

| <p>The Top 26 unanswered questions from the Living With and Beyond Cancer PSP (in order of priority as agreed at the final workshop). For questions received by the PSP that have already been answered, out-of-scope questions, and other types of questions received, please see further down this spreadsheet</p> | | <p>H = health professional, P = patient, R= relative/ carer, O = other, U = unknown</p> | |
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| Qn No: | Original questions | Category of Respondent | Relevant literature |
| <p>1. What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology,</p> | <p>For some people, newer medicines mean that cancers and leukaemias are treated more like a chronic disease now, so what's the best way for them to get their healthcare - do they always need to see a specialist or can follow ups be done at their GPs surgery?</p> | R | |
| | What type of long term follow-up/support services would patients value? How can the NHS accommodate this? | H | |
| | What role do patients see their GP having in their cancer treatment and follow up? | H | |
| | What would patients like to see in a cancer care review in primary care and at what point does a patient feel it would be appropriate to have a review of their cancer and treatment by their GP? | H | |
| | What is the role of community pharmacy in supporting patients living with or beyond cancer? | H | |
| | How can pharmacists better support patients living with and beyond cancer with their medicines? | H | |
| | How can pharmacy professionals contribute to helping patients live with and beyond cancer? | H | |
| | At what point to we explore the needs of people following their diagnosis and treatment of cancer? | H | |
| | How can I get rapid access into the system if I am concerned | H | |
| | How to avoid overmedicalising subsequent care for people who have undergone curative surgery, particularly for low risk cancer | H | |
| | In people LWOB, are PROMS improved if they are cared for by HCP with recognised LWBC competences? | H | |
| | Ask GPs what would help them in caring for patients who are discharged after treatment in secondary care | H | |
| | What is the most appropriate way for GP practices to support patients | H | |
| | The relevance of social work in supporting patients with cancer. | H | |
| | The relevance of social work within an oncology medical team in serving the needs of the patients. | H | |
| | Post treatment surveillance strategies: the number of cancer survivors is rising and becoming a strain on resources (clinician time in particular). With increasingly reliable detection tools such as circulating tumour DNA (ctDNA, liquid biopsy), and smart phones, could patients monitor themselves using AI (artificial intelligence)? Self directed post treatment surveillance? | H | |
| | what is the economic impact on the healthcare system of patients who are not coping well with life with and beyond cancer (e.g. health anxious, depressed, agoraphobic, panic, socially isolated)? | H | |
| | What barriers, if any, would prevent them contacting their GP or practice nurse to ask for support? | H | |
| | How could health care professionals in primary and community care improve their patient's experience when living with and beyond cancer? | H | |
| | Living well with metastatic disease- how can allied health professionals support patients in self managing their disease and symptoms to live well. | H | |
| | Supporting patients and carers at home and how can carers help more with their relatives care and can they do more. For example injections with supportive therapies? | H | |
| | What is the best way to train informal cancer caregivers to support cancer patients during and after treatment? | H | |
| | How can digital technology be harnessed to support those living with cancer or beyond cancer? | H | |
| | How are PCT's expecting to transfer relevant clinical information between acute and community to ensure a seamless provision of patient centered care ? | H | |
| | Will cancer patients use digital health adjuncts in their care pathway | H | |
| | How can telemedicine (remote / computer based / telephone) support help transform the care of people LWBC? | H | |
| | how should follow up for lung cancer be done? in primary care with specialist support or via respiratory medicine? | H | |
| | for indeterminate lung nodules, can these be managed in primary care? | H | |
| | How do we engage primary care with all this? GPs don't view cancer as a long term condition so often aren't happy take on their management. It can't be sustained in secondary care so how do we change things? Is there any role for oncology specialists in primary care? | H | |
| | Our local Cancer Alliance wants to see a consistent model for re-stratified pathways across the footprint. Not surprisingly, specialists favour hospital based programmes while the expertise in management of long term illness in primary care might have more to offer patients. Has there been any investigation of the patient view on this? Are there any shared care models? | H | |
| | do they [PATIENTS] have confidence that they can get back into the correct system if they need to? | H | |
| | Are outpatient oncology review appointments of benefit to patients? | H | |
| | How can the voluntary eg charitable cancer support work in greater partnership with NHS providers rather than in an often rivalrous relationship. The current commissioning model seems too compet | H | |
| | How can communication / continuity of care be improved for people LWBC who access care in NHS / private / voluntary sectors? | H | |
| | How can the activities of third sector organisations interested in LWBC be co-ordinated to avoid duplication of effort and serve the patients more effectively? | H | |
| | How and who do you highlight the long term effects you are suffering too? | H | |
| | Who should be exploring these issues with the affected people? Where, when and how? | H | |

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| | How can pharmacists better support patients living with and beyond cancer with the late side effects of anti cancer medicines? | H | |
| | What is the best care model for managing consequences of treatment? | H | |
| | Should there be a new medical speciality created to manage and deal with late and long term cancer treatment consequences? | H | |
| | Given the range of late-effects includes every system, and given the frequency and epidemiology of the problem. how will all the medical colleges ensure that long term and late effects is a mandatory part of doctor's specialist training? | H | |
| | Should cancer patients have an annual review (by the GP practice nurse) of their health taking into account all other long term conditions and any lifestyle needs? | H | |
| | what ongoing specialist advice regarding symptom control should be available for those who have been treated with curative intent? | H | |
| | How can we best take a multidisciplinary approach to managing side and late effects of cancer and treatment? | H | |
| | how can we implement proven interventions that benefit patients into the NHS in the current fiscal climate - e.g. exercise to prevent effects of hormonal therapy or specialist gastroenterological assessment and management for pelvic radiation disease | H | |
| | Who is best placed to advise about late effects | H | |
| | How can services be developed to support me with my quality of life beyond cancer? | H | |
| | How will people affected by cancer be supported to self manage the late and long term effects of cancer and its treatment? | H | |
| | How do we practically (Health and Wellbeing events in my opinion are not a long term practical solution) deliver good quality patient self management post treatment, that then actually reduces the burden on secondary and primary care? | H | |
| | I am very interested in Managing Long term effects post Cancer Treatment. I would like to carry out some research on a tool that can be used in oncology clinics to assess and document long term effects and ensure patients are referred to specialist clinics when required. | H | |
| | What is the best model for assessing and managing late effects | H | |
| | Are GPs properly equipped to deal with post radiotherapy/chemotherapy side effects? | H | |
| | Should we be encouraging patients to self manage? Or does the NHS have a duty of care to manage patients in the long run following cancer treatment. How does cancer compare to other long term conditions and what patients are responsible for | H | |
| | How much do GP's understand about late effects of treatment? What tools do GP's need to be able to recognise late effects? | H | |
| | Is "late effects " recognised? | H | |
| | What models of care support people closer to and in their own homes | HR | |
| | How well are we supporting AYA patients treated for Hodgkin's Lymphoma in the 1980's, who are now facing late effects and second cancers as a result of their treatment? Can anything be done to reduce their considerable risks? | HR | |
| | How do CCGs, Secondary Care, Primary Care, Community sector and voluntary sector work better together to give cohesive support to those living with and beyond cancer. Especially when there are competing priorities for funding and resources. | O | |
| | To what extent do people affected by cancer receive adequate, long term support from their primary care team after finishing cancer treatment? What does good look like? | O | |
| | To what extent do people affected by cancer receive adequate, long term support from community based services (NHS, local authority and third sector) after finishing cancer treatment? What does good look like? | O | |
| | What are the most effective interventions to support self-management in people living with and beyond cancer? | O | |
| | What is the role of health charities in working with the NHS to provide support to living with and beyond lymphoma? | O CHARITY | |
| | Does a yearly check up post treatment meet a recovering cancer patient's holistic needs | P | |
| | The range of advice/treatments applicable to survivors is numerous. Should survivorship be a formally diagnosable condition so that appropriate 'treatments' are prescribed? | P | |
| | NCSI identified self-management as a key enabler of successful survivorship with a shift from a clinically led approach to follow-up care to supported self-management, based on individual needs and preferences. What models of supported self management are being employed which are effective from a patient viewpoint ? | P | |
| | DFSP - why do I have my follow ups with my plastic surgeon instead of an oncologist or dermatologist? | P | |
| | Could I have an 'open referral' at the hospital after my 5 years of ct scans and consultant appointments have ended? | P | |
| | Why do UK patients have to 'see your GP? When we know whom we need to see for the next step in our care pathway, yet we have to waste time talking to a GVP with no knowledge of cancer care, who is often indifferent and uncaring. In other countries cancer survivors can access the correct treatment in a hospital directly, and don't waste our time having to get a GP referral | P | |
| | Why isn't there a cancer GP where we could go to with concerns who would have expertise to know whether to escalate a situation or if a new symptom is just a common after affect. | P | |
| | Would patients be better supported if there was better fluidity and communication between primary and secondary care. | P | |
| | Research to develop and see the effects of an online survivorship course at the end of treatment. This could have units on diet/ exercise/ sleep/ mental health/ sexual health/finances/ etc and could be tailored for different age groups. It might help people to have a sense of "doing something" at the end of treatment and could be developed as an NHS app for both patients and carers. | P | |
| | Who do you turn to for re-assurance about minor physical symptoms which nevertheless cause extreme anxiety but are not urgent enough to bother the hospital or GP? | P | |
| | fast track referral in place not just for five year follow up but longterm. Patients should not have to go through GP for this. | P | |
| | Do people who have no other health problems feel they are being adequately followed up in primary care after being discharged from acute care? | P | |

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| | How prepared are GPs to deal with the increased nervousness about health issues in general that (presumably?) most of us living with cancer experience. (Things I would've previously either not noticed or ignored are become are now all sinister in y post-cancer diagnosis world) | P | |
| | The link between survivor & GP. I feel I could be let down by ignorance & indifference to my previous health problems. I know when my body need medical help..... | P | |
| | Would it be possible to have a medical person available to patients for ever to answer what might be simple questions- does not need to be a Doctor? | P | |
| | Following on from the question above, I worry that, a) I won't be able to get back into the acute system should my cancer rear up again. I worry constantly that my Oncologist, who, I've been able to build quite a good relationship with, will leave or retire and I'll be back to square one dealing with complete strangers, who don't know my history or me personally and will make the wrong decisions on my behalf. I still feel even after 12 years of living with secondary disease that my Oncologist actually controls life and death and that I have little say over my future, such as it is. | P | |
| | The link between hospitals and local services is obscure. My experience of discharge was awful. Local services refused to do injections for me; to the extent that my partner was in tears, I ended up saying that I would travel Leicester to London to get this done. In the end we used around three separate Leicester services to get simple things like wound dressing and injections done. | P | |
| | Models of follow up to suit various lifestyles - working full time/part time, not in employment. Models needing to respect the time of people living with and beyond cancer. | P | |
| | Stop the NHS delaying patients getting follow-up appointments. The system that now makes us return to our GP for referrals is counter-productive. Let's go for European system where patient is deemed intelligent enough to be able to request a follow-up appointment directly with a Consultant whom they are under. | P | |
| | Who is best suited to answer questions on follow up, local GP or hospital. | P | |
| | care post cancer - how to education and involve GP's with issues such as the above - why there seems to be a lack of understanding and knowledge in primary care. | P | |
| | Is primary care equipped to support people in the community after hospital based treatment has finished? | P | |
| | How can I get reassurance that new symptoms are not cancer when my GP mis-diagnosed me with my first cancer? | P | |
| | Appropriate methods to deliver long term treatments (e.g. 10 years of endocrine treatment for breast cancer) with minimum disruption to everyday life. | P | |
| | Should primary care have a designated 'cancer contact' that specialises in the after care of all cancer patients in that surgery? | P | |
| | Who should deal with cancer treatment side effects? Primary care or secondary care team? | P | |
| | Why don't GP's and cancer professionals communicate more with each other to benefit their post cancer patients? | P | |
| | Are GP's fully informed of the impact on patients and family members of living with cancer? Things like having access to GP appointments sooner than the usual 3-4 week wait! And up to date medication list from oncology!! | P | |
| | Are the long term effects of cancer often ignored/ underestimated? And how can we better support patients? | P | |
| | Why do the medical profession generally not seem interested in the after effects of radiation treatment? My specific experience is with pelvic radiotherapy (prostate cancer), and my oncologist/radiologist didn't warn me about many of the possible after effects. Unfortunately I now have three of them - radiation cystitis; proctitis; SIBO. To make matters worse when I told her about my problems after my treatment there was no procedure or process to have me seen by specialists i.e. urology and GI. I had to wait for many months. | P | |
| | How much support can we expect from our GPs as we try to cope with the side affects of the treatment.? | P | |
| | Why is there no help for patients living with the late effects of radiation treatment, e.g. Radiation Induced Lumbar Plexopathy? | P | |
| | Should a MDT approach be introduced to treat late effects of radiotherapy? | P | |
| | Would having a "named GP" (as is done for the over 75's) improve long term health care for cancer survivors. At the moment primary care is not doing well on late effects or secondary cancers due to people falling through the system? | P | |
| | Are you receiving adequate support from your GP to deal with side issues such as skin complaints, swellings and pain (unconnected directly with your original diagnosis)? | P | |
| | Do you stay away from your GP regarding side issues such as such as skin complaints, swellings and pain (unconnected directly with your original diagnosis) as you feel you have taken enough from the health service with treatment of your cancer, and you don't what to be a problem to busy people? | P | |
| | Would you find it useful to have a forum where side issues such as such as skin complaints, swellings and pain common to certain cancers (yet unconnected directly with your original diagnosis), could be discussed with a view to finding most effective treatments. | P | |
| | why are there not enough gastroenterologists who have an understanding of the diagnosis and treatment of PRD [pelvic radiation disease]? | P | |
| | How should my ongoing nutritional and immunological status be tested? Low vitamin D at diagnosis was recommended 6 weeks of over the counter supplementation - but was never tested again. | P | |

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| | I am really struggling with painful side effects after chemotherapy as well as the physical changes to my body after all surgery so far (I still need more Surgery due to brca1 status), the consultants looking after me & BCN seems to have taken a huge step back, now I am left feeling like I have nowhere to turn, my gp says contact the team, my consultant seems insistent I contact my gp, meanwhile I'm expected to take a cocktail of painkillers and just get on with it since the X-ray's & scans show no bone problems..... So that's it I still have pain, something is causing it, but nobody can give me answers or reassurance which only adds to the anxiety I already feel. Surely more investigation, support & ongoing help should be available post "active treatment", I was triple negative, so no hormone therapy ongoing, just left to swallow painkillers all day with nobody to help me understand why I'm in pain | P | |
| | When a patient develops Lymphoedema as a direct result of their cancer treatment: Why are cancer patients not being treated by the NHS? | P | |
| | We need a more reliable and robust way for patients to have symptoms and late effects managed. Too many do not get access to pain management clinics until far too late. Can we find out why and what interventions would help. | P | |
| | Who do you contact/ how can you manage the life long effects of cancer surgery /treatment, especially when those symptoms mirror recurrence or new primary cancers? A gp knows very little and doesn't seem at all suitable, however nice they may be. | P | |
| | How do we best care for those who have had cancer? GPs not properly equipped and oncologists only treat 'active' disease, but there is unmet need in those who have come through treatment but are now living with the effects of that treatment and the psychological effects of their illness. | P | |
| | Addressing the issue of late effects and getting support for these, particularly when no longer in active follow up. | P | |
| | Ease of access (fast-track) back to medical system if concerned about recurrence | PH | |
| | Once active treatment has finished it feels like a bit of a black hole as to who to contact about any concerns, GP, surgeon, oncologist? | PR | |
| | At what point should you look to your local GP / health centre for support rather than the hospital team? | PR | |
| | Who is consulted about the support treatments offered by the NHS to cancer patients? I find it quite strange that while - for example - breast reconstruction surgery is offered routinely, getting help with painful toenails or dodgy joints following chemo is difficult. For me, the loss of a breast was not particularly difficult and I don't like the idea of reconstruction. However, hobbling around with dodgy joints for a year was very, very depressing. Some easily available physio would have been nice - and I guess much, much cheaper than the cost of a reconstruction op. | PR | |
| | Side effects of medication - for example I am on Tamoxifen with a 10% chance of developing cataracts (which my mum did whilst on this drug but didn't realise the link at the time) I and everyone else is left to their own devices, when really it should be important to have an eyetest once a year, but no-one has told me this, and I would have to pay for it myself, it is as if you are just prescribed the drugs and then pick up yourself any continuing tests you may need | PR | |
| | No ongoing support when living beyond cancer if long term side effects occur and GPs lack knowledge and ability to refer on - "well you've had cancer and have to live with it" | PRH | |
| | How do you use technology to help people with cancer to live at home? | R | |
| | Following my husband's diagnosis with stage 4 inoperable maxillary sinus cancer, he was on an intricate cocktail of pain medication, including morphine, pregabalin, ketamine, etc. etc. It was expected that either my husband (or in view of his confusion and extreme pain levels myself) would have the knowledge and education to take this cocktail of medication, sometimes from syringes with very small doses and huge room for error, to the extent that an overdose could very easily have occurred. What support/training for carers is available when such a detailed, complex prescription is made to control severe pain? I was given none and just expected to know what I was doing. Luckily, I was able to do this, but many would not be able to. In fact, some of the nurses in the non-cancer ward hospital setting struggled with dosages, timings, etc. | R | |
| | How do patients and families bypass existing healthcare systems to get the care they need? | R | |
| | Why are the medical profession not trained to recognise the symptoms of Pelvic radiation damage. It would save the NHS money as patients would not be put through unnecessary expensive tests. | R | |
| | Does nurse led follow up improve quality of life for patients? | RH | |
| | What is the economic impact of self-management on the patient; primary care; secondary/tertiary care? (including open access telephone and nurse-led clinics) | RH | |
| | Why can't hospitals and GPs work more closely together to ensure e.g. successful medicines management? | RH | |
| | Formalised survivorship care programmes | RH | |
| | What is the best way for primary care colleagues to support people living with cancer or beyond cancer? | RH | |
| | What support is available in primary care for managing long term conditions affected by cancer? | RH | |
| | Should there be a specialist nurse to support recovery? With the growing number of cases and CNS's pulled out already with new cases (and this will rise), should there be an interim type of specialist nurse - between "remission" and "palliative care"? | RH | |
| | Once under the care of an Oncologist / Breast Care Surgeon and subsequently discharged, why does the referral for any further concerns / problems have to be back via the GP? | U | |
| | Value of proactively monitoring for hypothyroidism arising from radiotherapy in the year after treatment ends. Several researchers highlight a 40% rate of hypothyroidism. Two thirds of those affected will suffer depressive symptoms as well as physical manifestations of hypothyroidism. | H | |
| | I have heart failure from Adriamycin (probably, but not Herceptin which I had to stop after 5 when an Echo was done) which showed up one year on. I am now 8.5 years on (and doing well). What are we doing to stop patients getting heart failure now (the questions, and weighing were a bit random in my case, and I didn't have an Echo before Herceptin). | P | |

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| | Screening post primary cancer treatment - how can screening for late effects be implemented by existing technology or new? Particularly thinking heart problems. | P | |
| | What is the best way of following up people after treatment for cancer. How can we best ensure we detect recurrence in a timely manner, address concerns and long term toxicity without increasing anxiety, falsely reassuring or raising expectations all within increasingly stretched health care resources? | H | |
| | What is the optimum management of cardiovascular/cerebrovascular risk in patients with cranial/craniospinal/neck radiotherapy? | H | |
| | How do we identify whether long term cancer survivors are at significant additional risk of further health problems as a result of previous cancer treatments. | P | |
| | What additional monitoring should be put in place to mitigate any increased risks posed to long term cancer survivors? | P | |
| | What is the most effective way of monitoring patients for late effects of radiotherapy? | P | |
| | How should the health services monitor and support patients living with long term side effects | | |
| | What is the best way to monitor patients who have received treatment for thyroid cancer? | H | |
| | I had whipple surgery for pancreatic cancer 7 years ago. There is no protocol for monitoring beyond the 5 year scans. I would like to see a protocol adopted as this is drastic surgery changing the digestive system permanently. I would like to see monitoring for deficiencies before these arise. My gp cannot order them. Monitoring regularly glucose and iron levels both maybe affected longer term by the surgery. | P | |
| | Should there be screening for lymphoedema pre and post breast or pelvic cancers? | RH | |
| | What screening will occur after treatment on a national basis. | P | |
| | After having a cancer diagnosis and treatment sometimes patients can suffer with depression and this can come out many years after the treatment has stopped - what is being done to monitor the mental health well being of cancer patients | P | |
| | Also, one Trust might routinely screen cancer patients for osteoporosis (for example), a side effect of treatment; the adjacent Trust does not. | P | |
| | A known side effect of an oesophagectomy is the risk of vitamin D and B deficiency as well as iron and zinc deficiency. Despite this after care does not include routine blood tests for these problems. Nor are you given either advice by all hospitals or supplements. | P | |
| | Why don't we screen for treatment related lung cancer? Screening is already in place for breast cancer, but not for lung cancer. Screening for lung cancer using low dose CT has recently been shown to be cost effective in the general smoking/ex smoker population, and this question should now be tested in groups who don't feature in the population risk models due to a lack of smoking but are nevertheless at increased risk due to previous cancer treatment with thoracic radiotherapy and/or chemotherapy. The risk of treatment-related lung cancer is multiplied in patients who smoke, and this group in particular warrants urgent research to establish a role for lung cancer screening. | H | |
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| | At the end of active treatment for breast cancer I feel that there is no one who specifically keeps an eye on me as a whole. I go for yearly mammograms but don't see the oncologist at all. If I have concerns I go to GP first who then refers me if he thinks it's necessary. E.g. At the moment I suspect I have developed lymphoedema in my arm. I wish we could have a yearly all round check up alongside the mammogram. | P | |
| | Should all head and neck cancer patients be screened repeatedly for psychological distress? | H | |
| | How should we screen patients treated with anti-cancer therapies for future risk of cardiac disease | H | |
| | Should we have more check ups after chemo? Not seen mine since before last chemo session over a year ago! | P | |
| | How do we go about developing a protocol for regular monitoring of the rare group of survivors of the massive surgery for pancreatic cancer...there seems to be no organised system for making sure that our nutritional needs are met..eg vitamins.. calcium supplements.. regular blood checks for essential minerals etc...this must also be true for other survivors of stomach / oesophageal cancer. | PR | |
| 2. How can patients and carers be appropriately informed of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices? | Following Treatment for Prostate Cancer I have been left impotent. Fortunately at my age this is not a problem, but for younger men it may be of major importance. My attitude and that of my wife is that as long as the cancer has been stopped it is a price worth paying. | P | |
| | How well informed are patients of the potential long term effects of treatments for cancer? | H | |
| | Why is it not really recognised as an illness as most doctors say before radiation treatment there is not that many side effects yet I suffered from day 1 of radiation to the point where I wanted it to stop. | P | |
| | Now I have what doctors call radiation burn bowel and bladder are narcotic so surely these are common symptoms of side effects of radiation yet you not told this before treatment you given a list of side effects for chemo and none for radiation when it's clearly damaging to the pelvic area. | P | |
| | Over forty years ago I had radiotherapy for testicular cancer, and no one mentioned Radiation-Induced Lumbosacral Plexopathy. I am led to believe that even today this is still the case. Why? | P | |
| | Who is going to really tell me the truth about the after effects of cancer treatment? | P | |
| | Information given to patients during or after treatment about possible long term side effects & how to manage them with treatment options & where to go for help | P | |
| | Would more time to talk through the implications of cancer treatment have altered treatment decisions? | H | |
| | Is the 'quality of life' following cancer treatment what patient's had been lead to expect? | H | |
| | regarding long term side effects: were you suitably prepared and warned of the long term effects of treatment? | H | |
| | Did you worry about the long term effects of treatment at the time you received your diagnosis? | H | |

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| | Were you concerned about the possible long term effects of treatment whilst receiving treatment? | H | |
| | If you were /or had been aware of the possible long term effects of treatment ,would you still have accepted treatment ? | H | |
| | the theory of living with is great- reality and resources are completely different. | U | |
| | Why is there not more information given to patients before they undergo treatment about the possible long term side effects. How can patients give informed consent to treatment if they are not told all the facts? | P | |
| | Whilst the treatment and information are clear their should be more details of the respective side affects associated with the various actions | P | |
| | Why were we not told about possible side effects of Chemo and Radiotherapy beforehand? | PR | |
| | Why are the side affects not talked about in more detail | P | |
| | How the NHS deals with the risk, and explains the risk of adjunct therapies e.g. radiotherapy and chemotherapy to patients | P | |
| | Why don't doctors tell you what could happen after radiation | P | |
| | I have no vagina due to radiation damage and I was only 32 when it happened , it has ruined every relationship I've been in . So I think it's important to find a less invasive procedure especially for really young female's who still have their whole lives ahead of them . when I had cervical cancer no one told me that this could happen. So for the sake of all other ladies out there please could you consider this in your research ? | P | |
| | more honest answers when the patient asks questions about their medical problems left by chemo, | P | |
| | More explanations of the after effects of treatment ,especially the late effects | P | |
| | Where you made fully aware of the side effects of your treatment before you started treatment | P | |
| | Why are patients not given information about radiotherapy side effects and that many people suffer from them to differing degrees? | P | |
| | What is it that changes, psychologically, when someone finds it possible to accept their cancer diagnosis and become orientated into a position of self-efficacy and hope? What factors bring this about? | H | |
| | I'm also have arthritis, it's been brought on by the chemo, as a side effect it was not mentioned at the start of my diagnosis, will more explanation on treatments be disclosed to patients at the start of treatments? | P | |
| | How might patients be better informed about long term toxicity effects of their cancer treatment, | O | |
| | Are we as health professionals giving patients enough information about the long term side effects of cancer treatments to enable them to make and informed decision around what treatment they have to treat their cancer? i.e. Do patients say "If someone had told me this would happen I wouldn't have had the treatment". | H | |
| | Giving cancer patients feedback on what to expect during treatment. | P | |
| | What to expect in relation to long term side effects of treatments and procedures. | P | |
| | I believe that emphasis should be made by the consultants on the possible side effects of RP and issues that may be experienced with incontinence and ED. | P | |
| | How do you decide - quality of life v's quantity of life when prescribing treatment? | R | |
| | What consideration is given to the impact on partners / families when treatment such as hormone therapy is given to cancer patients? | R | |
| | What influenced your decision to opt for the type of cancer therapy you chose? | H | |
| | Are the possible long term effects of treatment made clear to you when treatment decisions were being made? | H | |
| | What treatments may have been declined if the long term/ late effects were spelt out more clearly | H | |
| | Why aren't hysterectomy patients warned or educated more about prolapse? | PR | |
| | One of the biggest things for me was the early onset of the menopause, following my first chemo regime at age 37. It was never discussed, not actually mentioned as a side effect, and rarely re-visited since. | P | |
| | Why was depression never mentioned in the side effects. | P | |
| | Do women/people really give fully informed consent to chemoradiation treatment for cancers affecting the pelvis - my specific concern is treatment for anal cancer, given the huge 'lifestyle' impact on sexuality and bowel (and bladder) function? | P | |
| | When offered a Clinical trial at the start of a diagnosis should we not be told the long term side effects | PR | |
| | Why aren't the long term effects of reconstruction properly explained. | P | |
| | Why do we get neuropathy and why isnt more said about it during treatment? | P | |
| | For many patients with advanced cancers there are treatments available (such as chemotherapy or newer drugs) which have marginal benefits but potentially major impacts on quality of life. To what extent do patients feel they receive a balanced choice including 'no drugs'? To what extent do patients regret their decisions in this regard? | H | |
| | How do these regrets differ from those of family members? (who often influence the patient's decision when faced with choice). | H | |
| | How to properly balance the long term risks of cancer treatment that persist beyond cancer against the benefits of treatments to the time of cancer? i.e. Individualised decision making about management at diagnosis with attention on survival. | H | |
| | Why do the drs never give you the full information of all side effects and let u experience them and report back? | P | |
| | Do patients regret treatments when they are cured but left with the long-term side-effects | H | |
| | Communication between Dr and Patient - an anthropological approach | H | |
| | Should oncologists and multi disciplinary health care teams have formal communication training | P | |
| | What are the best ways to explore with patients letting go of futile treatments and enjoying quality of life? | H | |

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| | How can information services on various types of cancer that are available be improved to meet the needs of people with particular types of cancer? Linked to this is the need for good accessibility. Also needs to be informative that takes out the unnecessary medical jargon and can empower people appropriately. (This was why former charity CancerBackup was set up.) | P | |
| | Whether it is preferable to map out all treatment options for cancer patients or just discuss one step at a time. | P | |
| | What information do Teenager and Young Adult survivors of childhood cancer want included in their treatment summaries and Long Term Follow Up care plans and when do they want receive this information? | H | |
| | When do you think is the best time to receive such information? by who? and in what format? | H | |
| | how does communication across medical and other professionals impact or not on someones cancer experience. how can we improve across professional communication | H | |
| | At what point is it right to tell patients the positive benefits of supportive care as opposed to treatment and who decides? | P | |
| | How should the potential impacts of treatments on cancer patients and their families be communicated? | P | |
| | Does routine sharing of results with the patient, help or hinder the healing process? | P | |
| | WHY ARE DOCTORS STILL SO POOR AT COMMUNICATING EFFECTIVELY/ | PRH | |
| | Would the offer of continued information and education be beneficial in the first year of receiving a cancer diagnosis? | H | |
| | What are the most effective ways of letting people living with or beyond cancer know what support is available to them? | H | |
| | How can we best prepare patients for Late and long term effects of cancer and it's treatment without exacerbating anxiety about the future? How do we give them the awareness of what is "normal" in terms of physical health? | H | |
| | What is the best way to advise cancer patients that continuing treatment (e.g. chemotherapy) is not in their best interests? | H | |
| | How can the NHS provide better information to patients about living - hopefully long term - after hospital cancer treatment has finished? | P | |
| | are patients happy to receive cancer specific information about their stage/ treatment/ management plans | H | |
| | How to properly deliver post-treatment information? There are leaflets (but sometimes patients don't read them) and there are health&well-being events (but sometimes patients aren't able to attend them), but there does not seem to be an ideal "tool" to deliver information. | O | |
| | On receiving a diagnosis of cancer how are the options for treatment discussed with the patient and how long are they given to consider these? | P | |
| | How best to impart the diagnosis and prognosis - both to the patient and to the relatives. | P | |
| | What are the lived experiences of people with cancer from diagnosis to treatment and how can communication by medical staff be improved? | H | |
| | When is the 'right' time to give information to patients and families affected by cancer to ensure they don't slip through the net and don't get any support, which can happen | U | |
| | How to communicate the on going effects of a cancer, diagnosis and it's treatment when the active treatment phase is completed to manage the expectations of family, employers etc. during the recovery phase | H | |
| | Patients still don't know how much activity they should do during and post treatment - we run prehab and rehab sessions and this is always a revelation - leaflets don't get read! | H | |
| | Patients need more than a leaflet when being advised about the impact of the diagnosis on relationships - again this could be short and sweet. I have been in Canada where they do a consultation that hits all key points - this is what I now do on a Living well through your treatment day - we look at cognition, emotional impact, exercise, activity, intimacy etc - its a short intervention but all patients say they wish they had had it sooner | H | |
| | It's important to have rapid and clear information about your cancer and the treatment proposed. Shock and confusion means this information may need repeating. | P | |
| | Effective communication and provision of clear, honest, comprehensible information is still a recurring problem in the context of both active cancer treatment and LWBC. What can be done to address this ? | P | |
| | Are Cancer Patients at the point of diagnosis sometimes overwhelmed with too much information that is given at that time? | O | |
| | After a very successful laryngectomy by a marvelous surgeon. Followed by tip top post op and recovery nursing. All I wanted to do was get home . Later of course the specialist nurse explained that I had had a TEP. inserted. But then there are so many questions that you think of, so you start googling every different support sites . some helpful, some would probably make things worse . my question is could there be more information on the various aspects of care before or after the operation? | P | |
| | Working out when and how best to tell other people about the diagnosis. There were really very few resources available to help us sort out our communication needs. We spent a lot of time trying to manage the impact on them whilst we were dealing with the impact on us. | R | |
| | Why is there no honest conversation about cancer? From health specialists, to family, to social network, the communication is crippled by taboos. It leaves everyone in the dark. The patient cannot express their true feelings as they might offend the carers. The carers have to stay strong and positive regardless, sometimes ignore the elephant in the room, with the only result that the patient sometimes feels like in an absurd film. Medical staff is overwhelmed and overworked. Care, especially psychological and emotional, is so fragmented and discontinuous that one has to repeat the same excruciating story again and again. If lack of resources is the main reason, perhaps this should be the very first honest conversation to be had about cancer, and the rest will follow. And if the prospect of one in two people affected by cancer is so close, perhaps the honest conversation should start with let's stop saving everyone, despite long-term terrible consequences. | PH | |

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| | I think one of the biggest issues for me in moving on / living with, having had cancer was/is confidence in the future. I have managed to find things through Macmillan to help but I did most of the seeking help myself. I feel research is still needed into how best to inform patients of the mental effects cancer and its treatment has and where to get help. I feel the physical effects were fantastically well dealt with but the psychological effects come along later when you are no longer seeing 'professionals' so regularly | PR | |
| | How can information relating to available services be reliably provided for elderly people and their carers with a terminal diagnosis? | PR | |
| | How can we do better to provide easily accessible information about practical matters (e.g. finances, help for those with a caring role, getting back to work) both for the individual and for their family or friends after a cancer diagnosis? | H | |
| | Late consequences What are the best ways of preparing patients for the risks of developing late consequences of anti-cancer treatments, such as post-surgical pain; endocrine and metabolic changes; longterm bowel complications following radiotherapy? | H | |
| | Can we train surgeons (and indeed other health care professionals) to be better at communicating risk in relation to possible outcomes (both for quality of life and for long term survival) and if so does that change choices patients make about surgery (or other treatments) that can impact their quality of life later on? Indeed do we even know the current 'real' practice in this regard vs what is meant to happen or is considered best practice. Not all patients want to be alive at any cost and some may be denied the chance to make an informed choice. | R | |
| 3. How can care be better co-ordinated for people living with and beyond cancer who have complex needs (with more than one health problem or receiving care from more than one specialty)? | How people are treated by other specialties eg asthma/ breathing clinic. I am now seen by many other specialties, not directly related to my cancer and they almost never consider my years of treatment, side effects or psychological effects. They focus exclusively on their area. Also almost never read my notes. | P | |
| | Multimorbidity and polypharmacy in cancer patients - does the oncology pharmacist have a role? | H | |
| | As someone who supports those with Learning Difficulties in the community in the county in which I live I would like to know what additional support is or can be provided to those with Learning Difficulties, pre and post diagnosis/treatment, to ensure that they can make their own fully informed decisions as far as possible about the treatment/support they receive? | PR | |
| | Ask a patient about their general health and other serious conditions they may have and actually be worried more by that medical condition and the after effects of chemo may have on the other medical condition. | P | |
| | How should people with multiple health conditions including cancer (either as a chronic condition or in disease free survival, not at end stage) be best assessed and managed by health and social care services in order to provide best supportive care within a very tight financial environment for those who need it most? | HR | |
| | How do I manage my cancer alongside my other health conditions? | H | |
| | One person who can advise me on options to get better. At the moment I get advice from my Consultant, my GP, the Outlook team, nurses, charities, but it would be better if there was one person who is the focal point. They may not have all the answers but it would be more efficient if they contacted the other party. | P | |
| | If the patient has other medical conditions how much cooperation and discussion takes place to bring about a holistic approach to dealing with all the needs of the patient? | P | |
| | I am living with cancer this requires me to see consultants from many disciplines. How does an involved patient who wants to play a full part in managing their conditions make sense of often confusing and sometimes opposing views expressed by different consultants? I am forming the view that treatment is as much art as science. I feel alone trying to manage my main condition whilst minimising impact on other organs or conditions and feel obliged to experiment with my various medications to limit adverse impact in other areas. This is stressful. I work as a volunteer in a cancer charity and see that my dilemma is experienced by many others. | P | |
| | How can improvement be made between oncology and urology teams for people with invasive bladder cancer eg stent changes and flexis after radiotherapy? | H | |
| | Living with complex survivorship symptoms physical and psychological. What is the best pathway to support this group? MDT, GP other | H | |
| | Why are services for people LWBC so fragmented | H | |
| | How do consultants from various disciplines (ie conditions beyond cancer) work with oncologists to optimise treatment for their patients? | R | |
| | I had Prostate Cancer 13 years ago aged 58 and got serious anxiety and depression for years after and had to retire with Ill Health. I have since aged 70 been diagnosed with ASD High Performing Asperger's. Question Is there any special Measures put in now at oncology Centres to cater for Patients with Learning Disabilities and/or Autism ? | P | |
| | What do Oncology Centres do with Patients who have a severe Mental Health illness and a Cancer diagnosis ? | P | |
| | How do we ensure people with a learning disability receive equitable support when LWBC? | H | |
| | We know there are specific LWBC long term sequelae that are unique but there are also lots overlap with other LTC and we know in our areas the %ages of patients with one or more LTC How do patients with LTC inc cancer want their care planning to be - we assume they do not want a care plan per condition how do patients see this as being practical? what do they see as CCR? or how would then envisage reviews happening | H | |
| | How can we as Allied Health Professionals demonstrate that our interventions with people are cost effective and benefit patients and family/carers due to the interdependencies involved in their interventions? | H | |
| | Ability of GPs and primary health care professionals to consider complexity of need and the way issues interact. | P | |
| | Why is there a real lack of joined up working amongst inter-disciplinary teams in hospitals that effect post cancer treatment patients particularly AML? This also applies to other cancers. | P | |
| | Why is there no link or communication between the medical professionals? This appears to be much worse when someone has a more complex case such as dementia and cancer. | R | |

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| | and if secondary cancer struck, will the newer drugs be excluded from me due to their risk of worsening the heart. Is research looking at how to give these newer drugs to people who also have heart failure should cancer return? | P | |
| 4. What causes fatigue in people living with and beyond cancer and what are the best ways to manage it? | What causes fatigue after cancer treatment? | P | Causes of fatigue – some known. |
| | Fatigue - how we can help with this | H | Spathis A, Fife K, Blackhall F, Dutton S, Bahadori R, Wharton R, O'Brien M, Stone P, Benepal T, Bates N, Wee B. Modafinil for the treatment of fatigue in lung cancer: results of a placebo-controlled, double-blind, randomized trial. <i>Journal of Clinical Oncology</i> 2014;32(18):1882-1888 |
| | Why do some people become extremely fatigued, even after their disease is in remission, and what can be done to really improve how they feel | R | |
| | I am so tired what will help? | H | |
| | What are the best methods of dealing with cancer and drug related fatigue? | PR | |
| | What is the answer for long-term fatigue and anxiety as a result of surgery and radiotherapy for head and neck patients? Previously capable and independent people lose their energy and resilience making them unable to return to their previous lifestyle. Impacts are on work and ability to earn enough money to maintain financial commitments made before cancer diagnosis. This lasts at least a year after the end of treatment and suggests long term effects of illness and treatment and medics do not appear to have any answers to this. | P | |
| | What is the best way to get through the fatigue | P | |
| | What are the best foods to eat that give you natural energy | P | |
| | What can be done to reduce the effects of fatigue during and after treatment? | P | |
| | What strategies could be developed to help manage post cancer fatigue and educate others that this is not "normal" tiredness'. For many LWBC fatigue is their most disabling symptom | PH | |
| | Why do cancer patients continue to suffer from fatigue for many years after treatment and why is chronic fatigue not recognised as a major side-effect by clinicians ? | P | |
| | What is the best care that can be given for cancer related fatigue? | H | |
| | I HAD AN OPERATION FOR BOWEL CANCER FOLLOWED BY SIX SESIONS OF CHEMOTHERAPY I FINISHED MY TREATMANT 4 MONTHS AGO I AM STILL FEELING VERY TIRED JUST WONDERING HOW MUCH LONGER IS THIS LIKELY TO GO ON FOR?OR IS THERE ANYTHING I CAN TAKE TO HELP MY ENERGY LEVELS ?PS I HAVE HAD MY BLOODS TESTED AND THERE OKAY LOOKING FORWARD TO YOUR COMENTS | P | |
| | Is there anything, apart from exercise, which will ease the fatigue which continues years after treatment? Many people suffer and some answers from research in this matter would be good. | P | |
| | What are the various approaches to managing fatigue and what approaches suit which patients? | P | |
| | What interventions and strategies are most effective in reducing the impact of fatigue in cancer survivors | H | |
| | Managing post cancer fatigue - how to improve this ? | PH | |
| | What nutritional factors have an impact in post cancer fatigue? | PH | |
| | How to manage post treatment fatigue which is extremely debilitating and impacts on employment and other activity. | P | |
| | Post chemo (even several years after) are people's energy levels affected compared to the general population and what can be done to improve this if so? (Does exercise or diet help)? | P | |
| | Strategy to tackle post-treatment issues that are not "medical" but significantly impact on patients QoL eg fatigue. A better defined treatment strategy would be great or option to enrol in a trial of different techniques/approaches. | H | |
| | How can I minimise the effects of fatigue | H | |
| | Is there any way to watch the onset of severe long term fatigue before it happens? | P | |
| | What strategies and coping mechanisms are available to people living with cancer and beyond regarding managing their fatigue after cancer treatment? | H | |
| | How can I manage the long term effects such as prolonged fatigue | H | |
| | How to deal with long term fatigue post chemo | P | |
| | What are the contributory causes of chronic cancer-related fatigue after treatment ? (Does a compromised immune system after chemo result in successive minor infections which require all the body's resources, resulting in energy depletion ?) | P | |
| | One of my problems is tiredness. Are there any vitamin treatments or supplements that will combat that ? | P | |
| | Many new treatments have evolved yet I am still very tired all the time. If treatment is available to relieve this why is it not offered? | P | |
| | Why does exercise help fight fatigue in the speed of recovery? | P | |
| | How can I increase my energy levels when I am tired all the time yet suffer from being unable to sleep? | P | |
| | Management of fatigue | U | |
| | How can fatigue be best managed | H | |
| | How to deal with fatigue in remission | P | |
| | What are the most effective psychological interventions for patients with long term fatigue and depression? | H | |
| | Fatigue persisting many years after treatment | R | |
| | Fatigue, following cancer treatment, is very debilitating and can have an impact on people's lives for a very long time after their treatment ends. What is research doing to combat this to enable people to return to 'normal' as swiftly as possible? | H | |
| | What can I do about my utter exhaustion, this really affects my life. | P | |
| | How to deal with and beat chronic fatigue. | P | |
| | Reason behind cancer fatigue? | H | |
| | What are the most effective ways to combat post -chemotherapy fatigue? | P | |
| | How does one cope best with long term side effects, e.g fatigue, changed body shape etc | P | |
| | Tiredness/stamina - Although I was treated for Bowel Cancer nearly 10 years ago and didn't need Chemo I never regained the stamina I had (thought I had) previously. I still quite often get a sudden drop in energy where I need to sit down for a few moments. | P | |

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| | is there more that can be done to manage fatigue when I've been given a cancer diagnosis? | R | |
| | He suffers severe fatigue some days and can hardly function how can this be helped. | R | |
| | What are the most effective ways of dealing with the effects of fatigue from cancer treatment? | H | |
| | Some days my fatigue is that bad I cant leave my house | P | |
| | Coping with symptoms like fatigue. Should I do sport. | H | |
| | Why does lethargy continue even when treatment has ended years before? | PR | |
| | How to manage side effects such as fatigue to provide the best quality of life? | P | |
| | What is the most effective way(s) of managing post cancer fatigue ? | P | |
| | fatigue - the mechanism for this when all avenues explored and exhausted for some, energy is never the same again, even if a long time from treatment and they are cured | H | |
| | how do I manage fatigue?, how can I get people to really understand what this is like? what interventions are effective for fatigue? | PRH | |
| | Ever since my cancer treatment (over a period 5 years, ending 12 years ago) I have never regained the same energy levels despite following all national guidance about diet, exercise etc. I cannot remember not being at least a little bit tired at all since then. | P | |
| | What is the cause of cancer related fatigue? | RH | |
| | How effective is fatigue management for palliative patients | H | |
| | Cancer Related Fatigue, is not well documented but is a real and debilitating side effect of cancer treatment. What advice or remedies are out there | P | |
| | How do I cope with Cancer Related Fatigue when exercise is given as a help method but it is limited because of other problems, example, I now find that due to osteoporosis exercise is difficult and not advised. | P | |
| | Morbidity of fatigue post radiotherapy | H | |
| | Why is fatigue so often reported and experienced after cancer treatment? | P | |
| | How can we better understand the causes of fatigue and provide better strategies or treatments to cope with it? | P | |
| | Fatigue is greater after cancer treatment, what can help patients and is there more information | R | |
| | Fatigue when working - is there anything I can do to either prevent it, predict it or manage it better? - exercise - diet - "pick me ups"? | P | |
| | How long fatigue lasts and useful management strategies | H | |
| | How should fatigue be helped? | H | |
| | management of fatigue / sleep disturbance | H | |
| | What is the best treatment for fatigue, when going through treatment for cancer and when completed treatment. | H | |
| 5. What are the short-term and long-term psychological impacts of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families? | Who is a patients first point of contact after their treatment has finished? | H | |
| | What psychological support helps people and their carers transition to living with cancer. | R | |
| | When treatment ended I felt dumped by the healthcare system. How can patients be supported in getting back into their lives after treatment without feeling unsupported? | H | |
| | Following the completion of treatment, how many patients feel cast adrift and isolated, as the regular contact with health professionals drops off to some degree? | P | |
| | How does ending of treatment effect expectations of survivors | P | |
| | What is the most effective way of supporting cancer patients post hospital discharge? | H | |
| | Effect of lack of support after treatment in overall health | P | |
| | Is there any organisation that can provide support and information after treatment stage before you go out into the world on your own? | P | |
| | What support services are the most important to patients and their families in the 6 months post treatment? | H | |
| | Will you set up an ongoing contact person for patients as they stop their treatment , radiotherapy or chemotherapy? At present it's like being pushed out into the cold ,there is a sense of safety while undergoing treatment , if a single person was responsible for contacting the patient once a fortnight to follow up it would give a security now absent | P | |
| | Why still patients diagnosed with cancer feel abandoned after finishing active treatment? | H | |
| | How can UK support people and their carers through investigation diagnosis and treatment without them feeling abandoned at the end of active treatment. Hospices Often left to pick up the pieces | RH | |
| | NHS successfully treated my cancer but I had to seek out emotional support and help myself. I didnt do this until after my treatment had finished but actually it would have helped me earlier on. Why dont Oncologists tell us about the benefits of complementary therapies. It will save NHS having to deal with mental health problems later on. | P | |
| | The psychological effect of living with cancer particularly once regular treatment has stopped | R | |
| | How to reduce dependency on health service resources and 'victim mentality' in people who are cured of cancer | H | |
| | What support is needed/would be effective for those who have had cancer but been discharged after their 2/5/10 year follow up with respect to their mental wellbeing. | P | |
| | Can they move on | R | |
| | What is the best way to support patients psychologically finishing treatment for cancer? | H | |
| | How to cope with the period after the treatment is finished and the "clear all" has been given. It feels as if professional support has been withdrawn but you still feel vulnerable and anxious. Everyone thinks you should feel great but depression kicks in and it's hard to get back to normal life. You don't want your life to be defined by your cancer but you can't ignore it either. | RH | |
| | Where to find support once treatment ends without feeling that you are still in the cancer bubble? | P | |
| | What interventions would help people coming to the end of treatment prepare for adjusting to life with and beyond cancer? | H | |

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| | How best to support people in the transition period after treatment ends and beyond | H | |
| | Do patients feel able to attend their GP following a cancer diagnosis and at end of treatment? | H | |
| | What are the best methods to support someone post surgery/treatment? | R | |
| | When I was having chemo from CLL I got lots of support, in case I needed so did my support network, I am still struggling with this lack of support six months after chemo ended | P | |
| | Is there an NHS support for post-chemo patients? | P | |
| | Does access to ongoing psychosocial support reduce A&E and GP visits by patients finishing hospital treatment for cancer. | P | |
| | Why are we abandoned after 5 years, no Tamoxifen, follow up or anything | P | |
| | Being diagnosed and treated for cancer is a journey. It relies on the trust of the medical team. That relationship comes to an end and it is a double grief process. There is a loss due to the cancer and the loss of professional support. How do people deal with this? | PRH | |
| | When you finish your treatment (after 10 years of anti-hormone therapy/chemotherapy drugs), what support is given? | P | |
| | At the moment, cancer treatment feels as if you are on a conveyor belt. When active treatment ends, it seems as if you fall off the belt and there is a huge void and you are left alone with no support. Can things be improved for those living beyond cancer at that stage? | P | |
| | also between PTSD and living beyond cancer when treatment has finished. | P | |
| | How can people understand and engage with the notion of self-management without feeling abandoned by services or feeling that self-management is a cheaper option | H | |
| | Why is it that once you are in remission you feel as if you are left totally alone with this big weight on your shoulders. | P | |
| | How can health professionals help patients to navigate the transition from active treatment to recovery? | P | |
| | Why is there no psychological support, as in counselling after treatment has ended, in order to adjust to life after cancer? | P | |
| | How and when to access emotional support? Sometimes you don't realise that you are struggling mentally, it can hit months and years after diagnosis. I found the hardest time was after treatment had finished when all my friends and family thought I should be back to normal I no longer knew what was normal. | PR | |
| | It's important to have rapid and clear information about your cancer and the treatment proposed. Shock and confusion means this information may need repeating. After treatment, in my case chemotherapy, there remain many questions. Support is not so intense, there is a feeling of being cast adrift. How can the health service best provide links to support groups that will continue to inform patients beyond treatment? | P | |
| | Long term effects of treatment. Had both chemo and radiotherapy for 3 different cancers. Once treatment is over you are relieved but then you need support. It might be emotional support but it seems to be in short supply. | P | |
| | Information on recovering from operation, diet etc it all faded away apart from regular (6 months) appointment with consultants | P | |
| | Why are you left in limbo once your treatment and follow ups end. | P | |
| | How best do we facilitate / support people living with cancer or beyond cancer when they move from 'active' follow up to detect recurrence & morbidity, to the 'beyond cancer' phase? | RH | |
| | patients undergoing radiotherapy (RT) become accustomed to having daily support from their radiographers. At the end of treatment there is then a 'black hole' where there may be no specific support available from radiotherapy professionals and when side effects will be at their peak. How can patients be better supported during this period between end of treatment and start of follow up? | H | |
| | A month later after treatment has been completed why doesn't the patient have contact from a medical professional as this is when it hits most of us. | PR | |
| | What happens when the treatment stops? | RH | |
| | As a healthcare professional (within radiotherapy) having ways to sign post patients for additional support post treatment would be useful and to have ways of advising patients as they complete their treatment | H | |
| | Did you feel you had somewhere to go with worries after you were discharged following cancer treatment? | RH | |
| | I've been taking adjuvant Tamoxifen for 9 years and due to end next year. After having this 'safety blanket' with me for so long what can I expect in terms of psychological effects? | P | |
| | Feeling alone and weak after treatment stops | P | |
| | Living with long-term and late effects (see Treanor et al. (2014) for a rapid review). Often there is a lot of support during diagnosis and treatment from healthcare staff and people with cancer are left to actively seek support after treatment which is usually from other sources that are not situated in the health care system. This support is often provided by advocacy or charity organisations. | H | |
| | What level of psychological support do patients feel they need after finishing treatment. (example) | P | |
| | What support/services do you feel you would have benefitted from within 3 months post treatment? | P | |
| | What happens after 5 year follow up? Till, this date you are monitored, then nothing, this is when you need the support more | P | |
| | How much support is there as there is plenty before treatment | P | |
| | Qualitative look at the transition period between curative and palliative treatment or active treatment then being cured and how this affects people | H | |
| | Once off the hospital conveyor belt I felt there was nowhere to turn for reassurance | P | |
| | What are the areas that men with prostate cancer feel unprepared/ unsupported in when living with and beyond prostate cancer? | H | |
| | How do people regain their social life following treatment and avoid feeling isolated. Cancer experience does open up new social groups, amongst fellow cancer survivors but people often find it difficult to socialise with those who have not had the same experience. When the cancer experience is so all-consuming, you can end up with little in common with those who have not had the same experience. | P | |
| | What is the psychological morbidity of these patients? | PH | |

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| | The psychological impact on patients and how it affects their decision making when deciding treatment and holistic care | O | |
| | The psychological impact on patients and how it affects their long term decision making | O | |
| | What is the psychological impact for patients and relatives living with a cancer diagnosis in terms of how their coping mechanisms change and the impact on their life in general. As a professional is there an alternative way of working with this group of patients from the newly diagnosed group. | RH | |
| | Why do I feel guilty? | P | |
| | How we can help people move on from thinking of themselves as a cancer survivor and getting a new normal | PH | |
| | What is the emotional impact of chronic symptoms related to cancer treatment? | RH | |
| | How long is one a survivor before one become a 'normal' persons again? | P | |
| | How does diagnosis setting effect quality of life | P | |
| | What psychological support can be offered to patients even 5+ years on, re relationship impact (all relationships - daily, friends, colleagues, significant other etc) - not exclusive to those living alone. People can still be isolated emotionally even if living with others... often not recognised.... as people expect patients to 'be over that by now' and 'getting on with life' | P | |
| | What is the long term psychological impact of cancer on patients LWBC greater than 10 years post diagnosis? | H | |
| | What emotional/ psychological changes have you experienced since your diagnosis? | O CHARITY | |
| | When do cancer patients and their families feel most vulnerable, immediately finishing treatment, 6 months post treatment or 2 years on..... | H | |
| | WHAT ARE THE LONG TERM EFFECTS PSYCHOLOGICALLY FOR THOSE LIVING WITH STAGE 4 CANCER? | H | |
| | How are the psychosocial consequences of undergoing appearance changes associated with cancer treatment? | H | |
| | The psychological well being of living with body dysmorphia after major abdominal surgery and having a stoma in place is horrendous not only for the patient but dealing with is fear by the wife or partner puts a strain on the relationship why are they not better prepared? | RH | |
| | Psychosocial outcomes of immediate breast reconstruction in comparison delayed breast reconstruction following mastectomy for cancer. | H | |
| | Psychological effects of survival | H | |
| | What are the psychosocial long term effects for people following a cancer diagnosis | H | |
| | How will my mental state be affected | P | |
| | How does a cancer diagnosis impact upon long term mental health. | H | |
| | What are the long-term consequences for illness recovery / progression / recurrence of poor psychological wellbeing during cancer treatment? | H | |
| | What are the common longterm psychological effects of a cancer diagnosis? I ask this as a Burkitt lymphoma survivor and Psychotherapist, as I see various reactions in practice | P | |
| | How has coping with the long term side effects of radiation treatment for cancer affected your mental health and well being? | P | |
| | How has a cancer diagnosis affected the person's mental well being? | PR | |
| | What alternative therapies are helpful in dealing with psychological impact of being told you have a slow growing cancer such as cil and dealing with the watchful waiting approach. | P | |
| | What are the major differences in coping mechanisms with people who require treatment immediately v people who are put on a watch and wait approach? | P | |
| | What is the psychological impact of being on "watch and wait" on those with cancer? | P | |
| | What are the on going psychosocial consequences of treatment for thyroid cancer? | H | |
| | How mentally competent they feel in leading life after cancer treatment | H | |
| | Is it ever possible to 'go back to normal'? We are told to 'go about your normal life' - does anyone understand how impossible that is? | RH | |
| | Consequences on 'normal life'. Moving on and being seen as yourself rather than a Cancer Patient For example, condition may be well managed but getting health insurance for travel is more complicated and costly. | P | |
| | Will I ever return to the way I was before I had cancer - or do I just have to appreciate my limitations and get used to the 'new' (post cancer) me? | P | |
| | What is the difference in psychological impact in being told things during diagnosis and treatment that turn out to be untrue or change vs not being told anything unless definite. For instance I was told at diagnosis I would have chemo and if that was successful would have conservative surgery (lumpectomy/WLE) or if not successful a mastectomy but could have immediate reconstruction. I found out (incidentally) 3 months later part way through chemo that although my chemo was wholly successful but that I would have to have a mastectomy with no immediate reconstruction. I still feel misled and it undermined my confidence in my clinicians and sent me into a spiral of despair. | P | |
| | Overcoming a sense of guilt having survived a full cancer experience and reconciling against those that did not win. | P | |
| | how is it best to manage feelings of failure, exclusion and disappointment at other people's inevitable lack of understanding when you feel you have to manage your life differently after cancer diagnosis and treatment? | P | |
| | What are the long term psychological effects of surviving cancer? | P | |
| | How does a patient live with the fact that his prostate cancer was left undiagnosed until it became advanced and spread outside the prostate because of the lack of knowledge and training by the GP's | R | |
| | Survival guilt. | P | |

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| | Why the focus on living with cancer and beyond? We are moving towards a majority of people living with a cancer diagnosis. Whilst accepting that there will be some people who will require on-going support following e.g. disfiguring surgery, please can progress towards disabling people with a cancer diagnosis cease. I have lived with a cancer diagnosis for 25 years. I am a healthcare professional. I am also an academic with expertise in cancer care. Having cancer is 'normal' for me. Few people know about my diagnosis. I accommodate the long-term effects within my daily life, consider them trivial and would be surprised if others are aware. Having a child impacts the rest of life there after, but it doesn't result in life-time support other than for a small minority. So, I suggest a research question such as 'what is the profile of someone diagnosed with cancer who will have support needs arising from diagnosis, disease and treatment five years into survivorship?' | PH | |
| | what is the psychological effect on having cancer in the following years after treatment. How does that differ between disease sites and are there any similarities. | H | |
| | How do you adjust to changed life and capacity, for example, if less physically able - what psychological processes help people come to terms with this and make successful adjustment, to enable them to live life in a meaningful and valued way? | H | |
| | The psychological impact of treatment. | H | |
| | The psychological impact of successful / unsuccessful treatment. | H | |
| | The mental health effects | RH | |
| | How much are the emotional effects of a cancer diagnosis recognised and talked about with patients prior to their ending treatment, or is the focus solely on the physical and is this helpful | U | |
| | In the future will there be more research into the effects cancer has on a person both psychologically and emotionally | P | |
| | Is there any way to really prepare people for the realities of life after Cancer? I managed OK during treatment, and in the "recovery" and "recuperation" phase, but now 2 years after treatment I don't seem to be able to make any more progress. The fear and anxiety of a recurrence are worse, my fatigue hasn't gone away, although it occurs less often, the side effects of the active treatment and the side effects of hormonal treatment are now an everyday part of life. The more I read the more I realise that this seems to be the norm for most women post breast cancer (and other cancer) treatment. Everything is so different, and it is so hard to get used to, and most of us thought that once treatment was over, given a bit of time and rest and recuperation, we would be almost back to our usual selves. It's like aging 20 years in 1 year, and the impact of that isn't something that is dealt with. Sorry that's a bit long winded! I don't know how else to explain though! | PH | |
| | More research and understanding into the long term impact on people's mental health and how this can best be supported. | H | |
| | Being 35 at diagnosis I feel like a stranger to myself now, yet I am expected by everyone to be positive that I have survived, well it's just that I survived ... I don't feel like I am living, I feel anxious, scared, I am stuck with a strangers body, and I have been told that despite being diagnosed bi-lateral stage 3 grade 3 aggressive triple negative breast cancer & BRCA1 positive ... Moving forward I will not have any routine scans to check for any signs of secondaries..... Why are CT scans or mri scans not offered to patients post treatment? Surely it cannot be my sole responsibility to just worry about new symptoms? But not given any general info on what I'm looking for? | P | |
| | When will the medical profession realise the psychological affect on cancer patients? It is this side that has the longest effect with very little support or knowledge | P | |
| | In the long term affecting attempts at forming some social life because nervous of going out | P | |
| | How do you stop that 'raw door' opening even years after your treatment? There are some events, things said or an experience that brings the more challenging and negative aspects of having experienced a cancer diagnosis and its treatment flooding back into your mind. As I get older I am finding these thoughts about negative experiences sometimes even more upsetting. I find this quite strange as I would have thought the years would have 'softened' the memories. | PRH | |
| | How can the medical/nursing team better recognise, understand, appreciate and acknowledge the impact of psychological and emotional wellbeing on a patient from diagnosis onwards? | H | |
| | How do you come to terms with the fact your one of just a few that have made it. | P | |
| | what are the psychological issues after a diagnosis of melanoma | H | |
| | How do I live a 'normal life' knowing the cancer is likely to come back at some stage | H | |
| | The impact on cancer survivors once all hospital treatments end is enormous. Cancer never leaves your mind, and no one is there to help, in my opinion. | P | |
| | Mental effects of having cancer | P | |
| | what are the likely mental and emotional problems encountered post operative tumour removal? | P | |
| | Should more attention and support be focused on Cancer survivors Several Cancer survivors have commented to me about the considerable difference in support at the end, or after the end of their Journey, compared to the beginning | O | |
| | Did cancer change you as a person and would you like to have a forum for support locally to your home to express these changes? | RH | |
| | How do people cope with the initial wait? There's such a awful time between diagnosis and the start of treatment or the plan for treatment, what long term impact does this have. | P | |
| | We receive a lot of questions about the emotional and psychological impact of a cancer diagnosis from women seeking support - but we don't have much data about the type of psychological difficulties women face and 'depression' is often used interchangeable with anxiety, sadness, low mood etc. Is there a way to determine the specific impact of a cancer diagnosis on women's mental health? | H | |
| | Does anyone ever really get over the diagnosis? | P | |

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| | How can we determine which patients are at greatest risk of psychological problems during and after cancer treatment, and are there interventions that can be used around the time of diagnosis, during treatment or in the early recovery period which will reduce the frequency and severity of problems experienced? | H | |
| | Things I used to find fun are now boring. What can I do to change This? Is this normal? | P | |
| | Finding a new normal | P | |
| | Role and status. Regaining and maintaining social equilibrium, issues in transcending the sick role | R | |
| | More research on the mental health affects of cancer | PR | |
| | The psychology of living long term with cancers is fascinating. We are told how to improve our lifestyles and live better but little thought or research has been undertaken on how to live with the disease long term. What are the better mind sets,? How do you ensure that you remain positive and happy? What works? What is most likely to work? What are the key influencing factors making living with cancer better psychologically.? | P | |
| | What research has been done to support survivors best? is there a country/hospital that particularly does this best and can we use their knowledge to replicate the same system here? | P | |
| | What can be done to support long term survivors? why is the system failing so many? | P | |
| | Does regular social interaction with other cancer "survivors" improve psychological, emotional and physical health? | P | |
| | whilst our Moving On Programme is well evaluated - I would like more evidence on its longer term impact on patients ability to cope with uncertainty | H | |
| | how useful are current practices to our patients-we run a Moving On Group but I would like confirmation that it is as useful as it is enjoyable -always rated well but consider the impact long term | U | |
| | Is telephone-based CBT counselling a useful service for anxiety and depression associated with cancer? | H | |
| | What role can telephone services and on-line support play in supporting PABC in this area? | H | |
| | How could we better prepare our men to live with and beyond prostate cancer? what our men think | H | |
| | What is the best kind of emotional support that should be available for those living with cancer and also for their loved ones? | PR | |
| | Could more emotional support from a carer during living with cancer be beneficial in living beyond cancer prognosis? | P | |
| | What is the impact of a strong network on living with (and after) cancer? Network can include, people, resources, activities. | P | |
| | What is the impact of mindfulness training on people with / after cancer | P | |
| | What methods of psychological support are most effective with cancer patients and carers? | H | |
| | Does mindfulness meditation help during and after treatment, and if so how? | P | |
| | What strategies are most effective for helping men deal with the emotional impact of living with cancer? | P | |
| | What kinds of wellbeing support is demonstrably effective in helping people cope in the aftermath of cancer treatment (specifically relating to those who are left with emotional scars, and who worry about recurrence, following treatment and 'all clear'. | R | |
| | What types of support can really help people living with cancer? (helpful to be based on experiences of people who have cancer rather than experts' opinions) | P | |
| | How best to support people psychologically in the months and years after treatment when the assumption is that people have 'recovered' when actually this can be the most difficult time. | P | |
| | What are the benefits of mindfulness practice for people affected by cancer? | H | |
| | Should all patients who have been in intensive care and/or had extended stays in hospital be offered psychological support? Often, when you don't really know what happened to you in ITU or were very sick, you don't want to ask your nearest and dearest in case they also find it upsetting reliving what they saw you go through. | P | |
| | What are the most effective ways of supporting women experiencing body image concerns following treatment for breast cancer? | H | |
| | What psychological support should be provided for patients experiencing appearance concerns following treatment for cancer? | H | |
| | How can men with prostate cancer with post radical prostatectomy side effects be supported psychologically? | RH | |
| | Would the provision of psychological support for men with urological cancers be accepted - and would it have benefits for ongoing quality of life? | P | |
| | How much do people affected by cancer feel talking to someone helps them with their situation? | RH | |
| | what are successful interventions to improve mental health post-cancer (i.e. many people feel a sense of 'lack of direction' after 'beating' cancer as there isn't a clear aim in their anymore) | P | |
| | Which tailored interventions and support strategies helps carers with mental health problems? | H | |
| | when should psychological therapy be offered within someone cancer journey (i.e. following diagnosis, following treatment) etc. | H | |
| | which psychological therapies are most effective for distress associated with cancer and how are psychological therapies currently being used | H | |
| | What psychological support should be available for those important to a person living beyond cancer? | H | |
| | Help with coping with the diagnosis | P | |
| | What mental support is there for early menopause brought on as a result of CLL/Chemotherapy | P | |
| | What is the effect of meditation/ visualisation techniques/ mindfulness on physiology, and what are the implications for health in the context of recovery from breast cancer (or cancer in general)? | P | |
| | What are the effects counselling on recovery after breast cancer diagnosis? | P | |
| | Why do patients with long term, incurable cancer, like Leukemia suffer worse mental health during watch and wait and how can they be helped from diagnosis even before treatment? | P | |

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| | What is the most useful psychological support for people living with cancer? | P | |
| | What is the most useful psychological support before and during oncology appointments? | P | |
| | Assessing the best support strategies; eg regular meetings or online forums or whatever | P | |
| | What is the best way to view diagnosis of cancer, this in particular regarding mentally. | P | |
| | What is the impact of relaxation & stress management interventions on individual ability to cope? (e.g. relaxation sessions, mindfulness, education on coping strategies). | H | |
| | What psychological support should be offered to people affected by cancer? | H | |
| | What psychological interventions reduce the impact on mental health for people affected by cancer? | H | |
| | In my experience after "active treatment" for breast cancer has led to a shocking down turn and deterioration in my mental and physical wellbeing. I feel very alone and a failure for not "recovering". What type of support could help women to keep going into the "beyond" whilst managing ongoing consequences (in my case lymphoedema, cording, fibrosis, menopause, extreme weight gain) and impacts of long term treatment for instance Tamoxifen. | P | |
| | What type of support could help women to keep going into the "beyond" whilst managing ongoing consequences | P | |
| | What do patients find beneficial when trying to learn to live with their condition? | H | |
| | Does training in basic mindfulness techniques help individuals undergoing treatment for cancer ? | H | |
| | What support best helps people cope and adjust to life with and beyond cancer? eg. support groups, counselling, clinical psychology, nurse led CBT, peer support etc. | H | |
| | Who is going to support me to adjust back to life | H | |
| | HOW CAN M-HEALTH SUPPORT THOSE DIAGNOSED WITH CANCER | H | |
| | what factors help women with breast cancer develop resilience in coping with cancer | H | |
| | Could cognitive behavioural therapy help people with cancer to deal with mental challenges of diagnosis, treatment and possible recurrence? | P | |
| | What support is most important/valuable to people living with or beyond cancer? | H | |
| | Which cohorts of cancer patients benefit most from individual psycho therapy and which benefit most from group therapy/support? | H | |
| | How can the long term psychological impact on patients be mitigated? | P | |
| | Investigate the psychological effects of cancer in the short term to mitigate any long term psychological impact. | P | |
| | How does cancer affect patient's self-identify and how does the identify of a cancer patient influence social and economic decisions? | RH | |
| | How to get psychological support after diagnosis. This is a very traumatic time and it's not at all supported. | P | |
| | Dealing with mental and emotional issues | PR | |
| | What self-help measures can contribute to recovery of independence following cancer diagnosis and treatment? | PH | |
| | if earlier counselling is of benefit would confirm and perhaps save future NHS expense when these feeling cause problems months or even years after treatment. | P | |
| | Is there any psychological help for long after you've had treatment as sometimes it hits you all later just as friends and family think you are "better" and seem to have moved on from talking to you about things. | P | |
| | Do adapted online psychological support programmes work better than generic ones for improving mental health for people living with and beyond cancer, and their carers/relatives? | H | |
| | Can we demonstrate not just the benefit to patients of good mental and emotional support following a cancer diagnosis, but also the financial benefits to the system in way that influences commissioners to treat it as a priority and not a 'nice to have'. | P | |
| | What can of programmes ie structured or support group (informal) would people want to see? | H | |
| | What support is valued by people during/after treatment for cancer and where is this best delivered? | H | |
| | How can arts-based psychological therapies (art psychotherapy) and arts and health interventions help people with the psychological burden of living with and recovering from cancer; and for those who have a terminal diagnosis, come to terms with death and dying? | H | |
| | How do you cope after cancer treatment? I would like to see how people have coped mentally after treatment. | P | |
| | Is there any psychological treatment for my sleeping and anxiety issues while im going through the trauma of pre op chemo , surgery and post op chemo? | R | |
| | what research is there to show the benefits of having psychological support right at the beginning of a cancer diagnosis? I don't think there is enough focus on emotional support | R | |
| | My wife was diagnosed with stage 4 bowel cancer and died. From my experience as her carer, I would like to suggest that there is a huge difference between the novice and the experienced cancer patient and carer - and that the novices may benefit from hearing the perspective of the experienced. It's pretty much a matter of 'the things I wish I'd known from day one'. As a novice, pitched suddenly into 'cancer world', you feel like you have an avalanche of new, complex and strange matters to deal with, and although the CNSs, oncologists and GP practices do their best, there are things only other more experienced patients and their carers know. So I guess the question is something like: what do experienced patients and carers wish they had known from day one? The practical question would then be: how to connect novices and those more experienced and willing, so this knowledge can be passed on? Thank you. | R | |

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| | Is enough practical help available to women dealing with the transition from pre cancer to post cancer??? E.g changes to her physical body; cognitive functioning; energy levels; relationships changes; emotional distress; lack of sleep; constant worry of re-occurrence; inability to perform/continue at work; lack of sex drive; loss of self; self-image issues; confidence etc | P | |
| | What are the factors (personal, social, societal) which aid recovery and readjustment after cancer treatment | HP | |
| | How do we ensure we're support those living with and beyond cancer psychologically especially once secondary care treatment has ended and it maybe months or years later that they need the support? | O | |
| | the role of acceptance and commitment therapy in helping people live beyond cancer | RH | |
| | How can the psychological effects of cancer be minimised, and their impact on relationships be minimised also? | R | |
| | How do you get back to normality. | P | |
| | How do people adjust to the loss of function they experience following treatment of the cancer, e.g. loss of fertility following ovarian cancer? | P | |
| | What support is available to help deal specifically with the mental health side of cancer? I don't just mean support anxiety and depression i mean specific specialised support which links in with needs of cancer patients, theirs carers and their families at different stages | PH | |
| | What long term support is there for people that have had cancer? Throughout life there may be times that consequences of treatment cause mental anguish, this may be years after treatment. For example fertility issues. | P | |
| | How do i cope mentally ie should Mindfulness or meditation be a part of the support for patients. | H | |
| | What is the role of peer support in reducing anxiety and depression among people affected by cancer? | P | |
| | As treatment improves how will you support the psychological wellbeing of patients living with cancer so they do not impact on clinic time? | P | |
| | Who supports men diagnosed with testicular cancer and their families after treatment has ended | H | |
| | What psychological support is the most useful for people living with untreated cancer such as watch and wait or terminal cancer? | P | |
| | How best to support patients post cancer diagnosis - by whom, where, what services etc. | H | |
| | Many people are now surviving a cancer diagnosis but at what cost? I have lived with a rare blood cancer for 17 years. The impact on work and relationships is huge and life changing. Surviving is not always an easy thing when you have to live with long term effects. What help is there to make these physical and emotional changes. | P | |
| | The value of counselling or cognitive therapy in supporting people after cancer | P | |
| | Are online methods to support people living with cancer or beyond cancer really effective compared with face to face support? | RH | |
| | How to promote mental wellbeing after the cancer has been treated and how to focus on the future. | R | |
| | How can people living with cancer be better emotionally supported through the rest of their life? | P | |
| | All cancer patients should be offered some form of counselling before they reach rock bottom, to stop them from reaching rock bottom. | P | |
| | Should all cancer patients routinely be provided with psychological support? | H | |
| | What kinds of support, information and interventions make a positive difference for women before, during and after chemoradiation treatment for cancers affecting the pelvis - my specific concern is treatment for anal cancer, and what has a negative impact? (Include referral to peer support, how peer support is organised and what approaches and activities are included in peer support. Also include professional services/skills/training. Access to psycho-sexual counselling, HRT discussion, and specialist bowel function clinic.) | P | |
| | How best good Emotional and mental support to be given to those with cancer | PR | |
| | Measure outcome from hope courses for patients lwbc | H | |
| | no one discussed with her how she wanted to die or where. I was the only one she confided in. I wasn't experienced but I was all she had. Life does go on and outside factors can have devastating effects on families. There is no provisions for life during & after cancer. | R | |
| | How do you support people who have recurrence even at a later stage. | PR | |
| | What evidence is there for group work in cancer survivors? | H | |
| | What are the methods to overcome the severe psychological aspects of coping with cancer? | H | |
| | As a sibling of a cancer patient and a health care professional I don't know how to help my sister filter all of the information and identify what is really important. this was true during her treatment and now in the period after completion of treatment. She doesn't know her new normal and may not actually want to accept it as such, there appears to be very little in terms of ongoing support that is offered rather than being available on request. She seems not to have a single point of contact who proactively asks her 'what matters to you'? | RH | |
| | How can support/help with close relationships be improved | RH | |
| | How do you cope with the psychological effects of having cancer? | P | |
| | Is there a way to identify specific points in treatment pathways where mental health is most likely to be affected and therefore points at which early psychological intervention, or psychological support, would be most beneficial? Often these support services need to be sought out by individuals which means the problem has developed and grown into something that takes longer to recover from. | H | |
| | What is done for mental strength building after cancer treatment | P | |
| | Who offers support for long term sequelae including depression, anxiety, loss of confidence and physical problems related to treatment. | P | |
| | Why isn't there anybody to call or talk to straight after diagnosis as it's then when your most vulnerable and then rely on Dr Google which in its self is soul destroying | P | |

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| | Why is more research not done into , and nhs support provided to build in as part of the treatment model, the benefits of peer to peer support both in terms of mental and emotional well being but also in terms of the benefits to patients and clinicians in terms of supporting patients and their families to become better informed and engaged and proactive in making treatment and appropriate lifestyle Choices? | R | |
| | Support at diagnosis stage There are not enough specialist nurses to support patients and carers directly with practical questions and solutions Info is good on McMillan site but having a key worker would have helped more | R | |
| | Is there evidence that patients who are part of patient support groups have better outcomes and better overall survival | P | |
| | What long-term social/psychological support is available to people in the years after treatment finishes? | P | |
| | What longer-term professional and social support do people need after treatment? | P | |
| | What are most effective ways to provide psychological and emotional support to patients who are on watchful waiting programmes, or who are at higher risk of relapse? Can this support be extended to the carers and family? | P | |
| | is the support consistent throughout the cancer journey | RH | |
| | What are the best strategies to reduce the psychological impact post diagnosis | P | |
| | My mum was diagnosed with Metastatic breast cancer two years ago and now feels her whole life revolves around treatment. She refuses to plan for the future because she may not be well enough. What will help her to LIVE with MBC? | PR | |
| | What benefits would psychological and psychotherapeutic input have for patients living with metastatic cancers? | PR | |
| | Is there any specific therapy for people living beyond cancer that is beneficial to the persons wellbeing? If so what is the therapy and how does it differ to other therapy outcomes? | P | |
| | How can I build/foster/maintain resilience through my cancer journey as a patient/carer | H | |
| | Do professionals have a role in building/ maintains resilience | H | |
| | Psychological support and counselling for patients, partners, caregivers and/or families after the cancer experience to enable relationship recoveries and adjustments | P | |
| | My experience is that people often struggle to accept themselves and their side effects and experience. How can we evaluate what works well for people to move on. I.e medical intervention, talking therapies, support group, educational HOPE etc on na large enough scale to count. | RH | |
| | How do the needs of carers evolve/change as patient survival extends? | P | |
| | How can you support carers of people with cancer to help the person with cancer and to take care of themselves? | R | |
| | As a mother/carer for Cancer patient who had a very poor prognosis of Breast Cancer from the beginning, living with cancer takes a very large chunk out of your normal life. Besides trips to the hospital. It is very difficult to "switch off" when returning home to make a dinner keeping housework up to date. It's easy for Help for Carers leaflets to say about looking after yourself. However in reality it is very difficult to to. On your mind is the results of last scan, what's this new treatment they are taking about, does this mean the last one hasn't worked. Having to talk to your daughter about what kind of funeral she would like. Worrying about what you can afford. Personally I had to spend 3 years paying off my daughter's funeral & it wasn't extravagant at all. Very difficult for carers to choose the right time to talk about these personal but necessary things. How do you talk to a 27 year old girl about a "Will" it's so unnatural especially when it again is very necessary when she has quite a few animals & special things that people have bought her | R | |
| | What is the best practice in supporting partners, families and carers over the longer term, for example up to five years and beyond? | P | |
| | What support can immediate family members/close friends receive in coping with the diagnosis of their loved ones? E.g. mother struggling to cope with her child's diagnosis, not reassured even if prognosis is good->fear, denial->not engaging with child's needs as a cancer patient->(unintentional)lack of support towards the child | P | |
| | Research on how family and close friends are effected with living with someone who is living with cancer or coping with the long term side effects. | P | |
| | The psychological well being of living with body dysmorphia after major abdominal surgery and having a stoma in place is horrendous not only for the patient but dealing with is fear by the wife or partner puts a strain on the relationship why are they not better prepared? | RH | |
| | The effect of caring for someone living with cancer, and how carers cope after regular treatment has stopped | R | |
| | What are the most important issues that carers feel they need support with? | RH | |
| | What is the long term effect to close family (partner, children, parents) of a person experiencing cancer and could more be done to support them during the person's treatment and follow up screening. | P | |
| | The psychological impact of living with a secondary cancer diagnosis on family members. | H | |
| | What sort of interventions can be viably implemented to support family members who care for people with cancer in the short- and long-term after cancer? | H | |
| | the effect of cancer on carer and how they could get help n support to overcome their fear | P | |
| | How do you feel that you living with cancer has affected your family? | P | |
| | What would help your carer through your cancer journey? | H | |
| | What support should patients and their careers/partners/family receive from the haematology team providing the medical care? | P | |
| | If you are the main informal carer for an adult with physical /mental health or problems associated with old age does this impact on your route and time to a cancer diagnosis, treatment decision making and survival? If this is the case what can be done to support carers? | HR | |
| | Ongoing support for family members of survivors whose lives have changed. | PH | |
| | How can unpaid carers be better supported? | H | |
| | What are the best ways to support the families of those affected by cancer and providing care? | H | |

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| | What is the most effective, inexpensive intervention can we make to meaningfully support carers of pts with advanced cancer | H | |
| | What education and support would best suit the needs of people supporting persons with a cancer diagnosis? | H | |
| | What the effects on relationships and families, how many couples separate? | RH | |
| | What help is there for my immediate family to cope with their feelings during and after my cancer battle? | P | |
| | What is the impact upon adult children and adult siblings of cancer patients, what is in place to support them and how effective is this? (focus of support is often on partners/young children) | RH | |
| | How can we support carers of those living with cancer or beyond cancer? | H | |
| | Long term impact physically and mentally, patient and family | P | |
| | I am supporting my wife through her illness. I found the emotional acceptance of her conditions difficult to come to terms with given the prognosis was undefined ... appeared not so good / possibly manageable. My wife voiced the position 'Its happening to me' was understood and was addressed by the professionals and they did their best. I also understood that position, But it did not make me feel better. I suppressed my feeling. But they tended to pop out when I least expected them to. So my question [?] is it understood the stress and distress impacted upon the immediate family of persons blighted by this terrible disease. | R | |
| | How does the carer cope when the patient lives life as if the prostate cancer is the central issue for both of their lives. | R | |
| | As a former carer of someone who died of a cancer that was never deemed incurable or terminal, I'd like to ask how carers can be better supported and their opinions listened to much more. I was shut down when I tried to tell the consultant how bad I thought things were for my mum (A positive attitude is half the battle is what she said to me). So my mother was started on chemo (not palliative but supposedly curative). The first time anyone admitted she might die was two hours before she did, a few days after her first round. The hospital ordered a post mortem which I was horrified about, and she had indeed died of cancer. No surprise to me - what were they expecting?? How many people does this happen to, and how can it be avoided? Carers can see what is happening but it is very hard to convey it to the doctors without feeling you might be saying the wrong thing. | PR | |
| | How are carers and friends better supported ? | R | |
| | how best to support families | H | |
| | Where can carers go for help and support? | RH | |
| | How can we help families understand the emotional and existential changes that might happen for people after cancer and cancer treatment. | H | |
| | How can we better care for 'carers' and harness the support network around each individual patient to improve outcomes? Is there a need for carer focussed clinic appointments to address their needs? | H | |
| | Is the Concerns checklist an appropriate checklist for the immediate family/friends of people who have been diagnosed with cancer? | H | |
| | when a woman dies from secondary breast cancer, and has young children, there seems to be very little support for the Fathers. The fallout is huge, and many men have to completely change the structure of their lives to cope. Children may have access to bereavement counselling, but how many Fathers are followed up? | P | |
| | The development of support for carers and family members. | O | |
| | How do you support those family members supporting those with CR cancer? | R | |
| | Were there people available to support your family/ | H | |
| | What support is available for the carers of people suffering from cancer, particularly when the cancer sufferer doesn't accept or want to accept what the likely outcome of the disease will be? | R | |
| | although there is some support available for parents to tell young children what is happening, I, once again, was left more or less on my own with this one and mid-teenage, early 20s children. They struggled to understand what was taking place, didn't know where to turn for support and, as a result, felt I was very much "doom and gloom" when it came to the cancer diagnosis, whereas my husband was very upbeat and positive. They would also have been loathe to admit how they were feeling, unless someone told them they had to. Would it be worthwhile having some sort of service who could speak to young adults and answer their questions, without them feeling they had to tell me (or their dad) at this very difficult time. | R | |
| | What care is there for carers of cancer patients to be able to live well | R | |
| | What is the impact of prostate cancer treatments which affect sexual functioning on the partner/spouse emotional relationship from both the patient and partner perspective? NB this question is not intended to focus on sexual activity but the whole quality of the relationship | R | |
| | Research the impact of cancer (particularly incurable cancer) on the partners of younger sufferers (ie still working, young children age) | P | |
| | Impact on family and keeping them in the loop | RH | |
| | How does a cancer diagnosis and treatment affect partners/families and carers?. | H | |
| | It is apparent that there was relatively little acknowledgement, encouragement or help for members of my family who were also affected by my cancer, and who helped care for me. How can this be improved? | P | |
| | What are the most effective ways of supporting carers of people with palliative cancer living at home? | H | |
| | I'm exhausted from looking after my Mum, do we both get help with relaxation, ie massage? | R | |
| | I was caring for a son who had cancer. Whenever anyone died from cancer it brought the whole cancer diagnosis back. Is there any way of easing this trauma. (my son survived and is doing well) | R | |
| 6. How can the short-term, long-term and late effects of cancer treatments be (a) prevented, and/or (b) best treated/ managed? | An RCT of Olanzapine as a treatment for psychiatric disorder caused by high-dose steroids - we currently rely on case series evidence to choose psychotropics in this context, despite the fact that up to 18% of people taking daily dose of dexamethasone over 10mg can expect severe psychiatric symptoms (notably mania, suicidal thoughts). | H | There are studies into chemotoxicity and its effect on the brain but not everything is known about it yet. Similar with radiotherapy we know it can effect cognitive function but we don't know how to manage it better. |

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| | How can the long-term, including the permanent, side effects of immunotherapy (e.g. Ipilimumab) be best managed by patients and professionals? | P | It is possible to have a profile of risks for each treatment but long term data is poor because clinical trials don't collect a) the right data b) long term data. This is an issue to raise with the wider research community. |
| | HOW MANY PEOPLE DIE FROM THE SIDE EFFECTS OF DRUGS EVEN AFTER BEING 'CURED' OF CANCER? | P | Schagen SB, Muller MJ, Boogerd W et al. Change in cognitive function after chemotherapy: a prospective longitudinal study in breast cancer patients. J Natl Cancer Inst 2006;98:1742-5 |
| | How does one cope best with long term side effects, e.g fatigue, changed body shape etc | P | Hermelink K, Untch M, Lux MP, et al. Cognitive function during neoadjuvant chemotherapy for breast cancer: results of a prospective, multicenter, longitudinal study. Cancer2007;109:1905-13 |
| | What research is being undertaken to alleviate the harsh side effects of cancer treatment, i.e GVHD. | P | Lots of advances in radiotherapy to minimise toxicity, limiting doses Proton therapy, SABR therapy. Less known about managing effects. |
| | Testosterone replacement therapy following testicular cancer and the way to cope with the ups and downs. | P | Publication pending on testosterone replacement therapy. |
| | Testosterone replacement therapy and the way it changes the way the body reacts to food | P | long-term effects of surgery are known. Getting assessment and referral to specialists are not done. |
| | What changes in my physiology and bodily functions (bowel) are normal in the years after surgery | P | |
| | What help is there dealing with functional issues such as bile malabsorption after bowel surgery? | P | |
| | What is the true incidence of low anterior resection syndrome after anterior resection for cancer of the rectum? How should we look for it and what are the best treatment modalities to improve quality of life? | H | |
| | Living with the after affects of cancer operations. E.g. Dealing with breathing issues following a lobectomy which was followed by radical radiotherapy. | P | |
| | How can insulin spikes best be avoided when you have had an oesophagectomy or other surgery that shortens your digestive system? | O | |
| | How can the possibility of small intestine bacterial overgrowth be avoided if you have had major surgery on your oesophagus / stomach and PPI medication switches off the stomach acid that keeps the normal healthy bacterial balance in your intestines? | O | |
| | Research the long term affect of surgery, radio and chemotherapy on bowel and bladder function for patient with bowel cancer. Specifically continence especially bladder (frequency and urgency) and problems with defaecation. I had a low anterior resection for ca colon 13 years ago after radio and chemotherapy to shrink cancer prior to surgery, diagnosis at age of 42 female Why do I sometimes wet my self when bladder is full as I cannot prevent myself emptying my bladder. Why do I have issues with passing stools, I can feel pressure so know I need to pass stool but cant without pressing on perineum to force out stool. Not constipated | | |
| | The long term effects of key hole hysterectomy as opposed to abdominal, when cancer suspected. | P | |
| | How do you adapt to the physical changes after your operation | P | |
| | Looking at issues around anterior resection syndrome - | P | |
| | Is "chemo brain" real? I started noticing my short-term memory sometimes being bad 3 or 4 years after treatment finished. Could this be an after effect of chemo? | P | |
| | Am I more susceptible to everyday bugs and viruses in the years after chemotherapy | P | |
| | The effects of chemo/ other drugs on fertility | P | |
| | Does chemotherapy alter patients cognitive development? | H | |
| | Did the chemo affect my teeth? | P | |
| | Whats the best way to improve my memory as its really bad since chemo 5 years ago? | P | |
| | What causes 'chemo brain' and more importantly, can it be treated or reversed? | P | |
| | What can be done to preserve fertility, other than conventional methods, during and after treatment? | P | |
| | How much of 'chemo brain'/memory problems are caused by the medication and how much is a result of emotional trauma? | P | |
| | Does chemotherapy negatively affect your digestive system long-term by killing off gut bacteria? | P | |
| | Chemo- brain, is this a real thing and if so what is the scientific basis for it and how can we prevent it and or manage it? | H | |
| | Heart problems are well known to be related to chemo and radiotherapy but is there any research about CVA/TIAs post treatment, either incidence or prevention? | H | |
| | The impact on the immune system of living with the disease (ie; how to minimise infections) | H | |
| | The impact on the immune system of treatment | H | |
| | What can you do to mitigate the after effects of chemo on your guts and immune system e.g. Allergies post chemo? | P | |
| | Are there alternatives to platelet transfusion for patients with chemotherapy-induced thrombocytopenia? | H | |
| | Effects on fertility | P | |
| | Does intensive chemotherapy for AML cause infertility in all cases? | P | |
| | Does chemotherapy itself increase the risk of further cancers many years in the future | P | |
| | How does it affect your fertility ? | R | |
| | chances of fertility returning in men who have intensive chemotherapy | H | |
| | More research into what many refer to as 'chemo brain' and how the effects might be lessened - several recent studies have suggested that chemo brain is not chemically-based but more of a form of PTSD from the trauma of having/being treated for cancer. | P | |
| | Is chemo brain real? | PH | |
| | What can be done to help brain fog? | PH | |
| | How best can we support people with cancer, who deal with cognitive impairment in the post-treatment period? | H | |
| | How common is it to have fertility effected? It seems as though it's assumed you will be infertile after chemotherapy but is that actually the case? | P | |
| | why has my memory become so bad since resection | P | |

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| | How to better manage chemotherapy side effects, such as neuropathy; 'chemo brain', toe nail infections (from biologics). There is very little attention given to the disastrous side effects that heavy chemos (suck as platinum based) have on patients, it's a case of 'get on with it'. For people who cannot be cured, the time they have left is precious and it should be the best possible in the circumstances. | R | |
| | what affects do cancer therapeutics have on higher mental function/ cognition and how can we mitigate this? | H | |
| | A lot has been written about 'chemo' brain (much of it claiming it doesn't exist; but a lot of people I know are affected by it) What is being done about this? Is anything being done about only giving chemo to only those it will work for? Do particular chemo regimes affect the brain more than others.? | P | |
| | Are there specific symptoms or body changes which in the longer term after cancer treatment should raise concern to seek medical advice? Ordinarily, these symptoms or changes may be relatively insignificant but does cancer treatment, for example chemotherapy, exacerbate subsequent conditions requiring medical intervention that without having that specific treatment would not have raised concern? | P | |
| | What can be done to improve outcomes for young people with fertility problems caused by chemotherapy? | O | |
| | What are the long term effects on organ function of anticancer treatment? for example cardiovascular, renal function. | RH | |
| | Does chemotherapy cause cataracts? | P | |
| | What is the long term impact of chemotherapy (for example FEC-T) on the immune system? | P | |
| | What can be done to help chemo related toxicity health problems after treatment i.e. chronic kidney disease, cardiomyopathy, migraines etc ? | P | |
| | Would like an explanation as to the damage your nerves suffer due to Chemo | P | |
| | What are the most effective interventions for reducing 'chemo brain' post treatment? | H | |
| | can you end up having a perforated bowel from chemo for head and neck cancer | U | |
| | Muscle pain and aches in thighs: My experience was very painful requiring strong pain killers and continued for a long time after treatment. my normal activities were difficult to carry out, especially walking any distance and going upstairs. I still feel, often the problem lingers on despite keeping myself fit. are muscles damaged by the chemotherapy? | P | |
| | Long term effects of chemo | P | |
| | More on the long term effects of chemo | P | |
| | Is there any research on or help available to support people with "chemo brain" in regaining their former mental agility? Two and a half years after finishing chemo, I still feel like a computer that's short of RAM. This makes it difficult to work at my former capacity. With increasing numbers of younger people being diagnosed with cancer while the retirement age is rising, we cannot afford to be complacent about the affects of cancer treatment on patients' mental abilities. | PR | |
| | Why is hearing loss not looked into as a result of high dose chemotherapy and/or antibiotics. I was shocked to lose so much of my hearing due to my treatment. It's been one of the hardest long term effects to live with. | P | |
| | Does chemotherapy adversely affect the gut biome, making post-cancer recovery harder/slower and would a fecal transplant taken before chemotherapy and replaced afterwards help? | P | |
| | What is meant by if the cancer doesn't kill you the treatment will and physically what happens ie chemotherapy and toxins | R | |
| | Assistance in recovery period whilst immune system achieves normal levels. | P | |
| | Can sexual organs be permanently damaged by surgery or chemotherapy? | P | |
| | Is "Chemo brain" a medically recognised condition? What are the causes? | RH | |
| | Causes, incidence and long term problems with chemo brain. | P | |
| | How does cancer treatment effect fertility? Rates of fertility over time, and how this depends on age at cancer treatment | R | |
| | Why chemo brain affects us long after treatment? | P | |
| | What is the cognitive impact | H | |
| | I'd to know how chemo has affected my immunity and if it's been affected I'd like repeat immunisations. | PH | |
| | Research into musculoskeletal side effects of cancer drugs such as hormonal therapies in breast cancer and strategies to improve arthralgia | P | |
| | I wake up feeling low and with no energy, 2 years after treatment- is this due to chemotherapy treatment? | P | |
| | Impact of cranial irradiation on cognitive function. determine rate of cognitive dysfunction, occupation, independent living, psychological impact, memory issues, depression and rate of deterioration over time. | H | |
| | How do we optimally treat bleeding from radiation psychopathy? | H | |
| | Does VMAT radiotherapy for head and neck cancer have long term affects on memory. | R | |
| | What is the real impact in the nervous system for cancer patients who have received radical radiotherapy? | R | |
| | How can bladder symptoms be prevented in people who have pelvic radiotherapy? | P | |
| | How to provide a definitive cure for radiation proctitis? | P | |
| | We are seeing significant numbers of patients with stroke (and also posterior fossa syndrome/cognitive decline) at a very early age. When should we intervene with primary prevention (BP/cholesterol etc) and will these (primary and secondary prevention) work in the same way as in non-radiotherapy related stroke (or are there multiple subgroups and pathogenesis to this-also a very pertinent and interesting research question). Also the influence of hormone replacement (particularly oestrogen (transdermal vs oral and testosterone) but also GH and hydrocortisone) on this risk. | H | |
| | There doesn't appear to have been much research done regarding tissue damage as a result of radiation - and if there has been there seem to be no answers. Why? I've been told the damage is permanent and nothing can be done, other than try to alleviate some of the symptoms. | P | |
| | What damage does radiotherapy | P | |
| | Will there be a cure for the damage | P | |

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| | What can be done to slow down or stop the progression of pelvic radiation disease? | P | |
| | Why is pelvic radiation disease not commonly talked about by oncologists and why are some patients not warned of the after effects? | P | |
| | What can be done to highlight pelvic radiation disease and the side effects of it ie stomas? | P | |
| | What can be done to avoid it? | P | |
| | Having had radiotherapy for Prostate Cancer and now having been diagnosed with Radiation Proctitis, what is the best way of coping with this condition I.e. Lifestyle, diet etc? | P | |
| | Why is there so little research interest in the UK into long-term consequences of pelvic radiotherapy? | P | |
| | Why is there little or no research being done on the late effects of radiation treatment and how to prevent them? | P | |
| | Long term side effects of pelvic radiation with information on treatments that may alleviate symptoms coping strategies. | P | |
| | Does stem cell therapy reverse severe radiation fibrosis? If not, what other options are there to reverse /halt the ongoing inflammatory action which is leading to fibrosis of the intestines, bladder, kidneys and sacral spine. | P | |
| | Is there any treatment for radiation cystitis causing chronic infection and haematuria? | P | |
| | I would like to know more about how radiotherapy can cause damage to nerves in the body particularly following radiotherapy of the pelvis and abdomen. I have experienced this particular condition and have great difficulty in walking as a result. I have bilateral foot drop and muscle weakness in my hips and buttocks; balance is particularly difficult for me. | P | |
| | I had radiotherapy follow up because I had a slight increase in PSA reading 6 years after radical prostatectomy, and this resulted radiotherapy cystitis. This condition caused two episodes of bleeding into the bladder, one of which required hospital in patient treatment to flush through my bladder. I have not had any blood in the urine for over two months. The question is "is there any other treatment or medication to treat this condition other than cystodiathermy via rigid cystoscopy as the latter can cause incontinence" ? | P | |
| | What are the long term effects of radiation? Especially on the lung and heart. | P | |
| | What are the longer term effects of targeted radiotherapy. | P | |
| | What is the latest proven treatment for late effect (chronic) pelvic radiation disease. | P | |
| | How effective is radiotherapy after cancer of the womb? It has ruined my digestion and makes life very difficult (frequent and urgent faeces); and actually killed my mother in the end (total blockage by scar tissue) | P | |
| | How can we manage late effects of radiotherapy? | H | |
| | Why is not more attention being paid to Pelvic Radiation damage? Patients are surviving longer but at a cost, often they have very bad diarrhoea, urinary problems and increasing mobility and bone problems. Much more research needs to be done as to how to help these people. | R | |
| | Why is there not further research into Pelvic radiation disease? | P | |
| | How do I cope with life long pelvic radiation disease, mainly bowel problems that cause incontinence? | P | |
| | Is anyone trying to help people with radiotherapy damage to the pelvic area? | P | |
| | Radiobiology: tissue recovery after radiotherapy (RT). Knowing how to measure tissue recovery from RT over time would allow safer subsequent courses of RT. With increased longevity, people are developing multiple malignancies concurrently +/- sequentially, and as a result we are increasingly having to deliver multiple courses of RT in a person's lifetime. | H | |
| | RADIATION PROBLEMS | P | |
| | Is there anything a patient can do to prevent/reduce fibrosis following radiotherapy? It's a big problem for patients, it's painful and limits mobility if in leg. Not really discussed at time of consent and GP's not knowledgeable about it. | P | |
| | What the possible long term consequences of radiotherapy for cancers in the pelvic area (e.g. prostate, colorectal, gynaecological)? | P | |
| | Does treatment with radiotherapy for prostate cancer, always mean patients will suffer E D? | P | |
| | I am 88 and I have been on hormone therapy for my prostate cancer for 6 years. I have a Gleason 9score. I declined to have radiotherapy which was suggested as I felt that the accuracy of aiming the radiation appeared to rely on having a full bladder. As I am not able to estimate just how full my bladder is (I know how inaccurate this feeling can be as I have been self catheterising myself for over 23 years) I feel therefore that if a "Full bladder" is a prerequisite for aligning the X-Rays there is an inherent risk of other sensitive structures being irradiated both unnecessarily and with significant adverse consequences. My PSA score has remained low and is currently 0.6 | P | |
| | How to deal with Trismus [lockjaw] after radiotherapy to cure mouth cancer | P | |
| | The role of hyperbaric oxygen therapy in late effect management of pelvic radiotherapy bowel problems | PH | |
| | will they ever develop something to make cancer patients who have had their salivary glands destroyed by radiation work again to improve oral health. | U | |
| | What are the long term effects after radiation therapy that don't get mentioned by medical team. Such as fatigue, rib pains, twitching electrical pulses, burning,swelling. Year after treatment. How can we manage it. Brain fog, memory loss. Feeling distant from the outside world. | P | |
| | During treatment I had radiotherapy next to my spine. I have now been diagnosed with oestropenia. Was it the radiotherapy that caused this? 63 year old male no previous history oestroporouses in the family. | P | |
| | What are the relative risks of disease recurrence and exposure to radiation? | P | |
| | How can the loss of control of bowels best be avoided for patients who have radiotherapy and chemotherapy treatment, especially in the pelvis area? | O | |

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| | Research the long term affect of surgery, radio and chemotherapy on bowel and bladder function for patient with bowel cancer. Specifically continence especially bladder (frequency and urgency) and problems with defaecation. I had a low anterior resection for ca colon 13 years ago after radio and chemotherapy to shrink cancer prior to surgery, diagnosis at age of 42 female Why do I sometimes wet my self when bladder is full as I cannot prevent myself emptying my bladder. Why do I have issues with passing stools, I can feel pressure so know I need to pass stool but cabt without pressing on perineum to force out stool. Not constipated | | |
| | Why Pelvic radiation disease can be present even when no physical damage to the gut. | P | |
| | More information about the side effects of radiotherapy | P | |
| | How do I live with radiation proctitis? | P | |
| | After diagnosis for squamous cell carcinoma, I was offered two treatment pathways: 1. Chemotherapy/radiotherapy, with the possibility of neck dissection if this failed 2. Neck dissection followed by Chemotherapy/radiotherapy, using a lower dose of radiotherapy I went for the former. However, it seems to me now that the lower dose of radiotherapy might have been a better option, considering the damage to my mouth and throat. Perhaps there has been research that would enable consultants to make clear the differences in long term side effects with these 2 pathways. In either case it could be beneficial to patients in making what is otherwise a rather blind decision. | P | |
| | How do we stop the side effects of radiotherapy? | P | |
| | Is there any effective treatment for long-term effects of radiation on swallowing? | H | |
| | Is there any effective treatment for long-term effects of radiation on speech? | H | |
| | How is (women's) sexuality affected by chemoradiation in the pelvis - my specific concern is treatment for anal cancer | P | |
| | long term effect of radiotherapy | P | |
| | Loss of taste with neck cancer treatments esp radiotherapy. | P | |
| | Long term side effects of the radiotherapy in the left breast. Does affect the heart? | P | |
| | how can saliva volume and quality be increased post-radiation to pre-radiation levels? | P | |
| | how can fibrosis be decreased and maintained - to allow better function on jaw opening, chewing, and general movement. question 4 (or replacement of 2:) how can soft tissue damage (tightness, flexibility etc) be repaired, reduced and function maintained post radiation. | P | |
| | I had the all clear after radiotherapy last april, left me with dry mouth, how much reseach is going in to find a cure for this debilitating condition, I have found little on the market that helps, and nothing that cure's | P | |
| | Dry mouth after radiotherapy/ chemo on mouth cancer is a condition that lets down the successful treatment of cancer, but there seems little treatment available to overcome this condition more research required | P | |
| | What are the causes of osteoradionecrosis? Does it relate to how much radiotherapy a patient receives? | P | |
| | The best way to overcome damage left by cancer treatment in the long term ie radio therapy burns in breast cancer | P | |
| | Do patients receiving pre chemotherapy and radiotherapy guidance and preparation have less comorbidities and use services less ? | H | |
| | Does physical exercise reduce the risks of anthracycline damage. | H | |
| | Can cancer patients be offered alternative treatment if they are at risk of developing hearing deterioration, or tinnitus? | H | |
| | What can I do to reduce my risk of late effects | P | |
| | Can physical activity help patients during treatment? | H | |
| | Role of organ specific enhancement / protection , general roles for diet/nutrition during radiation or chemotherapy, aspirin/lbuprofen/wine(!) etc | P | |
| | What is the best way to prepare people to manage the long term consequences of their treatment? | H | |
| | How beneficial is exercise at different stages of treatment? | O | |
| | What role does prehabilitation (rehabilitation right at the beginning of the cancer pathway i.e. before (in asymptomatic patients perhaps) or soon after diagnosis have in minimising or preventing side-effects of treatment. | H | |
| | Does doing prophylactic swallowing exercises improve long-term post-treatment swallowing outcomes for patients with head and neck cancer? | H | |
| | Does starting an exercise programme during chemo keep you fitter, and / or lessen neuropathy? | PH | |
| | Reducing treatment side effects whilst on treatment. | H | |
| | What are the best lifestyle changes one can make to support you through chemotherapy and after and also support you through living with a long term cancer such as CLL? | P | |
| | Does exercise help people on and after treatment, and how long do these benefits last? | H | |
| | What percentage of patients undergoing chemotherapy would benefit from routine access to an occupational therapist to help them address management of side effects e.g. fatigue, breathlessness, managing Activities of Daily Living. This would promote self management and reduce the likelihood of people dropping out of treatment due to impact on daily living. | H | |
| | What should I eat during treatment? | P | |
| | While undergoing cancer treatment what is the best diet to help with your treatment? | P | |
| | How much getting regular exercise helps with your treatment | P | |
| | Can personalised diets have an impact on outcomes | H | |
| | Does exercise have a synergistic effect on radiotherapy i.e. can exercising during radiotherapy enhance radiotherapy outcomes as well as other patient reported outcomes such as fatigue and QOL? | H | |
| | What is the impact of nutritional status on rates of long term side effects or complications of treatment in patients with cancer of the GI tract? | H | |
| | Vitamin C given intravenously and only by intravenous means has been shown in Germany to substantially increase the human bodies defence capability and even improves a patients recovery from Chemo - Why do the NHS NOT implement its use? | R | |

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| | How can I best prepare for my treatment - before surgery and during chemo - both in terms of what I should eat and what exercise I should take? | P | |
| | Will my response to immunotherapy be affected by my nutritional state - can by improving my nutritional state I improve my responses to immunotherapy? | P | |
| | What impact can diet have on my cancer. How can it help reduce the effects of chemo etc.? | H | |
| | How does exercise/healthy lifestyles affect treatment outcomes etc for cancer? | P | |
| | Would physiotherapist led, supervised exercise interventions started during induction chemotherapy and continued prior to stem cell transplantation in patients with hematological cancers, decrease hospital length of stay and improve long term quality of life and other outcomes after treatment? | H | |
| | What is the impact of Occupational Therapy interventions on quality of life for cancer patients during treatment? | H | |
| | Are there any specific foods, vitamin supplements, or herbal remedies which have a positive or negative effect on how well tamoxifen works? | P | |
| | Does regular exercise improve outcome in cancer patients | H | |
| | Is exercise going to help prevent long term effects of cancer especially if had radiation through the heart | P | |
| | Are there any synergistic ways to potentiate the effects of treatments that would mean the longer term side effects could be limited? Chemo is so harsh, but can we find something - co-factors, lifestyle things, anything, that would potentiate cancer cell apoptosis, but reduce induction of apoptotic mechanisms in healthy cells. Is there anything that could protect healthy cells before chemo is initiated? Can we turn on a cells protection/repair mechanisms temporarily, prior to chemo, then, turn them off again after? | PH | |
| | What is being done to prepare those living with Cancer for the long term side effects of medication? Example: Tamoxifen and cataracts Other drugs Neuropathy, Fibromyalgia, Various aches and pains, Chemo brain and the list goes on. | P | |
| | Does pre-habilitation reduce length of stay inpatients undergoing neo-adjuvant treatment. | H | |
| | Is an improved diet helpful alongside chemotherapy for colorectal cancer? If so, how much and what type? | P | |
| | Is exercise helpful alongside chemotherapy for colorectal cancer? | P | |
| | How does emotional stress impact on the effectiveness of radio and chemo therapy? | R | |
| | Can the provision of optimal diet / nutritional support influence tolerance to treatment (chemotherapy and / or radiotherapy) | H | |
| | Does pre treatment gastrostomy placement help improve the outcomes of head and neck patients? | H | |
| | After surgery for bowel cancer, and an ileostomy formed, I found my back was very weak. There doesn't seem to be any information on this, either how to strengthen things beforehand (if that would work) or exercises afterwards. On the Ostomy forum it seems to be a common problem with bowel surgery. | P | |
| | Whether there exists a protocol about ensuring that prostate cancer patients have adequately prepared themselves prior to receiving radiotherapy treatment to minimize the potential side effects of treatment. | P | |
| | What are the best supplements to take to support my chemotherapy treatment | P | |
| | Is there any medication that can help with the side effects of chemotherapy eg hair loss? | P | |
| | Research looking at the effectiveness of prehabilitation/ pre-treatment screening to prevent or minimise long term consequences of treatment | H | |
| | Do micronutrients interact with effectiveness and cancer therapies I. E. Immunotherapies | H | |
| | Why are patients not advised how to best prepare for surgery, and recovery? For example, for a fortnight before, if you can, take more exercise and sleep, eat proper food, take a quality multi vitamin, get some sunshine?. | P | |
| | Does taking prebiotics during cancer treatment or after reduce long term gastrointestinal side effects? | H | |
| | Helping to prepare people for the long-term for life after treatment as soon after diagnosis as possible and ideally before or during treatment. The idea of 'prehabilitation' is an important one that is used widely in other healthcare settings such as cardiac or orthopaedic surgery. | H | |
| | What's the truth about exercising while going through treatment | PR | |
| | What is the best time to introduce exercise initiatives in the (p)re-habilitation of cancer patients? (Before, during or after treatment) | H | |
| | At time of diagnosis - what is the best nutrition advice I can expect from my doctor? | PR | |
| | Is cannabis oil useful in dealing with the side effects of treatment? | P | |
| | How can we optimise physical and mental health and wellbeing before treatment starts, in order to enable people to live better with and beyond cancer? | H | |
| | Does medium to intense exercise during cancer increase stress on body during treatment / when immunity is low, or is it ok to push yourself. | P | |
| | Is there any evidence for a good outcome from mucous and bleeding by taking metronidazole and steroid suppositories | P | Interventions to reduce acute and late adverse gastrointestinal effects of pelvic radiotherapy for primary pelvic cancers 10.1002/14651858.CD012529.pub2 |
| | Why isn't there more research into patients of AML and post BMT who experience side effects particularly around cramps and spasms? | P | |
| | Does food/ diet have any significant affect on cancer/general health during treatment/ quality of life? | PR | |
| 7. What are the biological bases of side-effects of cancer treatment and how can a better understanding lead to improved ways to manage side-effects? | Can the side effects both short term and long term of any treatment for cancer be mitigated beyond 5, 10, 15 and 20 years by investigating the microbiological nature of these side effects? | P | |
| | at the cellular/molecular level, how does cancer treatment cause the mid - long term effects that patients experience? | PR | |
| 8. What are the best ways to manage persistent pain caused by cancer or cancer treatments? | Why is pain control often not optimal in patients, particularly the elderly, who are having to live longer with progressive disease | R | There are ways to manage acute pain but less is known about managing chronic pain. |
| | Can increasing exercise reduce pain from avascular necrosis? | H | |

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| | How to improve the quality of life of inoperable pancreatic cancer patients. This will relate at least to pain relief and diet. | R | |
| | the best pain relief for palliative care patients | H | |
| | When managing pain, are there any alternatives to opioids that do not give the same negative dizzying effects? | R | |
| | Neuropathic pain from surgery is poorly controlled except by painkillers with side effects almost as bad as the pain itself. What more should be done to arrive at a class of analgesia for neuropathic pain that doesn't turn the recovering patient into either a zombie or a psychopath | R | |
| | How to manage pain effectively, without recourse to opiates which have very unpleasant mental side effects. | R | |
| | What to do about muscular and nerve pain and how to avoid it after head and neck cancer. 8 Years after treatment I live with pain in my neck every day. | PR | |
| | Why aren't better pain killers provided | R | |
| | Could there be a combination drug therapy which relieved the pain that the actual cancer defeating drug causes? | P | |
| | How effectively is pain managed in some cancer patients? We have had an example recently where because of the siting of a patient's particular cancer she has been left with the choice of having the pain not very well controlled, or having an epidural which would make her wheelchair bound. Tough choices either way when she is palliative. | | |
| | Why can't cancer pain be properly controlled? (And why do so many professionals lie about it being possible to keep pain under control when the evidence of our own experience shows that it isn't?) | PR | |
| | The effectiveness of TENS in cancer related pain I see a positive effect in patients with right upper quadrant pain but not particularly found any evidence in palliative care to support this. | H | |
| | Causes of and treatment for chronic pain after chemo radiation and excision surgery for early breast cancer | P | |
| | Is cannabis oil useful in controlling cancer related pain? | P | |
| | The question of pain relief and the different drugs available for palliative and non palliative care. | R | |
| | Pancreatic Cancer and the question as to how to deal with the nerve pain which does not respond to the usual drugs. | R | |
| 9. What specific lifestyle changes (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve quality of life? | How does the balance of protein, fat and carbohydrate in the diet influence the body's physiological response in cancer (insulin resistance, efficient use of energy etc) | H | European Code against cancer 2016 – overall summary of their guidelines and specifically PA guidelines. |
| | Do exercise interventions improve outcomes for individuals living with and beyond cancer? | H | |
| | How does lifestyle and nutritional factors (eg diet obesity physical fitness body composition) affect outcome from cancer, and how can these be optimised? | H | |
| | Best diet to follow | P | |
| | Do nutritional supplements including energy drinks, omega-3 supplements etc improve quality of life in cancer patients? | H | |
| | Does exercise help with recovery and guard against recurrence? | P | |
| | How can a healthy lifestyle affect cancer outcomes following cancer treatment? | H | |
| | What lifestyle interventions (exercise, strength training) improves quality of life | H | |
| | How to stay strong and healthy? | P | |
| | I lead as healthy a life style as possible post cancer i.e. exercise a lot, seek to deal with stress, eat healthily etc. I believe this will give me a better chance of recovering from or dealing with any subsequent treatment/surgery however I have no evidence, other than anecdotal, that this helps. It would be good to have definitive research that showed how best to stay well after cancer. | P | |
| | What's the single best bit of lifestyle advice living with and beyond | H | |
| | Any good dietary advice, | P | |
| | What can I do to help myself after a diagnosis of cancer? | P | |
| | Are there any supplements which are useful to take? | P | |
| | What sort of exercise should I be taking? | P | |
| | What role does achieving and maintaining a healthy weight (preventing weight gain and weight loss during and after treatment) have in cancer survivorship? | H | |
| | Does following a healthy diet and lifestyle improve survival after cancer treatment? | P | |
| | How can diet and exercise assist in recovery? | P | |
| | What self-care and self-management strategies are most likely to result in improvements to patients' health and well-being? | H | |
| | What are useful exercises and techniques to regain lung and muscle function post-cancer? i.e. does cardio, resistance or HIIT type exercises work better? | P | |
| | Can exercise aid recovery and continued well being? | RH | |
| | What can I do to help my health care team manage my condition? | H | |
| | Does a structured physical activity programme help people recover from cancer treatment? | H | |
| | Is there a dose response to physical activity when living with cancer? Is it possible to do too much physical activity? | R | |
| | What food and drink should one take to regain strength n energy after cancer treatment | P | |
| | Would giving all cancer patients nutritional testing (e.g. Vitamin D levels) improve their background health? This does not seem to be routinely done and yet so many people seem deficient due to modern lifestyles. | P | |
| | About the importance of nutrition and modifying your diet. How clean eating affects your health. | PR | |
| | Is it possible to improve my partner's quality of life during "watch and wait" by strengthening her immune system through the elimination of inflammatory proteins such as gluten (wheat etc) and lectins (beans)? | R | |
| | What post-chemotherapy interventions are helpful to get patients back on track: psychological counselling, exercise, | H | |
| | What foods should I eat to help boost my immune system after chemotherapy for a long term condition such as CLL? | P | |
| | Can probiotics & microbiotics make more of an impact on managing my bowels than medication | P | |
| | Are there a suite of vitamins/supplements that I should be taking to enhance my well being? Can this be tailored to the vitamins in my body and the specifics of the disease I have? | P | |
| | The effects of lifestyle on disease progression with CLL | P | |

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| | What are the best ways for patients to manage their own recovery from cancer, eg. how much and how soon to exercise and what role does diet play in recovery. | H | |
| | Can changes in lifestyle improve quality of life when recovering from cancer treatment? | RH | |
| | Managing side effects; best strategies For example - does yoga / other exercise regimes really help? or specialised diets? There is an awful lot of information online, but knowing what's sensible and what's not can sometimes be difficult to assess. | P | |
| | Have you been advised on how your diet can affect your quality of life | R | |
| | What can women do to improve/enhance their wellbeing following breast cancer treatment? (especially in terms of managing weight, protecting bone health, exercising). | H | |
| | How should I change my diet for the optimum effect on my health after cancer? | PR | |
| | Does informing patients about the benefits of exercise improve their experiences of long term side effects? | H | |
| | How to improve the quality of life of inoperable pancreatic cancer patients. This will relate at least to pain relief and diet. | R | |
| | Does a full lifestyle intervention ie exercise, better nutrition, quality sleep, meditation, improve quality of life and survival.? | P | |
| | Our son, who has cancer, has recently adopted a healthier diet, trying to cut out sugar. He is in his early 20's. How important is it to maintain a healthy diet once his cancer is in remission? He is looking into taking curcumin as a supplement - what role could supplements have? | R | |
| | How to lose weight or prevent weight gain given that one of the side effects of the medication is weight gain | P | |
| | Does therapeutic dietary advice improve quality of life? | H | |
| | Can diet and exercise help? If so, how? | P | |
| | what information is there for diet and living with/beyond cancer | H | |
| | Does following a healthy lifestyle improve quality of life for overweight cancer patients | RH | |
| | Would giving cancer patients who were previously overweight or who have increased weight throughout the course of their treatment support and follow-up to follow a healthy lifestyle plan post treatment e.g. physical activity plan, diet, lifestyle help them recover faster from treatment and reduce recurrence | RH | |
| | What nutritional supplements or dietary changes might most support people with cancer? | P | |
| | HOW NUTRITION CAN PLAY A MAJOR PART IN CURING/ MINIMISING THE EFFECTS OF CANCER? | P | |
| | Does exercise help recovery | P | |
| | What is the best way to get back into shape after treatment, i.e what kind of exercise is best and how should one get started. | P | |
| | Until recently I was working full time. I have now retired and want to take up a structured programme of exercise, but am not sure how much or how often. Is there any research on this subject for different types of cancer and common side effects? | P | |
| | How important is diet and should there be dietary changes | R | |
| | Can practicing yoga have a healing effect on cancer? | P | |
| | What nutrition is helpful to recovery? | P | |
| | how Do active people return to their pre level of activity? Focus is on those who don't do activity before Cancer. | P | |
| | Are multivitamins, vitamin d3 or any other supplements recommended. Oncologist opinions seem to vary greatly which isn't helpful. | P | |
| | Should you make changes to your lifestyle and if so what should you change. Having had bowel cancer I would of liked to discuss my diet with a qualified dietitian and whether or not certain supplements would help, it turmeric, vitamin d, etc. | PR | |
| | Best diet moving forward? | RH | |
| | Best type of exercise moving forward? | RH | |
| | What is the role of nutrition in promoting recovery? | H | |
| | What kinds of exercise are helpful? | H | |
| | What's the impact of physical activity on physical and mental health outcomes for people living with or beyond cancer? | H | |
| | Does diet really play a positive role in quality of life during and post treatment? | H | |
| | Would changes in my diet help with living beyond cancer? | P | |
| | Would changing a stressful job help with living with cancer? | P | |
| | Would changing the way I live help with recovery? I.e move from a town to a rural place? | P | |
| | Does eating a healthy diet really make a difference to cancer survival times? | PR | |
| | What is the best diet to help people who have had bowel cancer treatment ? | P | |
| | healthy life style choices post treatment and the difference this can make to quality of life and longevity | H | |
| | General information on diet is available to the population, but as a cancer patient the vast majority of dietary information centres around maintaining weight with a short term view of the patient. So the question is, why is there no medium to longer term dietary advice for cancer patients? | P | |
| | What role does exercise play in improving recovery from cancer? | H | |
| | Nutrition and exercise are becoming more important to the successful rehabilitation and survivorship of cancer patients. there is evidence that good nutrition and increased exercise prolongs survival and improves recovery and wellbeing. How can RT health professionals better promote these issues towards the end oand immediately following radiotherapy? | H | |
| | why isn't research into beneficial /harmful foods (during and post treatment) included in mainstream cancer treatment, instead of sidelining the topic, whereby consultants dismiss evidence? | P | |
| | How important is diet beyond Cancer treatment? | P | |
| | What works best for patients to help them live well | H | |
| | How can dietary modification support patient improvements in patient symptoms | H | |
| | What are the key dietary components to improve cachexia in cancer patients | H | |
| | Dietary influence on bowel function after radiotherapy or chemotherapy? | H | |
| | The role of pre- & pro-biotics in improving bowel symptoms. | H | |

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| | After surgery -what is the best nutrition advice I can expect from my doctor? | PR | |
| | What difference can a good diet (e.g. 10 fruits and veg a day) make to overall survival? | P | |
| | Diet - post diagnoses, positive effect or not? | PH | |
| | Understanding the impact of the things I can control as a patient: Can eating healthily really impact your survival / quality of life living with metastatic cancer ? (and what is the optimal diet for a patient with metastatic disease ?) | P | |
| 10. How can we predict which people living with and beyond cancer will experience long-term side-effects (side-effects which last for years after treatment) and which people will experience late effects (side-effects which do not appear until years after treatment)? | The side effect left by cancer treatment like arthritis & lymphoedema | P | J Community Support Oncol. 2014 Apr;12(4):137-48. The late effects of cancer and cancer treatment: a rapid review. Treanor CJ1, Donnelly M.Myocardial infarction mortality risk after treatment for Hodgkin disease: a collaborative British cohort study. |
| | Long Term effects of Cancer Treatment | H | Swerdlow AJ, Higgins CD, Smith P, Cunningham D, Hancock BW, Horwich A, Hoskin PJ, Lister A, Radford JA, Rohatiner AZ, Linch DC. J Natl Cancer Inst. 2007 Feb 7;99(3):206-14. Similar papers for breast ca for chemo and XRT SE |
| | What are the common long term effects of treatments when you have been cured of cancer? | H | Macmillan document Shining the light on consequences of treatment which cites many references. We know that some treatments are associated risks of late effects. This depends on the disease, treatment and other factors |
| | What are the long term effects of taking a TKI for a patient under the age of 46? | P | There are a lot of papers, reviews and evidence about late effects from cancer therapy in breast cancer and lymphoma/haem malignancies and childhood cancer but maybe not in every adult cancer. |
| | What is the longer term outlook/prognosis for people who respond to immunotherapy treatments (in particular for metastatic melanoma)? | P | Cancer treatment and survivorship statistics, 2016. K Miller et al. American Cancer Society Vol 66(4), 271-289. |
| | long term symptoms for chronic patients | H | |
| | What are the long term side effects of cancer treatment? | H | |
| | the proportion of people living with a physical disability that impacts significantly on their lifestyle as a result of their cancer or its treatment. Or some better research looking at what the problems are that people face that's a bit more quantitative and robust than some of the macmillan stuff | PH | |
| | Are there any factors which could be identified which would give patients some idea of any increased risk of developing chronic peripheral neuropathy following platinum based chemotherapy? (e.g. genetic predisposition?) | P | |
| | I have returned o work full time as they say I am cancer free ! Which is great but I still have medical problems which the treatment has left with me! And that seems to be a guessing game with the none cancer doctors I now see. | P | |
| | What do we know about the long term side effects of cancer treatment? ie 30 or 40 years later | P | |
| | I am now 6 years post treatment finishing myself and other members of the support group I am part of experience similar side/after effects of our treatment is there any research being done on this? | P | |
| | Provide risk assessments for future treatment related consequences (benefits and adverse) with evidence, for example pelvic radiation benefits vs risks of long term adverse consequences. Much stronger emphasis on analyzing long term consequences in randomized trial studies with supplemental funding) [required follow up of 5, 10 ,15 years would not be very expensive] | P | |
| | What known percentage of patients can expect side effects from radiotherapy? | P | |
| | Research into the long term effects of oestrogen depletion treatment with aromatase inhibitors for breast cancer. Possibility of reducing permanent changes due to this treatment e.g. osteoporosis, joint problems etc. | P | |
| | More research into the long term physical and mental side effects of cancer treatments. | P | |
| | How can we predict who will develop long-term side-effects of treatment | H | |
| | Long term effects of cancer treatment | H | |
| | We need more information on long term side effects | P | |
| | What is my risk of developing secondary Lymphoedema after treatments ? (Will you measure my arms before they begin, will you look at my family history ?) | P | |
| | Is neuropathy more common in bowel cancer with right ascending hemicolectomy, and if so how often is this linked to B12 deficiency? | PH | |
| | What are the long term implications/side effects of treatments for cancer | P | |
| | Having completed treatment, what are the ongoing side-effects? | H | |
| | What has been the most common ongoing symptom suffered by people living with cancer and what has helped the most? | P | |
| | What are the long term side effects of chemotherapy and how likely are they? Particularly vein toxicity following vesicant chemotherapy, insomnia and depression. | H | |
| | What side effects do you suffer. | P | |
| | Effect on fertility and number of live births associated with different treatments | H | |
| | What are the long term effects a patient should expect to have to deal with e.g. physical and psychological | H | |
| | Quality of life is important. So why does there seem to be insufficient knowledge of how to combat, either by elimination or effective moderation, of long term side effects following cancer treatment? An example is the need to take long term medication after treatment to suppress possible return of the cancer and that medication gives rise to uncomfortable side effects which are problematical on a day to day basis. | P | |
| | The long term after effects of cancer and the treatments are not well researched and how to cope with them | P | |
| | What is the likelihood of lung problems following radiotherapy? | P | |
| | Long term side effects of chemo | R | |

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| | What is the incidence of long term side effects or complications of treatment in people with upper and lower l cancers and how does this impact on QOL? | H | |
| | What are the long term affects of radiotherapy | P | |
| | What impact does chronic lymphedema have on a patient's life as a cancer survivor and what can the severe effects of surgery and radiotherapy be? | P | |
| | How common is (permanent) chronic fatigue following treatment for Ewing's Sarcoma? | P | |
| | What are the long term side effects of treatment? | P | |
| | Why my discomfort is sometimes worse 2 years after my Wide Local Excision, axillary clearance and radiotherapy than it was at the time? | P | |
| | What are the actual side effects experienced by ALL patients undergoing chemotherapy? Most certainly, with the benefit of hindsight, I am quite certain that things I experienced were not noted as they weren't things known to be experienced...hmm... | P | |
| | What are the short, medium & long term effects of each of the treatments | P | |
| | The impacts of ongoing treatments. | RH | |
| | What are the possible long term consequences of the Whipple surgery? | P | |
| | 3yr post ER+, HER2 breast cancer and a recent hysterectomy with Bilateral Salpingo Oophorectomy has resulted in significant side effects incl fatigue and joint pain. Is this to be expected living beyond Cancer? | P | |
| | My husband has had cancer and is suffering lots of different side effects that are 'unexplained' although he has seen several specialists. He/We finds this very frustrating | R | |
| | The after effects of hormone therapy such as tamoxifen | P | |
| | What are the long term implications of cancer treatments? | H | |
| | What are the lasting effects of Radiotherapy and Chemotherapy. | P | |
| | What are the long term effects of having cancer and of the treatment, e.g. chemotherapy. | P | |
| | Research the long term affect of surgery, radio and chemotherapy on bowel and bladder function for patient with bowel cancer. Specifically continence especially bladder (frequency and urgency) and problems with defaecation. I had a low anterior resection for ca colon 13 years ago after radio and chemotherapy to shrink cancer prior to surgery, diagnosis at age of 42 female Why do I sometimes wet my self when bladder is full as I cannot prevent myself emptying my bladder. Why do I have issues with passing stools, I can feel pressure so know I need to pass stool but can't without pressing on perineum to force out stool. Not constipated | P | |
| | Neuropathic pain - how common an issue is this post surgery and post chemo | H | |
| | What are my chances of experiencing long-term "consequences of treatment" and what can be done about them? | P | |
| | what is the most common symptom people LWBC experience | H | |
| | Understanding our long term side effects | P | |
| | Long terms effects of chemotherapy and radiotherapy | H | |
| | what are the long term effects on your teeth | P | |
| | what number of patients suffer long term debilitating side effects of radiotherapy and to what severity | U | |
| | Long term effects of cancer and its treatment - how long do they last, the extent of the effect and its impact on patients lives. | H | |
| | How many people are living with subtypes of breast cancer and how long are these people living in the sub types and what are the side effects people are experiencing | P | |
| | What are the long-term effects of my treatment | P | |
| | How many people are left with significant longterm effects from the treatment received? | H | |
| | I'd like more data collection into what happens with people following treatment, eg longer and late side effects, incidence of secondaries, etc as it is only then these issues can be addressed. | PH | |
| | Impact of long term side-effects like lymphedema, fatigue, pain, and bone and heart health. | P | |
| | Pain How can we predict which patients are going to have more pain as a result of their cancer and/or as side-effects of their treatment? This should include screening for phenotype as well as biomarkers and genomic screening. | H | |
| | How are cancer treatment (chemo, adjuvant, radio) and hormone therapy affecting sports abilities of BC patients diagnosed before 40 years old? How is fatigue affecting the patients long term? | P | |
| | Now, having received chemo and radiation- what are the damaging side effects long term? I have to undergo dental extractions and cut off all my hair. | P | |
| | Consequence of treatment? Both short and longterm | RH | |
| | What are the most common late effects? | P | |
| | Late effects of bowel & bladder problems - where can patients be signposted for more support? Why do some patients get bowel problems and some don't | H | |
| | The impact of late effects on a person's life despite treatment success | H | |
| | What is the true incidence of symptoms after various different cancer treatments at different timepoints? | H | |
| | Do acute symptoms predict chronic 'late effects' after pelvic radiotherapy? | H | |
| | What are the long term health related consequences of immunotherapy agents such as brentuximab used to treat lymphoma and leukaemia? | P | |
| | What is the risk of late effects | P | |
| | What are the long term, over 20 years past radiotherapy treatment, effects on the body? | P | |
| | What is the outcome of drugs in Living with & Beyond Cancer? | P | |
| | What late effects can be expected after treatment for the common epithelial malignancies? | H | |
| | How long after treatments late effects can develop | P | |
| | What late effects can develop and for GPs to be provided with information on late effects and possible ways to deal with them . | P | |
| | are there any long term LWBC consequences of the immune checkpoints inhibitors | H | |
| | How common are the late effects of cancer and its treatments (prevalence of late effects)? | H | |
| | late effects of treatment | H | |

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| | What are the long-term (like 20+ years) health effects of the chemo and radiation that I received (for bowel cancer) aged only 26? | P | |
| | What will be the side effects of my treatment in the future? | PR | |
| | How will my immune system be effected as the years go by | P | |
| | What are the future implications to my health- | P | |
| | what are the mid and long term affects of chemotherapy and how does this affect the quality of life for the patient and their loved ones, friends and family etc. | PR | |
| | What long-term health issues can I expect as a result of my cancer and its treatment | P | |
| | Can treatment-related cardiovascular events and deaths be prevented? More research is needed to identify people at greatest risk of developing serious cardiovascular complications of treatment, and to develop more effective ways of treating early cardiovascular disease to reverse or reduce the disease course and prevent cardiovascular deaths. | H | |
| | There is lack of knowledge within the healthcare profession, including cancer services, and general public of long term side effect when living beyond cancer. Some side effects do not occur until years after treatment when to others it appears the cancer has been cured so therefore health problems can not related. This is made more difficult as health problems can not be seen e.g. fatigue, pain, neuropathy, cardiac damage, endocrine imbalance. Research has shown long term side effects in children and now that more of us are living longer these same or similar side effects in adults need to be documented. | PRH | |
| | Much is known about late effects of treatment but I am not aware of much if anything that has been done to try to predict the likelihood of particular late effects occurring based on what is likely from the type of treatment, the disease and site treated and the presence of other morbidities. A predictive tool to allow some degree of preventive or early treatment for the range of late effects would make a huge difference to the quality of life of those survivors affected by late effects that could either be prevented by early action or much better ameliorated. | R | |
| | Can we predict who will develop late effects from their cancer treatments? | H | |
| | When is a late effect not a late effect but a consequence of natural ageing? | H | |
| | Late effects of cancer, how this affects people's lives long term | H | |
| | Can I expect new side effects to appear after my treatment is completed? | P | |
| 11. What are the most effective ways to stop cancer coming back (combining treatments and life-style changes)? | What can I do to prevent cancer coming back | H | Very large topic and some known answers – not smoking, keeping a healthy BMI etc. |
| | What diet is best for those recovering from primary BC to try to avoid it recurring and avoid weight gain not helped by anti cancer long term medication eg tamoxifen. | P | European Code against cancer 2016 – overall summary of their guidelines and specifically PA guidelines. |
| | Stress and recurrence: Do environmental stressors, such as financial concerns following long term sick leave / ceasing of sick pay, have a bearing on the risk of recurrence? | R | |
| | Is there any proof of high quality nutrition improving prognosis/survival/recurrence rates? | H | |
| | What can I do to improve my chances of not having the cancer returning or becoming worse | P | |
| | How can we help people reduce their risk factors for recurrence, second cancers and other health problems after treatment. Eg by reducing obesity and blood pressure and stopping smoking. Preferably also involving the people important to them who are around them. Also to enable them to take control of their own health. | H | |
| | How can I help my chances of the cancer not returning or give me a longer remission. | P | |
| | Does exercise help with recovery and guard against recurrence? | P | |
| | There is a lot of confusion about what foods are good/bad for protection from cancer recurring. Is it possible to have a medically approved list of what is best/worst in terms of diet/ | P | |
| | Benefits of proper nutritional advice to prevent cancer reoccurring | PR | |
| | Particularly following breast cancer, is there evidence that a red meat-free and dairy-free diet helps to prevent a recurrence? | P | |
| | What can I do to reduce the likelihood of it coming back? | P | |
| | What evidence is there that tumeric mixed with black pepper for increased absorption reduces inflammations in the body of which cancer is one type of inflammation? | P | |
| | In the case of hormone positive breast cancer how important is dietary fat intake and its impact in aromatase production. Is there a recommended percentage of total calorie intake? | P | |
| | Effect of diet on cancer. Effect of milk intake in breast cancer (hormone in milk, Casein, etc) | P | |
| | What can I do to mitigate against its return or the development of another cancer? | PH | |
| | What can I do to prevent recurrence | H | |
| | What foods should patients eat that are most likely to prevent cancer reoccurring | PR | |
| | Does stopping smoking really reduce recurrence? | P | |
| | What is the optimal diet to help prevent cancer recurrence? | H | |
| | What diet changes have the most impact on future prognosis? | P | |
| | Does turmeric help ward off cancer? | P | |
| | Does participating in exercise after cancer treatment reduce the risk of recurrence | H | |
| | As a PET scan demonstrates that cancer cells thrive on sugar, do you think it would be helpful to eliminate sugar and refined carbohydrates (which metabolise to sugar) from my partner's diet? | R | |
| | Does a vegan diet help prevent cancer recurrence | H | |
| | Is there any real evidence from previous Research that a "non dairy diet" will prevent the return of my breast cancer? | P | |
| | Is it possible for those of use treated with surgery and chemotherapy up to 7 years ago to benefit from development of treatments to reduce the risk of recurrence? | P | |
| | Will diet effect the chance of cancer returning? | P | |
| | what is the effect of diet on cancer | P | |
| | Which diet is best to follow after a cancer diagnosis? Is there any research that says avoiding dairy and red meat will delay the return of the cancer? | P | |

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| | and how to reduce risks of secondary diseases? | O | |
| | Does stress increase the chances of breast cancer returning? | P | |
| | What can I do to help it from not recurring? | P | |
| | The medical profession doesn't give much, if any, advice on diet. As a breast cancer survivor I would like to see a more integrated approach to health and diet. So I would like to ask: What research is being done to discover a link between diet and a recurrence of cancer? Is there any truth in the acid/alkaline diet? | P | |
| | Do vitamin supplements help cancer patients to keep healthy and/or help to keep cancer at bay. | P | |
| | What are the 3 most effective things I can do to reduce the chances of the cancer returning? | P | |
| | what increases the chance of the cancer returning | P | |
| | What can I do to prevent it from returning? | P | |
| | Will eating healthily 5-a-day, low alcohol consumption etc really help to prevent cancer returning? Or is it just that generally being healthy and eating well means you are at a lower risk of return. | P | |
| | Would giving cancer patients who were previously overweight or who have increased weight throughout the course of their treatment support and follow-up to follow a healthy lifestyle plan post treatment e.g. physical activity plan, diet, lifestyle help them recover faster from treatment and reduce recurrence | RH | |
| | Impact of diet can have on cancer progression | R | |
| | I would like to know how diet can affect my cancer. Would it be better to give up dairy or meat and become vegetarian or even vegan? How about organic v normal products? Alcohol? I have read about ketogenic diet and how this may be beneficial for cancer patients. | P | |
| | What are the lifestyle choices that can impact the chances of cancer avoidance for the future | H | |
| | There is some research on the benefits of turmeric and green tea on cancer. But it doesn't explain how to best consume it and how often. It almost just encourages people to pop a curcumin tablet in their mouth when actually that may not be the best way of absorption. | P | |
| | Should I be making any lifestyle changes relating to what carcinogen I had? | P | |
| | How best to prevent secondary cancers or recurrences? | P | |
| | What should I do to try and prevent recurrence. | P | |
| | What can I do to help stop the cancer coming back? | PR | |
| | We would like solid evidence surrounding prevention of recurrence in cancer patients through exercise. So, does increased physical activity reduce rates of recurrence in survivors of cancer? | H | |
| | How can I change my diet to improve my chances of avoiding a recurrence of cancer ? | R | |
| | Are particular forms of exercise more protective in avoiding a reoccurrence of cancer | R | |
| | Are there certain foods that have been proven to reduce the risk of recurrence of breast cancer | H | |
| | What can I do to reduce my risk of recurrence? | RH | |
| | Can diet and exercise influence prognosis following a diagnosis of cancer | H | |
| | What can be done to help prevent recurrence? | P | |
| | Is there a special diet to discourage cancer? | P | |
| | What is the best diet/food for someone continuing on chemotherapy and to help fight cancer | P | |
| | The impact of exercise on recurrence rates | H | |
| | Does aspirin reduce progression/recurrence rates? | H | |
| | Does diet have an impact on recurrence? | H | |
| | The effects of diet and supplements on both treatment and prevention both of primary cancer and secondary. | PH | |
| | IN light of all the conflicting information out on the web, what foods should you avoid or increase in the diet? E.G Turmeric, with Breast Cancer. Constantly told just to have a balanced diet. Not helpful. | PH | |
| | What can I do to prevent recurrences | P | |
| | What steps can be taken to improve risk reduction for future health problems (cancer and other conditions) after treatment for cancer? Are there life-style risk factors (e.g. smoking cessation, dietary improvement, increasing exercise) which could be reduced by post treatment or post diagnosis education or intervention? | H | |
| | Does cannabis oil have anti cancer properties? | P | |
| | How can I prevent a recurrence or metastasis? | P | |
| | Solid research based evidence on diet and cancer | RH | |
| | Do any types of food diets make a difference (ketogenic / plant based / China study etc) | P | |
| | Which aspects of a "healthy lifestyle" - are most likely to stop a cancer coming back? - e.g diet, exercise or a medicine like aspirin or metformin | H | |
| | What should I have done to prevent the cancer from returning? Change of diet, healthy live style did not make a difference. You are left living in constant fear. | P | |
| | I need specific advice about how to reduce incidence of recurrence. | P | |
| 12. What are the social, financial and economic impacts of living with and beyond cancer – how does it affect families, relationships, finances, work and use of NHS services? | The cost of having cancer - debt as a result of a cancer diagnosis | H | |
| | How does surviving cancer affect subsequent career and life chances? | P | |
| | What has the overall financial impact of your cancer been for you and your family? | H | |
| | How does Cancer affect older workers stamina, especially as everyone will have to work longer? I am concerned that due to a compromised immune system that older workers, like myself, will have their energy reduced and this could have a negative impact in their working lives? | P | |
| | How do individuals who have been diagnosed with cancer or beyond cancer manage their life, both within the workplace and in their own family life? | H | |
| | what is the financial impact of life after cancer diagnosis? | RH | |
| | Financial considerations. We have been almost ruined financially because of my cancer treatment and subsequent Bone Marrow Transplant. And no state pension for me til I'm 67! And next to no occupational pension as I haven't worked | P | |
| | How are peoples working lives/earning potential affected by cancer? | H | |

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| | The financial impact of cancer and how welfare and support agencies respond to this. For example many people with cancer are forced to continue to work due to ineligibility for benefits | P | |
| | How does a patient feel about their role within the family unit whilst living with cancer and beyond? | RH | |
| | How might personal health budgets help people undergoing cancer treatments or recovering from cancer treatments? | H | |
| | How has life changed for you as a result of living with cancer? | P | |
| | How have the long term side effects of radiation affected your ability to be in full/part-time employment? | P | |
| | What were the financial costs during treatment and ongoing? | H | |
| | How has a cancer diagnosis affected their relationships with partner, family and friends? | PR | |
| | I would like to know more about incurable cancers, like I have. There seems to be a focus on drugs and treatments that cure and offer remission. Little works seems to be publicised on the quality of treatments for reducing symptoms, the spread of cancers and on palliative treatments at the end of life. <u>What are the impacts on people generally of living with cancers over the long term?</u> What are the best approaches to dealing with it for patients, medical staff and carers? How can living longer term with cancers be made more positive. | P | |
| | What are the financial implications of a cancer diagnosis - what costs are incurred with loss of earnings, hospital visits, parking etc | P | |
| | what is the economic impact of breast cancer diagnosis on women | H | |
| | It the same way financial pressures become real. During treatment there's an attitude that money is not important and you spend what it takes to keep everyone going. Then you realise that this is going to be a longer term struggle. | RH | |
| | long term effects of diagnosis and treatment on psychological health and effects on relationships. | H | |
| | does a lymphoma diagnosis effect job options/prospects. | H | |
| | what are the key factors that affect quality of life LWBC. Are nay of these amenable to health care intervention / different interventions during treatment? (Not thinking about clinical interventions necessarily here, but about support services, information provision etc) | H | |
| | Financial implications of having cancer | H | |
| | Financial worries and how they affect the patient and their family - how much q cancer patient's income suffers after their diagnosis. | P | |
| | Relationships issues that occur after cancer. I know of some younger women who have survived breast cancer whose partners and husbands subsequently leave them as they can't cope with the wider ramifications. This ties in slightly to my other question, but is also a separate issue that would need to be looked into differently. This leaves the women as single parents which has wider ramifications on career, ability to work, pensions etc. The husbands may need more support in coping with partners who have had cancer. | H | |
| | What can be put into place to ensure that those living with cancer or beyond cancer are not 'penalised' for having or having had cancer? I am thinking particularly about negative financial impacts or career progression in the short and longer term | RH | |
| | how many people of working age are returning to employment, either, FT or PT after cancer treatment? Have they been supported to return to work? Have adequate adaptations been made for them to return to work? | H | |
| | Support financially adequate or not | P | |
| | How does a diagnosis of colorectal cancer, regardless of treatment, impact on social life, work life and relationship? | H | |
| | How does diagnosis change people's life values - both of patient and of partner/family? ie what is impact in terms of what they prioritise and value and how they live their life? Equally, if no change, why is this? | H | |
| | What is the impact of cancer diagnosis on the family - short, medium and long term? | H | |
| | what were the main challenges for you on receipt of a diagnosis these should be categorised family/dependants coping with your illness financial worries. benefits. prognosis worries access to treatment locally communication re the implications of your diagnosis communication /contact with my GP | PH | |
| | i want to understand the comparisons of people with and without cancer diagnosis in relation to ability to take part in social and work lives. How many people living with or following cancer treatments are affected adversely in contexts such as home life, relationships, working lives and activity. For example, would people unaffected by cancer have less fatigue or is it just that we are getting older and blaming it on the treatment or disease | P | |
| | What is the impact of having a chronic blood cancer diagnosis on employment status/the individual's ability to work? I am specifically interested in indolent lymphomas/leukaemias where 'watch and wait' can be an appropriate treatment plan. I believe this is something not widely understood by employers or the public. | H | |
| | How much does living with cancer cost over and above previous living costs? Is there any help to reduce costs (not necessarily through benefits or allowances. | PR | |
| | how many patients are able to return to their normal pre-cancer life - whether that relates to work, hobbies, child/relative care, studies etc. and what stops them from doing the things they used to do? | H | |
| | How do the after effects of cancer treatment affect the patient's ability to continue to work at the same job they had before diagnosis/treatment | R | |
| | I'd like more qualitative research into the lived experience of cancer patients to aid understanding of doctors, nurses etc | PH | |
| | Impact on social systems - families, children and work. | P | |
| | Long term effects in daily life and quality of life disruption for people who finish treatment when life is still full on (30-50 years old) - carrier/job, mortgage, children who require full attention, partner etc...? | P | |
| | The main barriers to returning to work post cancer | PH | |
| | The biggest challenge to returning to work | PH | |
| | Financial impact. Economic cost. | P | |

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| 13. What are the best ways to cope with the fear and anxiety about cancer returning (combining self-management approaches, treatments and psychological support)? | Do you always think that every pain in your body is cancer after a diagnosis? | P | |
| | living with the fear of recurrence | P | |
| | what is the best way to support patients living with the fear if re-occurrence? | H | |
| | What are the best ways to deal with "scanxiety?" (Anxiety relating to follow up scans) | P | |
| | My cancer, multiple myeloma, is treatable, but not curable, I'm always looking to the next 3 monthly clinic appointment. How can I put these thoughts aside, or, who can help me do this in order to live my life to the full? | P | |
| | How can I stop the worry of a cancer recurrence becoming overwhelming? | P | |
| | I'm still concerned after nearly twenty years, why I'm still having polyps removed. Every time I wonder if the cancer is coming back | P | |
| | What can you do about the fear of recurrence. | P | |
| | Help how to get through each day and face an unknown future | R | |
| | To what extent can digital resources (videos / blogs / files etc) help patients cope with fear of recurrence , uncertainty and the psychological problems of cancer recovery | H | |
| | How can we help people to cope with living with the anxiety of recurrence. What strategies help and in whom? | H | |
| | How can health professionals effectively work together with patients and carers to manage the chronic uncertainty and long term treatment of relapsing cancer | R | |
| | Cancers vary considerably and some are never considered cured - how do people live with that worry of recurrence? | P | |
| | How care healthcare be delivered so every time I come to clinic I don't get scanxiety? | H | |
| | How do you best deal with anxiety about the disease returning? | P | |
| | How can people best be supported to cope with the fear of their cancer returning? | H | |
| | Best way to deal with uncertainty or worry of cancer coming back | PR | |
| | What can be done to alleviate 'scanxiety' i.e. Anxiety around scans and results | P | |
| | how to live with the knowledge | P | |
| | The benefit/worry of having follow up appointments for patients who have achieved complete response from chemo. | H | |
| | How can I deal with the worry and uncertainty of cancer returning | H | |
| | How is anxiety about cancer relapse in these patients? And what are doing about this? | H | |
| | Trying to stay positive is a constant battle and individual. post cancer is it normal feel always hangs over you even if cured? | PH | |
| | How do I live with the concern that cancer will come back? | PR | |
| | The anticipatory dread with Follow up scans etc | R | |
| | What are you long term anxieties and concerns about living with cancer and beyond, and how can health care professionals best support you through this? | RH | |
| | I have been diagnosed with a blood cancer but have been put on 'watch and wait' but I have these constant feelings of anxiety and tearfulness, especially around the time of my blood tests? | P | |
| | How do patients live with the uncertainty of their future? | P | |
| | How do they deal with uncertainty | H | |
| | I am most interested in the psychological impacts of living with cancer, long term. As someone with follicular lymphoma, I am well aware that, despite being in remission for 7 years, my cancer is most likely to come back at some point in the future. Not knowing whether that might be in 6 months or 6 years time can be a strain and I know that there is very little support available on the NHS for people like me. How can this situation be improved for those of us with a chronic but indolent cancer condition? | P | |
| | Does counselling help with the anxiety about the cancer returning? | P | |
| | How do you feel when you have a scan coming up? | H | |
| | How do I cope with the fear of cancer returning? | H | |
| | How to allay the fears that the cancer will return when you felt perfectly well before the cancer was discovered and you now feel well again? How can you trust your body again? | P | |
| | How can I cope with scan anxiety? | R | |
| | What is the most effective method to address the fear of recurrence experienced by patients at the end of treatment. | H | |
| | How can you reduce the inner fear of the cancer coming back? | P | |
| | Where can I find help to assist me with coping with the negative feelings and thoughts of recurrence after finishing treatment? | P | |
| | Has it spread, You say no but how do I know that? Every twinge ache or pain might be another tumour. | PR | |
| | What are the best ways to cope with the fear of cancer returning ? | P | |
| | How do I move on when I have been told I have a 20% that the cancer will return for the rest of my life. I feel like a ticking time bomb | P | |
| | How is it possible to try and live a new normal life after cancer? without it ruling your every day and fear that it will come back? | P | |
| | How best to support post-treatment cancer patients in coping with the fear of the disease returning. | P | |
| | What is the best way to manage fears of cancer recurrence | H | |
| | Is there an evidence base for group based psychological therapy to manage fears of further deterioration or spread of disease in people living with metastatic cancer? | RH | |
| | When do you stop worrying about recurrence? | P | |
| | I'm scared of cancer returning | RH | |
| | What CBT exercises might be available and helpful to assist with anxiety and fear of relapse? | P | |
| | How do you manage the anxiety about recurrence? | P | |
| | How to manage the issue with thoughts of recurrence of the cancer | P | |
| | What are the most effective ways of dealing with fear of recurrence? | H | |
| | Mentally i can never rid the thought of getting cancer back | P | |
| | How can people be supported with health anxiety related to cancer recurrence? | RH | |
| | How can health care professionals be trained/educated in the importance of not sending anxious people for multiple investigations as this worsens and maintains anxiety about recurrence | RH | |

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| | How do you take away the fear if the word cancer | P | |
| | How can people cope effectively with the worry that the cancer may return sometime later in their life? | P | |
| | What additional methods, support, activities are proven to help with living with the fear of recurrence in the future | H | |
| | What tools are effective in helping people who have been through treatment to manage their fear of recurrence? | P | |
| | What do professionals need to do to help support patients living in constant uncertainty? | H | |
| | How do I cope with the uncertainty of the cancer recurring | H | |
| | I've also struggled over the years I've lived with secondary disease to find a way to overcome the knot of fear that still remains in my stomach about when and how this disease will raise its ugly head and do its worst again. What to look for, and when to know it is the cancer and not the other usual illnesses and issues we all suffer when ageing. i.e. I often worry when I have a bad headache or migraine that I have a brain tumour. Or, what I believe to be arthritis often causes pain where I know the cancer could be causing me issues, and therefore I always fear that it has kicked off again. (I have bone secondaries, and have already had a replacement hip). | P | |
| | What are the most useful strategies to manage the psychological impact of outpatient appointments? | P | |
| | Will the fear of cancer returning ever go away? | P | |
| | living with uncertainty is hard. how can I make this easier? | PRH | |
| | How to manage the worry of a cancer diagnosis returning once in remission. | P | |
| | Returning to f/u clinic is quiet stressful and brings the whole initial diagnosis/treatment back as 'if it was yesterday' it feels like post traumatic stress disorder. If this happens to others it would be great to know and to develop or be given coping mechanisms. Triggers are not just the clinic visit but as little as the bleep of an alarm on an IV pump. None of this seems to get better with time | P | |
| | How do you look forward and not back ? Not become permanently worried well | P | |
| | How can we learn to cope with the thought the cancer might recur? | P | |
| | How can primary care professionals help patients who have had cancer deal with the ongoing worry of recurrence | H | |
| | How do you forget the fact you are living with cancer and try to live a normal life when you are being monitored every 3 months? I find I rarely switch off from thinking about it. | P | |
| | How do you help people when the future is really still unknow post primary treatment.? | PR | |
| | What mental support is available to aid recovery. Dealing with doubt and uncertainty is one of my biggest issues. | P | |
| | Does it help to have full information e.g. re prognosis predictions in order to be able to live more fully with cancer or does this restrict the ability to 'get on with life as normal'? | H | |
| | The fear of reoccurrence This was by far the most difficult problem for me and is something that never completely leaves you. I think anything that could be done to dispel many of the myths about cancer such as its always terminal and there is no cure would ease the fears of many patients. | P | |
| | How do you get over it? How can you not spend the rest of your life worrying about whether it will come back? | P | |
| | Will I ever be able to fully relax? | P | |
| | Dreading the next PSA and the time when PSA will start to rise again. | R | |
| | What is the best way to deal with 'has it returned' fear every time you feel under the weather? | P | |
| | Fear of recurrence is talked about by many researchers as being important but I am not aware of any practical approaches having been developed to help those survivors who suffer extreme anxiety from this | R | |
| | Recurrence fears - and reality - and how we fare with these challenges physically and psychologically. | P | |
| | Coping with fear of recurrence. Are there sufficient mental health support services/counselling to support both cancer patients and their families or those going through diagnosis. Having a diagnosis of cancer often creates a PTSD reaction - a threat to life and therefore recovery includes the need for supportive activities, such as art therapy, laughter, sharing stories and one to one counselling for both patient and relative. | RH | |
| | How can I stop worrying about it coming back? | P | |
| | Living with uncertainty | RH | |
| | How do you cope with psychological side after treatment and when you are cancer free with the uncontrollable fear of it coming back | PR | |
| | How to live with the fact that the cancer may return. Who would you seek support from? | P | |
| | Managing personal and family anxiety regarding fears of relapse | R | |
| | How do I overcome anxiety left behind from cancer and treatment? | P | |
| 14. How can we predict who is at risk of developing mental health conditions in people living with and beyond cancer (e.g. depression) and what are the best ways of supporting those with mental health conditions? | What is the answer for long-term fatigue and anxiety as a result of surgery and radiotherapy for head and neck patients? | P | |
| | And after 2 years am now facing some black thoughts. | P | |
| | Surviving cancer is a lonely, scary place for the patient and their support. | R | |
| | this can sometimes feel like additional pressure for patients to feel grateful/happy as certain milestones post treatment are achieved but sometimes as time goes on, the anxiety levels increase and often patients are on their way 'out of pathway' when it accelerates | P | |
| | How likely is it that someone with a cancer diagnosis will experience mental health problems as a result? | P | |
| | What impact does a Cancer diagnosis have on mental health? | P | |
| | Do ALL patients need some intervention- what proportion can just get on with life and which cancers | H | |
| | We all have mental health, good or bad, and I would like to know what additional support is given for those with mental health needs, existing pre or post diagnosis, in order that they may manage both their mental health and cancer? | PR | |

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| | How can I cope with a mental illness e.g. depression after my cancer diagnosis? | P | |
| | What are the most effective ways of managing anxiety following treatment? | H | |
| | What is the best way to deal with anxiety and depression following a cancer experience, particularly when the mental effects are felt long after the physical experience | P | |
| | How to deal with those dark thoughts in moments which every patient most get and how to cope with those periods leading up to reassessment by the professional staff, whilst positive thinking may help the constant media bombardment about Cancer and its consequences does little to help!!! | P | |
| | how best to identify and manage symptoms including depression and anxiety | H | |
| | How many breast cancer survivors who are on hormone treatment such as tamoxifen and zoladex, suffer with anxiety or depression | P | |
| | Ongoing anxiety issues around recurrence for younger patients who have had cancer. concerns about having children, looking after young children and life expectancy. My younger brother has had melanoma, now clear, but it has left him with lots of on-going anxiety and he is seeking counselling 8 months after definitive treatment. | H | |
| | Where can I find help to assist me with coping with the negative feelings and thoughts of recurrence after finishing treatment? | P | |
| | What are the most effective psychological interventions for patients with long term fatigue and depression? | H | |
| | It is difficult to deal with psychological/ mental penchant of 'I don't know' (pessimistic rather than optimistic) when trying to be positive. It wears you down. [?] How is it that patient optimism can be kept at a good level and how best can the family of the patient be made aware of the problems likely to be encountered and how at least to deal with this or at least how best not to be overly stressed by 'not knowing'. | R | |
| | At the end of treatment it becomes increasingly difficult to live with the uncertainty and preoccupation with my diagnosis. I would have liked to have been offered without me having to ask or search for sources of support which are practical | P | |
| | Is post treatment depression common ? | P | |
| | Why the depression never leaves. Why do I no longer feel like a whole woman. Why do husbands abandon you after breast cancer why is your life never the same again. Why am I angry all the time???? | P | |
| | The links between PTSD and cancer diagnosis - and | P | |
| | What suggestions do you have for coping with the anxiety after being diagnosed ? | P | |
| | links to cancer survival and long term depression | PRH | |
| | I have CML. I would like to understand more about support for mental health, anxiety and depression. Coming to terms with having a chronic condition. Are there plans to provide yoga/mindfulness/meditation training? I have found these very helpful. | P | |
| | How can I deal with my mental health as my thoughts are consumed with cancer and the what ifs | P | |
| | Learning what it means to live with uncertainty. Cancer moved in with us, we didn't move in with cancer. Abandoning time horizons without abandoning hope. Trying not to think too far ahead - particularly during the treatment(s) phase. | R | |
| | Why is mental health ignored when it is as damaging as cancer? Especially with "non sexy"/not socially acceptable cancers like bowel? If you are already vulnerable in some way and have ongoing post cancer symptoms it can lead to serious depression. | P | |
| | Would like to see more help given to people with stress and depression after treatment | PR | |
| | Are talking therapies the only way to deal with my annoying propensity to cry all the time? Isn't there a pill or infusion to rebalance me? | P | |
| | How many survivors of cancer go on to develop depression or other mental health conditions? | P | |
| | I suffer from anxiety and taking antidepressants - will it ever subside? | P | |
| 15. What are the best ways to support people living with and beyond cancer to make lifestyle changes to improve their health? | Does a health coaching approach to self-management support make a difference to key survivorship outcomes? | H | |
| | HOW CAN WE PROMOTE SELF MANAGEMENT OF CANCER AFTER CARE | H | |
| | I have found that by continuing a fitness regime through and after my treatment it is of benefit both physically and mentally, what is the current position on helping cancer patients with this? | P | |
| | More evidence and practical application of exercise in patients following treatment | H | |
| | What interventions are effective in encouraging healthy lifestyles for this group? | H | |
| | What can I do if other health conditions i.e. arthritis stop me from even walking briskly? What other resources are available to help me get more exercise? | P | |
| | What's the best way to lose weight post-treatment factoring in fatigue, changes to body and general lack of confidence in body? | P | |
| | How important is it to a cancer survivor to have control of what they do after cancer? Do can mean job, activities, lifestyle etc | P | |
| | How can we facilitate more holistic treatments such as gardening therapy, meditation/mindfulness, yoga being widely available as part of supported self management and regaining a sense of control to everyone who would find them useful. | PH | |
| | Why is exercise considered to be a universal cure for cancer-related fatigue when many patients suffer extreme "payback" after all forms of exertion ? | P | |
| | How and when is the best 'teachable moment' to create change behaviours in patients - particularly with respect to increasing exercise | H | |
| | How can we best achieve weight loss in the obese breast cancer patient post diagnosis | H | |
| | What resources and support can we offer to patients to help them recover their fitness after treatment. | P | |
| | What cancer patients are most likely to respond to self care interventions which can impact and optimise wellbeing | H | |
| | What strategies work best to enhance patient activation to undertake self care activities | H | |
| | Can intentional weight loss help cancer patients with overweight or obesity? | H | |

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| | How to exercise without causing exhaustion or further damage. | P | |
| | What is the best exercise prescription for cancer survivors? | O | |
| | Why is their so little support to improve lifestyle (physical activity and diet) and therefore my chances of living a long and healthy life? | H | |
| | When is the 'teachable moment'? How soon or long after 'end of treatment' is most effective for patients to attend educational events | RH | |
| | Should self management programmes be mandatory? | H | |
| | Why is there no fitness/physio programmer to help people recover from cancer? | P | |
| | How can people best be helped to stop cancer coming back? | PR | |
| | What are the most effective methods to teach people what they need to know living beyond their cancer in respect to how to manage their health and wellbeing? What is most effective in terms of emotional well being and physical health. i.e. teaching when to contact different professionals, what happens next, what new normal will look like, what symptoms/side effects are normal, what should be investigated, what activities to be cautious over or to definitely try, where to access support, financial implications of treatment/ recovery. | P | |
| | Using behavioral change/health coaching approach, how we can we help patients to be more physically active on and after treatment? | H | |
| | How much support do people living with cancer need to be physically active? Or Do people living with cancer receive the support they need to be physically active? | H | |
| | Does teaching self management techniques during treatment (such as active lifestyle, fighting fatigue, dirty advice or anxiety management) have a longer term impact on a person's physical and psychological wellbeing and quality of life. | H | |
| | How can we encourage survivors to continue to exercise in the long term to maximise secondary cancer prevention and cardiovascular outcomes? | H | |
| | How can we encourage all patients to participate in exercise programmes, particularly those who live far from cancer centres and cannot easily participate in supervised exercise trials or programmes? | H | |
| | Are many people are exercises post cancer treatment? do they find macmillan move more beneficial? do they know about it? | U | |
| | What behaviour change interventions related to lifestyle factors work for who and when | H | |
| | How can we best support those living with and beyond cancer to be physical active. We know there are huge benefits to be gained through regular exercise but we don't know - 1. when is the best time to discuss ways to become physically active and who should lead these discussions 2. how best to support people to be active through their treatment 3. how best to support people to be active in the months and years following treatment completion | H | |
| | Should wellbeing support be offered to all people diagnosed with cancer or living beyond cancer - if so what type? | R | |
| | How can patients who have lost significant muscle and mobility post treatment for cancer be supported to build muscle and mobility | P | |
| | Should cancer rehabilitation and support be part of other healthy living and recovery programmes? | RH | |
| | Would a exercise/fitness or physical function assessment as part of the usual treatment 'work up' prior to commencing chemotherapy treatment facilitate early positive lifestyle (exercise and/or physical activity) behaviour change in people with cancer? | H | |
| | Does giving the cancer patient a healthy lifestyle plan e.g. physical activity plan, diet, lifestyle changes make the cancer patient feel empowered and positive about something they can do to beat cancer | RH | |
| | How does gender influence access and engagement with supported self-management services and activities for those living with cancer? | R | |
| | Are Cancer patients able to access leisure activities on 'prescription' to enhance their overall wellbeing eg swimming, gym,art class, choirs, book groups etc? | H | |
| | Doctors prescribe a an exercise regime for patients to help themselves fight cancer. Could a trail be arranged that compared outcomes. | P | |
| | What rehab support and advice is available to enable people to be as independent and fit as possible during their treatment? | PH | |
| | I don't think anyone can say you will never get cancer again. My question is, how do you reinforce positive, healthy aspects of lifestyle that could reduce your chances of cancer recurring? | PRH | |
| | Can people who have been treated for cancer practically/feasibly perform vigorous intensity exercise in line with the evidence for survivorship? | H | |
| | Are people living with and beyond cancer aware of the evidence in vigorous intensity physical activity or guidelines and survivorship and if so would it change their level of physical activity? | H | |
| | What would help encourage people to make healthy lifestyle choices following diagnosis and/or treatment? | H | |
| | How can I find help to self-manage a recovery package such as advice on exercise, diet and dealing with a fear of recurrence? | PR | |
| | What factors influence people living with & beyond cancer to make changes in 'healthy behaviours' linked to diet and physical activity | H | |
| | Do Motivational Interviewing skills in nurses/staff affect/improve outcomes in people attending health & well being events eg readiness for change or actual change. | H | |
| | Support for people (healthy lifestyle, psycho-social support) for people in full time employment. Not having to take time off work to access this. | P | |
| | To investigate weight loss techniques in men after treatment for colorectal or prostate cancer | H | |
| | I try to exercise regularly as per national guidance (over the last 18 months my average is approx. 165 mins per week of vigorous exercise as measured with a chest strap heart rate monitor). However, it never invigorates me. Whenever I read about exercise in the media, or see people on TV they always say how they struggled at first but after a couple of weeks they really feel better etc etc. This isn't how I feel at all! (It is how I used to feel though). Now, I do it because all the evidence seems to point to it preventing all sorts of things but I just struggle through it. | P | |
| | How much can a person exercise during and after cancer? | H | |

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| | Does specific exercise in a group with people with similar conditions, led by a clinical professional have more of a benefit than exercising alone or in an 'ordinary exercise setting e.g. local gym. | H | |
| | how can we best support these patients to enable to more effectively self manage and get their confidence back. | H | |
| | How much do you value exercise advice from a physiotherapist. | H | |
| | What is the optimum way to deliver health & wellbeing support - timing in pathway, content i.e. generic versus site specific | H | |
| | Why are not the evidence-based research studies showing simple lifestyle changes increase the chance of surviving longer made mandatory recommendations to newly diagnosed cancer patients? | P | |
| | Following on from Q1, why are these patient-led treatments supported, encouraged by regular monitoring and feedback similar to clinical treatments, especially when such lifestyle changes would probably increase survival times comparable to clinical treatments? | P | |
| | How to keep active and fit | PR | |
| | What steps can be taken to improve risk reduction for future health problems (cancer and other conditions) after treatment for cancer? Are there life-style risk factors (e.g. smoking cessation, dietary improvement, increasing exercise) which could be reduced by post treatment or post diagnosis education or intervention? | H | |
| | How do we best advise patients regarding nutrition? | H | |
| | How can we make patients and their supporters aware of the importance of exercise in managing disease and improving wellbeing? And, also important, how can we better facilitate people taking advantage of this knowledge bearing in mind their lack of energy and their possible issues with body image? | H | |
| | What is the benefit of 'exercise prescription' in cancer survivors? i.e. Evidence for 'Exercise Oncology' | H | |
| | What type of exercise would be beneficial for patients with secondary cancer and how what would encourage more patients to participate | PR | |
| | Who can help me follow a vegan diet while I'm on chemo? | PR | |
| | What types of support are most effective - and most cost-effective - in enabling people LWBC to enjoy good mental wellbeing, be physically active eat a healthy diet etc. There are a multitude of apps, and self-help resources.....but which really work in enabling effective self-management? | H | |
| 16. If people with cancer are involved in their own healthcare decisions (including participating in multi-disciplinary team meetings with health professionals), does this lead to better outcomes? | Is the same true of patients who are actively involved in their own healthcare decisions [better outcomes and better overall survival] | P | BMJ Open. 2016 Jul 21;6(7):e012559. doi: 10.1136/bmjopen-2016-012559. Multidisciplinary team decision-making in cancer and the absent patient. |
| | What are the barriers to patients participating in MDT meetings that discuss their care? How can these be overcome? | R | |
| 17. What are the psychological and social impacts on children who have a parent (or parents) with cancer, and what are the best ways to support those children? | What have the long term implications of you cancer have been for your children/dependents? | H | |
| | What is the impact of experiencing a parent with cancer on the child's life chances? | P | |
| | Is there a long-term change in family dynamics after a cancer diagnosis and cancer treatment? | H | |
| | Include also effects on children, they both worked at weekends and holidays from age 16, affecting their A level results. Our middles feriens paid their children so they could study. | P | |
| | Psychological impact on children of those with parents living with cancer/ repeated cancer. | P | |
| | I am a GP. Cancer can have a devastating effect on the mental health of the children of people especially mothers who have cancer and particularly if there are protracted treatments/courses. Are there any plans to help these children? | H | |
| | The psychological impact on school age children of having a parent with cancer. | H | |
| | What are the key considerations for children of parents diagnosis with cancer? | H | |
| | What is the impact on children of people experiencing cancer on their view of health (eg are they more likely to experience health anxiety, thinking they may have cancer because their parent had this condition) | P | |
| | Impact on children when a parent dies from cancer | H | |
| | I would like to see what the impact of cancer has on children of a parent who has cancer, not just the short term impact but the long term. How do they manage the cancer of a parent? If and when should they be told? How are their anxieties met? Do they fully understand? Do they need to fully understand? Should the parent die from cancer, is there services for this child to access to help cope with the loss of a parent. Specifically is there a service dedicated to children whose parent has died of cancer, rather than a general bereavement service? | RH | |
| | Are there long term psychological effects for children who have had a parent diagnosed with cancer? | PH | |
| | How do I best support my children financially and emotionally? | RH | |
| | What is the long term emotional impact on children and teenagers when a parent has cancer? | H | |
| | anxiety in children and their perception about cancer and their own health. | RH | |
| | Family impact where cancer causes early death | R | |
| | How can we support children and young adults who have lost a parent to cancer? | H | |
| | How can a parents cancer impact emotionally and psychologically on their teenage children? | PR | |
| | How can children whose parent has been diagnosed be supported? | P | |
| | What support is currently avilable to dependent children who's parent's have been diagnosed with cancer. What impact does this have on them long term. | PRH | |
| | Why is there very little done to support teenagers / kids who look after their terminally ill parent .. I've been talking to young lass who's mum is near the end of her cancer journey... she screams and says hateful words and although there's home help twice a day , there's no one there talking and counselling her .. I know she could phone help line but she had no info on this . Why can't young carers have someone go visit them so they can talk about how they are suffering... | P | |

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| | How can we offer support for families who are struggling with changes in their loved one post cancer and want to reassure and 'focus on the positive' | H | |
| | How can I support my children during cancer diagnosis, treatments & living with uncertainty | H | |
| | How do I ensure my children are not adversely affected by my cancer diagnosis? I'm not dying but have a very uncertain future ahead of me. Not sure if I'll be here in ten years. | P | |
| | What happens to people who miss the criteria for certain supports e.g. older parents of young children, who miss out on support for young families affected by cancer (e.g. I was diagnosed with BC at 46 when my son was 6 - didn't qualify)? | P | |
| | What can be done to support children who have parents with incurable/terminal cancer? | P | |
| | I have 2 young children aged 11 and 8. No support has been offered to us as a family to help us cope with my cancer diagnosis. what is the impact on my children without any support and how could this be offered more readily without having to fight through the system to get it? | P | |
| 18. What is the best form of rehabilitation and other support to help people living with and beyond cancer return to or maintain their usual activities (e.g. work)? | How can we better support patients who are hoping to return to work. | P | |
| | Back to work support programmes. | P | |
| | How can people be supported to regain confidence and return to normal activities, such as work, once cancer treatment is over? | H | |
| | What support should be offered to patients returning to work after/during cancer treatment? | P | |
| | A lot of men / women do physical work and are unable to return to their previous jobs this comes as a shock to them and affects their whole lifestyle and adds financial burden and distress so need all their options explained | RH | |
| | How should the health services monitor and support patients living with long term side effects | H | |
| | The age for retirement is increasing. Cancer is a disease, in the main, of older age. How can people of employment age, a growing group, be best supported to return to work? What kind of rehabilitation programme for return to work would be cost effective in the short term and long term? | HR | |
| | What is the most effective way to help people return to work after cancer treatment, especially those who weren't working at diagnosis (in education/parenting/unemployed) | H | |
| | Impact of non medical holistic care on getting people back into the workplace (ie reducing numbers claiming benefits etc), or particularly young people back into education and having fulfilled 'normal' lives | H | |
| | Quite a few of cancer patients have to go back to work full time after treatment and have trouble accessing help with regards to health and wellbeing out of normal working hours, what can be developed to help working cancer patients to gain access to support especially around coping and dealing with fatigue. | P | |
| | What is the best way to support those with cancer to continue working ? | PR | |
| | Employment support, whether returning to previous job or seeking work after cancer experience | P | |
| | What help would be most useful [RETURNING TO WORK] | PH | |
| | What do we need to include in a support/rehabilitation program for end of life cancer patients that are no longer classed as end of life? | R | |
| | What are the key components of cancer rehabilitation for optimum outcomes? | H | |
| | If each cancer MDT had access for its patients to a cancer rehabilitation team (PT, OT, clinical psychologist) would a) clinical outcomes b) patient reported outcomes be improved? | H | |
| | Do you feel there would be a place for more support/rehabilitation for patients living with cancer and beyond? | RH | |
| | What is the value of early rehabilitation interventions in people who need treatment for musculoskeletal cancer | H | |
| | How does OT input facilitate discharge | H | |
| | How many GP appointments can be saved by patients attending community cancer rehabilitation? | H | |
| | To what extent do people affected by cancer require specialist rehab versus generic rehab services? It would be helpful to know this for key areas such as lymphoedema, pelvic radiation disease, cardiovascular disease, osteoporosis, and sexual dysfunction. | O | |
| | Does early rehabilitation help after surgery or should this wait till after radiation therapy? | H | |
| 19. What are the best ways to manage the consequences of nerve damage caused by cancer treatments? | Peripheral neuropathy is a major ongoing side effect of some chemotherapy drugs. How can it be avoided? | P | |
| | What new drugs can be developed to reduce the pain of those who already have it [peripheral neuropathy], given that steroids often cause more problems than they solve? | P | |
| | How do I best manage peripheral neuropathy long term? | H | |
| | What can help patients live with peripheral neuropathy? | H | |
| | Is research being done into effective pain management of nerve damage resulting from cancer treatment | R | |
| | How do I prevent or manage postural hypotension related to chemotherapy – autonomic neuropathy? | H | |
| | Does compression hosiery exacerbate neuropathic pain? | P | |
| | What can help in the management of peripheral neuropathy which begins to be noticeable 5 plus years after treatment and becomes progressively worse, causing difficulty lifting up feet properly when walking and particularly using fingers for some of the fiddly every day tasks such as doing up buttons, doing up zips and belts, putting on shoes and doing them up, writing, using cutlery, holding food to prepare and to eat, holding handles of cups, washing and drying up, picking up small items, opening cards and so on. This impacts so much on daily living, causing dependency eventually. | R | |
| | Would a programme of fine exercises, concentrating on hands and feet, started immediately after treatment, with ongoing encouragement to continue, help patients with peripheral neuropathy? | R | |
| | If we know what causes peripheral neuropathy, can adjustments to treatments prevent or lessen it? | R | |
| | Late side effects of chemotherapy e.g late onset peripheral neuropathy | PH | |

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| | Late effects of platinum based treatment - are there any cures for these including paraesthesia in feet? | PH | |
| | I have come through 8.5 years of Mesothelioma and as I'm the only one alive from the MK3475.28 Immunotherapy trial. How do you build your body back up from the Chemo Wreck that I am. Peripheral Neuropathy means I still lose my balance when tired and my hands still are twisted. | P | |
| | neuropathy - mechanism for this, how to prevent and any way of improving it. | H | |
| | How can peripheral neuropathy be prevented or minimised (I had oxalyplatin), or healing encouraged? | P | |
| 20. How do the support needs of people with rare and less common cancers differ from people with more common cancers, and how are those needs best met? | How do survival needs of rare disease patients differ from more common diseases. With my interest in sarcoma I would highlight: a) mutilating surgery - amputation, facial reconstruction b) endoprosthetics, especially in those originally treated as children/teenagers c) those on daily medication - imatinib for GIST, where we have 16 years survival | P | |
| | How can sufferers from rare cancers be given adequate support? | P | |
| 21. What can be done to reduce and manage the impact of cancer treatments on people's sex lives? | What are the most effective interventions for the management of sexual pain in women after multi-modality treatment for pelvic malignancies? | H | |
| | What are the most effective psychological or psychosexual interventions for the management of persistent loss of sexual desire / interest (accompanied by distress) associated with treatment for cancer? | H | |
| | What are the most effective interventions for the management of orgasmic changes in men and women following treatment for cancer? | H | |
| | What is the best way to manage sexual concerns? | H | |
| | How can the sexual health needs of gynaecological cancer patients be better addressed? | P | |
| | Are biopsychosocial interventions readily advertised and available to women experiencing sexual dysfunction post treatment for cervical cancer and are these interventions effective in improving pain and sexual function? | P | |
| | How to mitigate the possibility of erectile dysfunction as a consequence of treatment? | P | |
| | Are vaginal dilators used during/after radiotherapy for pelvic cancers effective? Are they acceptable to patients? Are there any alternatives? | H | |
| | How do you regain libido that has been lost as a result of breast cancer and subsequent treatment? | P | |
| | The psychological impact of having my body decimated by the radiotherapy is profound in terms of my sense of being a woman, and the impact on relationships subsequently. I had pelvic chemoradiotherapy for rectal cancer. My whole genital area is wrecked as far as any subsequent sex life goes and more than the physical problems the psychological impact of feeling profoundly unattractive to men now is a cost which nobody can imagine unless they have experienced it. This goes to the very deepest levels of a sense of identity. Is anyone doing any research on what can help people like me - hopefully more targeted treatment so it doesn't wreck the whole area, but also educating professionals in why the treatment can be so devastating as well of course as saving lives. | P | |
| | Long term effects on sexual relationships following a cancer diagnosis in younger people .. | P | |
| | What Psychosexual support should be provided for patients who experience late effects of radiotherapy? | P | |
| | The impact of cancer and the associated treatments on sexual functioning. | H | |
| | Is there any real sex life after cancer for men | P | |
| | How your sex life is affected. | PR | |
| | Are post-treatment supportive interventions additive (i.e. Is psychological support plus sexual function support better than either alone. | H | |
| | what advice should be given to men (and their partners) who have prostate cancer in order to help them with the loss of libido and with their relationships? | PR | |
| | Can ED be reversed in patients treated with radiotherapy for prostatic cancer? | P | |
| | What help can be given to men suffering from ED as a result of hormone and radiotherapy? | P | |
| | How can sex and romantic relationships recover after one partner has been a care for the other? | P | |
| | Is there any research being done to alleviate or even overcome erectile dysfunction which occurs after a radical prostatectomy ? | P | |
| | How is libido and an enjoyable sex life maintained after hormone related cancer? | P | |
| | I lost my sex drive after and have never got it back | P | |
| | REAL interventions re sexual intimacy - I run an intervention for patients which is more than signposting - it is short and sweet and patients report it is very helpful | H | |
| | Orgasm triggers a spate of reflux which is unpleasant for both parties. | R | |
| | In the future what treatments may be available which significantly reduce the risk of erectile dysfunction? | P | |
| | One of the biggest things for me was the early onset of the menopause, following my first chemo regime at age 37. It was never discussed, not actually mentioned as a side effect, and rarely re-visited since. I have had I assume all the usual side effects of the menopause, well I assume so anyway, but have always just assumed they were as a result of various chemo's and therapies that I've received and that I just have to put up with them. My sex life has been severely affected by all this, which has had an enormous knock on effect for my personal relationship with my husband. | P | |
| | How to have/maintain a sex life | PR | |
| | How does cancer treatment affect patient's ability to have a normal (i.e. as before) sex life? | R | |
| | How much is sex life disrupted by a cancer diagnosis and treatment? Is this area routinely addressed by oncology staff? | P | |
| | Why do some people experience a loss of libido after chemotherapy and how might this be managed? | P | |

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| | As a woman is there enough consideration and help about sexual function after cancer treatment? | R | |
| | Best way to support men with impotence | P | |
| 22. What are the best ways to support people living with and beyond cancer who live alone? | What should the priorities be for patients living with and beyond cancer, particularly those living by themselves, to maximise quality survival? | P | |
| | What is the best way to support older patients who live alone through chemotherapy and recovery. | RH | |
| | How do we reach those facing cancer alone who find it difficult to access help, and who would benefit from professional support? | H | |
| | There is not enough after care for people who are on their own, this in turn leads to depression & a possibility that the cancer will return, will more care be available to single people? | P | |
| | How will I continue to cope with daily living and cancer on my own - I have no family nearby- as the end comes nearer | P | |
| | How does a patient get help and support if he/she lives alone | R | |
| | Living alone with physical difficulties in addition to cancer | P | |
| | Having been diagnosed with two very different cancers, breast cancer and Sarcoma. I am being treated in three different hospitals and I have found it sometimes difficult to explain my medical history to the different departments and hospitals. I have no immediate support so I am often on my own and sometimes feel rather overwhelmed with trying to put everything together. The NHS is amazing and I am so grateful to them but sometimes I do feel a bit alone and confused with my different cancers and specialists. | P | |
| | What happens if the patient is elderly and has no family, no support but effectively alone, when they have cancer | H | |
| 23. How is cancer perceived across multiple black and minority ethnic groups – what are the similarities and differences? | How is cancer conceptualised across multiple black and minority ethnic groups – what are the similarities and differences. | H | Cancer fear and fatalism among ethnic minority women in the United Kingdom. Vrinten C, Wardle J, Marlow LA. Br J Cancer. 2016 Mar 1;114(5):597-604. doi: 10.1038/bjc.2016.15. Epub 2016 Feb 11. Multiple small studies characterising cancer concepts in individual groups. |
| 24. Can lymphoedema be prevented? If not, how is it best treated/ managed? | How should lymphorrhoea be managed in advanced cancer? | RH | There is some literature on managing. |
| | Lymphoedema - what can be done to identify at risk individuals before treatment starts? | P | |
| | How can lymphoedema be prevented in people who have lymph nodes removed? | P | |
| | Ways to prevent lymphoedema after ovarian surgery | P | |
| | What interventions could be made to help with hypertension caused by untreated lymphoedema and fibrosis? | P | |
| | Are aquacise and/or aquajog effective in managing lymphoedema? | P | |
| | Prevention if possible. Information(better now than 18 years ago) on possible development of lymphoedema | U | |
| | Why has lower limb lymphoedema been ignored? And why are those suffering with this life long legacy (from radiotherapy and/or surgery) not being referred to musculoskeletal specialists for possible help? | P | |
| | How can I prevent my lymphoedema in both legs from getting worse ? And will there ever be a cure for it ? | P | |
| | What is the best way to support people to empower and manage themselves living with and beyond cancer, particularly with lymphoma which becoming akin to a long term condition. | O | |
| | What can I do to lessen the risk of lymphoedema? | P | |
| | What information about lymphoedema, reducing its risk and early intervention should be provided for people with gynaecological or male genitourinary cancers? | RH | |
| | How can I prevent any delayed side effects of treatment ie Lymphoedema . ? | P | |
| | Has the treatment you received for cancer caused other ongoing medical conditions e.g. Lymphoedema? | P | |
| | Does early physiotherapy help prevent lymphoedema in limb following surgery and/or radiotherapy? Some patients get very limited access to physiotherapy, it varies around the country. | P | |
| | Does early referral to a Lymphoedema Clinic make a difference to development of lymphoedema? Especially thinking of leg lymphoedema in sarcoma. | P | |
| | Why is the subject of lymphoedema not properly covered during and after cancer treatment? | P | |
| | Lymphoedema cure ? | P | |
| | Preventing lymphoedema following breast cancer surgery - we need a much better evidence base on what would help | P | |
| | Any benefit in offering 'carers' simple help/advice in basic massage techniques? Specialist help was available in our case but has now been withdrawn. | R | |
| | Lymphoedema issues and treatment and more general knowledge from those who don't know of the complications for living beyond cancer. | P | |
| | Are patients with potential lymphoedema aware of the early symptoms? What should they do if they become apparent? How to avoid the condition as much as it is feasible? | P | |
| | How can patients with chronic lymphoedema get help, support and training to manage the condition so they can lead a full life socially and professionally? | P | |
| | How can we better help people with cancer-related lymphoedema to successfully self-treat and control their lymphoedema symptoms and live as normal a life as possible, unrestricted by lymphoedema and its treatment. | H | |

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| | <p>what impact does venepuncture, and other medical procedures which puncture the skin, have on the development of lymphoedema - both for those 'at risk' of developing lymphoedema following cancer treatment and for those who already have developed swelling. Which procedures are relatively low risk and which are high risk? A recent systematic review recommended that these precautionary measures were not supported by the evidence, but in my opinion the review was flawed and their conclusions contentious. The cited evidence was drawn from studies where the impact of venepuncture was never the focus of the study. I am not aware of any study which compares the outcomes of individuals who avoided venepuncture and those who did not. Fear of developing lymphoedema is one of the greatest concerns for women post breast cancer, and I don't know whether we are unnecessarily fuelling this fear with the precautionary advice. However, most practitioners know of women who developed lymphoedema, or whose existing swelling was exacerbated, following venepuncture.</p> | H | |
| | <p>Despite improvements in cancer treatment which will reduce the incidence of lymphoedema, cancer-related lymphoedema clinic caseloads appear unchanged or increased. Treatment is generally focussed on self-management, and educating the individual to successfully control and manage their swelling. But is this the most effective use of resources? Is it possible to use therapist-delivered treatments to more effectively reduce the swelling/symptoms and return the swollen limb/body part/s to as near normal as possible for the patient to manage long-term? Would this ultimately be more cost effective if, by achieving a smaller and less complex swelling, the ongoing treatment and follow-up costs were reduced/minimal and more patients could successfully be discharged earlier?</p> | H | |
| | <p>Would offering ICG to people post cancer treatment, particularly for breast and gynaecological cancers, prove effective in identifying those who have or will go onto have lymphoedema so that early management strategies can be implemented sooner to prevent or slow down the progression of the disease?</p> | P | |
| | <p>Would offering LVA microsurgery and lymph node transfer on the NHS to suitable candidates who go on to develop lymphoedema post cancer treatment prove cost effective by reducing the cost of future hospital stays and antibiotic use for cellulitis?</p> | P | |
| | <p>Could offering ICG scans to lymphoedema patients post cancer treatment with personalised self massage techniques taught specific to the outcome of the scan reduce the incidence of cellulitis?</p> | P | |
| | <p>I want to understand more about lymphedema care. This information is available for Breast cancer not with gynaecological issues. It was a focus for Me and prevention where possible is suggested but without clarity of information.</p> | P | |
| | <p>Treatment and management of lymphedema secondary to cancer and cancer treatments. As there is only little research in regards to Manual Lymphatic Drainage therapy, it would be very helpful to have more research in this area. There are clear, visible and measurable outcomes but as there is not enough research to show the effectiveness of this treatment it is difficult to obtain on the NHS.</p> | H | |
| | <p>Management of chronic lymphoedema</p> | H | |
| | <p>will my body become immune to prophylactic antibiotics for repeated cellulitis attacks.</p> | P | |
| | <p>The psychological aspect of living with lymphoedema as a consequence of cancer treatment needs further research. Some of my patients tell me it is worse than the diagnosis of cancer itself.</p> | H | |
| | <p>How can lymphoedema be prevented?</p> | P | |
| | <p>Is it necessary to take rest of lymph nodes out if sentinel node biopsy shows cancer, especially as chance of getting lymphodema in arm afterwards</p> | P | |
| | <p>How can we prevent lymphodema and/or shoulder/arm pain caused by lymph node dissection and sentinel node biopsy? Self help works, so why are breast cancer rpatients not told about it before the arm starts to swell? Pain killers are not the answer. We need to start prevention immediately the wound from surgery is healed.</p> | P | |
| | <p>Why is there no organised specialised treatment for Head and Neck Lymphoedema post radiotherapy?</p> | P | |
| | <p>How can I help myself avoid lymphodema after surgery without taking up NHS resources.</p> | P | |
| | <p>Why is cording reoccurring despite compression sleeve and massage? Why isnt it understood by the medical profession?</p> | P | |
| | <p>Is kinesiology taping an effective way to manage lymphoedema (resulting from treatment for cervical cancer) in the lower abdomen/pubis and upper leg?</p> | P | |
| 25. What is the optimal follow-up approach to detect whether a cancer has come back? | <p>Do regular long term (>5 or 10 years) follow-ups with healthcare professions, improve quality of life outcomes?</p> | P | |
| | <p>Follow - up - wanted or not</p> | H | |
| | <p>Why is there time inconsistencies with scans between geographical areas. I have been advised 12 months for the first scan to see if my cancer has spread yet others falling in different health authorities wait only 6 months?</p> | P | |
| | <p>What are the best methods of monitoring and follow up</p> | H | |
| | <p>What is the best way of following up people after treatment for cancer. How can we best ensure we detect recurrence in a timely manner, address concerns and long term toxicity without increasing anxiety, falsely reassuring or raising expectations all within increasingly stretched health care resources?</p> | H | |
| | <p>Frequency of scans and consultant appointments</p> | P | |
| | <p>Can more biomarkers be developed (e.g circulating tumour DNA) which could routinely be used in blood tests for people who are past the 3 year follow up period but not yet at the 5 year 'cured' stage? This would enable recurrence to be spotted early and would also give peace of mind to people who have been 'signed off'.</p> | P | |
| | <p>Is there a willingness amongst patients who have been given the all clear, to pay a nominal fee to continue with annual check ups to maintain peace of mind?</p> | P | |
| | <p>Why do I feel abandoned now after chemo and radiotherapy and my cancer is supposedly under control. I was told that we don't scan all the time. I need some real reassurances that it hasn't progressed?</p> | P | |
| | <p>study to monitor Survival outcomes of those with routine MRI/ Ultrasound follow-up every six months, versus standard NHS follow-up.</p> | P | |

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| | How many times will I need to be monitored for the first five years? | P | |
| | Benefits of regular screening ie ct scans which may pick up secondaries early, as opposed to waiting until symptoms are apparent by which time treatment may be too late or more costly or invasive. If regular mammograms are recommended why not regular ct scans? | PR | |
| | Does stratified risk at discharge increase or decrease anxiety for patients (e.g. clinic vs discharge or shared care) | H | |
| | Benefits or not of remaining in long-term follow-up | PH | |
| | When and how often blood tests should be made , to assure people that things are going well. | P | |
| | Would patients and their families like active follow up or just to be given information of who and where to go for support once they complete treatment..... | H | |
| | I would like to be able to know if the CLL is no longer in my lymph without 4 monthly CT scans and the risk that entails | P | |
| | Why patients have to attend follow up at hospitals | H | |
| | How do we stratify patients for psychosocial factors - rather than genetics | H | |
| | What type of follow-up/aftercare do people want following completion of therapy? | H | |
| | Is a new follow up potocol needed for survivors of PNETs who have undergone a Whipples procedure? | U | |
| | Would more detailed screening for recurrence/secondaries save more lives from breast cancer in the UK? | P | |
| | Should PET scans be available every 5 years for life for cancer survivors? | R | |
| | Should treatment ever stop? For peace of mind should checkups be available for life for cancer survivors? | R | |
| | Why the follow up procedures and checks vary so much. | P | |
| | How can we help consultants to see how much it means to have the check ups, even though it is normally a quick in and out visit, the security you get from seeing them is tremendous. I was told by my oncologist she was discharging me after 3 yrs instead of 5-10 and it has made me feel like a baby losing her security blanket!! I understand the reasoning... more and more patients but selfishly we tend to think of ourselves! | P | |
| | Why haven't I ever had a scan (except mammogram and ultrasound) people I know who have breast cancer have ct scans. I am sure that must help to allay fears of cancer being any where else | P | |
| | How safe is it to rely on 6 monthly check ups on Active Surveillance? | P | |
| | Is 5 year monitoring effective? Should it be longer? | P | |
| | How can we positively identify areas where cancer has spread? Once hormone therapy has started it is difficult to identify effected nodes as the cancer is "inactive". Analysis of scans can be subjective and this is psychologically difficult for patients. | P | |
| | For each disease site, what is the optimal time point for discontinuation of follow-up? Does the expectation follow-up duration, established during treatment, affect acceptance of discharge and level of associated anxiety? | PH | |
| | How do you gain confidence that you are well, when you had few symptoms to begin with, then have an intensive 6 month of chemo seeing medics and district nurses every week, then told to come back in 3 months time to discuss a blood test. If your diagnosis was for 3 months to live and you still have a possible symptom, then how do you know you are ill or not when you have such a short time to live if you do not spot a symptom. Maybe it helps confidence to start off by having a monthly blood test | P | |
| | How can cancer be monitored accurately to ensure that it does not worsen? | P | |
| | How much follow up is required post diagnosis | H | |
| | What do patients want in terms of follow up after completion of treatment eg intensive follow up versus 'as required' | H | |
| | In what ways do regular visits and scans / blood tests help and harm those people living beyond cancer? | H | |
| | will patients accept risk stratified follow up | H | |
| | Is the current follow-up schedule for melanoma patients effective in identifying recurrence and new lesions or would a more risk-stratified, individualised approach be better? | H | |
| | Moving forward I will not have any routine scans to check for any signs of secondaries..... Why are CT scans or mri scans not offered to patients post treatment? Surely it cannot be my sole responsibility to just worry about new symptoms? But not given any general info on what I'm looking for? | P | |
| | Are there any standards applied for considering a person for imaging for mole checks post melanoma? | P | |
| | Should I have repeat CT scans and is benefit outweighed by risks? | P | |
| | Are the follow up processes adequate and sufficiently quick once a person has been discharged following the initial cancer? | P | |
| | Follow-up do patient need to go back on a regular basis. Developing the use to technology to help with follow-up. | H | |
| | How often should I be monitored or seek check up advise. | P | |
| | How can someone like my dad be cured of bowel cancer and skin cancer only to find out that he had lung cancer that had progressed too far for surgery? Surely, screening for all cancers following 2 previous cancers would ensure that he would not have died of lung cancer. | R | |
| | when you have your routine visit to clinic, why are no tests or scans given to give peace of mind to any re occurrence of your illness | P | |
| | Why are annual PSA tests not offered to patients who have previously been checked because of Prostate problems? | P | |
| | How am I being monitored to prevent it becoming serous | P | |
| | After 5 years, the follow up stops and normal life returns (they say). From having access to specialist service to be discharged to GP care, i.e. waiting for a long time just to see GP. Is 5 years the correct follow up for everybody? Can a "twilight period" be useful? | RH | |
| | Colonic polyps get intensive colonoscopy surveillance for many years. Colonic cancer (that presumably originated from a polyp) doesn't. Is there any benefit to make the surveillance more uniforme? | RH | |
| | What to expect after treatment finishes and why are we not scanned for signs of metastatic breast cancer? | P | |
| | Should we be monitored beyond 5 years (maybe at 2-yearly intervals)? | P | |
| | Having had cancer, I would like to be regularly monitored for reassurance. | P | |
| | What levels of medication and follow up is necessary. | P | |

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| | Is there a way to support patients that are LW&BC so they don't feel alone? It isn't always necessary to see a physician in clinic and yearly appointments can be done via a phone call/Skype specially for the younger generation. | P | |
| | For endometrial Cancer, following my CT scan at 1 year 4 months post hysterectomy, why am I not being given a routine annual CT or MRI? I know that breast cancer patients get annual mammograms for 5 year's post treatment; instead I am only to be investigated if I report further symptoms. Surely by the time I notice symptoms the new cancer will have spread already? | P | |
| | How long will I be monitored after treatment? | P | |
| | How do patients feel about risk stratified follow up, do they feel supported or isolated? | H | |
| | People are surviving longer after initial diagnosis of cancer, but just because they are surviving doesn't mean they always feel well. many will have recurrences, numerous treatments over several years. What can be done to make these people feel less isolated and more "actively monitored" during lengthy periods of disconnection from the helathcare system. | P | |
| | Protocols around scanning and monitoring and describing the situation to patients: why do different trusts follow up differently, why does grade of cancer not influence screening regimes, why the mix up of language around remission/NED cancer free survival rates Grade 4/terminal/ prognosis | R | |
| | Why isn't routine follow up with CT scans done across the whole body instead of just certain areas. is money better spent on prevention rather than treating patients to prevent a premature death. | P | |
| | What methods of follow up can be effective but least intrusive into everyday life? | P | |
| | Why are patients with breast cancer not routinely screened via CT scan etc following completion of treatment? Surely better checks post treatment will allow metastatic disease to be identified sooner and in turn prolong life & be more cost effective? | P | |
| | I find living beyond Cancer scary at times & think a yearly scan for at least the first 5 to 10 years should be available to everyone living beyond cancer but it seems to depend on each individual consultant or nhs area can there be some set guidelines on this to give us all the same chance of peace of mind and/or catching a secondary cancer quicker. | P | |
| | How do patient feel about risk stratified FU? | H | |
| | Quality of life impact on patients and carers of shorter v. longer monitoring - e.g. CT, MTI - intervals. | R | |
| | Evidence to support remote surveillance following curative intent intervention for cancer, rather than clunky hospital based follow-up. | H | |
| | Why we don't get regular scans | P | |
| 26. What are the spiritual care needs of people living with and beyond cancer? | What is the impact on a patient if they do not receive adequate spiritual care? | RH | |
| | Has your faith helped you cope with your cancer diagnosis and treatment? If so, in what way has your faith helped? Do you think you would have coped as well without your faith? | H | |
| | What are the differences in spiritual support needs during active treatment, compared with when active treatment has stopped? | H | |
| | How do different faiths or being an atheist assist or undermine living with cancers? | P | |
| | Spiritual care comes up frequently as a need in cancer, including survivorship. Every patient has questions, some well articulated others less so. The very few research papers in this area of care have been dominated by Church of England clergy, yet over 50% of the population does not admit to any religious belief let alone Anglicanism. Studies which set out to consider the needs of the "no religion" patients would encompass those with a religion. The research need is not "what" or "why" but "how" and "who" and should start from a rational base rather than a belief base. | P | |
| The remaining shortlisted questions (not in any order) | | | |
| How well are current models of support helping with recovery for people living with and beyond cancer (e.g. The Recovery Package)? Could they be improved and are they cost effective? | Do standardised Health and Well being events prepare patients for follow-up/managing after cancer adequately ? | H | Measures are being developed to evaluate the Recovery package but they are unlikely to answer these questions. |
| | Do Health and Well being events provide cost effective support to patients? Do patients/what proportion of patients diagnosed with cancer find these events helpful? What are patient's perceptions of Health and well being events and has attending these events changed patients ability to live with their cancer diagnosis, perception of their illness, treatment and or prognosis | H | |
| | Does the recovery package really make a difference to patients | H | |
| | The impact of different aspects of the Recovery Package | H | |
| | How do patient use treatment summaries of post-treatment care plans following holistic needs assessment? | H | |
| | What is the evidence that each of the individual components of the Recovery Package makes a significant improvement to a) clinical outcomes and b) PROMs? | H | |
| | do health and wellbeing events help patients and carer's adjust to life after a cancer diagnosis? What is the optimum time for these to take place. | PH | |
| | does a health and well being clinic produce long-lasting benefits (in terms of knowledge, activity, engagement with services, reduced cancer anxiety) | H | |
| | What are all the elements that need to be lined up for people to tap into in order to live their lives beyond cancer? e.g. physical, emotional/ psycho social, | O CHARITY | |
| | Have your holistic approaches to cancer treatments been supported by doctors? | R | |
| | Health and Well Being Events are intended to provide patients with the information and confidence to live their lives well following their cancer diagnosis, but what should be included and at what point in the patients pathway (e.g.. is 'on discharge' from acute care too late?... a missed opportunity in terms of introducing patients to beneficial self-management techniques?) | H | |

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| | What should be content of a H&WBE include to ensure beneficial impact? It appears they can be extremely costly in terms of staff time without any clear objective evidence of the benefits they bring. This might need to be explored in the context of the entire 'Recovery Package'. In theory it seems sensible to invest in interventions to enable self-management but there is limited evidence of objective health and wellbeing, survival or health usage data. Without this some commissioners are reluctant to make the necessary investment. | H | |
| | What is the long term impact of attending a Health and Wellbeing Event. Does it improve the quality of survival in terms of physical and psychological health? | H | |
| | How health care professional support patients to be more involved in the community and social life? | H | |
| | Goes the recovery package work ie does it help people to self manage and identify resources/services that will help them do this | H | |
| | Does the use of treatment summaries and cancer care reviews increase well being/quality of life for cancer patients. | P | |
| | Are holistic needs assessments and/or end of treatment reviews more effective at helping people improve their performance status and return to work after cancer treatment if they are conducted by an allied health professional (such as a physiotherapist or occupational therapist) compared to clinical nurse specialist/nursing staff? | H | |
| | Impact of non-medical holistic care on reduced hospital stays / admissions, fewer visits to GP's / Practice Nurses, Mental health services.. | H | |
| | Benefits of exercise, support groups, 'listening ear', of clinical services valuing the 'holistic' care of patients and not just seeing it as 'fluffy' and optional. | H | |
| | Are Health Needs Assessments accurate in addressing patients concerns? | H | |
| | did you have free access to health and well being programmes to aid your recovery in your local community ? if yes what worked well | PH | |
| | what is the evidence that the recovery package is being delivered and that it makes a difference to peoples recovery from cancer. | HP | |
| | Health service treatments, while excellent in their medical input, sometimes miss the 'whole human' input, what some might call emotional and spiritual needs of patients. How can busy professionals encompass these aspects of care in their provision? | P | |
| | Is the Recovery Package beneficial for people with cancer? | H | |
| | is the Recovery Package beneficial to people with cancer? Is the whole greater than the sum of the parts? | H | |
| | do health and well-being events reduce unnecessary clinical appointments? | H | |
| | The impact of holistic needs assessment and support planning on outcomes for people with cancer | HR | |
| | Do health and well being events actually help anyone in the long term? | H | |
| | What proportion of patients completing treatment engage in health and well-being activities and what factors influence this? | H | |
| | The value of Holistic therapies Holistic therapies are of proven value but it's definitely not a one size fits all scenario and some in my opinion can actually be detrimental to recovery. I know most of the assessment is done by the CNS's and I'm not sure how much training they receive. | P | |
| | as a g caring for patients LWBC: what do patients want to see in their treatment summaries as a professional we are not getting tx summaries - we pts and gps do not know what to look for ..when should a patient come back etc fundamental to this if the communication of HNA and Tx summaries - how can we use research platform to explore with patients - how they want to be communicated to on these 2 things - do they want hand held records - can patients become more integral to these documents so they are useful and can also be a group advocating theses docs being sent to GP/between professionals | H | |
| | We have noticed that there is quite a high rate of patient DNA's to attend health & wellbeing clinics despite being told it is part of their pathway. How can this be addressed, improved, what information do we need to be getting across to patients to help their understanding of importance of these events? | O | |
| | How to evaluate the effectiveness of HNA and health & wellbeing events and other types of self-management support | H | |
| | in using Patient Activation Measure PAM how can we accurately estimate cost savings against reduced health and social care needs as a result of patient knowledge increasing by various education / health and wellbeing events attended? | H | |
| | How useful are holistic needs assessments in managing patient need? | H | |
| | How do we utilise the patient data collected as part of the electronic holistic needs assessment tool which enables the deliver of care to better understand patients' needs, outcomes of interventions and to improve services in a way that makes this simple, routine and emotional embedded into clinical practice and service development | H | |
| | We need to understand from patients and staff how we can ensure the offer of an HOlistic needs Assessment (HNA) can be viewed as having the potential to enhancing the care and support provided to patients. As one of our challenges in implementing the electronic version of the HNA remains understanding why patients may not undertake the offer of undertaking the assessment | H | |
| | Understanding the value of providing health and wellbeing events for patients and how to offer this to ensure patients will take up the offer to attend. For example we need to understand what information patients and carers need and how they want to receive it I.e format, venues, topics etc. As currently locally and nationally we are seeing only small numbers of patients attending events them. We would like to understand how we can make them more accessible to the wider cancer patient population and their carers | H | |
| | Screening for holistic needs and specialist care What are the best ways of screening for patients' and carers' holistic needs at all stages after diagnosis and the start of anti-cancer or palliative treatments, up till the point when patients enter the end of life stage? | H | |
| | What is the long term impact of a one off health and wellbeing event in changing patient health behaviours? | H | |
| | what is the value of an eHNA? | H | |
| | What does emotional support mean in cancer services -are we applying it correctly? -Used HNAs but means different things to different people -Sometimes it turns people off | H | |

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| | How can we measure the impact of attending a Health and Wellbeing event? | H | |
| How could palliative care service/ hospices play a greater role in caring for people living with and beyond cancer? | Why are patients with incurable cancer not referred sooner to specialist palliative care services when the research suggests this would be to their benefit? | H | Some evidence from the US but this may not be relevant to the UK. CG -Bauman JR, Temel JS. The integration of early palliative care with oncology care: the time has come for a new tradition. J Natl Compr Canc Netw2014;12:1763-71 |
| | How can palliative care be offered as a therapeutic option for treatment for some people | RH | |
| | Would patients who are not ultimately going to be cured benefit from earlier referral to hospice? | H | |
| | Would services be more efficient working more closely, ie, hospice and cancer services? To dispel the myth of patients 'just being referred to hospice to die' and to allow greater access to specialist symptom management. | H | |
| | What are the best service models for providing both general and specialist palliative care to people living with cancer? | H | |
| | Who do they feel should be supporting patients with a non-curable illness even when the prognosis may be many months or years. Does the Hospice have a role at this time? | H | |
| | How do people who have embraced survivorship notions transition into Palliative Care services without feeling like they have failed | H | |
| | How to facilitate earlier referral to specialist palliative care as this seems to contribute to better survival in incurable cancer? | H | |
| | Do clinicians feel confident in delivering palliative rehabilitation? | H | |
| | In what ways can involvement with palliative care specialists help those people living with cancer, even when cure is likely? | H | |
| | Much palliative care is predicated on a 'model' patient. Could more be done to help people who don't fit this (and the people to whom these patients matter) - less systems based, more truly person-centred care. | PR | |
| | Why do palliative care services only get involved at the very last minute (literally)? | R | |
| | Misconceptions about the hospice. | H | |
| | We know that supportive and palliative care given early to cancer patients (not just at end of life) improves symptom control, leads to better quality of life and can even prolong life - how can we better integrate earlier supportive and palliative care into routine patient care (I mean the whole package of physical, spiritual etc. not just pain relief) ? | R | |
| What are the costs/ benefits to the NHS of better managing the long-term and late effects of cancer treatments? | What is the cost to the NHS, society and patients of not optimally managing the long term consequences of treatment, such as bowel & bladder incontinence/urgency/bleeding, lymphoedema, pain, fatigue, swallowing/speech difficulties, etc | P | |
| | How can I quantify the benefits of exercise and psychological support in respect of use or resources/cost as well as patient experience. | H | |
| How can quality of life be measured in a way that is relevant to people living with and beyond cancer? | Do people from the BME community report a poorer quality of life after cancer than the whole population? | O | Impact of cancer and its treatment on quality of life is known. |
| | Do people with a learning disability report a poorer quality of life after cancer than the whole population? | O | |
| | How does poverty affect quality of life after cancer? i.e. if I come from a poorer background am I more likely to report a poorer quality of life than if I come from a richer background? | O | |
| | Impact of cancer on patients Global QOL and long term changes in this | H | |
| | quality of life due to side effects of treatment | H | |
| | is there one quality of life methodology which can be used in Survivorship to provide a single tool capable of delivering results which patients can understand, can use to draw comparisons, and which help inform choices between different therapies. | P | |
| | has the cancer treatment affected the patients quality of life? | H | |
| | Impact of treatment side effects on quality of life | P | |
| | What are the most important issues affecting people living with and beyond cancer from the affected peoples perspective? | H | |
| | What is the impact on quality of life of long term cancer treatment. We currently treat aggressively putting up with side effects but long term life with cancer can be ruined by the chronic impact of intermittent steroids for example | R | |
| | The changes in quality of life experiences | P | |
| | and how the treatment affects life afterwards | P | |
| | Quality of life assessed by patient and relative(s), rather than just Overall survival/PFS, particularly in the setting of onerous/toxic treatments, eg HSCT | H | |
| | Do blood transfusions for anaemia improve quality of life? | H | |
| | How have long term consequences of cancer treatment affected your quality of life? | O CHARITY | |
| | More research on long term survival rates and long term quality of life. | P | |
| | Quality of life after cancer | H | |
| | How do we balance chronic toxicity of targeted agents against response when evaluating quality of life | H | |
| | What will my quality of life be like once I have finished treatment? | H | |
| | Which treatment for my cancer will give me the best quality of life in the long run? | H | |
| | On a scale of 1-10 how would you rate your quality of life after receiving radiation treatment for cancer and having to live with the long term side effects? | P | |
| | How significant are co-morbidities in relation to quality of life beyond cancer? (eg development of neuropathy after chemotherapy or dealing with wound infections after surgery) | P | |
| | Planning for the future. It would be useful to know what typically the course of the disease might take and the likely impacts on a cancer patients future life, lifestyle and plans. This is really difficult to discover. I have so many potential plans for our future that I am excited. This is not about a prognosis or treatment plans. As cancer patients how does suffering from the disease impact on the lives of patients and carers? What can be done to make planning decisions for future life with cancer more credible and informed? How can quality information and data be made available to enable cancer patients and their families to make plans for living with cancers? | P | |
| | What life expectancy can we anticipate and what quality of life can be anticipated | R | |

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| | The QALY (quality adjusted life year) is too simple a tool to assess disease burden (1=perfect health, 0.5=bedridden). I would to see clinical trials report value for money of medical interventions, incorporating both physical + mental disease burden. | H | |
| | Where are the gaps between the quality of life of those living with and beyond cancer compared similar individuals who do not have/have never had cancer? | H | |
| | What are the quality of life implications after radical chemotherapy/radiotherapy for squamous cell cancer of the oesophagus? | H | |
| | looking at patients quality of life | H | |
| | What is the incidence of long term side effects or complications of treatment in people with upper and lower l cancers and <u>how does this impact on QOL?</u> | H | |
| | How will quality of life be affected following cancer treatment and thereafter? | P | |
| | Quality of life of cancer survivors | RH | |
| | what are the mid and long term affects of chemotherapy and how does this affect the quality of life for the patient and their loved ones, friends and family etc. | PR | |
| | What are the quality of life issues for men after treatment for testicular cancer | H | |
| | How to quantify outcomes for improvement projects/interventions/new services | H | |
| | Does living with and beyond cancer affect a person's quality of life? | H | |
| | What are the best measures/scales to assess quality of life for people living with and beyond cancer? (Most tend to focus on symptom reduction or mood/anxiety changes rather than measures of quality of life). | H | |
| | What is the quality of life of people living with advanced and recurrent bowel cancer? And, how can we improve it? | H | |
| | quality of life questionnaires need to be holistic but ensure cancer components covered it may be QOL questionnaires and cancer survivors - how can patients contribute/mould/how can these be "tested" etc | H | |
| | What makes the biggest difference to quality of life in the recovery phase 1-5 years after treatment? | H | |
| | Quality of life issues | H | |
| | How can we measure/ quantify/ qualify participant psychological improvements in health and wellbeing programmes | H | |
| | How much does the effective management of side effects and long term consequences of treatment improve quality of life and survival? (In both those who are NED and this who have treatable but not curable disease) | P | |
| | What is the quality of life and is it worth living with and beyond cancer | H | |
| | quality of life and side effects of treatment | H | |
| | When measuring QoL, how can we properly measure and account for the emotional, financial and practical impact on family life (children, partners, parents, siblings etc.) when a person is diagnosed with metastatic disease. | P | |
| What are the safest and most effective ways of managing early menopause caused by cancer treatments? | How can younger women with BRCA1 and BRCA2 patients who have undergone risk-reducing oophorectomy have their menopausal symptoms best treated and managed? | P | |
| | what is the best form of oestrogen replacment for young women- HRT or OCP. looking at effects on bone density, fertility ie prepping the endometrium, symptoms, sexual function. And side effects/safety eg rate of secondary breast cancer, thrombotic epsidoes, lipids/CVs events. | H | |
| | How can i control menopause symptoms without hrt? | P | |
| | What is the optimal HRT in young patients following premature ovarian failure secondary to cancer therapy? (mainly transdermal vs oral vs OCP)Considering fertility issues, uterine size, cardiovascular/cerebrovascular risk | H | |
| | Treatment of menopausal symptoms on Tamoxifen. | PH | |
| | What are the physical and neurological short and long term affects of not having any ovaries and not having hormone replacement ? | P | |
| | What are the long term side effects of being put in an early, chemical induced menopause | P | |
| | How many breast cancer survivors who are on hormone treatment such as tamoxifen and zoladex, suffer with anxiety or depression. Contrasted with those not on those hormone therapies. | P | |
| | Following Ovarian cancer diagnosis and a complete hysterectomy I had to live with early menopause. I would have like support about supplements that are safe to assist with menopausal symptoms and longer term affects of this. I would have liked the support to be aimed at younger women. | P | |
| | What are the alternatives to tamoxifen for premenopausal women with hormonal breast cancer, and how effective are these alternatives in terms of disease free survival compared to tamoxifen? | P | |
| | If men got menopausal symptoms would there be more drugs available to counteract the side effects of tamoxifen | P | |
| | What are the real consequences of starting HRT in your 20's due to cervical cancer treatment? How long is too long to be on HRT? Will we ever see a shift away from tablet form to something similar to contraceptive implant? | P | |
| | hormone imbalance after gynae cancers (premenpausal women) | H | |
| | In women, impact of surgical or chemically induced menopause. | P | |
| Do complementary therapies benefit people living with and beyond cancer (e.g. improving treatment outcomes and quality of life post-treatment)? | What role do complimentary therapies have for patients living with and beyond cancer? | H | |
| | Can massage affect negatively cancer patients? I'm talking about deep tissue, aromatherapy, therapeutic massage the kind one can get at a spa. | PR | |
| | Patients often attribute survival to a complementary therapy they take without reference to their clinician(s) and reluctance to tell them. How can we gather that information and use it to help determine research questions which look into such therapies? | P | |
| | Benefit of complementary therapy for positive outcomes | P | |
| | What are the most effective complementary therapies, adequate for cancer patients? We need more research on these. | H | |

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| | How useful are holistic treatments in complimenting medical treatments | P | |
| | Benefits of various forms of alternative/complementary therapy | P | |
| | Can alternative therapies such as high dose vitamin C help alongside traditional treatments such as chemotherapy? | R | |
| | Is it safe to avail of treatments such as reflexology and massage when being treated for cancer? | R | |
| | Does acupuncture help in recovery from breast cancer? | P | |
| | How important are self care therapies in living with and beyond cancer ? (things such as yoga, massage, reflexology, acupuncture) | P | |
| | Does taking/using complementary therapies or treatments improve survival? | P | |
| | What impact can alternative therapies have on my wellbeing during cancer treatment? | H | |
| | Which alternative or complementary therapies improve/extend quality of life post cancer treatment | PR | |
| | Can complementary therapies speed my recovery? Are they beneficial in more ways than providing relaxation and in palliative care? | H | |
| | How can yoga and mindfulness support people with and beyond cancer? | P | |
| | Apart from conventional medicine what help is available to patients to access complementary therapies ie Rieki, Aromatherapy, Aquapuncture, Mindfulness/Meditation and is there research which can demonstrate if there are any measurable benefits. | H | |
| | I would like to know about the effects of complimentary and alternative therapies on living with cancer - homeopathy, reflexology, osteopathy, acupuncture, amatsu etc. | P | |
| | How effective is holistic and complementary cancer care such as reflexology or mindfulness? | PR | |
| | Research on massage and bodywork therapies for people living with cancer and their caregivers. | O | |
| | Which complementary or alternative treatments really help cancer patients and side affects of treatment. | P | |
| | What are the benefits of complementary therapies to people affected by cancer/LWBC? | H | |
| What are the best ways to maintain healthy bones and teeth during and post-cancer treatment? | Bone health in young adult cancer survivors. mode of treatment, bone density , fracture rate, if hypogonadism, use of high dose steroids. | H | |
| | dental issues after chemotherapy: more support needed from dentistry - and an awareness of dental issues which continue 10+ years after chemo | PR | |
| | Bone health - what can be done to provide more targeted & effective treatments to maintain bone health while reducing side effects (particularly thinking of post menopause ER+ breast cancer) | P | |
| | Can assessment of risk and optimisation of bone health prior to/during cancer treatment/pelvic radiotherapy prevent vertebral fractures and insufficiency fractures? | H | |
| | There is a big question around consideration of optimal bone health in patients LWBC. I see a number of young patients cured from their cancer who are totally debilitated by vertebral fractures induced by high dose steroids/underlying condition and this becomes their major problem. We do not currently have any evidence for optimal management of these young/premenopausal patients in terms of risk stratification/calcium/vit D status and use of bisphosphonate/anti-resorptive therapy | H | |
| | The other major bone issue is pelvic insufficiency fractures post pelvic radiotherapy. This is common and a significant cause of morbidity in these patients. There are a number of descriptive studies but none that actually allow us to understand pathology, consider bone density/risk factors and no evidence for any intervention that works (and theoretical concern that bisphosphonates, which are reflexly used may actually worsen healing). It might be that early bisphosphonates (ie at start of radiotherapy in certain at risk subgroups might be of benefit). | H | |
| | If, at some point, bisphosphonates become a prescription drug funded by the NHS (or indeed, if women are given the option to pay for their own), would these be available to, and benefit people living beyond cancer? | P | |
| | Are those people who suffer from damage to pelvic bone damage and accompanying pain offered any form of support package? | P | |
| | BONE PROBLEMS | P | |
| | Can I eat anything or take supplements to help with the loss of bone density after chemo? | P | |
| | Is there any research into osteoradionecrosis | P | |
| | Can you do anything to improve/ slow down bone density damage from pelvic radiation given to someone in their 20's? | P | |
| | What effects does Chemotherapy have? I had bowel cancer and 30 weeks Chemotherapy. I was diagnosed with Chronic Lymphocytic Leukaemia and this year alone I have had 16 dental appointments, 2 abscesses under teeth 2 root canal fillings I tooth re-crowned and numerous fillings, I have facial pain and may have Sjogrens Disease are these things related? | P | |
| | Radiotherapy damage to bones (following pelvic radiotherapy/ brachytherapy/chemo) | P | |
| | How does radiotherapy affect strength of bones in weight bearing bones? | H | |
| | Why are there no National Patient Leaflets about the benefits of Bisphosphonates eg Zoledronic acid infusion in prevention of bone metastases in relation to breast cancer in particular but maybe relevant for other disciplines also? The only leaflets available talk about metastatic disease treatment rather than prevention. They also don't mention that some of the younger ladies have horrific side effects with lasting bone pain and fatigue. Observationally it is the older ladies who take this that have less side effects. | RH | |
| | After having osteoradionecrosis on my left jaw, what are chances of getting it at a later date on my right jaw? Is there anything I can do to prevent recurrence? | P | |
| | How well do we apply known research on bone health in prostate cancer across the UK? | H | |
| Does having a positive attitude influence the outcomes of cancer and improve quality of life? | How much does a positive attitude - to both the cancer and its treatment - aid recovery after chemotherapy and/or radiotherapy? | P | |

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| | How does mental health impact on physical health e.g. Does anxiety lead to more experience of symptoms? | P | |
| | How can being supported through identifying positive outcomes improve psychological wellbeing? | H | |
| | How much does a positive outlook /positive mindset affect outcomes for cancer? | P | |
| | What effect does positive attitude have on avoiding recurrence of the cancer? | P | |
| | Does monetary and mental wellbeing improve the patient's outcome? | P | |
| | What role does expectation have in someone's experience of chemotherapy/surgery - does the expectation that the treatment will work make any difference, or is it more about positive mindset leading to positive behaviours after treatment? | H | |
| | Understanding the impact of the things I can control as a patient: Can your mental attitude really impact your survival / quality of life living with metastatic cancer ? (i.e. does having a positive attitude make any difference ?) | P | |
| Single question | What would help women with breast cancer to continue with and complete their hormonal treatment? | PH | Multiple studies have recorded compliance rates. Ann Oncol. 2018 Jan 1;29(1):186-192. doi: 10.1093/annonc/mdx630. Influence of patient and tumor characteristics on early therapy persistence with letrozole in postmenopausal women with early breast cancer: results of the prospective Evaluate-TM study with 3941 patients. |
| Single question | What role does the return to a workplace environment play in psychological wellbeing following cancer treatment? | R | |
| Single question | What is the effect of media campaigns or the portrayal of cancer in TV drama/soaps on individuals living with cancer and their families? | H | |
| Single question | What is the impact of musculoskeletal cancers on physical fitness? | H | |
| Single question | Should people who have had chemotherapy be offered repeat childhood vaccinations? | P | "Advice is clear to boost everything relevant after chemo – this is mostly based on zilch evidence though". Feedback from Dr Mary Ramsay, Consultant Epidemiologist and Head, National Infection Service, Public Health England. |
| Single question | How can bowel obstructions be prevented in people surviving bowel cancer? | P | 3 separate reviews on management of malignant bowel obstruction but not on obstruction as a consequence of therapy. |
| Single question | How much fibre should be included in the diet when a person has a blocked bowel as a result of cancer? | H | |
| Single question | What are the best ways to deliver chemotherapy in the short and long-term, and/or when there are problems delivering it via an arm? | P | Studies looking at this Portacath, cannular vs hickman vs pick. Study at the Christie. No RCT comparing methods. |
| Single question | What are the best ways to support people living with and beyond cancer and their families if they experience prolonged insomnia? | H | Multiple small intervention studies (mainly breast cancer) |
| Questions that have already been answered by research | | | |
| Not included in the second survey | | | |
| How long do the side-effects of cancer treatment last? | Will my immune system return to its pre-cancer/treatment level? If so, how long will it take? It's more than 8 years since my treatment (chemo and radiotherapy) finished and I still seem to pick up every cold and bug that's in the area, whereas before cancer I rarely got any. | P | This is known through clinical practice/ experience/ clinical trials and very variable. We know how long bone marrow takes to recover for instance (anaemia and immunosuppression) but long term damage we know this can be permanent (i.e. chemo induced neuropathy/radiation induced lung fibrosis). It is being addressed through ongoing studies. |
| | What is the true incidence of symptoms after various difference cancer treatments at different timepoints? | H | |
| | I HAD AN OPERATION FOR BOWEL CANCER FOLLOWED BY SIX SESIONS OF CHEMOTHERAPY I FINISHED MY TREATMANT 4 MONTHS AGO I AM STILL FEELING VERY TIRED.JUST WONDERING HOW MUCH LONGER IS THIS LIKELY TO GO ON FOR? | P | |
| | How long does the chemo stay in your system and are the side effects permanent? | P | |
| | I would like to know how long I will continue to have side effects from my radiation treatment...will this be a lifetime thing?? | P | |
| | How long do symptoms keep presenting | P | |
| | Following radiotherapy I have suffered from Proctitus. This condition started around 6 months after the end of the radiotherapy, but 2 years after the start of the problem the damage seems to have almost repaired itself. Is it usual for this improvement to happen, and will it continue? | P | |
| | When does chemo brain finish after treatment | P | |
| | Does the aches and pains of active treatment ever go away | P | |
| | Will any damage caused by radiotherapy slowly get better Or do we have to live with the pain the damage has caused. | P | |
| | how long will tiredness last already over a year | P | |
| | when will my stamina return | P | |
| | My daughter had ernal radiotherapy, she has lots of back pain, bladder problems and kidney n problems, will these lesson with time? | R | |
| | to what extent (percentage wise) does your immune system recover after having chemotherapy treatment like R-CVP or R-CHOP and what type of timescales are involved? | P | |
| | How common is (permanent) chronic fatigue following treatment for Ewing's Sarcoma? | P | |
| | After effects of treatment - how long are they after-effects and not a "new" problem or illness. | P | |
| | My memory is poor as a result of chemotherapy for Brain Tumours - will it ever recover | P | |
| | Is chemo brain long lasting after Treatment finishes? | PH | |
| | How Long can we expect post-chemotherapy fatigue to last (from taxol + carboplatin treatment) | P | |
| | How long did it take for recovery to the best achievable level? | H | |
| | how many years does it take to get strenght and enegy and clear head back to normal. | U | |
| | How long does the chronic fatigue last after radiation? | P | |
| | Is tinnitus permanent for head and neck radiation patients ? | P | |
| | Hormone treatments e.g Zoladex and Bicalutamide, hammer testosterone production, one consequence being severely reduced libido. With the cancer in remission and erectile dysfunction recovering what proportion of men recover their testosterone production naturally and over what time period? | P | |

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| | How long does the fatigue and brain fog last for following treatment? | P | |
| | Fatigue: it is chronic and underestimated when having treatment. Is it expected that it can continue up to 2 + years after treatment has finished. | P | |
| | 3 yr post BC treatment and at the grand old age of 48, I continue to suffer joint pain, peripheral neuropathy and fatigue. I am on Tamoxifen. Is this it for me? | P | |
| | After my operations to remove Bowel Cancer my mind took a while sort itself out. I didn't have Chemo. Minor forgetfulness. Occasional wrong words. Slight slowing down in responses. Ability to focus on more than one thing at a time. After ten years either I'm getting used to myself or thing are starting to get better. | P | |
| | Can you ever fully recover from all the treatment | P | |
| | I would like more in depth understanding of the long term side effects of cancer treatment and how it affects people, not just in the immediate phase, but in 5, 10, 15 years etc. There needs to be evidence that employers can use to gain a more objective understanding of the needs and adjustments needed for people going back to work post cancer. For example, my OH doctor quoted MacMillan research that says 75% of people take 6 months or more to go back to full time working. However, that isn't enough to quantify an early retirement and so the individual is faced with making many changes to their life in order to work less hours if at all and even move home or become homeless as a result of that | P | |
| | Will the patient who is in remission ever feel like their old self again | P | |
| | Is it possible that side effects from chemotherapy could continue for many years, e.g. spells of complete exhaustion- not general weariness which can suddenly occur. Not to ask for treatment for this but just to reassure the patient. | P | |
| | Has the chemo permanently damaged my body? | P | |
| | Are there long term affects from Radiotherapy. will it continue to affect me for the rest of my life? | PH | |
| | When will the fatigue stop? | P | |
| | The chemotherapy tablets treatment I had after my operation did terrible things to my toe nails and the big toes have never recovered will they ever? | PR | |
| | For those who don't have a stoma bag, do changes that occur to your normal bowel functions due to surgery, ever improve, or do you have to accept that your body is different forever? | P | |
| | Long term effects of cancer and its treatment - how long do they last | H | |
| | It's been a year since chemo when will the shortness of breath stop? | P | |
| | It's been a year since chemo when will the tiredness end? | P | |
| | How long do aftereffects of chemo usually last | P | |
| | Chemotherapy affected my ability to digest certain foods. What research has been on whether this is a long time problem or if the stomach adjusts over time. | P | |
| | Extreme tiredness still affects me irregularly. What are the findings on this on the long term. | P | |
| | I was on Herceptin, and my teeth are now weak, I have breathing difficulties and chest pains. Will this improve over time? I feel older now. | PR | |
| | How long fatigue lasts and useful management strategies | H | |
| | I suffer from Perapheral Neuropathy in my feet due to chemotherapy. Will I ever walk unaided again? | P | |
| | I hear people saying that they have been given "the all clear" following Cancer Treatment. Can this be so? | P | Risk of recurrence for each cancer is known through trials. Consensus on when people are truly 'cured' is changing as we are seeing more late relapses > 5 or 10 years in some cancers i.e. breast or melanoma. Other things such as small cell lung cancer – if no relapse within 5 years it is very unlikely to. |
| | After what time period can one feel confident that cancer is unlikely to return due to initial diagnosis - either Breast Cancer or Bowel Cancer as they seem to be referred to differently ie Breast as 'in remission' and Bowel as 'cured'....how can we be clear what these terms mean to individuals to enable them to lead productive lives not overshadowed by the spectre of cancer? | P | |
| | How can we reassure insurance companies that living with cancer is not necessarily and life sentence as in wanting to travel and take short term risks in lives. To reduce premiums (potentially cap through government directives) could broaden peoples perspective on their own self worth and potential to have long lives after a cancer diagnosis. Research element would be to utilise up to date data to underpin policies to restrict practice that takes advantage of the disadvantaged. Do we have this data? | P | |
| | When do you know you are cured of cancer? | H | |
| | What is the risk of recurrence or new primary when factoring in complex genetics such as having "lynch like syndrome". Why is this group not being tested for double somatic mutations, to distinguish them from Lynch/sporadic, when the psychological impact is so great? | P | |
| | Where can I find prognosis rates beyond 5 year survival? | P | |
| | Will my cancer come back and when? | P | |
| | At what stage can you say your cancer is no longer active or cured. It is very difficult to get insurance cover for many things but especially for travelling. | RH | |
| | What is the true likelihood of my cancer returning after being given the all-clear? Mine did! | P | |
| | When will I be cured? | P | |
| | When will it come back? | P | |
| | What are the chances of my cancer coming back? | H | |
| | What are the chances of my cancer returning? | RH | |
| | Am I cured or am I in remission? I have an elderly friend who insists that she has terminal cancer even though she has been discharged and has had a number of years cancer free. I have tried to move her on but to no avail. | RH | |
| | Is my type of cancer likely to return | PH | |
| | How can diagnosis of the likelihood of a cancer returning be improved? | P | |
| | chance of Prostate cancer coming back there or elsewhere, after ending HT after 3 years. | P | |

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| | How great are the chances of cancer coming back in any form when you have had it once ? | R | |
| | How likely is my cancer to return after my treatment is complete | P | |
| | Time before we know for sure about expectancy for the future | P | |
| | Why is the length remission such an unknown factor is it the lack of empirical data for treatments such as FCR. It was put to me I could have up to 7 years before relapse, what is this based on. | P | |
| | Remission length for various treatments for CLL, this can assist in planning lifestyle. | PR | |
| | My daughter was,diagnosed with stage 3 cervical cancer 6 years ago. Se got the all clear in January of this year. How likely is it that the cancer will return? | R | |
| | How likely are cancer cells to break away and appear many years later in other parts of the body? | P | |
| | What is the risk of my cancer coming back, or me getting a different cancer? | P | |
| | The chance of recurrence depending on the type/size of breast cancer. | P | |
| | Will it come back? | PR | |
| | How accurate a prognosis can I get? | P | |
| | How often does DCIS of the breast result in cancer / metastatic cancer? | PH | |
| | How long the treatment keeps cancer at bay | P | |
| | Progression rate and life expectancy. | P | |
| | After 5 years,are we cured | P | |
| | If you have underlying autoimmune conditions too what is the chance of it coming back? | P | |
| | Does cancer ever truly go away if you have had it once? | P | |
| | Stage 3 bowel cancer after five years are you then all clear . | P | |
| | What are the chances of cancer coming back? | H | |
| | I'd like to know recurrence rates for my cancer. I can find survival rates and the fact that 75% of recurrences happen within three years but not the actual rate of recurrence. | P | |
| | What chance have I got in suffering a secondary cancer episode? | P | |
| | How likely is a recurrence once you have had cancer | P | |
| | Is it true the longer in remission the likelihood of it remaining so | P | |
| | How soon can you have a recurrence after cancer | P | |
| | What is the percentage of cancer recurring after a oesophagectomy 21/2 years ago. | P | |
| | Will it return | P | |
| | What are my chances getting cancer again | P | |
| | What is the likelihood of my cancer returning? | P | |
| | What are the chances of developing metastatic breast cancer? | P | |
| | What is the incidence of second primary cancers after treatment for a first primary cancer? | H | |
| | When you are in remission does this mean that you are cured or is this just a period of uncertainty until you are given the "all clear"? | P | |
| | In which way we can say that cancer are cured to who living with cancer ? | U | |
| | Why is an all clear given after 5 yrs when we know there never really is an all clear? | P | |
| | Unsure of the likelihood of my breast cancer returning | P | |
| | I'd like more data collection into what happens with people following treatment, eg longer and late side effects, incidence of secondaries, etc as it is only then these issues can be addressed. | PH | |
| | I'd like you to be able to tell me that the cancer has gone, not likely to have gone. I want to be no risk, not low risk. (Maybe this would stop me crying). | P | |
| | How likely is it to come back in a few years /after stopping tamoxifen? | P | |
| | After completing immunotherapy treatment for 2 years how long would you expect the treatment to continue keeping new mets away? | P | |
| | the incidence of relapse | P | |
| | Recurrence rates | P | |
| | What is the life expectancy for longer than 5 year research if you have grade 2 or grade 3 cancer. No one talks for longer than 5 years. | R | |
| | What is the probability of estrogen sensitive breast cancer to return if you are in fertile age and you get pregnant. What is the mortality rate in such circumstances. | R | |
| | I had ovarian cancer stage 1C. I had a totally hysterectomy. Will I ever get a secondary cancer elsware? | P | |
| Are people living with and beyond cancer at risk of developing another type of cancer, different from their first cancer? | Are patients at risk of developing a secondary cancer ? (New Primary) | H | Second cancer risk after chemotherapy for Hodgkin's lymphoma: a collaborative British cohort study. Swerdlow AJ, Higgins CD, Smith P, Cunningham D, Hancock BW, Horwich A, Hoskin PJ, Lister TA, Radford JA, Rohatiner AZ, Linch DC. J Clin Oncol. 2011 Nov 1;29(31):4096-104. doi: 10.1200/JCO.2011.34.8268. Epub 2011 Oct 3. PMID: 21969511 |
| | What is the risk of recurrence <u>or new primary</u> when factoring in complex genetics such as having "lynch like syndrome". Why is this group not being tested for double somatic mutations, to distinguish them from Lynch/sporadic, when the psychological impact is so great? | P | Breast cancer risk after supradiaphragmatic radiotherapy for Hodgkin's lymphoma in England and Wales: a National Cohort Study. Swerdlow AJ, Cooke R, Bates A, Cunningham D, Falk SJ, Gilson D, Hancock BW, Harris SJ, Horwich A, Hoskin PJ, Linch DC, Lister TA, Lucraft HH, Radford JA, Stevens AM, Syndikus I, Williams MV. J Clin Oncol. 2012 Aug 1;30(22):2745-52. doi: 10.1200/JCO.2011.38.8835. Epub 2012 Jun 25. |
| | Is someone living with and/or beyond cancer more likely than someone without a history of cancer to have a second/new cancer? | P | We know that are treatments cause malignancy. Haem malignancies following chemo and solid cancers following radiotherapy. There is plenty of literature on this. |
| | Could I get cancer else where other than the cancer for which I was Treated | P | |
| | Why are people with CLL more susceptible to skin cancer? | P | |
| | an Chemotherapy be the cause of Chronic Lymphocytic Leukaemia? I had bowel cancer and after operation had 30 weeks of Chemotherapy, I was diagnosed with CLL is there a link? | P | |
| | What does treatment of radiotherapy for breast cancer have any relation to diagnosed with CLL | P | |
| | What are the absolute risks of being diagnosed with other forms of cancer after having been tested for another form | P | |

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| | Why do some cancer patients go on to develop a second, totally separate cancer. | P | |
| | What cancers are linked, if any and what ones increases your chances of developing a sarcoma. | P | |
| | Does having one type of cancer make you more susceptible to having another in the future? | P | |
| | The relationship between different cancers. | P | |
| | What is the risk of my cancer coming back, or me getting a different cancer? | P | |
| | What effects does Chemotherapy have? I had bowel cancer in and 30 weeks Chemotherapy. I was diagnosed with Chronic Lymphocytic Leukaemia and this year alone I have had 16 dental appointments, 2 abscesses under teeth 2 root canal fillings I tooth re-crowned and numerous fillings, I have facial pain and may have Sjogrens Disease are these things related? | P | |
| | What, if any, links are there between different types of primary cancer? I had breast cancer, but am worried about other types of cancer being more likely as a consequence. | PR | |
| | Having had pancreatic cancer does this make me predisposed to having another type of cancer? | P | |
| Are people living with and beyond cancer at risk of developing another health condition (e.g. dementia and osteoporosis)? | Will having had cancer have a negative impact on health as we age? | P | Med J Aust. 2018 Jan 15;208(1):24-28.Comorbidities in Australian women with hormone-dependent breast cancer: a population-based analysis. Ng HS1, Koczwara B2, Roder DM3, Niyonsenga T4, Vitry A14. |
| | Incidence of Cancer and Dementia sufferers. | PH | Med Clin North Am. 2017 Nov;101(6):1115-1134. doi: 10.1016/j.mcna.2017.06.006. Epub 2017 Aug 25. Cognitive Changes Related to Cancer Therapy. Vannorsdall TD1. |
| | Is "watch and wait" associated with developing apparently unconnected co-morbidities? | P | Osteoporosis from steroids, chemo and oestrogen blockers plus bone damage from radiotherapy is all well documented. |
| | Co-morbidities. Is there a link between a particular cancer and other illness? | P | Yes by virtue of the risks of their previous cancer history and treatment. |
| | Is there an algorithm, like Google's search engine, that relates interrelated illnesses with a particular cancer? | P | |
| | I want to know the long term health affects that my cancer treatment can cause | P | |
| | What health risks do I face as a consequence of cancer and treatment | P | |
| | Physiological effects of cancer and their impact on other illnesses | P | |
| | Having being diagnosed with melanoma do I have an increased risk of developing any other health related diseases and conditions? (What should I be especially vigalent of?) | P | |
| | I would like to ask about the connection between living with cancer and the susceptibility to catching and getting clear of the side effects of shingles? | P | |
| | I would like to ask the connection between living with cancer and osteoporosis? | P | |
| How can patients be better informed about possible early signs of their cancer coming back? | What is the best way to diagnose Graft Versus Host Disease (GvHD) when you don't see your oncologist as often/discharged? | P | The signs of cancer coming back are well known but there may be an issue because PLWCB are not aware of them. |
| | How will I know if cancer has comeback? | H | |
| | It is important to recognise that some survivors will relapse. In my own case I have had a seven year remission, a three year remission and I am currently on four years. What methods can be employed which enable/support/inform early recognition of the signs and symptoms of further disease among those surviving on self-managed follow-up? | P | |
| | Having had a cancer diagnosis, breast cancer in my case, the fear that a breast cancer might reoccur or another primary cancer might develop, is very real. What are the symptoms that I need to look out for? If the primary cancer spreads are the symptoms different to another primary cancer forming? | P | |
| | How do I know what to look out for after scans? | P | |
| | Can patients see a role for patient involvement in the "safety-netting" of vague symptoms or do they feel this should be solely down to the clinician? | H | |
| | What are the indicators of decline and how to stay one step ahead. | P | |
| | Information relating to what to expect from specific secondary cancers | P | |
| | Are they aware what symptoms to look out for, which need medical attention again? | H | |
| | what are the symptoms of the cancer returning | P | |
| | How can we empower those living with or beyond cancer to recognise symptoms of recurrence? | H | |
| | How do you know which â€œaches and painsâ€™ are worthy of a visit to the doctor after being told you are in remission? | P | |
| | What should I look out for 5 10 or more years post treatment? | P | |
| | Instead of I have any new or unusual symptoms then I should contact the team, yet I am not being told what signs, symptoms to look for??? | P | |
| | How do I look for or identify the signs of recurrence. | P | |
| | How far can people be aware what to look for as early indications that their cancer is coming back ? | PR | |
| | I have lost a number of friends with secondary cancers and I also lost my brother, who was ten years younger than me, five years ago. Are there any symptoms to look out for? | P | |
| | Why call my situation watch and wait. I know my cancer will come back (had it twice already) but emotionally it does not help to know you are watching and waiting - for what. | P | |
| | Is there any way of telling if my cancer has come back but isn't giving me any symptoms? | PR | |
| | How can the medical profession really listen to my underlying concerns when I go for check ups? for example I go through periods of worrying if I have aches and pains, or if I get a lump that appears or if I have a sore that seems to take forever to heal - but I really don't want to run to the doctor with every little thing, however, what if I am missing the early signs of a return of my cancer? | P | |
| | Having had cancer, what should we be aware of within our bodies that it might have returned - apart from general aches and pains? | P | |
| | When do I call s doctor and when is what I'm experiencing normal | P | |
| | Patients fear metastasis, but know that early treatment is vital. Why aren't they given a list of symptoms to watch out for so they can be aware and take early action? (The list will vary for each type of cancer?) | P | |

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| | What's the best signs to look for to see if my cancer has come back | P | |
| | What signs should I look out for regarding my cancer returning or spreading? Is there a hotline I can call for advice? | P | |
| | The signs of relapse | P | |
| Can treatments be developed with fewer side effects, including short-term, long-term and late effects? | Treatment that does not make you ill | R | Yes. This is happening all the time – RAPID study in lymphoma, immunotherapy TKIs etc. |
| | How can the side effects of the chemo be reduced? | P | |
| | What alternatives to chemo are being developed which are as effective or more effective but with less side effects | P | |
| | How will targeted treatments benefit how we treat cancer | P | |
| | reduction in side effects | P | |
| | I would like to know how the side effects of Tamoxifen can be reduced. I am to take this drug for 10 years and it is causing muscular/joint aches and pains, bladder issues, nausea, mood swings and hot flushes. | P | |
| | I have been prescribed an Aromasin Inhibitor (Exemestane) to take for the rest of my life. The side effects (or effects as I call them) are quite dramatic. The fatigue is sometimes overwhelming. And my life has been seriously changed by the painful and restricting arthralgia I get. Question: What research is being done by pharmaceutical companies to address these very serious side effects? | P | |
| | Having the cancer was not as bad as living with it post surgery and their are side effects to the treatment. For example, it has been proven for some that the meds can have an impact on the heart. Again, similar to Question 2, what is research doing to minimise those adverse reactions? | H | |
| | What are the possibilities for future treatment of prostate cancer which will obviate the risk of ED? | P | |
| | How can treatments be made kinder and less damaging? | P | |
| | Why haven't more targeted treatments been trialed? | PR | |
| | Trying to reduce side effects of treatment, both short and long-term. | H | |
| | Does extending the treatment intervals of say an immunotherapy treatment such as Nivolumab from 14 to 21/28 days impact on the treatment efficacy, side effects and survivability? | R | |
| | Continue search for treatments to modify (reduce) treatment adverse effects - in particular radiation . | P | |
| | How can radiotherapy be improved for head and neck cancer sufferers | P | |
| Single question | Can neuroSERMs (eg Raloxifene or similar) protect younger women who have had bilateral oophorectomy from the increased risk of depression, anxiety and dementia in later life? | H | Ann Intern Med. 2018 Jan 2;168(1):39-51. doi: 10.7326/M17-1529. Epub 2017 Dec 19. Pharmacologic Interventions to Prevent Cognitive Decline, Mild Cognitive Impairment, and Clinical Alzheimer-Type Dementia: A Systematic Review. |
| Single question | What is the best method for treating the anti platelet effects of ibrutinib in a haemorrhaging patient? | H | Incidence and description of autoimmune cytopenias during treatment with ibrutinib for chronic lymphocytic leukemia. Rogers KA, Ruppert AS, Bingman A, Andritsos LA, Awan FT, Blum KA, Flynn JM, Jaglowski SM, Lozanski G, Maddocks KJ, Byrd JC, Woyach JA, Jones JA. Leukemia. 2016 Feb;30(2):346-50. doi: 10.1038/leu.2015.273. Epub 2015 Oct 7. Rapid flare of immune thrombocytopenia after stopping ibrutinib in a patient with chronic lymphocytic leukemia. Sato R, Jacob J, Gaballa S. Leuk Lymphoma. 2017 Oct 30:1-4. doi: 10.1080/10428194.2017.1387907. |
| Single question | What strategies and coping mechanisms are available to people living with cancer and beyond regarding managing their shortness of breath after cancer treatment? | H | 3 separate Cochrane reviews (Exercise, corticosteroids and benzodiazepines) |
| Single question | What problems arise from the severe workforce shortage in radiotherapy? I would want such a question to look at the hindrance of research within radiotherapy and oncology due to staff shortages, potential for errors to increase, and future workforce planning and management if the diagnosis of cancer is set to increase. Also look at patient experience and staff satisfaction. This research would provide the solutions to such problems by also looking internationally to their models of education and retention of the workforce | H | Int J Radiat Oncol Biol Phys. 2014 Jul 1;89(3):448-57. doi: 10.1016/j.ijrobp.2014.03.002. Epub 2014 Apr 18. Radiation therapy infrastructure and human resources in low- and middle-income countries: present status and projections for 2020. Multiple published editorials and think pieces looking at staffing in LMICs as a comparator. Also reports on workforce from RCR and CRUK |
| Single question | Appropriate fibre restrictions for colorectal cancer | H | Cochrane: Nutritional interventions for reducing gastrointestinal toxicity in adults undergoing radical pelvic radiotherapy. Cochrane: Dietary fibre for the prevention of recurrent colorectal adenomas and carcinomas. Online Publication Date: January 2017 |
| Single question | How does prior mental health history influence what psychological difficulties people have and how they are treated, when they later have cancer. | H | |
| Single question | Are there any links between CLL and a decline in periodontal health? | P | Acta Stomatol Croat. 2016 Mar;50(1):23-33. doi: 10.15644/asc50/1/4. Evaluation of Periodontal Parameters in Patients with Early Stage Chronic Lymphocytic Leukemia. |
| Single question | Is there any research on the effects on child health where the mother has had cancer during pregnancy? | U | Multiple observational studies reporting outcomes. |
| Single question | How can immunocompromised patients such as those who have had a stem cell transplant be better protected from recurrent infections and viruses post transplant | P | Multiple studies of different antibiotic / fungal protocols. |
| Single question | The effects of testosterone deficiency syndrome on men after treatment for testicular cancer | H | There have been studies into this and we replace it routinely now. Clin Endocrinol (Oxf). 2017 Dec 15. doi: 10.1111/cen.13534. [Epub ahead of print] High risk of hypogonadism in young male cancer survivors. Isaksson S1,2, Bogefors K1,2, Ståhl O2, et al. Greenfield et al JCEM 2007. A randomized double-blind study of testosterone replacement therapy or placebo in testicular cancer survivors with mild Leydig cell insufficiency (Einstein-intervention). |
| Single question | Pet therapy - mental well being or physical effect? | PH | Already known to be both – all psychological therapies affect well-being and have a physiological basis. |
| Single question | What are the long term implications for educational attainment following treatments for brain cancer | RH | 2 Cochrane reviews |

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| Single question | Do partners and carers influence the decisions of patients and healthcare professionals? | H | Triadic treatment decision-making in advanced cancer: a pilot study of the roles and perceptions of patients, caregivers, and oncologists. LeBlanc TW, Bloom N, Wolf SP, Lowman SG, Pollak KI, Steinhilber KE, Ariely D, Tulskey JA. Support Care Cancer. 2017 Nov 4. doi: 10.1007/s00520-017-3942-y. Patient's Cognitive Function and Attitudes Towards Family Involvement in Cancer Treatment Decision Making: A Patient-Family Caregiver Dyadic Analysis. Shin DW, Cho J, Roter DL, Kim SY, Park JH, Yang HK, Lee HW, Kweon SS, Kang YS, Park K. Cancer Res Treat. 2017 Jul 4. doi: 10.4143/crt.2017.201 |
| Single question | What are the biological changes associated with complementary therapies? | H | What Is the Molecular Signature of Mind-Body Interventions? A Systematic Review of Gene Expression Changes Induced by Meditation and Related Practices. Buric I, Farias M, Jong J, Mee C, Brazil IA. A Systematic Review of Mechanisms of Change in Body-Oriented Yoga in Major Depressive Disorders. Meister K, Juckel G. Pharmacopsychiatry. 2017 Jun 1. doi: 10.1055/s-0043-111013. [Epub ahead of print] Front Immunol. 2017 Jun 16;8:670. doi: 10.3389/fimmu.2017.00670. eCollection 2017. Review. Longitudinal and Immediate Effect of Kundalini Yoga on Salivary Levels of Cortisol and Activity of Alpha-Amylase and Its Effect on Perceived Stress. Garcia-Sesnich JN, Flores MG, Rios MH, Aravena JG. Int J Yoga. 2017 May-Aug;10(2):73-80. doi: 10.4103/ijoy.IJOY_45_16. |
| Single question | How can we prevent, cure or improve the symptoms of people living with GVHD. | P | 10 separate Cochrane review on GVHD treatments. |
| Single question | What is the biological mechanism causing hot flashes in women living with and beyond breast cancer, and is this different to women without breast cancer? | H | Understanding the complex relationships underlying hot flashes: a Bayesian network approach. Smith RL, Gallicchio LM, Flaws JA. Menopause. 2018 Feb;25(2):182-190. doi: 10.1097/GME.0000000000000959 Cardiovascular, hemodynamic, neuroendocrine, and inflammatory markers in women with and without vasomotor symptoms. Gordon JL, Rubinow DR, Thurston RC, Paulson J, Schmidt PJ, Girdler SS. Menopause. 2016 Nov;23(11):1189-1198. |
| Questions that are out of scope | | | |
| Questions about access to services | How do patients access Q of L improvement/support/assistance services ? | H | |
| | Why is there so little psychosocial support to improve psychological adjustment post-treatment? | H | |
| | How can large and growing numbers of vulnerable and isolated elderly people who then get cancer be realistically cared for in our now fragmented society? | R | |
| | Why is it after diagnosis it is up to the patient to find support services available to them? | P | |
| | Why after receiving news of new or changes to tumours there is a lack of support available to patients? | P | |
| | How to deal with the aftereffects of steroids and/or chemo when in remission. They've dealt with the cancer, but there is little support which naturally follows for the after effects. (I lost the use of my arm with one form of chemo) | P | |
| | There doesn't seem to be much support for carers within the NHS they have to resort to other charities. Will this improve? | P | |
| | Why isn't there more support available for people who want to have palliative care in their own homes? | RH | |
| | Why is support for breast cancer so much better than for other cancers, As a survivor of breast cancer and now fighting bladder cancer, the gap is very evident | P | |
| | More clinical specialist nurses so you gave access to them | R | |
| | Unmet supportive care needs of cancer survivors | RH | |
| | depending on type of cancer why does level of support differ | P | |
| | Why is there not enough help to help sufferers. Of lc with emotional needs and the unknown | R | |
| | Access to specialist dietary advice was almost life-saving for me but access to this service is low, through GP referral channels. How can cancer patients access prompt nutritional advice? | P | |
| | what online help is available for patients with a diagnosis of melanoma and does it adequately address their issues? | H | |
| | ARE PATIENTS WHO ARE DIAGNOSED WITH CANCER, BEING OFFERED THE HELP THEY MAY NEED STRAIGHT AWAY. | R | |
| | When will carers be cared for, too? | U | |
| | Why are there less well being activities built into treatment for adults. Quality of life issues are important. I know kids get lots when they are in to boost their morale. I was offered nothing during my 6 week inpatient stay and nothing in the year, so far, since my stem cell transplant. | P | |
| | Why is it so difficult to get treatment for long term effects post cancer treatment? | P | |
| | I have had problems contacting specialist nurses and had 3 different consultant surgeons I would like more consistency also if I have a question that someone gets back with an answer. I have spoken to other patients and they say the same | PR | |
| | Who is responsible for discussing palliative care with patients and those close to them and then initiating it? There may be a recognition in the cancer community that palliative care can begin earlier in the pathway but do patients actually know that? | R | |
| | I feel I have fallen through a gap as I have several different cancers, tumours and conditions at different times over 30 years. Where is the support for people with multiple long term conditions - caused by the treatment for Leukaemia?? Why did I have to pay for psych help when the referral took 9 months to come through?? | PH | |

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| | Why is there no effort to put cancer patients in touch with people who may be able to help, or give information EG support groups, MacMillan, etc, and why is it apparently impossible to contact the consultant supposed to be in charge of your treatment? | P | |
| | When planning treatment and access to appropriate ancillary services, how can it be right that a late stage lung cancer patient is given an appointment for physiotherapy 6 months hence? So perhaps a question like "How do patients feel about the length of time they are waiting to access physiotherapy services which have been clearly identified as being necessary as part of their treatment planning. And what has been their perceived impact of this". | O | |
| | Why aren't the health services utilising all available screening resources for the purposes of earliest possible detection of cancer risk? | P | |
| | Do people get access to palliative care when they need it? | H | |
| | Appropriate walking aids for patients with cancer- I'm finding that there are items not available on the market that would meet the needs of my patients comorbidities particularly with increasing obesity within the population, taller patients or petite patients. | H | |
| | As patients and main carer giver (ages:30-60) there is not enough community support | H | |
| | Why are some treatments only available in a few places forcing patients to travel for hours? | PR | |
| | why are level 1 incontinence pads not available to prostate surgery patients? Thicker, bukieer pads are available, but don't improve confidence. | P | |
| | Why is there not enough emotional support for cancer patients | RH | |
| | Why is there no psychological support available during the initial 12 months post surgery? | P | |
| | Why is dental care and follow up not part of the standard after-care plan post radiotherapy? | P | |
| | My mother was given a diagnosis of stage 4 pancreatic cancer yesterday but no CNS available. I know guideline say this should be happening but there are clearly loopholes. I am a CNs in a different cancer discipline so hard to transfer necessarily the relevant information other than the fact I know the procedures and time lines. | RH | |
| | Why is the service offered to patients different depending where you live ,should it not be a National standard for everyone ? | P | |
| | There seems to be serious inequality in terms of supportive and palliative services available to patients in different areas of the UK - given we know they make a difference to the quality of life of patients why is their such variation and how can it be solved? | R | |
| | Why isn't there a fast track system in place for the mental health of those diagnosed with cancer, especially when the diagnosis is life threatening? There should be an offer of immediate referral, no wait. | P | |
| | Why is there such a long wait when six weeks can be very bad for some cancers | P | |
| | Access to psychological support services | P | |
| | Why is there not a consistent approach to psychological care of cancer patients from on NHS trust to another? Compare the Fountain at Surrey Hospital that is supported by counsellors and listeners vs RBH which has none. | P | |
| | Equitability in the management of complex and rare cancers, especially surgical management. | H | |
| | At no point have we as a family be offered any emotional support following my mothers diagnosis of cancer and dementia. WHY? | R | |
| | Why has my mother (the patient) never been offered any counselling or emotional support? She is so scared. | R | |
| | How can a supportive infrastructure be set up for each patient who has/had metastatic spread? | P | |
| | how can we integrate support for emotional / mental health issues during/after oncology treatment | PR | |
| | How can I get emotional support as well as medical care | P | |
| | Why am I only offered medical care and not a holistic, patient-centred package | P | |
| | Should counselling be a mandatory part of treatment for cancer patients | P | |
| | How to improve psychological support to empower the patient and carers | H | |
| | Can a counsellor be classed as part of the treatment process | P | |
| | Patient leaves hospital and usually there isn't any one to ask questions of as they don't get to be seen for 6 months by this time the patients have often sunk in to depression why isn't counselling automatically given it shouldn't need to be asked for it should be automatically arranged. | RH | |
| | When is the emotional and psychological aspects of a cancer diagnosis going to be taken into account and patients get the support and help they need? Many suffer for years with the after effects of a cancer diagnosis. | P | |
| | When an individual has other medical difficulties or diagnosis on top of cancer how are they treated and supported holistically with everything being taken into consideration? A personal example: I have a serious heart condition (5 heart attacks), severe asthma and complex mental health difficulties as well as prostate cancer (6 years so far) and have found that medical professionals focus only on their expertise. This is particularly true for having my mental health needs ignored by those addressing my physical health needs. | PR | |
| | I'm a three times survivor of cancer, my mental health has been affected, trying to get help from the hospital has been traumatic, will this research make it easier for cancer patients to receive the counselling before & after a diagnosis? | P | |
| | Should all cancer sufferers be offered counselling to help come to terms with whats happening? | P | |
| | Cancer counselling | R | |
| | The treatment and swiftness of treatment I received for Breast cancer was without question excellent. However I do feel help for the short and long term impacts on mental health are something which is lacking. A cancer diagnosis changes the way you look at life and life experiences. Friends I have spoken to have confirmed this especially feelings around confidence issues. Research into these mental health impacts, if earlier counselling is of benefit would confirm and perhaps save future NHS expense when these feeling cause problems months or even years after treatment. | P | |

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| | I feel there are certain cancers that get a lot of research funds and focus, but less is known about the experiences of those who have less researched cancers. I had endometrial cancer at a young age (37). Care was not great (if we compare it to the gold standard of breast cancer treatment, which has psychological support in-built). Treatment had huge impact on my quality of life. I would like to see these issues examined because they matter to the individuals affected. | P | |
| | How can we treat the whole person during cancer treatment, not just the physical illness? ie, emotional support, managing shock, reducing PTSD etc. | P | |
| | How is the mental health and wellbeing of patients and carers considered as part of the post cancer recovery? | R | |
| | Would it benefit cancer patients & their partners long term to be offered sex and relationship counselling automatically as an adjunct to any form of cancer treatment i.e the counselling is offered to everyone not just those who ask for help | P | |
| | How can support services and the promotion of them/accessibility be improved? What other therapies/treatment have you experienced and would recommend to other people living with the effects of cancer? | P | |
| | Will the postcode lottery still exist for drugs to help with living with cancer and beyond? | P | |
| | Would it be possible to create a more central, user friendly and inclusive advice service, that would allow cancer patients a clearer understanding of suitable trials that may be available. My own experience is that this information can be quite dis-jointed and open to individual perception. | P | |
| | Why can't GP's provide more support and facilities close to home | H | |
| | I received no counselling during or after treatment .I wonder why some people aren't offered in support in the mental health issues that can happen during and after treatment and diagnosis | P | |
| | Prof X announced personalised treatment for Prostate Cancer. Despite money continually being thrown at this research (like a bottomless pit). Why is it that it appears that only the privileged few or patients only have access to it ?? | R | |
| | Is more psychological support needed? | U | |
| | Why is there no support after surgery? | P | |
| | Why do palliative care services in hospitals not work at weekends? | R | |
| | I think there needs to be more support for patients with rare cancers, to support the lack of information and feeling of isolation. | P | |
| | Why can you only have a DNA profile of your cancer if you live in the areas that fund it? Surely 1 NHS should give the same chances to all cancer CLL patients. | P | |
| | Head and neck cancer patients, especially laryngectomies, need a lifetime of aftercare. There is a higher proportion of suicide among laryngectomies. It is important therefore that they have access to a support group. We are running a peer-led group but get very little support from the hospital if at all. What can be done to rectify this? | P | |
| | our Macmillan Speech & Language Therapist left last month. Head & Neck Cancer patients, especially laryngectomies were assured there would be no break in the service provided. However, I requested a valve change four days ago and have been told there is no-one available to do it and that I would have to wait until the consultant has the time. In the meantime I am unable to take liquid via mouth nor am I able to talk at all. It is known there are staff qualified available to perform this procedure and we sometimes wonder what is going on. | P | |
| | Can on-line resources adequately compensate for a lack of workforce in Survivorship / LWBA? | H | |
| | How easy is it for these patients to access [psychological] help? | H | |
| | Whether timely psychological support is available | H | |
| | If offered psychological support, whether it is available enough (length of sessions, number of sessions, location of sessions) and appropriate to needs (i.e. referral accepted or given to another service) | H | |
| | Did you have a key contact throughout your cancer investigations, diagnosis and treatment ? | H | |
| | What provision is there for alternative therapies for young people with cancer? | P | |
| | Are there enough local support groups where young people can meet up and share their experiences? | P | |
| | I have RCC stage (iv) I have noticed on forums . It's treatment depends on your postcode. Yes it's another postcode lottery. Basically London and SE is good but the further north you get if your not near cancer specialist hospital good help you . I appreciate all Drs can't be specialist in all types of cancers . So why not have a std database online for all Drs to use once diagnosis has been confirmed. Why isn't there a standard treatment package for all cancers. A database that oncologist or Drs could refer to to help them out if they are not sure if the current available drugs. We know if Drs who arnt aware of the early access to drugs fund . We know of Drs who recommends line 3 treatment after line 1. (people will die earlier if they are missing out on a line of treatment) Problem is "some" not all Drs think they are "gods" and they know everything and come across as arrogant . Believe me when you've been diagnosed and have "the rabbit in the headlights" look you'll want to believe anybody . Please make sure everybody has access to ALL available treatments. | P | |
| | What is the quickest, most direct and efficient route to get into the health system when you have systems suggestive of recurrence. At present it may be GP, surgeons or Oncology. | RH | |
| | Is there adequate support to facilitate the return to work for those suffering long term effects as a result of treatment? i.e. if patient unable to return to their trained profession (eg. disability affecting ability to do job) or difficulty in securing a job post treatment for recurrent disease and/or where regular (ad hoc) treatment still required. | R | |
| | Why is counselling so hard to access in order to "learn to live with" the consequences of having cancer? | P | |
| | Why isn't there more support regarding emotional and mental health well being ? | P | |
| | Why isn't there psychological / emotional support regarding developing individual resilience from the point of initial diagnosis or pre treatment ? Cancer has an immediate impact psychological ! | P | |

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| | Why is there such a wide range of different treatments and interventions up and down the country for the same cancers? Do individual consultant practices take precedent over standardised practice ? | P | |
| | What mental health/counselling provision is in place for those given the "all clear" but who are concerned about their cancer returning? | P | |
| | Is there equity in the routine services in the 3 Radiotherapy centres | H | |
| | how we can achieve the same treatment across the country ? | H | |
| | Why is there limited support available to people living with progressive cancer depending on where you live? | P | |
| | Should cancer survivors be able access treatment for problems associated with their cancer in less than 18 weeks waiting for an appointment. | P | |
| | Why is it easier to get a £50 000 cancer drug of dubious effect than it is to find a physiotherapist or social worker to help a cancer patient? | H | |
| | Some patients remain anxious, understandably, following cancer. Is there enough patients have access to these health and well being events etc, or does it depend on your postcode? Is there enough services for patients who live in rural areas? | RH | |
| | Why is there different facilities for LWBC in different towns i.e. drop in clinic, well being events | H | |
| | How aware of you of the services that are available in your area to support you, and how accessible are these services? | H | |
| | Why is there no pelvic radiotherapy damage aftercare in Scotland? | P | |
| | Is there any further help possible for more acupuncture to help people with dry mouths as a result of their treatment? The acupuncture course I went on was beneficial yet too brief and I have heard nothing more about it and I am anxious to get more of it. | P | |
| | MacMillan cancer specialist nurses are spread thinly throughout NHS hospitals. If the hospital sees the value of paying a charity to supply their expertise and knowledge, why don't the health trust employ specialist nurses? | R | |
| | Support/counselling that is immediately available in terms of psychosocial, emotional or physical concerns.. | P | |
| | Do people living with or beyond cancer know all of the support available? If so how did they find out about it? | H | |
| | Now more people living with and beyond cancer are returning to work, can services be provided outside office hours? | P | |
| | I would like counselling offered alongside treatment for throat cancer | R | |
| | why is counseling not offered with treatment and after | P | |
| | why is the not any physio offer as part of treatment and after | P | |
| | Why does there seem to be no-one at the weekend, support lines, Cancer nurse Specialists if I need to ask questions or get advice ? | R | |
| | Equipment for endoscopy and expertise varies widely. Is this being addressed? | PH | |
| Questions that could be answered by audit | What numbers of patients successfully claim benefits they are entitled too having being diagnosed with cancer ? | H | |
| | Is there sufficient psychological support for those affected by cancer? | P | |
| | What support is there for parents/carers/family and friends? | P | |
| | What support is available for people going back to work? | P | |
| | What tools if any did the hospitals provide you with living with cancer/ how to cope with cancer and also once your treatment had finished? | P | |
| | The importance to survivors of their 'quality of being' was highlighted during NCSI as something different from 'quality of life', although this was forgotten in the final report. What psychological services are provided in the NHS to support cancer patients and survivors? This is not simply the nature of services but the volume/quantity, locality and number of practitioners. Analysis of need against this provision should be included. | P | |
| | Did you get to meet other people in the same situation to find out how they coped / their life changed? | P | |
| | What support is there after treatment | P | |
| | How are patients and their carers signposted to relevant services if they experience tinnitus during or following treatment? | H | |
| | What is there available to help people mentally to live with a diagnosis of Cancer | P | |
| | What NHS services are available to cancer patients for the period between finishing treatment and being discharged back to GP care and are these services advertised and readily available to all patients or is it location dependent? | P | |
| | The 2 -week referral available to GP's is great but how can you be sure that all GP's are offering that if they suspect cancer? | P | |
| | How do men who have received radiotherapy or surgery for prostate cancer evaluate the late effects of treatment on sexual function in relation to their pre-treatment expectations of the physical and emotional impact that treatment would have and how they would adapt? | H | |
| | Since your diagnosis what support have you received related to long term consequences of cancer treatment? | O CHARITY | |
| | What is the availability and quality of NHS resources specific to young adults with cancer to help them to deal with the mental health effects of a cancer experience? Do these resources support the best way to deal with the mental health impacts? | P | |
| | What help and strategies are available to people living with cancer and beyond regarding returning to paid employment? | H | |
| | Patients experience of undergoing a Holistic Needs Assessment - was it helpful, were they given or signposted to any or all the support needs identified, was the outcome of the support followed up at consequent HNAs. | PR | |
| | what support services are you able to access for management of long term side effects (for patients more than 1 year post treatment)? | H | |
| | If so, when were you provided this information, and by whom? | H | |
| | What psychosocial support is available to someone living with cancer? | P | |
| | What longer term support is available to those who have finished treatment and are no longer in the 'system' but still have concerns and worries about living with cancer and potential recurrence? | P | |
| | Have you been put in contact with an Occupational therapist to support you ,to consider what your priorities are and enable you to live with and beyond cancer? | H | |
| | Has there been enough support for the person diagnosed with cancer from local health services,such as GPs and specialist clinical staff? | PR | |

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| | what percentage of women under 65 years of age return to usual employment after a diagnosis of breast cancer treated with curative intent | H | |
| | what percentage of women with metastatic breast cancer under 65 years continue in active employment | H | |
| | Did they get HNA during their treatment? | H | |
| | What support is there for those wanting to change career after cancer? | U | |
| | Is provision of support services LWBC equal e.g. variation by protected characteristics or by social deprivation. How should services be tailored / designed to minimise any variation? | H | |
| | How many women diagnosed with oestrogen positive breast cancer go on to have a baby after treatment ends? And what are their survival rates? | P | |
| | How many In-patients experience a delay in their discharge from hospital due to 'waiting for discussion at cancer MDT', sometimes for a management plan which recommends simply best supportive care ? | H | |
| | Do you receive adequate support to manage any such condition? | P | |
| | What improvements could be made to support you in managing any condition which has resulted from your cancer treatment? | P | |
| | what is the experience of Open access follow up (risk stratified pathways) patients who develop metastatic breast cancer | H | |
| | is compliance of endocrine treatment affected or impacted by open access follow up | H | |
| | What services do people access up to 5 years post a cancer diagnosis? | H | |
| | What are patient perceptions of rehabilitation received / undertaken whilst undergoing treatment or following treatment | H | |
| | Do patients feel that there should have been greater access to rehabilitation during or after their treatment | H | |
| | Are people who have experienced pelvic radiation being offered physiotherapy to help with secondary more long term effects that may impact on bladder? bowel? sexual dysfunction? pelvic floor? how early are these people being referred? | U | |
| | What psychological support is available for people during diagnosis and treatment ? | R | |
| | We know that patients who are 'cured' are left with complex post treatment problems. What services are really available for these patients. | H | |
| | What community services are available to support patients/families/carers LWBC in each locality ? | H | |
| | How are local PCT's aiming to fill these inequalities in community support ? | H | |
| | What support is available for family/relatives following a diagnosis of cancer? | H | |
| | What services are available in the community for patients with a recent cancer diagnosis? | H | |
| | What support is available to carers | R | |
| | Are the psychological needs of people with Head & Neck cancers undermet in comparison with other cancers e.g. breast? | RH | |
| | Differences in care, wellbeing and treatment between those who live in cities and those who live in rural parts of the UK. Issues include transport, travelling time, access to wellbeing services and access to support for families and carers. | R | |
| | What support is available for people who have finished their treatment | O | |
| | What support is available in the community for people living with cancer and need emotional support | O | |
| | What support is available in the community for families and carers that are affected by cancer | O | |
| | What support is there for people living with and beyond cancer in the community when their cancer treatment has completed? | H | |
| | Is there access to rehabilitation in the community for people who are going through and who have completed cancer treatments? | H | |
| | Have you had any rehabilitation offered during your illness (physio, OT etc) | H | |
| | What support exists for the immediate family who have a cancer sufferer in their midst? | P | |
| | Are people likely to travel very far to access support eg in rural areas. | H | |
| | What are the experiences of those diagnosed with conditions considered uncommon or rare for their age group? What is their experience of care (poor I suspect!) | P | |
| | How available is counselling for people diagnosed with cancer? | P | |
| | What is available for managing the side of living with cancer | RH | |
| | Do all cancer patients have access to specialist pain teams to optimise pain control | H | |
| | Are there regional differences for patients living with and beyond cancer and how can local services support these differences to best help patients and families, and to meet their needs | U | |
| | how were you supported by your employer in your return /phased approach to work | PH | |
| | did you have access to a specialist nurse for the duration of your treatment was this support beneficially and in what way ? | PH | |
| | What services are people living with cancer accessing | H | |
| | How many people living with cancer, who are not acutely ill are in our community? Broken down into counties. I feel there isn't enough information on people living with cancer who are currently not accessing secondary care | H | |
| | What are the needs of local counties, what do people want access too? Whether its psychological, benefits, etc what do they actually want? | H | |
| | What support is there for those in long term remission? | P | |
| | What help is available for people who's cancer treatment causes them long term problems even after their cancer treatment is finished? | H | |
| | What are people LWBC saying they are struggling with | H | |
| | Does every person LWBC have an holistic needs assessment and are they told of what services are available in the community | H | |
| | What services are available to meet the needs of this patient group? | H | |
| | How many extra appointments with primary care do patients, in the 1st year after completing (hopefully) curative cancer treatment, make as compared to pre diagnosis. ie how much extra demand is generated for primary care services. | H | |
| | What support is available for people with cancer ? | P | |
| | Did you receive advice on fatigue and breathlessness management. | H | |

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| | What psychological support is available for partner of person with diagnosis? | P | |
| | How is financial advice given? Getting the correct advice and support is very difficult | P | |
| | After discharge from active treatment, did your GP offer a Cancer Care Review ? If you had one with your GP - was it helpful, was a treatment/support plan offered and developed with your involvement. | PR | |
| | What is the health care utilisation of patients diagnosed and treated for breast cancer once they are discharged from oncology service | PH | |
| | Are there variations in the levels of investment in Radiotherapy equipment and services across the 3 Radiotherapy centres, and is there a correlation in survival outcomes | H | |
| | What is someones satisfaction of OT intervention to facilitate and hospital discharge. | H | |
| | Patients experience of a Holistic Needs Assessment (HNA): was it helpful, were any particular support needs identified, were you offered/signposted to the appropriate service/support, did this service/support help, was the outcome of the service/support followed up in any subsequent HNA. | PR | |
| | Cancer Care Review in primary care: following your discharge after your main course of treatment were you offered an Cancer Care Review by your GP. If yes, was it helpful, was a care/support plan developed jointly with your involvement, was any follow-up care agreed. | PR | |
| | What was your biggest worry after treatment? | RH | |
| | the benefit of HNA [HOLISTIC NEEDS ASSESSMENT] 's to patients, is there a difference between quality of care plan if people have had more than 1 done by different people. What has the process of HNA and care plan added to patient experience | H | |
| | Do patients feel confidence in their cancer care | H | |
| | What 3 aspects of your care during your cancer journey have been most helpful (eg information, timely response to referral, the person who sat and listened, changes to medication). The idea is to consider and maybe capture information to encourage clinicians - we hope we are helping our patients but maybe alongside the big things we do the little things are so important | H | |
| | What influences equity of access to (1) medical services (2) other support (e.g. psychological, financial, community nursing) for patients living with life-shortening cancer & uncertainty about prognosis? | H | |
| | How are patients in primary care with and cancer diagnosis supported by occupational therapists to stay in or return to work | H | |
| | Is there really a post code lottery about treatment options? | P | |
| | what help is available to people struggling with the emotional impact of 'watch and wait'? | PR | |
| | Have patients been asked if they would prefer a oncology appointment just with other secondary cancer patients rather than being mixed with primary? | P | |
| | Patients experience of a Holistic Needs Assessment (HNA): was it helpful, were any particular support needs identified, were you offered/signposted to the appropriate service/support, did this service/support help, was the outcome of the service/support followed up in any subsequent HNA. | PR | |
| | Cancer Care Review in primary care: following your discharge after your main course of treatment were you offered an Cancer Care Review by your GP. If yes, was it helpful, was a care/support plan developed jointly with your involvement, was any follow-up care agreed. | PR | |
| | How much support do you get/should you receive in returning to work. What should we expect especially if you are 'living with cancer' | P | |
| | I want to know how employees can get a better more evidenced based support from their employers when living with the consequences of cancer and cancer treatments, such as fatigue and chemo brain | P | |
| Questions about employment | How to make healthcare professionals and employers acknowledge the effects of living with fatigue following cancer and not just say its a side effect to live with. Patients are told to pace themselves but employers still expect the work to be done so no allowance is given for fatigue hence the patient is unable to pace themselves. Fatigue should be categorised like any other disease that has to be lived with and acknowledged as a disability. | PRH | |
| | Employers - Why do they feel that they can't help you when you have cancer? Why don't they offer help with work? | P | |
| | Not enough understanding and support in the workplace for those in employment | H | |
| | I would like to see more research into living AFTER the completion of treatment. Returning to 'normal' life, or perhaps it should be 'creating a new normality' can be difficult. I returned to work after a 13 month absence. The 'welcome back' was superb but after several days it was as though I had never been away - there was a distinct lack of understanding that while I was back at work I was still living with my cancer experience. Of course, how could there be much understanding, most people's experience is probably a bad 'flu which leave little or no trace after several weeks. The aftermath of a cancer experience is so much different, more profound. The cancer survivor may spend months or years processing/coming to terms with the monumental experience they have been through, something their colleagues haven't a snowball's chance in hell understanding. Employers need education [especially the Human Resources staff]. In my case after having been treated for Testicular Cancer I spent five years with low levels of testosterone which resulted in behaviour which could have landed me in a disciplinary situation [my good luck that Management was inept] and could potentially have resulted in me being sacked - sacked because of an undiagnosed medical condition! | P | |
| | What can be done to communicate the mental health needs of cancer patients and survivors to employers more effectively? | P | |
| | As a working carer, I have been lucky in that my Company and management have been supportive. But then I am able to work at home and can catch up at weekends. My experience is not necessarily what other carers have the support and flexibility that I have relied upon. Lack of support could be ruinous to the lifestyle, finances, relationships and the concerned individuals. [?] Surely reasonable Employer's should have a sympathetic support plan. Is there a reasonably equitable best practice that can be applied with wholesale support across the UK. With Legal underpinning if necessary. | R | |

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| | Apart from the Equality Act how can employers in the UL be encouraged to compose long term absence policies to cover Cancer with some 'humanity' incorporated? Some of the wording such as taking further action is quite inhumane in the 21st century. | P | |
| | I have found that since having cancer when going for jobs I believe I have been discriminated against because of my long term health conditions and side effects of cancer. I now do not mention the fact I have had cancer when applying for jobs | P | |
| | Flexible working arrangements for those not feeling 100% but who still can work. | P | |
| | Can there not be an employer's pack giving them the information needed for them to ensure their employee's return to work is smooth and not stressful? Currently it is down to the person living with cancer to find out about their entitlements and cancer isn't a quick fix. My daughter has had successful treatment but because of the nature of the cancer is under her consultant's care for 10 years. | R | |
| Questions about financial support | Why does travel insurance have to be so expensive after a cancer diagnosis? Patients feel they are being penalised for wanting to have a holiday after getting through what can be very tough going treatment. | H | |
| | Given the unpredictable nature of recurrence and also the effect of cancer drugs, how can we provide financial support to people unable to continue working because of this? | PR | |
| | I am aware one established side effect of chemo is damage to gums and costly dental treatment following chemo. I am in this position yet on half pay, live alone and my priority is paying the mortgage. Why is there a disparity between pregnant women who receive free dental care during pregnancy and the 12 months after because of the risk yet cancer patients on chemo who are at high risk of gum damage receive nothing. Surely any research would establish chemo is a greater risk than pregnancy. Following completion of my chemo I will need to get my gums and teeth repaired yet I'll not be able to afford it until back on my feet and working full time again. I can't understand why there is no help available unless you are on benefits yet we qualify for free prescriptions. | P | |
| | Financial support when suffering with late side effects and struggling to stay in employment | PH | |
| | Why don't (pip) assessors understand the on going impact of fatigue and anxiety on activities of daily living? | P | |
| | What changes need to be made in hospital based welfare and benefit support for those undergoing treatment and living with side effects of disease or treatment. | P | |
| | Financial problems I am afraid I slipped into Patient Rep mode for this one as I did not suffer from financial problems due to the generosity of my employer, however it is a massive problem for many patients and more help and advice needs to be provided. | P | |
| | The financial side of living with cancer is a problem. With few exception, the wealth of the patient will change, specially if they cannot get back to full time employment. So why are the ethics around financial help so rigid and horrendous? Financial help should be adapted to the needs of someone who has had to shift their mind-set from immortality to short-mid term future. Helping with monthly housing benefits is not real help, it is business as usual adjusted to such radically different circumstances that it simply cannot work. Lump sums could perhaps better cater for financial struggle. E.g. one could go and recover in a sunnier, happier place, for a lot less money, rather than stuck at home, where every single corner reminds one of their life before and after diagnosis, and how it can never be the same. | PH | |
| | How can applying for PIP be simplified for those living with and beyond cancer, and be made less stressful? | P | |
| | Travel and other insurances are affected by a cancer diagnosis but I am not convinced that the insurance industry's actuarial base for increasing premiums is based on evidence of the actual likelihood of survivors having problems related to their cancer. As a result survivors are discriminated against by either not being able to get insurance or by premiums that are much higher than reasonable | R | |
| | Should there be easier access to financial support? Fast Track Funding without the need for mountains of form filling to support both patients and carers? Simplify! The CAB provide a very good service, but MacMillan could do with stopping ramming down people's throats their own agendas. Marie Curie provide a high quality service, but there are not enough of them. | RH | |
| | Benefits and other allowances advice available within a hospital setting... as a walk-in. I realise this could potentially be a very busy service with the option to make an appointment to return. | P | |
| | When you have an inoperable Tumour...mine is in the brain...and are life limited...and have been approved for ESA and other benefits...why do the DWP make you fill in "suitability for work" questionnaires..aprox every three years.. and often make you attend ridiculous "health" check appointments..ATOS...that really have no relevance to our condition? | P | |
| | Will the government ever give travel allowances for hospital visits for cancer treatment | P | |
| | Why is there no financial assistance from government when people have to take time off work due to the effects of cancer? | P | |
| | Help with claiming benefits where the affects of the surgery have no diagnosis. I have debilitating fatigue and many other issues. As there is no diagnosis as such for the affects of the surgery there is great difficulty applying for benefits . | P | |
| | Insurance implications when patients do better in trials than those who don't enter - how come insurance companies do not like insuring patients in trials | H | |
| | How can we encourage Insurers of Life, Critical Illness & Income Protection to stop trying to find any clause to prevent a payout on a claim? This understandably causes a great deal of stress at a time when Cancer can affect your household income. | P | |
| | The lack of financial support | H | |
| | why should people living out f the uk not get help our grants i have lived their all my life its not faire | R | |
| | Is there a way that we can insure ourselves against the costs and financial burdens that are posed by living with cancer and being unable to work? For example, a short term disability living allowance? | P | |

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| | we need to make sure that patients are supported so that they can access all the potential financial benefits available to them. Young peoples services do this well but I worry that the vast majority of patients do not get this support | H | |
| | Has the governments drive to reduce certain benefits affected cancer survivors ability to manage financially? | P | |
| | Having cancer can cause real financial hardship, charities are good at helping out but there really should be a more co-ordinated approach for anyone suffering because they are ill, it is bad enough dealing with the physical and emotional stress without worrying about money | PR | |
| | Holiday insurance is very difficult to get and feel confident with. They certainly don't understand retuximab. How can we make it simpler for them and us to understand and also obtain so we can feel secure when our consultant says we can go on holiday. | P | |
| | difficulties obtaining travel insurance due to ignorance on the part of insurers about current/new treatments whereas clearly they think I am a high risk (I always use specialist sites for those offering insurance for existing conditions and use comparison sites such as 'paying too much' that compares several operators - still very expensive and an annual policy is unavailable for me meaning I pay much more. | P | |
| | Why are there not short term benefits for those cancers that only incapacitate for a few months such as testicular cancer | H | |
| | What financial assistance is there for cancer patients. Especially around getting private healthcare and life insurance. | P | |
| | Insurance Companies - why do they believe that everyone with living with cancer is a high risk? | P | |
| | why is some travel insurance so difficult when I have been cancer free for 19 years? | P | |
| | I feel that financial support for people with cancer is completely inadequate , I am a young, single parent to 2 children , I've never been in debt until cancer, I applied for PIP to be refused as I am not disabled enough, only my MP getting involved made them offer me the lowest living element of PIP which is a pittance, the universal credit system is inadequate & the 12 week delay left me in debt, so now I have to go back to work even though I don't feel ready, because I can't afford not to, I have been told of funds like British gas hardship.... But I'm expected to give them my entire income & outgoings everything down to my food bill even then I may not get the help, it's feels degrading to have to justify my need for this help to that depth..... I already feel bad enough that I can't even take my kids for a simple day out, that some weeks we eat the minimum because that's all I can afford, never mind having to send my entire it's & out's..... Make me feel ashamed when actually I've fallen on hard times due to cancer treatment but I'm young & was fit so I'm not as physically immobile as someone would be in their 60's with my symptoms & diagnosis , surely more can be done ? | P | |
| Questions about funding cancer services | Why after being left with long term effects from my cancer treatment for life - because I am no longer taking specific drugs to do with Cancer but all the treatments I had caused me to have long term health effects requiring drug treatment I now have to pay for my medication for life. | P | |
| | Why can't the NHS allow lymphoedema patients to access most suitable treatment? Having closed down M.L.D services, there are many who now have to pay for this themselves, because they have limited use in their arms (arthritis, polio, etc) and can't pull on compression stockings. The NHS will pay £80 for stockings which I can't pull on, but won't pay £75 for me to have M.L.D. | P | |
| | How can programmes for patients living with and beyond cancer be funded? | H | |
| | How is the NHS going to be able to offer new, cutting edge treatments when they're so expensive and therefore become controversial? Many of the new research projects produce amazing results, but then are only available to those who can afford it. Britain cannot trail behind other countries, as we'll be in danger of losing our brightest researchers. | P | |
| | How do we deliver cancer care most effectively in the community at a time when General Practice is so overstretched | PRH | |
| | How can we ensure that patients and families receive all the support they need with the ever changing horizon of a cancer diagnosis and long term treatment and scans etc. E.g. A Macmillan nurse. It's vital that access to informed support is available to as many people as possible. Perhaps the drug companies, who now have created long term immunotherapy treatments, can contribute financially to this? | R | |
| | What is the impact of using old machines in radiotherapy for treating cancer, and how can an effective rolling replacement programme be successfully implemented and funded regardless of future Government politics? | H | |
| | Why is Pelvic Radiation Disease (PRD) not made a tariff? | R | |
| | Are all G.P.s going to be given the training and resources to support patients with long term side effects. | P | |
| | In the last few years I have had constant problems with my teeth, this year alone I have been to the dentist 16 times mostly as emergencies having lost fillings, crumbling teeth - 2 abscesses - 2 root canal fillings etc. I am currently awaiting an X-ray on my face due to having jaw ache for 8 months, on my last bone and marrow biopsy 1 year ago it showed I had 80% CLL infiltration in the bones & marrow, is this related to the CLL and if so why isn't dental treatment free? | P | |
| | Why are cancer drugs so expensive? It seems immoral for drug companies to profit through the suffering of others and for NICE to withhold drugs which may work from patients when it is often linked to cost | P | |
| | Why is there no money set aside in the NHS for pelvic radiation damage? | P | |
| | Possibly the above would not have happened if funds were available for adequate training, I appreciate that the Government have little money for extras in the NHS but will your research put pressure on the Government to improve funding? | R | |
| | Research has shown that people living with cancer is on the increase. This is excellent news. However, research has also shown that people with cancer have deep seated psychological problems. As frequently reported, the NHS is in crisis in respect of funding and resources. How can we be certain that sufficient resources will be available in the future to prevent this epidemic spiralling out of control? Action is required now not just recommendations. | H | |
| | Why can't dental treatment be free for head and neck cancer patients? | R | |

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| | Why can't the NHS provide dedicated staff to support people once their hospital treatment is finished? | P | |
| | Why aren't there more specialist cancer nurses in Bladder Cancer? | H | |
| | Should you be able to have NH treatment combined with private treatment or therapies that are not available through the NHS. | PR | |
| | If there's a link between Cancer/ Chemotherapy and CLL with dental problems why isn't dental treatment free? The costs have been very high as all these appointments have been 'emergency' and have had to be paid for with the exception of one of the abbeesses where the 111 service sent me to the hospital in the middle of the night. | P | |
| | When patient pressure had already secured funding for a NET cancer service, why did the ponderous NHS Wales bureaucracy take years to even start to implement it? | U | |
| | Do people within the NHS realise their importance and deserve more money provided they work efficiently | P | |
| | New Treatments available for rare cancers - NETS Cancer NICE assistance with finance and better communication with medical companies to lower the price of some treatments. | P | |
| | Will LWBC have more funds available | H | |
| | When Consultants say that a drug is available, but not funded by NHS. Why is the NHS so 'dog-in-the-mangerish' that is it difficult for us to find the way to buy a drug ourselves? | P | |
| | Also concerned about funding of the NHS and is the country investing enough in research for new treatments, equipment and would they be available on the NHS? | P | |
| | What is the cost of dental care for patients after head and neck cancer - can they get free dental treatment? | H | |
| | Why cant rare cancers receive the same funding as more common cancers. Many rare cancer patients are left floundering - fewer clinical trials, less follow up and less support, fewer treatment options - further to travel . fewer experts. Where is the equity in that? | P | |
| Questions about care quality | Whether care was experienced as truly MDT (or very medically led) | H | |
| | Did you feel that you had the relevant support throughout - in what ways ? what was most beneficial? | H | |
| | Information about side effects of treatment short term and long term and whether support was available? | H | |
| | When first diagnosed, many people are given very little information and have to look for it themselves. How can the NHS deliver a tailor made information package from day one of diagnosis? | P | |
| | When the shock of the initial diagnosis is over or diminished, do you as professionals feel that there is enough time to re-iterate the information and to re-explain everything, which may not have been taken in, in the first place. | R | |
| | Carers or partners may well have questions which they don't want to utter in front of the patient. Do THEY get a chance to ask these privately and separately? | R | |
| | I do a lot of reading and use the Kidney cancer support network KCSN. However I found this by myself . Why wasn't I directed to this site by the NHS. It offers more support and knowledge than any other website as it's specific to my cancer. These patient led sites among with NHS representatives are fantastic.They offer support, facts , and lots of data regarding treatments. The NHS could really learn from these . | P | |
| | In a time when dignity is being promoted by health authorities I have found it a shock about the total lack of privacy when being assessed for my next chemo cycle. There is no private room and I sit with all others plus their family members on chemotherapy drips whilst I am asked questions about my bowels, sores on my body, my bleeding mouth and then have bloods and weight taken. This is my biggest shock since my cancer diagnosis that there is no privacy or dignity for cancer patients. It is so public that I find myself whispering in response to the chemo nurses. | P | |
| | Is spiritual care information lost in the plethora of information given as a person is diagnosed? | RH | |
| | Research has to be done to get better response to patients after operations. I found that very poor but that was a long time ago | P | |
| | After being given pain killers to ease the pain after treatment, why did no one tell me about the possible side effects of such strong painkillers (Codeine) | P | |
| | Why is the word "benign" still used by Dr's ?...no tumour "does no harm" and it gives the wrong impression to those hearing it ...cancerous and non cancerous are far better descriptions. | P | |
| | Why do the Drs/Oncologists not explain your "Treatment Plan" from the end of your hospital treatment to approximate time you have left. With suggestions as to what to look for what things can help at end of life, an emotional plan ,a contact no. for worrying questions. In other words What is the Next Step. After all your treatment dates diary of appoints for approximately 4 years. Scans, bloods, in & out of hospital with high temps. Then "Nothing" | R | |
| | Staffing resources in the 3 Radiotherapy centres - are they appropriate | H | |
| | Why wasn't I allocated a care key worker when I was first diagnosed with cancer to help me through a very stressful time? | P | |
| | Why wasn't I given a written cancer care plan so that I could refer to for information and should be reviewed as my treatment progresses? | P | |
| | There is evidence - and a growing understanding by oncologists - that it is essential to address the physical, psychological and social impact of a cancer diagnosis. This will only be adopted by the NHS if there is funding in place. At the moment this is undertaken by charities like The Breast Cancer Haven/Future Dreams and Maggie's Cancer Caring Centres. Why are GPs and oncologists resistant to referring patients to these particular, professional centres? Counselling/complementary therapies (working with breast cancer nurses) would free up appointments with GPs and hospitals. | P | |
| | What support has your healthcare team provided you in 'holistic' support and how can we ensure everyone is given a care package that works the best for them? | P | |

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| | As a parent of my daughter in her ,20's was diagnosed with Breast Cancer. She was looked after extremely well by the doctor who diagnosed her serious position. However all the information about her treatment was explained whilst she was starting her first chemo including a booklet/diary she need to fill in daily. There was no discussion about alternative treatment or what exactly her diagnosis entailed how serious it was or what could be her eventual out come. I'm at a loss as to why an in-depth discussion about the seriousness of her cancer which killed her within 5 years was not discussed with both her & her sister & me as her mother was requested to keep us all in the loop as my other daughter was at University in Dundee. | R | |
| | During her treatment I was asking questions as to why the chemo had changed. We got no answers. | R | |
| | When my daughter had been in hospital with a collapsed lung I was not allowed to be kept informed obviously due to the fact that it wasn't written on her notes. She was in a totally different ward. I could see her deteriorating, & Was certainly not kept in the loop. I had no one to talk to about her condition. | R | |
| | How can care particularly for elderly people with cancer be better co-ordinated, even with the new cancer teams communication continues to be poor at times, particularly cross-over points like failure of curative treatment, people can feel they have been dropped, are in limbo etc at an extemely vulnerable point | R | |
| | Why is the hotel Discharge process so longwinded? Get patients out of hospital sooner once theyre ready to go and NHS will save loads on catering and unnecessary bed blocking. On my 2 admissions i was waiting until 7pm for meds after being told at 9-10am ready to go home. | P | |
| | Ive got lots of left over drugs after chemo. Such a waste. Is there a way to reuse them or not give so many out. Could Patients manage their meds...? | P | |
| | Were you provided information about local services available to support you? | H | |
| | Why do cancer MDTs not comply with national cancer rehabilitation guidelines despite the evidence ? | H | |
| | Seen that womb cancer is the fourth most common cancer in woman why is there not much awareness !! | P | |
| | Gynaecological cancers, specifically womb/endometrial cancer are often seen as an "easy cancer". Many women who have been diagnosed have been told this by their Consultants or Gynaecologists. Why do they do this? If you are still of child bearing age and are told you have to have your womb removed, become incapable of having a child of your own, go into sudden menopause and deal with a cancer diagnosis there is nothing "easy" about it. | P | |
| | As a carer why was I not told of the likely affects of treatment on the patient | PR | |
| | As a "carrier" of CLL for 7 years why was I not given any advice on what to avoid and what to expect? | PR | |
| | In NHS hospitals how can communication between haematologists, medical doctors on the wards and the pharmacy departments be improved to ensure drugs that have been prescribed are received on the wards quickly to patients who are hospital because their immune systems are compromised by their cancer and treatment ? | P | |
| | What training will be given to those giving news about cancer to patients and friends (we were told to go home and say everything you ever wanted to say to one another - that was quite a shock!) | R | |
| | Not to shy away from a patients question about some of the dionostic tools used to detect cancer and the return of cancer. | P | |
| | Why was I not told the risk of nerve damage | P | |
| | Why did it take a year of being in constant excruciating pain before being referred to a pain clinic with follow up appointments taking between 3/6 months | P | |
| | How do cancer care professionals maintain the compassion in delivery of care I so very much need? | H | |
| | The treatment of relatives { close family} get from the Hospital it varies a lot depending on what area you are in | U | |
| | Quicker scan results | R | |
| | Proper, written statement of diagnosis. It's only given verbally or in the form of a release letter if patient is hospitalised. | P | |
| | How can we encourage all professionals managing patients with Cancer to use the word Cancer instead of using avoidance tactics? How can we encourage them to be more open and transparent as without this is leads to more patient anxiety. | P | |
| | why can't there be a much more clearly defined care plan for patients? Something tangible and easy to refer to at any time. Something I can update and so can the Nhs staff looking after my care. This could be as a hard copy which can be routinely updated and/or an app accessible online via your phone or tablet which is electronically updated. | P | |
| | Can there be more detailed information into exactly what happens from start to finish with any surgey or treatment.? Not just told you will be here on that day, that time and you will have treatment. Well, what is the exact process? Who is who and what are there rolls in your care? Because if you can visualise it, you can take some of the fear out of the situation and how it's making you feel. | P | |
| | How to make sure carers are kept in the loop. I understand patient confidentiality, but ai found it very hard to get info when my mum was an inpatient because they did ward rounds outside visiting hours, and she was confused and couldnt remember what they said well enough to tell me. | PR | |
| | why was my fertility not discussed with me and that I might be able to have children | P | |
| | When given the diagnosis of cancer, the options for treatment follow on very quickly even if the need is not immediately urgent. How long is given to the patient and relatives to carefully consider these options? | P | |
| | How much counselling is given to the patient to carefully consider the treatment options? | P | |
| | Have you felt supported on your journey by HCPs | H | |

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| | Why, when diagnosed with cancer initially, do oncology departments at hospitals disappear into a black hole and tell patients nothing about what their plans are, when is the MDT meeting to discuss a cancer, what are the treatment options, what are the pros & cons of those options, when will treatment begin, and how long will it probably last? (Locally the oncology department think it is quite appropriate to get patients in within the govt target for first appointment then forget about them altogether till they then get to the top of the next list. | R | |
| | Having seen mother,sister,sister in law and wife all suffer with cancer, the common thread for them all was transport, parking and time taken with treatment.'looking to the future,will a time come when mobile units may attend the residence of the patient and administer treatment. Obviously this sounds a fanciful idea but it would solve the parking problems,cut down on waiting times for the patients and reduce the stress levels for the patients.change of practise and a lot more thought required I know...just thinking outside the box. | R | |
| | When in hospital to have surgery for cancer why is the food not nutritious? | P | |
| | Why do people that have multiple cancers and where everything is failing, still get chemo / radiation treatment .. I've talked to a few older patients who feel they want quality over quantity but have felt pushed to have more treatments... it gives false hope and often has no effect on a late stage .. I respect if they ask for it ... but there has to be more respect back, to have minimal interference, and not made to feel guilty ... | P | |
| | When my daughter & were brought into an empty room which was "found" in Fracture Outpatients and told. Verbatim. All your treatment is now stopping we can't do any more. My daughter asked "How long have I got? About 3 months the Oncologist said. Could there not be a more empathetic way to tell a girl if 28 years of age who already knew from the beginning it was terminal, for example perhaps a nurse or a Macmillan member or even a Marie Curie member could have been there to answer any questions. This was very cold. We walked out of the Hospital not knowing what to do next. | R | |
| | Reference to the above. Three days later I had to take her to hospital for oxygen. I knew she was really I'll at this stage. Another Oncologist said oh no she's got weeks & weeks. I disagreed & she asked me what I thought. I said I thought she wouldn't survive the weekend. She died on Saturday. Doctors do not see patients 24/7. Parents need to be involved in the prognosis based on their home experience. | R | |
| | Can surgeons giving bad news receive much better training? I was given 12 months and it felt like the news was pretty much delivered in 1 sentence. With realistic training the surgeon could have said something like you'll feel awful for a few days, then you'll start to pick yourself up and work on what's best for you. Just the slightest hint of positivity would ease the news, I didn't receive that till I saw my oncologist 3 weeks later | P | |
| | Can the benefits of receiving first dose of chemotherapy Monday to Thursday be explored? I received a first dose on a Friday and had nausea and vomiting for 4 days with a variety of UC24 doctors visiting me at home at great cost to the NHS, if I had received my first dose Monday to Thursday then my GP would have been able to visit and provide personal and improved care which would have benefited both myself and the NHS | P | |
| | Is it luck as to whether or not you get to see an oncologist that specialises in your particular cancer? My husband had a NET in his pancreas. The oncologist seemed to know very little about it. | R | |
| | Why does it take so long for hospitals and GP surgery to refer to palliative care team,my husband has advanced prostate cancer spread to his spine,neck,shoulders,ribs,pelvis and hips he is in really bad pain,can hardly walk,he has had telephone conversation with doctor who has prescribed zomorph and oral morphine but that is it,have appointment with cancer nurse tomorrow and waiting to hear outcome of case conference at hospital.I feel as though been told diagnosis and that's it.n | R | |
| | Upon my surgery in this country it feel far short of my surgery in in Boston, America. There are a number of reasons for that however nurses speaking in Hindi to each other whilst I lay in bed and nurses not knowing what medication to give to me. | P | |
| | the patient knows best ? After my first surgery I knew I did not I did not take well to steroids. However the surgeon and the doctor put me on them as a result I had to spend 10 days in hospital and I got clinically depressed because they would not listen to me and did not know how many pills to administer. I had to set multiple alarms on my iPhone to nurses to administer my pills, they were not enough of them on duty and up to the day I left were unable to answer me when I was to go home. | P | |
| | I had to spend 12 months on antidepressants all because the hospital did not listen. This would have been longer if I had taken matters in to my own hands. Which again leads me to the Doctor / patient relationship. | P | |
| | why do medics treat survivors with discrimination? I have had health issues since cancer, but once tests for mets are concluded nothing else is done. Cancer history obscures everything. If a non cancer survivor presented with other conditions they would get full investigations which wouldn't end at only, 'well it's not cancer, goodbye'. | P | |
| | Why are private hospitals and consultants allowed to ignore clinical guidelines? Regulators are not inspecting on this | P | |
| | The nurses in charge of care can't answer questions we have. | P | |
| | Trusting the professionals have got it right. | PR | |
| | Why are Appointment so far apart 3-4 months is not good enough. | R | |
| | Why are there no regular 'follow up' tests for patients who have previously been diagnosed with prostate problems and continue to have symptoms? | P | |
| | WHY ARE PEOPLE WITH CANCER NOT GIVEN INFORMATION ON GOOD NUTRITION, EXERCISING AND DESTRESSING WHILE THEY LIVE WITH CANCER? | P | |
| | Why are survivors' long term side effects from cancer drugs badly handled? | P | |
| | Why was I not warned of the dangers of rectal examination | P | |
| | Why was I not warned of risk associated with prostate biopsy. | P | |

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| | Why was I told they were taking four biopsies and they took Seventeen. | P | |
| | How often has treatment been delayed because test results are not available? | H | |
| | After my tumours were found incidentally during an operation, my general surgeon was very unsure how the outcome of the mdt meeting would be communicated to me. Why is there no better 3 way communication between the patient, general surgeon and the specialist mdt team? | P | |
| | Why because my tumours were rare I had to wait for over 6 weeks after diagnosis for an outcome? | P | |
| | Lymphoedema - Who cares about reducing the burden? 1. Little or no access to surgical advances made elsewhere for NHS patients. 2. Little or no money spent on delivery of even basic level of treatment in the UK, e.g. MLD delivered by an AHP. At the moment patients are "lucky" if they get a new compression garment every six months. This is not a question on care, it's a question on how much neglect we are prepared to watch. Patients administer SLD badly or not at all and frequently end up as inpatients or housebound, with cellulitis, or ulcerated limbs, requiring IV antibiotics with dreadful QoL outcomes. This damage is avoidable. | PR | |
| | Why can't cancer patients have access to their own medical notes to help them keep track of what is happening to them? | RH | |
| | The most anxiety that I have felt, apart from initial diagnosis, is the waiting between CT scan and consultant appointment when my stress levels rise enormously. Is there a better, quicker solution to obtaining the results? | P | |
| | Information wasn't given all in one go, there was no one to contact to ask. WHY?? | R | |
| | Support wasn't offered. Just a pile of information given, with go and read. You read but don't understand. Why is there no automatic support given. It is a scary time, and no one there. | R | |
| | The confusion after your primary cancer has spread, more talking to the patient and caregiver to explain what is going on and what treatment options there are | R | |
| | question Should you have complete control over what treatment you have. Plus be involved? Example I attend Darent Valley which is 85 miles away for my treatment. My choosing!, but I could for example, do pre ops in Canterbury south east Kent, but as I am officially under Darent Valley west Kent This is not allowed, in today's world of technology, there is no reason why every appointment has to be at a given hospital. | PR | |
| | Talking of side effects: Why is more not being done to warn about the possibility of a lymphoedema diagnosis? | P | |
| | The length of time for results, living in turmoil and high anxiety | P | |
| | Cancellation of surgery? | P | |
| | I had womb cancer why are the very painful examinations done without anesthetic? | P | |
| | Being given the correct diagnosis and plan of action immediately after diagnosis. My partner was diagnosed with scic after a biopsy and the doctor looking after him telephoned him at home and told him he would have surgery followed by chemo. We were then invited to meet his oncologist who told a completely different story, no surgery because of spread to lymph nodes but chemo and radiotherapy instead. You can imagine his devastation and my anger although I didn't make a fuss about being given inaccurate results and false hopes. | R | |
| | Who gives the right for a Macmillan nurse to blurt out that you are coming to the end of your life when you don't want to know this information | R | |
| | Why don't the doctors explain the diagnosis in ways that can be easily understood, rather than explaining in medical terms. | P | |
| | Why was I seen by a doctor who said to me this is not my field | P | |
| | Why didn't my GP refer me sooner when I had a lump which was growing for over six weeks | P | |
| | I went home the day after my hysterectomy and was told to go back in 6 weeks in that 6 weeks I never had an appointment for my dressings and I when I phoned up I was told to go to the clinic surely just to be reassured by a visit would help more to put our minds at risk | P | |
| | When a patient moves from Terminal to not terminal, it should be wonderful news. Instead there is confusion between your staff on how to deal with this patient. ie. Hospital staff treat a patient as if they are dying, let things slide and lack respect when a patient should be treated as a chronic patient | R | |
| | Lack of information and support for sufferers of very rare cancers | PRH | |
| | My husband experienced mis-diagnosis several times with the second of his major cancers. The hospital merely tried to sweep this under the carpet. The hospital should realise its responsibility towards patients and any errors that are made in treatment or lack of them, and be honest enough to admit they were wrong. | R | |
| | If patients and their families clearly state they want resuscitation, this should be respected. Instead in my husband's case, although the medical and nursing staff knew this, some doctor called in the death squad (end of life team) and within 24 hours he was dead, although he had previously responded to a couple of earlier resuscitation treatments. This action totally over-ruled all our wishes and actions like this should never happen without clear unequivocal discussion with the patient and family. | R | |
| | As patient and family we were offered no help (Macmillan/Marie Curie) for home care. The adverts for these (You are never alone) are totally misleading. | R | |
| | Do people within the NHS realise how inefficient they are. | P | |
| | I'd like doctors to write to me, rather than just copy me in when writing to GP. Copy the GP into the letter to me! Obviously understand writing to GP for prescription requests! | PH | |
| | Macmillan advertise all this "help" - my experience was that there was no help - especially financially! | P | |
| | I feel that proper scanning and tests for diagnosis should be improved to avoid further surgery which could have been avoided with more in depth testing. | P | |
| | Receiving written test reports and not having to wait many months for results | P | |

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| | I am very concerned about hospital closures, bed closures, long waits for appointments and treatment. Patients not being seen quickly enough to get a good outcome, | P | |
| | Do cancer care professionals make their patients feel supported? | H | |
| | How do you tell people the severity of the cancer in "layman's" terms? | R | |
| | I feel that sometimes, perhaps many, relevant and valuable information is not conveyed at the appropriate time, even not at all. I have picked up this comment from several Cancer Patients. | O | |
| | I wonder if it would be more helpful if patients were treated more as individuals by doctors. Each person has an individual response to their disease and I don't think doctors give enough credence to this. I think it would be more helpful to give a range of outcomes instead of an amount of time someone may have left, especially as the information given is based on research findings 5-10 years old and averages not what might happen to you. People may be misled and think what the doctor says is what is going to happen to them and thus they accept all the doctor says without realising what they can personally contribute to outcomes. | P | |
| | People with Serious Mental illness present late in a cancer diagnosis and are usually given a terminal diagnosis. HCP profs do not know how to manage their needs. | O | |
| | Should more support be offered to those of a child bearing age as like myself I was told I had to start treatment straight away and that there was no time to freeze my eggs. It was never spoke about since and it was not being able to have my own kids which was actually harder than getting a cancer diagnosis. | PR | |
| | My GP seemed unaware that I should be given daily Tadalafil for two weeks prior to my prostate surgery, in order to improve erectile function after surgery. Should GPs be aware of guidelines? | P | |
| | Why don't clinicians in general in general hospitals know that pancreatic pain, as a nerve pain, may not respond to opiates? | R | |
| | How can the cross-county issues regarding Hospital/service/Hospice transfer, communications, etc. be overcome for the benefit of patients? | R | |
| | the vast majority of health care professionals (GP, dentists, hygienists, max-fax doctors, consultants, head and neck doctors, nurses) dealing with me whilst suffering with ORN symptoms pre-diagnosis (approx 7 months) had zero understanding of ORN - this resulted in pain, infection, damage, delays. I had inappropriate community care advice - resulted in further damage and infection, whilst hospital doctors treated me as a simple run-of-the-mill rather than the more significant ORN case. can this be improved. | P | |
| | Why is the serious issue of ethics in genetic testing not considered more? I have been diagnosed as "lynch like". This leaves one in a category of not knowing if you have a serious cancer predisposition syndrome or not, and having to undergo invasive procedures for life, that may well be completely unnecessary. Further testing is possible (double somatic testing) but is not and in fact cannot even privately be carried out in the UK, which I find deeply unethical. Waiting one and a half years to be "diagnosed" and a further year to see a geneticist is also unacceptable. | P | |
| | Why aren't mastectomies finished off with at least a nice well sewn scar? | P | |
| | Why aren't health professionals such as Drs, Health Visitors able to help you? They seem to see you as dying rather than living. | P | |
| | Why doesn't someone contact you after you leave hospital to see how you are rather than finding someone yourself? | P | |
| | Why doesn't someone explain about colostomy and ileostomy and what can go wrong. i.e. leakage, bad skin like nappy rash, pain. | P | |
| | Why can't radiotherapy be mandatory after a radical hysterectomy? I had recurrence less than 3 months after my radical hysterectomy! It had then spread to the top of my vagina, my bowel and lymph glands in my pelvis. I was terminal and given months to live. I found out since that my smears were marked normal but were actually abnormal (cin3) but now I'm dying because of the NHS and one of their employees! | P | |
| | Why aren't next of kin contacted and offered the chance to come with their lives one when they are told they have cancer. | P | |
| | Why do your our nurses never call back let alone stop by when your visiting for treatment? | P | |
| | I do not feel my doctors tells me everything- he has not provided any treatment, is this because of my age (80 years) and I am not worth the cost implications? | P | |
| | When a patient has zero quality of life due to over 100 hot flushes a day, and the patient has tried all options suggested to them, why is it ok to just give up on her? | P | |
| | Consent. Still important even prior to a cancer operation. Usually there are far more alternatives than a surgeon's preferred choice. Make sure that you see a person first and not the disease or a learning opportunity for yourself. | P | |
| | Many decisions about treatment do not require an insane level of rush. Why can't most patients be encouraged to research get 2nd opinions and be placed in the driving seat. | P | |
| | Why are so many surgeons with big fat private practices in London and the South East, such a bunch of entitled in-it-for- themselves dangerous bastards that deserve locking up. Or perhaps that bit is just my experience of The Royal Marsden .. | P | |
| Questions about professional training | Do GP's really understand the anxieties that patients living beyond cancer treatment have? | H | |
| | Why do GPs believe that being young means your symptoms are not cancer related? | PR | |
| | Do you feel that your GP is aware of the potential late effects of your cancer treatment? | H | |
| | Do GP practices have health care professionals who have the knowledge and skills to help people Live the best lives they can with their cancer? | P | |
| | Do community care health care professionals have skills and knowledge to support people to enable people to live with their cancer to the best they can? | P | |
| | How do you get health professionals to deliver true personalised care and have time to listen to people with cancer? | R | |

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| | Do GP's have enough training and education to be able to safely advise patients regarding the management of early menopause; specifically due to pelvic radiation? | P | |
| | GP's appear unaware to correlate that emerging health issues could be the result of earlier treatments for cancer. | R | |
| | Why are oncologists and workers in cancer related fields so loathe to accept that radiotherapy often has long term side effects? | P | |
| | Why are so few GPs aware of symptoms of radiotherapy side effects? | P | |
| | WHY ARE SOME NURSES BETTER THAN OTHERS/ | PRH | |
| | How are training needs being met in the case of district nurses called to give care at home for post-op patients? Specifically, the 'drain' was problematic in one instance. | R | |
| | Fatigue - especially many years after treatment finishes. GP views of this and education about it. | PRH | |
| | Evidence to show that educating GP's in initial diagnosis of primary cancer, and or knowledge of late effects can help prevent or improve patients being diagnosed earlier. | H | |
| | Why are GPs so bad at providing ongoing support to survivors... they don't seem to have any training on this and don't understand that not everyone recovers from treatment. | P | |
| | What is the most effective way to educate HP's regarding caring for patients LWBC? | H | |
| | What is the best way to measure the competences of GPs to ensure they have a basic knowledge and clinical skill to look after people living with or beyond cancer with treatment consequences? | H | |
| | Lymphedema. Can GP be trained to be more aware if this condition | PR | |
| | How best to train GPs and medical staff (who are not oncology /cancer specialists) to be sensitive to the effects and fear associated with having a cancer diagnosis? | P | |
| | What training do healthcare professionals need in order to meet the needs of this patient group? | H | |
| | How much training do physicians receive in dealing with Lw&BC? How can we improve their knowledge and understanding in order to support patients better? | P | |
| | In my experience GP's do not keep themselves fully informed & up to date regarding their patient's treatment plan & show little or no empathy & support when patients present with ongoing effects of treatment. When will GP's engage in up to date training regarding treatments & side effects to enable them to treat patients appropriately? | P | |
| Questions asking for advice | How to develop relationships with others following a life changing event such as having a diagnosis of cancer | P | |
| | What benefits do and can they claim ? | H | |
| | What long term financial and emotional support is available for patients? | H | |
| | Is there still a stigma attached to telling work colleagues, friends and family that you have cancer? | H | |
| | My treatment has finished and my doctor tells me I am cancer free, but I'm still so fatigued. What are my rights at work when I'm still struggling with treatment related tiredness? | P | |
| | How can I let my family know that I'm still struggling with the impact of cancer even though my treatment has finished | P | |
| | what projects are locally available to young people post treatment | H | |
| | How should I return to work after treatment? How long should I stagger it? What's the best to build it up? How do I explain to my boss and colleagues that although I may look well I am suffering from post-treatment fatigue? | P | |
| | Dating after cancer - when to tell someone? How to start that conversation. | P | |
| | How do I plan for my future? | P | |
| | How does the future look without cancer? I'm scared I will be left behind! | P | |
| | More people are surviving cancer, and you often hear people saying things to the effect, "you've finished treatment, you must be ok now" How do we get more people to understand it's not that easy? And be understanding without being over-sympathetic or patronising? | P | |
| | Would you treat someone differently for RCC who is under the age of 46 and why? | P | |
| | how do I get access to support after my treatment finishes? | P | |
| | Will the treatment work for me? | P | |
| | What are the likely side effects and how do I overcome them? | P | |
| | How can I know I'm getting the best possible treatment | P | |
| | How do you get on with a normal life after a cancer diagnosis? | P | |
| | Why don't I feel better a year after my diagnosis? | P | |
| | What psychological support can be provided? | P | |
| | I would like to understand why as standard, a full gene screening is not recommended by oncologists? | P | |
| | What options are there for people who were diagnosed with cancer as a young adult and are unable to have a biological child who would like to start a family? | P | |
| | Re clinical trials: is it my consultant's responsibility to recommend one for me, or is the onus on me to do the necessary research to find one? | P | |
| | What counselling is available for bowel cancer patients (post op)? | P | |
| | What is the best way to tell a new partner that you have survived cancer? | P | |
| | What financial institutions offer reasonable rate loans to cancer sufferers? | P | |
| | How can I access chronic/persistent pain management services when my treatment has been completed? | P | |
| | Is there any way that eggs can be extracted from ovaries following chemotherapy and/or radiotherapy for successful embryo creation. | P | |
| | How can we ensure that everyone LWBC understands their cancer diagnosis, treatment , likely prognosis and potential long term side effects. Detailed, comprehensible treatment summaries are still only patchily available. | PH | |
| | DFSP, it's a rare cancer. I had surgery to remove my tumour. Why is it not treated with medication? | P | |
| | DFSP - why did I not get a full body scan to check it had not spread? | P | |
| | Who can I go to talk about me, and the problems I have, having survived the illness? | P | |
| | How to cope with telling others, especially work colleagues | R | |

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| | Is there a better method of fixation of my femoral stem (customised endoprosthesis for osteosarcoma of the distal femur) to prevent aseptic loosening and the need for revision surgery? | P | |
| | What support should be given when diagnosed with sarcoma? | P | |
| | Could I have more advice about coping with one kidney? | P | |
| | How can we connect cancer survivors of rare cancers? Especially for those not online? | R | |
| | What support is given to patients and their carers if hearing deterioration occurs as a consequence to treatment? | H | |
| | How do you rebuild intimate relationships living with cancer? | RH | |
| | how do I advise patients and carers on local living with and beyond cancer services? | H | |
| | Are there any specific guidance for prescribers in medication to avoid in patients with a history of cancer | H | |
| | did the radiation treatment cause scaring of my lungs when treating my upper GI cancer? | P | |
| | Why are all the research figures ,only quoted' at 5 years after diagnosis? | P | |
| | Are enemas really necessary when undergoing pelvic radiotherapy? | P | |
| | Is any research happening in the UK to improve current treatments for chronic peripheral neuropathy? (e.g. like 'Scrambler' treatment currently being tested in the Mayo Clinic) | P | |
| | Does wearing a prosthetic breast have an effect on security if I fly. Do I have to remove it? | P | |
| | If I'm worried about something can I request a scan? | P | |
| | I have erectile dysfunction after prostate cancer. I take tadalafil but still can't get an erection. What else can be done for me? | P | |
| | How can I access psychological support when I've been discharged from treatment? | H | |
| | When can someone living with and beyond cancer get back to a normal working life? | P | |
| | If Blood Cancer is one of the bigger killers in this country, why are so many people unaware of what to look out for, to enable a quicker diagnosis? | P | |
| | How can I find out if others have the same symptoms and what medication they are on that helps ,instead I feel like a Guinean pig. | P | |
| | Should I be concerned about doing physical activity after finishing chemotherapy course of treatment. | R | |
| | Why can't I give blood? | P | |
| | Where can I find good independent financial advice re impact on long term financial planning such as pension/investment considering diagnosis/treatment? Poor 5+ year prognosis for certain cancers makes decision making really difficult and travel insurance and similar products really difficult | P | |
| | I've heard that cancer can be detected by having a blood test ? Is this correct ? and if so will it become the normal way of diagnosis alongside the 2-week referral? | P | |
| | How do you live beyond cancer? There is no guidance. Nobody to help you when things go wrong 10 years post op. It feels like all the effort goes into the treatment and that after that, nobody cares. | P | |
| | Is there a cure anywhere close in the near future? | P | |
| | What are the long term effects of the medication I have been given? | H | |
| | Is there anything I should not do because I have had cancer? | H | |
| | Is there any possibility of beating stage 4 pancreatic cancer? | R | |
| | How can I access the best and latest treatment for my particular cancer? | P | |
| | Can I access counselling post-treatment to help me adjust to normality? | RH | |
| | How quickly can the cancer spread | PH | |
| | How can we educate those around us more about the side effects of treatment - what that means long term for our health and that we aren't 'tired' but actually suffer from life long fatigue. | P | |
| | How likely is chemotherapy to work? | P | |
| | What are the financial implications of the fertility options for young women with cancer who go through chemotherapy? | P | |
| | What support is available after I stop treatment. | P | |
| | And what should me employer be doing? | P | |
| | WHAT EMPLOYMENT LAW/SUPPORT IS THERE FOR PATIENTS WHO CHOOSE TO WORK THROUGH PALLIATIVE CANCER TREATMENTS E.G MONOCLONAL ANTIBODIES. | H | |
| | Are there any knowledgeable people to talk to | P | |
| | What interventions can be offered to reduce impact of long-term consequences of treatment (eg peripheral neuropathy; bowel toxicity; bladder incontinence) as well as return to work | RH | |
| | Should young adult males with low sperm count post childhood cancer treatment store sperm? | H | |
| | What long term issues might I expect from having a course of oxyplatin and 5FU? | P | |
| | What long term or late onset health/lifestyle issues might I expect from a 25% large bowel resection ? | P | |
| | What long term health/lifestyle issues might I expect following a portal vein embolisation followed by a 75% resection? | P | |
| | Are there any cancers that are hereditary | R | |
| | Is there any support/help for mums with young children | P | |
| | Prevention of hair loss during treatment | RH | |
| | Do pelvic exercises improve continence? | RH | |
| | How can I manage financially if the cancer returns-I am self employed so therefore have no sick pay or benefits? | P | |
| | Thankfully, so many new findings regarding the behaviour of breast cancer and why it spreads to other parts of the body etc are being discovered on a regular basis. My question is does the success of this type of research benefit people who were diagnosed several years ago and whose treatment (apart from hormone treatment) has now finished? | P | |
| | Can I request a copy of my Healthcare records? | R | |
| | Can prescriptions from CNS be faxed through to my local pharmacy as I do not wish to go through my uncaring GP? | R | |
| | Both parents with Terminal cancers, living together in their own home day to day tasks and self-care is becoming difficult for them. What are their entitlements and what is the criteria etc? | R | |
| | How do I strike a balance between presenting myself as 'back to normal' (which in many ways I am, and want to be, and want others to think I am - especially in work contexts), and conveying the reality (fatigued, poor memory and concentration, periodically concerned about the future)? | PR | |

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| | If I develop secondary Lymphoedema what treatments and care will you provide me with ? (Are all treatments/ procedures available on the NHS ?) | P | |
| | What support, both emotional and practical, are available to help me after treatments ? | P | |
| | how much research is being done on cll | P | |
| | Do breast cancer survivors suffer more in the heat | H | |
| | Cervical cancer can cause cervical incompetence how will this effect a persons chance of getting pregnant and or carrying a baby and what can be done about it?? | P | |
| | How to manage cancer treatment, when you have young children to look after? | P | |
| | Plus the wider scope of friends and relatives. How much information to reveal. | PR | |
| | Having reached normal blood levels with CLL I would like research to tell me if reducing or cutting the daily dose is safe and effective in maintaining the good health I am now enjoying | P | |
| | Where can I access information about how effective different cancer treatments are at prolonging life and improving/maintaining quality of life? | H | |
| | Is there any chance my bowels & digestive system would improve or go nearer to being what they were before treatment | P | |
| | What happens in the later stages of CLL? There is very little information on this apart from giving rough guides to life expectancy. | P | |
| | How long will it be before I need treatment for CLL | P | |
| | I have been diagnosed with a blood cancer but have been put on 'watch and wait' so the symptoms that I have like fatigue, night sweats, weight loss etc. I still have, How do I carry on living with these symptoms? | P | |
| | I have been diagnosed with a blood cancer but have been put on 'watch and wait' so how do I explain this to my employers, especially the fatigue? | P | |
| | Why can't we have a full DNA profile done with clear profiling of the mutated gene causing cancer | P | |
| | Finding out or Signposting to alternative therapies that are accredited or affiliated to respectable professional bodies | P | |
| | What support you can get within the community where you live to support a patient and/or carer. | R | |
| | What help can you get accessing information on financial support if you become a carer/patient off work adn receiving treatment for cancer? | R | |
| | Why is CCL only treated when white blood count is high? | P | |
| | Do i have the choice of what hospital I can attend if i'm not happy with current choice? | P | |
| | What help is available to CCL patients. | P | |
| | Do you think it's essential for another person to be present each time you visit hospital/consultant to also listen to the information given. | P | |
| | I had a collapsed lung which was cured by Pleurodesis which left me somewhat breathless, how much of my current shortness of breath is the Pleurodesis | P | |
| | Once diagnosed should/can I ask for a specialist consultant to see me rather than a generalist. | P | |
| | Can I challenge the consultants to use worldwide knowledge and treatment | P | |
| | Practical support available for single cancer patients, during and after treatment | PR | |
| | How do I find an expert in my kind of cancer and how will I know he/she is an expert. | P | |
| | what other changes occur (such as to the immune system) in relation to the primary cancer and are these related to actual blood results ? For example I have low level CLL but joint pain which is really affecting quality of life. | P | |
| | I am on wait and watch CLL I want to know what are my best options in my treatment. | P | |
| | With CLL on watch and wait , the likelihood of needing treatment when, given historic blood results. | P | |
| | Why is insomnia a prominent symptom of CLL? | P | |
| | When can a cancer patient say that they no longer have a pre existing medical conditions in relation to insurance quotes | P | |
| | Available options for treatment | P | |
| | I worry that the cancer is hereditary, how difficult is it to have genetic testing? | R | |
| | What characteristics are the most indicative of local recurrence of malignant phylodes tumour? | P | |
| | What characteristics are the most indicative of phylodes tumour metastasising | P | |
| | I like to participate in groups that offer information and interesting speakers. Post op three years ago the physio suggested I target days / meetings to keep my brain alert. This has worked but now meetings tend to come on the same day. Yes, you have to draw a line but how do you decide what not to attend?? when you enjoy all three meetings. | P | |
| | After three years post colostomy does one's stomach shrink or have I made it shrink by not eating enough.? My weight has stayed level at 10st 7 lbs for the last two years. I am aged 81 now. | P | |
| | I have just had my 3 year colonoscopy check up and now 5 days later I still feel sleepy. Have I asked too much of my body? It was conducted without anaesthetic or sedative and was fairly pain free. | P | |
| | What support is there if my cancer gets worse ? | RH | |
| | How do I keep my cancer diagnosis a secret from my work colleagues ? | RH | |
| | More information about certain blood cancers, in my case Smouldering Myeloma. | P | |
| | consultant just reading the blood tests every month, including paraproteins. More information as to how the tests compare to the previous months, instead of just saying "thats fine". What is the maximum paraprotein count before Myeloma becomes treatable? | P | |
| | what are the side affects to be looked for at the smouldering myeloma stage? It compromises the auto-immune system, so what places or events should I avoid to keep safer from infection? | P | |
| | How can it be treated? | R | |
| | What help is available in form of emotional/mental support? | R | |
| | If my periods don't return after 2 years does that mean I have gone through the menopause? | P | |

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| | How best to explain the side effects of treatments, often many treatments and / or side effects? | P | |
| | Can and how to get help with finances during treatment? | P | |
| | Why do patients have to undergo traditional treatments before being considered for trials? | R | |
| | How to explain to loved ones that although you have responded well to treatment and latest scans are clear. You are still living with cancer and the possibility of it returning? It hasn't simply disappeared and you don't just fall back into the old 'normal'. | P | |
| | When a man is diagnosed with advanced prostate cancer, why isn't his children or siblings (potentially at higher risk) automatically tested for Bracc1 / 2 gene ? | R | |
| | What is being done to support those living with side effects many years after cancer treatment? | U | |
| | Why was I told Lymphodema was a small risk | P | |
| | What is the smallest size pancreatic metastatic growth to liver that will show up on a CT scan | P | |
| | Do more lymph nodes affected mean a higher chance of cancer spreading? | P | |
| | Are there any new drugs being developed for MDS? At what stage is the development? | P | |
| | What is the success rate for Clinical trials? | P | |
| | Improved early detection including the potential for mass screening | P | |
| | What publications is being made in respect of the cancer NETS Neuroendocrine Tumours? | P | |
| | What research is being done for NETS Neuroendocrine Tumours? | P | |
| | Is NETS Neuroendocrine Tumours a priority for research to prolong many peoples lives? | P | |
| | Why are there never any posters or leaflets offering help with Head & Neck Cancer and information pertinent to this condition? | P | |
| | What help can be offered to partners and families worrying about the patient's diet? | P | |
| | WHY ISN'T THERE A NATIONAL SCREENING PROGRAM FOR PROSTATE CANCER? | PRH | |
| | My husband died from malignant melanoma...are there any inherited factors my daughters and grandchildren should consider. | R | |
| | The psa test, although not definitive, is a good indicator of prostate cancer. At this time I believe it to be all we've got before we start into the realms of biopsies and scans. It would appear to be sensible to have periodic psa tests done over years to plot the change in level of psa and it's trajectory in men of a certain age, so early intervention can take place. Why are so many GPs so reluctant to let men have this psa test, often talking men out of it or refusing point blank? | R | |
| | I have been told to expect pains for maybe a year or more after radiotherapy, but how severe may these pains be? Nightly or very painful at times. | P | |
| | can carrying on as normal with 'heavy' tasks and long distance driving cause any lasting damage after a mastectomy? | P | |
| | Are homeopathic remedies such as glucosamine, pro-biotic capsules, magnesium etc as well as ibuprofen and headache remedies contains aspirin and codeine, safe to take after having a mastectomy | P | |
| | Is Cancer Research still a priority in Trusts? | H | |
| | Why when breast cancer spreads to the bones does it lie dormant often for several years before it shows itself. | P | |
| | How do I support my family to cope with my impending death? | H | |
| | How can I support my partner who is supporting me through cancer? | P | |
| | How can I improve my confidence in dealing with cancer? | P | |
| | What are the likely symptoms that I will experience that means treatment needs to begin? | P | |
| | What additional or extra precautions should I take given my condition (things like sunscreen and insect repellent, for example) and at where should I not travel to | P | |
| | Where in my local area can I access the best support for issues relating to getting back to normal after my cancer treatment has finished? | H | |
| | How and where can I access reasonable travel insurance to allow me to travel during and after my cancer treatment has completed? | H | |
| | Do cancer patients ever resume their working life to the same extent as they did before their diagnosis | P | |
| | How can my story help others to prevent them getting cancer in the first place ? | P | |
| | Simple ways to give back and support others being treated | P | |
| | In people presenting with brain tumours does the onset of neurological symptoms equate to the beginning of progressive brain damage? | RH | |
| | How is it best to plan your life after cancer when other people are making long term plans and assume 'there is always next year'? | P | |
| | How can I find out if there is a specialist dealing with long term consequences of radiotherapy for pelvic-area cancers in my area? | P | |
| | Where can I find help and advice with getting the best fitting prosthesis when I am not a 'normal' or 'standard' size? This has a negative impact on daily living after breast cancer. | P | |
| | The implications of treatment on ability to do previous sporting activities. | P | |
| | I am 3 yrs post Chemo/radiotherapy. I still have problems with tiredness/out of breath. I still can't eat apples! Drink plain tap water! and still get dry mouth. Is this normal | P | |
| | If the person with the Cancer is traveling a distance for treatment, There should be an easy access to information where he or she can get good transport or financial help | U | |
| | To be pointed to what services are there for them and family locally | U | |
| | Cancer has made me poor what can be done to help | PR | |
| | I have read that an untreated sinus infection may be the cause of CLL is this true? I am also aware of the fact that I have insomnia which I never had before I had CLL I have read other peoples experience this too. | P | |
| | I do not feel that there is enough explanation about CLL I was just told by the haematologist at the hospital "yes you do have Leukaemia" no other information was available. | P | |
| | Information about what services are available during and after treatment. There are many services available, but it's difficult to get the information. | P | |

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| | I am infertile due to cancer treatments. I take the regular pill instead of hormone replacement therapy. Is this the best long-term solution and what else should I be doing? | P | |
| | What symptoms do you have when undergoing chemotherapy and what should your daily routine be? Is it best to rest all day in bed, or get up and try to stay active even if you are in pain? | R | |
| | Radiotherapy treatment 30 years ago have caused nerve damage, muscle wastage and burning sensation in back. Was not told when going through treatment about possible side effects. I would like to know if there is anyone that can guide me through symptoms I am now experiencing? | P | |
| | Gene connections, is my child safe | P | |
| | What avenues are available for financial help and assistance when off work for a long period and relieving reduced pay | P | |
| | What support or new skills training is available if I have to give up current career after treatment which includes limb amputation | P | |
| | What non medicinal treatments are available to compliment the sometimes harsh treatments of chemotherapy and radiotherapy | P | |
| | Why does the patient having hormone therapy smell musty despite a high standard of hygiene, it doesn't seem to affect him but the carer finds it very off putting. | R | |
| | How many different types of prostate cancer are there and which are least and most aggressive | P | |
| | Having been recently diagnosed with PC, I am amazed at how just how many of my friends and colleagues seem to think it isn't much worse than toothache which can be easily treated! So I guess my question is how do official organisations promote the reality of awareness of, and treatments for PC. I now accept I'm on a mission to do my bit! | P | |
| | When I finish all my treatment chemo when do I find out when I go into remission | P | |
| | How can a person jump from stage 2 to stage 4 cancer without any node involvement and clear margins after surgery? | P | |
| | What are the effects of having lymph nodes removed (e.g long term pain/discomfort) | P | |
| | How high must your PSA be to start to be worried about the spread of the disease. | P | |
| | what are the latest treatment for a rising prostate. | P | |
| | What supplement do you recommend. | P | |
| | What makes the risks associated with surgery too high to make it an option when the cancer has not spread beyond the capsule of the prostate gland? | P | |
| | Are there any new treatments available for dry mouth | P | |
| | What are the chances of me getting cancer with having the brca1 gene | R | |
| | How to support and relate to close friends and family during and after cancer treatment | PR | |
| | Why do Medical professionals refuse to accept that there are alternatives to treating or preventing the spread of prostate cancer by means other than Radical Prostatectomy surgery or "watching and waiting" involving repeated painful biopsy sampling. | R | |
| | Prostate cancer is said to be slow growing (compared to some other cancers). But how slow is slow? Having been diagnosed with an "aggressive" form of the cancer, it took six months to "act" at which point the initial diagnosis of a localised tumour i.e. confined to the prostate gland, was "upgraded to locally advanced, and further scans then "upgraded" again to metastatic, outside the normal area treatable with wide area radiation. Is this because the cancer had progressed in the nine months or so since first diagnosis or because it is moving faster than the correct treatments can be identified | P | |
| | Just how does Prostate Cancer spread from inside the Prostate | P | |
| | What makes Cancer aggressive | P | |
| | When a hospital orders a post mortem, they should tell the relatives why. And they should meet the relatives afterwards to explain the findings. Instead of it all being handed over to the coroner. | PR | |
| | How can side effects of chemo especially hair loss be prevented? | P | |
| | If I have breast cancer can I breast feed ? | R | |
| | My husband has had prostate cancer for 20 years. He had radiotherapy when he was first diagnosed and it kept it at bay until 5 years ago when his psa started to rise again. He then had cryotherapy which he was told hadn't worked and he was left totally impotent and needs to wear pads as he leaks urine. He wishes now he had never had it done. He then had hormone injections for 3 years and is currently having a break from them as they have given him a lot of side effects. He saw the consultant after 3 mths and his Psa hasn't gone up. They have now said he doesn't need to return for 6 mths. I worry that his psa could shoot up in that time. Should he be seen more often. Lately he has been getting very out of breathe and having back pain but no one checks him to see if the cancer could have spread. The dr did blood tests and an ECG and chest xray and said everything was normal but on going for a flu jab the nurse said his blood count was very low and he should go back to the DR. Could all of this be related to his cancer | P | |
| | What questions do you ask the consultant when you see them every month. It is hard when you know very little about the topic, and the progression of the disease when every one is different and you do not want to frighten yourself when you look at the internet | P | |
| | I cant get to grips with pelvic floor exercises, is there anything else that can help me with bladder control. | P | |
| | I am still using pads 9 months after having my operation is there anything that can be done to stop/reduce my incontinence? | P | |
| | How can patients and their carers find out what is available to help them and then access them? | R | |
| | Why immunotherapy is ineffective according to the degree of cancer classification. | P | |
| | How realistic is individualised treatment for advanced cancer. | P | |
| | Why are men aged 60 or over not automatically offered a PSA test? | P | |
| | Diagnosed with Prostate Cancer and given radiotherapy then aged 65.1 ask if it is true that the average survival rate is approx.10 years? | P | |
| | How are survival rates calculated? | P | |
| | Recently completed pace trial, psa dramatically dropped to 1.6. Will it rise? | P | |
| | After successful treatment what happens if one's PSA goes up again? | P | |

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| | What are the possible treatments available if prostate cancer comes a second time? | P | |
| | How will my chemotherapy treatment affect my nutritional needs, and how can I ensure that my needs are met when I have problems with nausea, diarrhoea and poor appetite? | P | |
| | What services are available for family/relatives following the death of a loved one? | H | |
| | How do I know I am receiving the best treatment? | P | |
| | What innovative treatments might be coming on stream and how can I access them? | P | |
| | How can I go about hunting for a job if after having leukaemia I don't want to go back to what I used to do. Will people still want to take you on if they know you might get your cancer back at anytime and allow you out of work for all the appointments you still have to go to. | P | |
| | Some of my side effects seem trivial. Is there someone you can ask about them without having to wait to see or bother the consultants. | P | |
| | I have survived 2 brushes with breast cancer; DCIS and invasive. I am a person who "needs to know" so I would appreciate being told what my statistical chances are of surviving into old age. I am 74 yrs old. | P | |
| | I have 2 daughters and I would like more information re what health screening is available for them - both in their 40s - and also how it can be determined whether they have a genetic tendency to developing breast cancer. | P | |
| | How can I have control over my end of life care and death | R | |
| | What are the chances the same thing could happen to our children? | R | |
| | If you suffer from low grade Non-Hodgins follicular Lymphoma is it inadvisable or potentially dangerous to take herbal remedies like Echinacea? | P | |
| | Is it potentially harmful for Lymphoma suffers to drink diet fizzy drinks as some articles intimate that it is? | P | |
| | Is the NHS planning to use freezing caps to help prevent hair loss during chemo.? | H | |
| | After a auto SCT is the immune system still compromised and can you have a second auto graft if you relapse? | P | |
| | What benefits are available to cancer sufferers and those in remission when you've lost your job | P | |
| | How can patients with ongoing hair loss post treatment for leukaemia be supported to find hair loss solutions | P | |
| | If the patient and relatives ask for time to consider the treatment options how is this recorded in the notes? | P | |
| | Due to only being 30 doctors are reluctant to start any form of treatment other than venesections. Why is this? | R | |
| | Can regular help be accessed for routine chores such as shopping, when patients are housebound? | R | |
| | Who can help me with financial support and tell me what benefits I can access? | RH | |
| | Is there a specialised cancer care mental health service? | RH | |
| | What are the chances of returning to work? | RH | |
| | how easily would it be to create a "one stop shop" for the latest research findings on cancer or have a contact who could provide a "fact check" re latest research findings to stop "trawling the net" | P | |
| | What trials or studies can those living with and beyond cancer take part in to help the medical profession which has helped us so much, to help others, short of actually searching for such trials, is there any way to register my interest and willingness to join? | P | |
| | Are there any regular blood tests that I could pay for privately that might act as an early indicator of cancer (particularly melanoma). | P | |
| | Will there still be continuous support from the NHS while living beyond cancer? | P | |
| | Raised liver function results... do they precede liver cancer? | PH | |
| | How do cancer patients who cant go back to work get benefits? | PH | |
| | Are there any natural sunscreens recommended by the FDA or Skin Cancer Foundation or British Association of Dermatologists? We are told to avoid chemicals to help prevent return of cancer but then use chemical loaded sunscreens on our bodies to 'protect' them from the sun? | P | |
| | What care I receive after I have had cancer. I lived a healthy life before I got cancer. I would be good to know what I can claim (for example the freedom passant council tax). | P | |
| | Can you physically do what you could before the cancer was diagnosed? | H | |
| | Where does one find support to help ones adult child with Special Needs/ Autism to have an understanding of what is happening. There seems little awareness that there could be many families struggling to cope with this scenario and need specialised understanding and support for the whole family. | P | |
| | Why is a PSA test not carried out for ALL men over 50 as a matter of course. Surely it is better to have the PSA reading, even though it is not foolproof, so that it can be discussed? | P | |
| | Who can a carer ask about the type of cancer how the treatment is going to affect the patient (in my case my daughter) what the plan of care is short term/long term | R | |
| | What things should I look out for which are "Red Flags" to get her back to hospital apart from obvious ones is high temp. | R | |
| | Who can keep me up dated on treatment, why it changes. Updates on X-rays. Is the treatment working. | R | |
| | What is the evidence base for those interventions that are currently available? | H | |
| | When cancer is diagnosed as extensive yet following surgery it is found not to be and need no further treatment, what support is available for patients in this situation? | P | |
| | How can family members of a cancer patient find out if they have a genetic predisposition to developing the same cancer? | R | |
| | What screening is available for different cancers and how do we access them? | R | |
| | Who exactly is accountable when local/national policies/guidelines and protocols are not adhered to, as far as providing safe and compassionate care for cancer patients goes? | R | |
| | The law on informed consent seems fairly clear-yet it seems there is huge variations across regions and healthboards as far as actively involving patients in decision making/considering their wishes/beliefs goes.What is being done about this? | R | |

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| | Who ensures adhesion to national guidelines, such as the BNF, as far as prescribing medicine goes? | R | |
| | Does the treatment for Prostate Cancer also treat any areas it could have spread into ? | P | |
| | You often hear of Prostate Cancer spreading to the bones, is it possible for it to spread to other organs / parts of the body? | P | |
| | What treatments are available to me & how much input do I have on choosing the right treatment to suit me | P | |
| | My case is with The University Hospital North Staffordshire. Q. Will the oncology unit be fully versed regarding latest research and, therefore, would my consultant be in a position to advise me on future treatment options based on current thinking? | P | |
| | Q. What is the expected duration for the ongoing hormone therapy? | P | |
| | Does this really impact blood donating | R | |
| | Will you get cancer if you have an enlarged prostate. | R | |
| | If so what is the treatment | R | |
| | Can you have your prostate removed if it's enlarged | R | |
| | Does taking opioid painkillers such as codeine whilst on tamoxifen affect how well tamoxifen works? Do all opiates have a similar effect on tamoxifen, or are some more or less likely to affect how well it works? | P | |
| | How long will zoleredex work for | P | |
| | What vitamin deficiencies are likely after removing the duodenum? Are we prone to b12 deficiency? How many develop Bile Acid Diarrhoea? Fat soluble vitamin deficiencies? Doctors are too reactive, waiting until deficiencies have already developed before providing any supplements | P | |
| | Likelihood of developing diabetes? And what sort of diabetes - type 1,2 or 3? | P | |
| | I had pancreatic cancer and then had a Whipples operation followed by chemo. What should I eat/drink to ensure that I absorb all the required nutrients and vitamins after my operation? | P | |
| | I had pancreatic cancer and then had a Whipples operation followed by chemo. How much Creon should I take with my meals? | P | |
| | I had pancreatic cancer and then had a Whipples operation followed by chemo. Should I take a PPI eg Omeprazole? | P | |
| | How best to help a partner cope with living with a "death" sentence. A bit dramatic, I know, but having cancer means that one knows what will kill one and approximately when rather than it being a random event. | R | |
| | Is testosterone supplementation safe? | P | |
| | How can artificial testosterone best be administered to enable spontaneous rather than contrived intercourse? | P | |
| | Where can I get support request side effects of the treatment? | P | |
| | Do you keep having camera on a regular basis | P | |
| | Is the use of medicinal cannabis oil likely to be approved for cancer patients? | P | |
| | What support is there for grieving family members? | R | |
| | Where to get insurance to go abroad/ u s a ... with cancer .. couldn't one be set up ? | P | |
| | Why with Radio Therapy for Bladder Cancer don't they pin point the Tumour and area of suspected cancer when they have the photographs from the Flexible Cystoscopy and the one under anaesthetic i.e. Rigid Cystoscopy | PR | |
| | Why after 3 sessions of ONCOTICE treatment have they stopped it? | PR | |
| | Am I making the correct progress after my surgery ? | R | |
| | What are the different types of radiotherapy and why do they use that type on me ? | R | |
| | Does dark nail varnish stop your nails peeling during chemo? | P | |
| | Why is there no register of doctors who specialise in treating long term side effects of cancer drugs? | P | |
| | Again acting as an involved patient I read the leaflets associated with medication and realise that these are really produced as a back covering exercise for pharmaceutical companies. How is a patient to understand the impact of medications like antibiotics on primary conditions? | P | |
| | Why aren't there more support groups for bladder cancer, and how are support groups set up? | H | |
| | As a post-allo Stem Cell transplantee I would like to have contact with others who have been through the same treatment & are still walking the planet. | P | |
| | If I have a recurrence, what issues will any future treatments bring? | P | |
| | How will my health and wellbeing be supported? | P | |
| | How to assist with private education when the cancer patient is the money earner. | R | |
| | How common is parastomal hernia | R | |
| | Is there a national data base which can give information about social, emotional and psychological support available? | H | |
| | What will the end be like for me with my present multiple cancers | P | |
| | When and what can I do exercises wise when having treatment? As told to avoid gym and pools due to infection - what are the other options? | P | |
| | How do you manage other peoples comments which sometimes add to your fears | P | |
| | Your loved one or maybe a colleague or fellow school parent or friend is being treated for cancer. What are the things that you can say or do that are actually helpful. | P | |
| | What are the side effects of having a hysterectomy on your body, physically , what damage can occur during the surgery i.e. Hip problems | P | |
| | I have been diagnosed with uterine carcinosarcoma. There is literally no easily available information about this. My question is that information on this rare form of cancer is urgently needed. | P | |
| | Dealing with your partners emotional distress when you barely have the energy to hold it together yourself | P | |
| | Lack of confidence - Dealing with the worsening weaknesses in your body after being quite fit for your age and the lack of confidence this brings (e.g. Your leg /knee giving out with no warning and landing in a heap on the ground and unable to help yourself up). | P | |
| | What provision is made to support families manage their finances and cover the costs, post cancer treatment? | R | |
| | My mental stability seems to have changed considerably to the point where I do not recognise myself and my feelings, could this be hormone related as the oestrogen is being artificially restricted? | P | |
| | How many people live more than 5 years with lung cancer? | R | |

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| | is it true that once a nodule is cancerous, all other nodules in the lungs will eventually turn cancerous? And why? | R | |
| | what is a flare up or exacerbation?? And what do you do about it? | R | |
| | Given that relationships can fail with the effects of a cancer diagnosis, how can they best be sustained and renewed after cancer particularly when fatigue and depression may be issues? | PR | |
| | I've had a double mastectomy and I find it very difficult to find bras that are comfortable with my scars and don't ride up and are affordable, can anyone suggest any company to contact to help? | P | |
| | I am struggling with lymphedema in my left arm and I can't find anything to help with the pain and discomfort. I've tried loads of different sleeves including ones that include the hand they are all painful. The doctor has given me painkillers but they don't touch the pain. I have also tried reflexology and massage which is pleasant but the pain and the swelling returns within hours. Has anyone got any suggestions as to what might help? | P | |
| | Can you get help at home? | P | |
| | What benefits can you get? | P | |
| | Can you get help with depression? | P | |
| | How soon should you return to exercise and what exercises are best when recovering from major abdominal surgery, should you wear support to prevent hernias. | PR | |
| | Even though one has been "signed off" by the Oncologist are further checks done on you to make sure cancer has not returned? | P | |
| | How do I tell my family the truth, or possible truth? | PR | |
| | How do I help myself cope in between tests to see if the cancer has worsened? | PR | |
| | How do I support myself financially? | PR | |
| | In light of evidence demonstrating health care professionals should be encouraging vigorous exercise to improve survival rates, we are we not? | H | |
| | How can I cope with having a rare brain tumour and not being able to research it and its patterns of regrowth and how it takes different types of treatment? I have a rare central neurocytoma. | P | |
| | who is there to help me to get through remission | P | |
| | What treatment is currently available other than chemo and radiotherapy | P | |
| | How does the medical team balance the priorities of "getting the numbers down" with minimising side effects? | P | |
| | How likely is it I can have children after chemotherapy? (I am a 40 year old woman, two years after last chemotherapy for oesophageal cancer). | P | |
| | What were the benefits of ivf before starting cancer treatment? | P | |
| | What can my workplace do to support me after returning to work after cancer treatment and what are my rights? | P | |
| | How long does it take for the past operation to repair. | P | |
| | How is information on the results of clinical trials shared between researchers? | P | |
| | Is there a way that we can show to the public how their donations to charities like cruk are spent on research? | P | |
| | How can patients access research on differing preventative approaches? | H | |
| | To whom can I turn for practical day to day support if family can't cope? | PR | |
| | I was treated at a centre of excellence in Oxford, do these exist throughout UK? How do the stats compare? | P | |
| | We have at least 2 generations passed from LC aged early 50s. How close are we to a genetic test to determine a risk before lung cancer develops | R | |
| | Where can I find consistent, evidence-based nutritional advice following a cancer diagnosis? | PR | |
| | How to deal with sleeplessness caused by reflux when all possible medicants offered have not helped. | R | |
| | Dealing with eating food and knowing how much to eat before it causes sickness and diarrhoea. | R | |
| | I AM A CARER, WHERE DO I GO FOR HELP | R | |
| | how do I go back to work after the diagnosis | H | |
| | I have heard the term "consequences of treatment" - so, are any possible for my proposed treatment? | P | |
| | Does your sex drive return after androgen therapy? | RH | |
| | How can I manage my bowels after rectal cancer surgery? | H | |
| | My cancer of the oesophagus was diagnosed at T1N0 which meant that it could be removed endoscopically. The problems making the exact diagnosis were histological with inflammatory cells masking adenocarcinoma cells. Is this a common problem? | PH | |
| | How to get funding for Lymphoedema treatment bilateral secondary to cervical cancer . | P | |
| | Will cancer come back if I have Manual lymphatic drainage | P | |
| | Constipation is a problem to me following my Prostate cancer diagnosis. What can help me apart from taking laxatives regularly? | P | |
| | How to live with swallowing problems and lead a normal life | P | |
| | Is Scottish research as good as British, European or worldwide research and how do I know I am getting the best available. | P | |
| | what things should a patient NOT do when on treatment. Many patients seem to get advised about not working, not doing various things like swimming- yet I am not aware of much evidence that there are any activities that should be forbidden during treatment. | H | |
| | Are there specialist clinicians in my area so that I can obtain the best medical care? | P | |
| | Are there local support groups in one's area? | P | |
| | Assuming I live to 100, I may be a cancer survivor for over 60 years. During this time, new discoveries will be made, new genetic involvements, new treatments, new advice, new identification of cancer subtypes. Can I be proactively contacted if new research that is relevant to me with clinical implications emerges? For example, a gene (like BRCA) may be identified for which a bilateral mastectomy is recommended - in which case I want to know as, with my predisposition, I would want a bilateral mastectomy too. For example, my triple negative breast cancer may actually be identified as 'quadruple negative' and I would want to know - to have my records updated, to have my pathway of care re-assessed. | P | |

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| | I don't want 1:1 consultations on health topics: living well, data consent, diet etc. I don't want the NHS medical staff brains/training to be used on signposting information and behavioural change when this could be done by charity volunteers on-mass. I understand that on-mass rollouts of information to the NHS patients is difficult because it has to be agreed by NICE and have irrefutable evidence. Can we have a series of information events which has 'we currently believe this to be the best advice' which include semi-proven behaviours that are not harmful (like sleeping in a darkened room etc.)? This is a request for meta-analysis and translation to clinic EVEN if doubt remains in the cases where it can do no harm. | P | |
| | What effect do hormone injections have on prostate cancer. | P | |
| | would like to know who is the responsible health professional for over all care of the patient? Feel that after treatment you seem a bother so you do nothing | PR | |
| | Reporting and analysis of rarer cancers in statistics of survival and quality of life. Often cancer types are not even broken down into rarer sites e.g. head and neck cancer and extremely rarely do we see head and neck sub-types such as salivary gland cancers | P | |
| | What if patients are doing well and don't want to attend Health and wellbeing events and Cancer Care reviews? | RH | |
| | If I have a relapse, what treatments could I expect to be available, and will they be effective? (AML) | P | |
| | Why doesn't every cancer patient have a genetic profile, including analysis of their cancer for future reference, given the emphasis on developing targeted treatments (that may yet come to fruition...)? | R | |
| | dealing with comments from clinicians that 'you look well' when I am describing my symptoms/illness or am able to walk about in hospital compared to much older patients as if not taken seriously due to the efforts I've made to regain fitness (and steroids making me gain weight and appear well) | P | |
| | how to relate to some people who don't seem to know how to treat me as a person anymore since cancer diagnosis | P | |
| | My mouth is vulnerable to bacterial and fungal infections following intensive radiotherapy. I find a salt mouthwash twice daily works wonders, and I now only experience soreness if I forget the treatment. However, this has never been recommended by professionals as, I am told, research has not been carried out, which might support this. If research did support it a lot of people might benefit from a simple, safe and cheap treatment | P | |
| | Head & Neck Cancer patients, especially Laryngectomies, often wish to make a suggestion or a complaint but so often there emails go unanswered by the professionals. It is not known who to approach. And there is a fear that it might denigrate their future treatment if they make too much noise about anything. How can this best be rectified and how can the patients be reassured? | P | |
| | How long can someone keep taking chemotherapy tablets for four tumors which cannot be operated on? | PR | |
| | Taking antidepressants what happens when you gradually come off them does it come back? | PR | |
| | what suddenly happens to the body immune system when someone dies of cancer ie how does it happen so quickly and why suddenly does one get an internal bleed | R | |
| | What is the cumulative effect of TURP and radiotherapy, in terms of impotence? | P | |
| | where can support be found to deal with these issues? | P | |
| | Why is there not a full scan/examination at the end of treatment? | P | |
| | How can you support a relative who was previously diagnosed with cancer who is waiting for tests results to find out if the cancer has returned? | R | |
| | What support will I get emotionally? | P | |
| | Is there any chance that my bowel cancer will affect my lung cancer? | P | |
| | How can I access after care counselling? | P | |
| | Barrett's Oesophagus and side effects of PPI's | P | |
| | Effects of Ablation treatment for Barrett's Oesophagus | P | |
| | How much work is going on into Secondary Breast Cancer? | P | |
| | In Radiotherapy Centres what do radiographers do to keep Patients still on the machine if they have tremors owing to Mental Illness Learning Disabilities or Autism ? | P | |
| | How can the same amount of medication e.g. anastrozole at 1mg be suitable for all sizes of women? | P | |
| | What are the symptoms of metastatic breast cancer? | P | |
| | Does scar tissue, or adhesions have an effect on other organs in the area of bowel surgery? | P | |
| | Living with a bag that bursts is the worst thing about having bowel cancer. It has stopped me having quality of life. I am always anxious | P | |
| | How many times do you have to change your bag? Does it leak? | P | |
| | How do the public find out About the most up to date research about cancer ? | PR | |
| | Need an easy way to see reviews of evidence for secondary prevention, maximising treatment outcomes. Very complicated and needs scientific education at the moment. The Google phenomenon is not helpful! | R | |
| | When do my children need to be checked if I got now/bowel cancer early ? | P | |
| | Do people get enough information about support groups in their area? | H | |
| | Where do people with learning disabilities diagnosed with cancer get support and information? Do they use opportunities such as Macmillan information centres and Maggie's? Do they rely on carers to provide support and information? This question comes from some initial discussion in the North East and Cumbria where the Macmillan and Maggie's had not had any people with a learning disability use services. | H | |
| | What reasonable adjustments are available to support people with a learning disability manage LWBC? | H | |
| | How the drugs affect other health and well being issues, eg diet, physical pain, mood etc | R | |
| | How do you de-jargon the terminology? | R | |
| | What support / training is available to patients who can no longer do the job they did before ? | H | |
| | how long does it take to get over the physical effects of my prostate removal | P | |

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| | If my consultant can't answer my questions to my satisfaction, who else can I turn to? | P | |
| | How can I best prepare myself for possible late side effects of cancer treatment and where do I find this information/support? | H | |
| | How do you cut through the mass of information that is found online and separate the right from the wrong? | P | |
| | What is the best way to approach telling family & friends you have cancer without them instantly thinking you will not survive? | P | |
| | Do I give up work? | P | |
| | Can more be done to "coach" those that require colestomy bags after surgery. | R | |
| | Getting patients involved with research. e.g. my mum had vaginal cancer which I understand is very rare - but there appeared to be no interest in her apart from as a patient | R | |
| | More about the inherited/ passed on nature of cancer. e.g. doctor's suspect my mum's cancer was due to an STI she had years before I was born - what is my risk? | R | |
| | Are RFA and cryoablation available under NHS for treatment of metastases after first ACC treatment and if not why not and what alternatives exist or are likely to exist over the next decade? | R | |
| | How do I explain this to my family? | RH | |
| | How to deal with the reaction/feelings of close family and friends? | H | |
| | Given that the statistical chance of having cancer is higher if one has had a cancer already, how could I access periodic "whole body" reviews to detect any other new cancer early and hence enhance the chance of beating and surviving the new cancer? | P | |
| | As a sibling of a cancer patient and a health care professional I am unsure of what questions to ask her to help her manage her condition/return to work/ongoing life without feeling patronising or lacking in compassion. | RH | |
| | How long can people stay in hospice care ? | P | |
| | Will I be able to return to breastfeeding my baby after surgery for cancer? And if so, can I have help to maintain my milk supply until then? | P | |
| | What are the risks/effects on my unborn baby of diagnostic tests for bowel cancer whilst pregnant? | P | |
| | What are the risks (to both mother & baby) associated with remaining pregnant once diagnosed with a cancerous bowel tumour? | P | |
| | I need more help in understanding when to move to supportative care and stop treatment with long term blood cancer. | PR | |
| | Where do I get help for counselling/mental health, help adjusting to life living with cancer | P | |
| | Are there differences between the brands of Tamoxifen and causes of side effects? | P | |
| | Do employers, friends etc ever get over you having cancer? Are you constantly treated like a victim? | P | |
| | I experienced 3 specific terrifying mental episodes during chemo, NOT depression, but some sort of drug episode. My doctors dismissed it. What was it? | P | |
| | What already exists in the local area that people can access | H | |
| | Lots of the Cancer support groups do great work running support groups/courses for their patients but it still seems quite hard to find out about these courses Do they give enough info to people Should one central organisation coordinate all info about local courses/help available? To make it more easily accessible For example if you go onto a MacMillan website you will find loads of info on how you can help them Trek Himalayas/ volunteer etc but no info on local support groups? Again this info would have to be collected into local geographical areas | P | |
| | Is okay for breast cancer patients to vigorously exercise their arms after axillary node surgery? | RH | |
| | Why are neuroendocrine tumours/cancer not included for funding from CRUK? My family gave money on the assumption that Nets were included in research funding. | R | |
| | my husband died of cancer 7 years ago and I nursed him through the chemo etc. He was very poorly. I now have cancer and have no surviving relatives to take care of me. I have therefore refused any treatment as I don't want to end up in a care home earlier than I need. What else can I do | PR | |
| | Since the Meals on Wheels service is no longer there, I am living on ready meals from the Supermarket as I am too ill to cook. Any suggestions | PR | |
| | After a prostatectomy which was followed by a session of conformal radio therapy, my PSA levels have steadily risen to 22 now. If PSA readings can only come from prostate material, why am I getting such readings when the prostate was removed and was followed by the r/t? | P | |
| | I would like to ask about the support available for couples where the person with cancer has become infertile due to cancer treatment and the postcode lottery for the availability of free NHS IVF treatments? | P | |
| | What drugs are on the horizon for my specific cancer | P | |
| | Do I have the right to request a second opinion from a centre of excellence? | PR | |
| | Can I request an MRI scan if I haven't had one? | PR | |
| | Support with practical things like continue to work and financial matters ie Pip and blue badge entitlements | R | |
| | Help for relatives when they say they did not need any, my husband/carer is very depressed even though I am now well but will not admit this or seek help and when I have asked for help on his behalf I am told 'if he doesn't ask he cannot get any' | P | |
| | Where can you get information from about eating well when you have cancer | R | |
| | Where can you find out what new drugs are available in your area or what new drugs are available to the patient | R | |
| | What medications and supplements can you take with your medications/chemotherapy or not? E.G Turmeric supplements need to be avoided with Breast Cancer and avoiding herb supplements with Tamoxifen / Anastrozole. | PH | |
| | Why are the investigations different for each cancer diagnosis, eg. MRI/CT scans not for all? | PH | |
| | What follow-up tests / examinations are there for patients once given the 'all clear'? | U | |

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| | Glioblastoma multiform (GBM) why cant it just be cut out? | R | |
| | Is there a blood test that can test for certain types of cancer? i.e. prostate if you are the child of someone who has had it? GBM if your father died from it? | R | |
| | Who will support me after treatment and where can I find out about this support | PR | |
| | How long will I be followed up for. | P | |
| | How effective are holistic therapies and which ones are suitable for me | P | |
| | After the therapy for my prostate cancer had been completed I asked my oncologist about the present, and possible future state, of my prostate. The oncologist drew the analogy of a garden in which nothing grew. Is this a good analogy? I have the feeling that this is overkill and that my prostate no longer performs any useful function. (Sorry for the unintended upsetting picture) Sledgehammer to crack a nut?! | P | |
| | How can I make sure that I am not doing too much or the wrong sort of exercise? At one stage I was not even allowed massage because of diagnosis of heart failure seven years after treatment which was connected to the way my disease presented. Medication has improved this, but I struggle doing simple tasks | P | |
| | Should I have had a bilateral mastectomy not just the side that was affected | P | |
| | When is a stoma a good thing or is it always a bad thing? | R | |
| | My relationship really struggling immediately after treatment - what are the best methods for lessening the impact on treatment on loved ones and friends | P | |
| | Returning to work and managing 'getting Back to normal' | P | |
| | Why is there not much research or publicity on cervical cancer? | P | |
| | What is the procedure to reassure a patient who has gone through stage3 aggressive BC, 2 mastectomies, an oophorectomy and 10yr tamoxifen? Told 'no need for scans now you have little breast tissue left'! I am high-risk and have been having cysts removed since I was 23! | P | |
| | Why is there never any information/support on long-term joint pain and arthritis after 10yr tamoxifen plan and no ovaries? | P | |
| | To now the latest information & tests available for patients . | P | |
| | Where are we with new treatments which could be used alongside or instead of chemotherapy and radiotherapy? | R | |
| | After almost 20 years of living with cancer, my wife became ill daily with pain, could this have been due to years of morphine usage administered daily? She suffered from racing headaches. | PR | |
| | Having lost my wife, I now have prostate cancer, what is the best way to prepare my children who also may be diagnosed one day? | PR | |
| | Having had chemotherapy treatments, I know have mobility difficulties. What can I do to improve this? | PR | |
| | Information on physical and social activities | P | |
| | How to support return to work person, returning to work after breast cancer diagnosis. | P | |
| | Rebuilding relationships after cancer treatment | P | |
| | Where can people find help with late effects they have, following cancer treatment? | H | |
| | Local support groups-tumour specific and age specific. Have not been able to find much information on support groups specifically for people living with cancer after treatment, for those struggling to come to terms with the end of treatment but not attached to a cancer charity or course eg: HOPE | P | |
| | Is there a risk to my daughter or any grandchildren? | P | |
| | Does the treatment which I had have any long term effects? | P | |
| | Where can I get emotional help to decide to check if my cancer could also be genetic & how to broach this with my children if it is & support them to get tested if they want to? | P | |
| | How do you know that lumps in your remaining breast aren't cancerous - haven't turned cancerous eg fibrous but then feel like lumps? | P | |
| | Is pain in the breast an indicator of cancer starting...? | P | |
| | Speaking with work colleagues after a diagnosis is a difficult conversation for both the person with cancer and the organisation/ employer. Is there any statutory guidance relating to how employers must behave and how and what their responsibilities are in relation to the Equality Act 2010 or data protection regarding disclosure to colleagues / managers? | P | |
| | How people perceive you after diagnosis | PR | |
| | Can my family and I look forward to a average life expectancy, after being NED ? | R | |
| | As a stage4 melanoma patient even after 2 years immunotherapy I do expect the appearance of new mets... I'm I being realistic or overly cautious? | P | |
| | How can cancer survivors who wish to support research in the future do this effectively? | H | |
| | I have just received a one- year 'all clear' from my oncologist. The test for this, however, did not include an FDG-Pet scan. Without this, how can we be certain that I am really 'all clear'? | P | |
| | As a volunteer- how do I obtain information to help and support cancer patients? | O | |
| | What research is going on for each of the less prominent cancers? | RH | |
| | My mother had the same cancer as me - breast + pancreatic- will my children have the same? | R | |
| | When will the drug MLE4901 be licensed and available? | P | |
| | Why can't I go on to MLE4901 at my own risk, as it has already passed phases 1 & 2 in its trials? | P | |
| | Should women of fertile age and with estrogen sensitive breast cancer be given the option of freezing eggs and then using a surrogate mother as a protective measure against cancer relapse. | R | |
| | What help is available for a sibling supporting a parent through terminal cancer? | R | |
| | I don't know how to ask my parent about her wishes for her funeral. Too upsetting. How do you ask this type of question? | R | |
| | How can I be sure I will get the same level of support from the next hospital as I have this? As I need to go their for a particular treatment | RH | |
| | How do I find out how we can get extra support financially | RH | |
| | Who can help us with housing as my condition makes it difficult to go upstairs | RH | |
| | Should I take vitamin supplements after kidney removed? | P | |
| | What food can I eat during treatment | P | |

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| | How do I understand the jargon of my diagnosis | P | |
| | What is the best support my family can provide | P | |
| | Why does female cancer screening stop at 65 and 70? (cervix and breast) | P | |
| | Why can't I give blood or donate organs after 19 years cancer free. | P | |
| | My mother and myself have been diagnosed within 7 months of each other! 30 year age gap between us. No genetic link evident! Are we just very unlucky or is there a further link as yet undiscovered- I have a younger sister who is naturally incredibly worried. | P | |
| | Who monitors internationally all the research into breast cancer | P | |
| | Where can I find specialist counselling to help me to cope with my diagnosis? | PR | |
| | To what extent is urinary retention a problem following a radical hysterectomy for cervical cancer? | P | |
| | When should a patient be assessed/start treatment for lymphoedema resulting from treatment for cervical cancer? | P | |
| | There are so many charities working for cancer patients? I don't know how many of these are actually benefiting cancer patients or their families. I lost nearly everything when my teen age son was diagnosed with cancer. Now that he survives(after going through a tortuous path of chemo and amputation of leg) he has to face educational and his parents financial difficulties. | R | |
| | why chemotherapeutics agents are the same as they were 25 years ago | R | |
| | What experiences can a bowel cancer survivor expect from pregnancy and childbirth? | P | |
| | Lack of energy and tiredness due to nocturia is most disconcerting. Is this due to radiotherapy damage or continued hormone injections? | P | |
| | Thinking about work age patients, are employers making allowances for hospital appointments? Not all employers give time off for such appointments and I know of patients who have to take annual leave to attend outpatients. | H | |
| | What new treatments are in development for primary bone cancer? | R | |
| | How soon will new treatments be available? | R | |
| | Who is going to point me, honestly, with no regard to their own standing in the research limelight, where the best and most effective treatment is coming from? | P | |
| Questions that were broad or off-topic | Why is Britain lagging behind rest of Europe in survivorship, and what should we copy to improve our chances of living as long as they do | P | |
| | Why is post cancer care so bad in UK? Why don't we learn from other countries? e.g. in Germany it is State law that hospitals have to provide a meeting place for a support group once a month. | P | |
| | Why is it that UK is 25th out of 27th on table of ratings for European hospitals for cancer? | P | |
| | Why are other countries better in helping cancer survivors to handle long term side effects for cancer treatment? | P | |
| | How do you measure financial impact of a service development? Both impact on Patient experience Secondary care costs including a and e Primary care costs patient costs other govt costs | H | |
| | How are the different needs of young adults recognised and met during and post treatment vs older adults? | R | |
| | Why is there so little support available (counselling, financial advice, sex and relationships) for young adults going through cancer? | PR | |
| | Impact of being diagnosed with cancer as a young adult. | P | |
| | What are the prejudices faced by young adults with cancer: in the work place and socially? | P | |
| | How do we ensure that there is enough community psychological support after treatment for Teenagers and Young Adults ? | H | |
| | How do we support those from the younger generations for health and wellbeing events? Our current events seem to attract those from the older age group (50 plus) who can afford a whole day's session. | O | |
| | What is the cause of late effects? | P | |
| | Sexuality | H | |
| | Best evidence on treatments including complementary therapies. | R | |
| | What about patients who DO NOT ask questions and who receive any information in silence? | R | |
| | Minimising late effects of cancer treatments | H | |
| | Role of rehabilitation | H | |
| | How long have I got? | P | |
| | Managing long term side effects | P | |
| | not being labelled with the awful word "survivor" | P | |
| | What research can be done on rarer diseases even if there are smaller population groups? | P | |
| | Are drugs and alcohol more dangerous after having a brain tumour | P | |
| | what information is given to patients | H | |
| | What would you say has been the single biggest consequence of your cancer for you and your family? | H | |
| | how has your life been affected after having cancer? | P | |
| | How do you cope with cancer or living beyond cancer? | P | |
| | Better ways of managing people post treatment/diagnosis in th long term | H | |
| | mental attitude to life | H | |
| | What are the long term (worldwide) effects of moving to more targetted therapies? | H | |
| | How to live longer | R | |
| | How to best manage long term side effects of treatments? | H | |
| | Is living with cancer the same as living with the fear of recurrence? | H | |
| | Do family members still support you knowing that you have been diagnosed with cancer? | H | |
| | Do you feel that there is social stigma associated with being diagnosed with cancer? | H | |
| | From the day of diagnosis, the truth | R | |
| | How can long term function and mobility be improved? | P | |
| | Is it fair to have a child after cancer? | P | |
| | Offer all sarcoma patients genetic testing | RH | |
| | Nation wide collaborative research on both above | RH | |
| | What interventions help people live well after treatment for cancer | PH | |

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| | Societal issues. Massive education issues. 'Oh my friend had 'x' cancer and they're doing really well now'. Thanks but was it leukaemia? 'Oh at least your hair hasn't fallen out'. Nevertheless I am going to die without a transplant. And the worst thing are charities - with the possible exception of Macmillan - with their happy clappy positive campaigns. Being positive does not improve cancer survival. (There's a large US study of over 40K people that disproved the positivity connection to cancer survival. | P | |
| | The biggest pain is not when the person dies. There is deep down a release from the pain both yourself & others & more specific the patient a peace is felt. Afterwards the pain begins slowly at first then it becomes the most acute pain you have ever experienced in the empty days ahead knowing you won't see them again. It's a hole in your heart where the emptiness can never be filled. | R | |
| | Side effects of the disease and treatment some of which occur much later than the treatment date. | P | |
| | Better coping environments during and after treatment. | P | |
| | Long term survival research rather than cure could be done | P | |
| | What about returning to work post treatment ? | P | |
| | Why have my doctors surgery not put up any leaflets or posters that I have taken in to them? | P | |
| | There is nothing in my surgery relating to Blood Cancer - why not? | P | |
| | What support would be beneficial to help with survivorship? Psychological/financial/social/physio/OT/SALT/dietetic | H | |
| | Is it curable | P | |
| | Course of treatment | P | |
| | What are the steps to developing cancer services so that they reflect the needs of people with cancer who use them and leading to good shared decision- making? Linked to this is the way research is developed- which may at present rely too much on pharmaceutical companies' priorities rather than people's real needs. | P | |
| | How do I get through the confusion and anger [DIAGNOSED AS A CHILD] | P | |
| | Issues regarding support for post cancer treatment issues e.g. in my own case rectal cancer, | P | |
| | why don't Dr act when telling them about your problems | P | |
| | dismissed with after effect put to bottom of like like nothing can be done to ease pain infections constant uti.s | P | |
| | unable to tell you when diagnosed long term effects of treatment | P | |
| | Is there anything I can do to make my 'issues' more able to cope with?? | P | |
| | Support and encourage all patients to be enrolled in inexpensive follow up studies (like the University of Washington Core Study) as a default with opt out option and share findings with participating patients | P | |
| | Does the treatment age your body or is it the drugs that u are given that can be highly addictive to relieve certain symptoms of the treatment. | P | |
| | How to control your symptoms better with medication. | P | |
| | How long can you live? | R | |
| | Statistics of how long you can live on average with a certain cancer | U | |
| | 30year survival rates for Breast Cancer and other cancers. | PH | |
| | I want effective treatment for secondary cancer that even if the diagnosis is terminal gives a good quality of life for whatever time left. | P | |
| | Who delivers more effective care: primary care or secondary care? | H | |
| | Who delivers more cost effective care: primary care or secondary care? | H | |
| | Who delivers better patient experience: primary care or secondary care? | H | |
| | Whether patient and cancer diagnosis can be linked more widely to GP and hospital records to look at long-term effect on health, with attention to appropriate control groups | PH | |
| | If doctors don't know knowsay it Don't ignore what parents have to say they see their children every day & know exactly what is happening. Ask them questions. Don't leave patients & parents in limbo. | R | |
| | Person my daughter & I were told she had 3 months. I knew she did not have three months..... not even three days. They chose to ignore me my daughter 2days later. I knew how she was feeling I saw the lumps on her body I knew by her bodily functions she did not have 3 months but no doctors or staff asked me why. | R | |
| | the diagnoses | P | |
| | the treatments | P | |
| | Is there any research regarding subcutaneous abscesses resulting from diverticula in a defunctioned rectum becoming infected and resulting in a fistula and abscess and why this can happen. | P | |
| | WHAT PROVISIONS ARE BEING PUT IN PLACE FOR THOSE PATIENTS LIVING FOR YEARS WITH ADVANCED CANCER WHO ARE RESPONDING WELL TO MONOCLONAL ANTIBODIES? | H | |
| | How to raise the profile of radiotherapy for patients and clinicians, and make it an attractive prospect for AHP's and clinicians to want to specialise within? | H | |
| | What problems if any are you having | P | |
| | How are you coping | P | |
| | What would have been the single most important thing that could have been done to improve your QOL following cancer treatment? | H | |
| | As a patient why are we told we have cancer - if we have no symptoms, we are well, there is no need for any treatment and no cure ? (Like many others, I was diagnosed with CLL following a routine blood test. I have been on Watch & Wait for 11years. I would have preferred not to be told until I need treatment) | P | |
| | How will research help deal with the many Side Effects of treatment? - Cure is not the end! | P | |
| | How is research helping to improve the QoL (Quality of Life) post treatment? | P | |
| | Once and for all, independent peer reviewed prejudice-free takes on nutrition roll on oncology. I know oncology institutions serving sugar drinks and croissants to patients on daily basis, others advise you to avoid too much sugar. Please, just some consensus. | PR | |
| | The effect of workplace culture on supporting cancer patients to continue to work and return to work; and also on supporting carers | R | |
| | Is the oncology workforce ready to deal with the needs of the ageing population? | H | |
| | Practical help for patients who have been debilitated by the consequences of cancer treatments but are cured of their cancer | H | |

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| | why is there only limited funding ,resources etc: for this type of research. | P | |
| | How is the food diet/ regimen for these patients? | H | |
| | What type of interventions will reduce cancer inequalities and how can these be best delivered? | H | |
| | How can transitions of care be improved between the NHS, social care and other agencies? | H | |
| | In past I was misdiagnosed and carried for 6 months TB. it felt like I had Aids 2 years later I got cancer. people treated me differently is that normal. | PH | |
| | I had test done family trait high risk I was under 50 what do people think about lowering the age 30 testing | PH | |
| | Why is the current model of care for cancer patients leaving so many with unmet needs? | H | |
| | How can we move away from a kind of blaming of people who've had cancer which is exacerbated by public health messages about prevention? It's not helpful for recovery! | PR | |
| | Do cancer patients want to talk about their cancer - or would they rather forget it and carry on as normal. | H | |
| | how can we have a life beyond cancer when there is no cure for clI - why are we side lined and brushed under the carpet | P | |
| | What are my responsibilities as a patient ? | H | |
| | How can I best support the NHS and ensure efficient use of services? | H | |
| | Why is clI not taken seriously? | U | |
| | there is no cure for clI so there is no beyond cancer where is the help we need | U | |
| | Long term side affects after treatment | P | |
| | What do people living with cancer really want? A lot of my patients dont want to be constantly reminded of their diagnosis and just want to get on with life! | U | |
| | What helps people most when faced with a life limiting illness? | H | |
| | Changes and support given my NHS | R | |
| | When should quality of life be prioritised above quantity of life? | H | |
| | Managing the long term side effects post treatment, chemotherapy, radiotherapy etc. | H | |
| | How can these long term side effects be managed & treated | P | |
| | How do we best support those patients with really poor prognoses, such as CUP [cancer of unknown primary]? | H | |
| | How can we best minimise and treat psychological distress and comorbidity? | H | |
| | Understanding of the tests | P | |
| | As the pharmaceutical companies are primarily interested in treatment and cure, how can we ring-fence research funds to properly investigate the effect of changing diet on quality of life? | R | |
| | what are the problems beyond cancer? | H | |
| | how can we help with these problems? | H | |
| | Containment or cure is the big issue! | P | |
| | How to reduce iron content of regular blood transfusions in order to prevent iron overload? | P | |
| | What is the best way to identify what patients need? | H | |
| | What is the most difficult factor for you in returning to work, day to day living and resuming your hobbies? | H | |
| | What's the worst thing about living with cancer? | P | |
| | Why has there not been any research into C.U.P? There is no information to speak of that is in anyway satisfactory at present. | P | |
| | How can people be helped to feel as well as possible generally after cancer? | PR | |
| | How can people be best supported socially if they have left work after cancer? | PR | |
| | Will there ever be more options for fertility with a quicker egg freezing process | P | |
| | Could the cocktail of drugs that need to be taken be made easier, as you are often in a place where it's difficult to concentrate on what needs to be taken and when. | P | |
| | Although I had transport eventually I was unaware that this was available initially. | P | |
| | Written confirmation of the cancer, as it is a lot of information to take in initially. | P | |
| | Will there ever be a cure for CLL | P | |
| | and how an individual can look after themselves when secondaries are in more than one area | P | |
| | How best to support people living with incurable but treatable cancer | H | |
| | How do we support patients on immunotherapy | H | |
| | Why do GP's refuse to refer patients who have massively enlarged lymph nodes and severe tiredness and general feeling of unwellness? It took me more than six months for any action and I had to pay for it by private healthcare as more than three GP's refused to refer me. This cost me over £2,500 to have a lymph node removed. I was also threatened by my GP that if I used the 'private' option it would cost me many thousands of pounds as I would only be able to use private health if a diagnosis was confirmed. | P | |
| | Will there ever be a cure for CLL. | P | |
| | Why is green tea helpful at keeping away infections | P | |
| | What are the main sources of support for people living with and for carers? | H | |
| | Prognosis expectations. | P | |
| | Why is there so little research in the field of lung cancer | RH | |
| | Why has survival rates in lung cancer lagged behind others | RH | |
| | Why does the uk have such poor cancer survival compared to usa | RH | |
| | would it help if we could talk more openly about death? | RH | |
| | Why is cancer treated differently to any other life limiting disease? | RH | |
| | How will genome research impact on both treatment and aftercare? | P | |
| | How have you adapted your life to enable you to live either with your cancer and/or the longer term side effects of any treatment | P | |
| | INCONTINENCE PROBLEMS | P | |

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| | Should a Consultant honestly and directly answer the patient's question about how much time is left or deal with question with a different? The honest answer, whilst not the doctor's fault or intention can cause many issues which include temporary insanity/irrational thinking, affect financial planning and financial affairs - current and future and cause emotional turbulence to family and friends and colleagues in the workplace. An honest answer can also be incorrect which can result in terrible financial and emotional consequences for the patient. | P | |
| | There are not many psychosocial oncology and survivorship studies available via the portfolio, I think there needs to be more research conducted in this area. | O | |
| | Which forms of support are most accessible for specific groups? (e.g. carers of people diagnosed with cancer, individuals with advanced cancer, different site-specific populations). | H | |
| | How does the language we use to talk about cancer in the media / society affect how it is perceived, and our relationship with it? i.e. talking about being a 'survivor', or 'battling' with cancer. How does this affect the individual? | H | |
| | How can I have a smooth journey in the healthcare system | H | |
| | I have had surgery for pancreatic cancer and have no pancreas and am therefore diabetic. My day-to-day problems are dealt with by current knowledge. I cannot think of a question about my situation that could be answered by research. Apologies for this not being helpful! | P | |
| | Why does it seem, that when prostate cancer is diagnosed a definitive range of drugs/ treatments are available and yet, when you approach doctors for treatments to help with the side effects of the drugs/treatments afterwards, there is little or nothing they can offer. For example peripheral neuropathy (after Chemo), dry and gritty eyes (after chemo), increased frequency and urgency to wee and pass motions (after radiation), erectile dysfunction (after nerve sparing prostate surgery), total exhaustion (after surgery, radiation x 40, hormones and chemo) | R | |
| | Will there ever be a Cancer Cure for any disease sites? | H | |
| | What interventions help symptoms due to progressive cancer, and in those living with the consequences of cancer treatment? | H | |
| | Why is drug development in paediatric cancer so slow compared with adult medicines? | O | |
| | Why don't people with GCT have the same support as people with cancer? | P | |
| | What support do people living with and beyond cancer want? | H | |
| | Much better discharge | R | |
| | Education and training of staff in Care Homes and how to prevent admissions to hospital. ? putting supportive personnel that can respond to to carehomes that need support and advise. A contact number with an immediate response. This could be done in zones. | H | |
| | How to live with an incurable cancer like myeloma | P | |
| | Times of recurrence | P | |
| | Bone spread | P | |
| | late effects now emerging from treatment of childhood cancers | R | |
| | The ability to transfuse to a higher limit than Hb 12 would be very beneficial. | P | |
| | Why is there no information about having womb cancer aged 15 | P | |
| | More info to parent on cardiac vascular invasion | P | |
| | Long term impact physically and mentally, patient and family | P | |
| | Length of time from diagnosis to treatment | P | |
| | Incontinence treatment | P | |
| | Help with the general public/friends/family who have not had cancer experience to realise that just because treatment is over it is not over! Still have fears, aches and pains, scans, appointments, ongoing medication and side effects. | P | |
| | Why do I feel guilty about | P | |
| | Given Vitamin C is a natural substance and therefore low cost - are we to assume it's use is not encouraged because drug companies - who often appear to be supporting cancer research into the use of new drugs - cannot profit from its production as compared to expensive courses of chemo. | R | |
| | Would it be possible to see medical research in the UK freed from the financial objectives, incentives and undue influence of 'Big Pharma'... e.g. a properly funded, state-owned and operated, cancer research facility which has shall we say 'different motives' than big pharma? In my opinion, until research costs and pricing for all medicines and treatments are taken out of the hands of privately owned pharmaceutical companies and incorporated into a healthy national or global health system with genuine motives, (or some system that can regulate the wildly fluctuating costs of treatments according to ability to pay) then all subsequent questions seem to me to be irrelevant. | P | |
| | Will my urinary continence deteriorate with age? | P | |
| | what are the accuracies of Prostate Cancer? | P | |
| | Do hormone injections(Zoladex) help, if so, in what way. | P | |
| | Can diet help, if so what should or should not be eaten. | P | |
| | Although the idea of research into living with cancer is very admirable, I think the ONLY important research is into the causes of cancer, treatment of cancer and the hope of extending life. Sorry | R | |
| | If we move away from the medical model, what is the most important issue for PABC? (persons affected by cancer) | H | |
| | How to improve the experience of cancer as a chronic disease? | H | |
| | Genetic | H | |
| | How near are we to a cure for non hodgkins lymphoma | P | |
| | How will my health be affected in the long term? | R | |
| | How does the health workforce need to be developed and supported to better serve an ageing population? | H | |
| | Length of life | H | |
| | Will cancer ever be eradicated completely | H | |
| | Surgical intervention as management for cancers which cannot be cured | H | |
| | Is research being done on JAK2 mutations and PV in young people? | R | |
| | Are TKIs viable long term ie 40/50+ years | P | |
| | What are your main symptoms | H | |
| | What is the lasting impact of having a cancer diagnosis and surviving it? | H | |
| | What does surviving cancer actually mean? | H | |
| | What is the expected life expectancy of a man diagnosed with hodgkins lymphoma at 16 if he has been in remission for 10 years. | U | |

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| | What are the long term effects of different cancer types on communication? | H | |
| | Why don't some children return to normal eating and drinking after treatment has finished? | H | |
| | What support do children need when they're returning to school? | H | |
| | What do people who are living with and beyond cancer consider to be most important to them? | RH | |
| | Progression rate and life expectancy. | P | |
| | How to help patients who survive cancer - we currently don't offer any survivorship programmes | H | |
| | what information do patients want | H | |
| | are they still accepting of dietary advice post treatment | H | |
| | How to properly assist BME communities? | O | |
| | Why do so many Doctors want to focus on extending life as long as possible? Many seem to regard this as their measure of success, I feel more emphasis needs to be given to quality of life. There has to be a limit to how many drugs can be afforded never mind tolerated. | P | |
| | what interventions exist where no harm is possible but benefits may exist (which are yet unquantified)? Can these be readily communicated to patients? E.g. use of eye mask for sleeping, use of turmeric. | P | |
| | Specific type of input people would find most beneficial | H | |
| | How will this affect our relationship? | RH | |
| | what are the most important aspects of care for people living with and beyond cancer? | H | |
| | What are the factors that enable people to have a fulfilling life during and/or after cancer treatment? | H | |
| | What is the best way to support people with cancer and their relatives - not just in relation to the treatment but to the emotional and financial advice/support they may need. | P | |
| | When I was told that I could wait for the surgeon to have their summer holiday before I needed my surgery, I couldn't help wondering at what point a cancer will start to spread as opposed to not? I always felt my cancer could well have decided to go walkabout while the surgeon took their (perfectly entitled, I'm not complaining about it) leave. Thankfully, it didn't. | P | |
| | Are patients yet acknowledged as their own carers? I caused much head scratching and dissent when i insisted i was my own carer too... | P | |
| | Relationships. | RH | |
| | Continuous investment in research to help improve outcomes for recurring cases. | P | |
| | A year after finishing chemo still not feeling well. Tired and having breathing problems had chest X-ray and that was fine. Was diagnosed with bowel cancer. | P | |
| | Why not listen to patients - and find out from us people who have bothered to find out how to help us. As far as I know, the doctors whom I mention above receive no help in funding their extra research to undertake to help us. | P | |
| | there needs to be more focus on rarer cancers but because there are nto many people who come forward due to it being rare, does this prevent research in these areas being a priority | R | |
| | Why do your follow on questions exclude people with MPNs [leukaemias] because of the way they are framed? | P | |
| | Why is it that people are not put forward for trials | P | |
| | What are the interventions which will help people live well on immune and targeted therapy | HP | |
| | Why are some cancers so underfunded when it comes to research | P | |
| | Another consequence of having radiation to my neck has been a jaw spasm with severe pain. At times when my salivary gland is stimulated with the sight and smell of lemon or chocolate the signal gets confused to a motor nerve response to cause cramping. Yawning can have the same effect. The pain is acute but fleeting, lasting around a minute. | PR | |
| | I would like to know why are there no accurate statistics for long term survival for Ovarian cancer in Wales,? | P | |
| | Why is sclc not researched has much has nscl there seems to be a lot more for nscl than there is for sclc | R | |
| | How can people LWBC be more involved in decision making about their care / treatment? | H | |
| | How to manage the long-term effects of treatment | H | |
| | 'Curative' treatment for brain tumours which leave patient disabled and the family as significant carers, but the patient's condition stabilises. What is the wisdom in living people with a fate worse than death? | H | |
| | Exercise and MND [motor neuron disease] | H | |
| | How can the mid and long terms effects of cancer treatment be prevented? | PR | |
| | What are the patient information needs of people being treated for a chronic blood cancer as out patients on a long-term basis with novel oral agents e.g. ibrutinib ? The toxicity profile is significantly different to chemotherapeutic agents & presents challenges in terms of managing people at home. | H | |
| | GP's, oncologists and nurse dont talk to one another if the patient going across regional boundaries. thats terrible. Patient notes. communication. knowing what drugs are on etc. awful. why? | R | |
| | Dry Mouth after H&N treatment | P | |
| | Swallowing difficulties after H&N treatment | P | |
| | How can professionals better understand the patient's experiences and perspective? | H | |
| | Will a cure be found for my particular cancer | P | |
| | What is my life span expected to be | P | |
| | From the moment I was diagnosed with cancer I had very good treatment | P | |
| | Why does womb cancer not get more publicity/ it's own awareness day? It is the 4 most common cancer in women. | P | |
| | How can we get more holistic therapies such as nature/garden therapy, therapeutic yoga, mindfulness higher up the agenda of "treatments" beneficial to individuals LWBC and their carers | P | |
| | How can I help current and future patients recover from there operations Oesophagectomy | P | |
| | How can we make sure people don't start smoking in the first place? | R | |
| | How can we make sure that there's less prejudice towards lung cancer sufferers? | R | |

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| | I was diagnosed with cancer of stomach after complaining of burning pain in the stomach for a week. The pain was worse after a meal or a snack. I tried to treat myself by drinking milk and gaviscon because I thought I was developing ulcers. I suffered from stomach ulcers a long time ago. | P | |
| | I went to the GP. From my complaints and other medical history the GP decided to send me for investigations. Endoscopy and CT scan. The results were bad and shocking. I thought that was the end of my life. I imagined all sorts of things including suffering from pain, death and my funeral. I also thought that there was a mistake in the diagnosis. The stomach was inflamed and cancer on a tumour. I was put on antibiotics to treat the infection first then referred to Cancer specialist team. | P | |
| | The consultant surgeon who was going to treat me explained very well the state of the cancer and how I will be treated. This raised my spirits and hope. I developed a positive attitude towards the treatment and my life. My family was there for me throughout the treatment up to now. | P | |
| | How do people cope after a diagnosis of melanoma | H | |
| | That G.P. surgeries investigate anyone with long term indigestion problems and use of cyto sponge or something similar in the surgery setting. Especially people routinely prescribed medication for indigestion over a long period of time. Regular checks on the condition of their oesophagus should be performed. | RH | |
| | all my questions have been answered by my excellent medical team | P | |
| | Given there can be terrible "consequences of treatment" what efforts are being made to understand them and to reduce their occurrence and impact? | P | |
| | Research seems to be ongoing across many areas but I | PRH | |
| | Why do you not believe that colonic resection for colon cancer can induce diarrhea? | H | |
| | How can quality of life be improved? | R | |
| | The ongoing side effects of treatment. | P | |
| | More help with research | P | |
| | Why did I get Cancer | P | |
| | Peg feeding and provision for it in socially acceptable places | P | |
| | These types of cancers to appear in more formal forms showing lists of cancers | P | |
| | Awareness of such cancers needs raising as a matter of urgency. | P | |
| | fertility | H | |
| | when I left school with 2 A-levels in biology and chemistry I became a Junior medical Laboratory Technician. I first did a Pre -HNC course in Medical Laboratory Sciences | P | |
| | When I completed this which involved spending 6 weeks in each of the medical health subjects I went onto to gain and complete a HNC in Med Lab Sciences in Histology and Cytology. | P | |
| | I was preparing to get married and changed to work in a Microbiology Lab in | P | |
| | Why do you get a Jak2 mutation and can it be treated? | R | |
| | I want my data to be used for research. I don't want bureaucratic bottlenecks to prevent my data (tissue / health records / genealogy / address for re-contact) being passed to researchers. What simple methods can be introduced to provide a conduit between willing patients and researchers? The bias of self-selection is not appropriate to consider when EHRs and genetic material are being studied. | P | |
| | Have services improved for people living with and beyond cancer | H | |
| | There isn't anything I haven't been able to find an answer for! | RH | |
| | I am under 4 different consultants - more at times. I would be great if they could all be advised of what the other is doing so my care is considered and consistent. | PH | |
| | Why is it difficult to be early | PR | |
| | This is in hindsight; I believe Zoladex shouldn't be prescribed for patients who have, or have had depression. Why isn't this asked as a part of the decision-making process? | P | |
| | How can a patient manage a cancer diagnosis? | P | |
| | What are the interventions that support physical and psychological wellbeing proactively, including those that support building resilience and self care | HR | |
| | Why does the NHS run a fleet of buses rather than ambulances between hospitals. this would be cheaper for cancer patients and the hospitals themselves. | H | |
| | Therapy for after effects after treatment. | P | |
| | How do we cure metastatic cancer? | P | |
| | All my questions have been satisfactory although I did feel that some questions should not be necessary to ask! | P | |
| | Ever since my cancer diagnosis, I'm poor at regulating my temperature. I get too cold before my colleagues and I get too hot before my colleagues - as though I have only a very narrow window of temperatures over which I'm comfortable. | P | |
| | long term/late effects of treatment , both radiotherapy and chemo therapy and how to manage them, what to look for | H | |
| | A clear statement on life expectancy | P | |
| | Is the life expectancy of someone that has had cancer significantly less than that of their peers? | P | |
| | The impact of a cancer diagnosis in children and young adults/teens can be devastating for parents, siblings and immediate family. But there can be far reaching and long term psychosocial consequences for close friends of the patient. How can the wider network of friends and family be better supported? | H | |
| | More robust evidence about long term effects of cancer treatment and how to manage them. | H | |
| | How do we get rid of the stigma around cancer when compared to other illness conditions which are equally as serious but treated differently in popular culture | PRH | |
| | Why are relatives not tested regularly to see if they have cancer | R | |
| | Everyday diet, what to and what to avoid | P | |
| | Does having goals help people to think more positively moving forwards or do goals make people fear failure to reach them and therefore don't set goals for what they really want but only those they know they will achieve. | H | |
| | how can you prevent lung damage by the treatment | P | |
| | Why is NHS chary of making a clear statement of follow-up in years after diagnosis and first treatment of ACC? | R | |

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| | the use of kinesiotape in pain and posture reinforcement within cancer patients-I had a case whereby a female had developed a kyphosis from no particular cause, attempted to use tape to positively reinforce the correct posture and engage muscles as it was affecting her use of her diaphragm and more importantly to her, body image. | H | |
| | Mechanisms to cope through the illness. | H | |
| | Why are patients sometimes told not to look up research and use the internet? | P | |
| | How can we minimise long term side effects of cancer? | H | |
| | Why do cancers present at an advanced stage in the UK ? | P | |
| | Why me? | P | |
| | Is there a gap between what the patient actually requires and what health professional thinks the patients needs to support the patients living with and beyond cancer? | O | |
| | When is the best time to attend an event, does this vary by site and or diseases stage | H | |
| | I was shocked to discover that my mother's lung cancer was so rare there was no specific treatment for it and no clinical trials. | R | |
| | Do oncologists discriminate against old people? | R | |
| | How does the NHS manage to cope & Care for the ever increasing amount of cancer patients? Marvellous! | P | |
| | When a cancerous tumour is removed how then does it spread to other organs or parts of the body? | H | |
| | which tests are available after cancer treatment | P | |
| | How are doctors trained appropriately to meet need and address what's important to patients | RH | |
| | Secondary breast cancer. | P | |
| | What better research there's is | P | |
| | How important is occupation and what does that mean to patients and carers ? | H | |
| | How has living with cancer improved over the years for patients? | H | |
| | Can't we stop the body from producing mutated cells once we know it is cancer? | R | |
| | How to help bloating and flatulence | H | |
| | How to cope with the effects of a mentally stressed partner | PR | |
| | How can information about clinical trials be best disseminated so that all relevant cancer patients are informed? | PR | |
| | Effect on other lifestyle issues- e.g. exercise, personal relationships, fatigue. | R | |
| | What is the best way of supporting patients living with incurable but treatable & asymptomatic breast cancer? | H | |
| | How can we best manage the side-effects of endocrine therapy in early breast cancer patients to ensure compliance, improve quality of life & overall survival? | H | |
| | Confronting the seemingly universal heteronormative assumptions endemic in Health provision | R | |
| | What support should be available 2 years + post treatment? | P | |
| | After treatment LWBC support is currently held in the hospital Can it be considered to offer support sessions in regional hubs, possibly Church or Community Halls which have facilities such as toilets for disabled and cafe facilities? | PRH | |
| | Can it be considered to have peripatetic Advisory Staff visiting Health Hubs on once a week, fortnightly or monthly visits to meet OUTSIDE of the hospital premises in such a Health Hub?. Can such peripatetic advisors answer specialist questions about symptoms and what to expect regarding surgery, physical recovery, radio therapy, chemo, effects on diet, dietary advice, financial advice Can there be regular visiting speakers and sessions run by specialists for gentle exercise, nutrition, skin care, and those coping with financial implications, stress, anxiety, loss and isolation. Body and Mind therapies CBT Alexander Technique Reflexology Cranial Sacral Acupuncture, Massage Reiki/Healing, Mindfulness, CBT, Counselling | PRH | |
| | Can there be hobby/interest groups such as Discussion groups, Writing,Music, Art, Craft, Needlework, Cookery such as The Cheat's Guide to Quick Fix meals for those with low energy but still have responsibility for running the home. Many of which would find purpose and fulfilment in fundraising activities. | PRH | |
| | It would be good to find out the quality of life cost in order to gain a few extra months...would it be better to go for quality rather than quantity | H | |
| | If over 80% of those diagnosed with a primary brain tumour die within 5 years, why has research into brain tumours been given such a low priority by the NCRI and larger cancer charities? | R | |
| | If brain tumours are the biggest cancer killer of children and young adults under 40 yrs old, why is so little being spent on research by the Government and larger cancer charities? | R | |
| | In a recent report on recurrence it says cancer can lie dormant for years. What is the plan for those who have already gone through this hideous disease? | P | |
| | What outcomes matter most to patients living with and beyond cancer? | H | |
| | Please look at all the projects/questionnaires already started in France by this organisation - they seem to try to answer what I feel I would like to know https://www.seintinelles.com | P | |
| | What reduces Chronic pain? | H | |
| | Better Chelation therapies | P | |
| | Faster access to drugs | P | |
| | Better and greater research into low risk MDS | P | |
| | Having lost both mother and father to metastatic cancer - father to prostate and mother to breast- how close are you to finding a cure and what advances have been made? | P | |
| | Exercise is so important | P | |
| | Eating well | P | |
| | Accessing personalised information and continuity of care | RH | |
| | Why are we offered support with counselling but never any feedback with our concerns? More upsetting than anything | P | |
| | Are there any new developments for the treatment and cure of cancer | P | |
| | what defines, if anything, a cure | P | |
| | Support for the patient once discharged with long term side effects from the cancer treatment | P | |
| | Managing longer term treatment effects | R | |
| | management of breathlessness | H | |
| | management of cachexia | H | |

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| | Is there any less invasive ways to find microscopic traces of cancer? | P | |
| | What kind of tests can be carried on eventual metastasis? | P | |
| | What is the best way to improve continuity of care in GP practices with several doctors? Unless I am willing to wait weeks for an appointment I never see the same doctor twice. | P | |
| | How can we prove efficiency and effectiveness and influence future care. | RH | |
| | How are ethical decisions made regarding palliative care for people living with dementia as well as cancer | H | |
| | What do patients feel are the best resources to help them move forward living with and beyond cancer | H | |
| | My first experience when I was diagnosed was shocking.I have been through all my treatment which was not nice.It was breast cancer.Her2 positive.I am still recovering at home hoping to go back to work soon. | P | |
| | support group for young cancer survivors.? | R | |
| | Importance of not being overweight in relation to cancer | R | |
| | I had Breast cancer 22 years ago in Leeds I felt I was treated very well at LGL. I feel a lot of research is duplicated throughout the world and more should be done to monitored from a central point. | P | |
| | If more funding was available could more research be achieved | P | |
| | Psychological benefits of being in an interventional trial | H | |
| | Why cant doctors tell a patient how long they have left to live | RH | |
| | What percentage of persons who have experienced cancer will die of a recurrence of cancer or other conditions before the expected norm. | P | |
| | What is the effect of exercise on cancer survivors? | PRH | |
| | How can we reduce the cost effective in treatment of cancer ? | U | |
| | Can limb salvage methods be improved, to retain maximum muscle mass, so aiding post-salvage recovery and long term function? | P | |
| | Catheters are still causing damage to the Penis and uretheta wall and also constantly blocking after day surgery which creates a merry go round with the Ambulance being called and the hours in A&E and then time in a hospital ward with irrigation. Today's Catheter is virtually unchanged since the one I had in the London Clinic 17 years ago, what are the manufactureres doing in their R&D ? | PR | |
| | Why is there no comprehensive research into exceptional survivors, with a view to gleaning whether there are commonalities of benefit others, especially the exceptional early succumbers? | P | |
| | How important is exercise on the cancer journey | H | |
| | What is a pelvic sling, how is it fitted, how successful is it in preventing incontinence? | P | |
| | What are the best methods for coping with the physical effects of the condition before treatment, such as how to deal with the discomfort of swollen tender and painful lymph nodes? | P | |
| | How do the different treatment options for rectal cancer (surgery, radiotherapy, watch & wait) compare in terms of bowel function, sexual function and overall acceptability to the patient | H | |
| | How to identify accurately if cancer had metastasized? | P | |
| | The experiences and support of LGBT individuals with cancer | O | |
| | What prophylactic approaches can be put in place to prevent mortality or loss of quality of life caused by serious or frequent infections? | P | |
| Questions about causes of cancer | Can primary bone cancer be addressed through other site research? | R | |
| | Why do some people have multiple (different) primary diagnoses if there is no genetic cause at play? What does this say about their physical makeup, lifestyle etc? | P | |
| | earlier warning if different cancers are hereditary | P | |
| | Risk factors that can influence diagnoses, not necessarily genetic | P | |
| | Why did the hormone that triggered my NETS act in that way? | P | |
| | When will there be more research into sarcomas | P | |
| | What role does stress play in the development of cancer? | P | |
| | Why have I got NET | P | |
| | Does everyone have the ability to develop cancer | PH | |
| | Why did I get cancer? What genetic mutations were present in my cancer? | PH | |
| | Are there any particular foods that can cause cancer | PR | |
| | It is my personal believe that many viruses and maybe some rickettsias and such could be originating neoplasms. I would like to see more research on this matter. | PR | |
| | I am convinced my breast cancer was the result of too much sugar and excessive stress (2 years prior to my diagnosis) has no one ever researched ones lifestyle prior to getting breast cancer? | P | |
| | I've heard that drinking alcohol (as little as a Martini or glass of wine a day) can be a cause of breast cancer - is there any truth in this ? Also vegetarians are less likely to get breast cancer so meat is not good for us? | P | |
| | HOW HAS MY BLOOD CANCER HAPPENED | P | |
| | What research is taking place about living healthily's effect on cancers? | P | |
| | I would like research into my earlier diagnosis of Vitiligo, would this have been a sign of CLL in later years. | P | |
| | What causes a fibroadenoma to change into a phyllodes tumour | P | |
| | I am BRCA1 and have ovarian cancer. Why do some women have the gene and develop breast cancer, some ovarian, some both and presumably some do not develop cancer at all? | P | |
| | What caused my cancer to begin with? | R | |
| | If 2 parents have cancer, does this increase the risk, for the children of having cancer? | P | |
| | Improved risk predictions for an individuals change of getting a particular cancer | P | |
| | Do pesticides and additives in our food play more of a role in cancer than originally thought. | P | |
| | Gene information within families. | P | |
| | Gain a greater understanding of the role sugar plays in the cancer cell? | H | |
| | Gain a greater understanding with specific nutrients such as tumeric | H | |
| | what can cause secondary cancer | P | |
| | How it is caused? | U | |
| | Does stress cause cancer? | P | |
| | why does it happen | RH | |
| | Why did it happen to my husband? | R | |
| | Why did I, a person who hitherto had good health get cancer, was there something I did/didn't do? | P | |
| | What research is happening at the moment to answer the "why me" question. Could I have done something differerenty? | P | |
| | Is there a genetic reason I developed my cancer? | H | |

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| | How did I contract the disease & what advice is available to best avoid 'catching' cancer | P | |
| | What causes the DNA to mutate and could it be worked to mutate back | R | |
| | More research into oesophageal cancer and its causes, especially in younger people and reasons other than lifestyle. | P | |
| | What is the actual impact of the Pill on breast cancer? Why are people not made aware of it at the time when its so readily prescribed and even encouraged. | P | |
| | What caused my cancer? | P | |
| | Is my cancer hereditary? | P | |
| | I feel that I have always looked after myself and been health aware as a health professional and that I was given a HRT medication that triggered my triple negative breast cancer. I don't have breast cancer in the family except one cousin who had dcis. I feel when I mention this to nurses etc. It is dismissed. I only had one application of Gynest but it certainly fits in for me as I have never taken any hormones in my life prior to this. I feel this is a very dangerous product and could affect more women. Please look into this to prevent further devastation of lives. | P | |
| | I went through a very tough divorce and wonder if this contributed to me getting breast cancer? | P | |
| | My mother died of ovarian cancer aged 70; my maternal grandmother died of multiple myeloma aged 60; my maternal aunt died of lung cancer aged 73; my father died of lung cancer aged 78 after being cured of bowel and skin cancer. I am aged 57 and go for all mammograms and cervical screening when called. Am I at increased risk of getting cancer with my family history. I do not have any siblings. | R | |
| | What causes Brain Tumours to grow? | P | |
| | Does being overweight (rather than obese) increase your risk of developing a cancer? | H | |
| | Is there a link with the teaching profession and cancer? | P | |
| | Is there a link with neurofibromatosis and cancer? (I have nf, not sure if 1 or 2, less severe one and although being very healthy got oesophageal cancer) | P | |
| | Is there a link between excessive consumption of neat spirits e.g. brandy, whisky etc. in, say, one's twenties, and the development of Barratts Oesophagus turning into oesophageal cancer later in life? | P | |
| | What caused my cancer to develop and why? | P | |
| | Was it inevitable that I would develop cancer? | P | |
| | Is there a link in Lymphomas and PV? Can it be passed on genetically | R | |
| | Cause of disease. | P | |
| | Looking at the genetic links and familial risks | H | |
| | Genetic links and risks. Bowel cancer at 39 lots of family history but tested negative for lynch so told not genetic. But I think that it may be a different gene defect that is not identified so could my children still be affected | P | |
| | How soon will it be possible to get an answer on if familial CLL is genetic and could be tested for? | PR | |
| | Is any research being undertaken to find out if there could be a link to the development of brain tumours in patients who have served in the armed forces? My elder brother and I were diagnosed with similar brain tumours; he died as per his prognosis e.g. 12 months. He served via NAAFI with the Royal Navy for 30 years. I served for 8 years with the Royal Navy and 22 years as a Reservist. | P | |
| | I would like to know if there was anything I could have done or avoided that would have led to me NOT getting cancer. | P | |
| | What triggers a cancer which has reached NED on scans to start growing again? | R | |
| | How do brain tumours begin and what causes them? | R | |
| | What caused my cancer? Was it stress, smoking, diet, lifestyle? | P | |
| | Does diet or lifestyle contribute to getting cancer? | R | |
| | can we build up more information on pre-malignant disease to reduce the burden of cancer | RH | |
| | Dietary advice | P | |
| Questions about diagnosis | How can prostate cancer be more accurately identified? | P | |
| | Are there improvements in diagnosis which can be offered to people who have been diagnosed from scans but have no biopsy results available because of location of the tumour? (eg brain and upper gastrointestinal tumours) | P | |
| | Can more support be given to educating GPs in detecting at an earlier stage the first signs of cancer. | P | |
| | Early Diagnosis | P | |
| | More accurate and quicker diagnostic process. | P | |
| | I was miss-diagnosed as having Mantle Cell Lymphoma and treated as such, receiving CHOP chemotherapy. It only transpired that I had CLL after moving and then being re-diagnosed at Mount Vernon Hospital. They could not understand why I was still alive after more than 10 years. I am still alive after 16 years but my experience with GP's has generally been disgusting. Should they have more training in recognising potential cancerous conditions? | P | |
| | In my experience the symptoms of CLL were/are unknown at the local GP level. Why is the diagnosis of CLL so difficult, I.E. why aren't blood tests compulsory at a shingles diagnosis. | P | |
| | How can diagnosis be speeded up | R | |
| | Would PET CT scans be helpful in diagnosing cancer of the stomach? | H | |
| | In people with brain tumours can accelerating diagnosis reduce the risk of progressive brain damage? | RH | |
| | When will an early detection method be produced for pancreatic cancer | P | |
| | When will G.P.s be quicker in diagnosing pancreatic cancer | P | |
| | When did it first appear? | U | |
| | Why couldn't You find out sooner? | U | |
| | Are there any other ways of diagnosing the presence of cancer more accurately | P | |
| | How can lymphnodes be checked for signs of cancer spreading without surgical removal first. | P | |
| | is it genetic and can you be tested | RH | |
| | What training is given to GP's to diagnose Cancer. I hear of many cases where people have been misdiagnosed | P | |

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| | Why does diagnosis of pancreatic cancer often happen too late for treatment? Where in the diagnosis pathway is it going wrong? What needs to change in the diagnosis pathway to enable early detection such that more patients can access treatment and improve the odds of survival? | R | |
| | Are paraneoplastic syndromes under diagnosed? | P | |
| | Why does many GPs not recognise symptoms of bowel cancer and make referrals for further investigation? | P | |
| | How to diagnose brain tumours earlier (rather than only when a seizure or other major symptom occurs) | R | |
| | How to get an early diagnosis. | R | |
| | Why wasn't my Neuroendocrine cancer (NETs) sooner? Although the symptoms were present for years, it eventually needed emergency surgery to save my life. Now I will live with the consequences of metastatic cancer for the rest of my life. | U | |
| | When the diagnosis was made my one fear was a partial oesophagectomy. It is important that symptoms are believed and an early diagnosis is made in order to avoid major surgery. Can research produce a more refined test for the diagnosis of adenocarcinoma of the oesophagus? | PH | |
| | To stage cancer more quickly | P | |
| | Find an early detection test for pancreatic cancer | P | |
| | Why isn't cervical screening offered to females from as soon as possible from the date they are sexually active? | P | |
| | I had a scan on my breast, which showed a fibroglandular growth. Why is it that I've had to turn to google for answers as to what this is? And secondly, why are the no follow ups for this despite a history of breast cancer in my family. I've not been offered genetic screening either despite my maternal grandmother being young when she was first diagnosed and I still have a lump in my breast. | P | |
| | When will there be an alternative to bone marrow biopsies in order to diagnose and stage Lymphoma? An alternative to trephining would be very welcome! | P | |
| | Differences of a diagnosis in childhood and adulthood | H | |
| | Has any research been undertaken to find out if the onset of a brain tumour could be picked up during routine eye check ups? Prior to my sudden illness; during a routine eye check up an Optician, he noticed something at the back of my right eye, which he was concerned with. He didn't know what it meant, so made a referral to the NHS for a specialist check up (Preston Hospital). At my hospital appointment, the person who conducted the check up identified something that concerned him and had to leave the room to consult with someone else. I was subsequently given an appointment to see a specialist. Over the following several years the appointment to see the specialist kept being cancelled at short notice! A few days prior to the onset of my first tumour, my wife noticed a yellow substance appearing from the tear duct of my right eye. As a result of the above, I do wonder if the potential development of my brain tumour could have been picked up at a far earlier stage. | P | |
| | Did you feel your GP was well-informed about your genetic disposition to bowel cancer? | H | |
| | Why are links between endocrinology and cancer not explored or strengthened: certain small details of people's medical history could provide clues or relevant information but don't seem to be explored routinely at all. They aren't captured as relevant to allow further research and that feels like a trick is being missed in terms of finding more early warning signs. | R | |
| | Better understanding of how early detection of kidney cancer can be achieved. It's diagnosis often happens once it's spread. | R | |
| | As my cancer was discovered by screening (I have a BRCA2) but I had no symptoms yet had cancer in both breasts - my concern going forward is that people like me have a higher risk of other cancers too but there is no screening for anything other than bowel. Therefore my question is - 'would people like me benefit from a whole body scan at perhaps 2 yearly intervals'. If so what type of scan would be most useful. | PR | |
| | Would early diagnoses and prognoses be improved by full body MRI at primary cancer diagnoses? | PH | |
| | When will an early diagnosis test be developed for pancreatic cancer. | P | |
| | Do those with a caring role present later with their cancers? and if so how can we support carers better in a time when carers are getting older in an ageing population. | RH | |
| | How can we improve early detection of cancer? My cancer was not identified until it was locally advanced. Should we start to be tested routinely for various cancers using circulating tumour cells? | P | |
| | My GP mis-diagnosed my case as a slight infection- once pushed for an MRI, cancer of the neck was found. Why is there no point of call for GP referral for scans? | P | |
| | Early diagnosis | P | |
| | why there are so many cases diagnosed at advanced stages of cancer? cause of late diagnosis Why there's such a high threshold for cancer suspicion for teen agers? and therefore delayed requests of diagnostic investigations ? | R | |
| | Why are people at high risk of cancer not tested before it's too late ? | R | |
| Questions about end of life care | Does referral to palliative care services prior to symptom development improve people's end of life experience? | RH | |
| | How much does a professional's own death anxiety prevent them from discussing death and dying openly with patients? | H | |
| | How can we identify "high risk deaths" in palliative cancer patients so that steps can be put in place to reduce this risk? | H | |
| | What are the advantages and disadvantages of planning the future content of their funerals with patients? | H | |
| | When doctors "say" you have X amount of months to live. I do not believe that doctors do know. Neither do I believe that doctors should try to hide how long the end of life will. I believe they should take time to ask what the patient would like to know. Not trying to hide it if by not giving bad news before Christmas etc. Patients & their parents are not stupid. | R | |
| | How can end of life pain be reduced for all cancer patients not only those fortunate enough to get hospice care? | P | |

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| | What is the criteria for treatment to move to Palliative - Pain relief only care. It sometimes seems to be the easy option taken by oncologists. Whilst my husband was in Guys Hospital with advanced prostate cancer, there was another man in an opposite bed with throat cancer, we heard his family being told exactly the same as what we had been told, palliative care, reasons why etc etc Different cancer but same words and explanations. We were astonished. Sometimes it seems the oncologists give up rather than the patients....The moment you take away hope and go to pain relief only, it is little wonder the cancer is allowed to spread and become terminal. Palliative care assisted suicide but with pain. | R | |
| | How to overcome professional death anxiety so they can talk more openly about this with patients? | H | |
| | How often to oncologists use euphemisms for cancer and death and what is the impact on patients and families? | H | |
| | How to deal with grief after losing a loved one to cancer | R | |
| | When a cancer patient is diagnosed as terminal, what support services should be offered to their carer? | R | |
| | Should there be more support available for families of those who have lost someone to cancer? This includes all types of support from help with wills and paperwork, emotional support to help with maybe moving/ downsizing etc. | R | |
| | How will I know that doctors are offering me the best possible end in terms of pain and comfort | P | |
| | It's really important to me, that I don't die in pain. My question would be. Would you prefer at the end of your life, to be spared a painful death? | PR | |
| | Do bereaved carers want to support other people facing loss and does it help with their grief? | H | |
| | What is the best way to support elderly people who choose to remain at home without treatment for a terminal cancer diagnosis? | PR | |
| | How can we reduce unnecessary hospital admissions for patients reaching the end of their life? | H | |
| | Dying with dignity as a general question but also with specific emphasis for LGBTX people | R | |
| | How do we improve access to healthcare for those with terminal diagnoses? (On a diagnosis of 2-3 months to life, we were still told the only avail GP appoint. Was in 10 days - all we wanted was a referral letter to a different hospital) | R | |
| | Counselling for terminally ill patient | R | |
| | Counselling for family once patient is deceased | R | |
| | Support for loved ones after a cancer patient has passed away | R | |
| | Counselling for a terminally ill patient | R | |
| | Many cancer survivors are elderly. What should we be considering as they move towards non-cancer-related end-of-life care from a position of living-well-with-cancer, especially when late recurrence is frequent cause of death? | P | |
| Questions about cancer prevention | What interventions should education in schools be including to ensure a healthy future generation in their older age | PR | |
| | How can the risk of my children being affected by the same cancer be reduced? | H | |
| | How could I have prevented my cancer? | H | |
| | If I am genetically programmed to have cancer mutations/family members who died with cancer are there steps I can take to lessen my chances of getting cancer again? | PR | |
| | What can my blood relations do to reduce their chances of having my cancer if it has a genetic component | P | |
| | I am BRCA 2. It would be good if when my relatives were screened for this genetic mutation there was then something they could do - other than radical surgery - to reduce/negate their risk developing ovarian or breast cancer. | P | |
| | What risk do my blood relatives have? What can they do to prevent cancer developing? | PH | |
| | Much is done to alert parents to the dangers of the sun on children's skin. Adults must also be alerted to the seriousness of sunbathing without protection. How can this be achieved when many still think a brown body is a healthy one. | R | |
| | If we all regularly took immune boosting medications would this prevent cancer | P | |
| | Which alternative or complementary therapies help to keep cancer at bay | PR | |
| | Why is there not more emphasis on prevention and support in the NHS in order to prevent or minimise life limiting conditions generally, and cancer in particular, surely in the long run it would save money? | P | |
| | Why is there not more education regarding the link between obesity and cancer | PR | |
| | In general why is there not more education about cancer in schools | PR | |
| | Why is the information emphasis put on care rather than prevention | PR | |
| | What could have prevented me developing cancer? | P | |
| | For women at high risk of ovarian cancer (with brca mutations) would removal of the fallopian tubes once their family is complete allow them to safely delay removal of their ovaries until they were menopausal? | PRH | |
| | Why are there not more prevention drugs for cervical cancer | P | |
| | Vaccine for children of melanoma patients, is that possible? | P | |
| | Prevention - more general health education - all ages | P | |
| | My relative does not smoke, lived a healthy life and has a healthy diet, yet got diagnosed with lung cancer. How is this possible, how can we help ourselves? What kind of prevention protocol can we follow? | R | |
| | If prevention is better than a cure, effort should be put into prevention | P | |
| Questions about cancer treatment | What is the likely progression of my NETS with Lanreotide injections? | P | |
| | How long will the Lanreotide work in slowing down NETS? | P | |
| | Is being given a poor prognosis a 'self fulfilling prophecy'? If you believe that your going to die in one year for example does it make it more likely to happen or is death or time out of the patients control? | P | |
| | Immunotherapy seems the way forward for some cancers, given that such drugs are not currently available (to me), what can I do, or who can help me improve my immune system as much as possible? NB, I might have my wires crossed here!! | P | |

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| | Will my hormone treatment (e.g. tamoxifen or ovarian function suppression) work for me? Is there any way to tell if I will benefit personally (I am aware that for a given group of women the ones who take treatment live longer and have less recurrences than those who don't BUT the drugs don't work for everyone). Could we be looking at e.g. genetic testing to see if there are commonalities amongst the women who live longer after (in this example) a breast cancer diagnoses. | P | |
| | Will there ever be a treatment to get rid of cancer | R | |
| | What is the level of life expectancy after the initial forecast has been reached i.e. 75% chance of living 10 years? What happens once the 10 years has been reached, as you have been discharged from the oncology department by then. Ids life expectancy then back to the normal levels? | P | |
| | How to measure any improvement in length of life (after palliative chemo for STS) and balance this with toxicity of treatment | H | |
| | Does treatment for cancer - chemotherapy and radiotherapy - whilst treating the cancer- ultimately shorten your life | R | |
| | I would like to know how far we are from curing all types of cancer | P | |
| | What is life expectancy according to how many years I have been cancer free and the type of aggressive tumour I had? Current statistics seem too simplified. | P | |
| | Identify effective therapeutic targets in sarcoma | RH | |
| | Alternatives to chemo that could be available | P | |
| | What's my life expectancy | P | |
| | What is the scope for the use of immunotherapy in papillary thyroid cancer? | PH | |
| | Is exercise beneficial for brain tumour cancers? | O | |
| | How can treatment of cancer be personalised? | P | |
| | whether a person's attitude to life has an effect on their survival rates | H | |
| | What are the benefits of taking cannabinoil as a natural treatment (non-pharmaceutical) to assist with pain reduction, improve sleep and contribute to treating cancer ? | P | |
| | Access to information about your cancer treatment and options appears to operate on an individual location basis. How can it be fixed so that everyone receives the same information and support irrespective of where they live? | P | |
| | Whilst I appreciate the professional concern about giving estimated life expectancy and the many variations, the most prudent and concerning problem is estimation of the remaining life span following diagnosis. | P | |
| | Realistic choice of treatments available. | PR | |
| | Other than tiredness and night sweats, I would not know that I have a CLL problem. Is there any likelihood of reversing the white blood cell problem that is the root of the diagnosis ? | P | |
| | What effective treatment for myelodysplasia? | P | |
| | What psycho-social barriers might there be to people accepting or being fully compliant with active treatments e.g. distance from the treatment centre, social support, finances? | H | |
| | WILL THERE EVER BY EARLY TREATMENT FOR PATIENTS WITH CLL STAGE A | P | |
| | Incurable cancers like leukaemia, how important is cost in the final decision on treatment. | P | |
| | Why are some cancers given such low priority for treatment | P | |
| | How can the haematologists provide a clear explanation of the survival statistics in relation to the patients personal condition? As opposed to bland assurances! | P | |
| | Well obviously I would like a cure | P | |
| | Is ongoing TSH suppression necessary for patients who have been successfully treated for thyroid cancer? | H | |
| | What is the evidence that improved psychological wellbeing extends the life of people 'recovering' from cancer? | H | |
| | what is the effect of multiple drugs for comorbidities on the effectiveness of primary cancer drugs | P | |
| | Is the period between initial visit to a GP and the diagnosis of cancers reducing? the diagnosis for Multi Myeloma took much too long and Was once attended to after my wife fell for the second time and s call to 111. In hind sight I should have called 999. I did not do so as the NHS was stretched. This was a STUPID move on my part I will not hesitate in a similar situation in future. NOW THE GOOD NEWS: After a month in hospital which could have been avoided by the GP who had not seen the disease before and two relatively short series of anti Myeloma chemo by mouth we are now on series 73 of 21/28 Lenalidomide. | R | |
| | What progress has been made with some of the rarer cancers e.g. pancreatic, brain etc.? What advances have been made for targeted treatments to these areas? | P | |
| | Have there been any advances made in the treatment of this cruel insidious disease. It so often shows no symptoms until advanced. | R | |
| | How many women diagnosed with oestrogen positive breast cancer go on to have a baby after treatment ends? And what are their survival rates? | P | |
| | Will there be more research into Lung Cancer? Still one of the most common of disease sites with big mortality rates. | H | |
| | Supportive therapies at home or in the community. For example a lot of metastatic patients need blood transfusion support when having chemotherapy. This causes a lot of anxiety re: missing chemo and where the patient can have their blood transfusion. | H | |
| | How to down stage pancreatic cancer, so that the patient may be operable. This will relate to patients with locally advanced pancreatic cancer. | R | |
| | How to treat metastatic pancreatic cancer, particularly in the liver. | R | |
| | Innovative ways of managing and treating stage 4 cancer; there seems to be a very fatalistic (understandably) view about it and this often seems reflected in the treatment options or rather lack of them. | P | |
| | If every cancer patient was given vitamin D supplements, to a high level, would that increase survival? | P | |
| | In people with brain tumours will drug delivery systems augment the effectiveness of the currently ineffective drugs? | RH | |
| | A cure for mds is needed, other than a bone marrow transplant, for the elderly. | P | |
| | There has been some recent laboratory research into the efficacy of using cannabis oil after chemotherapy - to help kill cancer cells. Would like to see some patient trials next. | R | |

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| | When best to have chemo after surgery | P | |
| | When will more research be done into pancreatic cancer to give better survival hopes | P | |
| | Life expectancy after cancer | P | |
| | My prostate cancer had progressed beyond the capsule, and was not completely got rid of . So following a prostatectomy and targeted radiotherapy I still have a slowly increasing PSA level. Is there any research being carried out into a treatment that will ' mop up' these rogue cells? | P | |
| | Most importantly I'd like to know why conventional cancer treatments like chemo, radio and hormone therapy are the only treatments available on the NHS? This in preference to developing, or in some cases returning to, natural cures and/or treatments that historically have been documented to successfully help fight cancer.... | P | |
| | can it be reversed/managed /eradicated naturally | RH | |
| | What is the prognosis when you don't complete the number of chemo cycles due to side affects. | P | |
| | This was my second bout of chemo fOr CLL Will there be a 3rd. Is there anything I can reasonably do to help prevent chemo for a third time? Many thanks! | P | |
| | To what extent has life expectancy been affected by the cancer and subsequent treatment? | P | |
| | More information about the effects of malnutrition on mortality/dose toxicity for specific cancer types | H | |
| | How likely are changes in my life style such as increasing exercise, losing weight, reducing stress, etc going to affect my chances of surviving additional years? | P | |
| | For women facing a much higher risk of breast cancer as a result of Hodgkin Lymphoma treatment in the 1980's (suggested to be as high as the risk of someone with the BRCA1 gene), would preventative mastectomy be beneficial to their outcomes? | HR | |
| | How long does the hormone therapy control the cancer and what happens when it begins not to control it? | P | |
| | Research into Immunotherapies for people with pre-existing auto-immune disease who are diagnosed with Cancer | P | |
| | Why is UK survival rate post cancer worst in Europe? And don't pull wool over our eyes - WHO says we have a good record re asking for tests if we suspect we have cancer, so what is it about our treatment that gives us such a poor outcome? | P | |
| | I am an 81 years old male diagnose with localised prostate . I have received hormone injection at 3 monthly intervals for the past 9 months. I also commenced radiotherapy at the outset but this was put on hold after just one treatment due to other health issues (AF) which are still to be managed effectively. Q. Will the latest research results give an indication that, in my case, continuation of rt for 20 days may be safely be avoided? | P | |
| | Is there a future for intravenous chemotherapy? Will it be something that is looking to be eradicated by pills/surgery? | P | |
| | For Sarcoma patients there seem to be huge variances in how the USA and U.K. treat the disease. As not much is spent on research of this cancer surely it would be beneficial to consolidate treatment protocol? | P | |
| | The outcomes of patients with meningioma and other low grade neurological tumours, compared against many other cancers, are poor. Can the burden be better recognised? How can it be reduced? | PR | |
| | Why does the treatment for what seems to be the same cancer (and also its effects) differ so much from NHS Trust to NHS Trust - the end result is that two people can have completely different treatments. | P | |
| | what are the treatments for future recurrences? | P | |
| | Life expectancy following RC | R | |
| | I would like to know why health professionals are tied to "1st and 2nd line treatments when a patient is diagnosed with a rare form of disease, or one that differs from the norm. | P | |
| | Why has bladder cancer treatment been stagnant for many years and only just started to move on. And why are they so many different treatments for bladder cancer being used in USA ,Canada and other counties that are not tried in the UK. | P | |
| | Is there any chance of a complete cure for grade 4 cancer within the next 25 years | R | |
| | What treatments can be developed to address genetic syndromes, like Lynch? Again, the research that is being conducted in this field is not available to the public. | P | |
| | There is no protocol for the treatment of uterine carcinosarcoma research data needs to be collated and a protocol for patients derived. | P | |
| | Watch and Wait does not sound very proactive, I was told last year it was time for Chemo, all the tests were done, ECG/CT scan/Bone & Marrow biopsies etc, it was then decided to delay treatment. This is both scary and confusing for the patient, particularly for someone like myself whom has previously had Chemo and knows the effects. | P | |
| | How to treat brain cancers more effectively with drugs/chemotherapy | R | |
| | Is Proton Beam Therapy the way forward to cure cancers and brain tumours? | P | |
| | Is there a correlation between tumour marker reduction and exercise? | H | |
| | How to weigh up treatment options | R | |
| | How much benefit do I get from neoadjuvant radiotherapy in rectal cancer? | H | |
| | More accurate survival estimates? | P | |
| | What are the treatments available as the condition worsens and what would trigger the decision for administration of treatment? | P | |
| | Treatment for PV in a 30 year old person. It appears to be older people. | R | |
| | The treatment of lung metastasis in rare salivary gland cancers such as Adenoid Cystic Carcinoma. The NHS do not routinely treat lung mets but in ACC where they are slow growing, treatment with surgery or RFA should be considered. | P | |
| | What are the priorities for treatment from the patients' perspectives? | H | |
| | How can we improve the quality of decision making for patients with musculoskeletal tumours | H | |
| | Does meditation really help slow down cancer growth? | P | |
| | Is there any hope for control or cure for formation of ACC metastases in life after first treatment? | R | |
| | How (as a lay person) do you make the best informed decisions on your care? | H | |

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| | What is the lowest dose of treatment required to kill the cancer but minimise damage to other cells? | H | |
| | When first diagnosed my MRI, PET scan and CT scans marked 'urgent' came through for a week or 2-3 weeks hence. Had I not chased these up and got cancellations the next day instead, by the time I was operated on my fast growing tumour would have spread. How can clinicians determine whether a cancer is dangerously fast growing sooner? My biopsy results were still inconclusive some 4 week's post op. Eventually reported as dedifferentiated. | P | |
| | what difference does it make if I start treatment asap? If I wait an extra 28 days does that impact on my survival for different cancers ? | H | |
| | Were you given the option of new chemo therapies directed at Lynch Syndrome cancers? | H | |
| | When I was diagnosed with breast Cancer with secondaries from day 1 I was told I would live about two & a half years that's now 7 years ago! Have treatments improved that much or have I just been lucky??? | P | |
| | More person centred approach to treatment options | R | |
| | What are the treatment guidelines for kidney cancer , which drug and when. | R | |
| | Why, given that survival rates are improving, is no data published for those with kidney cancer surviving beyond 5 years. Given that unlike may other cancers, a five year threshold doesn't necessarily mean the patient has survived, data for longer survival times would give hope to newly diagnosed. | P | |
| | do you think metformin has a role to play in preventing cancer , and improving survivors in those with certain cancers (?ovarian) | PRH | |
| | What is the survival percentage for patients with my condition and how do these change as time progresses. | P | |
| | What effect does financial problems have on survival rates and how can I obtain advice. | P | |
| | Was it purely by accident that it was noted that there was a connection between prostate cancer and testosterone production? If so, could there be a more rigorous scientific approach to the problem that might produce an alternative therapy? | P | |
| | to find out how likely it is that the treatment would work | H | |
| | A year ago I had surgery to remove the lymph glands under my left armpit which were the first signs I had noticed of secondary melanoma - no primary was found. Having undergone that surgery I was asked if I wanted to have radiotherapy under my armpit. Upon asking my surgeon and the radiotherapy consultant what their recommendation was they both said that there was no definitive position on this. There was an old Australian survey which was inconclusive as to the benefits or otherwise of radiation so the decision was mine. I chose to have that radiation treatment but it would seem that further research should be carried out to determine the efficacy of that treatment | P | |
| | What are the main drugs that can help? | R | |
| | What is the best treatment? Still far too many unaddressed questions. | R | |
| | How much longer is life expectancy for melanoma patients, especially with BRAF gene mutation? | P | |
| | What is the most effective treatment? Triple therapy or hypobaric? I had triple therapy for 18 months, but it didn't work and I ended up having surgical treatment. | P | |
| | How many people living 10 years on with metastatic breast cancer? | P | |
| | is there a treatment that can be more effective than infusion of calcium to correct the calcium levels due to hanging cancer . | R | |
| | Why isn't everyone offered some kind of treatment to prolong there life ? | R | |
| | What treatments can be developed to address genetic syndromes, like Lynch? | P | |
| | How to predict who will be a chemo responder | H | |
| | Better identification of patients who will receive benefit from different therapies and those that will not. | H | |
| | Why Cancer is controllable in some patients and others not,despite similarities in illness,staging and treatment etc.What makes the difference. | P | |
| | Are all treatments post surgical intervention necessary e.g. chemo and radiotherapy? Who would and wouldn't benefit. | P | |
| | Would my survival odds have been very different if I had chosen not to have chemotherapy? Did I really need chemo, does it 'work'? | P | |
| | More targeted treatment | P | |
| | Can we produce an outcome prediction score based on individuals' performance status pre cancer treatment? | H | |
| | Targeted chemo | P | |
| | How can we determine which men diagnosed with prostate cancer need aggressive treatment and which can be safely monitored with a low chance of progression? | H | |
| | Why does some kidney mets respond to treatment and others don't. | R | |
| | My question is whether any research is planned to identify patients who are "super-responders" to different types of chemo and check whether there are any genomic indicators which might be used to identify other patients who might have a similar "super-response" to that particular regime? I ask because I was diagnosed with Stage 4 incurable and inoperable cancer of the Oesophageal/Gastric junction . Due to the location and size of my primary, both surgery and radiotherapy were ruled out. I was told that without chemo I had a life expectancy between 2 months and 12 months and with chemo between 6 months and 18 months. This was 50 months ago and I am still in very good health. I undertook EOX chemotherapy for palliative care reasons, being told that at best it might shrink my cancer and slow its growth.Instead the EOX reduced the size of my primary by 60% and my mets by 50% and to date the cancer has been dormant since the end of chemo I have had no further treatment since then but have contrast CT scans every six months to monitor the situation. | P | |
| | What percentage of patients have an unusually positive response to chemotherapy - i.e. are "super-responders"? | P | |
| | Is treatment of benefit at all? Seems to me that there are many treatments given - especially after multiple relapses - that have virtually no chance of being successful. | R | |
| | How can health care professions best tackle expectations in those living with and beyond cancer | H | |

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| | Explore in more detail why/what is facilitating super responders to respond to treatment | P | |
| | Is staying positive in attitude and thought and feeling likely to help a cancer patient fight the cancer better than someone who doesn't stay positive? Is there any real substance to these ideas? Does positivity act as a 'medicine'? | P | |
| | to what extent does 'maintaining a positive attitude' contribute (or not) to improved clinical outcomes? | P | |
| | Who much work has been done around exploring the fatalistic attitudes of some Groups of patients with diagnosis where there is a very poor prognosis? We see that there is often a very different approach to seeking additional support services for people with a lung cancer diagnosis as opposed to women with early stage breast cancer. Perhaps this is another factor which impacts on quality (and perhaps quantity) of life post diagnosis. | O | |
| | How important is a positive mental Outlook to survival rate | H | |