



# TRUSTING: The development of a communication program for healthcare professionals talking about risk and uncertainty of testing in genetics

Rachel Starkings, Valerie Jenkins, Lesley Fallowfield  
SHORE-C, University of Sussex

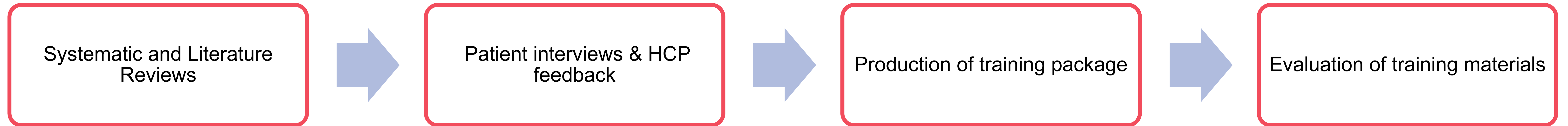
Correspondence: R.M.L.Starkings@sussex.ac.uk  
RacheltheResearcher



## Outline

- There is increasing demand for genetic testing within the sphere of hereditary breast cancer
- More healthcare professionals (HCPs) have conversations about family history and genetic testing
- These risk-based conversations impact patients and their families
- We reviewed patient, HCP and academic perspectives about these issues
- The TRUSTING training program aims to improve HCP communication, self-awareness, and knowledge about genetics in breast cancer

## Program Development



## Systematic Review

- Review of communication training interventions
- From 3,988 results, 7 papers/6 interventions identified
- Participants included various HCPs but not oncologists or surgeons
- Outcomes included communication and counselling practices, self-efficacy, knowledge, and participant satisfaction
- Communication skills were undefined and ambiguous
- Study design and assessment were not rigorous
- Registered on PROSPERO: CRD42019124010

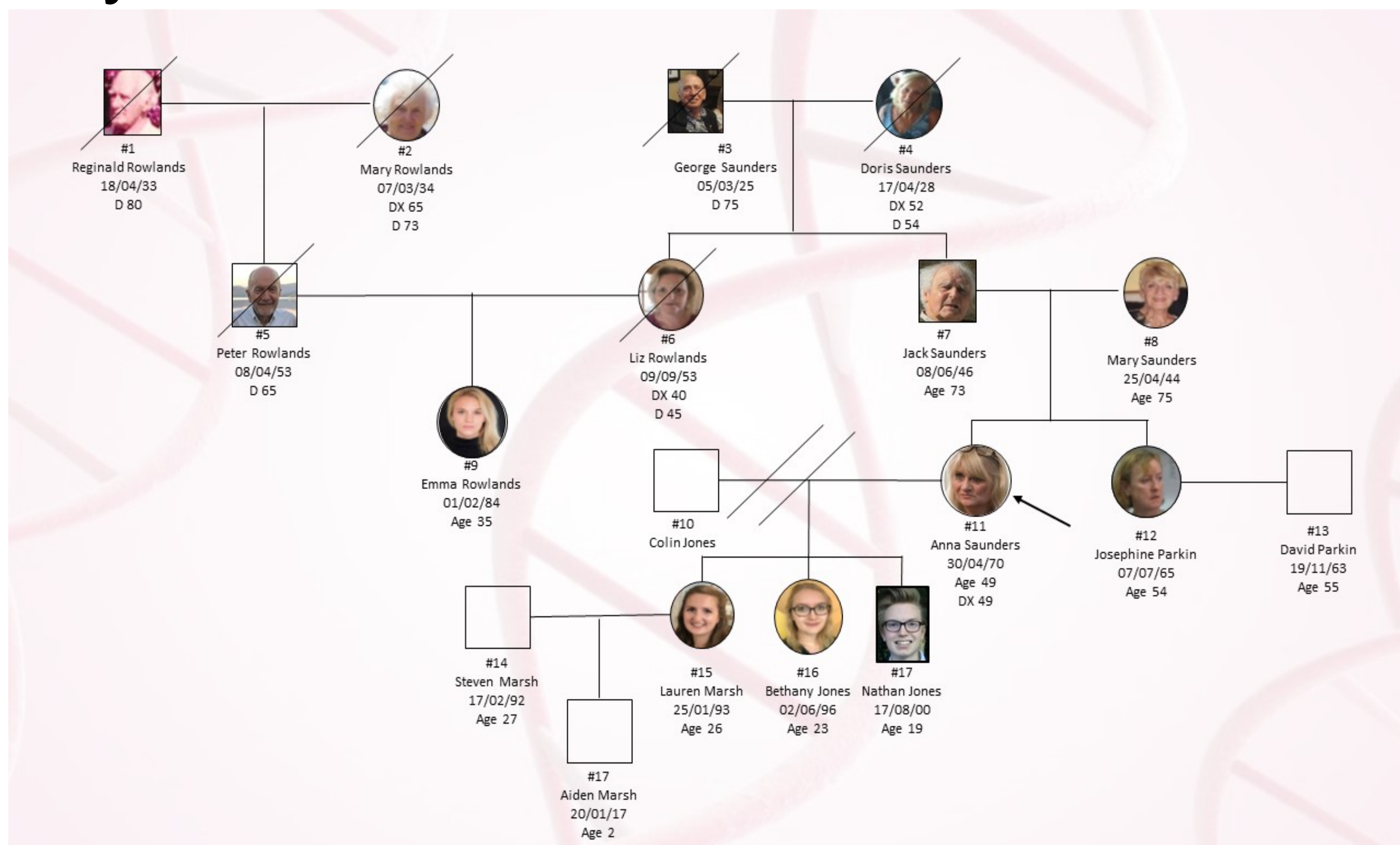
## Patient Interviews

- Explored views, knowledge and impact of genetic testing process
- 11 interviews with women with BRCA 1 or 2 mutation
- Common themes:
  - Emotional & social drivers
  - Risk
  - Decision making
  - Information and understanding
  - Communication and improvement
  - Accessing the system

*"It's very much data, numbers. And I don't think anyone can bridge the gap between that and ... the fear of actually getting the disease." Betty, 55*

*"My mum completely goes to pieces with stress. She doesn't want to know anything about the science behind it or anything. She just wants to be told what's the best thing to do and get on with it and she puts her head in the sand. Whereas I need to know my percentage of risk. I want to know the provenance of the information on which I'm making my decisions." Barbara, 43*

## Family Tree



- Program follows impact of BRCA2 test result on different members of a fictitious family
- Six filmed simulated scenarios with patient and family members
- Scenarios were unscripted but simulated patients and HCPs were provided with outline of either personal history or clinical details
- Scenarios are accompanied by a facilitator handbook including transcripts, discussion points, pedigree and additional background information
- Additional interview with geneticist Professor Gareth Evans and Professor Dame Lesley Fallowfield

## Scenarios



## Next Steps

- Evaluate program in workshops between April and July 2020
- Open to HCPs discussing genetic testing and hereditary breast cancer
- Workshops will include scenarios, group discussions and an interactive lecture
- Pre and post-course assessments of knowledge, self-awareness and communication
- Assessments will be a mix of multiple choice, self-reflection and practical tasks
- Results to be analysed and training evaluated
- If program is beneficial, HCPs to be trained as facilitators to reach peer groups

