ACT NOW for Cancer

CASE STUDY DOSSIER

cancer52

KYOWA KIRIN

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How to use this document

This case study dossier showcases work from across the Cancer52 membership. These are proven ideas and tools that are already working in parts of the NHS, but need wider adoption to start helping more people straight away. Readers are invited to study the details to learn more about how projects were planned, initiated and implemented.

About ACT NOW for Cancer

ACT NOW for Cancer aims to amplify a cross-section of projects from Cancer52's membership across different cancer types, populations, and geographies, which all have the potential to make an even bigger difference for patients if implemented on a larger scale.

The project is built on three simple principles:

1. Accelerate (speed up the changes that work);
2. Collaborate (work together across organisations and communities);
3. Transform (make a real, positive difference to cancer care).

And when we say NOW, we mean it. The aim is to put these changes into action without delay, so patients can feel the benefits sooner.

Contents

BCRT: National Sarcoma Awareness Project

INTRODUCTION AND SCOPE	Primary bone cancer, also known as bone sarcoma, affects an average of 610 people annually.[1] In our 2020 Patient Survey, patients shared that symptoms can be vague in presentation or similar to other conditions, such as sporting injuries, growing pains, and other MSK conditions. Respondents based in the UK visited their GP on average four times before being referred.[2] And we know from further consultation with our patient community and analysing national data that these delays can result in poorer outcomes.[3] When discussing bone cancer diagnosis with medical students, we hear that there continues to be limited education on rare diseases during their degree, and they have limited exposure to sarcoma patients throughout training. This indicates that future doctors could miss red flag symptoms, which could lead to delays in referral for diagnosis. Out of 200 medical students and resident doctors who participated in 2024, 71% said they did not receive teaching on sarcomas in school. In 2013, Bone Cancer Research Trust and Sarcoma UK collaborated with a consultant orthopaedic oncology surgeon at Liverpool University to fund the National Sarcoma Awareness Project (NSAP). Since its conception, the project has grown to educate more than 2,250 future doctors participating in the educational initiative and resulting in 48 funded fellowships at specialist sarcoma centres in partnership with sarcoma experts.[4] Both medical students and trainee doctors are provided with recommended learning materials (guidelines, charity resources, etc.) before undertaking an online questionnaire hosted on SurveyMonkey. Every applicant is given a certificate of participation, with the top 10 scorers being offered a fully funded week-long placement at a regional sarcoma centre. The project opens in the spring following the annual British Sarcoma Group conference, closing at the end of September. The Bone Cancer Research Trust assists with coordinating the fellowships with the relevant sarcoma leads, and funds are allocated once the dates are confirmed. The students and junior doctors are expected to complete their placement before the next British Sarcoma Group conference, where they are recognised for their achievement and receive a full day's admission complimentary for CPD points.

ASPIRATION	NSAP aims to improve the diagnostic experience for future patients, catching and educating early-career doctors with the aim of improving outcomes. • Continue to expand the NSAP programme to promote awareness and education to doctors, trainees, and AHPs • Engage with the Royal College of GPs to provide regular, structured training to GP trainees • Engage with AHPs to widen awareness at multiple points of contact so the signs and symptoms are recognised, no matter who a patient may see initially This project helps aid in earlier diagnosis. For sarcoma, lifestyle and environmental risk factors are not relevant for disease prevention, so this creative and collaborative solution allows for intervention in a future doctor's journey to aid in symptom recognition. This aligns with the shift of sickness to prevention, but also a workforce plan to upskill NHS staff.
SOLUTION AND IMPACT	As the charity has only taken over full administration of the project over the last year, there is a gap in evidence to demonstrate impact. This limitation is being addressed by requiring post-placement reflections and quantitative data analysis of participant feedback. Some key evidence from the most recent cohort includes: • Before the project, 62% of participants did not know the clinical signs of sarcoma, afterwards, this increased to 98% based on questionnaire responses • The programme has sparked retention in the field of oncology and research. For example, a previous participant is now a NIHR Academic Clinical Fellow in Trauma and Orthopaedic Surgery, who also leads the NSAP steering committee
KEY FIGURES/QUOTE	• *"The fellowship has had a profound impact on my career trajectory. I can only aspire to deliver the same standard of excellence and empathetic care that I witnessed during my time with the East Midlands Sarcoma Service."* • *"This experience has heightened my awareness of sarcoma presentations and will allow me to be more vigilant in recognising early signs and symptoms."* • *"This experience has solidified my desire to pursue a career in oncological surgery."* • *"I was involved in a six-hour surgery to remove a tumour and another case where curettage was required to remove a giant cell tumour of the bone. Both were operations I would never get the chance to see as a student or even junior doctor."*

ANY OTHER INFORMATION	The administration of the NSAP has been absorbed by the charities, with a 50/50 financial split of the fellowship costs at £750 each. This is used to cover travel, accommodation, and any additional hospital administration fees that might be incurred when enrolling in their short-term placement. The sarcoma leads across the centres are identified by the steering group and then coordinated with the relevant participants, where they will agree on specific dates. Participants from last year's cohort were surveyed and confirmed that the £750 is sufficient to cover costs, which was increased from a previous allocation of £500 for the years 2013-2023. Links: • The National Sarcoma Awareness Project | Bone Cancer Research Trust • I completed the National Sarcoma Awareness Project, here's why you should too | Bone Cancer Research Trust • Advocacy in Action Award - SPAGN - Sarcoma Patient Advocacy Global Network
CANCER52 MEMBER ORGANISATION	Bone Cancer Research Trust

BCRT: Living With and Beyond Primary Bone Cancer

INTRODUCTION AND SCOPE	National cancer registry data indicate that from 1995-2022, there are estimated to be over 8,000 people living with and beyond primary bone cancer in England.[5] These patients often face a long, protracted route to diagnosis with an average diagnostic interval of six months in the UK.[2] Both patient experience data and quality of life data reveal that those diagnosed with late-stage bone tumours have increased levels of depression, reduced social functioning[3] and report overall less satisfaction with their care compared to other cancer types.[6] Our patient community has identified the need to understand and address long-term and late effects as a key priority. They specifically refer to the 'patchwork' follow-up care and varying access to late effects services as an issue. In 2015, we published the *Living With and Beyond Primary Bone Cancer* report. Since then, in response to unmet supportive needs voiced by our community, we have initiated other projects in this area, such as the rollout of survivorship-focused peer-to-peer support resources, medical student placements in partnership with the University of Sheffield and University of East Anglia focused on understanding patients' experiences of long-term and late effects, and the UK-wide long-term and late effects service mapping exercise led by a six-month civil service secondee, which is ongoing. This service mapping exercise is the first of a two-phase, in-depth project, shaped in response to the needs of our community, which is looking to build a picture of primary bone cancer survivorship in the UK. The service mapping exercise (phase I) began in October of 2024 with the aim of mapping out long-term follow-up and late effects monitoring services available to UK primary bone cancer patients, as reported by medical providers. This information is gathered via a comprehensive online survey, which has been developed in close consultation with the project's Long-term & Late Effects Working Group. The group comprises 18 members, including those with lived experience of primary bone cancer and professionals such as oncologists, a specialist physiotherapist, an orthopedic surgeon and clinical nurse specialists within the NHS. Ethical approval has been granted by the University of Bath's Research Ethics Committee and the Health Research Authority. Data collection is ongoing, and widespread survey dissemination continues via a multi-faceted online recruitment strategy. The project's Working Group will advise on the point at which data collection should cease, in line with the representativeness of the final dataset.

	Where evident gaps in the data are identified, contingency plans are in place for a Freedom of Information request to be submitted to relevant NHS & HSC trusts. The results will be analysed and interpreted fully before the design and dissemination of results via online resources (a detailed service directory and visual map of UK service provision), internal and external reports, publications and conference presentations. Guided by the findings of the service mapping exercise, Phase two of this specific project will further investigate available late effects services through interviews and focus groups.
ASPIRATION	The aims of the long-term & late effects service mapping exercise • Improve awareness of and access to long-term follow-up services and support • Identify any gaps in currently available support for patients and loved ones in the months and years beyond active treatment • In the context of lived experiences gathered in subsequent phase II consultation, to determine what health service partners and the charity can do better to support patients With a deeper understanding of these specific services, we can collectively address the needs of patients and their loved ones by providing adequate and comprehensive care, no matter where they are located. And with the Government's ambitions for a healthier Britain, we hope to see more people surviving after cancer, which highlights the need for robust follow-up care.
SOLUTION AND IMPACT	The service mapping will compile the information gathered in phase one into a directory of late effects services available to be hosted on the charity website and disseminated widely. The results will also help to inform and shape a large-scale UK-wide consultation with the primary bone cancer community (phase II), exploring lived experiences of long-term and late effects amongst a larger cohort of patients and family members. Collectively, this research will build a much-needed, detailed picture of the survivorship experience and long-term supportive needs across differing contexts of service provision. This has been voiced as a major priority amongst the primary bone cancer community and BCRT's wider stakeholders, and will support the charity in meeting the collaboratively shaped strategic goal to ensure that, over the next ten years, more patients can survive and thrive beyond their diagnosis and treatment. Following the completion of phase II, wider work will commence to utilise the findings in collaboration with the NHS, Government, and

	relevant bodies, such as NICE and the British Sarcoma Group, to make recommendations for service improvement based on existing gaps, disparities, best practices, and experiences identified through the findings. Having presented the service mapping exercise to the CanUK nursing group working in cancer long-term follow-up, they suggested the potential for the project findings to evidence the need for increased investment into these services, such as staffing and wider service provision.
KEY FIGURES/QUOTE	• *"I was not prepared for how it would affect me afterwards. I understand the tumour had to be removed, but I should have been warned about how it would affect my life."* • *"There is a perception that you finish treatment, and you leave, and you start popping champagne bottles and life's back to normal, but the reality is quite different"* • *"It can feel like you're pushed off a cliff after finishing treatment and expected to learn how to navigate a life outside of cancer alone."* • 93% of friends and family are concerned about how the effects of long-term health of loved ones who have primary bone cancer. [7]
ANY OTHER INFORMATION	The service mapping exercise was started as a secondment with a Civil Service Fast Streamer in the fall of 2024. Since the placement has concluded, the project is being carried forward by staff members at the charity. The cost to host the secondee was £2,742. The cost to roll out the survey was £258. Working group members are consulted on an unpaid volunteering basis. There are anticipated costs for an additional analyst to synthesise the evidence of phase one and initiate phase II, which will also include freelance design costs. Links: • Long-term and Late Effects Resources | Bone Cancer Research Trust • Living with, and beyond, primary bone cancer | Bone Cancer Research Trust • About primary bone cancer | Bone Cancer Research Trust • Living with and beyond primary bone cancer, The Bone Cancer Research Trust.pdf
CANCER52 MEMBER ORGANISATION	Bone Cancer Research Trust

Eve Appeal: WID®-easy Test

INTRODUCTION AND SCOPE

In 2022, 10,440 women in the UK were diagnosed with womb cancer (also called endometrial or uterine cancer) and 2,695 died[8]. Overweight/obesity and longer life expectancies are leading to a rising incidence of the disease: increases in incidence of around 24% and mortality of approximately 45% are expected by 2050.[9]

Abnormal uterine bleeding (AUB) is the most common symptom of womb cancer. More than 90% of women with womb cancer present with AUB, yet only 1.25% in pre-&peri-menopausal women[10] and 3.4% of post-menopausal women[11] with AUB are eventually diagnosed. An estimated 300,000 peri- and post-menopausal women present each year in the UK with AUB. Clinicians must distinguish those women with cancer who require urgent treatment from those who can be quickly reassured and discharged.

GPs triage post-menopausal women with AUB according to NICE NG12 guidelines and the Faster Diagnosis Standard pathway[12]. The pathway requires transvaginal ultrasound to measure endometrial thickness followed by biopsy if the endometrium is thickened. The low specificity of the transvaginal ultrasound (52% in an international meta-analysis)[13], means that almost half of women undergo need a biopsy to find the 3% of women with cancer. Methods for collecting tissue for biopsy are highly invasive, often cause pain, and also miss some cancers (88% sensitive[14]).

Speed of diagnosis is particularly important in the case of womb cancer. A modelling study based on UK data found that womb cancer outcomes are more sensitive to delay than other cancers with a three to six month delay in diagnosis leading to 24% to 43% additional deaths from womb cancer each year[15].

Black women are twice as likely to die from womb cancer compared with white women.[16,17] One reason for the disparity is that ultrasound is less effective, missing four times more cases of womb cancer in black women than white women, partly due to a higher incidence of fibroids[18].

Rates of referral via NG12 to the Urgent Suspected Gynaecological Cancer pathway have tripled since 2009, with more than 280,000 referred in 2022/23. At the same time, prevalence of cancers diagnosed via this route has fallen from 6.6% to 2.9%. Those who do not meet NG12 criteria, often younger women with heavy menstrual or persistent intermenstrual bleeding, join the wait for a non-urgent appointment. In July 2025, more than 582,000 were waiting for a non-

	urgent gynaecology appointment in England, with more than 250,000 waiting more than 18 weeks.[19] The poor performance of the diagnostic pathway, where many have painful and unnecessary procedures, have led clinics to become overwhelmed with patients. Only 4 out of the 42 Integrated Care Boards in England meet current NHS targets to rule out cancer within 28 days for at least 75% of patients, meaning worrying wait times for women at greatest risk of womb cancer. Researchers at University College London, led by Professor Martin Widschwendter and with significant funding from The Eve Appeal over many years, have developed the WID®-easy test which detects womb cancer due to abnormal uterine bleeding in those aged 45 years or over. With this innovation, the researchers aim to transform the broken womb cancer detection pathway.
ASPIRATION	The WID®-easy test (in the literature referred to as WID-qEC) is a novel aid to diagnosis that detects womb cancer in a sample similar to the sample taken for cervical cancer screening. The WID®-easy test is a real-time PCR-based assay which detects an epigenetic change - DNA methylation – in two genes (ZSCAN12 and GYPC). The gene regions were identified in an epigenome-wide analysis of differences between DNA methylation in cervical smear samples from women with EC and those without (n=726)[20]. The prospective, consecutive cohort study (EPI-SURE) compared the performance of the WID®-easy test and ultrasound in the detection of womb cancer.[20] The WID®-easy outperformed ultrasound. It detected the same number of cancers as ultrasound (sensitivity 91%), whilst reducing by 90% the number of cancer-free women who required further invasive testing to have the diagnosis ruled out. Additional data confirm the performance of the test [21] including in black women[22]. An initial and very rapid NHS implementation of the WID®-easy test will be in the secondary care setting, where it will be used as an aid to diagnosis of womb cancer. Prioritising biopsy of those women with a positive WID®-easy result will accelerate diagnoses, lead to fewer appointments and lower rates of non-completion of the diagnostic pathway, improve patient experience and help clinics to meet their FDS targets. In the longer term, implementation of the WID®-easy in primary care as a replacement for transvaginal ultrasound is targeted. Additional studies in primary care will be required.

SOLUTION AND IMPACT	The WID®-easy test has been brought to the market by UCL spinout company Sola Diagnostics GmbH, in which The Eve Appeal are shareholders. The test has a UKCA mark and is distributed in the UK by Advanced Global Health Limited. The test has been extensively studied within the NHS setting and is being rolled out in a series of implementation pilot projects in partnership with Cancer Alliances and Health Innovation Networks.
KEY FIGURES/QUOTE	This innovation has garnered significant stakeholder attention including £2.1m of NIHR funding for a large clinical trial in North Central London (supported by the North Central London Cancer Alliance) and selection for the NHSE National Innovation Accelerator Program.
ANY OTHER INFORMATION	Each hysteroscopy+/-biopsy performed costs the NHS £572, assuming it proceeds without complication. The WID®-easy could reduce the burden of these invasive tests by up to 90% (see above). A health economic analysis of a pathway including the WID®-easy test, based on data from the EPI-SURE study, is currently underway and will highlight the potential for significant cost savings in the NHS.
CANCER52 MEMBER ORGANISATION	The Eve Appeal

Leukaemia Care: Navigator Support Programme

INTRODUCTION AND SCOPE	Supportive care that includes adequate support with financial, practical and emotional aspects of a diagnosis is long established as the gold standard of cancer care. Yet plenty of evidence shows, including from Leukaemia Care, Blood Cancer Alliance and Cancer52, that there are disparities in access to said care. These occur by geography, hospital set up (closeness of haematology to cancer services), age of person at diagnosis, clinical severity of diagnosis and type of cancer. This is despite our work also showing that emotional impact is not easily predicted, and is dependent on many factors. For example, many people diagnosed with CLL and placed on active monitoring (not immediately treated) report a large emotional impact that is unrecognised, due to the prioritisation of people acutely unwell. We believe that this is leading to increased burden on the cancer care system in the long term, compared to providing a basic level of care and support to all who need it.
ASPIRATION	Leukaemia Care navigators are staff that are placed with clinics and wards to provide care to those with leukaemia. They are there to listen to patient concerns, offer informal emotional support, triage and escalate patients with more complex needs, advocate for patient experience and signpost patients to further services. Depending on the location and the types of patients seen in each clinic, navigators can support patients with any type of leukaemia, as well as MDS and MPN patients. They can see both inpatient and outpatient attendees. Navigators are not trained or registered healthcare professionals, unless via a previous career, but they are trained in the support needs of people with leukaemia. *Expected outcomes include:* - improved access to support, as nearly all patients received follow up information, signposting, referrals or further interactions with the charity or medical team. - improved emotional health; navigators described many patients being in distress when they were interacting with them. - improved general wellbeing. This programme aligns with the desire within the Government to empower people to take more care of themselves, to enable them to use the digital technologies and community services as we shift towards these. It is an enabler to all the ambitions of the Governments health plan and cancer plan.

	This initiative runs on an honorary contract basis, where the people are employed by the hospital but managed and paid by Leukaemia Care. We currently work with 22 different hospitals across the UK.
SOLUTION AND IMPACT	Patients surveyed within 12 months of meeting a navigator report having access to support that they believe they would not have obtained easily alone. They also report increased activation, a measure of their ability to participate in their care and express concerns. Activation is linked to wellbeing, with people who are more empowered taking a greater part in their care, and more likely to be in good health as a result. Clinical nurse specialists and advanced nurse practitioners working with patient navigators reported the navigators to be professional, helpful to patients and time saving for their role. The role is likely to be cost saving compared to offering the same support via a nurse. It also provides a return on investment to society of at least 15 to 50 times the amount it costs to deliver the programme. A very rudimentary analysis of the users of the service found that most people who contacted a navigator within the last 12 months lived in an area below the average IMD deprivation score. We believe the provision of face to face support, offered proactively without needing to ask for help, is important in engaging underserved communities.
KEY FIGURES/QUOTE	All patients reported feeling more emotionally supported after meeting with the navigator. Only 2% of patients thought they would have accessed the same support without the navigator. 71% of those surveyed felt more confident to ask questions or raise concerns with their healthcare professionals. 90% of people felt their care was joined up and well co-ordinated since meeting the navigator. 88% felt they knew how to get additional help if they needed it in the future. 66% felt they were more able to manage their condition day to day without more support, and a further 17% said they felt more able if more support was provided to them.

	The average deprivation score (IMD) of the areas lived in by people accessing the navigator service was 4.3.
CANCER52 MEMBER ORGANISATION	Leukaemia Care

Sarcoma UK: Support Line

INTRODUCTION AND SCOPE	The Sarcoma UK support line was opened in February 2016, offering a healthcare professional-led support line to anyone affected by sarcoma. The aim was to offer confidential, expert advice and support. The close links with the sarcoma specialist centres have definitely increased the reach of the support line, and since opening, the team has had over 30,000 contacts with more than 6500 individuals. People can currently reach the team via freephone, email, and text, and the line is open between 10 am and 3 pm Monday to Friday. Two healthcare professionals are available each day to answer the contacts that come in to the team. The support line team have been contacted by patients, family members, friends, employees, and healthcare professionals as well as the general public who are worried about sarcoma.
ASPIRATION	The aim of the support line is to give everyone who is affected by sarcoma a platform to ask questions, be that in relation to sarcoma itself, treatment options, support available or for general support. The team want to be in contact with as many people diagnosed with sarcoma in the UK, as soon as possible after diagnosis, to offer the support them are not receiving within NHS services. For example, we know that 90% of people with sarcoma say their mental health suffered as a result of their diagnosis and treatment, but only 1 in 5 accessed emotional support during or after treatment.[23]
SOLUTION AND IMPACT	In December 2020 the support line team commenced a project with the South Wales Sarcoma team in which the team felt it would be an added benefit to their patients to be able to directly refer the patients to the support line team at the time of diagnosis. This would eradicate the need for people to find the SL team themselves and would offer that added support to them directly. It also aims to encourage interactions with different demographics that the SL has not reached organically (e.g. middle-aged men). The team would email the SL team a name and telephone number and the team would then reach out to that person.
KEY FIGURES/QUOTE	The success of the South Wales direct referral scheme inspired expansion to over 15 other services across the four nations of the UK, including Aberdeen. Buy in from clinical teams has meant the team has now had over 550 direct referrals, enabling the support line team has been able to offer direct support to those people from the point of their diagnosis. This has helped them navigate what is happening for them, allowed them to ask questions and ultimately help them to feel less isolated in the world of sarcoma, one of the loneliest cancers.
CANCER52 MEMBER ORGANISATION	Sarcoma UK

Shine Cancer: Shine Shake Ups

INTRODUCTION AND SCOPE	One in 10 cancer diagnoses occurs in people in their 20s, 30s or 40s and yet this group doesn't have a high profile as a patient population. Younger adults with cancer often lack visibility as a patient group and are underrepresented in clinical trials, limiting their access to optimal treatments.[24] Younger patients are less likely to give positive feedback on their experience of care - they felt less involved in the decisions around treatment, reported having fewer discussions about their needs, and were the least likely to report getting the right level of support for their overall needs.[25] The mental health challenges that result from a cancer diagnosis are notably higher in younger adults and from our work with young people, we know that they struggle particularly with feelings of loneliness and isolation. In the UK, there has also been a sharp increase[26] in the number of younger adult patients. There has been approximately a 22% increase in diagnoses within the group that Shine supports in the last forty years. With growing numbers and a resulting higher level of need, we need to look at ways to better support people in this age group with an approach that meets their specific needs. Taking this context into consideration, we aimed to develop an event that offered to support younger adults to discuss some of these issues and connect with others. Shine Shake Up events are open to anyone in their 20s, 30s or 40s who has had any type of cancer diagnosis. We don't put a time limit on when people can attend - we know the impact of cancer as a young adult is often long lasting and we want people to access support at the best time for them; sometimes this is years after diagnosis and treatment. We wanted the day to feel relevant for those living through cancer treatment, those in remission and those living with an incurable cancer diagnosis. We designed a day that could be delivered to as few as 8 participants and up to a maximum of 40. We also encouraged people to bring a 'plus one' if this would help them to attend the day. We piloted our Shake Up events in Edinburgh and Southampton, running the days in Maggies centres, on the grounds of NHS hospitals. We used the feedback from these pilot days to design a larger event in collaboration with the NHS team at the UCH Macmillan Centre in University College Hospital London. We worked predominantly with two members of that team. Vikky Reilly, the team leader of the support and

	information specialist team at UCLH who previously worked as a nurse consultant in TYA services in the trust. And Maxene Wickwar, a member of the same team, also a qualified nurse with previous experience working in haematology and chemotherapy units. We worked together to consider the content of the day, we discussed the patient population that the team support, and integrated Shine's research results and experiences of previous events into the plan. On Saturday Sept 21st 2024, we welcomed 39 participants to The Living Room at UCLH - we were conscious of making the venue as non-clinical an environment as possible. The UCLH staff attended, were present throughout the day and offered one to one conversations with participants who wanted to talk confidentially. Two members of the Shine Team led the day and we had two peer supporters in attendance. The day consisted of three workshop style sessions, interspersed with time for introductions, social conversations, and opportunities to learn about each other's stories. The day was co-designed by the Shine team, young adults with cancer, and the team at UCLH.
ASPIRATION	Shine Shake Up day events have been designed to offer younger adults with cancer the opportunity to meet in person; they provide the opportunity to discuss and share the mental health challenges that come with having a cancer diagnosis in this age group, to reflect on their experiences, and to connect with others in the same position. The intended outcomes are twofold: • to increase the wellbeing and experiences of young adults going through cancer • to provide connection to a community of others who can understand and offer peer support This fits with government ambitions and supports the NHS 10 year plan goals to: move more cancer related care into the community and empower patients to engage in supportive initiatives that are personalised to them. This also supports the earlier NHS Long Term plan which aims to improve both quality of life and patient experience outcomes. It also seeks to redress the inequalities in the experiences of younger adults of cancer care which have been consistently shown in annual national Cancer Patient Experience surveys to be less good than those of their older counterparts.
SOLUTION AND IMPACT	We used both qualitative and quantitative measures to assess the impact and outcomes of the Shake Up Days. In order to measure whether we were reaching our first aim, to improve attendees' wellbeing, we used the Short Warwick-Edinburgh Mental Wellbeing Scale[27] (SWEMWBS). We asked attendees to answer a short

	questionnaire immediately before and within the week following the event. This matrix allows us to measure levels of wellbeing amongst participants and to put a financial value on any increase in wellbeing achieved. Using this highly regarded measurement tool, Shine's Shake Up events have been shown to increase wellbeing by, on average, £3,831.96, per attendee. The average cost of a Shake Up event is approximately £200 per person and, as such, these events offer a significant positive impact on wellbeing for the financial outlay. We also asked attendees to report what they took away from attending the event and received the following feedback reassuring us that we are meeting our second aim of connecting people with a community that they can continue to find support from: • "In my 2 and a half years in dealing with cancer, it's been a lonely journey as I have always been the youngest person in every room by a mile. Being with people of a similar age group who just get it was hugely beneficial for me and for once I actually didn't feel alone. I feel like I've found connections for life which is just amazing. So thank you." • "The day was just what I needed. Simply having the opportunity to talk to other people who have experienced cancer was such a help for me - something I didn't get through 3 years of treatment." • "Was a brilliant group of people. Super welcoming, personable, no awkwardness or cringey moments. [...] I have made connections and feel really empowered by the day. Thank you for letting me be part of it." • "Thank you so much for allowing me the opportunity to meet other people with shared experiences. It's the first time I haven't felt completely alone in a long time." • "Just want to say a big thank you, the support you provide is just brilliant, you create a warm, easy going environment and help people to connect."
KEY FIGURES/QUOTE	We've been asked to run repeat Shake Up events at UCLH based on the NHS team's experience of the day and the feedback it received. We also have additional events planned in collaboration with other charities and NHS organisations in Exeter, Oxford and Brighton.
CANCER52 MEMBER ORGANISATION	Shine Cancer Support

Solving Kids Cancer: IMPACCT

INTRODUCTION AND SCOPE	The Initiative for Multi-stakeholder Partnership to Accelerate Children's Cancer Trials (IMPACCT) is a UK-wide, patient-led programme established by Solving Kids' Cancer UK to address persistent delays in the set-up and delivery of clinical trials for children and young people (CYP) with cancer. IMPACCT brings together NHS Principal Treatment Centres (PTCs), Clinical Trials Units (CTUs), research funders, patient advocates, research workforce and policymakers to identify and overcome systemic barriers in the UK's clinical trial ecosystem. • **Context:** Clinical trials are essential for improving survival rates, especially in hard-to-treat childhood cancers. However, the UK faces slow trial start-up times and increasing process complexity, limiting access for children in need. • **Timeframe:** Launched in 2024 • **Partners:** Chaired by Professor Pam Kearns, coordinated by Solving Kids' Cancer UK, and involving representatives of all stakeholders involved in academic paediatric cancer research across the UK. • **Reach:** National, with engagement from all UK PTCs and relevant CTUs.
ASPIRATION	IMPACCT's purpose is to accelerate access to potentially life-saving clinical trials for CYP with cancer by streamlining processes, improving coordination, and removing barriers to trial delivery. The initiative aligns with national cancer policy ambitions to embed research in standard care pathways and reduce health inequalities. • Ensure clinical trials remain a standard part of treatment for all CYP with cancer. • Initially address three critical bottlenecks in trial delivery: pharmacy processes, workforce capacity, and R&D efficiency. • Foster a collaborative, action-oriented culture across the CYP cancer trial delivery ecosystem.
SOLUTION AND IMPACT	IMPACCT's methodology is structured and action-focused, with each working group following a three-phase framework: Define, Understand, Propose. How Priority Areas Were Set

After initial sector-wide consultation, the IMPACCT Core Group identified three priority areas as the main bottlenecks to timely trial set-up and delivery:

1. Pharmacy – Streamlining trial set-up and drug management processes, especially e-prescribing and Standard Operating Procedure (SOP) harmonisation.
2. Workforce – Addressing staff shortages, skill gaps, and the lack of defined benchmarks for research staffing in paediatric cancer trials.
3. R&D Efficiencies – Reducing inconsistencies and duplication in trial site approvals, especially around standard-of-care definitions and research costing.

The Working Group Process

1. Define

Each working group begins by clearly defining the landscape and the core issues:

- Pharmacy: The group mapped out pain points such as complex paediatric oncology protocols, inconsistent pharmacy SOPs, delays in e-prescribing system set-up, and limited early pharmacy input in protocol development.
- Workforce: The group agreed to map the current workforce supporting clinical trials, including all relevant disciplines (clinicians, nursing, pharmacy, data management, R&D support), and to capture the level of interaction with Paediatric Oncology Shared Care Units (POSCUs) and funding sources for key posts.
- R&D Efficiencies: The group identified challenges such as inconsistent definitions of standard of care (SoC) versus research activity, prolonged site negotiations due to lack of a standard research costing tool, and limited knowledge exchange between R&D and CTUs.

2. Understand

The next phase involves analysing root causes and gathering evidence:

- Each group collects data (e.g., workforce surveys, SOP reviews), consults with subject-matter experts, and reviews real-world examples to understand the underlying reasons for delays and inefficiencies.

	• For example, the Pharmacy group engaged with trial pharmacists and reviewed trial manual SOPs to understand how they can better serve the needs of set-up teams at sites. • The Workforce group focused on understanding the current staffing landscape and the impact of workforce gaps on trial delivery. 3. Propose Finally, the groups co-develop pragmatic, cost-effective solutions: • Pharmacy: Recommendations include early, centralised pharmacy review of protocols, a standardised pharmacy set-up pathway, and improved trial pharmacy manuals. • Workforce: Solutions include a national workforce mapping exercise, defining clear roles and responsibilities, and advocating for sustainable funding for research staff. • R&D Efficiencies: Proposals include developing national guidelines for SoC, facilitating knowledge exchange, and implementing a standardised NHS research costing tool. Iterative and Collaborative • Each group's work is iterative, with regular review and refinement of objectives and solutions based on feedback and new evidence. • The approach is highly collaborative, involving a broad range of stakeholders and subject experts in each Task & Finish group. **Evidence of outcomes:** • High engagement from all UK PTCs and CTUs, with most sites completing the workforce survey and participating in forums. • Positive feedback from NHS and research partners including HRA on the value of a patient-led, action-focused approach. • Ongoing dissemination of findings and recommendations to national policy forums and Cancer Alliances.
KEY FIGURES/QUOTE	"It is a genuine honour to be the chair of IMPACCT. This important initiative is addressing the critical hurdles we are currently facing in delivering clinical trials for the benefit of our patients. Clinical trials have been the bedrock of our progress in improving outcomes for children and young people with cancer for decades. Both national and international consortia have successfully collaborated to design and deliver non-commercial clinical trials that have informed our current standards of care and given the opportunity for our patients to access innovations in treatment. For children and young people with

	cancer, being offered the opportunity to participate in clinical trials is part of the normal clinical pathway. In recent years, this has become more difficult because of the challenges we face in conducting non-commercial clinical trials in the UK. The reasons are complex and multifactorial, but I believe are not insurmountable. IMPACCT is bringing together stakeholders with diverse expertise and experiences of clinical trials, all highly committed to solution-based approach to these challenges, specifically focussed on the aspects of clinical trials delivery that are problematic for our specialty. The level of commitment from all stakeholders has been impressive and our progress to date is summarised in our Interim Report. Over the coming months, we will continue to develop proposals for tangible solutions. The work of IMPACCT is closely aligned with national efforts to improve the UK clinical trial landscape, including the UK Clinical Research Delivery (UKCRD) cross-sector implementation programme and the Government's Children and Young People Cancer Task Force, which will help in translating our proposed solutions into actions." *— Professor Pam Kearns, Chair, IMPACCT*
CANCER52 MEMBER ORGANISATION	Solving Kids' Cancer UK

Target Ovarian Cancer: ‘This Van Can’

INTRODUCTION AND SCOPE

‘This Van Can’ is a community outreach project designed to improve public awareness of ovarian cancer symptoms. The project was led and funded by the Greater Manchester Cancer Alliance (GMCA) in partnership with charities, Target Ovarian Cancer and the Dianne Oxberry Trust.

Ovarian cancer: the national context

In England there are 6,900[28] new cases of ovarian cancer each year, making it the sixth most common cancer in women. Ovarian cancer is most commonly diagnosed in women over the age of 50, with incidence peaking in women age 75-79 [29].

Just over one third (33 per cent) of women are diagnosed with stage I and II disease[29] falling woefully short of the national target in England of 75 per cent of cancers diagnosed at stage I or II by 2028[30]. Five-year survival ranges from 95 per cent among those diagnosed with stage I disease to just 15 per cent for women with stage IV disease[31].

Late stage diagnosis is driven by a range of factors including lack of awareness of ovarian cancer and its symptoms among the general public. Although 85 per cent of women report experiencing symptoms in the 12 months leading up to their ovarian cancer diagnosis[32], only 1 in 5 women are able to name bloating as a key symptom of ovarian cancer[33]. Over half (55 per cent) of UK women would change their diet before contacting their GP if they experienced persistent bloating, whereas only one in three (34 per cent) would contact their GP.[34]

Ovarian cancer in Greater Manchester

In comparison to other areas of England, a lower proportion of gynecological cancers are diagnosed at an early stage in Greater Manchester[35]. Furthermore, there has been a deterioration in early-stage detection for ovarian cancers over recent years across the North West despite improvements overall in England.

About the This Van Can campaign

Led by the GMCA Early Diagnosis team, the project team collaborated with Enabled Medical Solutions (EMS) to develop a mobile information van designed to raise awareness of ovarian cancer symptoms. The van was designed to be eye catching and welcoming, carrying on the outside key symptoms messages, and stocked with engaging resources and information on ovarian cancer. The van was staffed by ovarian cancer ambassadors, who were trained to engage members of the public, talk to them about the symptoms of ovarian cancer and signpost them to their GP if there were symptoms concerns.

	The van was on the road for six weeks from 22 February to 5 April 2025, covering ovarian cancer awareness month (March), operating from 10.00am to 6pm, 6 days per week. The van visited all ten boroughs across greater Manchester, visiting venues including retail and supermarket car parks, and public spaces. All venues were identified for their potential high footfall and located in areas where early stage ovarian cancer diagnosis was lowest. Dinosaur Creative was commissioned to lead the design of the van, onboard materials, and marketing and comms materials to achieve a cohesive campaign. Project Key performance indicators: • The improvement in awareness and knowledge of signs and symptoms • Engagement and reach • Behavioural intent following engaging with the van
ASPIRATION	The goal of the project was to improve public awareness of the signs and symptoms of ovarian cancer and encourage women concerned about symptoms to contact their GP. The project aligns with cancer policy to: • Diagnose 75 per cent of cancer at stage I and II by 2028.[30] It also aligns with the NHS England campaign 'Help Us Help You Clear on Cancer' which aims to raise awareness of cancer symptoms including abdominal symptoms associated with ovarian cancer and improve health seeking behaviour.
SOLUTION AND IMPACT	**Engagement and reach** The project delivered 36 events across the 10 localities of Greater Manchester. According to NHS Greater Manchester Cancer Alliance, the project enabled the partners to speak to 8,296 people in local communities, which exceeded the initial target by 135 per cent.[36] **Survey and behavioral intent** To capture a sense of how effective the van was, and all the activity happening within it, the team collected almost 2,000 surveys from attendees during the six-week period. Some key statistics from those surveys include: • 84 per cent of respondents said they were very likely to contact their GP should they notice signs and symptoms. • 84 per cent of respondents said they feel confident to ask their GP for the correct diagnostic testing for ovarian cancer • 87 per cent of respondents said they now had a very good understanding of the risk factors.

KEY FIGURES/QUOTE	**Comms and media reach** No budget was available for advertising the campaign, a comprehensive non-paid campaign making the most of our organic channels, our key partners and stakeholders and utilising local media. Highlights included BBC Northwest Tonight, which on average has an audience of approximately 639,000 viewers, and the Manchester Evening News which is the leading regional news website in the UK with monthly unique visitors ranging between 10.3 million and 12.6 million. In addition, the print version sells around 6,500 for non-digital audiences. Our social media posts were seen more than 1.1million times. **Other findings** Through conversations with the public, several important misconceptions and barriers to early diagnosis emerged: • Cervical Smear Misconception: Many women believe that a cervical smear test detects all gynaecological cancers, not just cervical cancer. • GP Appointment Access: There is a common perception that getting a GP appointment is difficult, which may delay people seeking help. • Lack of Awareness: Awareness of ovarian cancer symptoms was low across the community. • Positive Reception of Tear-Off Slips: The tear-off symptom slips provided for GPs were highly valued by the public and seen as a useful resource. *"It worked well taking early diagnosis awareness into the community rather than patients having to seek the information, the reach in rather than reach out approach was fantastic. Targeting the locations meant that hard to reach groups through the standard comms channels were able to access the information and were empowered to present to their GP practices with any concerns." Hannah Dixon, Commissioning Manager (Bury)*
ANY OTHER INFORMATION	https://gmcancer.org.uk/this-van-can/this-van-can-ovarian/
CANCER52 MEMBER ORGANISATION	Target Ovarian Cancer

Target Ovarian Cancer: Breaking Down Barriers to the Early Diagnosis of Ovarian Cancer

INTRODUCTION AND SCOPE

Introduction

Breaking Down Barriers to the Early Diagnosis of Ovarian Cancer was a two-phase primary care improvement project, focused on designing and implementing supportive interventions which promote the early diagnosis of ovarian cancer. The project was led in partnership between Target Ovarian Cancer and Pennine Lancashire CCGs, funded by a grant from the Peter Sowerby Foundation.

Ovarian cancer – current state of affairs across the UK

In the UK, each year 6,900 women are diagnosed with ovarian cancer.[28] Unfortunately, most patients with ovarian cancer will receive their diagnosis late, at stage III or IV. Like all cancers, the earlier ovarian cancer is diagnosed, the easier it is to treat, and the greater the chances of survival.

GP awareness is key to early diagnosis. Target Ovarian Cancer found that 43 per cent of women visit their GP three times or more before being referred for diagnostic tests[37]. Early diagnosis at primary care level requires expert detective work. Symptoms of ovarian cancer, like bloating or a change in bowel habit, can often to be tricky to pin down, as they can mimic benign disease. In women with ovarian cancer, misdiagnosis of benign conditions like IBS/diverticulitis is an unfortunate frequent occurrence. Patients will often face multiple repeat primary care appointments before being investigated via the correct urgent pathway.[38]

Safety netting is a crucial key to early diagnosis in the management of suspected ovarian cancer. Target Ovarian Cancer understand systems and processes for effective safety netting varied widely, from a whole practice approach down to different management techniques performed by individual GPs. A gold standard approach, focused on managing test results and persistent symptoms supports both GPs and patients to earlier and faster diagnosis.

The primary care interventions designed as part of this project aimed to improve the earlier diagnosis of ovarian cancer and shorten the diagnostic pathway.

Phase one research on barriers to early diagnosis

Our phase one research looked in detail at the different approaches taken by five Clinical Commissioning Groups (CCGs) in England to ovarian cancer investigation and diagnosis to better understand these geographical inequalities.

The research found four areas where improvements could usefully be made[38]: **Error! Bookmark not defined.**

- Using local level data to drive improvement.
- Promoting the role of technology in early diagnosis.
- Best practice for safety netting symptoms and the referral pathway.
- Developing support for GPs to better understand the symptoms of ovarian cancer and the opportunities for earlier diagnosis.

These findings led to the development of the next phase of the project, giving a starting point for designing innovative solutions to meet these challenges.

Phase two partnership working

Following publication of our phase one report, we shared the findings with Clinical Commissioning Groups (CCGs), Primary Care Networks (PCNs) and GPs in England, and invited teams interested in testing new innovative approaches to support earlier diagnosis to contact us. 25 teams expressed an interest in working with us - this level of engagement was incredibly encouraging, especially given the pressures facing NHS teams at this time (Covid).

Target Ovarian Cancer sought partnerships in regions that have lower than average rates of early diagnosis.

Pennine Lancashire CCGs agreed to a working partnership with Target Ovarian Cancer. A steering group was formed with clinical oversight from Dr Neil Smith, GP Cancer Lead.

Regions involved

Interventions were launched and tested within a selected group of Primary Care Networks within Pennine Lancashire:

- Rossendale West
- Rossendale East
- Ribblesdale
- Blackburn West

Regional insight

Pennine Lancashire faces marked cancer inequalities linked to deprivation. Local data show that areas such as Burnley have significantly higher rates of under-75 preventable mortality from cancer than the England average.[39] Cancer Research UK reports that cancer death rates are nearly 60% higher in the most deprived areas of the UK than in the least deprived, driven by preventable risk factors and later diagnosis[40], highlighting how deprivation contributes to poorer cancer outcomes in regions like Pennine Lancashire.

Several local authorities, including Blackburn with Darwen, Burnley, Hyndburn, and Pendle, are in the most deprived 10% or 20% of England for multiple deprivation indicators.[41] The region has a legacy of industrial decline, with many jobs being low-wage and low-skilled. This is reflected in the region’s lower Gross Value Added (GVA) per head compared with the UK average. For example, Blackburn with Darwen reports a GVA per head well below the national average, according to ONS regional economic data.[42] Blackburn with Darwen frequently ranks among the most deprived local authorities in England, particularly for health deprivation and disability [43]. Rossendale is noted for high employment deprivation.[41]

Across Pennine Lancashire, 57 per cent of ovarian cancer diagnoses are at stage III and IV [44], putting it at the Cancer Alliance average; however, net one-year survival is below average.

Addressing these inequalities involves community-level action to challenge social inequalities and improve the health system's ability to provide equitable care.

Project timeline
Interventions took place over a six-month period, involving 17 GP practices across the 4 Primary Care Networks, from December 2021 to May 2022.

Summary of interventions developed and introduced in Pennine Lancashire

Intervention one: Clinical IT alert

- Development and roll out of a clinical IT protocol that alerts primary care to possible common misdiagnosis of ovarian cancer as benign disease, namely IBS/diverticulitis. Patients with ovarian cancer often have multiple appointments with a GP or receive a misdiagnosis of IBS/Diverticulitis before investigation or referral of suspected cancer. This alert, which includes recommendations to test CA125 (where a recent result is not registered on the clinical record, along with any other recent investigation result likely to diagnose ovarian cancer) links to NICE guidance on ovarian cancer recognition and management.

Intervention two: Normal CA125 monitoring

- Development and roll out of a SMS/telephone safety netting system to encourage women with normal CA125 results back to primary care for reinvestigation, where symptoms persist or worsen. Patients with early stage ovarian cancer often have normal CA125 results and this contributes to late emergency diagnosis routes. This system helps GPs to raise awareness of ovarian cancer presentation and notify women that where symptoms persist, they are encouraged to revisit their GP for further testing.

Intervention three: Retrospective searches

- Development and roll out of audit search process to identify women diagnosed with a new diagnosis of IBS/Diverticulitis over the last six

	months, where no investigation for ovarian cancer (or other investigation likely to diagnose ovarian cancer) has taken place. Women included in the search are aged over 50, where any new diagnosis of IBS or Diverticulitis is unlikely and should require an initial investigation for ovarian cancer. Women from these lists are contacted by practices to raise awareness of ovarian cancer presentation and encourage presentation and re-investigation at primary care level where appropriate. **Funding** PCNs received incentive payments for undertaking project activity. • Finances were allocated for administration time (running searches and contacting patients) at £20 per admin hour, with 30 minutes to run a search and 15 minutes to contact a patient identified, for retrospective search and normal CA125 monitoring activities. • £20 was allocated per clinical IT alert activation, to cover possible extra clinical time ordering investigations for eligible patients. **Project key performance indicators and evaluation framework** Target Ovarian Cancer created an evaluation framework to ensure the programme could monitor the impact of each intervention against local collectable data. With pilot interventions running for six months, it was unlikely in this timeframe that we would see a change in stage of diagnosis data sets. Therefore, to track the efficiency and efficacy of the interventions we monitored three indicators to see if and how they made a difference towards diagnosing ovarian cancer earlier. These indicators were: • Numbers of patients contacted/actioned as part of the intervention. • Number of referrals to secondary care. • GP-reported confidence and feedback. In addition, Pennine Lancashire CCGs agreed to take part in case study interviews and evaluation events to gauge how easy it had been to deliver the interventions, any impact on primary care colleagues and how resource intensive the new tools were to embed and use.
ASPIRATION	The goal of the project was to improve the early detection of ovarian cancer by implementing a standardised diagnostic safety netting management system, to support both GPs and patients, and prevent late diagnosis, and/or misdiagnosis. The project aligns with cancer policy to: • Diagnose 75 per cent of cancer at stage I and II by 2028.[30]

	• Ensure GP practices have ‘safety-netting’ processes in place for patients sent for an investigative test.[45]
SOLUTION AND IMPACT	**Clinical IT Alert - impact on clinical decisions** A clinical IT alert protocol for EMIS Web was developed and tested by four PCNs (17 out of 18 practices participated) in Pennine Lancashire between December 2021 and May 2022.[44] This alert helped GPs and Physician Associates in Pennine Lancashire recognise and confirm misdiagnosis in one woman.[44] In project evaluation, 100 per cent of primary care colleagues in Pennine Lancashire agreed that the clinical IT alert[44]: • Helped professionals consider ovarian cancer as a possible diagnosis.[44] • Was simple to use.[44] • Was a tool they wanted to keep on their system.[44] **Case study of Clinical IT Alert** A woman presented with abdominal pain. She was coded with a diagnosis of diverticular disease, triggering the clinical IT alert. Upon reviewing our clinical IT alert, the GP was prompted to test CA125. The result was elevated. She was subsequently diagnosed with ovarian cancer, allowing her to access the care she needed.[44] The GP involved told us that the clinical IT alert is: [44] *“SMART in every way. Certainly, recommend to other practices as easily reproducible… It fulfilled PCN DES for early diagnosis of cancer… the pop up made me consider it as a differential diagnosis. This led to further risk assessment history and examination and additional CA125 tests that would not have happened without the prompt.”* **Retrospective audit search – impact on clinical decisions** The retrospective audit consisted of an audit search that brings up a list of women coded with a new diagnosis of IBS or diverticulitis in the last six months, with no recent CA125 result. In Pennine Lancashire, 51 women were identified by the search, 24 contacted and 20 tested across four Primary Care Networks.[44] Both the searches and patient communications were led by Physician Associates. • 92.31 per cent of respondents agreed that this audit exercise helped to identify possible misdiagnosis.[44] • Practices reported that patients were keen to undertake the test and be checked, with very few reports of women declining, and

seemingly only under circumstances where investigations for other conditions were ongoing.[44]

- Feedback included that this created a beneficial learning exercise for all staff within the primary care team, and highlighted the symptoms, presentation, and importance of early recognition of ovarian cancer. This resulted in ovarian cancer being discussed at an organisational level more often.[44]
- 100 per cent of participants agreed that their knowledge of ovarian cancer increased because of participating in the project.[44]

Case study of retrospective audit search

"I saw a patient (over 70 years) who was having epigastric pain.
She said she was diagnosed with IBS at 18. Because I was doing routine bloods, I asked to test her for CA125. And her CA125 was massively raised."
– Physicians Associate

The Physicians Associate explained that she had the opportunity to add a CA125 blood test at a time when she was focused on the symptoms of ovarian cancer through her work on the pilot. She noted that without the pilot the patient would have been potentially missed.[44]

Safety netting search – impact on clinical decision making

A safety netting search through the GP practice system that identifies patients with a recent normal CA125 blood test result. These patients can be clinically reviewed and contacted if required to discuss if symptoms have persisted.

This search was carried out by four PCNs in Pennine Lancashire.[44]

- 402 women were identified.[44]
- 365 were contacted and given advice about persistent symptoms and returning to their GP.[44]

Professional evaluation

- 100 per cent of respondents found the normal CA125 monitoring a worthwhile exercise for them and their patients.[44]
- 100 per cent of respondents felt this helped to provide an effective safety netting system for women.[44]

The workload was generally reported as positive and manageable. The Physicians Associates reported positively on their experience of delivering this service, and no challenges were identified.[44]

Additional impact on public awareness of diagnostic tests

An additional achievement in the contacting of patients was the increase of public awareness in the diagnostic tests for ovarian cancer.[44]

	"None of them (patients) knew what a CA125 was. They'd heard something about ovarian cancer maybe because it has been on the news lately, but they said they'd never really focused on it in terms of symptoms." – Physicians Associate The full report on our project can be found here.
KEY FIGURES/QUOTE	Due to the success of the pilot project, the Clinical IT Alert intervention is now in place as a permanent standard safety netting management system across the entire Pennine Lancashire Cancer Alliance patch.
ANY OTHER INFORMATION	*https://targetovariancancer.org.uk/sites/default/files/2023-03/Identifying%20and%20breaking%20down%20barriers%20to%20early%20diagnosis%20phase%202%20report.%20FINAL%20%281%29.pdf*
CANCER52 MEMBER ORGANISATION	Target Ovarian Cancer

WMUK: Active Monitoring Checklist

INTRODUCTION AND SCOPE	Active monitoring (AM, sometimes called ‘watch and wait’) is a key treatment management strategy for patients with indolent blood cancers, like Waldenstrom’s macroglobulinaemia (WM) and lymphoplasmacytic lymphoma (LPL). Most patients will be on AM at some point during their experience, and many will be on it for extended or multiple periods of time. Patients on AM are less likely to come into contact with healthcare professionals, especially as many checkups are moving to telephone or online. Whereas those on active treatments such as chemotherapy have their physical symptoms assessed on a regular basis and have more opportunities to discuss their emotional or psychological needs, patients on AM often do not have this. However, there is no standardised approach to managing and supporting patients on AM in the UK, and therefore patient experience varies widely. To compound the issue, there are no data on the consistency and quality of WM patient experience on AM. In the Big WM Survey, we found that 42% of patients on AM experience high levels of anxiety, whilst only 27% were confident about what symptoms to look out for and what to do about them.[46] Anecdotally, patients report feeling lost, forgotten or confused. As one patient, Andrea, put it: ‘you are just like a rabbit in the headlights… you don’t know quite what to ask or how to ask for it.’ When patients are unable to identify and manage symptoms, and are not empowered to advocate for themselves, it means their WM and related conditions cannot be identified or monitored as accurately, leading to a worsening quality of life, and potentially delayed treatment meaning declining overall health. WMUK exists to help people with WM and LPL to live better quality lives, and we saw this as a key area where we could significantly impact patient experience. In early 2024, we worked with BeOne to pull together an expert steering group of patients, clinicians and data experts to build a long-term project that would improve patient experience and be scalable across other indolent blood cancers.
ASPIRATION	Our goal is to create a new standard of care for AM in WM and LPL. The project was broken down into several stages. 1. Create consensus on recommendations to improve the AM experience of patients and HCPs

	2. Produce a tool that could be used in clinic by patients and HCPs to collaboratively navigate AM and improve discussions and overall the patient experience. 3. Assess the tool in clinical practice with the aim of proving its effectiveness across a sample of sites caring for WM and LPL patients on AM 4. Assess how the tool is impacting the experience of people with WM and LPL on AM 5. Roll out the tool to more centres with WM and LPL patients and work collaboratively across the blood cancer space to scale the project across other indolent blood cancers 6. Use continual monitoring and evaluation to create evidence base to create a new standard of care for AM in WM and LPL.
SOLUTION AND IMPACT	We have now concluded steps 1-3 of the project, and are currently working on steps 4 and 5. **Consensus study** Our consensus study involved 149 WM and LPL patients and 49 HCPs who manage WM. Data collected evidenced a strong need to improve patient experience: • 22% of patients did not receive an explanation of AM at diagnosis.[47] • 69% of patients did not receive written information about AM.[47] • 63% of patients said that their experience of AM could have been improved.[47] • 39% of patients were not advised when to contact their clinical team when on AM.[47] • 51% of patients were not given information on disease symptoms for self-monitoring.[47] • 64% of patients were not directed to support services whilst on WM.[47] A modified Delphi approach was used to establish a consensus on recommendations. No statements failed to meet the agreement threshold and 39 of 40 statements attained a very strong agreement From the consensus study, 7 recommendations were created to define AM, and the Active Monitoring Checklist tool was created to be used during consultation

	Results of the study were presented at the IWWM conference in 2024 **The Active Monitoring Checklist** • Created from the consensus study • A double sided A4 checklist of statements that patients and HCPs could use collaboratively before and during clinics to ensure best practice care for patients on AM, improve patient knowledge and confidence, and reduce anxiety. • Published in May 2024, this was distributed initially to patients • Following review from a UKONS Nurse Board, the 2nd edition was rolled out in 2025 to both patients and nurses and clinicians in five centres managing WM/LPL for evaluation **Clinical evaluation** • 27 consultations were evaluated over 12 weeks in five UK centres treating people with WM, LPL and CLL • Nurses completed an evaluation which was formed of: a) baseline demographic/pre-survey; b) post-consultation feedback after each consultation; c) a post-survey • The evaluation assessed the checklist's impact on communication, education, rapport-building, confidence, emotional wellbeing, and patient engagement • The Checklist was highly rated across all domains, in particular in guiding symptom discussion (mean score 4/5) • Nurses reported increased confidence, and many reported how the checklist had helped uncover unreported symptoms. • Although time-limits sometimes restricted its full use, the evaluation confirmed that the Checklist is a useful tool that improves experience for HCPs in clinic • An abstract on the evaluation results will be presented at UKONS conference in November 2025 **Assessing the tool's utility in improving patient experience** • Patients using the tool will be sent an evaluation created by an expert psychologist to help us measure changes in WM/LPL patients' experience through using the Checklist • This will commence on 29th September 2025, and the evaluation will be open initially for 2 weeks • Alongside evaluation of HCPs, we aim to submit the patient evaluation results to BJHaem in the New Year • Evidence will be used as a basis to create a standard care pathway for AM in WM/LPL, improving the patient experience **Scale project in other blood cancers**

	- We have connected with CLL Support, who are using our evidence base to create their own Checklist and improve CLL patient experience whilst on AM - Our HCP evaluation took into account CLL consultations for this reason, and showed that the WM/LPL template was limiting in some respects for CLL consultations - The aim of presenting this project to Cancer52 and partners will demonstrate: a) the need; b) the effectiveness of such a tool in improving patient experience on AM, improving quality of life, identifying problematic symptoms earlier and preventing serious illness through improved information and communication; and c) demonstrating that this type of project could be rolled out not just amongst other blood cancers but cancer in general, e.g. prostate cancer.
KEY FIGURES/QUOTE	The project was presented: - in a symposium at BSH 2024 conference - as a poster at the International WM Meeting in 2024 - as a poster at the BSH 2025 And is due to be presented: - at the UKONS conference in November 2025 Results from our patient study, we hope to present at BSH 2026.
CANCER52 MEMBER ORGANISATION	WMUK

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