Lisa Ingleby – Research Proposal Summary

**Clinical Genetics in a Palliative Care Setting: A Qualitative Exploration of the Barriers and Levers Staff Report when Discussing Family Risk**

The proposed research will be undertaken as part of the Doctoral Clinical Psychology course at the University of Leicester and is due for submission in April, 2015.

**Academic Supervisor** – Dr Noelle Robertson, Clinical Psychologist. Research Director – Clinical Psychology Doctorate, University of Leicester.

**Field Supervisor** – Dr Julian Barwell, Honorary NHS Cancer Genetics Consultant (UHL). Senior Lecturer in Cancer Genetics – University of Leicester.

**Chief Investigator** – Lisa Ingleby, Trainee Clinical Psychologist, University of Leicester.

**Research Rationale;** Clinical genetics is becoming increasingly important within a national context and preventative treatment options for those identified with familial Breast Cancer (BRCA) 1 & 2 mutations are constantly improving. At a local level, the clinical genetics team at University Hospitals Leicester (UHL) are carrying out innovative work to raise awareness and knowledge in the community and within health professionals about susceptibility to genetic mutations. Palliative and hospice care represent a final opportunity for those affected to provide the genetic material required to leave a lasting legacy for their remaining relatives, yet local audit data suggests referrals from this sector are infrequent. The proposed study aims to provide insight into what factors may prevent or promote discussion about family risk in palliative care and to develop a framework to inform psychosocial interventions in this area.

**Main aims and objectives;**

- Explore what interpersonal and organisational factors may act as barriers and levers to discussing genetic risk with families in a hospice context.
- Gain an understanding of how aware hospice staff are of availability of genetic testing and referral pathways to clinical genetics.
- Examine existing good practice and identify areas for development.

**Study Design;** Semi-structured interviews will be utilised to gather rich qualitative data regarding the research questions. Grounded Theory (GT) will inform data collection and analysis to facilitate the development of a theoretical model of how different factors influence the area of interest. There is a developing evidence base for the use of emotional touchpoints as a means of facilitating discussion about difficult topics and therefore this will be utilised in the collection of data in the present study. It is hoped that a collaborative, constructivist epistemological stance will enable the researcher and participants to collectively understand how clinical genetics can be implemented within routine practice.

**Sampling and Procedure;** It is proposed that a sample of 8-12 participants will be recruited from clinical staff working in hospices in Leicestershire, Coventry and Warwickshire. Any clinician for whom it would be appropriate to discuss genetic risk with patients and their families will be included. Clinicians who have no experience of face to face work with clients with breast or ovarian cancer will be excluded from the study.

It is proposed that the Chief Investigator will be available to attend team meetings to promote the research and to better understand the research setting. A small number of volunteers will be required to inform the development of the interview schedule during the piloting stage. Members of the team will be provided with an information sheet about the study and can
express interest by returning a reply slip with basic demographic information. An initial group of interviews will take place with those first to volunteer and the information gathered will inform further sampling. Interviews will last approximately 30-60 minutes.

All steps will be taken to ensure minimal disruption to the running of the hospice and all data will be stored in accordance with NHS confidentiality and information governance policies. Procedures will be in place for any participants who may require support and follow-up as a result of taking part in the research, or for any participant who may wish to withdraw their data.

Thank you for your consideration.

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