

LARGE-SCALE PARTNERSHIPS TO IMPROVE CANCER CARE AND SUPPORT

**WE ARE
MACMILLAN.
CANCER SUPPORT**

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Improving cancer care

Macmillan is working with health, social care and voluntary sector partners on innovative regional programmes across the UK to create more joined up care and support for people affected by cancer.

As part of this approach, Macmillan service development teams are working to plan and provide tailored local services with – and for – people affected by cancer. All of these large-scale system redesign programmes are based on identified local needs and the outcomes people affected by cancer tell us are important for them.

The programmes aim to provide more personalised and integrated support at all stages of the patient pathway, particularly around the transition from acute care to home. Through all of the different approaches we are testing out, the aims are to support:

- earlier assessment of people's holistic needs and plans to meet them
- a more knowledgeable and skilled cancer workforce
- increased confidence among people living with cancer about what to expect through their cancer journey and what good support looks like
- a more flexible system where teams can work collaboratively across organisational boundaries to provide more integrated care and support.

Ultimately, it is about people experiencing a better quality of life at all stages of their cancer journey.

This issue of Sharing Good Practice is based on interviews with leads from four of these programmes. Their accounts highlight some of the aims, successes and learning that have emerged so far from these programmes.

It is clear, from the four examples shared here, that successful change is always developed within a deep understanding of the local context, and through the strength of local relationships and good system leadership from all partner organisations.

Time is needed to build trust and to understand the perspectives of different stakeholders. There are no blueprints to follow for this sort of work and what works well in one place does not always translate easily to another area.

Health and social care systems are enormously complex and it is often difficult to attribute success to one factor or another. However, it is also important not to get overwhelmed by complexity and the size of the challenge.

Despite the turbulence, there is usually enough institutional and pathway rigidity in the system to be able to measure whether changes lead to improvement.

Nationally over the last three years, Macmillan has invested in a highly successful community of practice to support these programmes. (A community of practice is a group of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly). Three times a year practitioners from our large-scale redesign partnership programmes come together to solve problems, share best practice and learn from what we are testing out locally. These meetings and conversations enable us to capture the best ideas, solve difficult issues together and stay alert to new opportunities. From this shared experience we have also developed a team space, which includes a set of 'how to' guides for Macmillan service development teams to use when setting up these partnerships.

Our experience so far shows that in addition to developing new roles and services,

Macmillan's investment helps to create space for busy NHS and social care professionals to work together with patients and communities to design and test new ideas. And we make sure that people affected by cancer are at the heart of any change.

Macmillan also acts as a mutual convener, bringing together people who otherwise would have struggled to collaborate due to barriers in the system. Finally, we ensure that what we do is carefully evaluated and that the learning is shared across health and social care to spread change.

I hope reading about these programmes and their progress helps you feel inspired and gives you ideas about how services could improve in your region. The map overleaf shows the spread of these redesign partnership programmes across the UK. Please email me or speak to the regional Macmillan Development Managers to find out more about particular programmes.



Further information

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Currently, we are working on over 20 large-scale partnership programmes across the UK to change the way cancer care is delivered.

We're positive these programmes will make sure people affected by cancer receive the personalised support they need throughout their cancer journeys.

Forth Valley

Changing Cancer and Palliative Care



Glasgow

Improving the Cancer Journey



Glasgow

Glasgow Life – Information and Support Service



Altnagelvin

Health and Wellbeing Campus



Northern Ireland

Transforming Cancer Follow up



Isle of Man

Framework for Cancer (Palliative Care)



North Wales

Care after Prostate Cancer TOPCAT



Wales

Macmillan Framework for Cancer in Primary Care Programme



South Wales

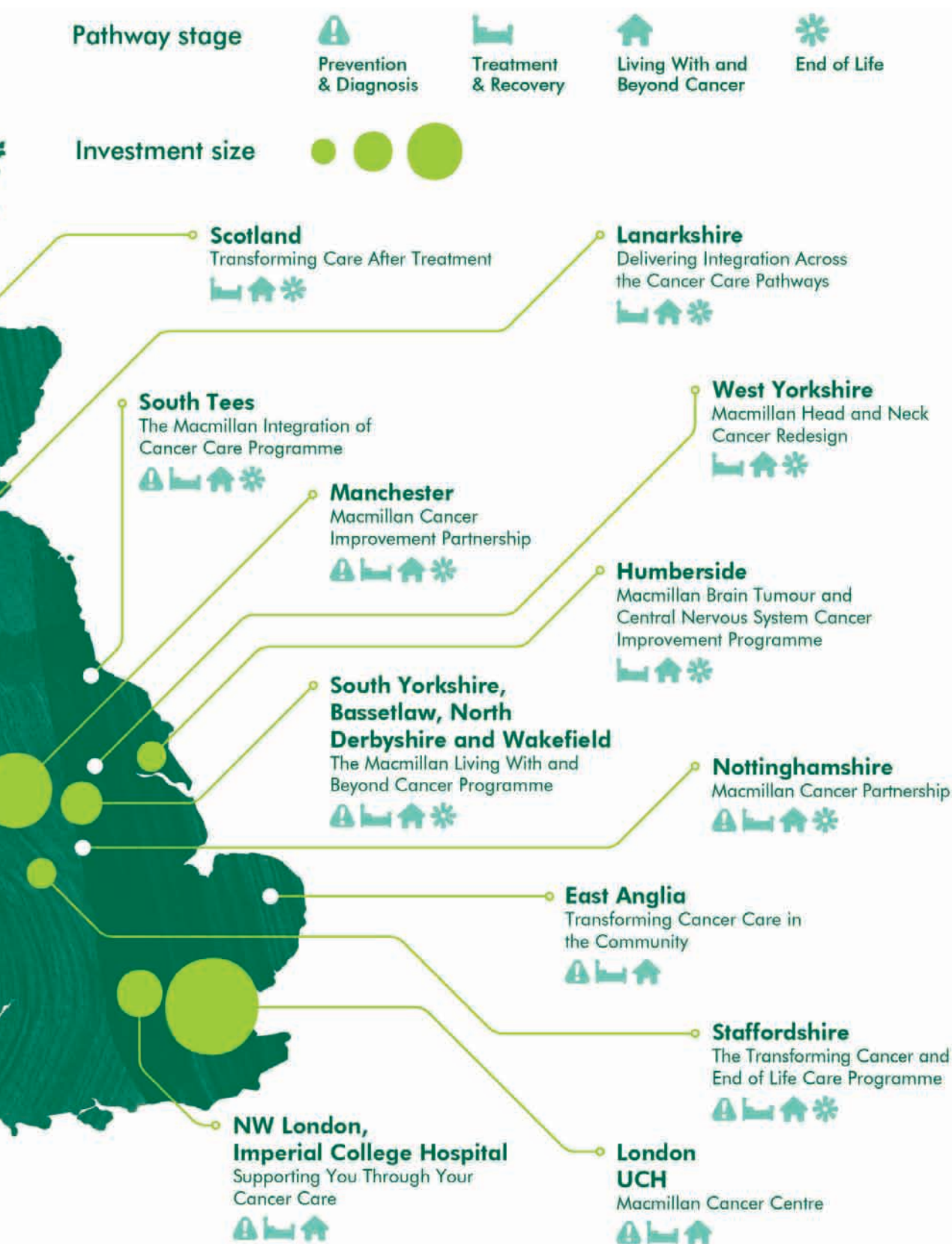
Beyond Breast Cancer



South Wales

Chemo/Acute Oncology/ Metastatic Spinal Cord Compression





Manchester: Macmillan Cancer Improvement Partnership

Janet Tonge, Programme Director for the Macmillan Cancer Improvement Partnership.



Caroline Aherne, above, has supported the partnership



Further information

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What are the aims of the Macmillan Cancer Improvement Partnership?

The Macmillan Cancer Improvement Partnership was publicly launched in June 2014 and is one of the largest system redesign projects in England. It is a partnership between Macmillan, the three Manchester Clinical Commissioning Groups, people affected by cancer, GPs, NHS hospital trusts, St Ann's Hospice and Manchester City Council, with the aim of improving and increasing integration of cancer care across the city.

What improvements have been made in primary care?

We wanted to raise the standards and the level of consistency provided by all primary care services in Manchester. To achieve this, we worked with local commissioners and developed a comprehensive set of cancer standards for GP practices. The standards include key areas for Macmillan such as early diagnosis and palliative care. They were developed in consultation with both people affected by cancer and professionals.

To help these standards have the right impact, we have taken the following steps:

- Macmillan and the NHS joined together to recruit GP facilitators who could support GP practices in meeting the standards.
- We established and trained clinical and non-clinical cancer champions in each practice, drawing on existing practice staff.

We were delighted that 90% of GP practices across Manchester signed up to be part of the standards. In South Manchester 100% signed up. This means we have about 160 cancer champions, all spreading the learning from training they have received, and taking the initiative to make improvements which they see are needed within their own practices. Alongside them are the GP facilitators. Macmillan information points have also been placed in each practice.

The non-clinical cancer champions have been extremely proactive. One member of the public had received a bowel screening kit but was unsure of how to use it. They spoke with a non-clinical cancer champion

at their GP practice, who was able to explain how the kit works. After the person had used the kit, it was identified that they had bowel cancer.

Much work has been done to improve the use of the cancer register and improve support through cancer care reviews. Simple, low-cost actions included as part of the standards – such as people receiving a call from their GP two weeks after their cancer diagnosis, to offer support – have been very well received. After one year of the programme, we can show strong progress against each of the standards.

An evaluation is now taking place and we expect most of the improvements to become embedded in normal practice. To help with this, GP facilitator support is in place beyond the end of the programme funding. Initial evaluation work indicates that there is more to do on GP practices and palliative care, and this is expected to be part of a proposal that will be considered by commissioners shortly.

What has been achieved in palliative care?

North Manchester has one of the highest rates in England for people who die not being in their preferred place of care. We looked carefully at a palliative care model pioneered by Macmillan in Midhurst, in the south of England, and how we could translate the model to North Manchester. In collaboration

with professionals from a Manchester hospice, hospital clinicians, patients, carers, district nurses and homecare staff, we opened a new community palliative care hub. The integrated service is open-referral and operates seven days a week from 7am until 8pm. It also provides a 24-hour information and support phone service. We are now evaluating the new service and qualitative research shows high levels of patient satisfaction. Staff have told us that integration has improved. From July to September 2015 we know that the service prevented around 30 hospital admissions, with an estimated cost-saving to health services of £70,000.

To find out more about the service and how it's helping support people with cancer, watch these short YouTube videos:

- tinyurl.com/mcip-video1
- tinyurl.com/mcip-video2

Can you tell us about the aspect of the programme looking at the needs of non-cancer specialist professionals?

We commissioned a workforce analysis to establish the learning needs of non-cancer specialist health and social care professionals. We did this because of the important role many health and social care professionals who aren't cancer specialists play in supporting people through their cancer journey.

We found there were significant gaps in the knowledge and confidence of non-cancer

specialist health and social care professionals when caring for people with cancer. Only around half of generalists felt comfortable providing information about cancer and discussing cancer risk. Two thirds lacked confidence to assess side effects of cancer treatment. Manchester University produced a scoping report suggesting it would take five years to address these issues, so we started looking at what we could achieve during a one-year programme. Initial training provided to key staff included general cancer awareness. We are currently considering the next steps in providing training and support to these professionals. Hundreds of generalist professionals have responded to our questionnaire asking what support would help them.

How are you looking to improve lung and breast cancer care?

North Manchester has the highest level of lung cancer in England. Central Manchester has the fifth highest and South Manchester the nineteenth.

We were aware of research in America where low-dose CT scans had been used to identify lung cancer early in a large scale random control trial, resulting in a 20% reduction in mortality rate. We weighed up the research evidence and after thorough debate within the Manchester Cancer Improvement Programme board, and with local clinicians and commissioners,

Manchester: Macmillan Cancer Improvement Partnership

we decided to develop a pilot operational lung cancer early diagnosis service. Sadly, lung cancer is often diagnosed at a late stage when treatment options are limited and survival rates are low. We know if we can find lung cancers much earlier in a population with our level of lung cancer incidence it will result in a lot of lives saved.

We have done a lot of work to design the new service, from developing the clinical protocols to procuring a provider for a lung health check and CT scanning. People will be invited to attend a lung health check. This will be a nurse appointment, during which they will be asked questions connected to a lung risk-assessment calculator. People above an agreed risk of developing lung cancer will be offered a low dose CT scan there and then. This will function as a one-stop shop for non-symptomatic people.

Although this will not be a research project, we will be evaluating and recording evidence from the pilot. We also expect it will also help us to diagnose some co-morbidities. This important project is part of the ACE Wave 1 – an NHS England, Macmillan and Cancer Research UK demonstration programme which is looking to learn from innovations in health care. The new service is in the final stages of development. When it goes live, by May 2016, we expect that it will be one of the first, or the first service of its type in the country.



The Manchester Cancer Improvement Partnership board

We are also committed to making changes in the breast cancer pathway. For this, we have looked at the Transforming Cancer Follow Up programme in Northern Ireland (see page xi) and how they have successfully integrated the Recovery Package into breast cancer care. We now have several groups of different clinicians and commissioners working with us and people affected by cancer to change the way in which the local system works, partially around the follow up for people affected by breast cancer.

How have the different partners in the programme worked together?

Each area of the programme has a work stream, a steering group and/or a subject area group, which allows new ideas to be co-designed and changes implemented. We act as change agents, provide improvement support and service planning,

support people affected by cancer to take part in design and decision making, gather evidence and report the impact of interventions. We have used other's good practice to help shape our thinking and I would like us to increase the amount of evidence we gather, so that learning from work we have undertaken can be used elsewhere.

We couldn't do this without the Macmillan service development teams across Manchester, who have been a huge support in providing advice, coordinating between organisations and championing the interventions publicly through communications.

Glasgow: Improving the Cancer Journey

Sandra McDermott, Head of the Glasgow Improving the Cancer Journey programme.

What are the aims of the Improving the Cancer Journey programme?

The main aim is to develop and deliver a clear and seamless care pathway that can be accessed by everyone with cancer in Glasgow. We want to make sure appropriate care is equitable and offered to everybody at the point of diagnosis and across organisational boundaries. Our aim is that care should always be based on need, as established through robust holistic assessment and care planning, in line with the Macmillan Recovery Package.

What has been achieved so far?

We have key partners across Glasgow working very closely together. This includes the NHS, Glasgow City Council, Glasgow Life (which provides physical activity and information services), social care and housing providers, and two other charities.

Since we started in February 2014, we have contacted just under 3,000 people in Glasgow who have had a new cancer diagnosis. That has resulted in just over 1,506 referrals into the service. Those people have identified 7,242 concerns using the holistic needs assessment tool. And we have made 4,345 onward referrals to more than 221 support services. People who have come through the service have accessed more than £1.7 million in additional benefits.

We haven't introduced new services, to meet people's needs once we have identified them – those community assets were already available in Glasgow.

We've just managed to map out where that support is against people's needs. I think that has been quite revolutionary, because we're enabling more people to access support across the city in a much more efficient way.

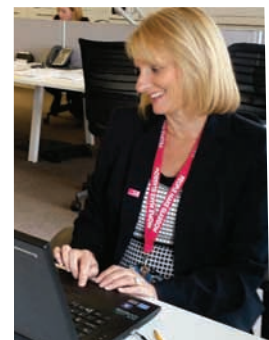
We are also making sure all carers who are identified are referred for a formal statutory carers' assessment. The national average for that referral is only 5%, so we're working with Macmillan to try to create an e-HNA specifically for carers.

When we asked people if the service improved their quality of life, 81% of people with cancer agreed it had. 79% said it had helped them regain control over their life and to manage their condition. 86% said it reduced their stress and 77% said it made life easier for them. 93% said it reduced their feelings of isolation, which is a key problem that Macmillan has identified in its research reports.

How are the partner organisations working together?

At an executive director level, the organisations have formed a board for the programme. Then below that, the heads of services also sit together on a steering group. So you have a governance structure, with senior members working together to develop the service.

A unique aspect is that we don't depend on



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referrals; we actually work with our NHS colleagues to contact everyone in Glasgow who has had a cancer diagnosis, through a data-sharing agreement. This means we can access everyone; we don't just reach people actively seeking information and support, who may already be more empowered than other members of the community. One of the amazing statistics is that 77% of people we see are in the bottom two quarters of the Scottish Index of Multiple Deprivation (SIMD). These are among the most socially deprived people in Glasgow, and historically this group has very rarely accessed the support they need. And 59% are level one of the index, so these are the most deprived people in Glasgow, accessing the help they need.

What have you (and Macmillan) learned through developing the programme?

We have learned there is a lot of unmet need. Almost everybody we have seen has had between six and eight concerns that are not about health. As Macmillan has found through research, we've found that actually the health journey is often quite robust – it's everything else people are worried about. It can include caring responsibilities, housing, family, spiritual and emotional concerns, social issues and sexuality. Only 3% of our assessments need to go back to health experts; everything else is picked up by social care, housing, or other charitable organisations in Glasgow. The biggest concern from colleagues in healthcare was that the needs we are uncovering would mean they became swamped, but that hasn't happened.

Are there lessons that Macmillan professionals reading this, who are involved in service development, could take away?

The biggest learning for me has been about the partnership working. It has been about people coming together and using various expertise to solve a complex problem. By working together you can break problems down. The project has seen everybody pull together to meet the needs of people affected by cancer; it's not just one organisation trying to fix everything, it's everybody bringing their strengths and expertise and knowledge to the table and being open to break down the barriers. It's about being aware of the needs of people affected by cancer and then seeing what the impacts are if we all work together to provide a joined-up holistic support and care planning.

How can Macmillan professionals become involved in the programme or support it?

A lot of the referrals we make actually go back to Macmillan colleagues. So they are a really important part of what we do. We have hundreds of referrals going back to Macmillan, whether it is Macmillan grants, the financial guidance and welfare benefit teams or direct volunteering services.

I think professionals can help by understanding the role that other agencies – including local authorities, housing organisations and social services – can play in improving the overall health and well-being of people affected by cancer and their carers and family. Health can't solve everything on its own. To meet the needs of people affected by cancer, we need multi-professional teams. If we can harness that within a city, or across organisations, we can deliver a bigger impact together than we can on our own.

Northern Ireland: Transforming Cancer Follow Up

Liz Henderson, Macmillan Special Adviser for Redesigning the System.

What are the aims of Transforming Cancer Follow Up?

There are currently 63,000 people living with cancer in Northern Ireland. By 2030, numbers are expected to rise to more than 110,000. Our existing healthcare system will not be able to cope with growing patient rehabilitation and secondary prevention needs.

Although cancer is increasingly becoming a chronic condition, traditional follow up was framed around acute illness, with the focus on monitoring and review. However, evidence shows that up to 70% of recurrence is picked up outside clinics.

The Transforming Cancer Follow up (TCFU) programme was the result of a strategic partnership between Macmillan, the Health and Social Care Board and Public Health Agency, facilitated through Northern Ireland's Cancer Network (NICaN).

The overall aim of TCFU was to introduce and test new models of cancer follow up across Northern Ireland which would:

- improve the quality of patients' aftercare experience and promote their health and well-being
- reduce inefficiencies in hospital follow up and enhance service coordination and integration
- guarantee sustainability.

What has been achieved so far?

The TCFU team was made up of Macmillan project managers based in Northern Ireland's five health trusts, with regional coordination via Macmillan programme managers within the cancer network. They began by redesigning breast cancer aftercare and replacing a 'one size fits all'

approach with a more individually tailored and patient-centred service. A risk-stratified approach places patients with breast cancer into one of three pathways: self-directed aftercare, shared care or complex care.

It was initially agreed that 30% of patients newly diagnosed with breast cancer should be placed on the self-directed aftercare pathway with the support of the Macmillan Recovery Package. This ensures that every patient has access to a clinical nurse specialist (CNS), who discusses all their needs in the form of a written 'care plan'. An additional treatment summary helps both patients and their GPs understand their treatment and possible longer term consequences. Finally, people are invited to go along to a health and well-being event, where they hear about all the practical things they can do to keep well.

The team paid particular attention to ensuring the new self-directed aftercare pathways were safe and responsive to patient need. This involved developing new self-directed aftercare codes for the Patient Administration System, redesigning the mammography system and developing rapid access back into the system via the patient's CNS. Clinical teams now have more time to focus on complex cases.

By December 2014, when an evaluation was carried out, 58% of newly diagnosed patients were on the self-directed aftercare pathway. That figure is continuing to rise. As a result, waiting lists for routine follow up appointments



Further information

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had been reduced over the two year evaluation period, showing a:

- 28% reduction in surgical breast waiting lists
- 39% reduction of patients in duplication between oncology and surgery review waiting lists
- 4% reduction in oncology breast review waiting list.

The establishment of a new review breast mammography system has proved highly successful. Every self-directed aftercare pathway patient now receives automated review mammography appointments, with results sent direct to their homes within two weeks – reducing waits and patient anxiety.

Patient experience has improved as a direct result of these changes. The final evaluation highlighted the following increases in satisfaction rates amongst patients on the new breast programme, compared to the baseline survey:

- 34% more patients said they were aware of the importance of lifestyle changes (45%–79%)
- 15% more patients strongly agreed/agreed that they had been supported to manage the practical impact of their cancer (40%–65%)
- 23% more patients strongly agreed/agreed that they had been supported to manage the emotional impact of their cancer (44%–67%)
- 16% more patients strongly agreed/agreed that they had been supported to manage the physical impact of their cancer (59%–75%).



The Transforming Cancer Follow Up Team

The learning from the breast cancer TCFU programme has been shared with other regional network site specific groups, namely prostate, colorectal, gynae, head and neck, dermatology and haematology. Prostate cancer patients are moving onto new pathways with the support of CNSs.

A Northern Ireland survivorship website has been set up at survivorship.cancerni.net

In terms of sustainability and in the context of efficiency savings, the partnership worked with the service to ensure changes were embedded at no additional cost.

What have you (and Macmillan) learned through developing the programme?

Governance infrastructure needs to be robust and aligned with decision-makers within the local health care economy. TCFU was developed in line with Northern Ireland's Cancer Services Framework, Transforming Your Care strategy and commissioning priorities.

A 'bottom up/top down' approach was adopted with change coming from within the TCFU team. Engagement of clinical teams and other key stakeholders is absolutely vital for ownership of the process.

Stakeholder engagement helped alleviate concerns about potential patient anxiety following the change of pathways. Improvements were made using the 'plan, do, study, act' cycle and close monitoring increased confidence in the new system.

Working closely with champions for change and early adaptors helped gain support in implementing the TCFU programme. Drawing on examples from models elsewhere and utilising external champions were also key to the success of the programme. It is important to lead with evidence, particularly evidence from clinicians' own caseloads. Having Macmillan Service Improvement Facilitators employed



Clockwise from left: Jim Wells, Health Minister; Dr Miriam McCarthy, Consultant in Public Health Medicine; Dean Sullivan, Director of Commissioning, Health and Social Care Board; Lisa McWilliams, Senior Manager, NICaN; Heather Monteverde, General Manager of Macmillan in Northern Ireland; Mary Jo Thompson, Cancer Nurse Consultant, NICaN; and Liz Henderson, Macmillan Special Adviser

by each trust who all met regularly with the regional Macmillan TCFU Managers proved critical.

Are there lessons that Macmillan professionals reading this, who are involved in service development, could take away?

Service improvement is challenging, given the complexities of the workplace. Teams need to buy into the overall vision to improve their service and take responsibility to work together to bring changes about. It's important to recruit champions at strategic, organisational and clinical levels. Macmillan provides great support in terms of supporting learning and helping with process changes.

However, the interests of people affected by cancer are central to any improvement. Wrapping services around their needs helps ensure that any change enhances patient experience.

Redesigning systems and processes sometimes requires changing practice, which should be seen as an opportunity to develop new knowledge and skills. The introduction of patient-led concern checklists gives nursing assessment a more holistic focus.

Breast care nurses lead on audits of patients' needs, which they present at MDT meetings – a process that has allowed them to develop their leadership skills.

How can Macmillan professionals in your area become involved in the programme or support it?

Breast care nurses in Northern Ireland were actively involved in the programme from the outset. They helped to develop the protocols and processes to ensure that the pathway changes were safe. They are the point of entry back into the system. The programme is now being rolled out across other tumour sites.

Newly appointed professionals should speak to their local Macmillan Development Manager and their clinical service manager about how to get involved in transforming cancer follow up across other tumour sites.

Macmillan Service Improvement Leads have now been appointed in all five health trusts. They are working on the further roll out of TCFU, action plans based on Northern Ireland's first Cancer Patient Experience Survey, published in October 2015, and ongoing peer review.

Is there anything else you would like to mention to Macmillan professionals about your programme?

While the formal TCFU programme has officially come to an end, the principles underpinning risk-stratified follow up and the Recovery Package are being rolled out across other tumour sites. It is important to keep this momentum going and Macmillan Professionals can be real ambassadors for people affected by cancer by ensuring cancer survivorship and more efficient follow up remains high on their own health trust's agenda.

North Wales: Trial of Personalised Care After Treatment for Prostate cancer (TOPCAT-P)

Caroline Morris, former Macmillan Prostate Cancer Clinical Nurse Specialist, spoke to us about her recently completed programme.

What are the aims of your programme?

The TOPCAT-P trial (Trial of Personalised Care After Treatment – Prostate cancer) was aimed at identifying the unmet needs of prostate cancer patients once they had completed treatment. We aimed to develop an oncology follow-on care and support pathway in primary care for this group of patients.

The patients that were recruited to participate in the trial were between nine and forty-eight months post-treatment. The inclusion criteria was for patients who had received radical, curative treatment (surgery, radiotherapy, brachytherapy, hormone therapy or a combination of these) or those within the watchful waiting category. All of these treatments have side effects, either short-term or long-term; some of these are often ongoing and can have a detrimental effect on patients' quality of life. Due to the longevity of some of these side effects, prostate cancer is often compared to a chronic disease, and it was therefore considered appropriate to support this group of patients within the primary care setting.

TOPCAT-P was a randomised control trial; we recruited 92 patients into the trial who were then randomised to either the control or intervention arm of the project. Patients in the intervention arm were all invited to an initial face-to-face appointment with a Clinical Nurse Specialist, where a person-centred approach was utilised within holistic needs assessments. This was supported by use of the Macmillan assessment and care plan tool. Follow-on appointments were then arranged on an individual basis, dependent on the patient need, either face-to-face or by telephone.

The unmet needs (physical, emotional, sexual or psycho-social) were identified through communication with patients, allowing them to explore their feelings and emotions surrounding these side effects of treatment, the psycho-social impact of this and how their quality of life may have been affected as a result. A personalised plan of care was then developed and advice given to help minimise these side effects where possible, liaising with the GP when



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necessary. Where side effects could not be reduced, patients were encouraged to identify ways in which they could alter aspects of their lifestyle to develop coping strategies that may help with symptom management and consequently improve their quality of life. This empowerment and supported self-management helped patients to feel more in control of the side effect rather than feeling that these symptoms were controlling aspects of their lives.

What has been achieved?

The evidence showed a strong association between the physical side effects of treatment and the psychological effect this has on prostate cancer patients. Many physical symptoms were shown to have a related emotional concern.

For example, urinary incontinence can lead to embarrassment, anxiety, loss of confidence and, in some cases, social isolation. Fatigue and low energy levels can lead to frustration and low mood at not being able to perform tasks. And men who suffer with sexual dysfunction often experience loss of masculinity and self-confidence. Through the trial it was demonstrated that by reducing one of these concerns (for example, by changing lifestyle to reduce the effect of the physical symptom, or listening to patients' psychological concerns related to this and advising as necessary) the level of concern for the other greatly reduced, or in some cases, disappeared all

together. Therefore, the need for psychological support post treatment was identified, as this appeared to have therapeutic benefits for those in the trial; use of a holistic needs assessment and the concerns checklist within the Macmillan assessment and care plan tool was an important factor to help achieve this.

Many patients had similar concerns but not all had the same level of need, which was easily identified with the concerns checklist. This enabled me to prioritise the symptoms people felt were causing them the most significant concern, and to ensure person-centred care, as patients were in control of the assessment process.

What have you (and Macmillan) learned through developing the programme?

We have learned that there continues to be a great deal of unmet needs among this group of patients. Although many prostate cancer patients have successful curative treatment they are often left with long-term side effects of treatment which impact on their quality of life. Following completion of treatment as patients become more stable, their hospital appointments naturally decrease, but patients can feel very alone with these concerns. The majority of these patients want to manage and cope better with these concerns and symptoms, but they do not know where to ask for help and support. It was often embarrassment that prevented

them from discussing symptoms such as sexual dysfunction or incontinence with healthcare professionals; for others the side effects appeared to become part of their new normality post-treatment and something they felt they 'had to live with'.

This group of patients appeared more than happy to self-manage their symptoms once they were signposted to the relevant services, and for some patients with a mild level of concern for their symptom, this appeared all that was needed. But for patients with a significant level of concern, the one-to-one support they received whilst in trial appeared to be very valuable; however, once the level of concern had reduced they appeared very willing to self-manage and it was important to ensure that they were signposted to relevant services at the end of their time in trial to enable them to continue with their self-management strategies and maintain their improved quality of life.

Are there lessons that Macmillan professionals reading this, who are involved in service development, could take away?

I think Macmillan professionals need to be aware of current support services that are available within their local area to be able to signpost patients correctly. These change quite often as services are improved or developed, so it is important to be aware of any updates to ensure patients are given correct information.



Patients' concerns and support needs change throughout their cancer journey. This should therefore be addressed at regular intervals, to ensure appropriate signposting occurs. A holistic needs assessment and person-centred care appears fundamental to this.

Time is a precious commodity, but it was this resource that was needed by the CNS to allow effective and sensitive communication with patients. It was also noted that some patients may take time to build a level of trust within the professional relationship with the CNS before they may be able to disclose personal concerns, such as those related to relationships or sexual dysfunction. However, it was acknowledged that the time allowed within the trial

may not always be possible with clinical practice. In view of this, on reflection it was considered important to allow the patient some time to identify the level of concern with their symptoms as this would then aid effective time management as it enabled the CNS to prioritise their concerns. Often, developing a self-management strategy for one symptom (physical) reduced another concern (emotional) or vice versa, which would also aid time constraints in clinical practice. It was also considered that the symptoms that may be perceived by health professionals to have the most significant level of concern might actually differ from the patients' point of view; this demonstrates how powerful person-centred care can be and will also help the progression of an assessment in a timely manner.

How can Macmillan professionals in your area become involved in the programme or support it?

The trial is now complete. However, Macmillan health and well-being clinics are a very useful format to provide patients with signposting information and support for any ongoing concerns or needs that they might have. They also provide patients with an opportunity to meet professionals from various disciplines and other people affected by cancer and their families, from who they may gain mutual support.

Is there anything else you would like to mention to Macmillan professionals about your programme?

I would like to mention the positive feedback patients gave me during follow-up appointments, relating to the copy of their written care plan that I posted to their GP. When I advised patients to speak to their GP regarding a symptom that they found very embarrassing, such as sexual dysfunction or urinary incontinence, I had several comments that this conversation was made easier by the GP already being in receipt of their care plan. This enabled the GP to be aware of why the patient may have the appointment and the GP would then be able to instigate this sensitive conversation, reducing patient embarrassment.