

East Lancashire Prostate Cancer Support Group Newsletter



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Ten per cent drop in prostate cancer death rate predicted

PCUK 22 Apr 2020

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Good news: 10 per cent fall in prostate cancer death rate predicted. We must act now to keep momentum.

New research suggests the adoption of new ways to treat and diagnose prostate cancer in recent years will be reflected in a significant drop in death rate from the disease.

A new Europe-wide analysis shows a radical drop in death rates from prostate cancer is expected in 2020. The reduction is

likely to be a result of 20 years of research culminating in new ways to treat and diagnose prostate cancer, and keep men living longer with the disease.

Research funded by people like you is bringing us closer to the day that prostate cancer is no longer a killer. But this progress is under threat by the coronavirus crisis.

Researchers at the University of Milan estimated death rates for common cancer types across

the EU. They also calculated over 400,000 prostate cancer deaths in the EU have been avoided since 1996, with over 40,000 in 2020 alone.

Improvements in the way prostate cancer is treated, like technological advances in surgery and radiotherapy in the last few years are thought to have made the biggest impact on the reduced death rates.

New drugs to treat advanced forms of the disease, like [abiraterone](#) and [enzalu-](#)



[tamide](#), developed in the last ten years are also likely to have contributed to the improvements. As well as treating men with advanced prostate cancer earlier with [chemotherapy](#), [radiotherapy](#) and [abiraterone](#). Together, these changes have helped avoid prostate cancer deaths in significant numbers of elderly prostate cancer patients.

The researchers were less able to understand the impact of techniques to diagnose prostate cancer, such as the frequency of PSA testing, on the reduced death rates. But the introduction of [mpMRI across the UK](#) to improve the accuracy of prostate cancer diagnosis will likely have contributed to better and more specific treatment for many.

More research needed as overall death toll still likely to increase

However, prostate cancer is still the [most commonly diagnosed cancer in England](#), with incidence rising as the UK population ages. It means that although the risk of dying from prostate cancer has decreased for individual men, the overall number of deaths from the disease is likely to continue rising. This year, it was revealed prostate cancer deaths hit [an all-time high](#) in 2017.

Director of Research Impact at Prostate Cancer UK, Dr Matthew Hobbs, said: “With incidence of prostate cancer rising in the UK, and the number of men reaching an age that increases their risk, combined with faster progress in other diseases, we need much bigger and quicker reductions in the death rate to stop the number of prostate deaths continuing to rise every year.”

But right now, due to the social distancing measures required to contain the coronavirus pandemic, prostate cancer labs are closed and research is at a standstill. Without urgent funds, there’s a risk much of this ground-breaking work may not re-start.

Urgent action needed as research comes to a standstill across the UK

Dr Hobbs continued, “Right now Covid-19 is having a major impact on research in cancer across the UK, but Prostate Cancer UK's vital role in funding research, getting that research into practice across the UK, and improving awareness, diagnosis and treatment of the disease remains absolutely critical to achieving the larger, faster reductions in death rate that we need to reduce the number of men dying of prostate cancer over the next ten years.”

Covid-19 is having a major impact on research, but Prostate Cancer UK's vital role remains absolutely critical to achieving the larger, faster reductions in death rate that we need to reduce the number of men dying of prostate cancer.

- Dr Matthew Hobbs, Director of Research Impact

We have 58 ongoing research projects, all of which were awarded funding because of their promise to lead to better treatments and ways to diagnose prostate cancer. But due to measures to contain the coronavirus pandemic, our researchers currently have no access to their laboratories or the specialised equipment and facilities they house. It’s meant all these life-saving projects have come to a stop.

This research coming to a halt means years of work, and millions of pounds are at stake. Key experiments and findings are often years in the making, with meticulous planning and preparation work involved in the lead up. A pause to research of just a few months could mean key milestones to collect data are missed, chemical shelf-lives are exceeded, and months of planning and preparation is made redundant.

No one knows when we will emerge from this crisis, but when we do, it’s critical we give our

researchers the time and resources they need to resume their work. Your support has never been more important to keep saving lives from prostate cancer.

We've made such powerful progress against prostate cancer so far. But we can't lose momentum. We need to secure the future of prostate cancer research to bring us closer to the day that prostate cancer is no longer a killer.

[We're calling on all our supporters to take the 2.6 challenge this weekend](#) to help protect the research gains that are now at risk

The 2.6 Challenge is for everyone - all you need to do is think of an activity based around the numbers 26 or 2.6 and complete it on or from Sunday 26 April. It could be as simple as using your daily exercise to run 2.6 miles, doing 26 minutes of yoga or 26 star jumps. Or do something different and flip 26 pancakes, hop 26m or make 26 balloon animals. The choice is yours!

Cycling fanatic Cameron Fraser will remember his late grandfather (Papa) as he takes on an epic 2.6 Challenge for us on Sunday. On what would have been London Marathon day the 39-year-old business development manager will virtually cycle 262km in loops of the capital via online cycling platform Zwift.

Cameron's grandfather Jack Fraser was an accomplished grass track cyclist, once beating the British champion twice in the same day in the Highland Games in the 1940s. Sadly Jack died of prostate cancer in 2000.

Cameron said, "I'll be thinking about lots of things on Sunday, about Papa, my dad and family and cycling friends I haven't seen for a while. Hopefully they will join me on the challenge. My ultimate

Take the 2.6 challenge to keep our research going

To mark what would have been the London Marathon's 40th anniversary the organisers of the biggest mass-participation events in the UK have come together and created the 2.6 Challenge. Join us and make a difference to the lives of men everywhere.

Prostate cancer research is at a standstill.

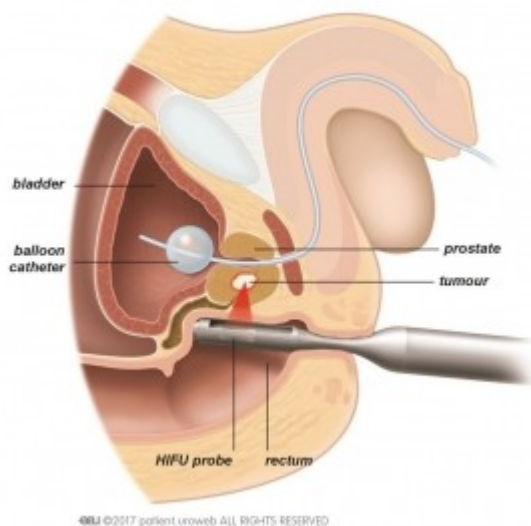
Men have never needed your support more to ensure vital progress is not lost.

Prostate Cancer UK is a registered charity in England and Wales (1005541) and in Scotland (SC039332). Registered company number 02653887. Registered office: Fourth floor, The Counting House, 53 Tooley Street, London SE1 2QN. VAT Registration Number: 905 9415 18.

Prostate 'lumpectomy' treatment is an effective and safer option than surgery for cancer that has returned after radiotherapy. A new study by Imperial College London has shown that targeted treatment to areas of cancer inside the prostate is effective and has low risk of side effects. The study was carried in men in whom the cancer had recurred in after previous radiotherapy. The study is to be presented at the international ASCO (American Society of Clinical Oncology) cancer meeting on 29th May 2020.

Every year, about 10,000 to 12,000 men with prostate cancer have radiotherapy. This is an effective treatment for prostate cancer but about 1 in 7 of them will have a recurrence years later. Patients who have a cancer recurrence contained within the prostate are traditionally offered anti-testosterone hormone treatment. This controls the cancer for 2-3 years before the cancer changes and needs more expensive second- and third-line drugs.

The hormone treatment can cause side effects such as obesity, tiredness, bone thinning and can also increase risk of diabetes and heart disease. The alternative is radical salvage surgery (called prostatectomy) which removes the entire prostate. This type of surgery is not commonly done because the tissues surrounding the prostate are scarred and stuck down due to previous surgery. As a result, 50-100% get urine leakage needing daily pads and 5-10% get rectal injury requiring colostomy and further major reconstructive surgery. Faced with these options, most men choose hormone medication.



Focal therapy uses either sound waves or freezing to selectively target and treat areas of cancer inside the prostate rather than the whole prostate. This is the prostate equivalent of a 'lumpectomy' performed for breast cancer. The soundwave technology is called High Intensity Focused Ultrasound (HIFU) and the freezing technology is called cryosurgery. There is no need for cuts to the skin and most men go home the same day and have a quicker recovery than salvage prostatectomy.

This current study is the largest ever with the longest follow-up in 356 patients from UK centres. It shows that the treatment is effective at cancer control with average 6 years of follow-up in this high-

risk group of patients where the cancer recurred after previous radiotherapy.

The results show that, after 6 years, 3 out of 4 patients treated with focal therapy had their cancer controlled and did not need hormones or surgery and the cancer did not progress. Cancer specific survival was 97.2%. The procedure is also safe in which less than 1 in 100 patients were noted to have a significant complication. Rectal injury was 0.3% whilst the researchers have shown in another study that urine leak needing pads was 12.5%.

Professor Hashim Ahmed, senior researcher for the study at Imperial College NHS Foundation Trust and Imperial College London, said that “Radiotherapy is effective in most men but for the thousands of men with recurrent prostate cancer after radiotherapy, the options are very limited. Focal therapy for these patients offers a treatment for their cancer that does not carry the high risk of side-effects from traditional hormones or major surgery.”

Dr Deepika Reddy, a urology research doctor, and lead author on the study, based at Imperial College NHS Foundation Trust and Imperial College London, said, “This study provides more evidence that focal therapy should be considered in men whose cancer is suitable for a minimally-invasive approach. Such evidence in combination with well-structured clinical trials will help patients, in partnership with their doctors, work out the most suitable option for them.”

Prost8 UK is the only prostate cancer charity working solely to promote awareness of the enhanced lifestyle outcomes provided by focal ablation for men with an early stage or recurrent prostate cancer diagnosis. The charity’s founder Paul Sayer said, “we will launch our high profile ‘Prostate Cancer – Know Your Choices’ campaign in July of this year to widen awareness of focal therapy for prostate cancer.

Sadly, right now up to 95% of men with a new diagnosis will not even be told about this treatment option, let alone offered it. And, too many GP’s and clinicians involved in prescribing treatments for this disease are unaware of this treatment pathway and its efficacy. We are working hard to change this as soon as possible”. In addition, the charity is actively fundraising to buy and deploy focal therapy equipment into strategic NHS hospitals across the UK to accelerate access to the treatment.

Please support by donating today. [Donate here](#)

Prost8 UK
One Hub, 7th Floor
Maitland House,
Southend-on-Sea
Essex, SS1 2JY
0203 858 0848
info@prost8.org.uk

1 in 8 men in the UK will be
diagnosed with prostate cancer in their lifetime...

...and one dies every 45 minutes!

Prost8 UK is a registered charity in the UK no: 1182590

Researcher: Cristina Da Silva, Psychology student

Are you a prostate cancer survivor?

If so, I am looking for prostate cancer survivors to participate in my master's online research project. I am investigating whether depression is a prevalent issue among prostate cancer survivors.

Participants will be required to fill in a short questionnaire before partaking in an online semi-structured interview.



Participation is voluntary, no reward of incentive will be given for partaking. If you would be interested in taking part in this study or would like to know more information in relation to prostate cancer, please contact Cristina Da Silva via email csilva1@uclan.ac.uk

[Thank you for taking time to read this](#)

#OneCancerVoice: we join charities to call on government to restore cancer services impacted by Covid-19. PCUK 22nd June 2020

Following the coronavirus crisis, there's danger of a cancer crisis. Today we launch an action plan calling on 10 Downing Street and NHS England to get cancer services back on track.

The COVID-19 crisis has had a profound negative impact on health and care services across the UK. The pandemic put our [life-saving research programmes on hold](#); many cancer patients have had their treatments postponed; and because people have had less access to GPs and scans, thousands more people with cancer have been left undiagnosed. We urgently need a national plan to recover. Cancer is the leading cause of death in the UK, and prostate cancer is [now the most commonly diagnosed cancer](#). It's so important that patients are diagnosed as early as possible, that men at highest risk of their cancer progressing are prioritised for treatment, and that we invest in research that will help us find the answers to stop prostate cancer limiting lives. The pandemic has made all of this more difficult.

The pandemic has also made existing health inequalities worse, placing a greater burden on those from deprived communities and those from BAME groups. People from the poorest communities are at increased risk of exposure to COVID-19 and more likely to suffer negative outcomes. This must be considered alongside the fact that [black men are twice as likely to get prostate cancer](#).

People with cancer have also experienced new anxieties during this crisis, with uncertainty about when their treatment and tests might restart, and the risks they face from COVID-19. Around 200,000 people with cancer in England have also been advised to 'shield'. For many, this has resulted in social isolation, anxiety and other psychological harm.

Ally Clarke was diagnosed with advanced prostate cancer ten years ago at age 60, and [says he owes his life to research](#). He understands the impact the pandemic has on people with cancer, saying: "Just before Covid-19 hit the UK and the world in a big way, I was due to start participating in a new [clinical trial](#) to start another new treatment to keep controlling my prostate cancer. I was gutted to find out that it had to be put on hold. Now all my treatment has completely stopped."

That's why, along with 25 cancer charities, we've developed a 12-point evidence-based plan to begin to address the complex challenges we now face to get cancer services back on track.



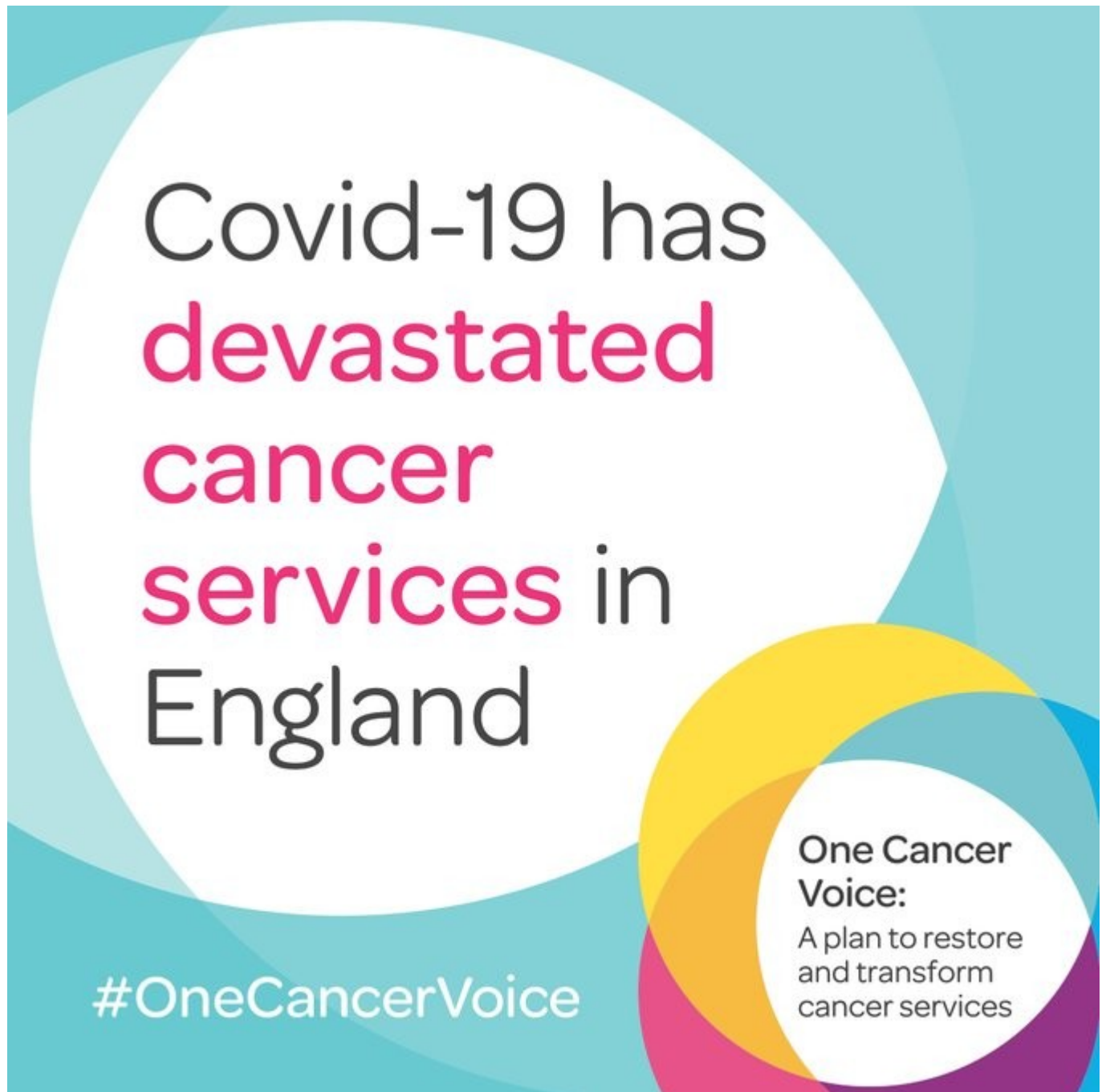
[Prostate Cancer UK](#)

✓ [@ProstateUK](#)

#COVID19 has made it even harder for cancer patients to get the tests and treatment they need.

That's why we've united with 25 cancer charities to ask Government for a plan to restore cancer services.

Read our proposal: <https://bit.ly/2V7hrCe> #OneCancerVoice



This plan acts as guidance for the government to build a national plan that can make sure men like Ally can continue to access the treatment that can keep them alive. The plan is not just about returning services to where they were, it's about responding to new challenges we'll face over the next few years in a way that will help us improve outcomes for everyone affected by cancer. So, as well as getting treatments and research back on track, it includes guidance on public health messaging to inform and protect high-risk groups, increasing and retaining the health workforce, building screening programmes, and much more.



Contact Information

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From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.

Our Director of Support & Influencing, Heather Blake, added: "Most men with early prostate cancer don't have any symptoms, but we know that very few of these men have been referred for tests during this pandemic. Until normal diagnostic services resume, many thousands of men risk being diagnosed too late, when the disease has already spread."

"Anyone with concerns about their prostate cancer risk should speak to their GP or contact our Specialist Nurses – particularly if they have symptoms or are at higher risk. Men who are most at risk are those aged 50 and over, black men and men with a family history of the disease."

The 12 steps cover:

- Keeping baseline services running
- Covid-protected environments
- Diagnosis and referrals
- Personalised care
- Clinical trials
- Supporting the vulnerable
- Preventing cancer
- Workforce
- Screening programmes
- Guidance
- Innovation
- Long-term plan ambitions

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FLEX

FLEXIBLE BRAIN TRAINING



South London
and Maudsley
NHS Foundation Trust



Patient Information Sheet

A novel online program for fatigue; a feasibility study

We would like to invite you to take part in a research study conducted by King's College London. The study will investigate how persistent fatigue can affect how people process information. It will explore whether we can change how the brain processes information using an online computer program.

Before you decide if you would like to participate, we will tell you why the research is being done and what it will involve for you. One of our team will go over this information sheet with you and give you the opportunity to ask any questions.

What is the purpose of the Study?

Research has shown that the experience of ongoing and persistent fatigue can affect how people process information. For some people, it can result in problems with attention and concentration. For others it can cloud how they see everyday activities, making planning and socialising difficult.

This research is interested in whether we can shift how people process information back to how it was before they experienced excessive fatigue. We are interested in whether shifting these processes can help reduce the distress caused by fatigue.

We have adapted an existing online program to make it specific to the experience of fatigue. The purpose of this study is to investigate whether this adapted online program is feasible; that is, is the program useful for patients who experience persistent fatigue.

What would taking part involve?

If you agree to take part, you would be asked to complete some computerised training. There are two types of this training and you would be randomly assigned to complete one of them. One is an active version of the training and one is a neutral version. This is so that we can compare them. Both types of training consist of 12 sessions completed over 3 weeks (4 sessions per week). The sessions will last about 20 minutes

and can be completed at home on a computer or tablet. You are able to select the days and time you wish to complete the sessions. In addition, you would complete some assessments online, before and after the 12 training sessions and again at 1-month and 3-months follow-up.

Why have I been invited?

You have been invited because you have experience of persistent fatigue.

Do I have to take part?

No, you do not have to take part. It is up to you if you would like to join the study. If you are interested in taking part, we will ask you to register your interest on the website and sign a consent form. You are free to change your mind and to withdraw at any time. This will not affect your standard of care. You do not have to give a reason for not wanting to take part.

Will my information be kept confidential?

Your personal information will be kept confidential. The questionnaires will be input into a computer. Only the researchers will have access to the computer which will have a password to protect all confidential files. Any personal details or identifiable information will be removed and contact details will be stored separately in a password encrypted file. The data will be kept securely at King's College London. Contact details will be destroyed at the end of the study whilst consent forms will be archived up to seven years after the research has finished.

In the unlikely event of any risk such as self-harm or suicide risk, confidentiality will need to be broken. Your safety is very important. Both you and your clinical team will be made aware of the breach of confidentiality.

Data will also be stored on an online platform. Questionnaires will be completed on Qualtrics whilst the training will be conducted using a website developed and hosted by SPIKA (for privacy statements, please see links: <https://www.qualtrics.com/privacy-statement/> ; <https://www.spika.com/privacy-policy/>).

How your personal data will be used in compliance with General Data Protection Regulation (GDPR)

King's College London (KCL) is the lead sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. KCL will keep identifiable information about you for 7 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the Chief Investigator Dr Alicia Hughes; alicia.hughes@kcl.ac.uk, or visiting the KCL website: <https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research.aspx>.

If you were recruited from South London and Maudsley NHS Foundation Trust, they

will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. South London and Maudsley NHS Foundation Trust will pass these details to King's College London along with the information collected from you. The only people in King's College London who will have access to information that identifies you will be people who need to contact you to regarding the research or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

What are the possible disadvantages / benefits of taking part?

The risk of taking part is extremely minimal. You can complete all parts of this study at home. The online program has been used before without any adverse effects. The assessments have also been used previously and should not cause any distress.

The study requires a 3-week time commitment from participants, in order to complete all 12 online sessions. To reduce the burden of this on participants we have made each session as short as possible. There is also a visual calendar built into the website to help you plan to complete these sessions.

This study is investigating whether a program like may be useful for people with fatigue, however in its current form it is not viewed as a therapeutic intervention. Whilst participants may not directly benefit from this study, the research is aimed at further understanding factors which contribute to fatigue. This knowledge can help us identify ways to help reduce the distress and disability fatigue can cause in people's lives.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [Alicia Hughes, 0207 188 5422, alicia.hughes@kcl.ac.uk]. If you remain unhappy and wish to complain formally, you can do this through the South London and Maudsley Patients Advice and Liaison Service (PALS) on 0800 731 2864, pals@slam.nhs.uk.

What will happen to the results of the research study?

The results of this study may be published in scientific journals and at medical and psychological academic conferences. You will not be identified in any report or publication. A lay summary will be sent to participants.

Who has reviewed the study?

This study has been checked by Research Ethics Committee, an independent group of people, to protect your safety, rights, wellbeing and dignity.

Any further queries?

If you have any questions or concerns about the study, you may contact the following organisations

For independent advice on participating in NHS research:

Patient Advice and Liaison Service (PALS) - 0800 731 2864

For independent advice about making a complaint:

South London Independent Complaints Advisory Service (ICAS) – 0300 456 2370

For information from the researchers:

Sophie Fawson: TAPPS-study@kcl.ac.uk 0207 188 5422 (Principal Researcher)

Dr Alicia Hughes: Alicia.hughes@kcl.ac.uk 0207 188 5422 (Chief Investigator)