

Institution: Leeds Beckett University		
Unit of Assessment: 4a		
Title of case study: Empowering women of childbearing age with cancer to make informed decisions about fertility preservation.		
Period when the underpinning research was undertaken: During this REF period		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Georgina Jones	Role(s) (e.g. job title): Professor of Health Psychology	Period(s) employed by submitting HEI: June 2016+
Period when the claimed impact occurred: During this ref period		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>Psychological research led by Jones at Leeds Beckett University (LBU) has made an outstanding contribution to clinical practice and policy support for women of childbearing age and diagnosed with <i>any</i> cancer to make fertility preservation (FP) decisions. The research has 1) informed the development of the first FP patient decision aid for this patient group (Cancer, Fertility and Me) which was published in September 2019 with 8,464 page views, 2) informed FP advice for the British Fertility Society (BFS, 2018), National Institute for Health and Care Excellence (NICE, July 2020), Human Fertilisation and Embryology Authority (HFEA, September 2020), European Society for Human Reproduction and Embryology (ESHRE, November 2020), and leading national charities including Cancer Research UK, and 3) improved clinical practice by demonstrably empowering women with cancer to make FP decisions, and enabling fertility and oncology healthcare professionals to better support this patient group.</p>		
2. Underpinning Research (500 words)		
<p>Between 40-70% of pre-menopausal women will lose the opportunity to have a biological child because of cancer treatment. Whilst FP treatments (such as egg, embryo, ovarian tissue cryopreservation) provide hope, the treatment has to be undertaken rapidly, <i>before</i> starting chemotherapy, otherwise it is too late. Ensuring women are supported to make the right FP decision for them rapidly, whilst dealing with a new cancer diagnosis, is therefore vital. The underpinning research of this impact led by Jones's and supported by LBU research staff Jane Hughes (2013-2016), Dr Neda Mahmoodi (2015+), Dr Kathy Vogt (2017-2018), Dr Rachael Moss (2018-2020) and Dr Frances Darby (2017-2020) is based upon four studies which has driven decision-making support needs for these young women in the UK.</p> <p>The first study involved a systematic review of the international literature (46 papers out of a total of 983) which was published in the number one journal (out of 83) within the field of obstetrics and gynaecology (3.1, 50 citations). It identified a wide range of internal and external factors that impact upon the FP decision-making process and recommended that decision support interventions may be of benefit within the clinical care pathway of FP for women with cancer.</p> <p>A subsequent longitudinal, mixed-method study (3.2) (G1) and an evaluation of a UK fertility preservation service (3.3) confirmed these findings. In the longitudinal study, 58</p>		

women of child bearing age and diagnosed with cancer completed a set of questionnaires at different stages in the cancer and fertility care pathway. Interviews were also conducted with some participants. The results indicated that receiving specialist FP guidance solely at the point of a fertility consultation hindered the decision-making process and negatively affected women's quality of life. Instead, women wanted to receive information sooner in the context of their cancer care, in *advance* of seeing the fertility expert. The local service evaluation outcomes affirmed these findings. It identified that 174 women with cancer had been referred for a FP consultation over a 12-year period. Of these, 79 women were sent questionnaires and a further 10 interviewed. Whilst the majority perceived their experience as excellent, the findings elicited key areas requiring improvement, including the need for enhanced referral pathways and increased information provision in oncology prior to arrival at the fertility clinic.

To address the aforementioned gap in NHS information provision, Jones then led the development of Cancer, Fertility and Me (CFM) - the first and only patient decision aid booklet to specifically better support UK women, diagnosed with *any* cancer to make FP choices, funded by Yorkshire Cancer Research [G2]). The study protocol (3.4) utilised a prospective mixed method observational study involving three stages 1) developing the PtDA using a systematic method of evidence synthesis (3.5) and multidisciplinary expert review of current clinical practice and existing patient information, 2) alpha testing the PtDA using questionnaires and interviews with patients (n=7), charity service user groups (n=5) and healthcare professionals (n=14), and 3) beta testing the resource by undertaking a quantitative and qualitative evaluation of the PtDA in clinical practice (n=51). Funding was subsequently obtained from the University of Edinburgh (G3) to develop an online version of the resource, making CFM freely available on a grand scale. The study is ongoing and finishes in March 2021.

3. References to the research (indicative maximum of six references)

3.1. Jones G, Hughes J, Mahmoodi N, Smith E, Skull J, Ledger W. What factors hinder the decision-making process for women with cancer and contemplating fertility preservation treatment? *Human Reproduction Update*. 2017 Jul 1;23(4):433-457. (Impact factor 12.878)

3.2. Vogt KS, Hughes J, Wilkinson A, Mahmoodi N, Skull J, Wood H, McDougall S, Slade P, Greenfield DM, Pacey A, Ledger W, Jones GL. Preserving fertility in women with cancer (PreFer): Decision-making and patient-reported outcomes in women offered egg and embryo freezing prior to cancer treatment. *Psychooncology*. 2018 Dec;27(12):2725-2732. (Impact factor 3.455)

3.3. McDougall S, Vogt KS, Wilkinson A, Skull J, Jones GL. Outcomes of delivering a fertility preservation service for women with cancer over a 12-year period at a UK assisted conception unit. *J Obstet Gynaecol*. 2019 Aug 8:1-8. doi: 10.1080/01443615.2019.1621823. [Epub ahead of print] PubMed PMID: 31392913. (IF 0.81)

3.4 Jones GL, Hughes J, Mahmoodi N, Greenfield D, Brauten-Smith G, Skull J, Gath J, Yeomanson D, Baskind E, Snowden JA, Jacques RM, Velikova G, Collins K, Stark D, Phillips R, Lane S, Bekker HL; (On behalf of the Cancer, Fertility and Me research team). Observational study of the development and evaluation of a fertility preservation patient decision aid for teenage and adult women diagnosed with cancer: the Cancer, Fertility and Me research protocol. *BMJ Open*. 2017 Mar 13;7(3):e013219. (Impact Factor 2.5).

3.5. Mahmoodi N, Bekker HL, King NV, Hughes J, Jones GL; Cancer, Fertility and Me research team. Are publicly available internet resources enabling women to make informed

fertility preservation decisions before starting cancer treatment: an environmental scan? *BMC Med Inform Decis Mak.* 2018 Nov 19;18(1):104. (Impact Factor 2.07)

G1: Jones GL, Greenfield D, Skull S, Pacey A, Slade P, Ledger W. Understanding the psychological impact and decision-making process of women with cancer contemplating fertility preservation. Sheffield Teaching Hospitals charitable Trust (£100,000) (2011-2015)
G2: Jones GL, Greenfield D, Collins K, Bekker H, Velikova G, Skull J. Cancer, Fertility and Me: The development and evaluation of a fertility preservation decision support intervention to support women with cancer in Yorkshire. Yorkshire Cancer Research (250,000) (2015-2021)

G3: University of Edinburgh: Creating an online version of the Cancer, Fertility and Me patient decision aid: Scottish Government. £6,000 (2019)

4. Details of the impact (indicative maximum of 750 words)

Since CFM became publicly available in September 2019 (**S1**), it has informed FP policy and practice guidelines, demonstrably improved clinical practice and empowered women with cancer to make FP decisions. The International Patient Decision Aid Standards scientific committee endorsed it for inclusion in their A-Z inventory, awarding it top marks (**S2**), with 30,243 views of the inventory overall (Dec 2020). Jones was awarded the Lisa Thaxter Trust Prize (July 2016) by the national charity 'Teenagers and Young Adults with Cancer' and colleagues from Sweden, Germany, America and Australia invited Jones to co-deliver a FP symposium at the International Psycho-Oncology Society Conference (Hong Kong 2018) (**S3**).

1. Improving fertility preservation policy and practice guidelines

NICE (July 2020) recognised the benefits of CFM to clinical practice, endorsing it as a tool that can facilitate and support healthcare professionals to implement six of their recommendations and quality standards relating to patient experience in adult NHS services, cancer services for children and young people, and fertility problems (**S4**). The UK government regulator, HFEA (September 2020) (**S4**) and ESHRE (November 2020) (**S4**) include CFM in their information provision and guidelines on female FP. Jones was invited to provide the psychological expertise to the policy and practice guidelines on FP for the BFS (**S5**).

This was considered "a landmark policy and practice paper" by the Editor-in-Chief of Human Fertility (**S6**) and was covered widely by the media, including the Telegraph and Independent, highlighting the significance of the guidelines and bringing them to national attention (**S6**). The guidelines are informing the clinical practice of other organisations such as the British Menopause Society (**S6**), with fertility centres across the UK, acknowledging the impact they have had on clinical practice in this area. For example, Chiltern Fertility report (**S6**):

"These new guidelines are a fantastic step forward in terms of fertility preservation. They meet the needs of modern times and provide an excellent resource for clinicians to ensure they are providing the very best fertility preservation advice and treatment."

2. Empowering patients with cancer

Benefits of the tool to patients have been reported. As of December 2020, there have been 8,464 page views of the online resource (73% of the page views are from the UK but the rest are from overseas demonstrating international reach). One cancer patient said:

"I so wish I had been offered these options when I was first diagnosed. The CFM booklet will give women the power to help make the best decisions for themselves in conjunction with their medical teams. I hope it is adopted by all hospitals. 30th May 2018."

Further exemplar quotes demonstrating the benefit of the resource to cancer patients can be found in **S7**.

This work is informing the ways that charities deliver their FP patient-facing content. Breast Cancer Now, Lymphoma Action and Cancer Research UK all signpost patients to the CFM resource (**S8**). Brainstrust have invited Jones to produce additional FP information for their patient members (November 2020), and she is currently co-producing a version of CFM specifically for teenagers with cancer with Lymphoma Action. She has adapted the resource for an Australian group of women (Cancer, Fertility and Me-Australia) led by the University of Sydney, which is in the early stages of evaluation and is scheduled to deliver an invited podcast with influential patient blogger/campaigner Becki McGuinness from Cancer and Fertility, UK, who has promoted the benefits of the CFM resource to her 3,967 followers (January 2021).

3. Improving clinical practice

Benefits of the tool to practitioners have also been reported. Seventeen healthcare professionals have responded that CFM is ‘a useful tool that could help me and my patients to make difficult treatment decisions’, 12 are using the resource ‘in my consultations with patients’ 13 are ‘Signposting it to my colleagues’ and 14 are ‘Signposting it to my patients’ (n = 14). A further 18 comments demonstrating the impact upon healthcare professionals who have read and/or visited the website can be found in **S9** but include:

“[the resource is] easy to use and have conversations with patients... Covers all the important topics and a useful prompt for me.”

“it is good to have a powerful tool to guide us and the oncologists on the best and most appropriate fertility preservation option for our patients.”

“I’ve directed them [patients] to the Cancer Fertility and Me website before their telephone appointment with me and it has definitely helped with the discussion.”

Jones continues to deliver annual FP decision-making training sessions to the BFS (2016). To date, 141 clinical fertility trainees have benefitted from her work, for example in 2019, a delegate wrote *“Good to find out relevant patient information to direct patients to. / Interested to see the decision-making tool released in August”. In 2020, 100% of their feedback (n=28) reported the best outcome, describing Jones’s FP decision-making lecture as “Very relevant and interesting”.*

Jones has also taken up invitations by National charities to help their members use CFM, including hosting a webinar for Brainstrust (February, 2021), Q&A sessions for the BFS (Sept 2020) and an ‘Ask the Expert’ panel session for Clic Sargent in November 2019 for service users aged 16+ who have or had cancer, following which, she received this feedback:

“Your expertise was invaluable for our young people to better understand their fertility options post-treatment. The Cancer, Fertility and Me website is such an amazing resource and will really help our young women diagnosed to better know their option” Laura Rohdich, Clic Sargent. December 2019.

Finally, as well as the psychological work that Jones and her team have been undertaking in the area of fertility preservation for women with cancer, she has also been influencing how other clinical teams address their patient’s treatment decision needs. For example, a team of gastroenterologists approached Jones to collaborate on the development of a new patient decision aid for patients with ulcerative colitis facing medical and surgical treatment choices. This was subsequently funded by the charity Crohn’s and Colitis, UK (**S10**).

5. Sources to corroborate the impact (indicative maximum of 10 references)

S1. Cancer, Fertility and Me made publicly available

www.cancerfertilityandme.org.uk

<https://www.leedsbeckett.ac.uk/cancer-fertility-and-me/>

S2. IPDAS Scoring of the PtDA: <https://decisionaid.ohri.ca/AZsumm.php?ID=1921>

S3. Jones, GL, Vogt, K, Darby, F et al. (14 more authors) (2018) Experience of developing and evaluating a fertility preservation patient decision aid for teenage and adult women with cancer for use in oncology settings, UK (The Cancer, Fertility and Me study). In: Psycho-Oncology. 20th World Congress of Psycho-Oncology, 29 Oct - 02 Nov 2018, Hong Kong. John Wiley & Sons Inc. p. 45. <http://eprints.whiterose.ac.uk/139803/>

S4. Improving fertility preservation policy and practice guidelines

<https://www.nice.org.uk/guidance/cg156/resources/endorsed-resource-cancer-fertility-and-me-8831608813>

<https://www.hfea.gov.uk/treatments/fertility-preservation/>

<https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Female-fertility-preservation>

S5. Yasmin E, Balachandren N, Davies MC, Jones GL, Lane S, Mathur R, Webber L, Anderson RA; British Fertility Society. Fertility preservation for medical reasons in girls and women: British fertility society policy and practice guideline. Hum Fertil (Camb). 2018 Jan 3:1-24. (IF 2.2) <https://www.tandfonline.com/doi/full/10.1080/14647273.2017.1422297> p15-17

S6. National Media and Professional Reach of the BFS policy and practice guidelines

S7. Examples of the benefit of the resource from patients in patient letters and patient quotes.

S8. Impact on charities

<https://www.cancerresearchuk.org/about-cancer/coping/physically/sex/women/losingfertility>

<https://lymphoma-action.org.uk/about-lymphoma-side-effects-treatment/reducedfertility>

<https://breastcancernow.org/information-support/facing-breast-cancer/breast-cancerin-younger-women/fertility-pregnancy-breast-cancer-treatment/options-preservingfertility-during-treatment>

S9. Further examples of the benefit of the resource to healthcare professionals

S10. Impact on further research

<https://www.crohnsandcolitis.org.uk/research/projects/an-aid-to-support-people-with-ulcerative-colitis-choosing-between-medical-a>