

Fertility and Cancer: Scoping Report

A compilation of the work undertaken between
November 2019 and March 2020

Transforming Cancer Services Team

December 2020

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About Healthy London Partnership

Healthy London Partnership formed in 2015. Our aim is to make London the healthiest global city by working with partners to improve Londoners' health and wellbeing so everyone can live healthier lives. Our partners are many and include the NHS in London (Clinical Commissioning Groups, Health Education England, NHS England, NHS Digital, NHS Improvement, trusts and providers), the Greater London Authority, the Mayor of London, Public Health England and London Councils. All our work is founded on common goals set out in [Better Health for London](#), [NHS Five Year Forward View](#) and the [Devolution Agreement](#).

About the Transforming Cancer Services Team (TCST)

The Transforming Cancer Services Team (TCST) is part of the Healthy London Partnership and supports the delivery of the NHS Long Term Plan across London. We are working to improve the early detection of cancer and access to personalised cancer care as well as the implementation of the new 28-day faster diagnosis standard. We work with patients, health and social care services, and the third sector. TCST supports all 32 London CCGs and West Essex CCG. Partners include—NHS England/Improvement, Cancer Alliances, providers; Strategic Transformation Partnerships/Integrated Care Systems, cancer charities, and social care.

Our **vision** is for all Londoners to have access to world class care before, during and after a cancer diagnosis

Our **mission** is to provide expertise and work collaboratively to deliver the best possible patient experience and clinical outcomes whilst reducing inequalities across London

The pan-London Transforming Cancer Services Team are responsible for:

- A once for London approach to implementing the NHS Long Term Plan
- Bringing together partners to enable strategic decision making and mutual accountability
- Providing subject matter expertise, evidence and intelligence for cancer stakeholders
- Developing strategic and clinical guidance as well as information for patients
- Ensuring the work we do is informed by service users and clinical experts
- Working to reduce variation and inequalities
- Supporting primary care development and education
- Targeted service improvement in secondary care

Acknowledgements

The Transforming Cancer Services Team's Fertility Project Manager and NHS Graduate Management Trainee, Clara Burr-Lonnon, would like to thank the following individuals for their time, participation, and passion to transform cancer patient's experiences with fertility services.

- The Fertility and Cancer Steering Group who have enabled this work to stay on track and provided constructive feedback and guidance for the project.
- The Transforming Cancer Services Team, specifically the Personalised Care for Cancer Team, for all their support and encouragement over the past few months.
- Liz Price, Associate Director Personalised Care for Cancer, Transforming Cancer Services Team for her project supervision and support.
- The many individuals across fertility and cancer services in London and the third sector who have taken the time to discuss this work and helped to shape the direction of the project.

Executive Summary

This document compiles the work undertaken in the fertility workstream within the Transforming Cancer Services Team between November 2019 and March 2020. It is important to note that this work ended prematurely due to the Covid-19 outbreak in March 2020 when NHS England declared a level four incident due to the pandemic. This meant project work unrelated to Covid-19 was halted in the top down command and control structure where NHS England determined local activity and priorities.

The aim of this document is to provide CCGs/STPs/ICSs, cancer alliances, clinicians and management teams with a greater understanding of the fertility preservation services and support offered to people aged 16 and over affected by cancer in London. This includes both Teenage and Young Adult and Adult Cancer Services for both men and women.

Whilst some work was put on hold due to Covid-19, this document includes the following completed components:

- An overview of why fertility is an important consideration for cancer patients
- A survey of cancer clinicians designed to understand fertility preservation and support services offered by cancer services and understand cancer team's education, training, and confidence levels in discussing fertility with patients
- A comparison of CCG/STP fertility preservation policies
- Thematic analysis of qualitative interviews with fertility and cancer clinicians
- An overview of cancer and fertility data
- A 'checklist' for systems who wish to reduce variation in fertility preservation services/support for cancer patients. The checklist includes:
 - Conducting patient focus groups and/or interviews
 - Mapping where cancer services refer their patients to for fertility preservation services and support
 - Conducting an up to date literature and policy review
 - Review STP/ICS fertility preservation policies in line with NICE guidance
 - Educating and raising awareness about fertility preservation and support with healthcare professionals and referrers in cancer services
 - Developing a clear, concise referral and communication pathway between cancer and fertility services.

1. Background

1.1 London Context

As cancer incidence increases and survival improves, the number of people living with a cancer diagnosis is increasing. Every year, approximately 34,000 Londoners receive a diagnosis of cancer. As of 2017, over 231,000 people (2.6% of the population) in London were living with and beyond cancer- a figure which is expected to increase by approximately 50% in 2030. It is known that people living with cancer can have a range of short and longer term clinical, functional and psychosocial problems both from the cancer itself and from treatment¹.

1.2 History of the Project

2016

- Dr Channa Jaysena, Consultant in Reproductive Endocrinology and Andrology, at Imperial College and Hammersmith Hospital gets in touch with Liz Price at TCST. Exploratory work takes place, looking at fertility preservation policies across London. However, there was no capacity within TCST at the time to do a deep dive into fertility and cancer.

2018

- In May, Dr Phillipa Hyman, TCST Macmillan Mental Health Clinical Lead, published [*The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychological support for adults affected by cancer*](#) (updated February 2020). This work included in-depth qualitative interviews and focus groups with cancer service users in their 20s and 30s, carried out in partnership with Trekstock, a third sector organisation supporting young adults with cancer.
- One of the themes from this work was the wider implications of cancer and its treatment, including wider factors on mental health such as fertility. The following are a few quotes from Dr Hyman's interviews and focus groups.
 - *"The chat about fertility needs to be more prominent."*
 - *"Oncologists are fantastic on focusing on cancer but they might not know the finer details of fertility."*

¹ Transforming Cancer Services Team. (2020). *What a faster cancer diagnosis will mean for Londoners - Healthy London Partnership*. Healthy London Partnership. Retrieved 14 June 2020, from <https://www.healthylondon.org/what-a-faster-cancer-diagnosis-will-mean-for-londoners/>.

- *“I know women who haven’t had those chats and now after having treatment are being told about fertility².”*
- TCST successfully bids for a second placement NHS National Graduate Management Trainee (General Management stream) for a strategy placement due to commence November 2019. TCST decided that the NHS management trainee will lead on the fertility work, scoping the fertility preservation services and support offered to people affected by cancer in London.

2019

- In November, Clara Burr-Lonnon, NHS Graduate Management trainee joined TCST to lead on the fertility work with the aim of understanding the fertility preservation services and support offered to people affected by cancer in London.

2020

- On 4th March, the Fertility and Cancer Steering Group met to discuss terms of reference, an overview of the workstream, CCG/STP fertility preservation policies, preliminary SurveyMonkey results, and further engagement. The next meeting was set for mid-May. For Terms of Reference, please see [Appendix 1](#).
- On 17th March, the project was presented to TCST’s Personalised Care for Cancer Partnership Board
- In mid-March, the fertility work was put on hold for the immediate future due to the Covid-19 pandemic, and the NHS directive to stop any non-essential business in order to deploy staff to help manage the Covid-19 crisis.
- In June, Clara Burr-Lonnon finished the NHS Graduate Management Training Scheme and left TCST. The workstream came to a close due to the ongoing Covid-19 pandemic and NHS focus on recovery planning.

1.3 Why is fertility an important consideration for cancer patients?

This section discusses NICE clinical guidance, NHS STP/CCG fertility preservation policies, and provides a brief literature scan regarding fertility implications for cancer patients, including sections on men, women, and childhood, teenage and young adult survivors of cancer.

1.3.1 NICE Clinical Guidance

At the time of diagnosis, The National Institute for Health and Care Excellence ([NICE](#)) [clinical guidance 156](#) recommends that:

‘the impact of the cancer and its treatment on future fertility should be discussed between the person diagnosed with cancer and their cancer team.’

² Hyman, D. (2020). *Commissioning Guidance for Cancer Psychosocial Support* [Ebook]. Healthy London Partnership. Retrieved 24 June 2020, from <https://www.healthylondon.org/wp-content/uploads/2020/02/Refreshed-February-2020-Guidance-doc-Psychological-support-for-people-affected-by-cancer-.pdf>.

The decision to offer fertility preservation should consider the following factors—the patient’s cancer diagnosis, treatment plan, expected outcome of subsequent fertility treatment, prognosis of cancer treatment, and viability of stored/post-thawed material.

Following a cancer diagnosis, the patient should be informed that:

‘eligibility criteria used in conventional infertility treatment do not apply in the case of fertility cryopreservation provided by the NHS. However, those criteria will apply when it comes to using stored material for assisted conception in an NHS setting’ (eg. IVF)

The guidance also states that cancer patients shouldn’t be subject to the same limitations (such as a lower age limit) as the general population.

When using cryopreservation to preserve fertility in people diagnosed with cancer, NICE recommends using sperm, embryos, or oocytes and storing cryopreserved material for an initial period of ten years.

For women of reproductive age and adolescent girls, NICE recommends that the NHS: ‘Offer oocyte or embryo cryopreservation as appropriate to women of reproductive age (including adolescent girls) who are preparing for medical treatment for cancer that is likely to make them infertile if:

- they are well enough to undergo ovarian stimulation and egg collection **and**
- this will not worsen their condition **and**
- enough time is available before the start of their cancer treatment’.

For men and adolescent boys, sperm cryopreservation should be offered to those who are preparing for medical treatment for cancer which is likely to make them infertile. For men who remain at significant risk of infertility, NICE recommends that the NHS should offer continued storage of cryopreserved sperm, beyond ten years³.

1.3.2 NHS CCG and STP Policies—Fertility Preservation

Whilst NICE recommends the above, local Clinical Commissioning Groups (CCGs) or Sustainability and Transformation Partnerships (STPs) dictate the fertility preservation treatment available to patients and the length of time sperm, oocytes, embryos can be stored for patients residing within their geographies. This means that fertility preservation treatment varies at a CCG level or STP level (depending on location in London). For example, depending on a patient’s local CCG or STP they could be eligible for 5 or 10 years of NHS funded storage of cryopreserved materials. Further details on

³ *Fertility problems: assessment and treatment—People with cancer who wish to preserve fertility*. NICE. (2013). Retrieved 10 June 2020, from <https://www.nice.org.uk/guidance/cg156/chapter/Recommendations#people-with-cancer-who-wish-to-preserve-fertility>.

all of London's CCG and STP fertility preservation policies can be found in [Section 4.3](#) and [Appendix 2](#).

1.3.3 Men with Cancer

Cancer treatment can cause temporary or permanent infertility in men, either by stopping sperm production or causing erectile dysfunction. The only way to conserve fertility in men prior to treatment is sperm banking (cryopreservation). Men having surgery for testicular cancer (bilateral orchidectomy) will never be able to produce sperm after their treatment, so will need to bank their sperm before treatment⁴. Fischer and Hammarberg (2011) reviewed the international literature on infertility in men, but didn't specifically address infertility as a result of cancer treatment. It is interesting that in the papers they reviewed, men in all countries (apart from Chile) "prefer to receive relevant emotional support from infertility clinicians within routine care rather than from mental health professionals, self-help support groups or friends"⁵.

Dohle (2010) reviewed male infertility specifically due to cancer, noting that particular types of chemotherapy (alkylating agents such as cyclophosphamide) are most likely to damage sperm production. Approximately 15% of men have to use their banked sperm to have children after cancer, and often require assisted reproduction using either in vitro fertilisation (IVF – egg and sperm are mixed in a laboratory then implanted into the woman's womb) or a type of IVF called intra-cytoplasmic sperm injection (ICSI – sperm injected straight into an egg)⁶.

1.3.4 Women with Cancer

Cancer treatment for women may affect future fertility in a variety of ways. Treatment targeting the pelvic area may damage the ovaries, the uterus, or fallopian tubes, including reducing the quantity and quality of the woman's eggs. Other treatments may affect female hormone levels which may block or suppress hormones, causing infertility by putting women into early menopause⁷. Women's options for fertility preservation funded by the NHS include freezing eggs or embryos prior to cancer treatment commencing. The timeline for fertility preservation for women is approximately two

⁴ The American Cancer Society. (2020). *How Cancer and Cancer Treatment Can Affect Fertility in Males*. Cancer.org. Retrieved 25 June 2020, from <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-men-with-cancer/how-cancer-treatments-affect-fertility.html>.

⁵ Fisher, J., & Hammarberg, K. (2011). Psychological and social aspects of infertility in men: an overview of the evidence and implications for psychologically informed clinical care and future research. *Asian Journal Of Andrology*, 14(1), 121-129. <https://doi.org/10.1038/aja.2011.72>

⁶ Dohle, G. (2010). Male infertility in cancer patients: Review of the literature. *International Journal Of Urology*, 17(4), 327-331. <https://doi.org/10.1111/j.1442-2042.2010.02484.x>

⁷ American Cancer Society. (2020). *How Cancer and Cancer Treatment Can Affect Fertility in Females*. <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-women-with-cancer/how-cancer-treatments-affect-fertility.html>

weeks due to the need to stimulate or suppress the menstrual cycle, followed by a course of hormone injections, and finally egg collection⁸.

A US study of oncologists nationwide showed that 95% of the 249 responding oncologists routinely discussed cancer treatment's impact on fertility with female patients. Although 82% reported referring patients for fertility preservation, more than 50% rarely refer. When planning treatment, 30% rarely consider a woman's desire for fertility. Gynaecology oncologists were more likely to routinely consider fertility compared with other oncologists (93% vs. 60%). Gynecology oncologists also were more likely to provide a less effective cancer treatment to better preserve fertility (61% vs. 37%)⁹. A UK study focusing on young (below the age of 45), childless women with breast cancer revealed that the amount of information given from cancer teams varied considerably. Only 50% were given the opportunity to pursue fertility preservation techniques prior to treatment. 'Most women were worried about what the future might hold, including their fertility, the impact of pregnancy on recurrence, and the health of the child.' The study also showed that women were often given limited information and support surrounding fertility¹⁰.

Another study looked at the information about treatment impact on fertility and fertility preservation given to both female and male cancer patients. 'The majority of male participants reported having received information about treatment impact on fertility (80%) and fertility preservation (68%), and more than half of the men banked frozen sperm (54%). Among women, less than half (48%) reported that they received information about treatment impact on fertility, and 14% reported that they received information about fertility preservation. Just 2% of women in the cohort underwent fertility preservation treatment¹¹.

1.3.5 Childhood and Teenage and Young Adult Survivors of Cancer

The childhood cancer survivor study (CCSS) followed up over 20,000 childhood cancer survivors. Those included in the study were age 0 to 20 at time of diagnosis. Causes of late deaths were changing, with recurrence of the original tumour less likely, and higher rates of secondary tumours or new medical problems due to treatment for cancer (e.g. heart failure associated with certain types of chemotherapy)¹². Hudson (2010) noted that with improving treatment, 80% of children treated for cancer were expected to survive long term, and that infertility was "one of the most common and life-altering

⁸ Breast Cancer Now. (2019). *Fertility, Pregnancy, and Breast Cancer*. Retrieved 23 June 2020, from https://breastcancer.org/sites/default/files/publications/pdf/bcc28_fertility_and_breast_cancer_2019_web.pdf

⁹ Forman, E., Anders, C., & Behera, M. (2010). A nationwide survey of oncologists regarding treatment-related infertility and fertility preservation in female cancer patients. *Fertility And Sterility*, 94(5), 1652-1656. <https://doi.org/10.1016/j.fertnstert.2009.10.00>

¹⁰ Corney, R., & Swinglehurst, A. (2013). Young childless women with breast cancer in the UK: a qualitative study of their fertility-related experiences, options, and the information given by health professionals. *Psycho-Oncology*, 23(1), 20-26. <https://doi.org/10.1002/pon.3365>

¹¹ Armuand, G., Rodriguez-Wallberg, K., Wettergren, L., Ahlgren, J., Enblad, G., Höglund, M., & Lampic, C. (2012). Sex Differences in Fertility-Related Information Received by Young Adult Cancer Survivors. *Journal Of Clinical Oncology*, 30(17), 2147-2153. <https://doi.org/10.1200/jco.2011.40.6470>

¹² Armstrong, G., Liu, Q., Yasui, Y., Neglia, J., Leisenring, W., Robison, L., & Mertens, A. (2009). Late Mortality Among 5-Year Survivors of Childhood Cancer: A Summary From the Childhood Cancer Survivor Study. *Journal Of Clinical Oncology*, 27(14), 2328-2338. <https://doi.org/10.1200/jco.2008.21.1425>

complications experienced by adults treated for cancer during childhood”¹³. Teenage Cancer Trust reports that for approximately 15% of young people affected by cancer there is a high risk for future fertility problems. However, 29% of individuals report not being provided with detailed information about the impact of cancer treatment on fertility at diagnosis¹⁴.

In children who survive cancer and reach adulthood, there are increased risks of having birth complications, such as pre-term labour. The risk of malformations in their babies (due to their own risk or their treatment) is thought to be low, apart from certain types of tumours of the male or female reproductive system¹⁵. Reproduction in this patient group is not just about the ability to conceive a baby. Other considerations are patients’ health in general, such as whether their childhood treatment has affected their heart or lung function¹⁶. Unsurprisingly, one of childhood cancer survivors most common concerns is their future fertility¹⁷. There is a reduced ability to have a baby in people who are childhood cancer survivors (using the childhood cancer survivors’ CCSS survey).

Reports from the CCSS showed that “compared to a sibling cohort, female participants were less likely to become pregnant (relative risk of ever pregnant 0.81; 95% Confidence Interval [CI], 0.73-0.90)”¹⁸ and male participants were less likely to sire a pregnancy (hazard ratio, 0.56; 95% CI, 0.49-0.63)¹⁹.

¹³ Hudson, M. (2010). Reproductive Outcomes for Survivors of Childhood Cancer. *Obstetrics & Gynecology*, 116(5), 1171-1183. <https://doi.org/10.1097/aog.0b013e3181f87c4b>

¹⁴ Daly, S. (2019). *Young People with Cancer Are At Risk of Losing The Ability to Have Children*. <https://www.teenagecancertrust.org/get-help/teenage-cancer-blog/young-people-cancer-are-risk-losing-ability-have-children>

¹⁵ Hudson, M. (2010). Reproductive Outcomes for Survivors of Childhood Cancer. *Obstetrics & Gynecology*, 116(5), 1171-1183. <https://doi.org/10.1097/aog.0b013e3181f87c4b>

¹⁶ Children’s Cancer and Leukaemia Group. (2018). *Childhood cancer: Health of survivors in adulthood-Information for general practitioners (GPs)*[Ebook]. Retrieved 25 June 2020, from [https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Childhood_cancer_-_health_of_survivors_\(GP\)_2018.pdf](https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Childhood_cancer_-_health_of_survivors_(GP)_2018.pdf)

¹⁷ Ibid

¹⁸ Green, D., Kawashima, T., Stovall, M., Leisenring, W., Sklar, C., & Mertens, A. et al. (2009). Fertility of Female Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. *Journal Of Clinical Oncology*, 27(16), 2677-2685. <https://doi.org/10.1200/jco.2008.20.1541>

¹⁹ Green, D., Kawashima, T., Stovall, M., Leisenring, W., Sklar, C., & Mertens, A. et al. (2010). Fertility of Male Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. *Journal Of Clinical Oncology*, 28(2), 332-339. <https://doi.org/10.1200/jco.2009.24.9037>

Scope

The scope of this work relates to care for individuals aged 16 and above affected by cancer in London across the whole pathway from diagnosis, through treatment, rehabilitation, and living with and beyond cancer.

In line with TCST's focus on adult services, children's cancer services were excluded from the scope. However, as NHS cancer services for Teenage and Young Adults (TYA) are aimed at young people aged 16-24, both TYA and adult cancer services were considered as part of this work programme.

The aim of this document is to provide Clinical Commissioning Groups (CCGs)/Sustainability and Transformation Partnerships (STPs), Integrated Care Systems (ICSs), cancer alliances, clinicians and management teams with a greater understanding of the issues regarding fertility preservation and support offered to people affected by cancer in London.

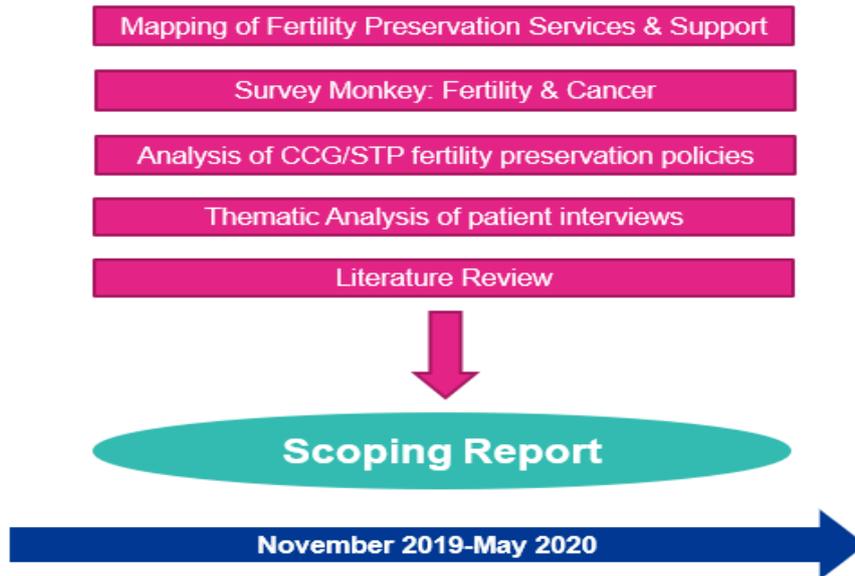
2. Original Project Plan

The fertility scoping project was initially planned in two phases: phase 1 from November 2019 to May 2020 and phase 2 from June to August 2020. However, due to the Covid-19 pandemic, the work was paused mid-March 2020. The timelines below detail the planned work in both phases.

2.1 Project Timeline



Planned Phase 1 Components



Planned Phase 2



2.2 Components of the Project That Were Stood Down Due to Covid-19

The below tasks remain stood down. It is recommended that these tasks should be undertaken locally when systems (cancer alliances, CCGs/STPs/ICSs, etc) prioritise fertility and cancer services as a strategic ambition locally.

- Patient focus groups and/or interviews should be undertaken in order to understand cancer patients' and survivors' experiences with fertility preservation and support services. Thematic analysis will be crucial to understanding patients' and survivors' experiences. Charities involved in the steering group, including Breast Cancer Now, Jo's Cervical Cancer Trust, Prostate Cancer UK, and Teenage Cancer Trust expressed their interest in being involved in these prior to the Covid-19 crisis putting the work on pause.
- Mapping of where cancer services refer their patients to for fertility preservation and support services
- A robust literature review should be conducted. At the first steering group meeting it was suggested this review should be informed by the patient focus groups/interviews.

3. Project Components

This section describes components of the project which were both completed and put on hold due to Covid-19. Including mapping of fertility preservation services and support, fertility and cancer survey results, CCG/STP fertility preservation policies, patient focus groups/interviews, qualitative interviews with fertility and cancer clinicians, a literature review, and various datasets related to fertility and cancer.

3.1 Mapping of Fertility Preservation Services and Support

This component of the work was put on hold due to the Covid-19 pandemic; however mapping was planned to understand which fertility service each cancer service in London refer their patients to. This mapping was due to include both fertility preservation and support services across London in addition to identifying whether or not each CCG/STP adheres to the [NICE fertility preservation guidance](#) published in 2013.

3.2 Fertility and Cancer Survey of Cancer Clinicians

A SurveyMonkey with 25 questions, including multiple choice and free text answers, was sent out through the Lead Cancer Nurse forum (both adults and TYA) and cascaded to team members (including, but not limited to clinical nurse specialists, oncologists, and surgeons) for completion over a six-week period during February and March 2020.

Please see [Appendix 3](#) for a copy of the survey questions. Please note that due to the Covid-19 outbreak, the survey was closed earlier than expected.

The survey was designed to:

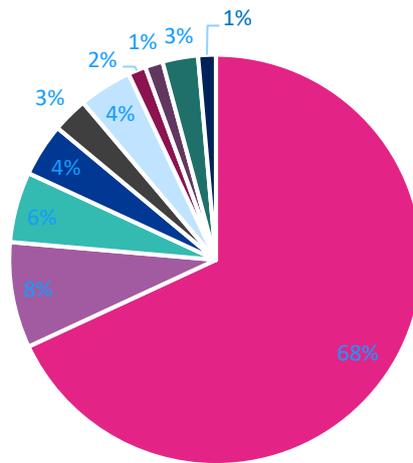
1. Identify fertility preservation services and support offered by NHS cancer services in London to male and female cancer patients aged 16 and above
2. Understand cancer team's education and training regarding fertility preservation and support
3. Understand confidence levels in discussing fertility preservation with patients.

All data recorded has been treated as confidential and raw data will not be shared with third parties. The survey data below has been anonymised.

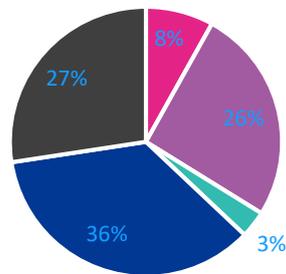
There were **72 respondents** to the survey, working with cancer patients from all 33 London boroughs.

3.2.1 Breakdown of Survey Respondents and Their Cancer Service

Survey Respondents



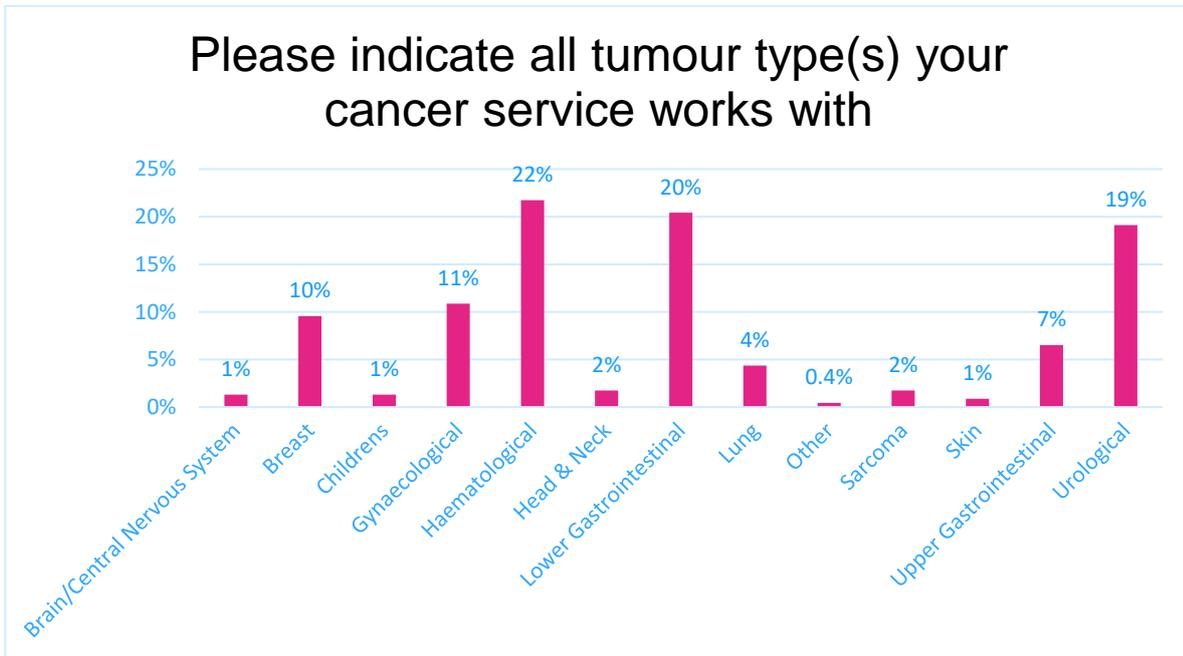
Respondent CCG/STP



The **72 survey respondents** can be broken down into **10 different categories**, seen above. It is important to note that the majority, over two thirds, of respondents were clinical nurse specialists. Further research is needed in order to determine other cancer healthcare professionals (HCPs) (eg. oncologists, surgeons, etc) understanding and awareness of fertility preservation.

Whilst each CCG/STP in London is represented, North Central London and North East London had a lower response rate than other STPs, therefore further work will need to

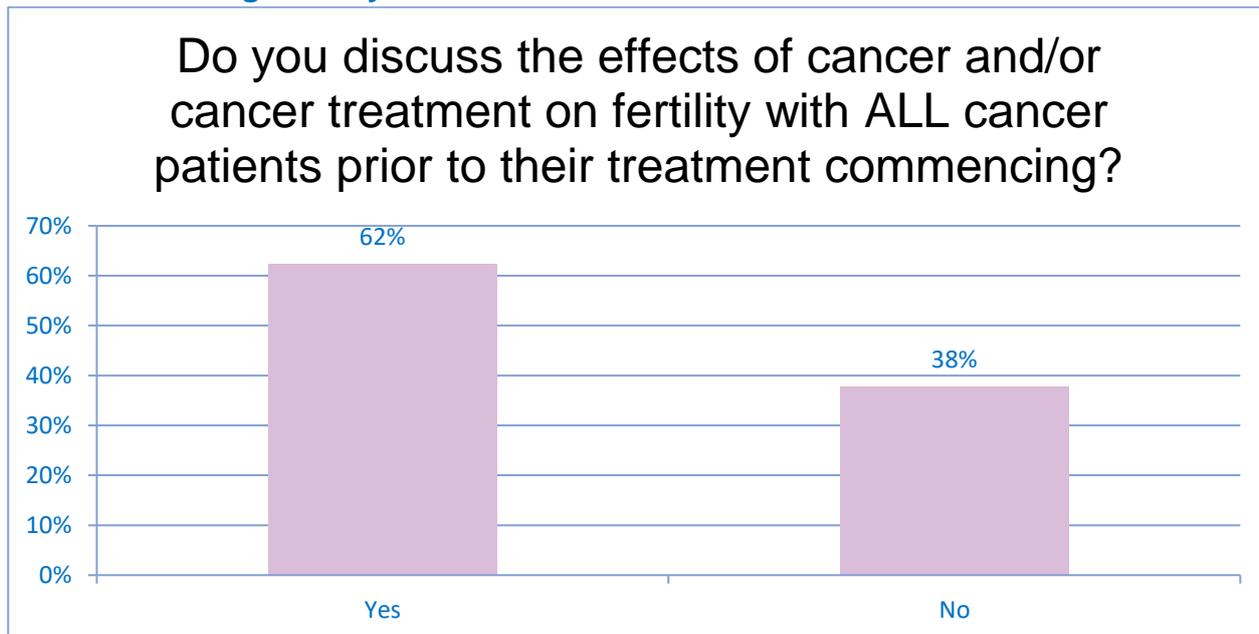
be undertaken in these two CCGs/STPs in order to gain a clearer picture of fertility preservation and support in those areas.



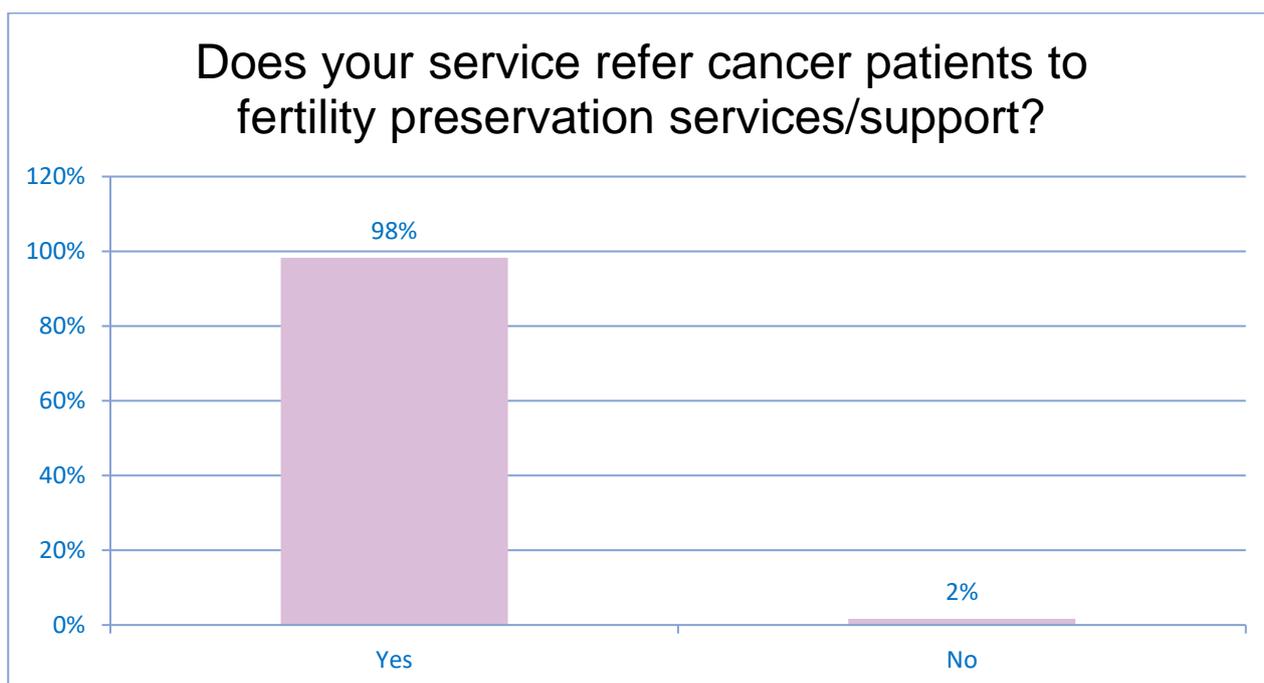
Across **72 respondents**, individuals worked with **all tumour types**. These groups are based on NHS England Cancer Waiting Times tumour groupings²⁰.

²⁰ NHS England and NHS Improvement. (2020). *Cancer Waiting Times*. England.nhs.uk. Retrieved 25 June 2020, from <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>.

3.2.2 Discussing Fertility with Cancer Patients



Whilst over **60%** of cancer HCPs discuss fertility with their patients almost **40%** do not. When asked which patient cohort fertility was not discussed with, responses included post-menopausal women, patients over the age of 45 (both men and women), male patients over the age of 60. It is important to note that the NICE guidance mentioned in [Section 1.3.1](#) does not mention specific age limits for fertility preservation treatments. NICE guidance mentions ‘women of reproductive age (including adolescent girls)’ and ‘men and adolescent boys,’ but no age cut off for eligibility. Further details regarding which patient cohort fertility was not discussed with can be found in Appendix 4.



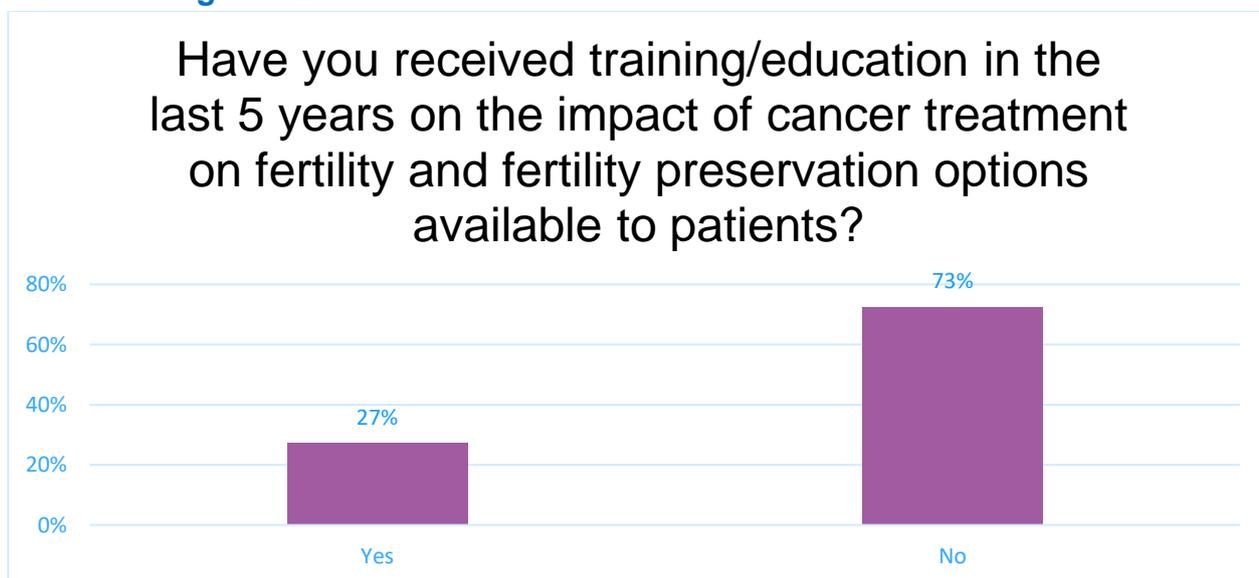
Although **98%** of respondents stated that their service does refer cancer patients to fertility preservation and support services, their criteria for referring varied greatly including:

- all patients “of child-bearing age”
- “patients wishing this”
- “patients that have no children. I believe that patients with a child are not eligible for services on the NHS”
- “younger patients” (age limits mentioned vary from age 40 to 60).

For the full list of free text responses please see Appendix 4. It is evident that criteria varies based on cancer service, but also based on the HCPs subjective opinion on fertility preservation. It is interesting that whilst almost every respondent refers patients for fertility preservation, not all HCPs have the conversation about the effects of cancer and/or treatment on fertility as seen in the previous chart.

For the NHS to deliver equitable treatment on every site, fertility discussions should be embedded into the cancer pathway before a cancer treatment is decided, in order for the patient to understand the potential impact of their treatment and their fertility preservation options.

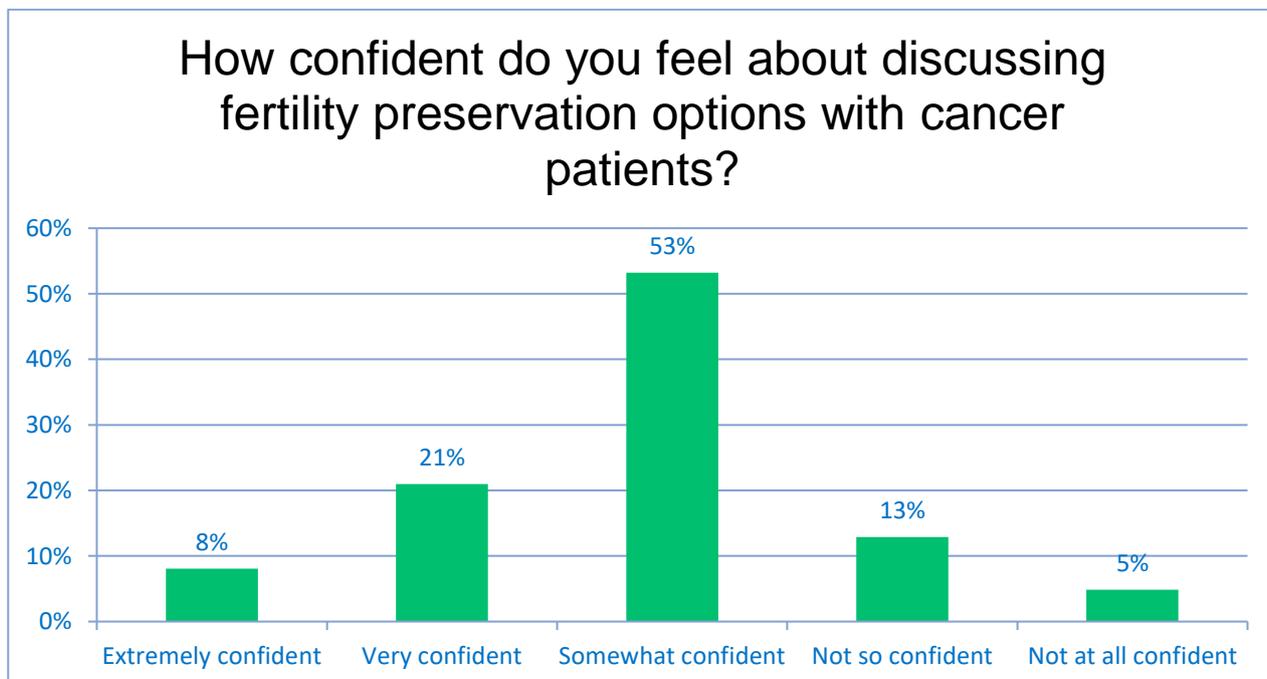
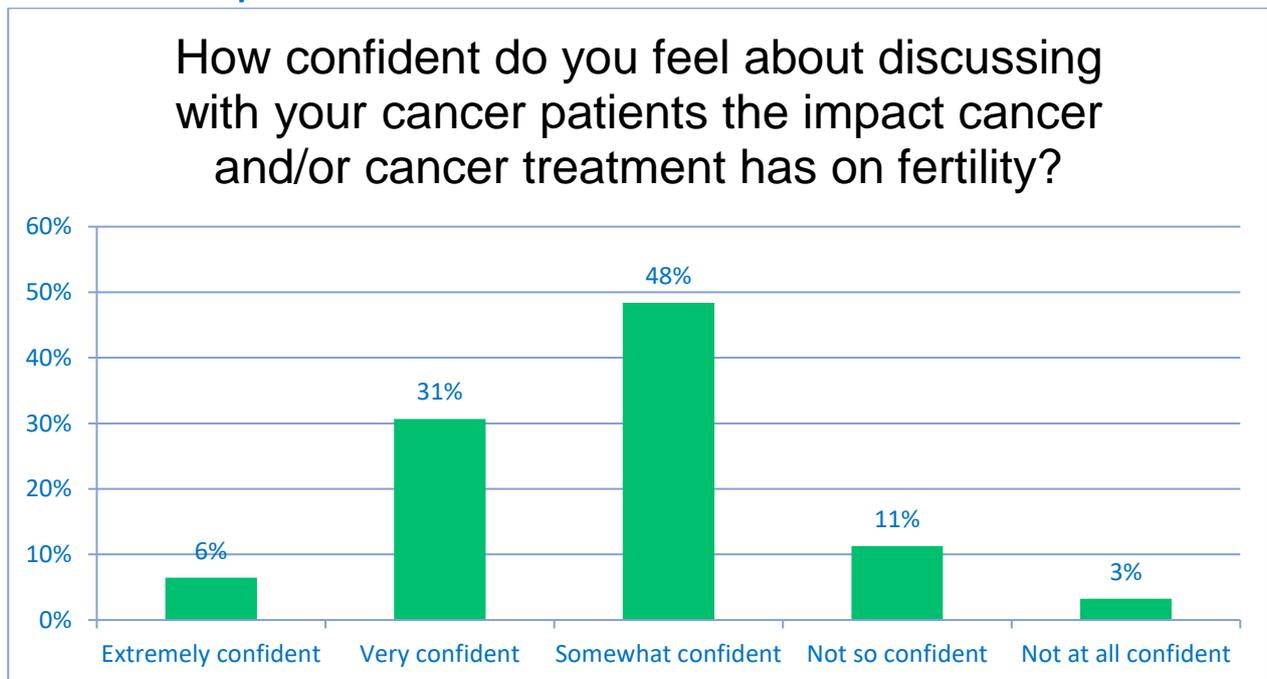
3.2.3 Training and Education



Almost **75%** of respondents had **not** received any training/education in the last 5 years on the impact of cancer treatment on fertility and fertility preservation options available to patients. Based on free text responses from those who had received training in the last 5 years, only **35%** of individuals who had received training/education, received their

training in house at their trust. Others received training/education through conferences/away days or through other NHS providers in London, specifically The Royal Marsden NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust.

3.2.4 Healthcare Professional Confidence Discussing Fertility and Fertility Preservation Options



Only **37%** of HCPs indicated that they were either extremely confident or very confident discussing the impact cancer and/or cancer treatment has on fertility, whilst almost **50%** only felt somewhat confident, and **14%** felt either not so confident or not at all confident.

Regarding fertility preservation, approximately **30%** of HCPs felt confident about discussing fertility preservation options with cancer patients, just over **50%** only felt somewhat confident, and almost **20%** felt not so confident or not confident at all.

Despite **98%** of respondents mentioning they refer patients for fertility preservation, it is evident that HCPs do not feel empowered with the information and confident to inform patients about fertility preservation services and support.

3.2.5 Obstacles to Referring and Improving Interactions Between Cancer and Fertility Services

Discussing obstacles to referring patients to fertility preservation services/support, time was frequently mentioned—including:

- concerns that waiting times (for fertility treatment) may delay cancer treatment and time delays if a patient chooses to go through with fertility preservation.
- lack of communication and complicated referral pathways between cancer and fertility services, making it difficult to refer patients in the first place.
- lack of knowledge/guidance, including not understanding eligibility criteria for fertility preservation or not knowing where to refer to as a barrier to referring
- fertility service being on a different site to the cancer service, making it far for some patients to travel
- Concerns around psychological impact for the patient — receiving bad news about cancer and then having to quickly think about family planning.

For the full list of responses please see Appendix 4.

Interaction between cancer and fertility preservation services is key to a successful patient experience. The survey asked respondents what needs to be done to improve those interactions. Themes included:

- the need for a clear and concise referral and communication pathway
- priority fertility preservation appointments for cancer patients
- increased education and training
- more local services
- more coordination across teams ensuring there are clear protocols or standard operating procedures
- knowing timelines for patients
- joint MDTs and regular meetings

- further interaction upon completion of a patient’s treatment (e.g. when the patient is considering starting or growing their family).

For the full list of responses please see Appendix 4.

3.3 Analysis of NHS London CCG/STP Fertility Preservation Policies

In [Section 1.3.1](#), we looked at the NICE guidance for fertility preservation in cancer patients which recommends when using cryopreservation to preserve fertility in people diagnosed with cancer to use sperm, embryos, or oocytes, and to store cryopreserved material for an initial period of ten years. No age limits are mentioned by NICE—instead it recommends fertility preservation for women of reproductive age and adolescent girls and men and adolescent boys.

It is important to note that no CCG/STP in London has a policy in line with the NICE guidance.

CCGs/STP	Number of policies	Years of NHS Funded Storage for Cryopreserved Materials
North West London CCGs (NWL)	1	5 years
North Central London CCG (NCL)	5	Varying from unspecified to 10 years
North East London STP (NEL)	5	Varying from 5 to 10 years
South West London CCG (SWL)	1	Dependent on patient’s age at time of fertility preservation
South East London CCG (SEL)	1	5 years

For full details of fertility preservation policies, please see full comparison in [Appendix 2](#)

Fertility preservation policies were accessed through NHS England Specialised Commissioning and discussions with local STP and CCG contacts in order to obtain current and updated policies (as of 23 March 2020). Please note that despite these policies being current as of March 2020, some had not been updated since 2014. Policies not updated for over two years included:

North Central London CCG:

- Camden CCG-last updated April 2015
- Enfield CCG-last updated January 2016

North East London STP:

- City and Hackney CCG-last updated January 2015
- Newham CCG-last updated September 2015
- Tower Hamlets CCG-last updated December 2014

The evidence is clear that a patient's access to fertility preservation varies greatly across London. It is clear that disparities occur both within CCGs/STPs and across London as a whole. It is important to note that there are disparities in access to fertility preservation even within two STPs in London—North Central London and North East London—where access to access fertility preservation depends on the patient's local CCG.

In North Central London, access to NHS funded cryopreservation varies from no specified length of storage in Enfield CCG to ten years of funded storage in Camden CCG, Haringey CCG and Islington CCG. Barnet CCG only offers five years.

In North East London, Tower Hamlets CCG is the outlier of the group offering 10 years of NHS funded storage, whilst the remaining CCGs offer just 5 years of NHS funded storage.

Discussions with NHS England Specialised Commissioning revealed that fertility preservation services can either be delivered through block contracts or through CCG-trust contracts where each individual patient has to be approved prior to fertility preservation treatment, allowing for the possibility of further delay to treatment whilst a CCG approves a patient's case for fertility preservation. Further research is needed to understand delays to fertility preservation treatment at STP/CCG level. For details of London STP fertility preservation policies, please see [Appendix 2](#).

3.4 Thematic Analysis of Patient Focus Groups/Interviews

This component of the work has been put on hold due to the Covid-19 pandemic. Patient focus groups and semi-structured interviews were due to take place in April 2020 in partnership with charities including Breast Cancer Now, Jo's Cervical Cancer Trust, Prostate Cancer UK, and the Teenage Cancer Trust. We hoped to gain insight from a cohort of patients in London who had both their cancer and fertility treatments through NHS London services. The plan was to use a dictation service to transcribe these interviews and focus groups and use thematic analysis to capture patient experience of these services and support in London.

Focus groups and interviews will not be conducted by TCST in 2020/21. It is recommended that these are undertaken locally when systems prioritise fertility preservation/support and cancer services as a strategic ambition locally.

3.5 Qualitative Interviews with Cancer and Fertility Clinicians

Over the period November 2019 to March 2020, **20 qualitative interviews** were held with a range of clinicians across London. Please see the table below for the full list of clinicians interviewed.

Job role	Number of Clinicians interviewed
Allied Health Professionals Lead	2
Clinical Psychologist (Adults)	2
Clinical Psychologist (TYA)	1
Clinical Nurse Specialist	3
Consultant Clinical Oncologist	2
Consultant Medical Oncologist	2
Consultant Gynaecologist	4
Consultant in Reproductive Endocrinology and Andrology	2
Trust Lead Cancer Nurse (Adults)	1
Lead Cancer Nurse (TYA)	1

These interviews were integral to the direction of the scoping report. Below are three themes which emerged from the interviews: timing, patient concerns, and communication and working together.

3.5.1 Timing

*“The fertility discussion including the effects of treatment on future fertility and fertility preservation options **should be raised with anyone of reproductive age**”.*

*“Timing is of essence, it [fertility preservation] is something which must be raised prior to cancer treatment commencing. **If it is raised after treatment has begun or post-treatment, it may be too late as treatment could have affected the patient’s fertility.**”*

*“**Ideally [a patient’s] fertility preservation should be undertaken at the same place as their cancer treatment for continuity of care**, however we know that in practice that doesn’t always happen depending on where the patient lives and their STP/CCG policy. Meaning patients can be swimming around the system feeling lost between different hospital sites”.*

3.5.2 Patient Concerns

*“**Concerns about fertility come up throughout a patient’s journey**—for some it may be a worry from the day they are diagnosed, for others it may not come up until after cancer treatment when fertility preservation is no longer an option.”*

*“**I had a patient last week upset when she came for follow-up and I found she only had 5 years of funding—others have 10 [years]**”*

3.5.3 Communication and Working Together

*“**It would be helpful to have information back from the fertility team once we [breast cancer team] send the fertility preservation referral.** Because we are located on different sites across London, patients often mention that the care between the cancer and fertility team feels fragmented.”*

“Cancer and fertility teams need to be working much more closely with each other. Fertility preservation should be integrated into the pathway, it shouldn’t just come up if a patient is lucky enough to be receiving care from a cancer team which routinely brings it up.”

3.6 Literature Review

It was decided by the Fertility and Cancer Steering Group on 4th March 2020 that the focus of the literature review should be informed by patient focus groups and interviews, therefore this component of the work was put on hold due to the Covid-19 pandemic. A brief literature search can be found in [Section 1.3](#) of this document.

It is recommended that a more in-depth review of the literature should be undertaken locally when systems prioritise fertility preservation/support and cancer services as a strategic ambition locally.

3.7 Cancer and Fertility Data

3.7.1 National Cancer Registration and Analysis Service (NCRAS) Data

The Transforming Cancer Services Team works closely with the National Cancer Registration and Analysis Service (NCRAS), part of Public Health England (PHE). It was explored whether any NHS patient data links cancer data to fertility treatment data.

NCRAS concluded that there is currently no single database housing linked cancer and fertility data. Data on patients diagnosed with cancer is recorded by NHS Trusts through routine care of patients but are collated, maintained and stored by NCRAS to form a national registry of cancer diagnoses.

National fertility data, including data regarding fertility preservation treatments is held and maintained by the Human Fertilisation and Embryology Authority (HFEA). Each organisation has its own remit and legal basis for the processing of these data. Any research proposing to link cancer and fertility data would have to undergo significant investigation as to the feasibility linking the data in a way that appropriately maintained patient confidentiality and adhered to the ethical and legal requirements of both organisations.

Linking patient’s cancer and fertility data would allow for an understanding of how many individuals decide to proceed with fertility preservation in addition to identifying any gaps in trusts and/or CCGs/STPs who do not routinely offer fertility preservation to patients.

It may be possible in the future to link cancer registry data with HFEA data. For this work to progress, an organisation will need to be identified to lead and undertake the work, with the endorsement/support of the relevant data set asset owners.

3.7.2 National Cancer Waiting Times Monitoring Dataset

We saw in [Section 4.2.5](#) that HCPs were worried about the impact that undergoing fertility preservation treatment had on delays to cancer treatment. Whilst cancer waiting time targets weren't explicitly mentioned, from 1 July 2020, new treatment adjustments are due to apply for egg harvesting as the National Cancer Waiting Times Monitoring Dataset will be updated to version 11.0²¹. The draft guidance document proposes the following:

“Where a patient opts for egg harvesting prior to their cancer treatment, an adjustment can be applied from the point at which the decision is made until the patient’s cycle allows eggs to be harvested. An adjustment cannot be applied for the period of time taken for the patient to wait to be seen by the egg harvesting service, only from the point at which the patient is seen by the service and agrees to egg harvesting to the point at which the patient’s cycle allows eggs to be harvested.”

The reason for this waiting time adjustment will be recorded as ‘Egg Harvesting.’

Cancer Waiting Times Version 11.0 guidance and the introduction of waiting time adjustments for egg harvesting will allow for some transparency in understanding how many females are undergoing fertility preservation, however it will not give us any further information on male sperm retrieval and cryopreservation prior to cancer treatment.

3.7.3 National Cancer Patient Experience Survey Data

The data below has been extracted from the National Cancer Patient Experience Survey (NCPES) for London CCGs. This 52 question survey ‘aims to improve a patient’s experience of their cancer care and to inform commissioners and service providers about the cancer patients’ experience.’ The data below is from the 2018 survey—sent out to all NHS patients over the age of 16 who had received a confirmed primary diagnosis of cancer or been discharged from an NHS Trust after an inpatient episode or day case attendance for cancer related treatment in April, May and June 2018²².

Data regarding five questions from the survey was extracted, particularly focusing on side effects of treatment, shared decision making, and Clinical Nurse Specialist knowledge. Whilst the questions are not specific to fertility, they are an indication of patient experience in London.

²¹ Ibid

²² Transforming Cancer Services Team (2019). *Patient Experience Survey*. Retrieved 23 June 2020, from <https://www.healthy london.org/our-work/cancer/patient-experience-survey/>

As is evident below, all CCGs/STPs in London are consistently below 2018 national average for each of the questions extracted. Both 2018 and 2019 national averages were included as a comparison, however STP level data for 2019 was not available at the time of this report being published²³.

Were the possible side effects of treatment(s) explained in a way you could understand? (2018 survey)	
National Average 2018	73.1%
National Average 2019	72.8%
NEL	70.3%
NCL	69.2%
NWL	71.2%
SEL	70.7%
SWL	73.0%

Were you offered practical advice and support in dealing with the side effects of your treatment? (2018 survey)	
National Average 2018	67.1%
National Average 2019	67.2%
NEL	63.1%
NCL	62.5%
NWL	62.2%
SEL	65.7%
SWL	65.9%

Before you started treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away? (2018 survey)	
National Average 2018	56.1%
National Average 2019	56.8%
NEL	53.9%
NCL	51.2%
NWL	53.5%
SEL	55.1%
SWL	55.1%

Were you involved as much as you wanted to be in decisions about your care and treatment? (2018 survey)	
National Average 2018	78.6%
National Average 2019	81.0%
NEL	73.1%
NCL	74.3%

²³ National Cancer Patient Experience Survey. (2019). 2019 National Level Results. Retrieved 25 June 2020, from <https://www.ncpes.co.uk/2019-national-level-results/>

NWL	73.7%
SEL	75.5%
SWL	77.5%

When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand? (2018 survey)	
National Average 2018	87.9%
National Average 2019	87.5%
NEL	82.0%
NCL	81.4%
NWL	82.4%
SEL	82.9%
SWL	85.6%

3.7.4 Holistic Needs Assessment Data

Holistic Needs Assessments are questionnaires which help cancer teams identify needs and concerns of an individual living with cancer. The data below reflects Electronic Holistic Needs Assessment (eHNA) data collated by RM Partners Informatics team via London NHS Trusts from 2016 to 2018.

- **2016:** ‘Sexual concerns’ were reported as the 9th (out of 45) most common concern across all tumour types. 9.1% of patients who had E-HNAs reported this as a concern. Sexual concerns were also reported as one of the ten concerns with the biggest percentage difference in concern by age band. In 16-49 year olds, sexual concerns were reported by 9% of individuals, in 50-69 year olds 12% mentioned it as a concern, and in 70+ year olds 4% reported it as a concern. Sexual concerns were also one of the ten concerns with the biggest increase from newly diagnosed to end of treatment—6% of newly diagnosed individuals who had an eHNA reported it as a concern, whilst 19% reported it as a concern at the end of their treatment.
- **2017:** Data unavailable
- **2018:** Across all tumour types and age groups, 7-8% of individuals completing eHNAs reported sex, intimacy, or fertility as a concern. Sex, intimacy, or fertility were reported as one of the ten concerns with the biggest percentage difference in concern for all patients in all age bands—In 16-49 year olds 11% reported these as a concern, in 50-69 year olds 8% reported these as a concern, whilst just 3% of individuals 70+ reported sex, intimacy, or fertility as a concern.

It is evident that fertility is a concern recorded in eHNAs, however it is unknown whether these concerns are translated into a care plan. Is the patient referred to fertility services for preservation or a discussion about the options available to them? Further research is needed to establish why more patients do not report fertility as a concern. It is hypothesised that it may be because their cancer team does not flag the possibility of

future infertility or changes in fertility as an effect of cancer treatment. In turn, this may be due to the healthcare professional's lack of knowledge or confidence in discussing fertility as seen in [Section 4.2](#).

4. Checklist for systems

Whilst the work came to a premature ending due to Covid-19, below are suggested actions based on the work which was completed between November 2019-March 2020.

Area	Suggested actions
Conduct patient focus groups and/or interviews	<ul style="list-style-type: none"> • should be undertaken in order to understand cancer patients' and survivors' experiences with fertility preservation and support services. • Thematic analysis will be crucial to understanding patients' and survivors' experiences. • Charities involved in the steering group, including Breast Cancer Now, Prostate Cancer UK, Jo's Cervical Cancer Trust, and Teenage Cancer Trust expressed their interest in being involved in these prior to the Covid-19 crisis putting the work on pause
Map referral pathways	<ul style="list-style-type: none"> • To understand where local cancer services refer their patients to for fertility preservation and support services
Conduct literature & policy review	<ul style="list-style-type: none"> • An up to date literature and policy review will need to be conducted. • At the first steering group meeting it was suggested this review should be informed by the patient focus groups/interviews.
Update CCG/ICS fertility preservation policies in line with NICE guidance	<ul style="list-style-type: none"> • Policies should be updated to include details of which individuals can access fertility preservation and the length of NHS funded storage for cryopreserved materials (oocytes, sperm, embryos). Comparison of NHS London fertility preservation policies indicates disparities across CCG/ICS in London. Local policies are not in accord with NICE and vary greatly across London. • Involve patients and clinicians in updating policies. Clinicians have also described complexities of working with varying policies at each site and discussed the negative patient experiences due to the varying 13 policies across the capital. • CCGs/ICSs aligning their fertility preservation guidance with NICE guidelines will improve patient experience. It is important that CCG/STP policies mention the following components: who is eligible (male, female, trans), the age limit for treatment, what fertility preservation treatment is available, where the treatment is available, and how long the NHS will fund the cryopreserved material storage for.
Delivery of training and awareness raising	<ul style="list-style-type: none"> • Healthcare professionals and referrers in cancer services should receive up to date training and awareness raising about fertility preservation and local support services. • The first step to ensuring patients are receiving the option of fertility preservation and understand the implications that their cancer and/or treatment could have on fertility is to

	<p>ensure HCPs are empowered to have these discussions through receiving up to date education and training. “In house” training is crucial for HCPs to understand the referral pathways in their trust as well.</p> <ul style="list-style-type: none"> • It is evident from the SurveyMonkey that almost 75% of HCPs have not received any training or education regarding fertility preservation and support (including referral pathways) over the past 5 years. • Additionally, over 60% of HCPs feel somewhat confident to not confident at all discussing the effects that cancer and/or treatment can have on fertility and the fertility options available to patients.
<p>Develop a referral pathway between cancer and fertility services</p>	<ul style="list-style-type: none"> • A clear, concise referral and communication pathway between local cancer and fertility services is required • Both the SurveyMonkey and clinician qualitative interviews revealed the need for clear, concise referral and communication pathways between cancer and fertility services. The referral and communication pathway was one of the main obstacles mentioned, therefore the need for a Standard Operating Procedure (SOP) for both cancer and fertility teams is crucial to a streamlined patient journey and experience. • Whether patients are able to receive fertility care on the same or different site as their cancer treatment, clear referral routes and communication pathways should be set out. This should also include information regarding support services for patients.

5. References

- ¹Transforming Cancer Services Team. (2020). *What a faster cancer diagnosis will mean for Londoners - Healthy London Partnership*. Healthy London Partnership. Retrieved 14 June 2020, from <https://www.healthylondon.org/what-a-faster-cancer-diagnosis-will-mean-for-londoners/>.
- ² Hyman, D. (2020). *Commissioning Guidance for Cancer Psychosocial Support* [Ebook]. Healthy London Partnership. Retrieved 24 June 2020, from <https://www.healthylondon.org/wp-content/uploads/2020/02/Refreshed-February-2020-Guidance-doc-Psychological-support-for-people-affected-by-cancer-.pdf>.
- ³*Fertility problems: assessment and treatment-People with cancer who wish to preserve fertility*. NICE. (2013). Retrieved 10 June 2020, from <https://www.nice.org.uk/guidance/cg156/chapter/Recommendations#people-with-cancer-who-wish-to-preserve-fertility>.
- ⁴The American Cancer Society. (2020). *How Cancer and Cancer Treatment Can Affect Fertility in Males*. Cancer.org. Retrieved 25 June 2020, from <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-men-with-cancer/how-cancer-treatments-affect-fertility.html>.
- ⁵ Fisher, J., & Hammarberg, K. (2011). Psychological and social aspects of infertility in men: an overview of the evidence and implications for psychologically informed clinical care and future research. *Asian Journal Of Andrology*, 14(1), 121-129. <https://doi.org/10.1038/aja.2011.72>
- ⁶ Dohle, G. (2010). Male infertility in cancer patients: Review of the literature. *International Journal Of Urology*, 17(4), 327-331. <https://doi.org/10.1111/j.1442-2042.2010.02484.x>
- ⁷ American Cancer Society. (2020). *How Cancer and Cancer Treatment Can Affect Fertility in Females*. <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-women-with-cancer/how-cancer-treatments-affect-fertility.html>
- ⁸ Breast Cancer Now. (2019). *Fertility, Pregnancy, and Breast Cancer*. Retrieved 23 June 2020, from https://breastcancernow.org/sites/default/files/publications/pdf/bcc28_fertility_and_breast_cancer_2019_web.pdf
- ⁹ Forman, E., Anders, C., & Behera, M. (2010). A nationwide survey of oncologists regarding treatment-related infertility and fertility preservation in female cancer patients. *Fertility And Sterility*, 94(5), 1652-1656. <https://doi.org/10.1016/j.fertnstert.2009.10.00>
- ¹⁰ Corney, R., & Swinglehurst, A. (2013). Young childless women with breast cancer in the UK: a qualitative study of their fertility-related experiences, options, and the information given by health professionals. *Psycho-Oncology*, 23(1), 20-26. <https://doi.org/10.1002/pon.3365>

¹¹ Armuand, G., Rodriguez-Wallberg, K., Wettergren, L., Ahlgren, J., Enblad, G., Höglund, M., & Lampic, C. (2012). Sex Differences in Fertility-Related Information Received by Young Adult Cancer Survivors. *Journal Of Clinical Oncology*, 30(17), 2147-2153. <https://doi.org/10.1200/jco.2011.40.6470>

¹² Armstrong, G., Liu, Q., Yasui, Y., Neglia, J., Leisenring, W., Robison, L., & Mertens, A. (2009). Late Mortality Among 5-Year Survivors of Childhood Cancer: A Summary From the Childhood Cancer Survivor Study. *Journal Of Clinical Oncology*, 27(14), 2328-2338. <https://doi.org/10.1200/jco.2008.21.1425>

¹³ Hudson, M. (2010). Reproductive Outcomes for Survivors of Childhood Cancer. *Obstetrics & Gynecology*, 116(5), 1171-1183. <https://doi.org/10.1097/aog.0b013e3181f87c4b>

¹⁴ Daly, S. (2019). *Young People with Cancer Are At Risk of Losing The Ability to Have Children*. <https://www.teenagecancertrust.org/get-help/teenage-cancer-blog/young-people-cancer-are-risk-losing-ability-have-children>

¹⁵ Hudson, M. (2010). Reproductive Outcomes for Survivors of Childhood Cancer. *Obstetrics & Gynecology*, 116(5), 1171-1183. <https://doi.org/10.1097/aog.0b013e3181f87c4b>

¹⁶ Children's Cancer and Leukaemia Group. (2018). *Childhood cancer: Health of survivors in adulthood-Information for general practitioners (GPs)*[Ebook]. Retrieved 25 June 2020, from [https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Childhood_cancer_-_health_of_survivors_\(GP\)_2018.pdf](https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Childhood_cancer_-_health_of_survivors_(GP)_2018.pdf)

¹⁷ Ibid

¹⁸ Green, D., Kawashima, T., Stovall, M., Leisenring, W., Sklar, C., & Mertens, A. et al. (2009). Fertility of Female Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. *Journal Of Clinical Oncology*, 27(16), 2677-2685. <https://doi.org/10.1200/jco.2008.20.1541>

¹⁹ Green, D., Kawashima, T., Stovall, M., Leisenring, W., Sklar, C., & Mertens, A. et al. (2010). Fertility of Male Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. *Journal Of Clinical Oncology*, 28(2), 332-339. <https://doi.org/10.1200/jco.2009.24.9037>

²⁰ NHS England and NHS Improvement. (2020). *Cancer Waiting Times*. England.nhs.uk. Retrieved 25 June 2020, from <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>.

²¹ Ibid

²² Transforming Cancer Services Team (2019). *Patient Experience Survey*. Retrieved 23 June 2020, from <https://www.healthylondon.org/our-work/cancer/patient-experience-survey/>

²³ National Cancer Patient Experience Survey. (2019). *2019 National Level Results*. Retrieved 25 June 2020, from <https://www.ncpes.co.uk/2019-national-level-results/>



Appendix 1:

Fertility and Cancer Steering Group Terms of Reference 2020/21

Introduction

As cancer incidence increases and survival improves, the number of people living with a cancer diagnosis is increasing. Every year, approximately 34,000 Londoners receive a diagnosis of cancer. Currently, over 231,0000 people (2.6% of the population) in London are living with and beyond cancer- a figure that is expected to increase by approximately 50% in 2030. It is known that people living with cancer can have a range of short and longer term clinical, functional and psychosocial problems both from the cancer itself and from treatment.²⁴

Purpose

The main purpose of the Fertility and Cancer Steering Group is to support and advise Clara Burr-Lonnon, Fertility Project Manager, and the Personalised Care for Cancer (PC4C) team at TCST to deliver Phase 1 and 2 of the fertility workstream. This involves scoping fertility preservation services and support offered to people affected by cancer in London, including mapping of these services, a report including thematic analysis of patient focus groups/in-depth interviews and a literature review. Phase 1 will go up to the end of April 2020 and once scoping is complete, Phase 2 will be developed, in conjunction with the steering group, depending on the recommendations from Phase 1. Phase 1 will help to understand the fertility and cancer landscape in London, identify best-practice for fertility preservation and support, and highlight patient experiences of fertility and cancer.

²⁴ <https://www.healthy london.org/what-a-faster-cancer-diagnosis-will-mean-for-londoners/>

Scope

The scope of this steering group includes representatives across the cancer and fertility pathway, including commissioners, clinicians, third sector organisations, and service users. The project relates to care for individuals aged 16 and above affected by cancer in London across the whole pathway from diagnosis, through treatment, rehabilitation, and living with and beyond cancer. Consideration will also include the needs of partners and families.

As TCST's focus is on adult services, children's cancer services will be excluded from the scope. However, as NHS cancer services for Teenage and Young Adults (TYA) are aimed at young people aged 16-24, both TYA and adult cancer services will be considered as part of this work programme.

Outputs

The outputs from this work are as follows:

- Mapping of fertility preservation services and support offered to people affected by cancer in London
- Thematic analysis of cancer and fertility SurveyMonkey
- Comparative analysis of CCG/STP fertility preservation policies
- Thematic analysis of patient focus groups and in-depth interviews
- Literature review focusing on the following areas:

Members

Role	Organisation	Name
Fertility Project Manager, Chair	TCST	Clara Burr-Lonnon
Associate Director, Personalised Care for Cancer	TCST	Liz Price
Senior Implementation Lead	TCST	Jason Tong
Patient Representative	Pan-London Patient Advisory Group	Emma Robertson
Macmillan Consultant Clinical Psychologist	St George's University Hospitals NHS Foundation Trust	Sahil Suleman
Consultant Gynaecologist	Imperial College Healthcare NHS Trust	Lisa Webber
Consultant Gynaecologist Chair Fertility Preservation UK, SIG of British Fertility Society	University College London Hospitals NHS Foundation Trust	Melanie Davies

Consultant in Gynaecology, Reproductive Medicine and Surgery and Director of IVF Unit	Imperial College Healthcare NHS Trust	Stuart Lavery
Consultant Gynaecologist Sub-specialist in Reproductive Medicine and Surgery	Guys and St Thomas's NHS Foundation Trust	Julia Kopeika
Consultant Medical Oncologist	Guys and St Thomas's NHS Foundation Trust	Janine Mansi
Teenage Cancer Trust Lead Nurse, Teenagers & Young Adults	Oak Centre for Children and Young Adults The Royal Marsden NHS Foundation Trust	Nellie Kumaralingam or
Lead Nurse for Teenagers and Young Adults with Cancer	St Luke's Cancer Centre, Royal Surrey NHS Foundation Trust	Claire Palles-Clark
Clinical Nurse Specialist, Younger Women with Breast Cancer	Breast Cancer Now	Grete Brauten-Smith or
Policy Manager		Emma Lavelle
Head of Support Services Deputy Chief Executive	Jo's Cervical Cancer Trust	Rebecca Shoosmith
Health Programmes and Engagement Lead	Trekstock (Young Adult Cancer Support)	Jemima Reynolds
Policy and Public Affairs Executive	Teenage Cancer Trust	Ellen Ferris or
Head of Policy and Public Affairs		Ben Sundell
Service Improvement Lead TrueNTH Head of Clinical Services	Prostate Cancer UK	Steven Rowntree or Laura James
Programme of Care Manager, Cancer-London region	NHS England	Mandy Sanderson
Oncologist -specialising in male cancer patients	TBD	TBD
Lead Cancer Nurse	TBD	TBD

Extended Members

Role	Organisation	Name
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Joint National Lead Macmillan GP Adviser and Macmillan GP Adviser London and Joint Clinical Chair, SEL Cancer Alliance	Macmillan & South East London Cancer Alliance	Anthony Cunliffe
Programme Manager-Commissioner	South West London STP	Andre Chagwedera

Accountabilities

This group is responsible to the pan-London Personalised Care for Cancer Partnership Board and accountable to the pan London Cancer Transformation & Improvement Board for London (CTIBL).

Conduct of Meetings

The Fertility & Cancer steering group will meet at minimum every 8 weeks until Phase 2 of the programme closes at the end of August 2020 (exact date tbd). Meetings will last for 90 -120 minutes and may be conducted in person or via teleconference. Agenda and papers will be sent prior to the meeting and action/decision logs will be sent after each meeting. Work will also take place in between meetings. Most meetings will take place in London at Wellington House, Waterloo or Skipton House, Elephant and Castle.

Related Workstreams

- TCST Personalised Care for Cancer workstream
- National Cancer Programme of Care workstream

Evaluation

Progress of the steering group will be demonstrated through the workplan and reported to the Personalised Care for Cancer Partnership Board. Terms of Reference/Workplan will be updated as required and when necessary.

Appendix 2:

NHS London Fertility Preservation Policies

Last updated: 23 March 2020

STP	CCG	What does the NHS fund?	Length of NHS Funded Storage	Provider	Policy Last Updated
NWL	Brent, Central London (Westminster), Ealing, Hammersmith & Fulham, Harrow, Hillingdon, Hounslow, West London (Kensington & Chelsea)	For patients undergoing treatment with significant risk of permanent infertility: <ul style="list-style-type: none"> Will fund cryopreservation, and storage of oocytes, embryos, sperm 	5 years	Hammersmith, UCLH, Chelsea & Westminster, GSTT, any other NHS provider in England	January 2020
SWL	Croydon, Kingston, Merton, Richmond, Sutton & Wandsworth	Will fund one cycle of fertility preservation, including sperm, egg and embryo cryostorage in the following circumstances: <ul style="list-style-type: none"> Patients who are preparing to undergo medical, non-medical and surgical treatment that is likely to have a permanent harmful effect on subsequent sperm or egg production. Such treatment may include but not limited to: Surgery, radiotherapy or chemotherapy for malignant disease Patients whose ongoing medical condition or treatment causes harmful effects on sperm or egg production or has possible teratogenic effects and stopping treatment for a prolonged period of 	Will fund fertility preservation for patients under 23 years of age until they reach their 23 rd birthday. At the point which the patient reaches their 23 rd birthday, funding will be available for up to an additional 5 years from this date, similarly to those aged 23 years or over. Fertility preservation will be funded for patients aged 23 years or over for up to 5 years, and will only be terminated sooner in the following circumstances: <ul style="list-style-type: none"> Following a live birth OR The period of cryostorage reaches five years OR The 	Not specified	March 2020

		<p>time to enable conception is not possible.</p> <p>SWL CCGs do not routinely fund the following:</p> <ul style="list-style-type: none"> ▪ Pre-pubertal individuals, as treatment is regarded as experimental. ▪ Egg (oocyte) or embryo cryostorage, if the female is over 42 years of age. ▪ Patients who choose to undergo medical or surgical treatment whose primary purpose is infertility, such as sterilisation. ▪ Patients who underwent sterilisation previously, even if it has been reversed. ▪ Cryopreservation of ovarian or testicular tissue, as it is regarded experimental. ▪ 'Elective freezing': where a man or woman requests this for non-medical reasons. ▪ Patients who are already infertile for any reasons. 	<p>woman's 43rd birthday for eggs or embryos</p> <p>Patients who continue to undergo active medical treatments that make them unable to start their families at the time their NHS-funded fertility preservation is over can apply for additional funding with the explicit written support from their treating clinician.</p>		
SEL	Bexley, Bromley, Greenwich, Lambeth, Lewisham, Southwark	<p>The following preservation techniques: semen cryostorage, oocyte cryostorage, embryo cryostorage, will be routinely funded by South East London CCGs in the following circumstances:</p> <ul style="list-style-type: none"> • Where a person under the age of 40 requires medical or surgical treatment that is likely to have a permanent harmful effect on subsequent sperm or egg production. Such treatment includes radiotherapy or 	5 years	Not specified	April 2019

		<p>chemotherapy for malignant disease</p> <p>OR</p> <ul style="list-style-type: none"> Where a person under the age of 40 requires on going medical treatment that, whilst on treatment, causes harmful effects on sperm or egg production, impotence or has possible teratogenic effects, and in whom stopping treatment for a prolonged period of time to enable conception is not an option. <p>One collection cycle will be provided.</p>			
NCL	Barnet	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other conditions which may impact on their future fertility with the following caveats :</p> <ul style="list-style-type: none"> Will not fund for the continued storage of eggs/embryos for a woman aged over 42. Will not fund for the storage of sperm for a man aged over 55. Transgender patients must be on an approved NHSE funded care pathway and not self-treating. 	5 years	Not specified	October 2019
NCL	Camden	<p>Camden CCG will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other illnesses which may impact on their future fertility with the following conditions:</p> <ul style="list-style-type: none"> Camden CCG will not fund for the continued storage of eggs/embryos for a woman aged over 42 	10 years	Not specified	April 2015

		<ul style="list-style-type: none"> Camden CCG will not fund for the storage of sperm for a man aged over 55. 			
NCL	Enfield	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other illnesses which may impact on their future fertility with the following conditions:</p> <ul style="list-style-type: none"> Will not fund for the continued storage of eggs/embryos for a woman aged over 40 (or 42 depending on 7 above) Will not fund for the storage of sperm for a man aged over 55. 	Not specified	Homerton Hospital	January 2016
NCL	Haringey	<p>Will fund fertility preservation interventions (ovaries, eggs, oocytes, sperm, embryos) for those at risk of future infertility as a consequence of their need to undergo life preserving treatment for cancer or other relevant conditions.</p> <ul style="list-style-type: none"> Will not fund the further storage of eggs/ sperm/oocytes for women aged 42 and over. Patients must be on an approved NHS England funded care pathway and not self-treating. 	10 years	Homerton Hospital	December 2018
NCL	Islington	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other conditions which may impact on their future fertility with the following caveats:</p> <ul style="list-style-type: none"> Will not fund for the continued storage of eggs/embryos for a woman aged over 42. Will not fund for the storage of sperm for a man aged over 55. 	10 years	Not specified	November 2018

		<ul style="list-style-type: none"> Patients must be on an approved NHS England funded care pathway and not self-treating. 			
NEL	Barking and Dagenham, Havering and Redbridge	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other conditions which may impact on their future fertility with the following caveats:</p> <ul style="list-style-type: none"> Will not fund for the continued storage of eggs/embryos for a woman aged 40 years and over Will not fund for the storage of sperm for a man aged over 55. Patients must be on an approved NHS England funded pathway and not self-treating 	5 years	Not specified	December 2018
NEL	City and Hackney	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other illnesses which may impact on their future fertility with the following conditions:</p> <ul style="list-style-type: none"> Will not fund for the continued storage of eggs/embryos for a woman aged over 42 Will not fund the storage of sperm for a man aged over 55. 	5 years	Not specified	January 2015
NEL	Newham	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other illnesses which may impact on their future fertility with the following conditions:</p> <ul style="list-style-type: none"> Will not fund for the continued storage of eggs/embryos for a woman aged over 42 Will not fund for the storage of sperm for a man aged over 55. 	5 years	Not specified	September 2015

NEL	Tower Hamlets	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other illnesses which may impact on their future fertility with the following conditions:</p> <ul style="list-style-type: none"> • Will not fund for the continued storage of eggs/embryos for a woman aged over 42 • Will not fund for the storage of sperm for a man aged over 55. 	10 years	Not specified	December 2014
NEL	Waltham Forest	<p>Will fund the collection and storage of eggs, embryos and sperm for individuals with cancer or other illnesses which may impact on their future fertility with the following conditions:</p> <ul style="list-style-type: none"> • Will not fund for the continued storage of eggs/embryos for a woman aged over 42 • Will not fund for the storage of sperm for a man aged over 55 	5 years	Not specified	November 2018

Appendix 3:

Fertility and Cancer Survey

You are invited to complete this fertility and cancer survey run by the Transforming Cancer Services Team (TCST) part of the Healthy London Partnership. We are currently conducting a project scoping fertility services and support offered to people affected by cancer in London following a diagnosis of cancer. This survey is designed to identify fertility preservation services and support offered by each NHS cancer service in London to male and female cancer patients age 16 and above.

This mapping survey will include NHS and third sector services commissioned by the NHS, and the local contracting arrangements with commissioners.

We hope this survey can reach many professionals as possible within NHS cancer services in London, including lead cancer nurses, clinical nurse specialists, oncologists, surgeons, etc. Please do forward on to relevant colleagues.

Please note this survey is only for NHS London services. Please only complete this survey if you work in cancer services in London.

We are collecting information on:

- The service and where is it located
- Access to the service
- What is provided within the service
- Commissioning

It is anticipated that this survey will take no more than 15 minutes to complete. **The survey will be closed at 11pm Monday 30th March 2020** and will be analysed by Clara Burr-Lonnon as part of a overall fertility and cancer scoping report which will be published by TCST. Please note, anonymised and summarised reports may be shared with third parties. All data will be treated as confidential and raw data will not be shared with third parties.

About the Transforming Cancer Services Team

The Healthy London Partnership Transforming Cancer Services programme was set up on behalf of London's Clinical Commissioning Groups (CCGs) and NHS England (London region) to deliver the Five Year Commissioning Strategy for London. Since then the Achieving World Class Cancer Outcomes: Taking the Strategy Forward national cancer strategy, Next Steps on the Five Year Forward View and The NHS Long Term Plan have also been published to guide the transformation of cancer services across London.

For more information about this mapping survey, if you have any comments or feedback, would like to discuss further, or if you are having trouble completing this Survey Monkey please contact: Clara Burr-Lonnon, Fertility Project Manager, clara.burr-lonnon@nhs.net

About You

1. First Name
2. Surname
3. Email Address
4. Phone Number
5. Job Title

About Your Service

6. Title/name of your service
7. Please indicate your main hospital site (drop down menu)
8. Please indicate your provider (drop down menu)
9. Please tick all London boroughs that your cancer service covers. If your service covers areas outside of the London remit (eg. Kent, Surrey), please indicate these in the 'other' section.
10. Please indicate all tumour type(s) your cancer service works with (tick box)

Training and Education

11. Have you received training in the last 5 years on the impact of cancer treatment on fertility and fertility preservation options available to patients?
 - a. Yes
 - b. No
12. If yes to question 11, please detail your training below:
 - a. Where was your training?
 - b. When was your training?
 - c. What was the course content?
13. How confident do you feel about discussing with your cancer patients the impact cancer and/or cancer treatment has on fertility?
 - a. Extremely confident
 - b. Very confident
 - c. Somewhat confident
 - d. Not so confident
 - e. Not confident at all
14. How confident do you feel about discussing fertility preservation options with cancer patients?
 - a. Extremely confident
 - b. Very confident
 - c. Somewhat confident
 - d. Not so confident
 - e. Not confident at all

Discussing Fertility and Cancer with Your Patients

15. Do you discuss the effects of cancer and/or cancer treatment on fertility with ALL cancer patients prior to their treatment commencing?
 - a. Yes
 - b. No
16. Which patient cohort do you NOT discuss fertility with (please specify age range, gender, whether tumour-type dependent, etc)

Referring Patients for Fertility Preservation Services and Support

17. Does your service refer cancer patients to fertility preservation services and support?
18. What is your criteria for referring cancer patients to fertility preservation services/support? (please be as specific and detailed as possible)
19. What fertility preservation service/support do you refer cancer patients to?

- a. Service name
 - b. Hospital(s)/NHS Trust(s)
 - c. Contact name and role
20. Which patients do you refer to fertility preservation service described in question 19?
- a. Male
 - b. Female
 - c. Trans
 - d. Other (please specify)
21. Why does your service not refer to fertility preservation services/support? (please be as specific and detailed as possible)

Obstacles and Improvements Needed

22. What do you think are the main obstacles for referring patients to fertility preservation services/support?
23. In your opinion, what needs to be done to improve the interactions between cancer and fertility preservation services?

Further Information

24. Are you able to share any local policies, standard operating procedures (SOPs), or services specs with TCST? If yes, please upload the file in the dropbox below
25. Are you happy to be contacted by TCST about any of the answers you have provided in this survey?
- a. Yes
 - b. No

Thank you so much for taking the time to complete this survey. For more information about this project, if you have any comments, feedback, or would like to discuss further, please contact: Clara Burr-Lonnon, Fertility Project Manager, clara.burr-lonnon@nhs.net

26. Any further comments?

Appendix 4:

Fertility and Cancer Survey-Free Text Responses

Question 16: Which patient cohort do you NOT discuss fertility with? (please specify age range, gender, whether tumour type-dependent, etc)

- Those above 45, only if they indicate they were considering future family.
- Post-menopausal women
- Prostate
- Post-menopausal ladies
- Older men and older women (<45)
- Tends to be done by consultant/CNS team
- Females peri/post menopause.
- Post-menopausal women. Where treatment will have no effect on fertility.
- Age range
- Those post-menopausal (unless early menopause and still eligible for treatment referral)
- Post-menopausal patients.
- For women that have not yet gone through the menopause. For men who state that they may consider having children in the future and want to discuss options.
- elderly- 60+
- Those who are postmenopausal
- Those who are post-menopausal, men over about 60 elderly patients
- Patients who are post-menopausal.
- Any patient who asks for advice
- 18-30
- Male and female
- Oncology and Haematology
- Older patients and those patient not receiving treatment which will affect fertility
- Patients whose treatments don't affect fertility For treatments that do affect fertility, I do not discuss in detail with post-menopausal females although I may mention that the treatment does affect fertility."

Question 18: What is your criteria for referring cancer patients to fertility preservation services/support? (please be as specific and detailed as possible)

- All patients under the age of 45 years unless they decline.
- Patient above 45 years if they wish to explore further with a specialist.
- Any patient that wishes to proceed to cryopreservation will be referred
- Pre-menopausal women, no children, about to undergo chemotherapy surgery or high dose chemotherapy
- Pre-treatment sperm analysis and sperm/egg cryopreservation; pre pregnancy fertility review
- likely loss of fertility due to removal of male reproductive organs and or effect of chemotherapy
- all patients pre-treatment offered the option
- Anyone who is diagnosed and potentially requiring treatment that may affect fertility. Or patients who have developed fertility issues post treatment needing specialist advice.
- When we have discussed with patient fertility may be affected and they wish to discuss further
- Having cytotoxic therapy that has the risk of compromising fertility in the future
- Unknown at present.

- Age, pubertal status and chemotherapy treatment
- When they are going to receive any type of cytotoxic therapy and radiotherapy
- Pre-menopausal
- No or less than one child
- Any young patient starting any trial treatment
- Males - all offered
- Females - depending on likely effect of treatment on fertility and speed required to commence treatment
- All females of child bearing age who wish to preserve their eggs.
- All males no age limits
- All female patient of child bearing age and all male patient. Women who are post-menopausal are not offered fertility options
- All men (after discussion and if they consent) for sperm preservation
- Women of child bearing age (if time allows and patient wishes)
- Pre TKI treatment and preBMT
- Young age < 40
- No children Chemotherapy that will affect Fertility
- Where fertility preservation is a viable option. Where a patient is struggling with the complexity of options and wants to discuss this with a fertility expert.
- Testicular and Prostate cancer
- Patient consent - younger patients
- Those undertaking primary chemotherapy, or likely to have endocrine post-surgery that eligible for fertility preservation. Or those that want to discuss options regarding fertility
- Likely impact of treatment on fertility. Clients wanting more information.
- For women that have not yet gone through the menopause. For men who state that they may consider having children in the future and want to discuss options.
- Men and women of child bearing ages
- Starting chemotherapy, radiotherapy that may affect their fertility. Patient request
- Those premenopausal who wish to consider more children in the future
- Patients wishing this
- Child bearing age. TYA
- Young patients having adjuvant chemoradio. Young patients having complex surgery
- Any patient wishing to have their fertility preserved.
- Women should be well enough to undergo stimulation and egg collection. The treatment does not delay planned chemo/radiotherapy.
- Patients who are having chemotherapy and who would like to think about children in the future.
- Younger patient who is for chemotherapy. Cut off age 42?
- We refer all patients wishing to preserve fertility for a discussion. However, due to the nature of the gynaecological cancers this is not always possible
- Younger pts. Most pts over 60 years old
- All testicular cancer patients who require chemo
- Age, patients wishing to have family
- Our fertility service will talk to all to discuss
- Men and women under 40 no previous children for sperm bank egg storage ovary protection Zoledex
- Young male and female (age as per CCG cut off)
- Those starting chemotherapy. Those 1 year post chemotherapy for sperm analysis and hormone bloods. Menopause symptoms.
- Anybody who asks

- The CNS and the oncologists will discuss with patient in clinic before the treatment date as part of the pathway
- Any patient of fertile age undergoing chemotherapy that may have an impact on fertility
- Patients who are starting any treatment that will impact their fertility (eg- chemo or endocrine therapy). We refer patients eligible for NHS preservation and those who would need to pay (having informed them of this). We also refer patients who would just like to know their options/ have a discussion about their fertility pre-treatment.
- Male or female < 40yrs with no prior children or any other who will be then charged
- Those receiving treatments that affect fertility - chemo, endocrine therapy, but we send anyone who asks even if they don't fit criteria for NHS care
- That they have no children. I believe that patients with a child are not eligible for services on the NHS
- Age, type of treatment they are to undergo
- All patients on systemic treatment but also who have advanced cancer diagnosis
- All suspected testicular pts have a fertility check pre surgery. Any patient having treatment which will impact on fertility will be referred.
- Reproductive age and / or no children

Question 22: What do you think are the main obstacles for referring patients to fertility preservation services/support?

- Time constraints
- Waiting times may delay cancer treatment
- Patients - those unsure if they want to explore this.
- Timing /type of diagnosis and urgency to start treatment.
- Patients who transfer care from another provider
- Time constraints
- Patients religious concerns
- Surgeons not discussing this with patients, being left to the CNS to bring up this subject
- Waiting times may delay treatment
- Lack of fertility update and education to cancer CNS
- Communication/information for patients re sperm cryopreservation
- Lack of time as often need to start treatment urgently - especially for females
- Service is quite a long distance for many of our patients
- Time dependent treatment
- The lack of knowledge and guidance
- Time, parental support, age,
- Patients are still young and do not want to consider that yet.
- Treatment needs to start asap so they do not have the opportunity for preservation (mainly females have this problem)
- Families wanting to be in the conversation
- No obstacles to referral
- Time to start treatment for women mainly
- Knowledge of services
- Speed of treatment commencing
- Clear information of treatments/chemotherapy and their fertility impact
- We have a wide range of area to cover and referral is not straight forward outside London.
- In our setting there should be no obstacles as we have time to plan.
- Often timing with acute leukaemia patients
- Difficult if patient is unstable or unwell as not on site
- Delay

- Understanding eligibility
- Patients are not always keen to travel as need to visit more than once
- Blood tests prior taking time, referral process slow
- Very few, other than speed of needing to treat occasionally. As we have an exceptional service with our unit and patients are seen very quickly once referred.
- No obstacles at our trust
- Previous walk in service. The blood tests required prior to referral.
- Not enough services available.
- Not on site and therefore difficult to know which form needed to refer
- No obstacles from my experience
- Not having clear referral pathways
- Knowledge about it
- Complicated process of referral and at times not knowing how to refer
- No local service
- Delay in treatment start time. Doctors not having the conversation early enough. Patients not being discussed fully enough at MDT to identify them due to time pressures. Lack of education of staff.
- We have very good service and personally never had a concerns with the referral.
- We always refer if patient's wishes to
- Lack of communication between departments
- Not understanding how to do it - fine if have information to do - we have a poster so ok
- Time- although we have a great working relationship with our fertility team to expedite referrals sperm bank pre surgery / chemo. egg harvest if time allows
- No obstacles in our service only for female sometimes not time for egg harvesting as patient needs to start treatment urgently
- The bad news to have cancer and now think about family planning , psychologically impacted.
- Timing- needing to start treatment quickly.
- Time delay
- Getting the right time to do this. For some patients it will be a priority at diagnosis, for others it will be too much information to take in at the beginning.
- No obstacles that I am aware of. I feel that patients with one child, often from a previous relationship, who may want a child with a new partner are discriminated against.
- We are very fortunate that our ACU team are very proactive
- Making sure seen and treated before cancer treatment
- Capacity and funding from CCG

Question 23: In your opinion, what needs to be done to improve the interactions between cancer and fertility preservation services?

- Clear and concise referral and communication pathway.
- Currently at our trust we have a smooth pathway
- Clearer pathway for referral, this is now done by email to our fertility counterpart
- Priority appointments for chemo patients
- Email referrals and ensure that Fertility/Andrology will reply back to acknowledge referral has been accepted and also informing team outcome of review through clinic letter to be placed on CDL
- More training
- Increased education
- More local services
- I have always found referrals to be quite timely, the delays have been due to patient side i.e. insufficient sample.

- Teaching sessions.
- Protocol
- EPIC referrals rather than paper
- Liaise with GP's to discuss with patient at the time of diagnosis.
- If patient already admitted and needs to start treatment asap, consider if it is possible to delay treatment in order to be able to start preservation first.
- More interaction upon completion of patient's treatment, when patient is considering trying for a baby
- More education and better links for patients, especially those outside of London
- Better education around impact and services
- There has to be a clearer pathway of referral and a more joined up service to areas all over the country.
- I think we have a very good service with the team at our hospital
- Better information and knowledge within the cancer team of options available
- Coordination in advance pre-treatment and pregnancy
- More interaction between specialities so we understand what they offer and they understand our patients needs
- None in our service
- Raise awareness of services available to give patients choice
- Clear protocols and flow charts of who to refer to and tests needed prior
- Ensuring service is always able to accommodate seeing patients quickly and in timely manner.
- That always cover if Consultant away so patients can still be seen rather than delays.
- That all clinicians also refer direct rather than awaiting other colleagues or BCN to refer, if away
- We have a fantastic service provided by our hospital's assisted conception unit.
- A generic email inbox to allow referrals to the service which can then be triaged and patients/referrers contacted.
- Knowing timelines for the patients in order to not delay treatment.
- Written information to provide.
- Known direct pathway.
- Engagement from surgeons so fertility preservation referrals can take place promptly
- Better signposting
- Improved communication , clear guidelines
- Clear guide lines/ pathways to be in place in all DGH hospitals.
- To have local service support
- Joint MDT meetings, study group sessions
- Clear pathways and education
- May be referral pathway for new team
- we work closely together in gynae oncology
- Numbers are so low, that we don't have any
- Working together. Maybe cancer fertility clinics. Regular training to cancer professionals
- More advertising to cancer services - so can better inform patients what to expect
- Keep using the service to speed the pathway
- very good relations in place, patients seen quickly here
- Possible pathway
- More public promotion given to public about cancer and fertility
- We are lucky to have our service 'in house' so communication is pretty good between the teams. Ensuring we give the same advice on things like using zolodex and the impact of hormone stimulation for those with an ER positive cancer is important. This could be improved by regular update meetings/training sessions between the 2 departments.
- Clearer criteria re who to refer/ eligibility

- We have very good links at our hospital with the ACU
- Unsure
- Regular updates on services available, particularly as staffing rotates frequently
- More reaction of referral when made
- Regular meetings and updates on changes to funding.
- Clear pathways