PRIMARY CARE

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Introduction

Dr Anthony Cunliffe, Macmillan’s National Lead GP Adviser, describes how Macmillan is supporting primary care professionals to deliver the best care for people with cancer.

Primary care has a vital role to play in addressing the changing needs of cancer patients. From supporting people through tests and diagnosis, to improving quality of life for people living with and beyond cancer, it is essential that GP practices get the encouragement and resources they need to support the growing numbers of people affected by cancer.

Macmillan has worked closely with primary care professionals for more than 20 years. We now have a community of more than 200 Macmillan GPs, who have protected time to support and enable the delivery of high-quality care for people with cancer.

As part of a new five-year strategy, Macmillan is keen to build relationships with professionals across primary and community settings, supporting them to help people find, navigate and access the sources of support they need at a time and place that is right for them.

Our new toolkit for GP practices
We have been working with practices across the country to develop our Cancer Care in Primary Care Quality Toolkit – a national piece of work designed to keep cancer as a priority and support the delivery of high-quality cancer care within primary care.

The toolkit is currently in different stages of testing and evaluation across England, Scotland and Wales. All versions take a whole-practice approach to quality improvement, and encompass modules that span the entire cancer pathway.

The toolkit contains suggestions of how to achieve high-quality cancer care, and explores:

- how a practice supports informed uptake into national cancer screening programmes
- what can be done to ensure prompt recognition and early detection of cancer
- the importance and quality of cancer care reviews
- the longer-term impact of cancer and cancer treatment on an individual
- the use and quality of advance care planning for people with cancer
- the importance of working as a whole team, with the most efficient use of skills and resources.

The toolkit was first implemented in Scotland, with uptake in 25% of practices. As part of this project, practices were asked to choose three of the six modules within the toolkit, and work through these over the course of a year, with our support. The feedback has been great, with many practices saying they have enjoyed the opportunity to sit down as a team and discuss how they look after patients with cancer. We are also starting to collect data that demonstrates the improvements in the quality of care that can come through implementation of the toolkit. For example, before the pilot, only 32% of practices said that their cancer care reviews covered financial support, but this has risen to 61% after the pilot.

In England, a pilot is currently underway in the North West and in London, building
on the work in Scotland. There is a continued focus on quality improvement with an added quantitative approach through the development of pre-prepared automated searches. These searches were developed in collaboration with IT provider EMIS Health, and allow practices to baseline current activity, and then revisit the searches after implementing the toolkit to measure any changes. We are now working with each of the three major primary care IT providers to ensure these searches are available across each of these three systems.

These searches will not only help us to evaluate the toolkit itself, but can also be used to support impact measurement at practice level, or within cancer alliances, clusters and health boards. You can find out more about this and our wider work with primary care IT providers on page vi.

A Welsh adaptation of the toolkit is now also in development, and we hope to make this available to practices in early 2019. Improvements are already being made across Wales through the Macmillan Primary Care Cancer Framework Programme, and on page x you can read about a recent pilot to support practice nurses to deliver high quality cancer care reviews.

We are also working with colleagues in Northern Ireland to develop a suite of tools and resources that can improve the quality of cancer care, with the option of developing a toolkit going forward.

For more information on the toolkit and some top-line findings, watch our video update at bit.ly/2PlSFwC

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**Other resources**

We also have several toolkits, guidance documents and online training modules available to support primary care professionals at macmillan.org.uk/gp

These resources span a range of topics, from early diagnosis and supporting carers, to end of life. You can see more detail about some of these on page xv.

And finally, the Primary Care Update is a quarterly newsletter developed by a group of Macmillan GPs to keep primary care colleagues updated on news, research, resources and improvements in cancer care. You can sign up by visiting the News and Updates section at macmillan.org.uk/about-us/health-professionals

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**Further information**

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Macmillan Primary Care Conference

If you missed this year's event, Macmillan Content Developer Ella Thompson provides an overview of our annual conference for primary care professionals.

The Macmillan Primary Care Conference took place in Gatwick in September, with a focus on the theme of championing Macmillan to influence positive change in cancer care.

As well as updates on our future strategy, and the ideas that will be key to its successful implementation, the event also provided learning experiences for professionals, highlighting best practice in cancer care within primary care.

During a breakout session over lunch, delegates were invited to hear about how they can support the development of NHS England's long-term plan. Our GP advisers hosted table discussions, looking at challenges around screening and access to diagnostics, access to optimal treatment, personalised follow-up and workforce, to gain insight from Macmillan's primary care community about the role that NHS England can play in overcoming barriers in each of these areas. Learnings from this session have been fed back to NHS England and will support ongoing conversations around each of these themes in relation to the organisation's long-term plan.

There were also opportunities to share perspectives and network with peers from across the UK, including Macmillan GPs, GP advisers, practice nurses, primary care nurse facilitators and consultant advisers.

Keynote addresses
The first keynote session was delivered by clinical trialist Professor Tim Eisen, who spoke about recent developments in genomic medicine. He focused on new therapeutic gene-editing treatment that has the potential to improve cancer care throughout the pathway, and could improve cancer prevention, early diagnosis, personalisation of care and management of cancer recurrence.

Professor Eisen acknowledged that, given the complex and fast-developing nature of the field, there is difficulty in keeping up with service development and ethical issues that arise when research and knowledge grows exponentially in this way. He identified the need for a shift in the types of resources that Macmillan will need provide to help support people undergoing genomic treatment in future. For example, an investment in workforce and education, the creation of new decision-making tools and a greater emphasis on influencing to make treatment more widely available.

Dr Fran Woodard, Macmillan's Executive Director of Policy and Impact, delivered the Macmillan address, highlighting some of the successes of the previous year and focusing on the strategic thinking behind the recent Macmillan brand refresh. She then moved on to the future of the organisation, announcing a greater investment in the workforce and emphasising the vital role the primary care community plays in helping to deliver our strategy.

David Fitzgerald, National Cancer Programme Director at NHS England, updated the conference on the achievements of the national cancer programme, including record survival rates and patient experiences. In the upcoming year, the programme will
focus on identifying cancer earlier, personalising treatment care and support and developing a strong and responsive infrastructure.

**Data-driven pathways**
A workshop on the four UK cancer registries highlighted key tools and publications available for different aspects of the patient pathway, for people diagnosed in the UK. Examples include:

- cancerdata.nhs.uk
- fingertips.phe.org.uk
- ncin.org.uk

Delegates learned how to use data to improve the experiences of people with cancer, including those who will be diagnosed in the future. Data can be used to highlight variation across and between pathways, helping to drive improvement in cancer care and outcomes.

**Innovating treatment models**
Macmillan Clinical Fellow Dr Archie Macnair and Macmillan Consultant Adviser Dr Richard Simcock delivered a session on innovating treatment models, looking at how best to guide patients through new treatment options in breast and lung cancer. Informed by practical insights from the Clatterbridge Cancer Centre and Sussex Cancer Centre, delegates were presented with case studies and given clinical updates on the latest treatments, including proton therapy and extended hormone therapy. The session also looked at treatable but not curable types of cancer, which are set to impact patients more and more, and are a key focus for Macmillan.

**Out of hours palliative care**
This workshop focused on the communication challenges around advance care planning when a person with cancer is approaching the end of their life. Specifically, the role of primary care professionals to provide essential information to those caring for them outside of practice hours. The session was hosted by members of the team behind Macmillan's partnership with the South West Ambulance Service. They guided discussions on negotiating conflicting IT systems and providing the right medications at the right time. Delegates explored what can be done to support a person’s understanding of what to expect at the end of life and how to empower others with the confidence to make decisions outside of primary care working hours.

Delegates were able to showcase new innovations in cancer care through a clinical poster competition and quickfire soapbox presentations. The aim was to motivate professionals and inspire them to take new ideas back to share with peers locally, and continue the conversation with fellow delegates after the event.

For more information about the conference and other networking opportunities for Macmillan professionals, contact eventsadmin@macmillan.org.uk
Support through system improvement

Macmillan Primary Care Adviser Sophia Nicola on working with IT providers across the UK to enhance cancer care reviews within primary care.

Progress in cancer diagnosis and treatment means that increasing numbers of people are surviving cancer or living for longer with incurable disease. It is vital that the health and care system adapts to meet this growing and changing demand.

Primary care has an essential role to play in effectively supporting people with cancer. GPs have contact with patients at key touchpoints throughout the cancer pathway, including promoting and encouraging the uptake of screening programmes, referring patients with suspected cancer symptoms for diagnostic tests, and providing support post-treatment.

Yet results from the National Cancer Patient Experience Survey 2017 (England) show that 40% of respondents did not feel that GPs and nurses did everything they could to support them during their cancer treatment.

In addition, the research shows that demand on general practice is growing. Fifteen months after diagnosis, patients had 50% more contact with their GPs than expected, highlighting the scale of need experienced by people with cancer in the aftermath of their treatment.

Effective cancer care reviews

Macmillan recognises that a cancer care review (CCR), if carried out and recorded effectively, can be used as a basis for planning care and better supporting patients who are living with cancer.

An effective CCR involves a conversation that focuses on the patient’s concerns and what matters to them. It should be structured and include both a clinical and non-clinical assessment of need. Reviews have been found to be most effective when they cover:

- diagnosis and past treatments
- previously documented conversations about identified needs, for example holistic needs assessment or treatment summary
- plans and actions to address needs
- signposting to holistic support including psychological support, discussion of family or carer needs or lifestyle changes
- risks and symptoms of recurrence.

In order to support primary care professionals to embed this practice, we have worked with the three major primary care IT providers (EMIS Health, INPS Vision and TPP SystmOne) to develop integrated cancer care review templates. These support a holistic conversation between a healthcare professional and a person diagnosed with cancer and should be informed by what matters to the individual.

The templates cover clinical, financial, emotional, practical and psychological needs that a person may have following a cancer diagnosis. They provide professionals with a framework through which they can have a high-quality conversation about what matters to the person living with cancer.

Macmillan has also worked with these IT providers to include links within the templates to further information and support, which can be printed off and given to the patient during this
Sharing good practice

conversation. These links include an introduction to Macmillan, which provides information on how people can get support from Macmillan as well as highlighting information resources that may be helpful, information on prescription payment exemption, and printable one-pagers addressing each of the most reported concerns that patients have during holistic needs assessments.

Macmillan recommends the use of a template to ensure all patients are robustly reviewed in an easily recordable and verifiable form. We have worked to ensure templates are embedded within practice IT systems, and these have been widely welcomed by the primary care community as a framework for conversations.

Use of the Macmillan cancer care review template has been shown to encourage patients to be more open about discussing their needs and in doing so, play an active role in shaping the delivery of their care. This is reflected in the evaluation where 71% of patients reported being ‘very satisfied’ with the process.

Quality improvement searches
In collaboration with EMIS Health, Macmillan has also developed pre-prepared automated searches, which have been built in to the EMIS system. These tailored searches pull Read-coded information from within the practice IT system, allowing practices to construct an accurate picture of their current cancer-related activities. For example, this might be the number of patients that have discussed the financial impact of cancer with their GP or practice nurse, or the frequency, quality and recording of cancer care reviews.

Practices can then measure changes and improvements in activities and outcomes over time, exploring the impact of quality improvement initiatives and identifying or prioritising areas for improvement.

Following initial development with EMIS Health, Macmillan is now working with TPP SystmOne and INPS Vision to support development of the searches within each of these primary care IT systems.

Further information

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References
1. ncpes.co.uk/reports/2017-reports/national-reports-2/3579-cpes-2017-national-report/file
Primary care

Clinical leadership for better cancer care

Macmillan Primary Care Cancer Framework GP Lead for Wales Dr Clifford Jones on building links between primary, secondary and tertiary care.

One of the biggest challenges facing the team of GPs and nurses working on the Macmillan Primary Care Cancer Framework programme is improving communication and integration between primary, secondary and tertiary care.

The programme launched in the summer of 2015 and now has a team of GPs and nurses, working in health boards across Wales and supported by a small office-based team.

The team has a GP lead and a nurse lead for Wales, who work with GP leads and GP facilitators based in each of the health boards, as well as a team of three regional lead nurses that collectively cover the whole of Wales.

The programme aims to influence at three levels: nationally through the Wales Cancer Network, at a health board level through the GP cancer leads and regional nurses, and at local practice and cluster level where GP facilitators provide peer-to-peer support.

I work alongside Susan Llewelyn, Nurse Lead for Wales, to provide clinical leadership for the programme. We influence clinicians and managers at the highest level, working alongside oncologists, radiologists, surgeons and senior cancer nurses to help improve cancer care across primary, secondary and tertiary care.

The programme’s GP leads and GP facilitators are based in each of the seven health boards and Velindre NHS Trust. They work closely with cancer teams to better integrate primary care needs into cancer pathways.

Dr Rachel Lee, GP Lead for Cardiff and Vale University Health Board, says: ‘Often, improvements in processes are a result of honest discussions between our team and secondary and tertiary care colleagues. We highlight problem areas for primary care and take part in improvement negotiations, as well as sharing good practice to enable GPs and nurses based in other health boards to implement similar process changes.’

The GP leads also work closely with primary care colleagues in the area, both through the GP cluster network and directly with individual GPs and GP practices when co-working on service improvement projects or arranging cancer-focused continued professional development events.

The programme’s GP facilitators share learning from the programme’s service improvement initiatives and promote the programme’s online framework of cancer tools, guidance and information designed specifically for Wales-based primary care professionals who are delivering cancer care.

The team of nurses work with health care professionals from primary, secondary and tertiary care to encourage improvements in support for people with cancer throughout treatment, and also in living with the long-term consequences of cancer and its treatment.
Since becoming Macmillan Primary Care Cancer Framework GP Lead, I have seen a definite change in the perception of the role of primary care in cancer care from colleagues in secondary and tertiary care.

Since taking on this role in 2015 I’ve seen a definite change in the perception of the role of primary care in cancer care from colleagues in secondary and tertiary care. The Cancer Peer Review programme is well established in Wales, however the focus has traditionally been on the part of the patient pathway that is delivered by secondary care and specialist tertiary services.

I have been working with the Wales Cancer Network and the Welsh Government’s Cancer Implementation Group to show the value of primary involvement in peer reviews and multidisciplinary teams. The establishment of the Macmillan Primary Care Cancer Framework team has provided an opportunity to demonstrate the unique contribution of primary care to Cancer Peer Review, with members of our team participating in the peer review process in various health boards. We have been looking at what primary care can, and should, contribute to peer review and what added value we can bring to the process.

When I first started in this role, we had to fight to make the voice of primary care clinicians heard in the cancer sector, and we were seen as ‘the problem’. Now our specialist colleagues tell me how important the primary care contribution is to cancer service improvement and that they need more of it. We have become part of the solution.

As part of the introduction of the Single Cancer Pathway in Wales, the national cancer site groups are reviewing and redesigning clinical pathways. Our GPs provide important input into this process and are integral members of the cancer site groups. Our health board GP leads are key links between primary and secondary care locally in this improvement process.

To find out more about the Macmillan Primary Care Cancer Framework visit primarycareone.wales.nhs.uk/macmillan
Supporting practice nurses to deliver cancer care reviews

Juliet Norwood, Macmillan Primary Care Cancer Framework Regional Nurse, on a new pilot to support practice nurses to increase their skills and understanding of cancer care.

The learning from a recent pilot initiative to support practice nurses in Wales to deliver high quality cancer care reviews has helped shape a practice nursing course developed in partnership with Macmillan Wales.

The pilot involves eight practice nurses from surgeries in the Cardiff and Vale and Cwm Taf areas. The nurses are equipped with the skills and confidence to carry out a holistic cancer care review within six months of diagnosis for every person with cancer. This review includes a holistic needs assessment and a co-produced care plan formulated between the person affected by cancer and the practice nurse.

Practice nurses are already involved in chronic disease management, and so these skills are transferable to supporting many people who live with the consequences of cancer as a chronic condition. Co-morbidities mean that nurses already know most of the patients, and have the skills to carry out holistic care, so the pilot supports them to use these skills to deliver cancer care reviews.

The nurses support patients through their treatment and rehabilitation, and provide long-term support for needs that may otherwise remain unmet, such as fatigue, financial or emotional needs, and the many other side effects that people affected by cancer often silently endure.

Ongoing training
All the nurses undergo foundation level cancer training with a toolkit of protocols, useful guides and information, supplemented by two hours of self-directed training per month. Crucially, I also support the practice nurses with regular meetings to help direct learning, discuss challenges and arrange links with relevant colleagues in secondary care.

Every two months the nurses undertake a Learning Needs Assessment to closely monitor and evaluate any increase in cancer care skills.

Practice nurses do a fantastic job and have a vast array of skills and experience, but they are often not fully utilised. Practice nurses have a critical role in the development of a practice’s multidisciplinary team and new models of service delivery, and so it is important that we create opportunities for the nurses to develop new skills.

Kirsty Miles, Practice Nurse at Morlais Medical Practice in Dowlais, says, ‘It has definitely been worthwhile being part of the pilot. It has opened up a completely new aspect to my work. Compared with the GPs we have more time to spend with the patients and my experience has been that people are very appreciative of us contacting them to talk through the care that we can offer. The training and support I have received through this pilot has made me so much more confident in talking to people about their cancer and the issues they are facing as a result.’

Making changes
Primary care can improve its provision of cancer care by adopting a changed pattern of care, with more proactive and
scheduled interactions with people who are living with cancer. These can be instigated and delivered by the practice nurses, bringing the GP in as required.

It is imperative that practice nurses feel confident in their ability to lead the cancer care reviews. This pilot provides the support they initially need in order to gain that confidence and ability to operate independently as a self-supporting community of practice.

The key to this pilot’s success is down to the enthusiasm and commitment of the practice nurses themselves, but also the support of the GPs within the practice who were able to see the potential of introducing new models of service delivery. Utilising the skills of the nurses to deliver cancer care reviews not only benefits the patients, it also lessens the burden of work on our GPs.

Dr Hannah Willoughby, also based at Morlais Medical Practice, says, ‘The formal teaching and mentoring has given our practice nurses the confidence to take on the provision of cancer care reviews, only getting one of the GPs involved when needed. They are a useful contact in the practice for patients at any stage of cancer diagnosis, treatment or survivorship. Previously I tried to fit cancer care reviews into the two days when I am in the practice. Now patients have contact with their GP, and with two full time practice nurses. I hope the pilot rolls out further as I am sure many more practices could benefit.’

Further information

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Improving care across the system

Primary Care Nurse Facilitator Judy Clapp on supporting primary and secondary care professionals in Cornwall to work together to support people with cancer.

After 27 years in practice nursing, taking on a new role as primary care nurse facilitator interested me as I was starting to become interested in the bigger picture of cancer care.

Three years ago, this was a new role, and as the only primary care nurse facilitator in Cornwall, one of the first things I did was a lot of scoping, meeting people and trying to get a feel for what was needed.

The first thing that became obvious was that professionals didn’t know where to signpost people to, so I developed a cancer services directory that goes out electronically to GP practices, the council and the community trust. This is updated about three or four times a year.

Throughout my role so far, I have specifically focused on the following objectives:

• supporting initiatives such as early diagnosis, survivorship and the recovery package
• influencing the development of cancer services within local commissioning structures
• informing and influencing the delivery of cancer care in primary care, from prevention and diagnosis to end of life
• facilitating the education of primary health care teams, especially in relation to cancer as a long-term condition
• enhancing communication between primary, secondary and tertiary care

Enabling education

We have developed a Macmillan practice nurse course, which has had a very positive response in Cornwall, and we have held three courses. We now have 22 practice nurses who are ‘cancer champions in practice’ – professionals who have been trained to have the knowledge and confidence they need to listen to people with cancer and provide extra support where needed. A further 11 practice nurses took part in the September course, meaning 50% of practices in Cornwall have a cancer champion. My goal is to have one in every practice.

To build on the practice nurse course and embed this learning into practice, all of the cancer care champions have bespoke Macmillan information points in their surgeries. This means that anyone affected by cancer can get vital information closer to home. This is especially important in a rural county like Cornwall.

I have also developed and delivered health care assistant (HCA) training to 51 HCAs across Cornwall. HCAs are often at the front line, for example taking pre-chemotherapy blood samples, but they may not have the confidence to offer further support to a person with cancer. The training helps give them the confidence to identify needs and signpost people to the right support.

I have also undertaken the Macmillan ‘very brief advice’ training on physical activity, and facilitated this training for 97 health professionals across Cornwall. This provides them with the knowledge that they are giving safe, evidence-based advice on physical activity for people with cancer.
Participants all say that these courses have improved their knowledge, confidence and how they look after people with cancer in a holistic way. For example, if a person comes in for a diabetic review, if they have a history of cancer, that history is now looked at and the nurses have the confidence to broach the subject. And the health care assistants now have the tools to empower them to encourage people with cancer to keep active, whereas before they simply didn’t feel qualified to say that.

Quality in cancer care reviews

Working alongside Macmillan GPs, we want to raise the profile and quality of cancer care reviews, as well as highlighting the role that practice nurses have in delivering these.

Through a recent initiative, working with Macmillan, Peninsula Cancer Alliance and NHS Kernow Clinical Commissioning Group, we have engaged 63% of practices in Cornwall to support improvements in delivering quality cancer care reviews. Each practice has sent a GP and a practice nurse to a primary care cancer event that we run over two days – the first day in the spring and the second in the autumn. Between these two days attendees are asked to undertake a significant event audit on an emergency presentation of cancer, and an audit of secondary care letters, to help influence the development of a meaningful local treatment summary.

To further support this work, I’ve worked with Microtest, a local computer provider in Cornwall, to develop a template for cancer care reviews. This is now being promoted with all practices in Cornwall, and we would like to develop this further in the future.
Primary care

Influencing change
As well as working with those that deliver frontline services, we want to help shape strategy at high levels, challenging established cultures and mindsets to effect change. Over the past few years I have built strong relationships with key stakeholders across Cornwall and Devon to raise awareness of cancer as a long-term condition.

Recently I was invited to take part in a steering group meeting hosted by Public Health England, which is looking at self-management of five long-term conditions: diabetes, ischaemic heart disease, chronic obstructive pulmonary disease, mental ill health and cancer. It is very exciting and positive that cancer is now being recognised in this way.

My role is evolving all the time and I'm now also very engaged with patient support groups, which means I can advocate and I can liaise on their behalf. It is important to talk to patients about what they need and what they want. I believe that when you are passionate about something it is a lot easier to find solutions, think outside the box and come up with different ways of working.

Judy Clapp's work was recognised at the 2018 Macmillan Professionals Excellence Awards last month. For more details about this year's winners, go to page 8 of the main magazine.

Further information

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Resources

Learnzone: Cancer in primary care
A range of scenarios showing good and bad experiences of patients when they present to their GP and how, on reflection, their experience could have been improved.

Learnzone: Coding and safety netting in the context of cancer
Raising awareness of the benefits of coding and safety netting in improving clinical care, diagnosis and community management of people with cancer and other long-term conditions.

Learnzone: Running a practice nurse cancer course
Includes a wealth of supporting material to accompany the Macmillan’s guide for content, planning and delivery to help you with arranging your course (see below).

These courses are all available at learnzone.org.uk

Macmillan cancer course for practice nurses: a guide for planning, content and delivery
Provides you with the information and knowledge you need to run a Macmillan cancer course for practice nurses, including objectives, process considerations and a content guide. https://learnzone.org.uk/downloads/guide_macmillan_cancer_course_for_pn.pdf

10 Top Tips series
Macmillan GP advisers have collaborated with members of the Macmillan primary care community to develop a series of downloads called 10 Top Tips. These offer practical hints, tips and information on a variety of different primary care situations and scenarios. macmillan.org.uk/about-us/health-professionals/resources

Other support
Visit macmillan.org.uk/about-us/health-professionals/resources for a wide range of resources to support primary care professionals, including:

- Rapid referral guidelines
- Consequences of cancer toolkit
- Advance care planning toolkit
- Guidance on how to identify and signpost carers
- Resources for patients

Primary Care Update
Macmillan’s GP Advisers, with the support of GPs and the wider Macmillan team, produce a quarterly e-newsletter to inform GPs, primary care cancer leads and the wider primary care community. It includes the latest developments, learning and case studies relating to cancer across primary care. To sign up, visit the News and Updates section at macmillan.org.uk/about-us/health-professionals
Have you got an idea for a future issue of Sharing good practice? Get in touch at macvoice@macmillan.org.uk