
CANCER DURING PREGNANCY:
DEVELOPING CONSENSUS AND
PRIORITIES FOR SUPPORTIVE CARE
RESEARCH AND EDUCATIONAL
RESOURCES THROUGH AN
INTERNATIONAL
COMMUNITY OF PRACTICE

ONLINE EVENT
WORKSHOP PROGRAMME

7 – 8 JULY 2021



NOT
TODAY
CANCER

OUR SPONSOR



The Institute of Advanced Studies (IAS) at the University of Surrey sponsors workshops and Fellowships at the 'cutting edge' of science, engineering, social science and the humanities. Through this scheme the Institute fosters interdisciplinary collaborations and encourages a flow of international scholars to visit, enjoy their stay at Surrey and leave behind excellent ideas and innovations.

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INTRODUCTION

A very warm welcome to everyone who is joining us for this international workshop and together we hope that we can achieve something special. We're here to raise awareness about the supportive care needs of women diagnosed with cancer during their pregnancy and find a way that we can work together to promote research and education in this area. There is never a good time for cancer, but to be diagnosed during pregnancy is particularly challenging. Most midwives and cancer nurses will not have much (if any) experience in supporting pregnant women with cancer, and yet there are so many complex issues, questions and dilemmas faced by women (and their families). This event has been designed to shine a light on these issues and explore how health care professionals can best provide support. This is an online workshop with a difference. We have the benefit of academic and clinical experts from across Europe, experts-by-experience as well as Mummy's Star, a dedicated charity with experience of providing support to thousands of families across the UK and Ireland. The pandemic has seen many conference and workshops shift to an online environment. For us, the plan has always to be online – we didn't want geography (and clinical commitments) to get in the way of bringing people together. We also decided it would be fun to take a creative approach – we've all had many hours of online meetings, so we approached Katie Chappell to join us throughout the workshop as our live illustrator, so we really look forward to seeing how she captures our discussions and recommendations in her own unique way!

The School of Health Sciences at the University of Surrey brings together cancer nurses, midwives and psychologists with an interest in research and education. The Institute of Advanced Studies provides the platform and support for us to be able to host this collaborative workshop today and we are honoured that so many experts in the field have agreed to share their knowledge and insights at this event. Rather than a conference, this is a workshop, so there will be time to listen to the experts, time for asking lots of questions, and importantly time to share ideas and reach decisions at the end of each day. So, don't be shy, we'd love to hear what you have to say. By the end of Day 1, we hope to identify the priorities for research and by the end of day 2, identified key issues for a free massive online education resource. We need your help to help shape research and education for women and their families affected by cancer during pregnancy. So, we hope that this is just the beginning of creating a community of practice. If you use social media, please use the twitter handle #cancerinpregnancy. We hope you enjoy this event, and feel welcomed into a community of practice that will develop research and education to improve the supportive care for women and their families.

We look forward to meeting you,
Karen, Jenny & Faith

Karen Poole, Jenny Harris and Faith Gibson
On behalf of the Cancer in Pregnancy
Group at the University of Surrey, School
of Health Sciences

PROGRAMME

DAY 1 – WEDNESDAY 7TH JULY

Priorities for Research

Aim: To develop a consensus statement for future research into the psychosocial wellbeing and support for women diagnosed with cancer and their families

(GMT)

10.00 – 10.10

Welcome and introduction

Professor Faith Gibson, Professor of Child Health and Cancer Care, School of Health Sciences, University of Surrey; Director of Research Nursing and Allied Health, Lead of Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID), Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), Honorary Associate Professor, University College London GOSH Institute of Child Health, UK

10.10 – 10.30

Introduction to the care of women diagnosed with gestational cancer

Professor Dr Federic Amant, Professor at the KU Leuven, Belgium and University of Amsterdam, Netherlands. Gynecologic Oncologist at University Hospitals Leuven, Belgium and at Netherlands Cancer Institute (Centre for Gynecologic Oncology Amsterdam). Chair of International Network on 'Cancer, Infertility and Pregnancy' (INCIP) of the European Society of Gynecologic Oncology (ESGO) (www.cancerinpregnancy.org)

10.30 – 10.50

The lived experience of being diagnosed with breast cancer during pregnancy

Assistant Professor Federica Facchin, Assistant Professor at the Department of Psychology, Catholic University of the Sacred Heart, Milan, Italy

10.50 – 11.10

Discussion facilitated by Professor Faith Gibson

Professor of Child Health and Cancer Care, School of Health Sciences, University of Surrey, UK

11.10 – 11.20

Break

DAY 1 – WEDNESDAY 8th JULY

Priorities for Research Continued

(GMT)

11.20 – 11.40

What research has been conducted in this field? Results from international Scoping Review & ongoing work

Dr Jenny Harris, Lecturer in Cancer Care, School of Health Sciences, University of Surrey

11.40 – 12.00

The view from my perspective

Laura Pearson, Author Laura Pearson (laurapearsonauthor.com)

12.00 – 12.20

Discussion facilitated by Veronica Blanco Gutierrez Midwife, University Hospital of Southampton NHS Foundation Trust, Member of Positive

12.20 – 12.30

Lunch Break

13.00 – 13.30

Modified Delphi results and consensus discussion

Facilitated by Dr Jenny Harris, Lecturer in Cancer Care, School of Health Sciences, University of Surrey

13.40 – 14.00

Agreed priorities for future research into the psychosocial wellbeing and support for women diagnosed with cancer and their families

Professor Faith Gibson & Katie Chappell, live event illustrator

14.00

Day 1 Workshop Close

Continued ►

PROGRAMME

DAY 2 – THURSDAY 8TH JULY

Priorities for Education

Aim: To develop the learning outcomes and a workplan for a Massive Open Online course (MOOC) for women diagnosed with cancer and their families and healthcare professionals providing supportive care.

(GMT)

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| 10.00 – 10.10 | Welcome and introduction to Day 2
Dr Karen Poole, Teaching Fellow in Integrated Care (Nursing), School of Health Sciences, University of Surrey, UK |
| 10.10 – 10.30 | Supporting women diagnosed with cancer during pregnancy: the role of a “cancer midwife”
Katrien Von Tornout, Midwife & Case Manager for Cancer in Pregnancy, University UZ Leuven, Belgium |
| 10.30 – 10.50 | Promoting a positive maternity experience across Europe: the POSMAT initiative
Maria Teresa Miletta, Clinical Psychologist, Psychotherapist and family therapist, Il Melograno, Centro Informazione Maternita e Nascita, Sede di Roma, Italy |
| 10.50 – 11.10 | Discussion facilitated by Dr Karen Poole Teaching Fellow in Integrated Care (Nursing), School of Health Sciences, University of Surrey, UK |
| 11.10 – 11.20 | Break |

DAY 2 – THURSDAY 8th JULY

Priorities for Education Continued

(GMT)

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| 11.20 – 11.40 | Providing educational support across the UK and Ireland to women and families and midwives
Pete Wallroth, Chief Executive Officer and founder of Mummy’s Star |
| 11.40 – 12.00 | Discussion facilitated by Dr Ann Robinson
Senior Teaching Fellow in Integrated Care (Midwifery), School of Health Sciences, University of Surrey, UK |
| 12.00 – 13.00 | Lunch Break |
| 13.00 – 13.30 | Modified Delphi results and consensus discussion
Facilitated by Dr Karen Poole, Teaching Fellow in Integrated Care (Nursing), School of Health Sciences, University of Surrey, UK |
| 13.40 – 14.00 | Agreed priorities for Massive Open Online course (MOOC) for women diagnosed with cancer and their families and healthcare professionals providing supportive care
Professor Faith Gibson & Katie Chappell, live event illustrator |
| 14.00 | Day 2 Workshop Close |

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BIOGRAPHIES

Follows Programme order

Faith Gibson



Faith is a Registered Nurse, qualifying in 1981, and then in 1986 completing a second qualification as Registered Children's Nurse: both qualifications gained whilst at the University Hospital in Nottingham. During 1981-1986 Faith worked in a number of adult cancer units and a hospice, and completed her Oncology Training at the Royal Marsden Hospital in London. From 1986 to date Faith has worked at Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), undertaking a range of clinical, educational and research roles. This period includes joint appointments with UCL Great Ormond Street Institute of Child Health and London South Bank University (LSBU). She was awarded her MSc from the University of Surrey (1984), and later her doctorate from London South Bank University (2001) for her working defining generalist and specialist children's nursing. Since completing her doctorate Faith has held a number of research posts, and was conferred as Clinical Professor of Children's and Young People's Cancer Care in 2009.

This was a joint appointment between GOSH and LSBU. Faith continues with her joint appointment at GOSH in the role of Director of Research-Nursing and Allied Health, and is now Professor of Child Health and Cancer Care at the University of Surrey. Faith has a research career spanning nearly 20 years. She is internationally recognised for her research in children's and young people's cancer care. This work was recognised in 2007 when she was granted Fellow of the Royal College of Nursing.

Frédéric Amant



Research activity

Frédéric Amant heads the Gynecologic Oncology research section at the University of Leuven, Belgium and at the Netherlands Cancer Institute. In 2005 he founded the ESGO taskforce on Cancer in Pregnancy, now the "International Network on Cancer, Infertility and Pregnancy" (INCIP) (www.cancerinpregnancy.org), and chairs this network up till now. Since 2014, INCIP also registers young women who aim to preserve their fertility. In addition, Frédéric Amant founded Trace, the tumor xenograft platform at the KU Leuven, aiming to bring basic research closer to the clinic. He co-founded ENITEC, the European Network on Individualized Treatment of Endometrial Cancer.

Clinical activity

Frédéric Amant (MD, PhD) received his medical degree from the University of Leuven (KU Leuven), Belgium in 1992, completed his specialty training as an obstetrician/gynaecologist in 1998 and his subspecialty training in gynaecologic oncology in 2000. He is professor at the KU Leuven in Belgium and at the University of Amsterdam (UvA) in the Netherlands, visiting professor at the university of Bergen, Norway, and honorary professor at the university of Pretoria, South Africa. He is specialist at the Netherlands Cancer Institute.

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Frederic Facchin



Federica Facchin (PsyD, PhD), obtained the National Scientific Qualification as Associate Professor (11/E4) in 2018 and is currently **assistant professor (RTDB, M-PSI/07)** at the Catholic University of the Sacred Heart, Department of Psychology, where she is also lecturer in Clinical Psychology of Family Relationships (Master's Degree), Psychodynamics (Bachelor's Degree), and Interpretative Phenomenological Analysis (PhD Program). Moreover, she is the coordinator of the Seminar on Ethics and Deontology in Psychology (Faculty of Psychology). Women's health issues (especially related to gynecological conditions) and gender-based violence (especially Intimate Partner Violence) represent the main focus of her research and clinical practice as a psychoanalytically oriented psychotherapist.

Jenny Harris



Jenny is a Lecturer in Cancer Care in the School of Health Sciences at the University of Surrey and Lead for Health Statistics overseeing the statistical advice service for Health Science students and staff. Jenny's background is in Health Psychology but her PhD (King's College London) focused on developing statistical risk prediction models in psychosocial oncology. Jenny has worked in Health Sciences research since 2003 having previously worked as a researcher at the National Centre for Social Research (NatCen), King's College London and at Surrey. Jenny is interested in using data-driven approaches to improve patient outcomes, experience and care and staff well-being. Jenny's research interests include digital health, clinical trials and feasibility studies, statistical modelling and patient-reported outcomes. She is particularly interested in health-related anxiety, the use of predictive risk models in psychosocial oncology and the statistical evaluation of complex interventions.

Laura Pearson



Laura Pearson lives in Leicestershire with her husband and two young children. She is the author of three novels: *Missing Pieces*, *Nobody's Wife* and *I Wanted You To Know*. Previously she lived in London and New York and worked as a copywriter and editor for QVC, Expedia, EE, Net a Porter and the Ministry of Justice. She was diagnosed with breast cancer during her second pregnancy and blogged about it at breastcancerandbaby.com.

Veronica Blanco Gutierrez



Veronica is a midwife at the University Hospital Southampton NHS Foundation Trust. She is very passionate about research and women's human rights in childbirth, among other interests. After having her daughter, Veronica became more interested in childbirth activism and joined the Association for Improvement of the Maternity Services in the UK and El Parto es Nuestro, a Spanish organisation that fights against obstetric violence and for the improvement of the Maternity Services in Spain. As a volunteer for El Parto es Nuestro, she was given the opportunity to collaborate in the European Erasmus + project PosMat, collaboration that started in 2019 and continues to the present day. She feels very honoured and proud to be part of this vital project and to be able to build a strong network of excellent professionals. Veronica also feels very privileged to learn more about cancer in pregnancy, to improve the care provided to women and families and to contribute to develop midwifery competences in the provision of cancer care during pregnancy and beyond.

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Karen Poole



Karen Poole trained as a nurse at University of Wales College of Medicine in 1994, graduating with a Bachelor of Nursing First Class Honours Degree. She became the first nursing student to be awarded the Lord Merthyr Medical Research scholarship to fund her PhD, which she completed in 1998. Her doctoral studies investigated the psychological impact of undergoing investigations for breast disease and formed the basis for her career in cancer clinical research. Since then, Karen has worked across academic, industry and NHS settings. After establishing the Surrey, West Sussex & Hampshire Cancer Research Network (2002-2007), Karen became the Research Delivery Director for the National Institute of Health Research (NIHR) Clinical Research Network (formerly National Cancer Research Network) responsible for the delivery of the national portfolio of over 500 cancer clinical research studies, across all disease types in the NHS (2007-2014). Karen has extensive experience of working across NHS organisations and networks and coordinating large scale initiatives. From 2015 to 2017, Karen returned to academic research as a Research Fellow with Professor Sara Faithfull on the True NTH Exercise & Diet project developing a pharmacy-led lifestyle intervention for men after treatment for prostate cancer. Most recently she was appointed as a Teaching Fellow (Nursing) (2019) with an interest in evidence-based practice and supportive cancer care.

Katrien Van Tornout



From 2001 until 2004 Katrien studied midwifery in Leuven (Belgium) and has been working as a midwife in the University Hospitals Leuven since May 2006 in the maternity ward and prenatal care. From May 2018 until now Katrien has been working as midwife and case manager in the research group on 'Cancer in Pregnancy' from Prof. Dr. F. Amant. Her main role is to accompany patients through the process of diagnosis – treatment – pregnancy and delivery, to include them in research projects and to coordinate the multidisciplinary care for patients diagnosed with cancer in pregnancy within our hospital. Within INCIP (International Network on Cancer, Infertility and Pregnancy) Katrien coordinates the participation of different international centers in our international studies.

Maria Teresa Miletta



Maria is a Clinical Psychologist, Psychotherapist, and Family Therapist offering individual, couple and family therapy with a specialism in cancer and neurological conditions (MND) and consequent expertise in bereavement support. After extensive professional experience in oncology and palliative care for the NHS in the United Kingdom, Maria Teresa has become a dedicated advocate for the improvement of holistic care through a multidisciplinary and patient-centred approach. As a consultant for Melograno – the Centro di Informazione, Nascita e Maternità in Rome, she is coordinating an EU funded project, Posmat, in order to develop strategies to normalise the pregnancy and maternity experiences of women with a diagnosis of cancer.

Pete Wallroth



Pete is the founder and CEO of the charity Mummy's Star, set up in 2013 in memory of his wife Mair, to offer support to women diagnosed with cancer during pregnancy or within 12 months of having a baby. He is passionate about ensuring that women are given all the normal choices in pregnancy that they would have without their diagnosis and works with hospitals and cancer centres nationwide to help improve knowledge about this area, sharing case studies and the various examples of good practice that help the families they support on a day to day basis. He also works to raise awareness of partners mental health, especially in a setting of caring for a sick partner or in loss and to try and break down societal presumptions about what partners, particularly fathers can do.

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Ann Robinson



As a clinical academic specialising in midwifery and sexual health, Ann has long been passionate about women-centred healthcare across the childbearing continuum. After training as Registered Nurse at St. Bartholomew's Hospital in London, Ann qualified as a Midwife in 1986, specialising predominantly in intrapartum care and foetal assessment at St. Thomas' Hospital. Whilst working clinically as a midwife at St. Thomas' Hospital, Ann undertook an Advanced Diploma in Midwifery and Post Graduate Certificate in Adult Education at the University of Surrey and from then began her midwifery teaching career. Today, Ann's teaching focuses predominantly on intrapartum care, women's health, leadership and research and design. Ann is developing her expertise in relation to qualitative methodology and enjoys being a research supervisor to BSc, MSc and PhD students. From an educational perspective, she is also an experienced external examiner focusing on both pre and postgraduate Midwifery Education.

In addition, Ann is a qualified Contraception and Sexual Health Practitioner, having established a teenage contraceptive clinic in 1996. I currently hold a contract with Central North West London NHS Trust focusing on contraceptive and sexual health. Ann completed a PhD at Southampton University (2012) with her thesis focused on The Role of The Consultant Midwife: An exploration of the expectations, experiences and intricacies.

Katie Chappell



Illustrator Katie Chappell is a virtual scribe and live event illustrator best known for her fresh wobbly illustration and giant live window paintings. She has created live illustrations for global clients including Apple, Facebook, Google, Chromebook, BT, Dove and Nespresso among many others.

[Katie Chappell Illustrator - Live Illustration](#)

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