

Supportive Oncology Research Team (SORT)
Mount Vernon Cancer Centre
2017 - 2018



Supportive Oncology Research Team Annual Report 2017 - 2018

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1. Executive summary

This report is published by the Supportive Oncology Research Team with the intention of making our research activities more widely available across East and North Hertfordshire NHS Trust and Mount Vernon Cancer Centre (MVCC) and beyond - and to highlight individual and team achievements.

The aims are:

- to broaden the knowledge of supportive oncology research across the various treatment arms of the Cancer Centre in order to promote the work of the team, and
- encourage future research collaboration across and outside the Cancer Centre.

Looking forward, the team are keen to expand research activities by collaborating across the Cancer Centre with clinicians and Allied Health Professionals (AHPs) including those who may previously have not considered research within their work streams, and collaborating more widely across other academic and NHS organisations.

We invite the reader to peruse the contents of this report and to contact us for further information on any of the areas discussed. We also welcome further discussion from individuals with regard to any potential research opportunities needing support to enable development of research projects in other areas across the Trust.



2. Introduction



Supportive Oncology Research Team (left to right) – Katrina Mindel, Tara Chalk, Beverley de Valois, Christine Brannan, Teresa Young, Clare Scarlett

When someone is given a diagnosis of cancer, they are routinely offered a cocktail of treatment options with curative or life-prolonging but palliative intention. What is not intended (although perhaps inevitable), is the assortment of distressing, painful and unpleasant side effects. Within the Supportive Oncology Research Team we are undertaking research on a range of complementary therapies to help with wellbeing and the consequences of treatment as well as developing and validating quality of life measures, assessing the psychosocial impact of cancer and looking at new ways of using technology to help assess and deliver care.

The team operates within the Mount Vernon Cancer Centre (which provides a tertiary service for a population of over 2,000,000) as part of East and North Hertfordshire NHS Trust. There is close joint working with the Lynda Jackson Macmillan Centre (LJMC), a drop-in support and information facility for people affected by cancer.

Members of the research team have academic links with universities and sit on a number of prestigious national research committees.

Using this first report as the historic overview and starting point (therefore highlighting some activities over the past few years) for ongoing yearly updates, we will be publishing our research activities year on year in an Annual Report format.

3. Academic achievements

The Supportive Oncology Research Team has expertise in supporting advanced academic work, and has had strong involvement in producing two PhDs:

Cathy Wilson

PhD from City University, awarded in 2007, used realistic evaluation to explore the impact of a holistic tool on nurses' assessments of patients receiving outpatient palliative chemotherapy.

Beverley de Valois

PhD (2006) Using acupuncture to manage hot flushes and night sweats in women taking tamoxifen for early breast cancer: two observational studies. (Awarded by Thames Valley University, now the University of West London.)
Beverley is also an Honorary Research Fellow in the School of Social & Community Medicine at the University of Bristol.

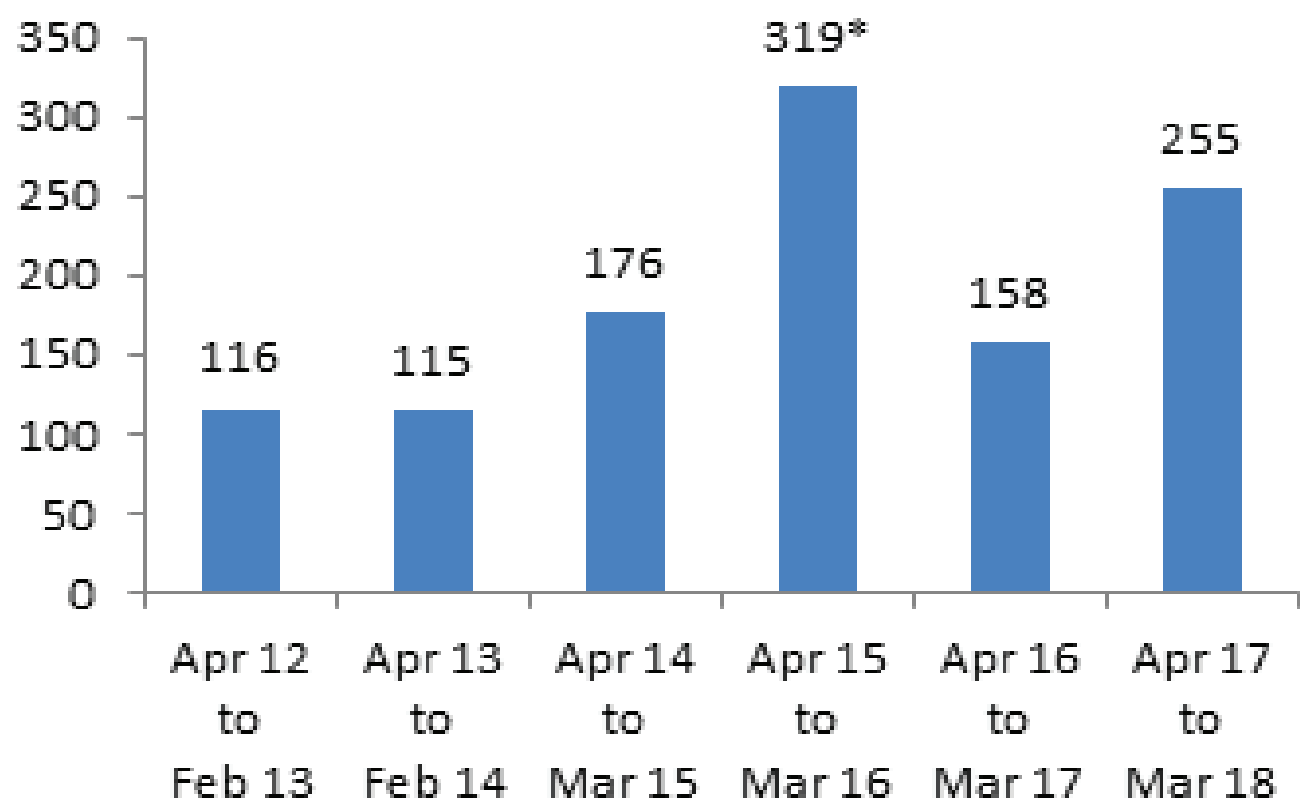


4. Supportive oncology research team activities

Over the past 6 years patient recruitment has seen a very successful steady increase:

Figure 1 Patients recruited into Supportive Oncology Research Team studies year on year.

*Computer adaptive testing study (CAT) - several questionnaire domains were ready for testing during this year, creating an unusually high number of study participants.





In addition, the team has undertaken the following:

	2016 - 2017	2017 - 2018
Projects Undertaken	4	10
Publications	10	9

Dissemination activities: 2017/2018 – 8 posters, 13 oral presentations (3 as invited speaker)

	Principal Investigators	Co-investigators	Total
Current	6*	4**	10
Completed	2	2	4
Total	8	6	14

* 2 of 6 studies are new in 2017/2018

** 3 of the 4 studies are new in 2017/2018

There are high levels of recruitment for quality of life and psychosocial research projects, with the Supportive Oncology Research Team achieving highest amongst the UK centres – as outlined further within the report.

Whilst recruiting to Supportive Oncology research studies members of the team are ideally placed to not only deliver the requirements of each study and obtain the necessary outcomes but also to deliver invaluable secondary benefits which provide additional support to our patients through their cancer journey. These are detailed within our report as the value and importance of this to patients cannot be stressed enough, or quantifiably measured.

The Team has much to be proud of in their activities this year and reflecting on previous years also (as this is our first Annual Report), as detailed over the next few pages.



5. Notable team achievements

Individual

Beverley de Valois is Chair of the British Lymphology Society Scientific Committee (BLSSC) – which is a great opportunity to develop leadership and networking with the potential to enhance the work of the Supportive Oncology Research team by increasing contacts across the lymphoedema community.

Beverley was Principal Investigator for two NIHR partnered research grants:

- “Using acupuncture and moxibustion to promote wellbeing and improve quality of life for patients with secondary lymphoedema” funded by NIHR Research for Innovation, Speculation and Creativity (RISC) Programme (Grant Reference no. PB-PG-0407-10086) 2008
- “Using daily self-administered indirect moxibustion to Zusanli ST-36 to reduce chemotherapy-induced pancytopenia”: a feasibility study funded by the British Acupuncture Council, an NIHR non-commercial partner, 2014.

Beverley and Teresa Young were co-authors on a paper that was runner up in the Scientific Article Prize competition awarded by the International Society of Complementary Medicine Research in May 2017 for their qualitative paper *“The monkey on your shoulder:” a qualitative study of lymphoedema patients’ attitudes to and experiences of acupuncture and moxibustion*. This was a significant achievement given that qualitative papers do not tend to receive the same recognition awarded to quantitative papers.

Teresa Young received two grants from the European Organisation for Research into Treatment for Cancer (EORTC) Quality of Life Group for the development of a Spiritual Wellbeing Module. The initial grant covered Phase I – patient interviews and a literature review to determine the issues. The second grant (in 2011) covered Phase IV – an international multicentre field test of the final measurement tool.

Teresa also received the Cancer Research Excellence Award in 2015/16 (non-medical and support staff) – and was Highly Commended for ‘excellence in research conduct in the National Institute for Health Research Clinical Research Network: Eastern region’.

Supportive Oncology Research Team

The team received funds for several years from **NHS Service Improvement and then the National Cancer Survivorship Initiative** for ongoing projects at Mount Vernon Cancer Centre looking at Head & Neck Cancer follow-up pathways - replacing alternate consultations with nurse led telephone follow-up in low risk patients.

NIHR Achievement Awards 2013 (National Institute for Health Research): Supportive Oncology Team, Mount Vernon Cancer Centre ‘For an Outstanding Achievement by a Research Support Team’.

BMA Patient Information Awards 2017 (British Medical Association) - Highly Commended - Using moxa to reduce the side effects of chemotherapy.

BMA Patient Information Awards 2016 - Highly Commended – A patient’s guide to radical chemo radiotherapy/radiotherapy for lung cancer at Mount Vernon Cancer Centre.

There is a need to diversify the team’s portfolio whilst continuing to recruit patients to studies. There is considerable interest and expertise in supportive oncology at MVCC. Whilst most oncology research in the Trust is led by clinicians, there are many senior nurses, psychologists, physicists, dieticians, complementary therapists and allied health professionals (AHPs) with interesting research ideas for supportive oncology projects which could be fostered and supported to reach the Trust’s vision and aim.

The team has therefore been joined this year by Katrina Mindel, as Strategic Lead for the team’s activities. Katrina will work across the Trust to encourage independent research activity amongst health professionals working in oncology and develop new grant applications to ensure that supportive oncology research within the Trust has a sustainable future, given the large contribution it could make to the Trust’s overall research agenda.



6. National leadership

Teresa Young is a member of the NCRI Supportive and Palliative Care Group (National Cancer Research Institute) and regularly reviews papers for the following journals:

- European Journal of Integrated Medicine
- Integrated Cancer Therapies
- European Journal of Oncology Nursing
- Radiotherapy & Oncology
- Clinical Oncology

Beverley de Valois was awarded Fellow of the British Acupuncture Council for her work with cancer survivorship. Beverley regularly reviews papers for the following journals:

- European Journal of Integrated Medicine
- European Journal of Oncology Nursing
- Medical Acupuncture
- Acupuncture in Medicine
- Journal of Alternative and Complementary Medicine
- BMJ Open
- Cochrane

Both Beverley and Teresa regularly present at national and international scientific conferences.

7. Local leadership

Supportive Oncology Research team members regularly undertake presentations to staff and at patient support groups within the MVCC, for example presenting:

- information on ScarWork to the Head and Neck Cancer Support Group in November 2017
- data from the NADA prostate study on MVCC study days
- acupuncture awareness sessions to the Lymphoedema Support Group (November 2017) and to Stepping Stones (a LJMC support group).

Clare Scarlett, the team's Health Improvement Practitioner, has presented at a number of training event days at MVCC on the Survivorship Initiative work, covering areas including patient follow up pathways, patient information, rehabilitation and survivorship.

Clare has also been a keynote speaker at the following education days: 'Introduction to cancer care day' the 'Living with the consequences of cancer treatment' and at the 'Supportive palliative care for cancer patients' education days held at MVCC.

Traditional Acupuncture Improves Wellbeing in Cancer Survivors with Lymphoedema
 *Supportive Oncology Research Team, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Rickmansworth Road, Northwood, Middlesex HA6 2RN
 ‡Mount Vernon Lymphoedema Service, Mount Vernon Hospital, Northwood, Middlesex HA6 2RN

Introduction
 Acupuncture is not usually considered as a treatment option for people with lymphoedema. It is assumed to involve needling the affected area, raising concerns about aggravating the lymphoedema or risking cellulitis. This early stage exploratory study investigates the following:

Key Questions
 □ Can traditional acupuncture improve wellbeing in cancer survivors with lymphoedema?
 □ What symptoms are most troublesome for these individuals?
 □ Is acupuncture a safe intervention for people with lymphoedema?

It was not an intention to treat the lymphoedema itself. Participants continued their usual care programme as specified by the Lymphoedema Nurse Specialist, who monitored them throughout the study.

Methods
Participants
 □ Breast cancer and head and neck cancer patients, with:
 □ Mild to moderate uncomplicated lymphoedema
 □ Assessed and referred by the Mount Vernon Lymphoedema Service.

Treatment schedule
 □ Traditional acupuncture treatments were offered, comprising:
 □ Series 1 - 7 treatments
 □ Series 2 - 6 treatments (optional, and decided by the participant).

Identifying symptoms
 Participants set their treatment priorities using the **Measure Your Medical Outcome Profile (MYMOP)**, they specified and / or rated these items:
 □ Symptom 1 (optional)
 □ Symptom 2 (optional)
 □ No bother (optional)
 □ Wellbeing

They rated each item on a 7-point scale:
 □ 1 = 'as good as it could be'
 □ 7 = 'as bad as it could be'

Measurement
 MYMOPs were completed prior to the:
 □ 1st treatment (4 each Series (Treatments 1 & 6) - "Baseline"
 □ Final treatment of each Series (Treatment 7 and 13) - "Followup"
 New symptoms (if any) could be specified at the beginning of Series 5.

Acupuncture
 Treatments were administered twice weekly by two acupuncturists who are members of the British Acupuncture Council.
 □ No treatments were individualised for each participant.
 □ Needling was avoided in the affected area/quadrant.

Results
 □ 24 breast and 6 head and neck cancer patients completed Series 1 & 2.
 □ 2 breast and 1 head and neck cancer patients completed Series 1 only.
 □ 1 breast and 1 head and neck cancer patient were lost to the study.

Can traditional acupuncture improve wellbeing in cancer survivors with lymphoedema?
 □ A change of over 0.5 to 1.0 on the MYMOP Score is clinically significant.
 □ * indicates significant results ($p < 0.05$) for paired sample T tests.
 □ MYMOP Profile = the average of the sum of the specified items.

MYMOP Series 1

Symptom	Baseline	Followup
Symptom 1	1.5 (0.5-2.5)	1.0 (0.0-2.0)
Symptom 2	1.5 (0.5-2.5)	1.0 (0.0-2.0)
Wellbeing	1.5 (0.5-2.5)	1.0 (0.0-2.0)

MYMOP Series 2

Symptom	Baseline	Followup
Symptom 1	1.5 (0.5-2.5)	1.0 (0.0-2.0)
Symptom 2	1.5 (0.5-2.5)	1.0 (0.0-2.0)
Wellbeing	1.5 (0.5-2.5)	1.0 (0.0-2.0)

Symptoms specified by participants and their relative occurrence

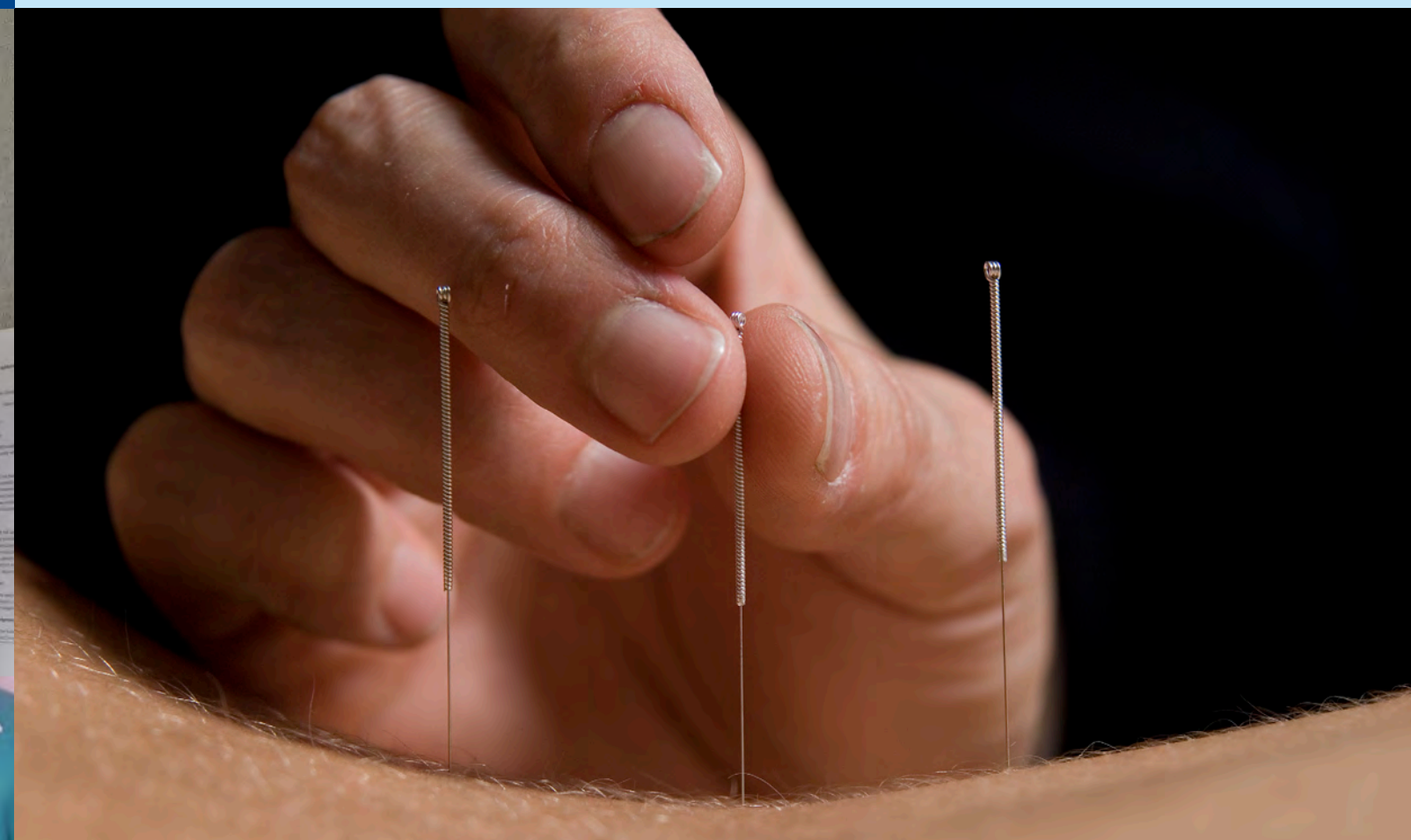
Symptom	# Breast Cancer	# Head & Neck Cancer
Neck/shoulder	10	2
Arm/shoulder	8	1
Hand/wrist	7	1
Leg/ankle	6	1
Weight	5	1
Swelling	4	1
Stiffness	3	1
Discomfort	2	1
Itching	1	1
Redness	1	1
Wound/ulcer	1	1
Other	1	1

Is acupuncture safe for people with lymphoedema?
 □ No serious adverse effects were observed or reported.
 □ As a safety check, breast cancer participants were measured at intervals throughout the study. There were no increases in volume outside of the normal range for each participant.

Additional benefits
 The Lymphoedema Nurse Specialist noted improved local prescribed care programmes, as well as improved self-management in many participants.

Conclusions
 □ Acupuncture can significantly improve the wellbeing of cancer survivors with upper body lymphoedema.
 □ It addresses a range of symptoms experienced by individuals, including:
 • Lymphoedema associated problems.
 • Other non-lymphoedema related problems.
 □ Acupuncture is a safe intervention for people with lymphoedema.
 □ Additionally, improved concordance and/or self-management were observed in many participants.
 □ This approach is not intended to affect volume.
 □ Further research is warranted.

Acknowledgements
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 Funded by the Mount Vernon Cancer Centre.
 □ Professor Christine Moller, International Lymphoedema
 □ Anna Wilson, Mount Vernon Cancer Centre
 □ Thank you to the Mount Vernon Cancer Centre
 □ For further information contact Beverley de Valois



8. Research vision and strategy across East and North Hertfordshire NHS Trust

National and local research context

The NHS Constitution commits to innovation and to the promotion and conduct of research to improve the current and future health and care of the population. The Trust is part of the National Institute for Health Research (NIHR) which has a vision: "To improve the health and wealth of the nation through research". NHS policy frameworks and guidelines place a duty on the Trust to protect and exploit innovation / intellectual property for the benefit of patients and the wider health care community.

East and North Hertfordshire NHS Trust

The research activity at the Trust is a mixture of studies which staff have gained through external funding via grants, studies that are commercially-funded and also participation of studies funded via national and local charities. The Trust fully supports the Health Research Authority and is committed to fully implementing the UK Policy Framework for Health and Social Care Research.

The Trust has 'University Status' through a formal partnership with the University of Hertfordshire and has a number of joint professorships and posts such as the Florence Nightingale Foundation Chair in Clinical Nursing Practice Research.

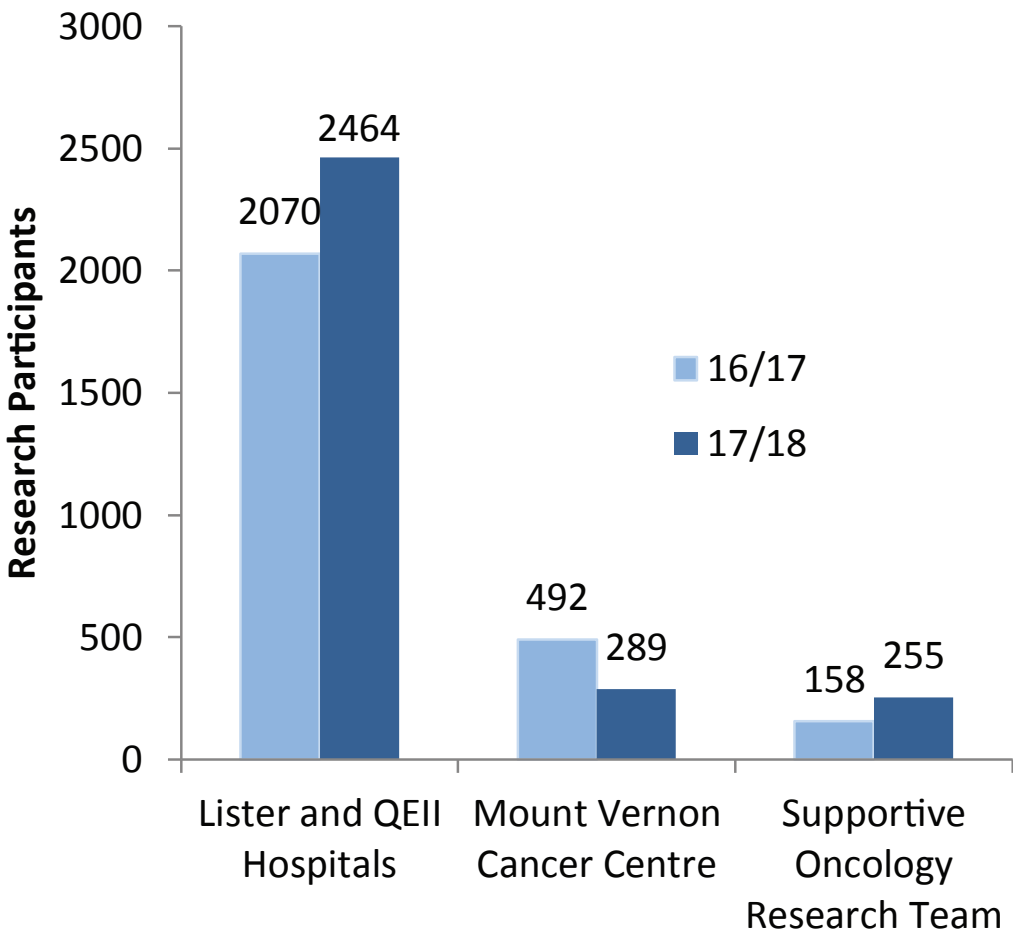


Figure 2 East and North Herts Trust patient recruitment numbers for 16/17 and 17/18

Linked to the Trust Research Strategy, Supportive Oncology Research Team activities include:

Aim 1 "The Trust to be an internationally recognised centre of excellence for research and patient outcome". At least 19 publications in peer reviewed journals were published since 2016.

Aim 2 "Patients and public to be engaged with, participate in, and benefit from research and innovation". Research participation has increased considerably from 2016/17 to 2017/18.

Aim 3 "Research is funded via external grant applications, from industry and with the support of charities". The Supportive Oncology Research team has undertaken a commercial pharma study, and we are collaborators on a European grant for the eSMART study. The European Organisation for Research & Treatment of Cancer (EORTC) Quality of Life group funds the Supportive Oncology Research Team to recruit patients for several studies to develop and validate quality of life questionnaires specific to disease sites or domains (Modules).

In addition the team's new strategic lead (Katrina Mindel) has commenced a programme of public and patient involvement during February and March – this will be developed further and increased as part of the team's strategy for 18/19.

Aim 4 “Research is embedded into the planning and delivery of routine patient care for all patients”. The team have built excellent relationships across the Trust over many years; this has led to the transfer of charitable funds to the team by a retiring consultant, enabling dissemination of the team’s acupuncture research. With clinical support from several consultants the team has been able to explore novel interventions such as moxibustion (a form of heat therapy), reiki and acupuncture across a wide range of cancer tumours and different points in the patient pathway. There is consultant support for the running of an acupuncture clinic for colorectal cancer survivors resulting in two joint publications and a third is planned.

Further engagement is planned from the Supportive Oncology Research Team across clinical areas within MVCC to support and encourage more research linked to patient experience and supportive outcomes. Based on research from the de Valois PhD, ear acupuncture is now delivered within the LJMC as an evidence based service for women, and is being further expanded to prostate patients with ongoing evaluation.



Aim 5 “Research is well governed, managed and supported so studies are delivered, as promised”.

The team delivers study requirements for all research projects and consistently meets (and exceeds) patient recruitment targets, for example:

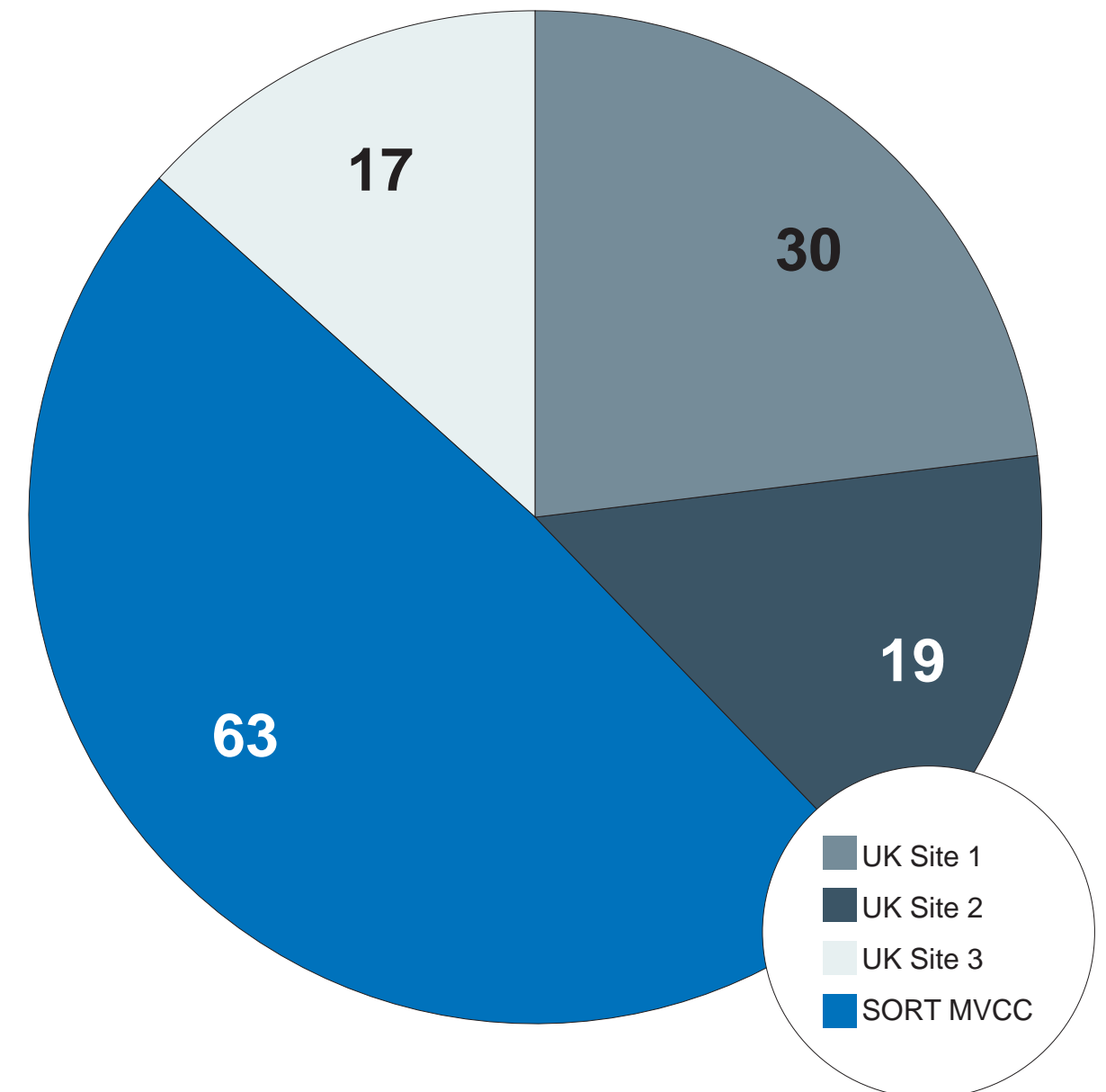
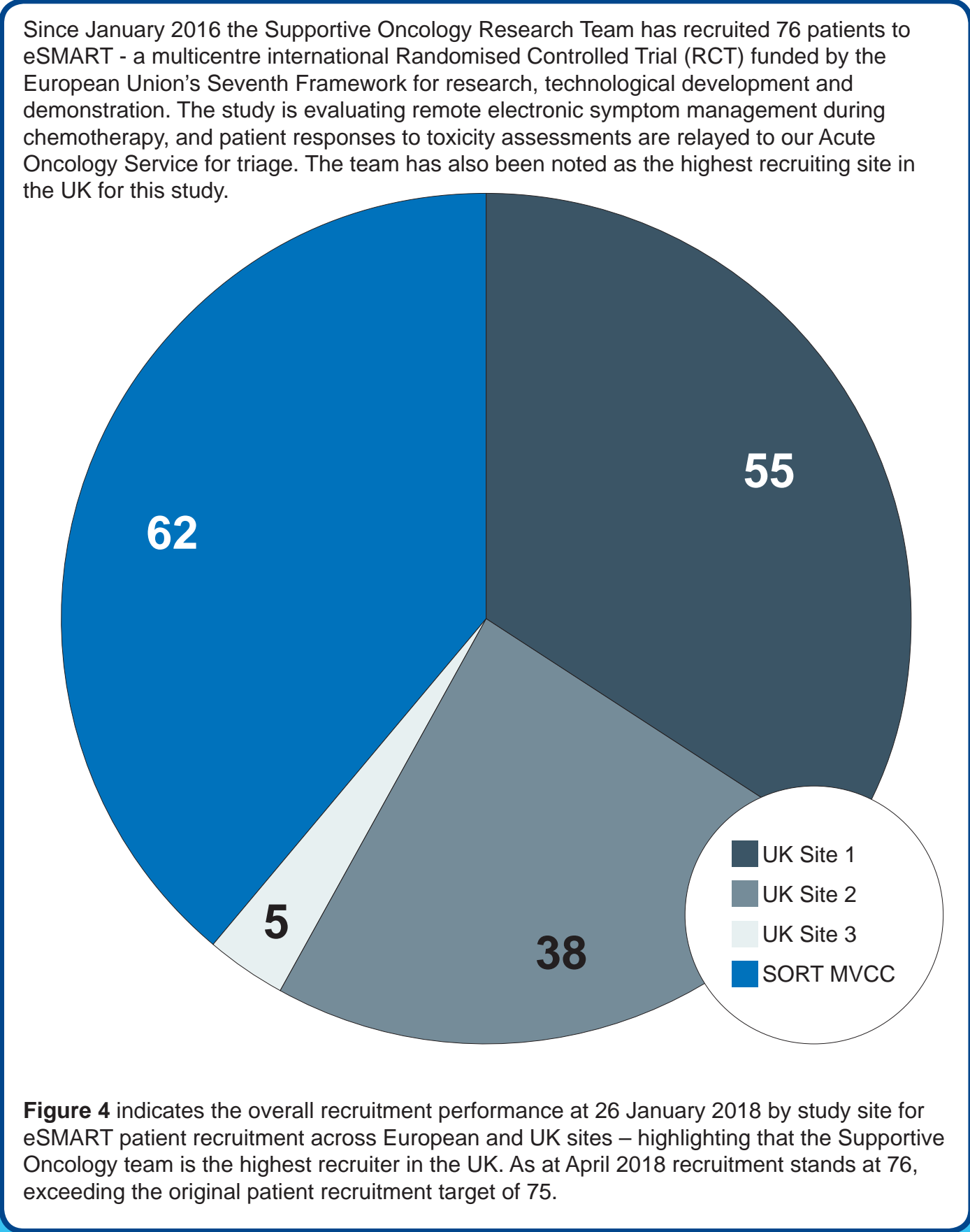


Figure 3 The Supportive Oncology Research Team is the highest recruiting UK site, contributing 50% of the EORTC Survivorship Module UK patient recruitment from July 2014 to March 2018

9. Research activities



A research grant from the British Acupuncture Council was used to test the feasibility of introducing moxibustion into an NHS setting to help with symptom management during chemotherapy.

Working in collaboration with the EORTC Quality of Life Group, the Supportive Oncology Research Team have helped develop and validate six Quality of Life Questionnaires/add-on modules and have contributed to the development and validation of 13 'Item libraries' for a Computer Adaptive Testing (CAT) version of a widely used core cancer quality of life questionnaire comprising of 30 questions. Another study is looking to determine threshold values for the 13 Quality of Life domains, as an indication to clinicians for when interventions might be required.

Two successive studies (the first a RCT) have investigated the use of Rivaroxaban – an oral anti-coagulant used to treat venous thromboembolism in cancer patients.

The team was also jointly responsible for the development of an EORTC Spiritual Wellbeing Measure for use in palliative patients. The final field study recruited 458 participants from 14 countries (11 languages) across four continents. Efforts are now underway to promote the use of the measure in hospices and international clinical studies.



10. Public and patient involvement / engagement (PPI/E)

The Supportive Oncology Research Team regularly undertakes patient engagement to highlight the work of the research team, disseminate information (for example a talk on cancer related fatigue) and to gain patient insight for future study development.

Before research grant funding is available, initial PPI/E is undertaken on the basis of a very small clinical pilot with four to ten participants, followed by a focus group, with a further invitation to patients to participate in and help develop a research grant application.

For grant funded studies relating to complementary therapies, our patient involvement has been highly rated (for example lymphoedema), and followed a similar process:

1. Inviting patients and clinicians to a focus group to discuss the proposed project to ascertain their priorities and if they had any safety concerns.
2. Following this with a clinical phase, so that patients could experience the therapy and initial response and compliance data could be collected.
3. This would be followed by another focus group to collect qualitative data, and interested participants would be invited to become PPI experts for a further research grant application.
4. This expert team would input into and comment on the next grant application as it was developed.

Interestingly, the team's applications for grants to extend and continue the lymphoedema research were unsuccessful as the funders required a focus on volume reduction as a primary outcome, whereas our patient group had identified a different priority around wellbeing, acceptance and coping/adjustment.

The team will expand on our patient involvement activities as we move into 2018/19, so that our patients and carers can have active involvement with our studies. They will help us identify new areas for research, help us to develop our studies, co-author our grant applications, and help us deliver and evaluate the studies.



11. Patient benefit from research activities

Supportive Oncology Research Team activities have directly contributed to patient care delivery as is outlined below:

NADA ear acupuncture service for breast cancer treatment related hot flushes and night sweats

Based on the National Acupuncture Detoxification Association (NADA) protocol - this study dates from initial research from early in the 2000s (see de Valois PhD). It has had a number of ongoing impacts:

- Adopted as a service offering by LJMC in 2005.
- The approach has influenced services nationally (acupuncture service delivery at the Fountain Centre, Guildford) and internationally (a Gynaecologist in Germany adopted the approach to treat socially disadvantaged women in his clinics).
It is one of two studies cited for using NADA for cancer care on the NADA International website, in their summary of the evidence for using NADA [https://acudetox.com/phocadownload/Research_Summary_2013%20\(2\).pdf](https://acudetox.com/phocadownload/Research_Summary_2013%20(2).pdf).
- Clinical outcomes data for the first 10 years of the service has been analysed and presented as a poster at several scientific events; a publication is planned.

NADA ear acupuncture service for wellbeing for prostate cancer survivors

This project evolved from the ear acupuncture service for breast cancer related hot flushes as a result of the desire of the LJMC's complementary therapy team to offer a service to male cancer survivors. While there are several centres in the UK using NADA for breast cancer survivors, there are few, if any, such services for prostate cancer survivors. This service was initiated by a "seed project" - a pilot study (funded from a charitable donation) - treating 20 patients, collecting clinical outcomes data, and publishing a paper. In this project, the team pioneered the concept of using NADA to address overall wellbeing of prostate cancer survivors rather than focusing on a single symptom (usually prostate cancer treatment related hot flushes and night sweats). Data from this service is currently being analysed.

Using acupuncture to improve wellbeing and Quality of Life for cancer survivors with upper body lymphoedema

This NIHR funded study dating from 2008-2010 continues to influence current service delivery and training, and was innovative in the following areas:

- It focused on improving overall wellbeing rather than a specific symptom (volume in lymphoedema is usually arguably incorrectly cited as being the primary outcome for lymphoedema interventions).
- Unusually it included head and neck cancer survivors with lymphoedema (a very under-researched group) alongside the more frequently researched breast cancer survivors.
- A major investigative aspect was to avoid needling in the body quadrant on the affected side (lymphoedema patients are advised to avoid accidental and non-accidental skin puncture in the affected or at risk area). It demonstrated (as far as any early stage study can) that benefits could be obtained by this ultra-conservative approach to acupuncture needling.

- The qualitative paper from this study ("The monkey on my shoulder"...) was a runner up in the Scientific Article Prize competition awarded by the International Society of Complementary Medicine Research in May 2017. One of the unique features of this paper is it proposes a model for using acupuncture as a catalyst to improve self-care.

Using daily self-administered indirect moxibustion (moxa) to reduce chemotherapy induced pancytopenia.

Another ground breaking study (funded by the British Acupuncture Council, an NIHR partner) introduces a novel intervention (moxa, a form of heat therapy used in traditional oriental medicine) into the NHS. Essential features include self-care and the inexpensiveness of the intervention; we are also explicitly reporting safety issues (a neglected aspect of published moxa studies). This is an area that has great potential for further research, including translational research.



12. Direct patient benefit from clinical evaluation

Not all work undertaken within the Supportive Oncology Research Team is funded research, but comprises clinical projects that are evaluated to provide either initial or ongoing data about patient outcomes. This is largely (but not limited to) the work undertaken under the heading of complementary and alternative medicine (CAM), and has highlighted some significant service improvements and quality of life enhancement for patients.

This includes:

Patient Support within the Lynda Jackson Macmillan Centre

The team's Health Improvement Practitioner has facilitated and is currently co-ordinating several courses held at the LJMC - HOPE for patients, Take Control for patients and Time and Space for Carers. The HOPE course, as an example, is delivered in six consecutive weekly sessions, each of 2.5 hours duration. There is a mix of psychological education, skills practice and reviewing of self-management goals. Patients attend the course usually once they have completed their cancer treatment. These courses are evaluated and submitted to Macmillan Cancer Support – feedback is extremely positive from patients and also from Macmillan.

Wig service evaluation

A change to the previous wig service at MVCC has led to an evaluation of the new service (wigs provided by four high street salons rather than on site through an orthotics service). The development of the questionnaire used and subsequent evaluation aims to ensure the patients are receiving a good service and to address any issues arising.

Pre chemotherapy group consultation evaluations

These are ongoing, as and when requested and involve developing the questionnaire used, running the evaluation with patients, analysing the results and reporting on findings. Changes to the service are undertaken where required. (e.g. a new consultation was introduced for immunotherapy patients.) This has proven to be very useful in ensuring that all required information is given to the patients and any gaps revealed are filled.

Impact of immunotherapy on quality of life in patients with advanced melanoma

A semi-structured interview/questionnaire is being developed to help understand the benefits of immunotherapy treatments to melanoma patients with advanced disease. There is no currently available questionnaire that is an ideal fit for this patient group but by interviewing patients and capturing the issues raised the team have a first draft of a questionnaire which highlights the benefit of this new treatment and addresses the patients' specific concerns. This is an ongoing initiative and the questionnaire will be pilot and field tested in a multicentre study, and possibly extended to other Cancer Centres at a later stage.

'PICC' (peripherally inserted central catheter) audit (2016): Published - Proactive PICC placement: evaluating the patient experience, Karen Harrold, Annette Martin and Clare Scarlett. The study was published in the British Journal of Nursing and presented at the MVCC clinical governance meeting for internal clinical dissemination. The study was undertaken to validate the local practice of placing PICCs proactively, to show there was no patient harm and to determine patient view of this routine practice.

The outputs of this ensured a better understanding of patient experience and identified areas for improvement. An indirect outcome of this is that the information is used as reassurance to reduce anxiety for new PICC patients – there is a poster on the chemotherapy suite waiting room wall highlighting the study and outputs. Verbal feedback from the nurse leads is that patients find this reassuring and informative.

Lung rehabilitation pathway redesign project: Macmillan project (2016)

Lung patients experiencing breathlessness and anxiety were taught self-management strategies, including relaxation and breathing techniques. Outputs include:

- Producing the flow-charts for this project, to show current and redesigned (rehabilitation) pathways of treatment.
- Quality of life baseline and follow-up data (collection and analysis).
- Producing the on-treatment paperwork used by the Multi Disciplinary Team in the clinic.
- Information award – see above.

The Fatigue Interest Group

Working within a group of healthcare professionals at MVCC (Palliative care, Education team, Information team, Radiotherapy, Occupational Therapy, Research) two audits were conducted - published (January 2015) in the journal Supportive Care in Cancer and presented at Clinical Governance meeting at MVCC with Dr Humaira Jamal and Pamela Wright (Michael Sobell House education). The group also held annual 'Fatigue Awareness' education weeks at MVCC. The aim of this work was primarily to improve patients' experience of cancer related fatigue (CRF). It also raised patient and staff awareness of CRF and what can be done to improve the symptoms.



Acupuncture for colorectal cancer survivors at Barnet Hospital (“seed” project)

Initially proposed as a six month service offering to be followed by a research project, low numbers referred mean that it has evolved into a service offering long-term follow-up care for colorectal cancer survivors with complex needs. This philanthropically funded project is an unusual opportunity to explore the long term consequences of colorectal cancer treatment providing rich insight into the problems faced by some survivors.

- Two case studies papers report the range of complex issues faced by these survivors. The papers are innovative in that they involve the survivors in the writing of their cases, and include commentary from the oncologist (Dr Rob Glynne-Jones). This in itself is ground breaking as these are the first papers the journal (European Journal of Oriental Medicine) has published that include an oncologist’s comments.

This service was also the innovator for using ScarWork, as many colorectal cancer survivors have extensive scarring but do not wish to be needled around the scar and led to its use in other tumour groups (see overleaf).

ScarWork for head and neck cancer survivors (“seed” project)

Another unique ground breaking project – using (recently introduced to the UK) ScarWork light massage techniques to reduce scar related discomfort and dysfunction, and to improve appearance of cancer treatment related scars.

- Existing cancer-related ScarWork projects in the UK focus on breast cancer; we now have a unique opportunity to offer treatment to the under-catered for head and neck cancer survivors.
- As per the usual approach of the team, an initial pilot service is being offered to assess effectiveness and acceptability to head and neck cancer survivors, as well as to test outcome measures.
- A case study paper is planned for publication which we believe will be the first paper to report using ScarWork for this cohort of patients.
- Our findings will form the basis of future research grant applications.

The following case study is an example of the effect of Scarwork on one of our patients, with kind permission from patient RW.

Evaluation of clinical outcomes is a key feature of all of these projects – whether ongoing service offerings or “seed” projects. The NADA ear acupuncture services are evaluated on an ongoing basis; the team is therefore building a rich collection of data about clinical outcomes. Although this is service related data, rather than research data, this is a pragmatic approach that provides “real-life” outcomes as opposed to those from a highly selective research environment. This can provide important evidence to determine future service delivery to patients living with and beyond cancer as well as inform future bids for research funding.

The “seed” projects provide initial data on which to build future bids for funding. Publication of these early findings also ensures the Supportive Oncology Research Team’s reputation as innovators.

13. A patient perspective of the ScarWork treatment programme

"I am an ongoing attendee of the Head & Neck Support group which holds its meetings the second Tuesday of each Month at the Mount Vernon Post Grad Centre. As a group we strive to get guest speakers of various skill sets relating to Head & Neck Cancers to attend and present to the group. November's meeting saw our group introduced to the ScarWork Treatment research programme being undertaken by Beverley de Valois. The presentation given was very pertinent to myself as I have numerous scars following my treatment for a T2 NO MO Squamous Cell Carcinoma right tongue and floor of mouth by way of right partial Glossectomy, right neck dissection and reconstruction with left radial forearm flap.

The subject of manipulating scar tissue to stimulate the area to try to repair or even change the physical appearance was very appealing as I do suffer after effects from the surgery I received in February 2015. Beverley mentioned that she was conducting a trial and needed volunteers to undergo a course of treatment. Now I am a very sceptical person as a rule and although I would normally just sit in the background listening and not get too involved especially in putting myself forward as a volunteer, I felt this subject had me hooked and well what did I have to lose other than some time out of my Fridays to attend the Lynda Jackson centre for the treatments.

17th November 2017

I attended my first 1hr session where we did the necessary as regards filling out forms etc. Then Beverley started work on my left forearm radial scar which is the most sensitive of the five scars I inherited during my Cancer surgical treatment. The forearm scar as stated was the most sensitive and if I could explain the sensation I have is like a sharp spiking pain that travels through my inner wrist all the way through to the tip of my thumb when a certain part of the scar is touched. It seemed strange that I was allowing someone to not only touch that area but repeatedly touch this spot, this treatment session was around 30 minutes and following this I experienced a few strange sensations later in the day. I sensed a hot feeling all down the inner part of my arm just after the treatment and also later into the afternoon, I also felt extremely tired towards the end of the day which is very unusual for me.

1st December 2017

I attended my second 1 hour session where Beverley continued the treatment on my left forearm where she started to manipulate even deeper on the scar, this obviously in certain areas caused more discomfort dare I say pain so a lighter approach was taken on this area. Again following the treatment, I had the sensation of heat along the scar but the fatigue wasn't there on this occasion. I did over the next few days feel a noticeable relief in the spiking pain and also the appearance seemed to have changed by way of a less noticeable recess of some of the scar tissue and a softer feeling of the scar tissue. I have since surgery started to sleep in a different way and this is when I sleep on my left hand side I always had to put my left arm behind my body and my right arm in front as I couldn't put weight or pressure on my left arm.

This may seem a silly thing to note but when I wanted to roll over to my right side I couldn't as my arms were acting as anchor points, this caused some degree of sleep deprivation. I have over the weeks managed to sleep where I can lay my body weight on my left forearm with little to no discomfort. I am also able to wear a watch on the left arm with no discomfort at all both metallic and leather straps, this again may seem a silly thing to note but is a big positive to me as I have some lovely watches that were just sat in the drawer. I did try to wear a watch on my right arm but never felt comfortable, so to be able to wear these watches over my scar on my left arm is a fantastic move forwards to me. I also found that lifting of weight with my left arm prior to the treatments starting always left my left wrist aching, however this has now changed too where my wrist just feels stronger and I get very little discomfort now.

15th December 2017

I attended my third 1 hour session with Beverley and again the treatment for my left forearm carried on, I am very comfortable with this scar both in sensation and appearance so Beverley was able to manipulate more than previous sessions. I have little to no spiking pain now and this was after just three sessions so my scepticism proved to be unfounded to be honest. I feel the benefits in many areas from sleeping, to wearing of watches and even lifting of weight with my left arm. I am now looking forward to having other scar work treatment certainly around my neck.

5th January 2018

I attended my fourth 1 hour session to commence the scar work treatment on my neck dissection scar. I raised a query with Beverley regarding surgical staples that were used to cap off the capillaries when I had my lymph nodes removed from the right hand side of my neck following my surgery. My concern was that any work carried out may cause my neck to blood blister as I am on Clopidogrel tablets following stents placed in the arteries of my heart, this causes my blood to be thinner and therefore I bruise reasonably easy in the weirdest of places so hence my concerns. We decided that we would seek clarification from the Consultant and in the meantime Beverley followed up another session on my left forearm. This although unexpected reinforced for me the sterling work Beverley had performed as I had no adverse sensations whilst she performed the treatment. It is fair to say that my left forearm although scarred is in good working order and I have no repeats of the pain or strange sensations I had prior to any treatment. Looking forward to a green light from the consultant so we can commence treatment on the scars around my neck."



14. Indirect patient benefit from research

There are some activities undertaken within the Supportive Oncology Research Team which are not directly research related, although due to the close working between the LJMC and the team, ensure enhanced quality of life for patients. These may include identifying gaps in services and signposting. Whilst patients are given a vast range of relevant information to help them through their treatment (including details of support services offered by LJMC), the team's experience based on communication with patients is that much of the information is not read/digested. A significant portion of the Supportive Oncology Research Team's day to day work involves asking patients to complete quality of life type questionnaires, either face to face or on the telephone. The team are therefore in an excellent position to provide a secondary "wellbeing" service giving patients additional signposting to any relevant support services within the LJMC which they may need, but might not be aware of. Some examples of this are:

Identifying unmet needs of carers of patient with brain tumours (neuro-oncology)

A secondary indirect patient benefit was highlighted as part of a brain tumour study – where team staff identified gaps for carers of brain tumour patients. As the formal research interviews were undertaken in a private setting separate from the patient, it provided carers the freedom to speak openly and honestly about their concerns. Many were tearful and initially distressed; they felt out of their depth to deal with the deterioration of the patient and had valid safety concerns about their behaviour. This data was gathered and presented to the Clinical Nurse Specialist, who included this feedback when setting up a project for additional support for the needs of carers. Whilst this was not the initial study intention this was an additional positive outcome of the study.

Breathing / relaxation techniques

Lung patients: Most lung cancer patients approached for our studies that were about to start their first line chemotherapy did not know about the practical assistance and expertise with breathing techniques which is provided within LJMC. Referrals and recommendations to this service are highly valued. As a consequence of this "gap" the team have arranged for lung patients to be specifically identified during their pre-chemo consultation, and signposted to the service.

Patients with anxiety/insomnia/claustrophobia also benefit greatly from the breathing relaxation classes, and where possible carers are also permitted to attend. Patients find these sessions extremely valuable as can be seen from a snapshot of feedback comments collected by the facilitators:

"I stopped taking Prozac, started to get a daily routine at home... my self- confidence has improved considerably.... It didn't take long to feel comfortable in my own company ... started to write a journal and realised I was feeling better and happier. I am learning so much about myself all the time.... I enjoyed the breathing exercises and was able to control feelings of panic."

"I feel I am a more relaxed individual than I was and feel more able to cope with my radiotherapy after-effects eg exhaustion"

"It was a positive and pleasant class, after months of ... unpleasant treatment... I'm much more positive and have a lot more energy... definitely an important part of my recovery"

"The first time I came to the class, my chest felt very tight and I was unable to breathe deeply. The problem disappeared during the class and has not recurred"

Financial concerns / benefits

Patients often do not know that the LJMC has a benefits advisor – a service which is extremely important for those who are unable to work because of diagnosis or treatment. It is invaluable therefore when the team inform patients that this service is available.

Counselling services

Patients who are distressed, tearful and unable to cope are often signposted by the Supportive Oncology Research Team to the Counselling Service. This service is valuable for patients in active treatment, and also palliative patients struggling to come to terms with their prognosis.

Patient support groups

Patients are informed about support groups, including those for breast, prostate, gynae and head & neck cancer plus various 'after-treatment has finished' courses held within LJMC.

15. Living with and beyond cancer

The team recognise the shift towards prioritising longer term consequences of treatment - living with and beyond cancer, which has always been a focus within the acupuncture studies (prioritising recuperation and rehabilitation after active cancer treatment is completed).

We are proud of what we have accomplished to date and look forward to furthering our ability to enhance the experience and outcome for those living with and beyond cancer.

The Supportive Oncology Research Team is sufficiently large to enable them to be flexible and adapt to the requirements of different studies – allowing very efficient and constructive working, cross cover and improved knowledge and insight sharing. This has subsequently been extended to cross-team working in collaboration with other tumour group research teams across the cancer centre who had previously worked in isolation.

The East & North Hertfordshire Hospitals' Charity, including Mount Vernon Cancer Centre Charitable Fund, aims to make a real and positive impact to enhance patient care.

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