

Cancer during Pregnancy: a Call to Research and Education through an International Community of Practice

7-8th July 2021

Institute of Advanced Studies Online Workshop Report

Dr Jenny Harris, Professor Faith Gibson and Dr Karen Poole



7TH JULY 2021 - 8TH JULY 2021 | 10:00 - 14:00

Cancer during Pregnancy: Developing Consensus and Priorities for Supportive Care Research and Educational Initiatives through an International Community of Practice

Held over two-half day online workshops, to maximise participation by busy NHS professionals, international partners and those with caring responsibilities, this event was co-organised by Dr Jenny Harris, Professor Faith Gibson and Dr Karen Poole.

The event was attended by 60 delegates from nine different countries, including oncology and maternity health care professionals and support staff, representatives from charities including women and partners with lived experience, and academic researchers and educators. Each day of the workshop comprised of a keynote speaker followed by invited presentations and interactive workshops with day one activities focused on identifying research priorities and day two educational priorities to develop a Massive Open Online Course (MOOC).

Workshop Context and Aims

Every day in the UK, two women are diagnosed with cancer during pregnancy or post-partum. The increasing use of non-invasive pre-natal testing to detect chromosomal foetal abnormalities has led to increased diagnosis in asymptomatic women. With the increasing trend to postpone childbirth to a later age, the incidence is expected to increase further. Cancer in pregnancy presents complex challenges covering medical/bioethical, psychosocial and supportive issues where decision-making can impact the mother, the foetus/new-born, partners and wider family. In recent years, clinical guidelines for the medical management of pregnancy in women with cancer have been developed but these have not yet been extended to guide psychological and supportive care.

The workshop had several key aims:

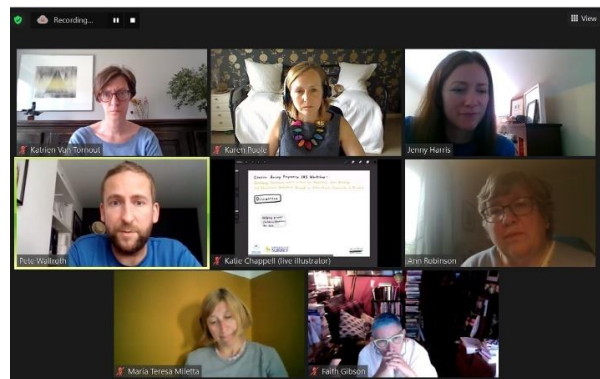
1. To initiate a community of practice bringing together expertise from a multidisciplinary group of researchers, educators and clinicians (cancer nurses, midwives, obstetricians, psychologists, oncologists, cancer surgeons) from Surrey, across the UK and Europe; and a panel of experts-by-experience to guide our future work, and foster links with key charities and foundations.
2. To gain consensus on the priorities for future research into the psychosocial wellbeing and support for women diagnosed with cancer and their families.
3. To gain consensus on the priorities for Massive Open Online course (MOOC) for women diagnosed with cancer and their families and healthcare professionals providing supportive care.

To facilitate achieving these aims remotely we employed two key innovative approaches;

- First, we enlisted artist Katie Chappell (www.katiechappell.com) who was able to capture the workshop discussions and recommendations live.



Katie Chappell



Panel discussions with Katie illustrating live (centre)

- Second, to enable aims 2 and 3, upon registration delegates were asked to complete two questions about their own top three research *and* education priorities in this area. Ahead of the workshop the event organisers conducted content analysis to identify the main themes from these responses.

Event themes

Day One: Priorities for Research

After welcomes and introductions by **Professor Faith Gibson**, gynaecological oncologist **Professor Dr Federic Amant** (KU Leuven, Belgium and University of Amsterdam, Netherlands. University Hospitals Leuven, Belgium and at Netherlands Cancer Institute) and Chair of International Network on 'Cancer, Infertility and Pregnancy' (INCIP) of the European Society of Gynaecologic Oncology (ESGO, www.cancerinpregnancy.org) provided a clinical introduction to the medical care of women diagnosed with gestational cancer. Professor Amant provided a comprehensive overview of the surgical and medical management and spoke about the treatment choices women have once they are diagnosed with cancer. An important message from this talk was that chemotherapy is possible and safe after the first trimester and up until 37 weeks.

Assistant Professor Federica Facchin (Department of Psychology, Catholic University of the Sacred Heart, Milan, Italy) presented work from her qualitative study exploring the lived experience of being diagnosed with gestation cancer and **Dr Jenny Harris** presented the preliminary results of a scoping review of existing studies. An important theme was that few international studies have explored this important area with only one small study in the UK. Author **Laura Pearson** drew on her own lived-experience and spoke about her perspective of being diagnosed with cancer during pregnancy, her experiences of care and the impact this had not only on her and her immediate family but also wider family and friends.

Day One ended with a presentation by **Dr Jenny Harris** on the content analysis of the delegates research priorities and a lively discussion on what the key priorities should be for the group going forward. Some key themes were the importance of supporting women and their families/partners, enabling 'usual' maternity experiences wherever possible and choice for example access to breast milk.

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Day Two: Priorities for Education

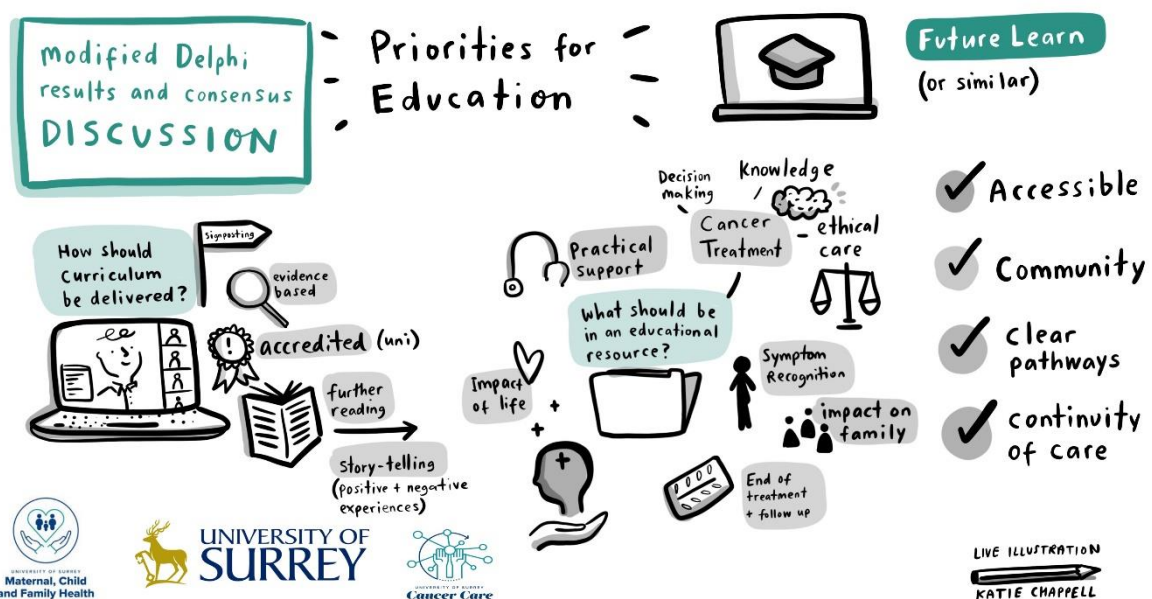
A highlight was a talk by the world's only specialist cancer midwife, **Katrien Von Tornout** (University Hospitals Leuven, Belgium), who talked about her role in empowering women and their families and supporting other clinicians to provide women-centred care. This was followed by clinical psychologist **Maria Teresa Miletta** (Centro Informazione Maternita e Nascita, Roma, Italy) who has led an initiative (www.pregnancyandcancer.eu/), to promote a positive maternity experience for women with cancer across Europe (referred to as POSMAT).

Peter Wallroth, CEO and founder of Mummy's Star (www.mummysstar.org), talked about the aspects of care which made a positive difference when his partner was diagnosed with cancer, and described how Mummy's Star provides educational support across the UK and Ireland to women, their families and midwives. Surrey's Senior Teaching Fellow and Midwife, **Dr Ann Robinson** facilitated a discussion where many delegates reflected on their own experiences of caring for women and their families affected by cancer during pregnancy, and some reflected on the types of information they would have found helpful.

Day Two ended with **Dr Karen Poole** presenting the results of the content analysis of the delegates education priorities, a demonstration of the possible digital platforms and useful discussions about some of the key content for such a MOOC. **Professor Faith Gibson** brought the workshop to a close by explaining how we will use the workshop discussions and illustrations to follow up with all delegates to create a final set of priorities for both research and education to improve the supportive care of women diagnosed with cancer during pregnancy.

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Next steps and outcomes

This workshop enabled us to forge key strategic links with a community of multidisciplinary researchers, educators and clinicians from across the UK and Europe, and make new links with our experts-by-experience and charity partners.

Through hosting this workshop many delegates expressed an interest in future collaboration in both research and educational initiatives which we are following up:

“It was an absolute pleasure to see the tons of work already done and the enthusiasm to promote more awareness regarding cancer and pregnancy. The workshop was fantastic” (Clinical Academic delegate)

“I just wanted to say thank you for an excellent workshop this week. It was so interesting and well organised I really enjoyed it.... My background is in research, social psychology, so the workshop was a great chance to get my brain ticking again.” (delegate from third sector organisation)

“Thanks so much for delivering such an insightful workshop. I was only able to attend today's session but have learnt a huge amount. Just wanted to say that I would love to be involved in the educational resource.” (delegate from third sector organisation)

“Congratulations for a wonderful two-day workshop, the speakers were amazing, very thought provoking and with such experience. As for Katie Chappell's illustrations, she is so talented.” (Clinical Academic delegate)

We have also been approached as invited speakers to the 4th **Global Adolescent and Young Adult (AYA) Cancer Congress** (1-2 December 2021) <https://ayaglobalcancercongress.org/> as well as feedback key findings to the next International Network on Cancer, Infertility and Pregnancy Meeting (13 September 2021).

We are currently writing up the results of the research priorities for publication in a peer review journal and the final recommendations will be visually captured by our conference artist.

Our team are planning to create a MOOC alongside partners identified through this workshop together with the Digital Learning Team at the University of Surrey. The educational priorities identified will feed into its design.

Acknowledgements

We gratefully acknowledge the support of our sponsors: The Institute of Advanced Studies at the University of Surrey. We would like to thank Mirela Dumic and Vicki Blamey from IAS for all their support and advice throughout the process. Our sincere thanks to our esteemed European Clinical Academic partners who generously shared their expertise and to Laura Pearson for sharing her very personal story in this online space.

We would like to extend our particular thanks to Pete Wallroth from Mummy's Star. Pete has transformed the support provided to UK & Irish women diagnosed with cancer in and around pregnancy over the past 8 years and inspires us to continue our research and education for these families.

Working with a live illustrator, Katie Chappell added a whole new dimension to our online workshop. Watching the creation of live illustrations and reviewing these after each session, really helped us all to focus on the key messages as well as being a valuable resource in communicating our next steps.

Finally, we would like to thank our colleagues in the Cancer in Pregnancy Team (Dr Ann Robinson, Professor Emma Ream, Professor Jo Armes, Dr Afro Marcu, Julia Boon) for their ongoing enthusiasm and support in seeking out opportunities (such as this) to advance education and research in this field.