanda R, et al. J Med Genet. 2018;55(8):538-545;

Current detection rates and time-to-detection of all identifiable *BRCA* carriers in the Greater London population

Ranjit Manchanda,[1,2,3] Oleg Blyuss,[4,5] Faiza Gaba,[1,2] Vladimir Sergeevich Gordeev,[6] Chris Jacobs,[7,8] Matthew Burnell,[4] Carmen Gan,[2] Rohan Taylor,[9] Clare Turnbull,[1] Rosa Legood,[10] Alexey Zaikin,[4] Antonis C Antoniou,[11] Usha Menon,[3] Ian Jacobs[12]

BETTER TARGETED SCREENING & PREVENTION

- **RRM: RISK REDUCING MASTECTOMY**
- **RRSO: RISK REDUCING SALPINGO-OOPHORECTOMY**
- **RRESDO: RISK REDUCING EARLY SALPINGECTOMY + DELAYED OOPHORECTOMY**
- **CHEMO-PREVENTION: BC**
- **BREAST CANCER SCREENING : HIGH RISK**
- **Life Style + Reproductive choices**
- **PGD**

BRCA Carrier

- **Surgical Prevention**
  - Breast tissue removal - Mastectomy
  - Removal of tubes & ovaries
- **Medical Prevention**
  - Tamoxifen
  - Anastrazole
  - OCP
- **Screening**
  - Mammogram
  - MRI
- **Life Style + Reproductive choices**
- **PGD**

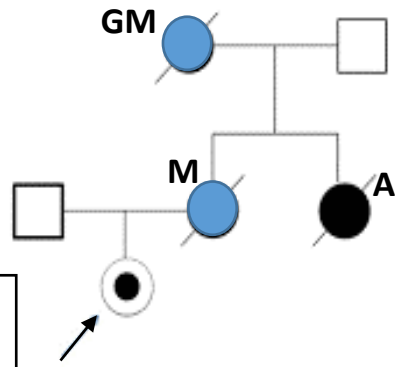
BRCA Carrier

- **Family Dynamics**
- **Emotional impact**
- **Anxiety/ Distress**
- **Confidentiality**
- **Insurance**
- **Marriage-ability**
- **Stigmatization**
- **Cost effectiveness**

Conventional Clinical Criteria/ FH-based approach: 10% BRCA probability

BRCA1
BC = ~71%
OC = 44%

Mother- Breast + Ovary
Aunt- Breast
Grandmother- Ovary



60% of BRCA carriers are missed with FH clinical criteria

Huge Underutilisation of genetic testing

<20-30% Eligible Patients undergo testing

MANY LIMITATIONS
Only a small proportion of carriers have a significant FH know about it and act on it
Limited Awareness & access

JOURNAL OF CLINICAL ONCOLOGY

Genetic Testing and Results in a Population-Based Cohort of Breast Cancer Patients and Ovarian Cancer Patients

Allison W. Kurian, MD, MSc[1]; Kevin C. Ward, PhD[2]; Nadia Howlader, PhD[3]; Dennis Deapen, PhD[4]; Ann S. Hamilton, PhD[4]; Angela Mariotto, PhD[3]; Daniel Miller, MS[5]; Lynne S. Penberthy, MD, MPH[3]; and Steven J. Katz, MD, MPH[6]

National Estimates of Genetic Testing in Women With a History of Breast or Ovarian Cancer

Christopher P. Childers, Kimberly K. Childers, Melinda Maggard-Gibbons, and James Macinko

npj | Breast Cancer

www.nature.com/npjbcancer

PERSPECTIVE OPEN

Check for updates

Do current family history-based genetic testing guidelines contribute to breast cancer health inequities?

2022

Samantha H. Jakuboski[1], Jasmine A. McDonald[2,3] and Mary Beth Terry[2,3]✉

Exacerbation of Inequalities

NHB BRCA women twice less likely to have pos FH than NHW women

nature medicine

LETTERS

https://doi.org/10.1038/s41591-020-0982-5

Population genetic screening efficiently identifies carriers of autosomal dominant diseases

J. J. Grzymski[1,2]✉, G. Elhanan[2], J. A. Morales Rosado[3,4], E. Smith[2], K. A. Schlauch[2], R. Read[2], C. Rowan[1], N. Slotnick[1], S. Dabe[2], W. J. Metcalf[2], B. Lipp[2], H. Reed[2], L. Sharma[5], E. Levin[5], J. Kao[5], M. Rashkin[5], J. Bowes[5], K. Dunaway[5], A. Slonim[1], N. Washington[5], M. Ferber[3,4], A. Bolze[5] and J. T. Lu[5]✉

BIOBANKING STUDIES –
75-80% PV carriers do not have a strong FH fulfilling clinical testing criteria

THE SYSTEM HAS NOT BEEN WORKING WELL ENOUGH !!

>90-97% unaware

60-80% cant be identified

DIAGNOSING A BRCA CARRIER AFTER A CANCER DIAGNOSIS IS I WOULD ARGUE - A FAILURE OF CANCER PREVENTION!

WHY DO WE NEED TO WAIT FOR PEOPLE TO GET CANCER TO IDENTIFY PEOPLE IN WHOM WE CAN PREVENT CANCER??

POPULATION TESTING – unaffected, unselected

Personalised Risk

Risk adapted Targeted Screening + Prevention

Risk assessment: Validated Risk

Clearly defined interventions of clinical benefit to reduce burden disease

Well defined thresholds of risk for undertaking the intervention(s)

POPULATION TESTING – unaffected, unselected

Technology ✓

Falling Costs ✓

JNCI J Natl Cancer Inst, 2015, 1–11
doi:10.1093/jnci/dju379
First published online XXXX XX, XXXX
Article

ARTICLE

Population Testing for Cancer Predisposing BRCA1/BRCA2 Mutations in the Ashkenazi-Jewish Community: A Randomized Controlled Trial

Ranjit Manchanda, Kelly Loggenberg, Saskia Sanderson, Matthew Burnell, Jane Wardle, Sue Gessler, Lucy Side, Nyala Balogun, Rakshit Desai, Ajith Kumar, Huw Dorkins, Yvonne Wallis, Cyril Chapman, Rohan Taylor, Chris Jacobs, Ian Tomlinson, Alistair McGuire, Uziel Beller, Usha Menon, Ian Jacobs

JNCI 2015

JNCI J Natl Cancer Inst, 2015, 1–14
doi:10.1093/jnci/dju380
First published online XXXX XX, XXXX
Article

ARTICLE

Cost-effectiveness of Population Screening for BRCA Mutations in Ashkenazi Jewish Women Compared With Family History–Based Testing

Ranjit Manchanda, Rosa Legood, Matthew Burnell, Alistair McGuire, Maria Raikou, Kelly Loggenberg, Jane Wardle, Saskia Sanderson, Sue Gessler, Lucy Side, Nyala Balogun, Rakshit Desai, Ajith Kumar, Huw Dorkins, Yvonne Wallis, Cyril Chapman, Rohan Taylor, Chris Jacobs, Ian Tomlinson, Uziel Beller, Usha Menon, Ian Jacobs

JNCI 2015

YHEC York Health Economics Consortium **2020**

NHS Innovation Accelerator

Economic Impact Evaluation Case Study: Population Genetic Testing
Final Version

GCaPPS Genetic Cancer Prediction through Population Screening

Annu. Rev. Genom. Hum. Genet. 2020. 21:13.1–13.40

ANNUAL REVIEWS

Cluster-randomised non-inferiority trial comparing DVD-assisted and traditional genetic counselling in systematic population testing for BRCA1/2 mutations

Ranjit Manchanda,[1,2,3] Matthew Burnell,[1] Kelly Loggenberg,[1] Rakshit Desai,[1] Jane Wardle,[4] Saskia C Sanderson,[5] Sue Gessler,[1] Lucy Side,[1] Nyala Balogun,[1] Ajith Kumar,[6] Huw Dorkins,[7] Yvonne Wallis,[8] Cyril Chapman,[9] Ian Tomlinson,[10] Rohan Taylor,[11] Chris Jacobs,[12] Rosa Legood,[13] Maria Raikou,[14] Alistair McGuire,[14] Uziel Beller,[15] Usha Menon,[1] Ian Jacobs[1,16]

J Med Genet 2016

Jewish cultural and religious factors and uptake of population-based *BRCA* testing across denominations: a cohort study **2021**

D Reisel,[a,*] M Burnell,[a,*] L Side,[c] K Loggenberg,[a] S Gessler,[a] R Desai,[a] S Sanderson,[d] AF Brady,[e] H Dorkins,[f] Y Wallis,[g] C Jacobs,[h,i] R Legood,[j] U Beller,[k] I Tomlinson,[l] J Wardle,[d,†] U Menon,[b] I Jacobs,[a,m] R Manchanda[b,n,o]

BJOG An International Journal of Obstetrics and Gynaecology

Cost-effectiveness of population based *BRCA* testing with varying Ashkenazi Jewish ancestry

AJOG American Journal of Obstetrics & Gynecology

Ranjit Manchanda, MRCOG, PhD; Shreeya Patel, MSc; Antonis C. Antoniou, PhD; Ephrat Levy-Lahad, PhD; Clare Turnbull, PhD; D. Gareth Evans, PhD; John L. Hopper, PhD; Robert J. Macinnis, PhD; Usha Menon, MD; FRCOG; Ian Jacobs, MD, FRCOG; Rosa Legood, PhD

2017

Annual Review of Genomics and Human Genetics

Population Screening for Inherited Predisposition to Breast and Ovarian Cancer

Ranjit Manchanda,[1,2,*] Sari Lieberman,[3,4,*] Faiza Gaba,[1,2] Amnon Lahad,[4,5] and Ephrat Levy-Lahad[3,4]

Randomised trial of population-based *BRCA* testing in Ashkenazi Jews: long-term outcomes

R Manchanda,[a,b,c] M Burnell,[c] F Gaba,[a] R Desai,[c] J Wardle,[d,†] S Gessler,[c] L Side,[e] S Sanderson,[d] K Loggenberg,[f] AF Brady,[g] H Dorkins,[h] Y Wallis,[i] C Chapman,[j] C Jacobs,[k,l] R Legood,[m] U Beller,[n] I Tomlinson,[o] U Menon,[c] I Jacobs[p]

2019

BJOG An International Journal of Obstetrics and Gynaecology

CANCER PREVENTION RESEARCH | COMMENTARY

Population-based Genetic Testing for Precision Prevention

Olivia Evans[1,2] and Ranjit Manchanda[1,2]

2020

Published OnlineFirst May 14, 2020; DOI: 10.1158/1940-6207.CAPR-20-0002

BJOG An International Journal of Obstetrics and Gynaecology — Royal College of Obstetricians & Gynaecologists

RANDOMISED CONTROLLED TRIAL

Randomised trial of population based BRCA testing in Ashkena Jews: Long term secondary lifestyle behavioural outcomes

Matthew Burnell, Faiza Gaba, Monika Sobocan, Rakshit Desai, Saskia Sanderson, Kelly Loggenberg, Su Gessler, Lucy Side, Angela F. Brady, Huw Dorkins, Yvonne Wallis, Chris Jacobs, Rosa Legood, Uziel Belle Ian Tomlinson, Jane Wardle, Usha Menon, Ian Jacobs, Ranjit Manchanda ... See fewer authors

First published: 04 July 2022 | https://doi.org/10.1111/1471-0528.17253

2022

Attitude towards and factors affecting uptake of population-based *BRCA* testing in the Ashkenazi Jewish population: a cohort study

R Manchanda,[a,b] M Burnell,[c] F Gaba,[a,b] S Sanderson,[d] K Loggenberg,[e] S Gessler,[c] J Wardle,[d,†] L Side,[f] R Desai,[c] AF Brady,[g] H Dorkins,[h] Y Wallis,[i] C Chapman,[j] C Jacobs,[k,l] I Tomlinson,[m] U Beller,[n] U Menon,[c] I Jacobs[o]

2019

BJOG An International Journal of Obstetrics and Gynaecology

AJOG American Journal of Obstetrics & Gynecology

GYNECOLOGY

Cost effectiveness of population based BRCA1 founder mutation testing in Sephardi Jewish women

Shreeya Patel, MSc; Rosa Legood, PhD; D. Gareth Evans, PhD; Clare Turnbull, PhD; Antonis C. Antoniou, PhD; Usha Menon, MD, FRCOG; Ian Jacobs, MD, FRCOG; Ranjit Manchanda, MRCOG, PhD

cancers MDPI

Review

Population Based Testing for Primary Prevention: A Systematic Review

Ranjit Manchanda [1,2,3,*] and Faiza Gaba [1,2]

1 Barts Cancer Institute, Queen Mary University of London, Old Anatomy Building, Charterhouse Square, London EC1M 6BQ, UK; f.gaba@qmul.ac.uk
2 Department of Gynaecological Oncology, St Bartholomew's Hospital, London EC1A 7BE, UK
3 Gynaecological Cancer Research Centre, Department of Women's Cancer, Institute for Women's Health, University College London, 149 Tottenham Court Road, London W1T 7DN, UK
* Correspondence: r.manchanda@qmul.ac.uk

Received: 29 September 2018; Accepted: 31 October 2018; Published: 5 November 2018

check for updates

EVIDENCE SUMMARY – JEWISH POPULATION STUDIES

Population Screening (Everyone)

Testing on FH

AJ BRCA FM

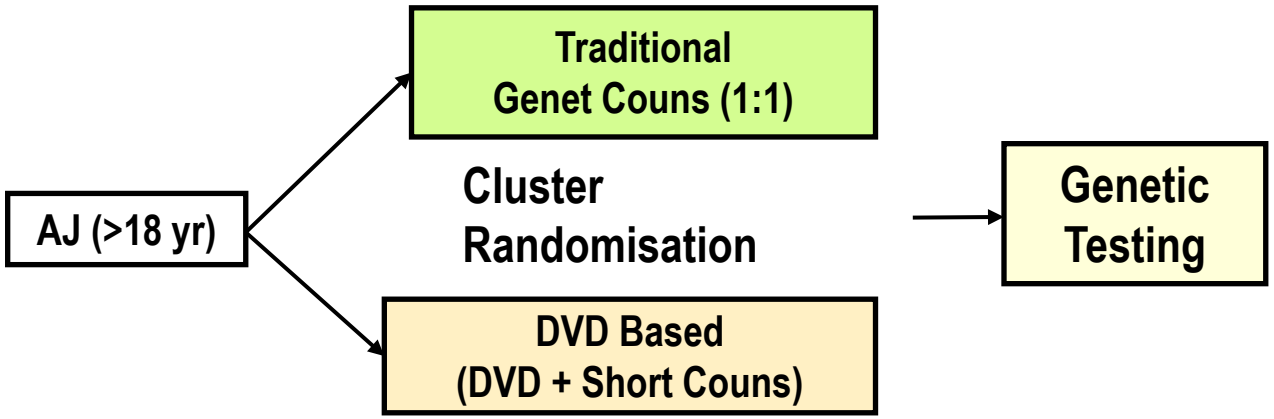
GCaPPS Genetic Cancer Prediction through Population Screening

60% BRCA carriers are missed through Family history based testing

Feasible, Acceptable, High satisfaction

2.9% (30/1034) AJ carry a BRCA mutation

BRCA1 in 1.55%. BRCA2 in 1.35%



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Cluster-randomised non-inferiority trial comparing DVD-assisted and traditional genetic counselling in systematic population testing for BRCA1/2 mutations

Ranjit Manchanda,[1,2,3] Matthew Burnell,[1] Kelly Loggenberg,[1] Rakshit Desai,[1] Jane Wardle,[4] Saskia C Sanderson,[5] Sue Gessler,[1] Lucy Side,[1] Nyala Balogun,[1] Ajith Kumar,[6] Huw Dorkins,[7] Yvonne Wallis,[8] Cyril Chapman,[9] Ian Tomlinson,[10] Rohan Taylor,[11] Chris Jacobs,[12] Rosa Legood,[13] Maria Raikou,[14] Alistair McGuire,[14] Uziel Beller,[15] Usha Menon,[1] Ian Jacobs[1,16]

DVD-based counselling

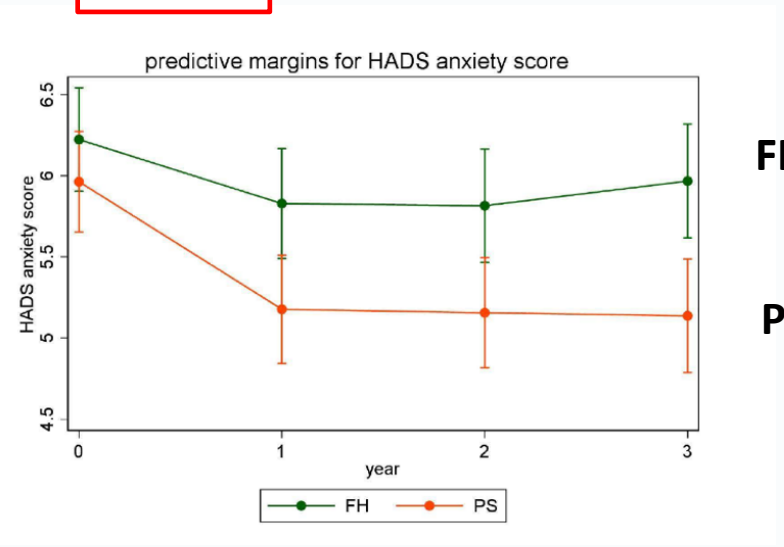
We can provide counselling & testing effectively in more time efficient ways in a community setting

NOT inferior in terms of Increase in Knowledge, Risk Perception, Satisfaction

Equal in terms of Uptake of testing

More time and cost efficient

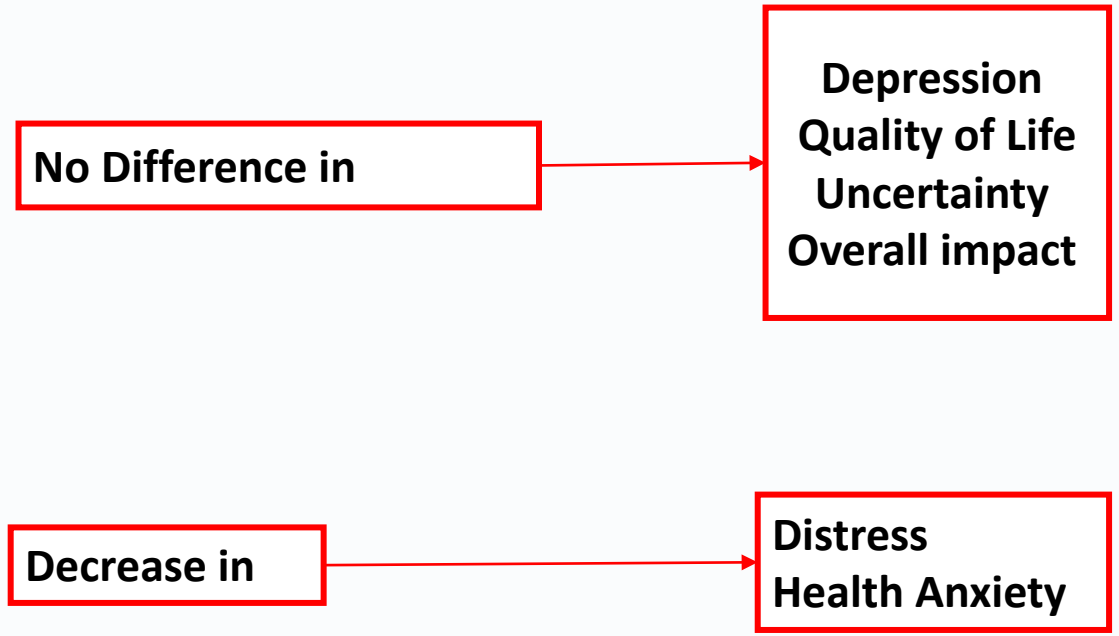
ANXIETY



FH testing

Pop Testing

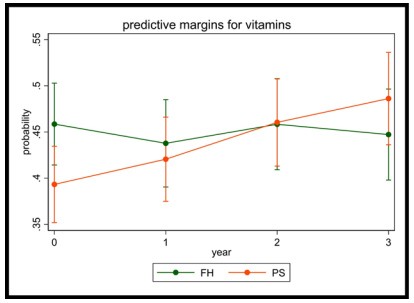
Reduction in Anxiety vs FH testing


No Difference in
Depression
Quality of Life
Uncertainty
Overall impact
Decrease in
Distress
Health Anxiety

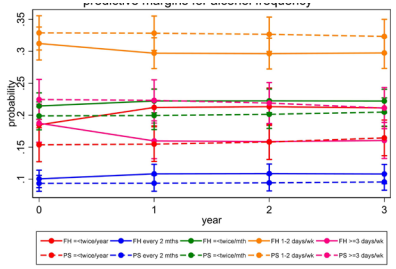
Lifestyle 3 years Follow up

Queen Mary University of London

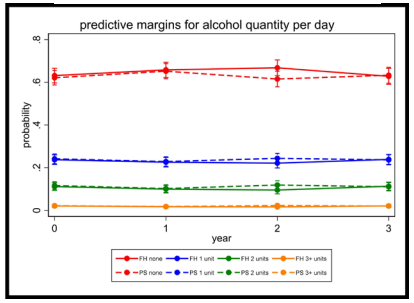
Vitamin



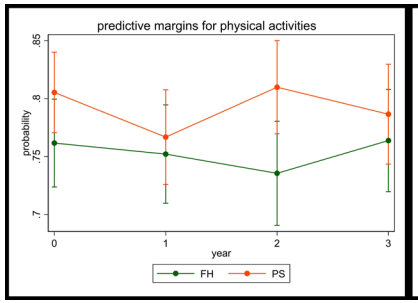
Alcohol Frequency



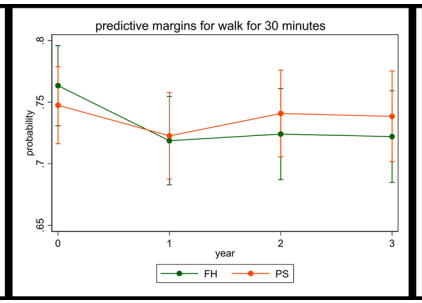
Alcohol Quantity



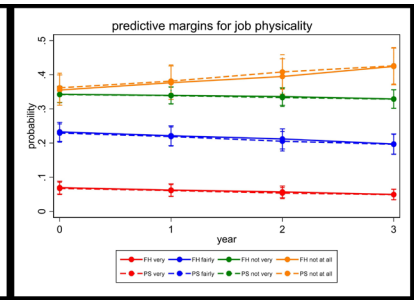
Physical Activity



30 min walking/d



Physical activity at work



NO DIFFERENCE

Alcohol Frequency/Quantity

Physical Activity

Diet: Fruit, vegetable, Meat, vitamin

Smoking

Routine Breast screening behaviour

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RANDOMISED CONTROLLED TRIAL

Randomised trial of population based BRCA testing in Ashkena Jews: Long term secondary lifestyle behavioural outcomes

Matthew Burnell, Faiza Gaba, Monika Sobocan, Rakshit Desai, Saskia Sanderson, Kelly Loggenberg, Su Gessler, Lucy Side, Angela F. Brady, Huw Dorkins, Yvonne Wallis, Chris Jacobs, Rosa Legood, Uziel Belle Ian Tomlinson, Jane Wardle, Usha Menon, Ian Jacobs, Ranjit Manchanda ... See fewer authors

First published: 04 July 2022 | https://doi.org/10.1111/1471-0528.17253

BJOG An International Journal of Obstetrics and Gynaecology

Jewish cultural and religious factors and uptake of population-based *BRCA* testing across denominations: a cohort study

D Reisel,[a,*] M Burnell,[a,*] L Side,[c] K Loggenberg,[a] S Gessler,[a] R Desai,[a] S Sanderson,[d] AF Brady,[e] H Dorkins,[f] Y Wallis,[g] C Jacobs,[h,i] R Legood,[j] U Beller,[k] I Tomlinson,[l] J Wardle,[d,†] U Menon,[b] I Jacobs,[a,m] R Manchanda[b,n,o]

96% interest

60% intention

88% uptake

Interest, intention or uptake of BRCA testing:

Did not significantly differ by

Jewish Cultural or Religious Identity

Or Denominational affiliation

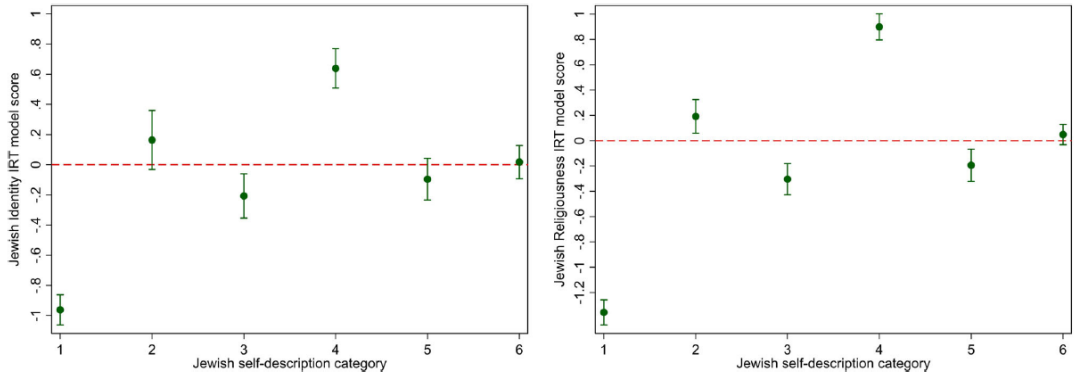
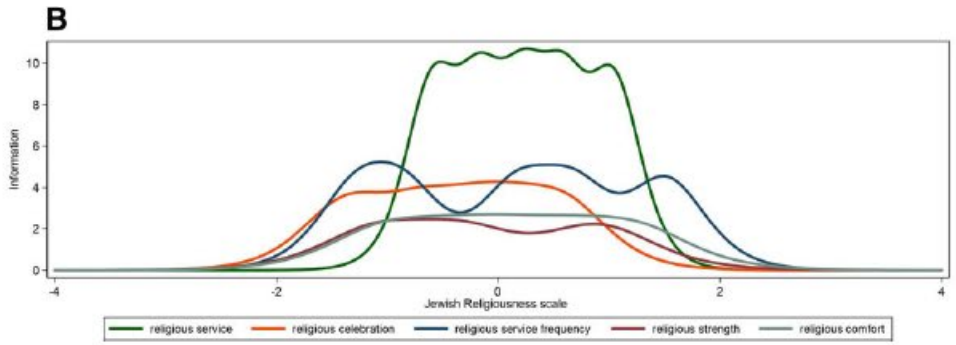
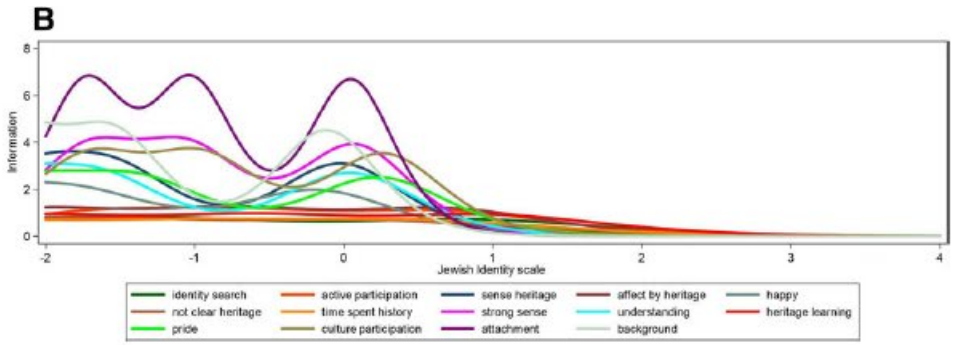


Figure 2. Jewish Identity scale and Jewish Religiousness scale IRT model scores by Jewish Denomination. *X-axis:* Jewish denomination categories: 1 = Non-Practising/Unaffiliated; 2 = Conservative/Masorti; 3 = Liberal; 4 = Orthodox; 5 = Reform; 6 = Traditional. *Y-axis: Left Panel:* Jewish Identity Scale Item Response Theory (IRT) model scores. *Y-axis: Right Panel:* Jewish Religiousness Scale Item Response Theory (IRT) model scores. This figure depicts the distribution of JI and JR scale scores across the six different Jewish denominations.





YHEC
York Health Economics Consortium

The AHSN Network NHS England
NHS Innovation Accelerator

NHS Innovation Accelerator

Economic Impact Evaluation Case Study: Population Genetic Testing
Final Version

SAVES LIVES & MONEY

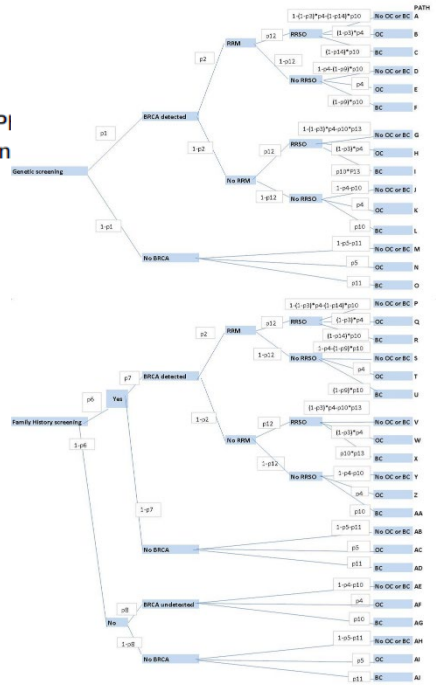
Confirms Cost saving of £4.4M

Reduction in breast and ovarian cancer cases

Cost-effectiveness of population based *BRCA* testing with varying Ashkenazi Jewish ancestry

Ranjit Manchanda, MRCOG, PhD; Shreeya Patel, MSc; Antonis C. Antoniou, PhD; Ephrat Levy-Lahad, Pl
Clare Turnbull, PhD; D. Gareth Evans, PhD; John L. Hopper, PhD; Robert J. Macinnis, PhD; Usha Menon
Ian Jacobs, MD, FRCOG; Rosa Legood, PhD

Manchanda AJOG July 2017



Cost-effective for 1 AJ Grandparent
Cost-saving for 2-4 AJ Grandparents

JNCI J Natl Cancer Inst, 2015, 1–14
doi:10.1093/jnci/djv380
First published online XXXX XX, XXXX
Article

ARTICLE

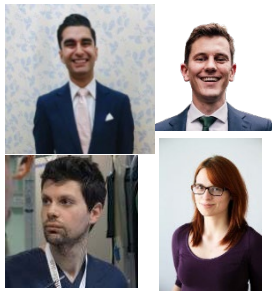
Cost-effectiveness of Population Screening for BRCA Mutations in Ashkenazi Jewish Women Compared With Family History–Based Testing

Ranjit Manchanda, Rosa Legood, Matthew Burnell, Alistair McGuire, Maria Raikou, Kelly Loggenberg, Jane Wardle, Saskia Sanderson, Sue Gessler, Lucy Side, Nyala Balogun, Rakshit Desai, Ajith Kumar, Huw Dorkins, Yvonne Wallis, Cyril Chapman, Rohan Taylor, Chris Jacobs, Ian Tomlinson, Uziel Beller, Usha Menon, Ian Jacobs

The JHC Review

A review of hereditary cancer awareness and BRCA testing in the UK Jewish Community

- **Aim to review current level BRCA awareness and info provision, testing provision and experience in the UK Jewish community**
- **QMUL – Apr 2022**
- **Endorsed by Jewish Leadership Council (JLC)**



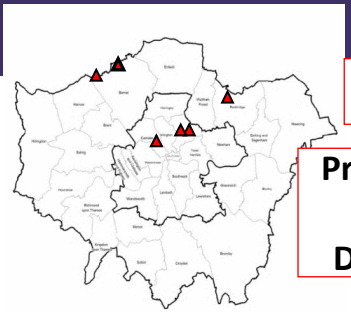
Research Streams:

- Jewish BRCA Carriers
- Jewish Organisations in the UK / BRCA Education and Testing Initiatives internationally
- National Cancer Charities
- Private BRCA testing services
- Dialogue about cancer pre-disposition genes across social media platforms

Outcomes:

- Community report + scientific papers
- Recommendations based on priority needs identified

Jewish BRCA population testing studies



RCT

Pre test counselling
1:1
DVD-based Group

GCaPPS Genetic Cancer Prediction through Population Screening

COHORT

Pre test Education

Basser Centre –
Pop testing consortium meeting May 2019

BFOR BRCA Founder Outreach Study

COHORT

Pre test Video
Online Education
Platform

JeneScreen Preventing cancer in the Jewish community

COHORT

1. Pre test Education
2. Group Counselling

COHORT

Pre test Education

Population BRCA testing in the Jewish Population

Is feasible, acceptable, has high satisfaction, is cost-effective and can be undertaken in a community setting using non-inferior, cost-efficient approaches.

Does not harm Psychological Health or QOL.

Population BRCA testing in the Jewish population – can save lives and monies

FULFILS PRINCIPLES OF POPULATION TESTING FOR DISEASE

CHANGING PARADIGM IN THE JEWISH POPULATION

ISRAEL:
2021: HEALTH SYSTEM IMPLEMENTATION STARTED

TheAHSNNetwork NHS England
NHS Innovation Accelerator

NHS CANCER PROGRAMME

NHS

NHS CANCER PROGRAMME EARLY DIAGNOSIS TASK & FINISH GROUP

UK PILOT NHS SITES – Early 2023!

UK NHS IMPLEMENTATION SITES – Early 2023

NHS CANCER PROGRAMME

NHS CANCER PROGRAMME EARLY DIAGNOSIS TASK & FINISH GROUP

NHS England
TheAHSNNetwork
NHS Innovation Accelerator

Expert Advisory Group

NHS North Thames
NHS Genomic Medicine Service Alliance
hosted by UCLPartners

Community Awareness Outreach Programme

chai cancer care
together we can cope

Jnetics

All community organisations

Expert Advisory Group

Chair- Prof Peter Johnson (National Cancer Programme Director)
Prof Ranjit Manchanda (QMUL, Barts)
Prof Gareth Evans (Manchester)
Prof Clare Turnbull (ICR)
Dr Francesca Faravelli (NT GMSA Lead)
Prof Rachel Butler (NT GLH)
Ms Beth Torr (ICR)
Ms Grace Kavanaugh (ICR)
Ms Jennifer Wiggins (RMH)
Dr Angela George (RMH)
Zoe Kemp (RMH)
Ms Susana Lukic (Programme manager) (NHSE)
Ms Emily Watts (NHSE)
Laurence Russell (NHSE)
Rachel Lovesy (NHSE)
Jane Deller (NHSE)
Sacha Howell (Christie)
Maxine Mackintosh (Genomics England)

Lisa Steele (Chai)
Alison Dagul (Community rep)
Ms Katrina Sarig (JHCR, QMUL)
Madeline Webb (BC Now)
Athena Lamnisos (Eve Appeal)
Aviva Lewis (Jnetics)
Ms Nicole Gordon (Jnetics)
Rabbi Julia Neuberger
Jo Ziff
Ms Caroline Presho (BRCA Umbrella)

Other stakeholders

National Cancer Programme Early Diagnosis Task and Finish Group

Clear pathway for access & registration

NHS England

Telephone Counselling HOTLINE

Informed consent

Virtual – Saliva based DNA test (North Thames GLH)

Post test counselling support

GP informed of result

Linked to Regional genetics services pathways- referral sent by programme team

Cascade Testing

High risk BC screening programme
Specialist NHS services-

- **Breast cancer risk management**
- **Ovarian cancer risk management**
- **PGD etc**

Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer

NICE guideline

NICE National Institute for Health and Care Excellence

BJOG An International Journal of Obstetrics and Gynaecology

Royal College of Obstetricians & Gynaecologists

DOI: 10.1111/1471-0528.16896

RCOG Scientific Impact Paper

Risk-Reducing Salpingo-Oophorectomy and the Use of Hormone Replacement Therapy Below the Age of Natural Menopause

R Manchanda, F Gaba, V Talaulikar, J Pundir, S Gessler, M Davies,* U Menon,* on behalf of the Royal College of Obstetricians and Gynaecologists

BRCA Community Engagement Campaign

Lead (tender award) - Jnetics & Chai

NHS England

Jnetics

chai cancer care
together we can cope

Creative & Commercial

Collaboration with stakeholders:

- Healthcare professionals
- Jewish community leaders (e.g. Rabbis) and other influential figures
- Jewish organisations with focus on medicine/cancer/BRCA
- Jewish charities
- Jewish leadership organisations
- Synagogue movements across the board
- National cancer and BRCA related charities

Acknowledgement: Slide from Aviva Lewis, Nicole Gordon

Three stages of planned engagement campaign

Oct 2022- Dec 2022

Jan 2023- Feb 2023

April 2023 onwards

All dates are tentative

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louisehager@chaicancercare.org

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Acknowledgement: Slide from Aviva Lewis, Nicole Gordon

cancers

MDPI

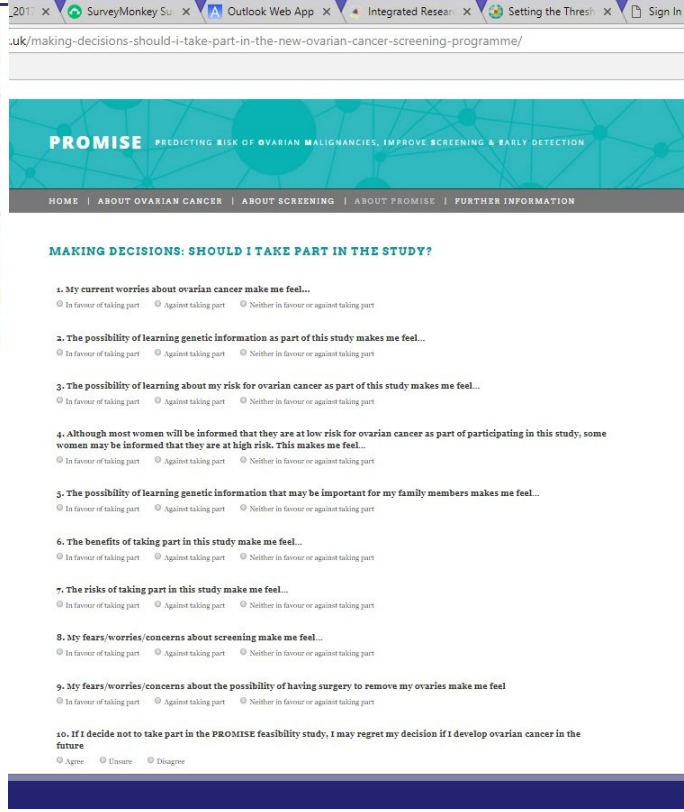
Article

Population Study of Ovarian Cancer Risk Prediction for Targeted Screening and Prevention

Faiza Gaba [1,2], Oleg Blyuss [3,4,5], Xinting Liu [1], Shivam Goyal [1], Nishant Lahoti [1], Dhivya Chandrasekaran [1,2], Margarida Kurzer [2], Jatinderpal Kalsi [6], Saskia Sanderson [7], Anne Lanceley [6], Munaza Ahmed [8], Lucy Side [9], Aleksandra Gentry-Maharaj [10], Yvonne Wallis [11], Andrew Wallace [12], Jo Waller [13], Craig Luccarini [14], Xin Yang [14], Joe Dennis [14], Alison Dunning [14], Andrew Lee [14], Antonis C. Antoniou [14], Rosa Legood [15], Usha Menon [10], Ian Jacobs [16] and Ranjit Manchanda [1,2,10,*]

2020

ISRCTN54246466

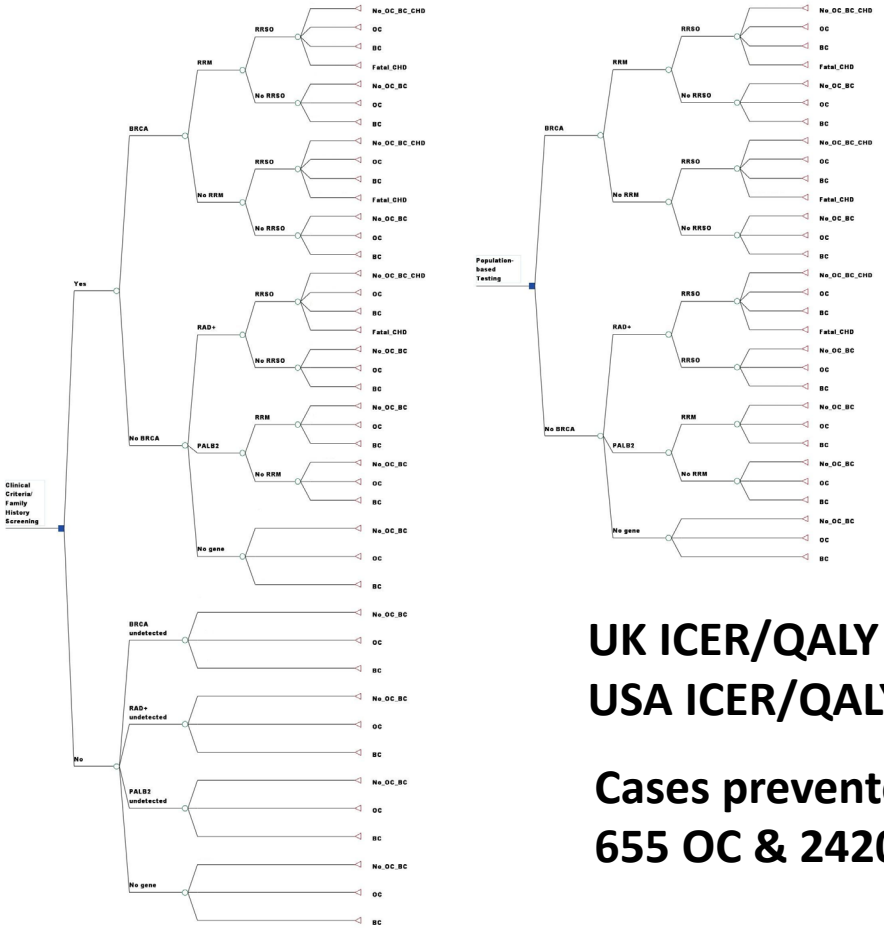


Primary Care → **Web DA + (Optional) Tel Helpline**

85% uptake of genetic testing and risk assessment (123 women)

Feasible, acceptable, high satisfaction (86-99%), reduces cancer worry and risk perception, Does not negatively impact psychological health/ QOL

POPULATION PANEL TESTING OC/BC MUTATIONS



UK ICER/QALY = £21599.96
USA ICER/QALY = $49282.19

Cases prevented
655 OC & 2420 BC/million

IMPACT

BC prevented	**64K (UK) – 240K (USA)**
OC prevented	**17K (UK) – 65K (USA)**

JNCI J Natl Cancer Inst (2018) 110(7): djx265

doi: 10.1093/jnci/djx265
First published online January 18, **2018**
Article

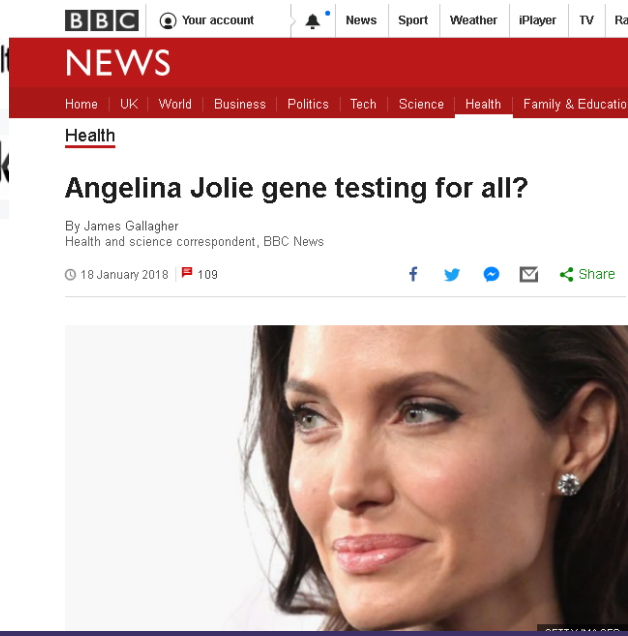
Cost-effectiveness of Population-Based BRCA1, BRCA2, RAD51C, RAD51D, BRIP1, PALB2 Mutation Testing in Unselected General Population Women

Ranjit Manchanda, Shreeya Patel, Vladimir S. Gordeev, Antonis C. Antoniou, Shantel Smith, Andrew Lee, John L. Hopper, Robert J. MacInnis, Clare Turnbull, Susan J. Ramus, Simon A. Gayther, Paul D. P. Pharoah, Usha Menon, Ian Jacobs, Rosa Legood


All women over 30 should be tested for fault gene, researchers say

Barts Cancer Institute research estimates around 83,000 cancers could be prevented if all women over 30 were screened.

All women over 30 should be screened for the faulty gene that can cause cancer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Health

Angelina Jolie gene testing for all?

By James Gallagher
Health and science correspondent, BBC News

18 January 2018 109 Share

Global Economic Evaluation – HIC / UMIC / LMIC

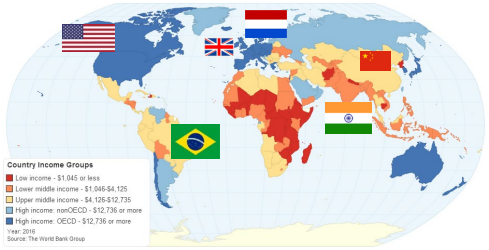
cancers

MDPI

Article

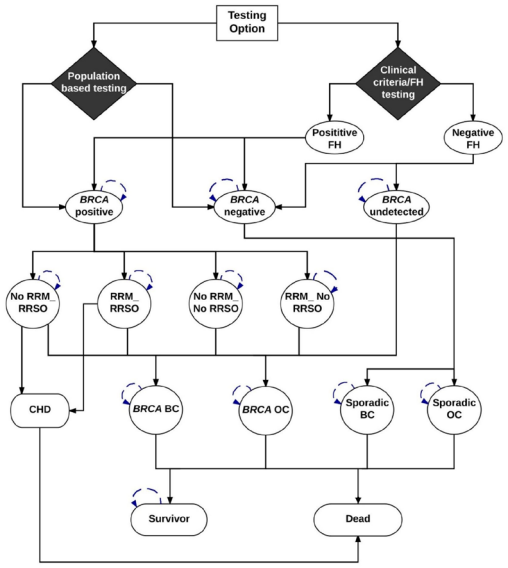
Economic Evaluation of Population-Based *BRCA1/BRCA2* Mutation Testing across Multiple Countries and Health Systems

Ranjit Manchanda [1,2,3,*], Li Sun [1,4], Shreeya Patel [1], Olivia Evans [1,2], Janneke Wilschut [5], Ana Carolina De Freitas Lopes [6], Faiza Gaba [1,2], Adam Brentnall [7], Stephen Duffy [7], Bin Cui [8], Patricia Coelho De Soarez [6], Zakir Husain [9,10], John Hopper [11], Zia Sadique [4], Asima Mukhopadhyay [12,13], Li Yang [8], Johannes Berkhof [5] and Rosa Legood [4]

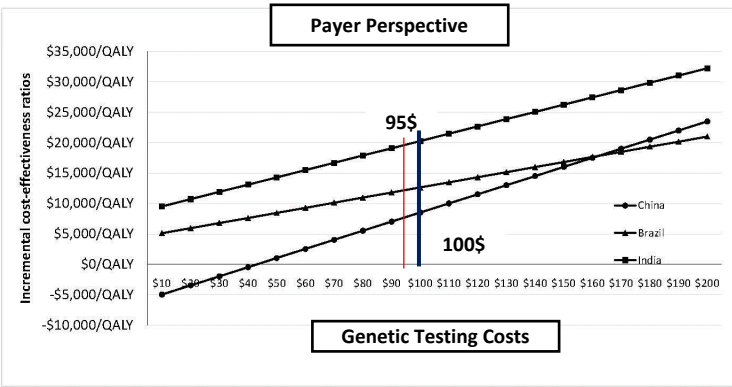


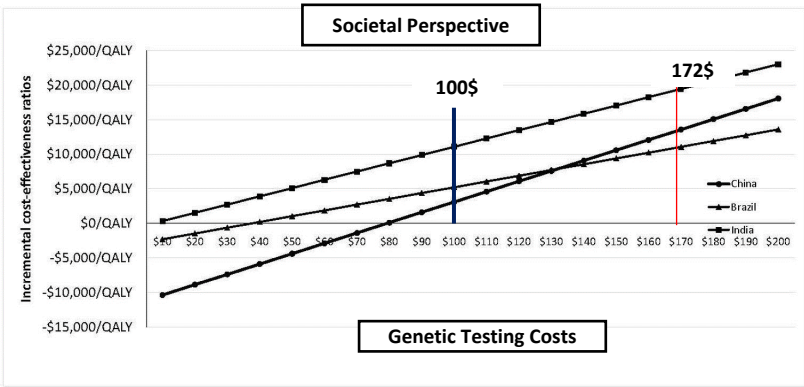
- UK
- USA
- Netherlands
- China
- Brazil

Cost Effective



India **LMIC**





CANCERS PREVENTED:
800,000 India, 1.2M China
300,000 USA, 70,000 UK, 182,000 Brazil

PROTECT-C: POPULATION BASED GERMLINE TESTING FOR EARLY DETECTION AND PREVENTION of CANCER

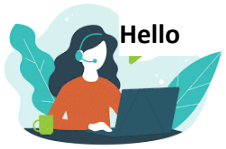
PROTECT-C study

Women
>18 years

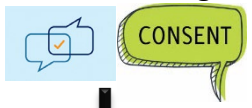
Primary Care Networks

Web/App Decision Aid

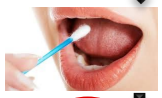
Telephone Counselling Helpline



Decision Making



Sample at home



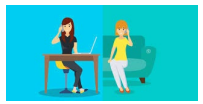
POST OFFICE

5 YEARS

Gene-Panel Testing

Digital Pathway

Qualitative Interviews



VUS Monitoring

Health Economic Analysis

5 YEAR ANALYSIS

3 YRS

LONG-TERM FU ANALYSIS

LONGTERM BENEFIT

Personalised BC & OC risk

Pathogenic Variant

Cascade Testing (Family)

Post-test Counselling

PREVENTION
SCREENING
LIFESTYLE
REPRODUCTION
PGD

PROTECT-C

POPULATION BASED GERMLINE TESTING FOR EARLY DETECTION AND PREVENTION OF CANCER

Yorkshire Cancer Research

the eve appeal fighting women's cancers

TheAHSNNetwork NHS England NHS Innovation Accelerator

Queen Mary University of London

MANCHESTER 1824 The University of Manchester

KING'S College LONDON

NCRI National Cancer Research Institute

Partners in cancer research

St George's University of London

UCL

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

ovarian cancer action

ovacome.. ovarian cancer charity

breast cancer care | breast cancer now

RCGP Royal College of General Practitioners

THE UNIVERSITY OF EDINBURGH

UNIVERSITY OF OXFORD

UNIVERSITY OF LEEDS

TARGET OVARIAN CANCER

gogirls SUPPORTING YOUR CANCER JOURNEY

BOWEL CANCER UK

CanGene CanVar

UNIVERSITY OF CAMBRIDGE

ICR The Institute of Cancer Research

LYNCH SYNDROME UK Registered Charity 1161840

BRCAUmbrella

wellcome centre ethics+humanities

VUmc VU University Medical Center Amsterdam

Chief Investigator

Ranjit Manchanda

Co-investigators

Prof Stephen Duffy

Prof Gareth Evans

Prof Clare Turnbull

Dr Rosa Legood

Prof Nina Hallowell

Prof Rhian Gabe

Prof Eamonn Sheridan

Dr Jo Waller

Dr Judith Hayward

Dr Nick West

COLLABORATORS:

Prof Usha Menon

Prof Ian Tomlinson

Dr Veerle MH Coupé

Dr Andrew Wallace

Dr Helene Schlecht

Dr Imran Rafi

Dr Samantha Quaife

SOME TAKE HOME MESSAGES

Do we prevent more cancers through population testing?	YES
Do we identify many more people at risk through population testing?	YES
Are we causing psychological/QOL harm?	NO
Is there high satisfaction?	YES
Is it feasible and acceptable?	YES

SOME TAKE HOME MESSAGES

Can we do it outside a hospital setting? — YES

Is it cost-effective? — YES

Has the time come to change paradigm and offer to all in the Jewish Population — YES

General Population Testing — More research: implementation studies

Collaborators

Dr Rosa Legood LSHTM

Mr. Dr. Huw Dorkins, Dr Angela Brady (KGC)

Dr. Ajith Kumar (GOSH)

Dr. Yvonne Wallis, Dr. Cyril Chapman (Birmingham)

Dr Michelle Ferris

Dr Rohan Taylor (St George's)

Chris Jacobs (Guy's)

TSC

Prof Mike Baum

Prof Max Parmar

Prof Ros Eeles

Charity representatives

GCaPPS Investigators

Prof Ian Jacobs (UCL)

Prof Ranjit Manchanda (UCL)

Prof. Usha Menon (UCL)

Prof. Jane Wardle (UCL)

Dr. Saskia Sanderson (USA)

Dr. Sue Gessler (UCL)

Dr. Lucy Side (UCL)

Prof Ian Tomlinson (CRUK)

Prof Alistair McGuire (LSE)

Prof Uziel Beller (Israel)

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Mr Rakshit Desai

Dr. Matthew Burnell

Ms Kelly Loggenberg

Ms Nyala Balogun

Mr. Robert Liston

Dr. Andy Ryan

Mr. Vijay Devineni

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Laboratory Team

Jeremy Ford

Nuno Alves

Kristin Tamm

Richard Gunu

Agudas Israel Housing Association

UCL

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Barts Cancer Institute Queen Mary University of London

Shreeya Patel
Faiza Gaba
Guida Kurzer
Li Sun

Asima Mukopadhyay

TATA MEMORIAL HOSPITAL
TATA MEMORIAL CENTRE

Keck School of Medicine USC

Leigh Pearce

UNSW AUSTRALIA

Ian Jacobs
Susan Ramus

Peking University 1898

Li Yang

Presidency University Kolkata

Zakir Husain
Mousumi Dutta

Cedars-Sinai Medical Center

Simon Gayther

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VUmc VU University Medical Center Amsterdam

Verle Coupe
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Rosa Legood
Vladimir Gordeev
Zia Sidique
Li Sun
Giovanna Bettoli

Medicina USP

Universidade de São Paulo

The University of Melbourne

Melbourne

John Hopper

Robert J. MacInnis

University of Cambridge

Antonis Antoniou
Andrew Lee
Xin Yang
Paul Pharoah
Alison Dunning

Sao Paolo Brazil

Patrícia Coelho de Soárez
Ana Carolina opes

Manchester 1824 The University of Manchester

Gareth Evans
Andrew Wallace
Kenneth Muir
Robert Graham

Monash University

Melissa Southey

ICR The Institute of Cancer Research

Clare Turnbull

PROMISE

Sydney- Ian Jacobs, Susan Ramus

Manchester- Robert Graham, Matthew Russell, Tony Whetton, Ken Muir, Andrew Williamson

Cambridge- Antonis Antoniou, Sarah Jervis, Andrew Lee, Xin Yang

UCL- Usha Menon, Jatinderpal Kalsi, Alex GentryMaharaj, Adam Rosenthal, Lyndsay Fraser, Danielle Margolin, Matthew Burnell, Andy Ryan, Anne Lanceley, Jane Wardle, Saskia Sanderson, Belinda Rahman, Susie Meisel, Susan Gessler, Lucy Side, Oleg Blyuss, Alexey Zaikin, John Timms

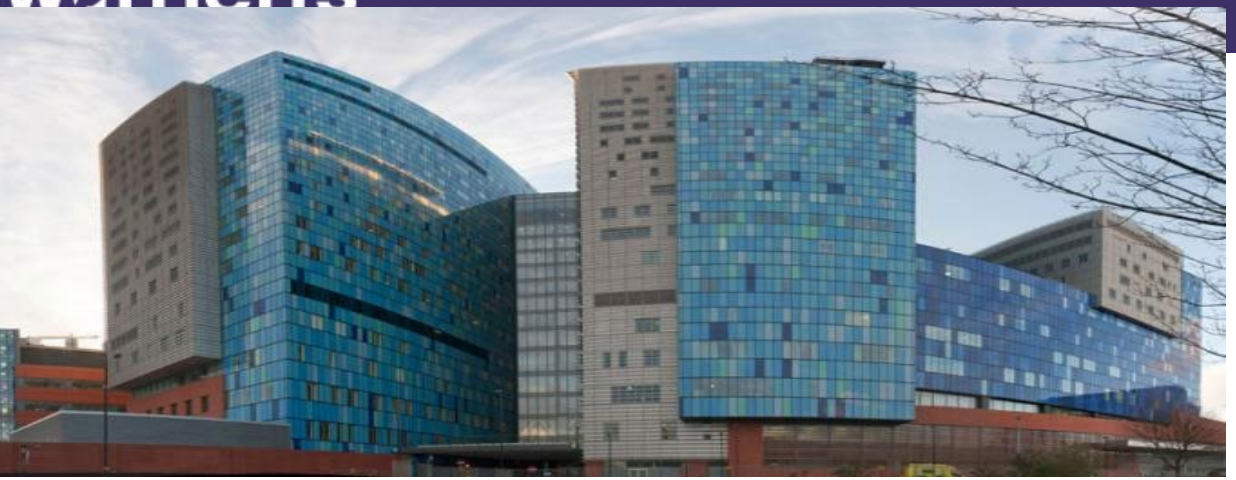
Cedars Sinai- Simon Gayther

Harvard- Steve Skates, Dustin Rabideau

Barts QMUL- Ranjit Manchanda, Faiza Gaba, Kelly Mousa, Krishna Bottla

CANCER RESEARCH UK

the eve appeal



THANK YOU

DIGITAL APPROACH

PROTECT-C

DIRECT TO PATIENT: WEB APP DIGITAL DECISION MAKING, CONSENT & TESTING PATHWAY

Digital Registration → Digital Data collection (Basic info) → Decision Aid Viewing, Decision Making → Digital Consent → Saliva Sample → Genetic Testing

Genetic Testing → Negative → Digital return

Genetic Testing → Positive → Tel - Nurse return

Genetic Testing → Written result report: Genetics service, GP, Patient

TELEPHONE HELPLINE