

The Evaluation of the Macmillan Cancer Quality Toolkit for Primary Care (Wales)

A QUALITY TOOLKIT FOR GENERAL PRACTICE

Macmillan Primary Care Cancer Framework
WALES CANCER NETWORK | MACMILLAN CANCER SUPPORT

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ACROYNYS

ABUHB	Aneurin Bevan University Health Board
ACP	Advance Care Planning
ANP	Advanced Nurse Practitioner
AOS	Acute Oncology Service
BCUHB	Betsi Cadwaladr University Health Board
BMI	Body Mass Index
BSW	Bowel Screening Wales
CCR	Cancer Care Review
CAVUHB	Cardiff and Vale University Health Board
CDS	Cancer Decision Support
COPD	Chronic Obstructive Pulmonary Disease
CoPI	Community of Practice and Influence
COVID-19	Coronavirus Disease of 2019
CPD	Continuing Professional Development
CRUK	Cancer Research UK
CTMUHB	Cwm Taf Morgannwg University Health Board
DN	District Nurses
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
EMIS	Egton Medical Information Systems
EOL	End of Life
FIT	Faecal Immunochemical Test
FOB	Faecal Occult Blood
GMS	General Medical Services
GP	General Practitioner
GSF	Gold Standards Framework
HB	Health Board
HCA	Healthcare Assistant
HCP	Healthcare professional
HDUHB	Hywel Dda University Health Board
HNA	Holistic Needs Assessment
HRT	Hormone Replacement Therapy
IT	Information Technology
LMC	Local Medical Committee
MCQT	Macmillan Cancer Quality Toolkit
MDT	Multi-disciplinary Team
MPCCF	Macmillan Primary Care Cancer Framework
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OOH	Out of Hours
PDF	Portable Document Format

PN	Practice Nurse
PSA	Prostate-specific antigen
PTHB	Powys Teaching Health Board
QI	Quality Improvement
QOF	Quality Outcomes Framework
QAIF	Quality Assurance and Improvement Framework
SBUHB	Swansea Bay Health Board
SPPC	Strategic Programme for Primary Care
UK	United Kingdom
UKONS	United Kingdom Oncology Nursing Society
USC	Urgent Suspected Cancer
WCA	Wales Cancer Alliance
WCN	Wales Cancer Network

EXECUTIVE SUMMARY

The Macmillan Primary Care Cancer Framework Programme

Launched in June 2015, in partnership with Macmillan Wales and the Wales Cancer Network, the Macmillan Primary Care Cancer Framework (MPCCF) was a five-year programme, to support primary care professionals, GP Practices and Cluster networks to improve cancer care. The programme aimed to:

- Support primary care professionals to improve knowledge and skills in cancer care
- Improve integration and communication between health sectors
- Develop and grow a sustainable community of practice and influence to support cancer service improvement in primary care

Project description

The Macmillan Cancer Quality Toolkit project, fully funded by Macmillan Cancer Support, was developed and delivered by the MPCCF programme to improve primary care knowledge and the provision of cancer care in Wales. This educational tool was comprised of five learning modules, covering the whole clinical pathway from prevention and diagnosis to end-of-life care. The Toolkit was offered to all 415 GP practices in Wales. GP practices were given £1000 to complete the Toolkit. Participation involved the completion of surveys to measure progress, identification of gaps, development of action plans and reflections on impact.

Context and purpose of evaluation

An internal evaluation was undertaken by the MPCCF team to determine the impact of the Toolkit by exploring the experiences of GP practices and assessing self-reported changes to knowledge, and processes to improve cancer care. The mixed-method evaluation of the MCQT included two components: pre- and post-evaluation surveys to measure knowledge and experience and document analysis of submitted Toolkits to capture current practice, action plans, reflections on the impact of changes and challenges faced.

Key findings

Between May 2019 and December 2020, 53 (12.8%) practices participated, and 685 primary care staff (clinical and non-clinical) engaged with the Toolkit.

Overall experience and views

- Most participants agreed that the Toolkit had a positive impact on clinical practice (94.3%, n=50/53) and facilitated peer-to-peer learning within their practice (83.0%, n=44/53)
- Almost all (96.2%, n=51/53) participants agreed that the Toolkit was a useful information resource and two-thirds of GP practices (64.2%, n=34/53) indicated that the Toolkit improved their access to information to support patients living with cancer
- Most participants (86.2%, n=45/51) acquired knowledge that was new to them and just over three-quarters of participants agreed that they accessed information that was new to them (80.7%, n=42/52)
- Most participants felt that the Toolkit facilitated quality improvement in cancer care (88.5%, n=46/52) and just over three-quarters agreed that it was a sustainable way to drive quality improvement within their practice (77.3%, n=41/53)
- Despite the reported benefits, GP practices identified several challenges including the lengthy time commitment to complete the Toolkit, usability issues with the interactive PDF, being overloaded with too much information and difficulties engaging with their whole team

Increased awareness and knowledge

Module 1: Detecting Cancer Earlier (n=30)

GP practices improved their knowledge in:

- Cancer risk factors - Practices reporting they were 'knowledgeable' or 'very knowledgeable' increased from 66.7% (n=20) to 96.6% (n=28)
- Risks of the Bowel Screening Programme - Practices reporting they were 'knowledgeable' or 'very knowledgeable' increased from 37.9% (n=11) to 96.5% (n=28)
- Benefits of the Bowel Screening Programme - Practices reporting they were 'knowledgeable' or 'very knowledgeable' increased from 51.7% (n=15) to 96.5% (n=28)
- Cluster and Health Board screening rates for all cancer screening programmes: Breast (6.7, n=2 to 41.4%, n=12), Cervical (6.7, n=2 to 48.3%, n=14) and Colorectal (6.7, n=2 to 44.8%, n=13)

Module 2: Prompt recognition and referral (n=42)

GP practices improved their awareness of:

- Summaries to support the application of the NICE suspected cancer referral guidelines. This included the CRUK Suspected Cancer Recognition and Referral Symptom Reference Guide (from 19%, n=8 to 76.2%, n=32) and C the Signs (from 17.5%, n=7 to 65.0%, n=26)
- The Macmillan Cancer Decision Support (CDS) Tool (from 47.6%, n=20 to 88.1%, n=37)

Module 3: Support through treatment (n=18)

GP practices improved their awareness of the:

- Acute Oncology Support (AOS) App (from 22.2%, n=4 to 83.3%, n=15)
- UK Oncology Nursing Society (UKONS) and Macmillan Cancer Support Tool (from 16.7%, n=3 to 72.2%, n=13)

Module 4: Cancer care reviews and the long-term consequences of cancer and its treatment (n=53)

GP practices improved their knowledge in the:

- Holistic needs of people living with cancer - Practices reporting they were 'knowledgeable' or 'very knowledgeable' increased from 60.4% (n=32) to 92.5% (n=49)
- Long-term health concerns related to a cancer diagnosis - Practices reporting they were 'knowledgeable' or 'very knowledgeable' increased from 49.1% (n=26) to 79.3% (n=42)
- Long-term consequences of cancer - Practices reporting they were 'knowledgeable' or 'very knowledgeable' increased from 54.7% (n=29) to 81.1% (n=43)

Self-reported changes to practice

Module 1: Detecting Cancer Earlier (n=30)

- Almost three-quarters agreed that the module improved practice processes for detecting cancer earlier (72.4%, n=21/29)
- Of those GP practices which did not have a process for contacting non-responders, 11 implemented a new process as a result of the Toolkit (91.7%, n=11/12)
- Self-reported practice changes for improving processes for contacting non-responders to Bowel Screening included:
 - Establishment of a proactive approach to encourage patients to respond to their Bowel Screening invite (e.g., GP endorsed letters mainly)
 - Improved coding and use of clinical reminders (e.g., alert box) to better highlight non-responders to clinicians
 - Actively promoted Cancer Screening Programmes within the practice (e.g., pre-pandemic: waiting room and during pandemic: websites and Facebook)

Module 2: Prompt recognition and early referral (n=42)

- Most agreed that the module improved practice cancer referral processes (80.5%, n=33/41)
- Improved coding practice for USC referrals by:
 - The establishment of a practice process for auditing USC referrals
 - The implementation of the recommended Toolkit code for 'Fast Track Cancer Referrals'
 - Increasing practice staff awareness of the USC referral process, Read code and summaries of guidance
- Improved safety netting of urgent referrals by
 - Increasing awareness and use of patient information to support verbal conversations regarding a USC referral
 - Increasing awareness and use of recommended codes for USC referrals

- Improving audit and follow-up processes for patients referred on a USC pathway
- Increased use of patient information leaflets

Module 3: Support through treatment (n=18)

- Increased use of the:
 - Acute Oncology Support (AOS) App (from 22.2%, n=4 to 44.4%, n=8)
 - UK Oncology Nursing Society (UKONS) and Macmillan Cancer Support Tool (from 5.56%, n=1 to 50.0%, n=9)
- Improved coding practice for:
 - Cancer key worker
 - Treatment modalities
- Established a formal process for contacting patients following a cancer diagnosis

Module 4: Cancer care reviews and the long-term consequences of cancer and its treatment (n=53)

- The majority felt that the module improved processes for supporting people living with cancer (83.0%, n=44/53)
- Positive changes reported by GP practices as a result of this module included:
 - Established structured CCRs
 - Increased use of templates (e.g., Macmillan Cancer Care Review Template) to ensure a holistic CCR
 - Increased awareness of CCR information, resources and tools
 - Improved the coding and recording of CCR information
 - Improved access to CCR training for staff
 - Implemented Practice nurse led CCRs (n=3)

Module 5: Identifying and supporting people with advanced serious illness (n=26)

- Almost all agreed that the module improved processes for supporting people with advanced serious illness (96.1%, n=25/26)
- Increased use of the Macmillan Palliative Care Template (from 7.69%, n=2 to 34.6%, n=9)
- Improved processes for identifying patients for the palliative care register by
 - Using the Traffic Light system to add structure to palliative care register
 - Improving the documentation and communication of key information between sectors
 - Increasing awareness of prognostic indicators amongst practice staff
- Made positive changes to palliative care meetings including
 - Increased use of needs-based coding system (e.g., Traffic light system)
 - Wider team involvement
 - Better internal and external communication (e.g., OOHs)
 - Improved documentation
- Enhanced ACP discussions with patients by
 - Establishing a formal process to initiate ACP discussions earlier
 - Increasing access to patient information leaflets within the practice
 - Incorporating ACP into templates already used by practices (e.g., CCR and palliative care template)

- Improved documentation of ACP information by
 - Increasing awareness of the importance of documenting ACP information
 - Establishing a formal process for sharing information with OOH

Conclusions

Eleven months into the launch of the Toolkit, the Coronavirus pandemic resulted in significant changes to working processes within the healthcare system, including primary care. For many practices, this presented a huge challenge to not only participate in the Toolkit project but to plan and act on the identified areas needing improvement. Despite this, 53 practices participated and over 650 primary care staff engaged with the Toolkit.

Overall, the evaluation findings demonstrate that a cancer quality Toolkit provides a framework to successfully review and improve the way practices diagnose, care for and support their patients living with cancer. Completion of the Toolkit resulted in a significant amount of change for many GP practices including:

- Increased cancer knowledge
- Increased awareness and use of cancer specific tools and resources
- Improvements in clinical coding
- Improved access to information to support their patients living with cancer
- A shift in mentality from cancer care being an individual clinician responsibility to a whole team-based affair
- Implementation of new or improved processes, which led to more proactive cancer patient care.

The Toolkit was deemed to be an effective quality improvement activity and a ‘one stop shop’ of useful information which enabled team discussion, reflection and learning. However, the Toolkit structure was not user-friendly, provided an overwhelming amount of information and required significant time commitments which was deemed to be unrealistic given the demands on primary care staff.

Key lessons learned

1. MPCCF GP facilitators were utilised to promote the Toolkit and engage with colleagues in local health boards including educational events, LMC meetings and email. This approach was vital to ensure buy-in at the local level and to maintain involvement throughout the project. It is essential that future projects engage with local GP clusters before rolling out similar QI projects.
2. The MPCCF programme team structure, which included local GP leads, GP facilitators, nurse leads and support staff (project management, project support, communication officer and an evaluation officer) to design, implement and evaluate the Toolkit were vital to the success of this project. The diverse skill mix ensured the ‘day-to-day’ running of the project moved forward at pace and any issues (e.g., challenges faced by participating GP practices) were dealt with in a timely manner. Future projects should ensure that adequate resources are planned for in order to design, implement and evaluate national projects like the Toolkit.
3. Multiple support processes were set-up from the outset which included one-to-one support via email and telephone from local Health Board GP facilitators and dedicated support through a Toolkit ‘Help’ Email covered by a project support officer,

- communications officer and an evaluation officer. This ensured that queries were promptly dealt with. Future projects should ensure that multiple avenues for support are established to maintain engagement with participants and encourage completion.
4. The MPCCF programme team and Macmillan Cancer Support ensured that monitoring and evaluation were considered from the outset of the project. This, combined with an adaptive management approach which addressed issues as they arose, were imperative to achieve the outcomes of this project. Future projects should consider evaluation from the outset of the project design.
 5. Several editorial groups were held to design the Toolkit based on previous pieces of work published by Scotland and England. Several areas needing improvement were agreed, however, participating GP practices felt that some of the modules were difficult to complete and the amount of information contained within the Toolkit was overwhelming. Module 4 focused entirely on one topic and the layout was structured around current practice, action plan and reflections on practice changes. Future QI initiatives should adopt a simple structure, which would lead to high quality data and higher participant satisfaction.
 6. The MCQT project utilised a collaborative approach to develop the Toolkit with representation from MPCCF Health Board GPs, End-of-Life GP Facilitators, MPCCF regional nurses and Macmillan Cancer Support Programme and Project managers. Whilst the collaborative approach was essential for the project, this led to long and repetitive debates about the content of the Toolkit. This resulted in limited time to adequately test the Toolkit before the national launch across Wales. Future projects need to secure a shared vision (e.g., aims and outcomes) between all stakeholders from the outset to ensure adequate time is available to develop and test the tool.
 7. During the planning and testing phases, the MCQT engaged with several stakeholders, however, upon reflection, most of the clinicians involved had an interest in cancer and/or quality improvement. To improve the acceptance and success of the Toolkit, intended users, particularly those without an interest in cancer, should be included in the design and testing phases.

Recommendations

1. Macmillan Cancer Support and the WCN should revise the Macmillan Cancer Quality Toolkit to increase uptake and facilitate effective QI in cancer care provision across Wales. To address this, the following actions should be considered:
 - a. Adopt a web-based platform to ensure information is updated, saved and shared instantly between participants and the MCQT project team.
 - b. Condense and re-structure Modules two, three and five to one or two key improvement areas (like the structure of Module four) to reduce confusion, information overload and to ensure adoption and completion of the Toolkit within busy GP practices.
 - c. Incorporate other educational strategies including training events and facilitated workshops to support and embed cancer quality improvement within GP practices across Wales.
 - d. Align the Toolkit topic areas with the Quality Statement for Cancer (Welsh Government 2021) as well as the priorities of the Strategic Programme for Primary Care (SPPC), Public Health Wales Primary Care Division, NHS Collaborative and the WCN. This has the potential to ensure targeted improvements in key priority

- areas as well as the opportunity to capture timely information on the processes, approaches and challenges within primary care.
- e. Re-design the roll-out of the MCQT from a one-off activity to a staged approach whereby the QI initiative is broken down into focused topics and smaller stages over several years. This would give practices more time to plan, implement and evaluate which could in turn ensure long-term and sustainable change.
 - f. The Toolkit needs to be adequately resourced in order to encourage participation and completion. To achieve this, dedicated support (e.g., facilitators) needs to be provided with any future roll-out.
 - g. In addition to lesson learnt point 7, a structured assessment of the resources (e.g., staff time) required is needed before any future roll-out of the Toolkit or its equivalent.
 - h. Macmillan Cancer Support and the WCN should engage with a broader range of stakeholders to develop and roll-out future QI initiatives including the SPPC, Public Health Wales Primary Care Division, the Wales Cancer Alliance (WCA) and GP clusters (through the LMCs). This has the potential to ensure inclusion of a broader range of evidenced-based resources and in turn, greater acceptability and usability of a cancer quality Toolkit.
 - i. Macmillan Cancer Support and the WCN should include different learning formats within or alongside the Toolkit such as videos, e-modules and educational events, in order to meet diverse learning needs within primary care.
2. Further research is needed to determine the long-term impact of this educational tool (e.g., sustainable changes) and the effect the Toolkit has on patient outcomes.
 3. Participating GP practices faced significant challenges in undertaking quality improvement, particularly in relation to staff time and competing priorities, GP clusters should work together to share resources, ideas and knowledge when undertaking QI initiatives such as the Toolkit.
 4. The MPCCF programme, Macmillan Cancer Support and the WCN, despite the sample size, should utilise the current practice data contained within the Toolkit to inform the development of future projects and programmes.
 5. With the introduction of the Quality Assurance and Improvement Framework (QAIF) as a contract reform to the GMS contract in Wales 2019/2020 there is an opportunity for Primary Care to incorporate the MCQT to encourage cluster working across Wales.
 6. Macmillan Cancer Support and the WCN should share the good practice (action plans and outcomes) identified within the Toolkits to all GP practices and clusters across Wales.

INTRODUCTION

BACKGROUND

In Wales, the incidence of many cancers is increasing due to lifestyle and environmental factors and an ageing population. The latest Welsh Intelligence and Surveillance Unit (WCISU) statistics on cancer incidence reported that 19,088 people were diagnosed in 2015 (WCISU 2017). This figure is expected to continue to increase by approximately 2% each year (Macmillan Cancer Support 2017). The number of people living with cancer is also increasing (Rubin et al. 2015). In 2015, 130,000 people in Wales were living with cancer and by the end of 2030, this number is expected to rise to 220,000 people (WCISU 2017).

In previous years, the role of primary care in cancer was mainly seen as marginal, however, due to a shift in focus in cancer policy, primary care has been recognised as a key component for prevention, early diagnosis, survivorship care, and end-of-life care (Rubin et al. 2015). The primary care workload related to cancer is expected to increase significantly in the coming years (Rubin et al. 2015). A GP with 2000 patients may expect to see between 6 to 8 new cancer cases per year (Rubin et al. 2015). In addition, with increasing survival rates and people living longer with cancer, a GP with 2000 patients will have approximately 70 people living with cancer under their care each year (Rubin et al. 2015) and this number is expected to double by 2040 (Maddams et al. 2012).

To support primary care professionals with their roles in cancer care Rubin and colleagues identified that educational strategies are needed (2015). New evidence and effective processes to deliver better care to patients exist, but there are challenges in translating this knowledge into clinical practice (Davis et al. 2017). In addition, resource challenges, such as staff time, hinder opportunities for staff to improve their understanding and knowledge of cancer (Rubin et al. 2015). Toolkits are an effective tool for the provision of educational resources and the facilitation of behaviour change by being a '*one-stop-shop*' resource of information and action-oriented tasks to facilitate practice change (Yamada et al. 2015). Therefore, the MPCCF started to shape plans to roll-out a Cancer Quality Toolkit to support primary care professionals across Wales.

The Macmillan Primary Care Cancer Framework (MPCCF) Programme

The MPCCF programme, an all-Wales strategic partnership between all health boards, Velindre University NHS Trust, Wales Cancer Network, Welsh Government and Macmillan Cancer support, was set up in 2015 to address the changing nature of cancer and its treatment. The team was comprised of health board-based GPs (Lead and Facilitator), regional nurses and a central programme team with GP and Nurse National leads, project management, project support, communications and evaluation expertise. The programme was fully funded by Macmillan Cancer Support until December 2020.

The overarching aim of the programme was to support primary care professionals to diagnose, care for and support people with cancer in Wales. The programme had three key objectives:

1. To develop and grow a community of practice and influence (CoPI) to support cancer service improvement in primary care.
2. To develop and support primary care professionals.
3. To improve communication and integration between health sectors.

To support the objectives of the MPCCF programme, an opportunity was identified to produce a Cancer Quality Toolkit for Wales. Financial support was provided by Macmillan Cancer Support to assist with the set-up of the project including project management, communications, evaluation and the design and implementation of the Toolkit.

Toolkit development

The initial driver for the Toolkit in Wales was the launch of a quality improvement practice-based toolkit in Scotland. To show 'proof of concept' in Wales, a pilot of module two from Scotland was successfully negotiated to be part of the GP contract for 2017/2018. In that year, the Quality Outcomes Framework (QOF) was suspended, and many GP practices did not finish completing the 'pilot module'. Despite this, initial feedback on the module was positive.

Following this, significant strategic influencing took place to develop plans to design and roll out a Toolkit in Wales with Macmillan Cancer Support, Wales Cancer Network and Welsh Government. An editorial group consisting of expertise from primary care (MPCCF GPs and nurses), communications, project management and evaluation was set up to adapt and learn from the Toolkits developed for England and Scotland. During the editorial meetings, the group reviewed and discussed literature, evidence-based guidelines, best practice and relevant resources and tools. This group ensured that the Toolkit was clinically relevant and tailored to Welsh strategic priorities including the Cancer Delivery Plan for Wales 2016 – 2020 (Wales Cancer Network 2016).

The Macmillan Cancer Quality Toolkit (MCQT)

The MCQT was an educational tool to help primary care improve their knowledge and provision of cancer care. The Toolkit launched on May 2nd, 2019, and GP practices were able to sign-up until June 2020.

The Toolkit had three overall objectives:

1. To enable the whole primary care team to review and improve services that diagnose, care for and support people living with cancer.
2. To create a framework of peer support that helps primary care teams to provide seamlessly coordinated care and high-quality patient experiences.

- To provide a current picture of cancer services in primary care, which will support future developments in Wales.

Toolkit content

The Toolkit was an interactive PDF document composed of five learning modules covering five key topic areas (Table 1). Learning objectives were set for each module (Appendix 1). The interactive PDF contained educational information, best practice resources and tools and action-oriented questions to facilitate practices to identify areas for improvement, establish action plans and assess change.

Table 1. MCQT module titles and descriptions

Module	Module titles	Description	Quality improvement areas
1	Detecting cancer earlier	Prevention and screening	<ul style="list-style-type: none"> ▪ Opportunistic health promotion ▪ Identifying and contacting non-responders to bowel screening
2	Prompt recognition and early referral	Application of NICE Suspected Cancer: Recognition and referral guidelines	<ul style="list-style-type: none"> • Coding – ‘Fast track cancer referrals’ • Safety netting USC referrals • Patient information and support • Cancer Decision Support (CDS) Tool
3	Support through treatment	Communication and documentation from diagnosis through to treatment	<ul style="list-style-type: none"> ▪ Contacting a patient following a cancer diagnosis ▪ Coding – treatment and key worker ▪ Practice assessment and management of people who have received cancer treatment
4	Cancer care reviews (CCRs) and long-term consequences of cancer and its treatment	Approach to CCRs and understanding the long-term consequences of cancer and its treatment	<ul style="list-style-type: none"> ▪ Holistic CCRs ▪ Practice nurse involvement in CCRs ▪ Long term consequences of cancer and its treatment
5	Identifying and supporting people with advanced serious illness	Palliative and end-of-life care processes	<ul style="list-style-type: none"> ▪ Recording and sharing of Advance Care Planning (ACP) information ▪ Timely ACP discussions ▪ Palliative care meetings

Toolkit structure and components

Key activities within the Toolkit were categorised into education, audit and feedback exercises, reflections and action planning. Within these activities, participants were encouraged to learn and work together as a team to facilitate practice change (Figure 1).

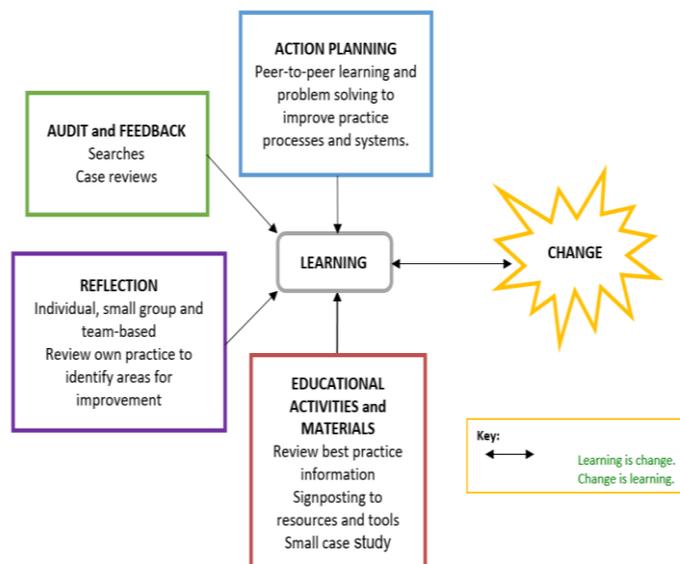


Figure 1. Toolkit activities and theory of change diagram

Participation requirements

GP practices were required to complete three of the five modules within the Toolkit. One module, Cancer Care Reviews and long-term consequences of cancer and its treatment was mandatory, and practices had to choose two other modules. Practices had six months to complete pre- and post-surveys to measure progress (mandatory), identify gaps, develop and implement action plans and review the impact of their changes. Upon completion of the Toolkit, participants received a certificate of completion.

Toolkit support

To facilitate completion, participants received a Macmillan grant of £1000. In addition to financial assistance, members of the programme team including health board-based GP facilitators, a project support officer, a research and evaluation officer and a communications officer provided one-to-one support to participating GP practices. Examples of the types of on-going support provided included running searches, provision of quality improvement tips and signposting to resources and leaflets.

EVALUATION PURPOSE

Aim and objectives

The purpose of the internal evaluation was to determine the impact of the Toolkit for participating GP practices in Wales. In order to assess the impact, two key objectives were set:

1. To explore the experiences of GP practices undertaking the Toolkit
2. To ascertain GP practices' reported changes to knowledge and approaches to improve cancer care

Evaluation framework

To guide the evaluation plan and design of the data collection instruments, a framework was developed based on the Kirkpatrick Model and Theory of Change model. The following components from each model were incorporated into the MCQT evaluation framework (Appendix 2):

- Kirkpatrick's Model: reactions, learning, behaviour and results
- Theory of change: Target population, activities, assumptions, outcomes and impacts

Methodology

A mixed method approach, using both quantitative and qualitative methods, was undertaken.

Sample and sampling

At the time of the Toolkit launch, 415 GP practices were identified in Wales (Public Health Wales 2019) (Table 2). Based on the uptake of the Scottish Toolkit (26%), the target sample size was 30% (n=126) of GP practices across Wales.

Table 2. Distribution of GP practices and clusters within Wales

	No. GP practices	No. GP clusters	Estimated no. GP practices needed for project
ABUHB	78	12	23
BCUHB	104	14	32
CAVUHB	64	9	19
CTMUHB	55	8	12
HDUHB	49	7	15
PTHB	16	3	5
SBUHB	49	10	20
All Wales	415	64	126

All 415 GP practices were invited to participate in the Toolkit. In the first instance, GPs and Practice Managers were contacted via email using the NHS Global Address Book. To further access the sample, a Toolkit promotional flyer was placed in 'Blue Bags' which go out to GP practices across Wales. Members of the MPCCF programme team (e.g., GP Facilitators) also promoted the Toolkit at conferences, local cluster meetings and at MPCCF educational events. The emails and flyers asked potential participants to contact a dedicated Toolkit email address for more information and to officially sign-up.

Data collection instruments

Pre and post online evaluation surveys

Cross-sectional online surveys were used to collect baseline and follow-up data from GP practices. Baseline survey questions were designed to capture information on practice knowledge of key topic areas, awareness and use of evidenced based tools and current processes for cancer care. Post toolkit survey questions captured the same baseline information along with additional information including the GP practices' perceptions and experiences of using the Toolkit (e.g., usefulness, satisfaction and factors that facilitated or hindered completion of the Toolkit). To reduce the burden on participating GP practices, one staff member completed the surveys on behalf of the whole practice.

Document review

All submitted Toolkits were reviewed to capture quantitative and qualitative data regarding current practice of cancer care, action plans for improvement and reflections on how the practice change went.

Informal feedback

Informal feedback during the Toolkit project was collected through the 'Toolkit Help' email and the GP facilitators based in the local health boards who were engaging directly with participating GP practices. This process was implemented to ensure that problems, challenges and queries were addressed in a timely manner.

Data analysis

Quantitative data from the online surveys were exported into Excel for analysis. Descriptive statistics were used to summarise the information provided in the surveys (e.g., number and of practices that had a process for contacting screening non-responders). The responses were aggregated to maintain the confidentiality of practices and/or individuals.

Qualitative data from free text boxes within the surveys and the Toolkit were transferred into Excel for data management. Thematic analysis (Braun and Clarke 2006) was used to guide analysis of all qualitative data to identify recurring themes at a national level. At least two additional clinical members (GPs and Practice nurses) from the MPCCF programme team independently read the data and discussed the key ideas and common themes arising across the data sets to identify errors in the coding of themes and to ensure consistency (Creswell 2009).

EVALUATION FINDINGS

This section presents the findings from the pre- and post- evaluation surveys including uptake, reach, demographics, perceptions of the Toolkit and the perceived impact of the Toolkit on clinical practice.

TOOLKIT INTEREST AND UPTAKE

Between May 2019 and June 2020, 3). The Health Board with the highest proportion of GP practices taking part was Powys Teaching Health Board (PTHB) (25.0%, n=4/16) followed by Hywel Dda University Health Board (HDUHB) (22.4%, n=11/49).

Table 3: Participating GP Practices

Health board	GP Practice Sample*	Participating GP practices		GP Cluster Sample*	Participating GP Clusters	
	No.	No.	%	No.	No.	%
ABUHB	78	10	12.8	12	5	41.7
BCUHB	104	7	6.7	14	6	42.9
CAVUHB	64	10	15.6	9	6	66.7
CTMUHB	55	5	9.1	8	4	50.0
HDUHB	49	11	22.4	7	7	100.0
PTHB	16	4	25.0	3	2	66.7
SBUHB	49	6	12.2	8	3	37.5
Wales	415	53	12.8	64	33	51.6

*Data as of May 2019 (Public Health Wales 2019)

Participating GP practices were asked why they chose to take part and just over half indicated that they completed the Toolkit because of an interest in quality improvement (45.3%, n=24/53) while 20.8% expressed that they participated to improve patient experience (n=11) (Figure 2). Other responses included an interest in cancer and palliative care (n=2) and because it was agreed at a cluster level to complete the Toolkit (n=1).

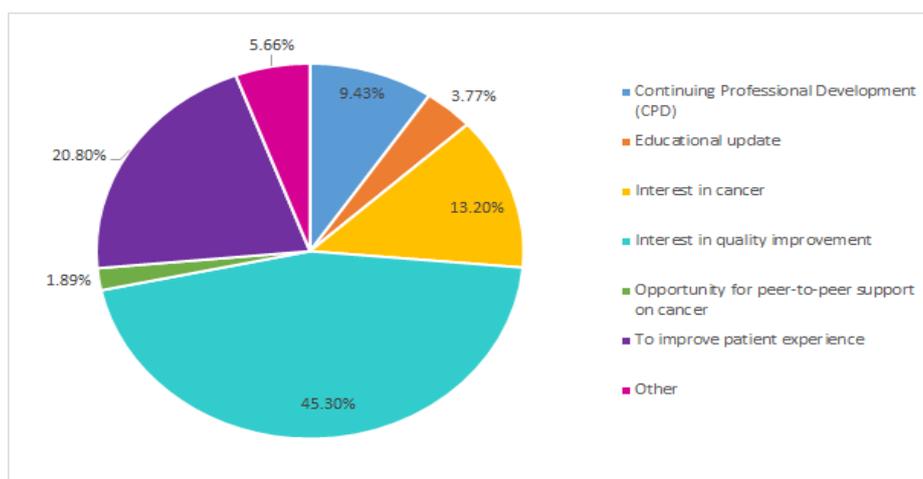


Figure 2. Participation reasons

PARTICIPANT DEMOGRAPHICS

At baseline, the patient list size varied across participants¹ with just under half of participants defined as a large GP practice (over 8,000 patients) (47.2%, n=25). Thirteen percent (n=13) of participants identified having a named clinical lead for cancer, a non-clinical cancer champion and held regular practice meetings to discuss new cancer cases. On average, participants took 6.58 months (range 4, 14) to complete the Toolkit (Table 4).

Table 4: Participant demographics

	No.	%
Practice size		
Small practice (up to 3,999 patients)	9	17.0
Medium practice (4,000 to 7,999 patients)	19	35.8
Large practice (Over 8,000 patients)	25	47.2
Named clinical lead for cancer*		
Yes	30	56.6
No	22	41.5
Not sure	1	1.9
Established non-clinical cancer champion role*		
Yes	14	26.4
No	37	69.8
Not sure	2	3.8
Regular practice meetings where new cancer cases are discussed*		
Yes	30	56.6
No	20	37.7
Not sure	3	5.7
Time taken to complete the Toolkit**		
Less than six months	18	40

¹ In this report, 'participant' refers to a single GP practice response. Only one clinician was asked to complete the surveys on behalf of the entire practice.

Six months	11	24.4
Greater than six months	16	35.6
*Responses from baseline survey		
**Some practices (n=8) submitted in one go so unable to determine time taken to complete		

PARTICIPANTS AND REACH

Across the 53 practices, 658 primary care staff were involved in the Toolkit reaching half of the eligible staff within those practices. The most common roles involved were GPs (mean 3.81 per practice), Administration staff (mean 2.44 per practice), Practice Nurses (mean 2.18 per practice) and Reception staff (mean 3.24 per practice). Almost two-thirds of staff involved were clinical (60.6%, n=399) while just over one-third were non-clinical roles (39.4%, n=259) (Table 5).

Table 5: GP practice staff involved in the Toolkit

Staff type*	Staff in participating GP practices**		Staff involved in the Toolkit	
	No.	No.	%	
GPs	300	202	67.3%	
Nurse Practitioners	46	27	58.7%	
Practice Nurses	152	94	61.8%	
Healthcare assistants	114	48	42.1%	
Pharmacists	52	20	38.5%	
Physiotherapists	14	3	21.4%	
Paramedics	7	1	14.3%	
Mental Health Nurses	10	0	0.0%	
Occupational therapists	2	1	50.0%	
Frailty nurses	4	3	75.0%	
Practice Managers	69	52	75.4%	
Administration staff	234	105	44.9%	
Reception staff	309	94	30.4%	
Dispensary staff	8	8	100.0%	
Total	1321	658	49.8%	
*Full and part-time staff included.				
**As reported by GP practices at the time of Toolkit completion.				

Sharing learning

GP practices were encouraged throughout the Toolkit to share learning with colleagues within their local GP cluster (Figure 3). Those who indicated that they shared learning (26.4%, n=14/53) circulated action plans, local contacts and key information from the Toolkit (e.g., importance of coding and copies of desktop cancer referral guidelines) while others shared the benefits of completing the Toolkit. Many of those who indicated they did not share learning within their cluster expressed that the Coronavirus pandemic hindered plans but that they intended to do this in the near future.

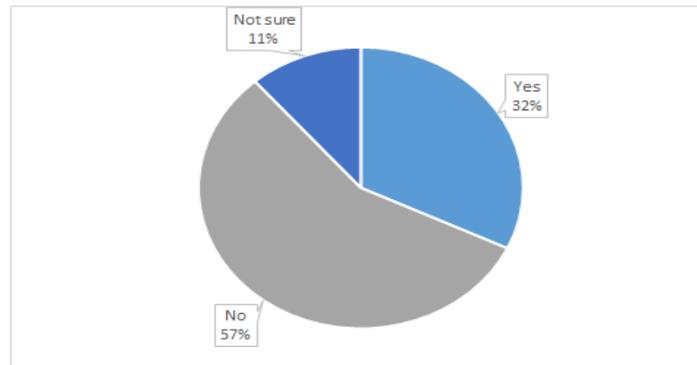


Figure 3. GP practices that shared learning with cluster colleagues

OVERALL TOOLKIT PERCEPTIONS

Participants were asked whether they agreed or disagreed with several statements regarding key elements of the Toolkit.

Quality improvement

The majority of participants 'agreed' or 'strongly agreed' that the Toolkit was useful to facilitate quality improvement in cancer care within their practice (88.5%, n=46). Just over three-quarters of GP practices believed that the Toolkit is a sustainable way to drive quality improvement in cancer care within their practice (77.3%, n=41) (Figure 4).

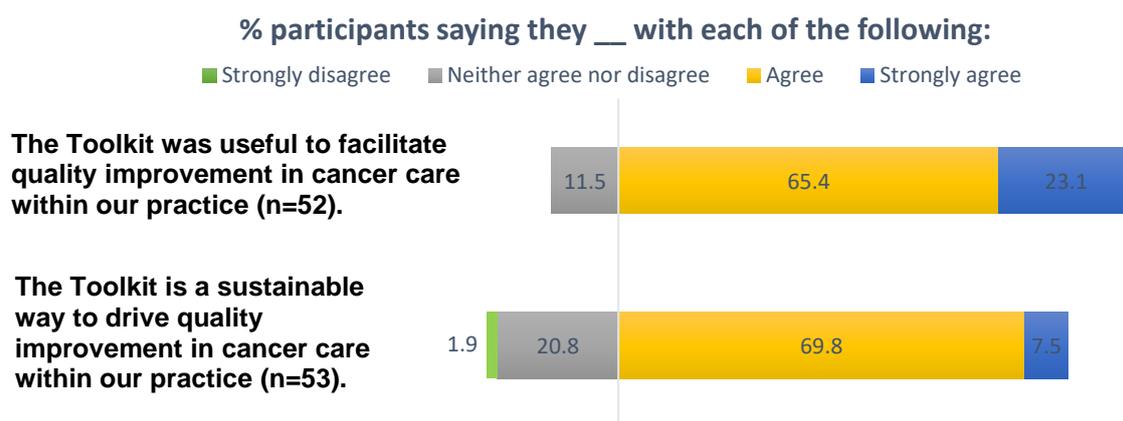


Figure 4. Quality improvement statements

Information resource

The majority of participants 'agreed' or 'strongly agreed' that the information provided within the Toolkit was useful (96.2%, n=51) and relevant to their work (90.6%, n=48) (Figure 5).

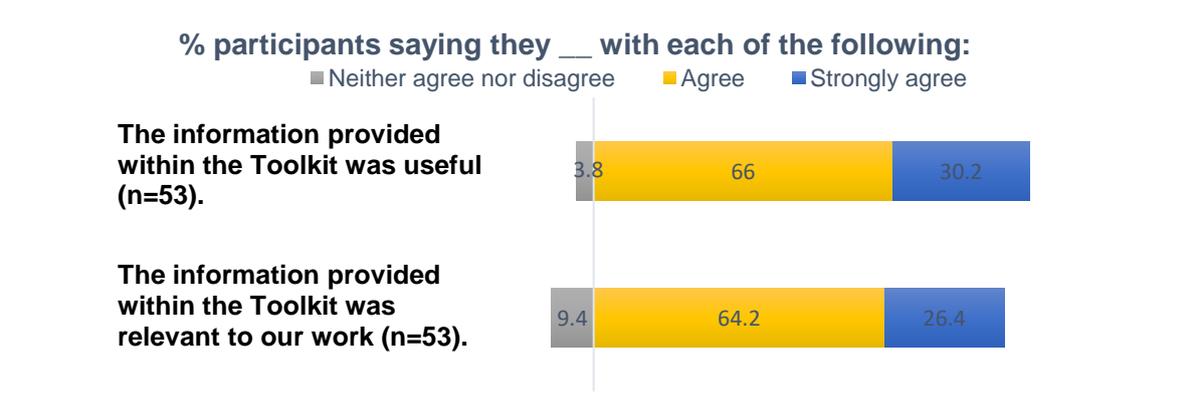


Figure 5. Information resource statements

Toolkit activities

The Toolkit had several key activities including audit and feedback (e.g., searches and case reviews), team-based reflections, action planning and reviews of education materials (e.g., prevalence of long-term consequences of cancer). GP practices were also encouraged to involve their whole practice team, including clinical and non-clinical staff. Under half of participants 'agreed' or 'strongly agreed' that it was easy to involve the whole primary care team in the Toolkit (Figure 6). Three quarters of participants stated that completing audit and feedback questions and team-based action planning were useful activities (75.5%, n=40). The majority of GP practices 'agreed' or 'strongly agreed' that reviewing educational materials were useful activities (86.6%, n=45). Just over three-quarters of participants felt that the team-based reflections were useful activities (78.4%, n=40).

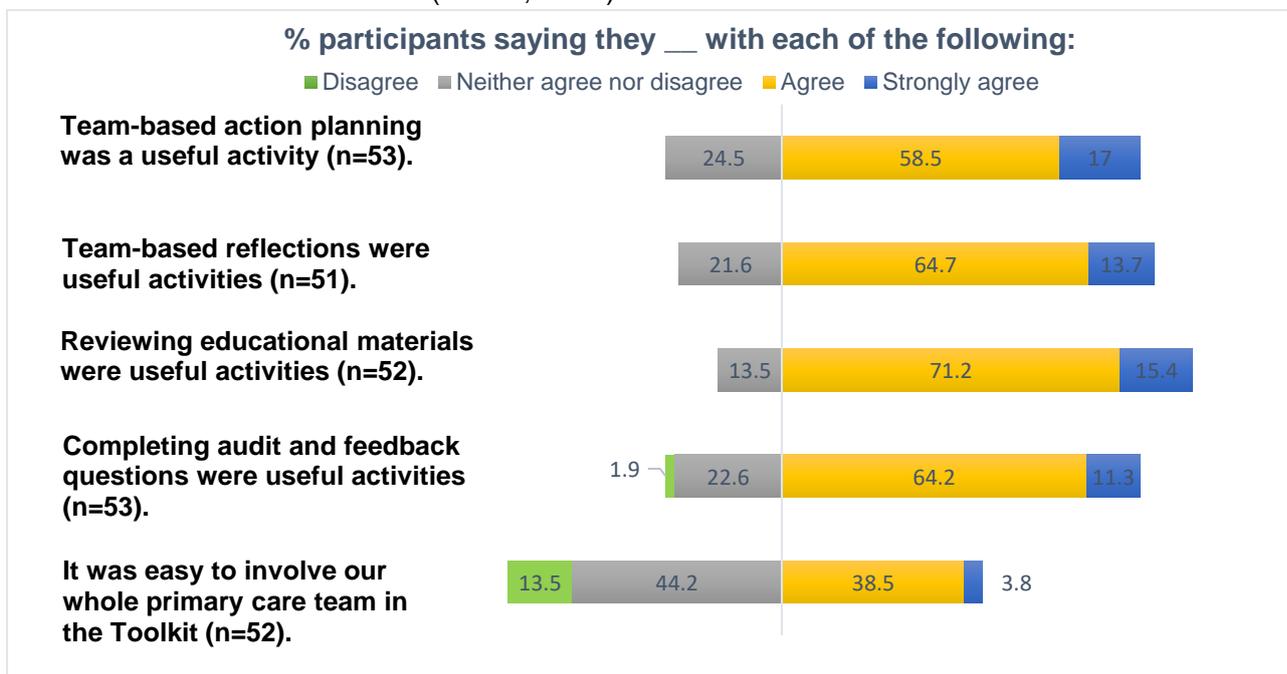


Figure 6. Toolkit activities statements

MPCCF support to complete the Toolkit

The MPCCF programme set-up included Macmillan GP Facilitators based in Health Boards across Wales as well as evaluation and project support based within the WCN. These roles provided practical support to GP practices participating in the Toolkit project. The evaluation

survey asked practices what support they received from the MPCCF team. Approximately one-third of practices indicated they received support from the MPCCF team (32.1%, n=17/53) (Figure 7).

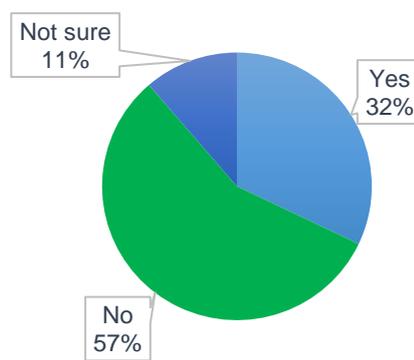


Figure 7. GP practices that received MPCCF support

Most useful aspects of the Toolkit

Participants were also asked what was most useful about the Toolkit. Four key themes emerged 'structure to review and improve cancer services', 'stimulated practice discussion', 'valuable information resource' and 'audit and feedback exercises'.

Theme 1: Structure to review and improve cancer care provision

Core elements of the Toolkit were individual and team-based reflections and the majority of participants deemed these activities useful. Some highlighted how the Toolkit provided a helpful structure to assess individual and team practice as well as established practice approaches, processes and systems for cancer and other chronic diseases.

"Very relevant to clinical practice and helped reflect on current work in the surgery." (P39, CAVUHB)

"We looked at this as a quality improvement activity, and the structure it provided for this activity was useful. It encouraged us to look at cancer as a chronic disease, using similar strategies to looking after conditions such as diabetes." (P58, HDUHB)

"Gave me the ability to reflect on my own practice, in terms of how I recognise cancer and investigate/refer..." (P73, CTMUHB)

Many other participants described how both the review and action planning activities were useful to not only to identify gaps but also provided a structure for improvement.

"Excellent to recognise and address key areas needing improvement and development within the surgery and to action these." (P20, CAVUHB)

"Formal way of addressing some of the aspects of cancer care in the community and trying to improve them wholesale rather than piecemeal..." (P32, CAVUHB)

"Good to consider different ways that small changes in the practice could highlight potentially easily addressed needs." (P67, BCUHB)

Other participants provided examples where the review structure was beneficial in key areas, which resulted in positive changes within the practice including USC referral processes, cancer care reviews, coding and early identification of patients for ACP planning.

“...Made us look at our USC referral processes i.e., informing patient USC at time and also safety net to check that all USC referrals have been seen within one month.” (P42, ABUHB)

“Being able to review the information we discuss in cancer care reviews. We have now set up our own template and discuss much more with the patient e.g., signposting, leaflets and lifestyle advice.” (P4, BCUHB)

“Made you reflect on current practice and to use the guides to influence changes...” (P72, HDUHB)

Theme 2: Stimulated practice discussion

Some participants explained that the Toolkit encouraged conversations among practice members and that this was a very useful element of the Toolkit. By prompting GP practices to utilise practice meetings this created opportunities for practice members to share information, learn from one another, discuss as a team, key areas needing improvement and agree ways to address gaps in practice.

“...The searches and analysis of them were stimulating to practice discussion and development. We gained as a team from discussion about the modules and some members of the team developed skills in new areas that have since been used in clinical practice...” (P12, ABUHB)

“It was a useful way for us to get together to discuss different aspects and to look at what we can do better.” (P35, SBUHB)

“Helpful to have time together to look at cancer patient care and see how we could improve it.” (P61, PTHB)

“...was a useful vehicle to share information with the whole team.” (P60, HDUHB)

Theme 3: Valuable information resource

Several participants felt that reviewing best practice information and the signposting within the Toolkit to resources and tools were particularly useful. GP practices reported that this activity was useful because it made their team more aware of tools, templates, resources and good coding practice. Some practices gained new knowledge of cancer specific information that covered the whole pathway from prevention to end of life care.

“...It raised awareness of many aspects of cancer as a whole, i.e., screening, diagnosis/referral, and support at diagnosis and beyond.” (P12, ABUHB)

“...Practice and clinicians were not aware of resources that were available like UKONS, CDS [tool], CCRs etc. We have started using more of these.” (P16, CTMUHB)

“...The information provided within the toolkit itself was very educational and encouraged a shift in mentality from cancer care being an individual clinician responsibility to a whole team-based affair.” (P29, SBUHB)

“Finding out about where we are relative to the cluster in screening and looking at the Macmillan pathways was educational and informative.” (P5, SBUHB)

“Providing tools, confidence and reassurance with the management of this complex safety netting requirement.” (P62, HUDHB)

Theme 4: Audit and feedback exercises

Searches and case reviews to facilitate GP practices with the evaluation of their own practice data were key Toolkit components. Similar to other activities within the Toolkit, the searches and case reviews were deemed useful exercises. Some practices highlighted that the audit and feedback exercises encouraged practice teams to identify what worked well, what didn't and areas needing improvement.

“The searches helped us realise that the practice is on board with all the modules of cancer including early detection, timely referral, diagnosis and cancer review during and post treatment. The practice has a robust palliative care team to look after our EOL issues.” (P70, CTMUHB)

“The searches were really helpful as we identified that our coding of fast-track cancer referrals, cancer care reviews, ACPs and DNACPRs was quite poor. It allowed us to very quickly and easily change our practice to ensure these things were coded correctly.” (P74, CAVUHB)

“It was great to run searches and review case notes of actual patients in our practice rather than just reading stats and generic information.” (P73, CTMUHB)

“Discovering screening rates and cancer diagnosis at practice level e.g., search 17. Why? - statistics are presented at national or international level; knowing own figures helps put this into context at a local level...” (P77, BCUHB)

Least useful aspects of the Toolkit

GP practices were also asked what was least useful about the Toolkit. The following key themes emerged ‘time commitment’, ‘usability issues’, ‘information burden’ and ‘engaging the whole practice team’.

Theme 1: Time commitment

Several participants highlighted the time required to complete the activities within the Toolkit was a significant challenge. Participants felt that the running of searches and completion of activities (e.g., reflections and sharing information) were too time consuming. Some participants expressed that the activities within the Toolkit were especially challenging during a pandemic.

“Very time consuming to get the information (we have 21,500 patients). First search and completion of first 2 modules took me about 2 days.” (P5, SBUHB)

“Too time consuming. I personally spent hours of my own time completing the modules and planning and sharing this information with my colleagues...” (P10, ABUHB)

“Having to find list of useful numbers and local resources available ourselves - took me a long time...” (P25, CAVUHB)

“Time consuming and a tedious process, not to mention the current COVID situation and the deadlines that the toolkit had imposed...” (P70, CTMUHB)

Theme 2: Usability issues

Use of an interactive PDF document to provide and gather information made it challenging to complete the Toolkit for some practices. Participants described how it was difficult to add information and save the document. Other participants highlighted how the format was ‘tricky’ to navigate and share with their practice team.

“Very difficult to save changes. Kept losing the form all the time due to this so have had to complete on multiple occasions.” (P42, ABUHB)

“Found completing as an online PDF a little tricky, minor IT issues.” (P20, CAVUHB)

“The format was rather difficult to manipulate and didn't lend itself easily to sharing workload amongst the team. It would have been helpful if individual modules could have been downloaded and worked on separately.” (P12, ABUHB)

“The actual kit was difficult to manage from an IT perspective when moving between modules otherwise useful. Difficult to disseminate to the whole team.” (P72, HDUHB)

Due to inconsistencies in coding within practices, participants felt that the ready to run searches were not useful. Some participants felt that the outcome from the searches did not reflect actual numbers (e.g., patients diagnosed with cancer in the last six months).

“It is based on (Consistent) Read coding - may limit accurate results.” (P18, HDUHB)

“...the coding was very specific - we often used a slightly different code and as a result the data wasn't picked up.” (P4, BCUHB)

“There may be some coding issues within the searches on EMIS as the outcomes did not make sense.” (P43, PTHB)

“Some of the difficulty in doing the audit reflects the fact that our practice does not use Macmillan codes and so I don't feel that the data is accurate.” (P78, BCUHB)

Theme 3: Information burden

Some participants expressed that the information and overall structure of the Toolkit was overwhelming and that this detracted from its usefulness. Other participants stated that the information within the Toolkit could have been more relevant to practice.

“Too many links and too much information...” (P27, HDUHB)

“...Very busy form. Could be more user friendly and fewer number of pages.” (P70, CTMUHB)

“Daunting format, a lot of information, not always clear what information needed to be gathered.” (P19, ABUHB)

“Some parts regarding tools and resources not always relevant to practice.” (P2, ABUHB)

Theme 4: Engaging the whole practice team

The Toolkit encouraged GP practices to engage with their whole practice team in order to complete the Toolkit, to share information between staff and to facilitate peer-to-peer learning. While this was an integral component of the Toolkit, some participants described how it was challenging to get colleagues on board to review the Toolkit or to implement the identified changes.

“...I personally spent hours of my own time completing the modules and planning and sharing this information with my colleagues. Although this benefitted me, feedback from my colleagues was less positive and they felt that apart from some health promotion, they are unlikely to change their practice...” (P10, ABUHB)

“Trying to get whole practice meetings was really quite a challenge as everyone so busy and so much on agendas already for practice meetings...” (P33, HDUHB)

“I found that it was difficult to implement change. There were too many reflective exercises for the whole team and therefore was difficult to get the time to organise meetings where everyone could attend...” (P78, BCUHB)

Suggested Toolkit improvements

GP practices were asked how the Toolkit could be improved. Several participants expressed that the Toolkit was useful as is and provided no suggestions for improvement.

“Cannot see any improvements needed at present. Found the whole toolkit beneficial and enjoyed taking part in this toolkit.” (P69, PTHB)

“Don't feel it can be improved in its present format, informative and helpful.” (P36, HDUHB)

“It was well structured with bite-sized sections which were easy to work through...” (P43, PTHB)

Others provided suggestions for improvement, and these were themed into the following: ‘navigation and usability’ and ‘additional features’.

Theme 1: Navigation and usability

While some participants identified the Toolkit was straightforward to use, several described IT issues, which made the document difficult to navigate. Others highlighted that the layout could be improved by restructuring the Toolkit to allow the document to be shared across a team more easily while some would've preferred a 'save as you go' function.

"Ability to print out one section at a time and to have the six-month review at the end of a section." (P27, CAVUHB)

"The format was rather difficult to manipulate and didn't lend itself easily to sharing workload amongst the team. It would have been helpful if individual modules could have been downloaded and worked on separately." (P12, ABUHB)

"Easier modules to break up and share learning examples." (P72, HDUHB)

"Subdividing the PDF document." (P58, HDUHB)

"Better ability to save on the system (without leaving the page) on word document." (P42, ABUHB)

"...When saving my work at any point saving would then result in the Toolkit automatically going back to page one which was annoying as then I'd have to scroll back through loads of pages to get back to where I was! That was quite time-consuming as I like to 'save' often to not lose work." (P59, HDUHB)

Many participants felt that the Toolkit could be improved by making the document shorter.

"Could be made briefer, it took a lot of time to go through." (P33, HDUHB)

"The toolkit was excellent, and we learnt a lot of new things, but this was very time consuming compounded by COVID, so for future may be make it a bit simpler." (P16, CTMUHB)

"It takes longer to complete and look for the information in patients records than was stated at the start of the toolkit. It took considerably longer than expected. Maybe looking at time spent and trying to streamline this would make it easier to navigate and also make more GPs want to take part." (P45, SBUHB)

"I think if it was more concise it would be easier for us to focus on." (P78, BCUHB)

GP practices felt that the delivery of the content and the Toolkit itself could be enhanced. Some participants expressed that the use of different learning formats such as e-modules and videos and templates would be beneficial.

"Could potentially have some e-modules for other practice staff members." (P2, ABUHB)

“Sometimes the toolkit asked a practice to develop an action plan. Examples or templates for a plan would be helpful in some areas, as it is sometimes difficult to “get the ball rolling” if you don’t know where to start.” (P76, BCUHB)

“More time but different modules submitted at different times.” (P37, HDUHB)

“Live on systems web access for example IG and CGSPAT.” (P62, HDUHB)

Theme 2: Additional features

Some participants identified other features that would make the Toolkit more useful including extending the audit time to one-year, clearer instructions detailing what was needed and increased financial support. Others stated that utilising the clusters and the QAIF to support the Toolkit might be helpful.

“I think it should take into consideration how GPs work on a day-to-day basis, rather than as a ‘one-speciality’ view.” (P28, HDUHB)

“Shorter and remunerate GPs appropriately for the time spent.” (P10, ABUHB)

“Increase MDT approach and increase cluster sharing.” (P6, CAVUHB)

“Develop guidelines that can be embedded into Vision to maintain consistency of Read coding, and remind clinician of things to consider.” (P18, HDUHB)

“Further audit at 1 year interval.” (P29, SBUHB)

“Embed the QI work in Quality Assurance and Improvement Framework (QAIF) so it is taken on across the whole HB.” (P32, CAVUHB)

Facilitators and barriers

Participants were asked to rank several factors that might have hindered Toolkit completion according to importance (Table 6). The most frequently reported barriers were staff time to undertake quality improvement (Total score=455), competing priorities within the practice (Total score=454) and staff numbers to undertake quality improvement (Total score=362).

Table 6. Barriers to Toolkit completion

Factor	Total score***	Overall ranking
Staff time to undertake quality improvement.	455	1*
Competing priorities within the practice.	454	2
Staff numbers to undertake quality improvement.	362	3
Staff skills in quality improvement.	323	4

Staff training in quality improvement.	306	5
Staff attitudes to quality improvement.	275	6
Leadership support.	195	7
Team working.	189	8
Technological resources to undertake quality improvement.	181	9
Financial resources to undertake quality improvement.	175	10**
*Most difficult **Least difficult ***Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is a sum of all weighted rank counts.		

Participants were also asked to rank factors that were the most important for facilitating Toolkit completion (Table 7). The most important factors were staff time to undertake quality improvement (Total score=346), staff attitudes to quality improvement (Total score=321) and team working (Total score=312).

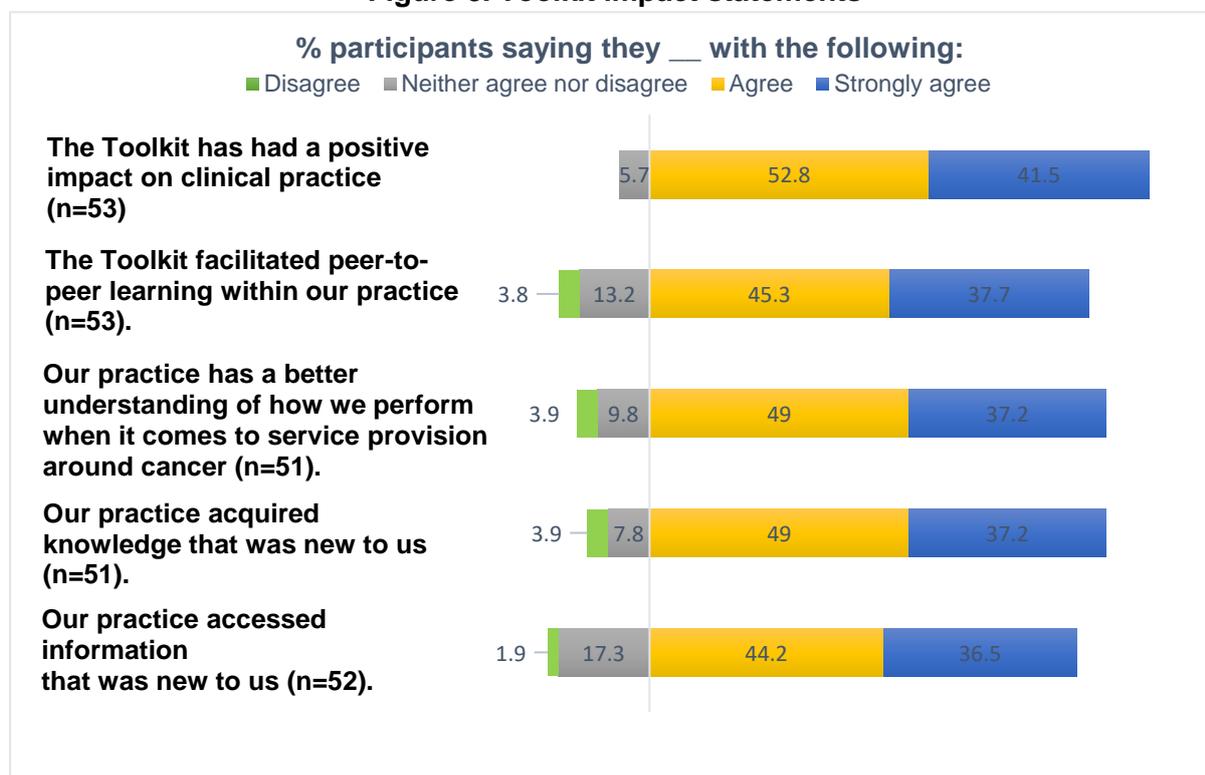
Table 7. Facilitative factors for Toolkit completion

Factor	Total score***	Overall ranking
Staff time to undertake quality improvement.	346	1*
Staff attitudes to quality improvement.	321	2
Team working.	312	3
Staff skills in quality improvement.	294	4
Leadership support.	267	5
Staff training in quality improvement.	237	6
Staff numbers to undertake quality improvement.	237	7
Technological resources to undertake quality improvement.	212	8
Financial resources to undertake quality improvement.	159	9**
*Most important **Least important ***Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is a sum of all weighted rank counts.		

IMPACT OF THE TOOLKIT

Participants were asked whether they agreed or disagreed with several statements regarding the impact of the Toolkit. Overwhelmingly, most participants ‘agreed’ or ‘strongly agreed’ that the Toolkit had a positive impact on GP practices’ knowledge, access to information, clinical practice and peer-to-peer learning (Figure 8).

Figure 8. Toolkit impact statements



Information and knowledge

The majority of participants ‘agreed’ or ‘strongly agreed’ that the Toolkit facilitated practices with accessing information that was new to them (79.2%, n=42) and acquired new knowledge (86.6%, n=45). 84.6% (n=44) of GP practices stated they had a better understanding of how they perform when it comes to cancer service provision (Figure 8).

Clinical practice

Almost all GP practices (94.3%, n=45) stated that the Toolkit had a positive impact on clinical practice. 83.0% (n=44) of GP practices also felt that the Toolkit facilitated peer-to-peer learning within their practice (Figure 8).

Improving access to information

Almost two-thirds of GP practices stated that their access to information to support people living with cancer improved since completing the toolkit (64.2%, n=34/53) (Figure 9).

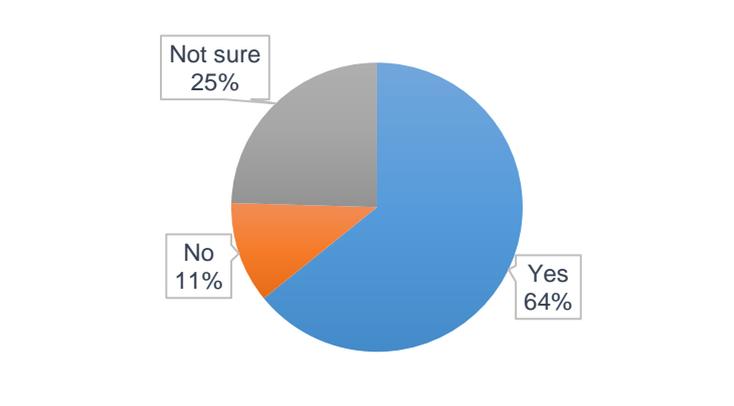


Figure 9. GP practices that improved their access to information

Participants were asked to describe how their access to information changed as a result of the Toolkit. The following three themes emerged ‘*Increased awareness of information and resources*’, ‘*Greater use of information and resources*’ and ‘*Improved access to information and resources*’.

Theme 1: Improved access to information and resources

Practices described how their access to information improved as a result of the Toolkit.

“Information available on Practice shared drive.” (P34, BCUHB)

“We now have a leaflet rack in the practice with useful information for patients.” (P4, BCUHB)

“We have dedicated links on our guideline page on Vision.” (P45, SBUHB)

“Better access to resources.” (P67, BCUHB)

Theme 2: Increased awareness of information and resources

Many participants described improvements in their awareness of cancer specific information, Macmillan resources and local support services.

“We know what information is available to us now and our admin team are more aware so they can support and signpost to patients also.” (P35, SBUHB)

“Increased awareness of Macmillan resources available.” (P61, PTHB)

“We are more aware of where to find additional resources for patients e.g., the Macmillan website and DEWIS.” (P74, CAVUHB)

“We have lovely Macmillan leaflets and know where to find them as needed online. We also uncovered local services to help in the course of completing the Toolkit.” (P59, HDUHB)

Theme 3: Greater use of information and resources

A few participants described how they increased their use of information, Macmillan resources and referrals to support services.

“Use of guidelines and support materials.” (P2, ABUHB)

“Increased referral to Macmillan for support and use of support groups.” (P14, ABUHB)

“Increased use of Macmillan support leaflets.” (P29, SBUHB)

“Greater use and signposting of Macmillan resources.” (P77, BCUHB)

MODULE UPTAKE

GP practices were required to complete three of the five modules within the Toolkit. Eight practices completed more than three modules (15.1%). The most popular modules were Module 2: Prompt Recognition and Early Referral (n=42) and Module 1: Detecting Cancer Earlier (n=30) (Table 8).

Table 8: Module Uptake

Module	Title	No.	%
1	Detecting Cancer Earlier	30	56.6
2	Prompt Recognition and Early Referral	42	79.2
3	Support through treatment	18	34.0
4	Cancer Care Reviews and Long-term Consequences of Cancer and its Treatment*	53	100.0
5	Identifying and supporting people with advanced serious illness	26	49.1
*Mandatory module			

MODULE IMPACT

In terms of the impact of each individual module, overall, participants agreed that the Toolkit improved practice processes. Of those who completed module one, almost three-quarters of participants agreed or strongly agreed that the Toolkit improved practice processes for detecting cancer earlier (72.4%, n=21/29). Of those who completed module two, 80.5% (n=33/41) agreed or strongly agreed that the Toolkit improved practice cancer referral processes. Of those who completed module three or four, 83% (n=44/53) agreed or strongly agreed that the Toolkit improved practice processes for supporting people living with cancer. Of those who completed module five, almost all participants agreed or strongly agreed that the Toolkit improved practice processes for supporting people with advanced serious illness (96.1%, n=25/26) (Figure 10).

% participants saying they ___ with the following:

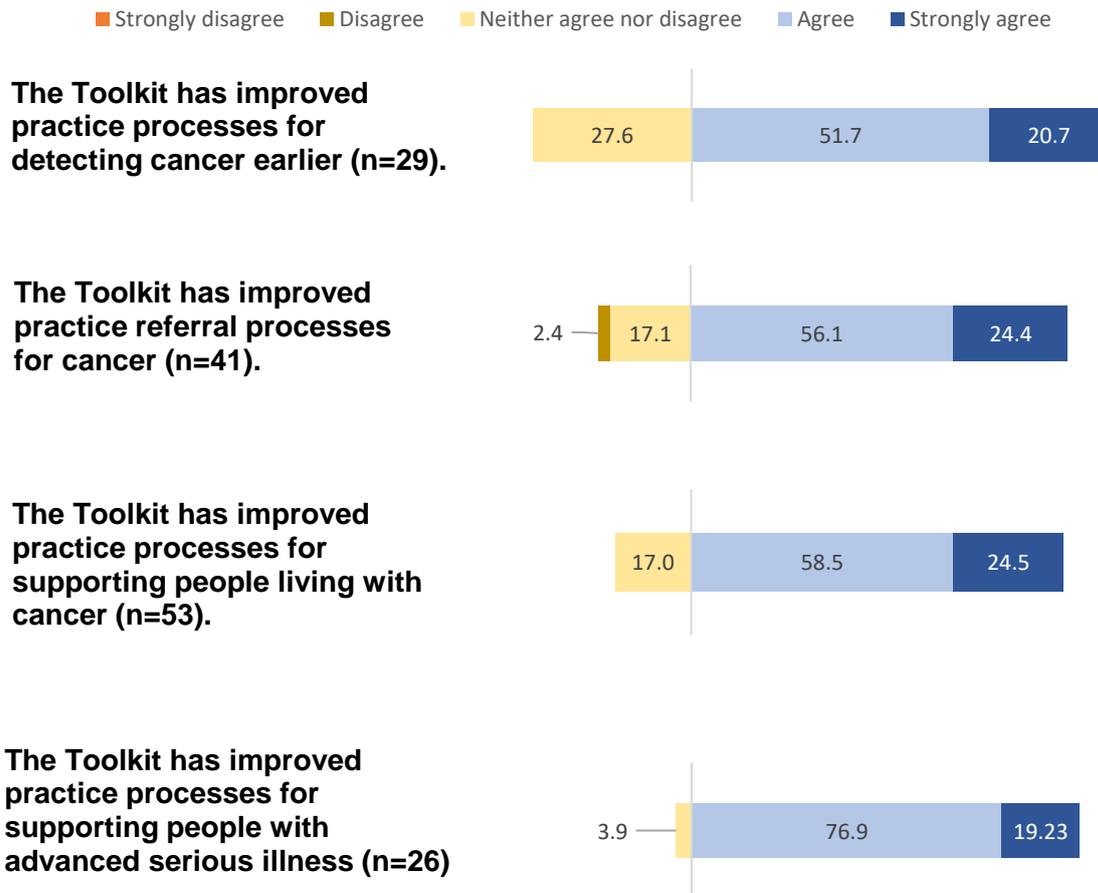


Figure 10. Module impact statements

SURVEY FINDINGS SUMMARY

- 53 GP practices completed the Toolkit – 12.8% of practices in Wales
- 658 primary care staff were involved with a mix of clinical and non-clinical staff
- Most participants felt that the Toolkit facilitated quality improvement in cancer care and just over three-quarters agreed that it was a sustainable way to drive quality improvement within their practice
- The majority of participants agreed that the information provided within the Toolkit was useful and a similar number felt that the information provided was relevant to their work
- Most participants felt that the Toolkit activities (e.g., audit and feedback) were useful, however, some highlighted that involving the whole primary care team was not easy
- Analysis identified four themes regarding the most useful aspects of the Toolkit: '*structure to review and improve cancer care provision*', '*stimulated practice discussion*', '*valuable information resource*' and '*audit and feedback exercises*'
- Analysis identified four themes regarding the least useful aspects of the Toolkit: '*time commitment*', '*usability issues*', '*information burden*' and '*engaging the whole practice team*'
- Several adjustments or additions were identified which could enhance the Toolkit and increase future uptake

- The most frequently reported factors that hindered Toolkit completion were staff time to undertake quality improvement, competing priorities within the practice and staff numbers to undertake quality improvement
- The most important factors for facilitating Toolkit completion were staff time to undertake quality improvement, staff attitudes to quality improvement and team working
- Most participants acquired knowledge that was new to them and just over three-quarters of participants agreed that they accessed information that was new to them
- Most participants agreed that the Toolkit had a positive impact on clinical practice and facilitated peer-to-peer learning within their practice
- The majority of participants felt that they had a better understanding of how they perform when it comes to the provision of cancer care
- Almost all participants agreed that the Toolkit was a useful information resource and two-thirds of GP practices (64.2%, n=34/53) indicated that the Toolkit improved their access to information to support patients living with cancer. This included improved access, increased awareness and greater use of cancer information and resources
- Of those who completed Module 1 (n=30), almost three-quarters agreed that the module improved practice processes for detecting cancer earlier
- Of those who completed Module 2 (n=42), most agreed that the module improved practice cancer referral processes
- Of those who completed Module 3 (n=18) or Module 4 (n=53), the majority felt that the module improved processes for supporting people living with cancer
- Of those who completed Module 5 (n=26), almost all agreed that the module improved processes for supporting people with advanced serious illness

MODULE 1 FINDINGS – DETECTING CANCER EARLIER

This section summarises the findings from the pre- and post- evaluation surveys as well as the document analysis of the module reflections on current practice and the impact of planned changes to processes and systems.

Of the 53 GP practices that participated, 30 completed module 1 (56.6%). Practice size varied with just under half of practices (46.7%, n=14) having a large patient list size (over 8,000 patients) (Table 9). Participating GP practices had on average: 5.37 GPs, 5.13 reception staff, 4.03 administration staff and 2.77 Practice nurses involved in the Toolkit. Just over half of staff within the GP practices were involved in the Toolkit (53.1%, n=364) with the most common roles being GPs, administration staff, reception staff and Practice nurses.

Table 9. Participating GP practice demographics

	No.	%
GP practices within each HB that completed module 1		
ABUHB	6	20.0
BCUHB	4	13.3
CAVUHB	5	16.7
CTMUHB	4	13.3
HDUHB	8	26.7
PTHB	1	3.33
SBUHB	2	6.67
Wales	30	56.6
Practice size		
Small (up to 3,999 patients)	7	23.3
Medium (4,000 to 7,999 patients)	9	30.0
Large (over 8,000 patients)	14	46.7
GP practice staff*		
GPs	161	23.5
Reception staff	154	22.4
Administration staff	121	17.6
Practice nurses	83	12.1
Healthcare assistants	58	10.1
Practice manager	34	4.96
Pharmacists	29	4.23
Nurse practitioners	22	3.21
Physiotherapists	10	1.46
Paramedics	7	1.02
Mental health nurse	3	0.44
Occupational therapist	2	0.29
Frailty nurse	2	0.29
Total staff	686	
Staff involved in the Toolkit		
GPs	110	30.2

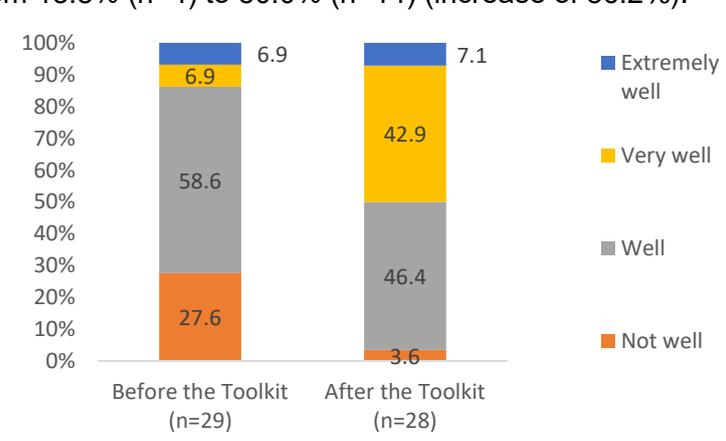
Administration staff	63	17.3
Reception staff	61	16.8
Practice nurses	51	14.0
Healthcare assistants	28	7.69
Practice managers	26	7.14
Nurse practitioners	11	3.02
Dispensary staff	8	2.20
Physiotherapists	3	0.82
Paramedic	1	0.27
Occupational therapist	1	0.27
Frailty nurse	1	0.27
Total staff involved	364	
*No. staff in GP practices at time of Toolkit participation		

IMPROVING CLINICAL PRACTICE

How well do GP practices believe they carry out the following...?

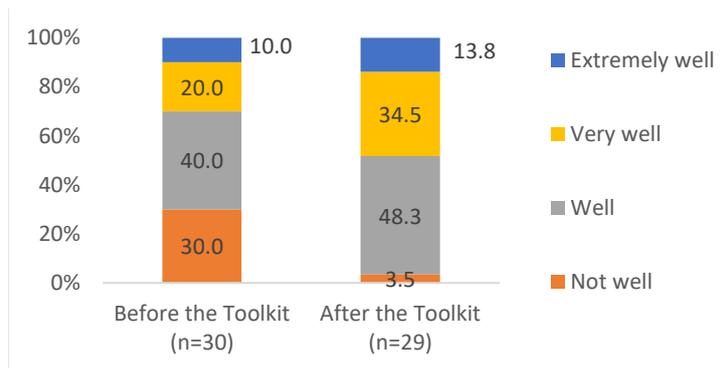
Opportunistic cancer prevention

At baseline, over half (58.6%, n=17) of practices believed that they carried out opportunistic cancer prevention 'well' while just over a quarter identified that they 'did not do this well' (27.6%, n=8). After the Toolkit, the percentage of participants who believed their practice carried out opportunistic health promotion regarding cancer prevention 'very well' or 'extremely well' increased from 13.8% (n=4) to 50.0% (n=14) (increase of 36.2%).



Supports patient engagement in cancer screening programmes

At baseline, most practices believed they supported patient engagement in cancer screening programmes 'well' (40%, n=12), 'very well' (20%, n=6) or 'extremely well' (10%, n=3) while 30% (n=9) did not believe they did this well. After the Toolkit, the percentage of participants who believed their practice supported patient engagement in cancer screening programmes 'very well' or 'extremely well' increased from 30.0% (n=9) to 48.3% (n=14) (increase of 18.3%).

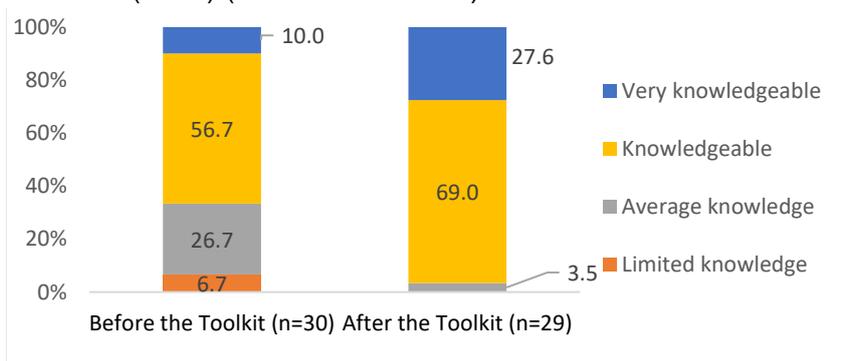


IMPROVING KNOWLEDGE

How knowledgeable are GP practices about...?

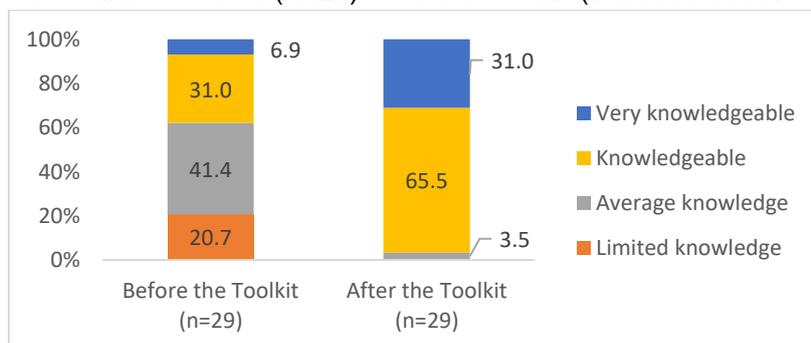
Cancer risk factors

At baseline, practices rated their knowledge of cancer risk factors as 'average' (26.7%, n=8), 'knowledgeable' (56.7%, n=17) or 'very knowledgeable' (10%, n=3) with 6.7% (n=2) stating they had 'limited knowledge'. After completing the Toolkit, the percentage of participants who rated themselves as being 'knowledgeable' or 'very knowledgeable' increased from 66.7% (n=20) to 96.6% (n=28) (increase of 29.9%).

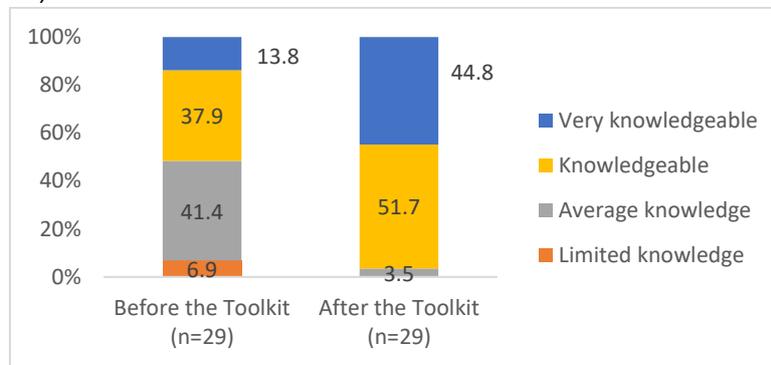


Risks and benefits of the Bowel Screening Programme

Before the Toolkit, under a quarter of practices (20.7%, n=6) rated their knowledge as 'limited' with most rating themselves either 'average' (41.4%, n=12), 'knowledgeable' (37.9%, n=9) or 'very knowledgeable' (6.9%, n=2). GP practices reporting that they were 'knowledgeable' or 'very knowledgeable' of the risks of the Bowel Cancer Screening Programme increased from 37.9% (n=11) at baseline to 96.5% (n=28) after the Toolkit (increase of 58.6%).



Before the Toolkit, most practices rated their knowledge of the benefits of Bowel Screening Programme as ‘average’ (41.4%, n=12), ‘knowledgeable’ (37.9%, n=11) or ‘very knowledgeable’ (13.8%, n=4). The proportion of GP practices reporting that they were ‘knowledgeable’ or ‘very knowledgeable’ of the Bowel Cancer Screening Programme benefits increased from increased from 51.7% (n=15) at baseline to 96.5% (n=28) after the Toolkit (increase of 44.8%).



EVIDENCE OF LEARNING

Practices were asked to summarise new learning after reviewing information on the Bowel Screening Wales’ website regarding the benefits and risks of Bowel Screening. The following themes emerged:

Theme 1: Increased awareness of the FIT test

Participants described how their knowledge of key information regarding the FIT test improved. This included better awareness of the accuracy of the new FIT test and the burden of the new FIT test compared to the previous test. Some participants specifically mentioned that they would endeavour to raise this new information with patients to encourage uptake of the test.

“New learning about FIT, which is more sensitive for human globin than the FOBT...” (P76, BCUHB)

“The new FIT test is much easier than the old FOB test, and so we will try and highlight this to our patients who may have been put off by having to do multiple samples over days. It is also a better test, so less likely to falsely end in an unpleasant investigation...” (P44, CTMUHB)

“We felt it was important that all clinicians were able to inform patients that the bowel screening was both easier for patients to do (single sample), but also better at detecting problems than the old test (in particular less false positives) ...” (P32, CAVUHB)

“The test kits being sent to patients are about to change, and will only require the patient to submit 1 sample, instead of the current 3 samples. If a patient needs another test kit, this can now be requested online, as well as by phone.” (P12, ABUHB)

Theme 2: Better understanding of benefits and risks of bowel screening

Participants described new learning around the benefits of the screening programme including completion of the test in the comfort of a patient's own home, early detection of bowel cancer, and improved survival chances for Bowel cancer.

"Benefits: Decrease in death from Bowel Cancer by up to 25%. It's easily done from home and led by the patient..." (P73, CTMUHB)

"Benefits to Bowel screening are primarily early detection of cancers, however other conditions for example polyps, haemorrhoids can also be detected and then advice and treatment can be offered..." (P56, CAVUHB)

"You're nine times more likely to survive bowel cancer if it's found early." (P28, HDUHB)

Participants also described how their knowledge of the risks improved including a better understanding of the risk of false positives, missed cancer cases and the side effects from further tests (e.g., colonoscopy).

"Risks: 98% positive results meaning 2% require colonoscopy, inevitably there will be cancer cases missed within the 98% result (as they had no bleeding, leading to a negative test result); there is a risk of bowel perforation or other complications when people have to progress on to invasive test (colonoscopy)." (P73, CTMUHB)

"...Some may find it difficult for example sensory impairments, mental well-being, religious beliefs or fear of positive results if diagnosed and follow-up further investigations such as colonoscopy..." (P62, HDUHB)

"...Still need to be aware of symptoms of bowel cancer as not 100% accurate. Direct patients to bowel screening website. Colonoscopy - small flexible camera into bowel - risks perforation 1 in 1000, risks bleeding 1 in 100-200, usually not serious." (P29, SBUHB)

Theme 3: Better awareness of bowel screening criteria

Participants highlighted new learning regarding the criteria for Bowel Screening (Ages 60-74 and every two years) and the implications of these criteria on their practice as a GP. Some participants emphasised the importance of being aware of the 'high cut off'.

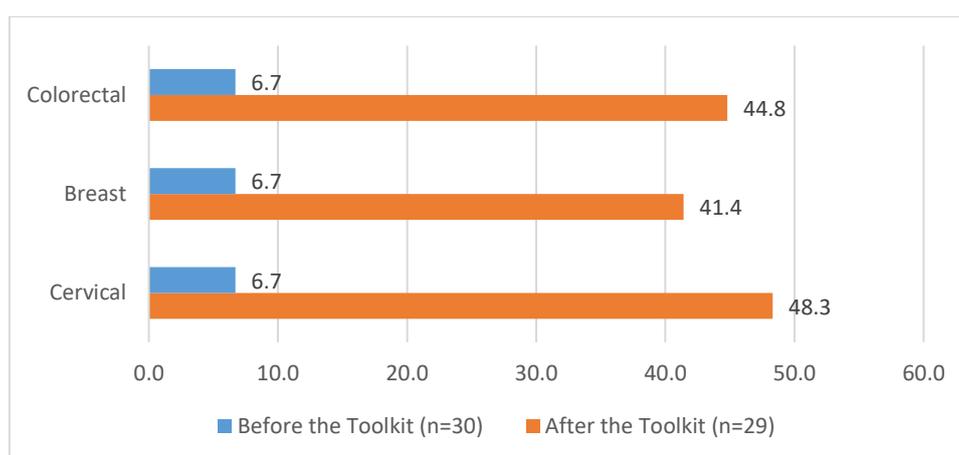
"All staff were not aware of the different age ranges. Posters to be requested from screening. We were not aware that screening was done every two years." (P41, ABUHB)

"It is also crucial that as clinicians we are aware of the high cut off used in screening, and so that a negative screening test could miss some early cancers/polyps - so if we see a patient with symptoms or high suspicion, we would need to consider further investigation..." (P44, CTMUHB)

“Equally important for clinicians to be aware of is that given the high cut off used in Wales currently, that if we see a patient with negative screening, who then develops symptoms, that we should not rule out cancer as there are going to be more false negatives at the current level set for screening. So, to consider testing in these patients (symptomatic FIT if available or endoscopy/CT if not).” (P32, CAVUHB)

Awareness of cluster and health board screening rates

Participants were asked if more than half of their clinical team were aware of their cluster and health board screening rates for cervical, breast and colorectal cancers. Awareness of local screening rates increased from 6.7% (n=2) to 41.4% (n=13) for colorectal, 6.7% (n=2) to 41.4% (n=12) for breast and 6.7% (n=2) to 48.3% (n=14) for cervical.



Opportunistic health promotion

Before the Toolkit

The range and type of activities undertaken in regard to opportunistic health promotion in primary care was diverse with many participants reporting multiple activities. Most GP practices focused on the use of ‘interventions’ where staff such as GPs, Practice nurses or Healthcare assistants would provide advice or support when patients attended for other reasons including for vaccination, cervical screening, blood pressure checks, chronic disease clinics (e.g., Diabetes). Generally, GP practices reported that they would actively encourage risk avoidance and educated patients on healthy choices (e.g., physical activity and healthy eating).

“Admin: opportunistically ask/offer smoking advice when speaking with patients. Poster/ leaflets in the waiting areas. HCAs & Nurses: during chronic disease reviews (i.e., COPD review). GPs: during consultations where relevant but also opportunistically offering health advice.” (P73, CTMUHB)

“Chronic Disease Clinic - We always ask for Smoking status, give Smoking Cessation advice and give out details of STOP SMOKING WALES. We do measure weight/BMI in most clinics (especially Diabetic, Health Heart and Blood Pressure) but are not as forceful in linking Obesity to increased Cancer risk.” (P58, HDUHB)

“Opportunistically in GP consultations as relevant to presenting complaint. Opportunistic routine blood tests for cholesterol and diabetes. Lifestyle advocate clinic for weight loss. Health care assistant checks for weight, smoking, alcohol. Chronic disease clinics in practice include lifestyle advice as well. We pick up patients through medication reviews to ensure they have their checks at least annually.” (P28, HDUHB)

Instead of just targeting high-risk groups, some practices educated all patients that attended the surgery by actively promoting healthy lifestyle services (e.g., smoking cessation) and cancer screening programmes in the waiting areas, consultation rooms, practice website and social media.

“Promotion of services/screening programmes on website and social media platforms.” (P60, HDUHB)

“Posters and TV slides promoting healthy lifestyle within waiting room. Posters for screening programmes in waiting room.” (P47, CAVUHB)

“Promotional material is displayed in the waiting room on noticeboards and on the TV screen. Actions with an individual are described as above, both to support interventions to stop smoking, reduce alcohol consumption, eat a healthy diet, exercise and also take advantage of the national screening programmes available.” (P12, ABUHB)

After the Toolkit

Most practices described multiple opportunities to improve the provision of opportunistic health promotion information to patients. This module enabled practices to identify key areas for improvement:

- Improving documentation
- Improving patient access to information

Theme 1: Improving documentation

Several participants identified that improvements could be made to the way information is collected and recorded which may facilitate the provision of opportunistic health promotion advice to patients. Participants acknowledged the importance of weight monitoring and took action to ensure that data on weight would be collected and recorded on the patient notes. In some cases, GP practices specifically mentioned the use of Read codes to ensure that information would be flagged to clinicians to prompt opportunistic health promotion advice.

“Also now plan to actively try and weigh our patient population. Plan to include cancer risk of obesity in advice.” (P42, ABUHB)

“Could improve by making more note of alerts in patient notes, checking if patients have been weighed recently...” (P33, HDUHB)

“We have agreed to weigh patients more often. We have run searches of all patients with BMI >40 and are going to contact them directly to ask to come in for

health check - 62 of them have not recently had HBA1c so we will get that and then get review. We have got a code that we are going to use for at risk of health problems due to overweight #66CM.00. Risk health associated with overweight and obesity, at increased risk and we will run searches of this regularly.” (P6, CAVUHB)

Theme 2: Improving patient access to information

Action plans from GP practices described how participants wanted to ensure that patients had access to key health promotion information. Participants identified that improvements could be made by using their practice website and social media accounts (e.g., Facebook) to share information on cancer screening programmes and healthy lifestyle choices. (e.g., healthy eating, physical activity and smoking cessation). Practices also wanted to increase the use of information in the waiting room such as leaflets and posters, however, due to Covid-19 these actions were no longer feasible as many patients were no longer attending the surgery.

“Practice has recently developed a website and Facebook page and will use these platforms to promote healthy lifestyle including stop smoking and healthy weight and educate about/ encourage participation in screening programmes. Also considering feasibility of ‘new patient’ review appointments with practice nurse, during which smoking cessation and healthy weight can be promoted, and previous participation in screening checked. Can actively promote programmes such as local park run and GoodGym within reception.” (P47, CAVUHB)

“Information regarding the local walking gym on the patient's notice board, info re parkrun on practice Facebook already and link to cancer research UK put on Facebook and practice website.” (P10, ABUHB)

“‘Spotting cancer early’ leaflets to be given out to patients, particularly during flu clinics. Take up offer of patient participation group members speaking to patients in the waiting room and handing out leaflets.” (P17, HDUHB)

Some participants reported that the connection between lifestyle and cancer risk was rarely discussed with patients, particularly for the link between obesity and cancer. GP practices recognised that this was an area for improvement and would promote this information in consultations verbally and through the CRUK Poster provided within the Toolkit.

“We discuss healthy lifestyles with our patients day in day out, but cancer does not always feature. It does feel a bit harsh to bring it up, but I think we need to normalise it, and the posters (CRUK one) could help with this. Endometrial cancer is on the rise, and this is very much obesity related, so we feel it is important to have these discussions.” (P70, CTMUHB)

“This is targeted with reference to their presentation, but we could start to incorporate where appropriate, information about the risks of cancer. This feels quite heavy handed, on a subject that is already heavily stigmatised. We felt that the use of the Wales CRUK infographic posters may help normalise this and allow us to weave it in to regular advice on weight.” (P32, CAVUHB)

“We do measure weight/BMI in most clinics (especially Diabetic, Health Heart and Blood Pressure) but are not as forceful in linking Obesity to increased Cancer risk. We should remember to bring this up when appropriate and give the same attention as we give for Smoking.” (P58, HDUHB)

“We need to focus more on risk of cancer with obesity and being overweight. Conversation that is more challenging, but we should not shy away from it.” (P24, ABUHB)

EVIDENCE OF PRACTICE CHANGE

Improving Bowel Screening Uptake

Before the Toolkit

Almost three-quarters of GP practices had an agreed approach for identifying non-responders to Bowel Screening (71.4%, n=20/28) and less than half had an agreed approach for contacting non-responders (42.9%, n=12/28).

Theme 1: Opportunistic approaches

Many GP practices reported that they used ad hoc approaches to encourage patients to take up the screening invite. Other practices highlighted that they used clinician reminders through their GP systems (e.g., alert box) to flag non-responders to clinicians so that they can engage in a discussion with the patient.

“A yellow alert box to remind clinicians about this. We then offer opportunistic advice. However, as consequence of this toolkit we have realised that this does not work. If the patient subsequently does a bowel screen the yellow box is not automatically removed, so in a lot of cases they are out of date...” (P6, CAVUHB)

“We do not currently contact non-responders, but we do read code all non-responders for bowel screening and flag it up on the yellow flag in the patient record, so that the clinician is aware that the patient did not respond to the screening offer and can discuss it with the patient if they attend the surgery...” (P58, HDUHB)

“Previously undertaken on an ad hoc basis by the GP who was reviewing result. Some GPs would send a letter and others not undertaking any action...” (P42, ABUHB)

Theme 2: Pro-active approaches

Some GP practices highlighted that they had an established approach for contacting patients using various methods including letter, telephone and text messages to encourage patients to accept their screening invite.

“Our process at the onset was of coding results from the bowel screening programme (we have patients on the English scheme, as well as the Welsh scheme). This highlighted non-responders who could then be targeted on an opportunistic basis. We have a member of staff who is the key person for contacting patients. This is done by telephone initially, if this is unsuccessful then a letter is sent...” (P12, ABUHB)

“We send letters to non-responders to explain importance of bowel screening.” (P44, CTMUHB)

“Admin /Lifestyle advocate contacts the patient - telephone and /or letter contact advising the benefits of participating...” (P60, HDUHB)

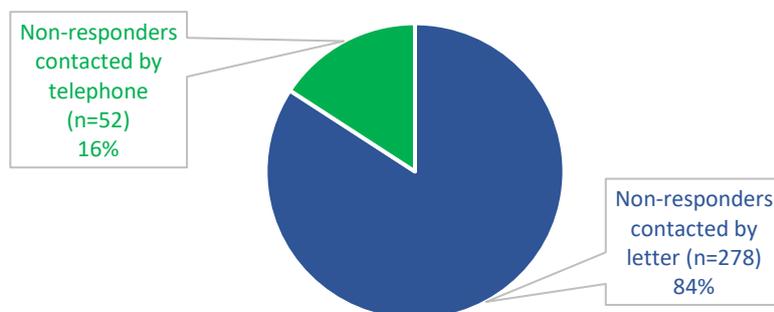
Two practices also highlighted that they were involved in Cluster Pilot Programmes for non-responders to Bowel Screening to increase uptake.

“Currently participating in the cluster pilot programme for non-responders to bowel screening. Non-responders are sent a letter after two weeks followed by a phone call from the practice. Pilot started in February [2020] but has been suspended since March...” (P47, CAVUHB)

“We have recently started sending letters as a whole cluster to the non-responders. We also have support with an officer contacting patients who then do not respond to this letter from bowel cancer screening Wales.” (P70, CTMUHB)

After the Toolkit

Of those GP practices which did not have a process for contacting non-responders, 11 implemented a new process as a result of the Toolkit (91.7%, n=11/12). Practices were asked to conduct searches of key information regarding non-responders to Bowel Screening over a six-month period. Of the 1,359 patients identified who did not respond to their Bowel Screening invite, 330 were contacted (24.3%) and 23 patients (6.97%) subsequently went on to participate in Bowel Screening².



This module enabled some practices to implement new processes and improve established approaches by:

- Proactively contacting non-responders to Bowel Screening via letter and/or phone
- Implementing new codes and flagging non-responders to clinicians (e.g., alert box)
- Actively promoting cancer screening programmes to encourage patients to participate

Evidence of positive changes made by GP practices as result of this module:

² Data from 11 GP practices which implemented a new process for encouraging Bowel Screening uptake.

“...we did send 39 letters to non-responders in months 2-5. The uptake of screening in this group was surprisingly good with six out of 39 (approximately 15.4%), even though these patients were selected at random. This surprised a lot of people. All of the people who subsequently went on to have the FOB screening had normal results.” (P5, no process before Toolkit, SBUHB)

“We did manage to approach a number of non-responders who informed us that they would be completing. Our numbers of non-responders did decrease so this worked well.” (P26, no process before the Toolkit, PTHB)

“We now have a more consistent approach for contacting patients who have not submitted their bowel screening sample.” (P42, established process before Toolkit, ABUHB)

“We have identified through the module that we were not coding patients being sent the bowel screening 'non-responder' letter appropriately which we have now corrected.” (P28, established process before Toolkit, HDUHB)

“Useful process! We had not realised we were no longer getting paper updates! We then set up a reminder/ encouragement letter but unfortunately, a different code was added. This was realised after six months. When the correct code was added, we found that 22 patient letters had been sent, an additional 2 patients were also found from before the system was properly set-up and running (with the six-month period). Of these 24 patients, the prompt led to 2 later returning their sample.” (P67, no process before Toolkit, BCUHB)

“We have started sending letters to non-responders endorsing Bowel Screening. Despite COVID pandemic, many patients have verbally agreed to engage with screening going forward.” (P73, no process before Toolkit, CTMUHB)

Challenges identified

GP practices were asked to describe any challenges that hindered their team from implementing or maintaining planned improvements. The following themes emerged:

Theme 1: Impact of Covid-19

The suspension of the Bowel Screening Programme (March 23, 2020, to July 1, 2020) due to the Coronavirus pandemic which meant that no invites were sent out to eligible patients and patients were unable to return their sample. This meant that some practices were unable to see evidence of change as the monitoring period was much shorter than initially intended (<6 months) or they were unable to implement the new process.

“Due to COVID a lot of patients who had agreed to go for the screening process or who were reconsidering this had not done so...” (P16, CTMUHB)

“There may have been a better response to our bowel screening letters but BSW deferred due to pandemic...” (P24, ABUHB)

“...Bowel screening was stopped for a long period and so we have not had much opportunity to address things, but it is a work in progress.” (P32, CAVUHB)

“The Covid pandemic has impacted on both the screening services and Primary Care...” (P60, HDUHB)

Theme 2: Inconsistent coding practice

Some participants highlighted that members of their team were not using or would forget to use the correct code.

“...They [opportunistic conversations] were happening but people aren’t using the codes. I have been and have a copy of them in my room so the majority of these codes will be mine. Again, just comes down to staff being busy and not keeping codes live.” (P6, CAVUHB)

“...Some although contacted were not read coded appropriately.” (P16, CTMUHB)

“Opportunistic discussion either did not occur on many occasions, or it was not coded.” (P18, HDUHB)

Theme 3: Inadequate resources

Participants described the financial impact of implementing a process for contacting non-responders. Some expressed that the extra costs associated with sending letters and the dedicated staff time needed to send letters, undertake phone calls etc. were barriers to initiating and sustaining this improvement.

“...The logistics/admin time and expense of sending out the letters to all the non-responders would have been considerable give the size of our practice (21500 patients) & the numbers of non-responders per annum could approach 1000 patients. Hence the reason we opted to perform a pilot. However, there may be an argument for doing so given the data provided funding were available...” (P5, SBUHB)

“...Changes in the process to contact non responders in bowel screening will attract extra cost and will need to be discussed at managerial level.” (P56, CAVUHB)

“...As a practice we feel we could send the letter but in the current climate we are already struggling to get outside lines because of the extra volume being undertaken on the phone so we would struggle to make 3 calls to all the non-responders and this would add to an already heavy workload...” (P33, HDUHB)

Some practices questioned the role of primary care in contacting Bowel Screening non-responders, particularly given the lack of resources to support this initiative.

“...Practice has previously participated with a pilot scheme regarding bowel screening, and this showed that patient contact via letter or telephone significantly improved the number of responders. We felt strongly that this was the role of bowel screening Wales rather than primary care, particularly with no additional funding and already scarce resources...” (P10, ABUHB)

“We felt strongly that contacting non-responders by phone/post was the role of Bowel Screening Wales rather than general practice and would impact already scarce resources and require additional funding.” (P11, ABUHB)

MODULE 1 SUMMARY

- 30 GP practices completed Module 1 (56.6%)
- As a result of undertaking and completing this module GP practices have:
 - Improved their knowledge of cancer risk factors, and the risks and benefits of the Bowel Screening Programme
 - Increased awareness of their Cluster and Health Board screening rates for all cancer screening programmes: Breast (6.7 to 41.4%), Cervical (6.7 to 48.3%) and Colorectal (6.7 to 44.8%)
- Reported improvements in how well GP practices believed they:
 - Delivered opportunistic cancer prevention
 - Supported patient engagement in Bowel Screening
- Of those GP practices which did not have a process for contacting non-responders, 11 implemented a new process as a result of the Toolkit (91.7%, n=11/12)
- Reported practice changes for improving processes for contacting non-responders to Bowel Screening including:
 - Establishment of a proactive approach to encourage patients to respond to their Bowel Screening invite (e.g., GP endorsed letters mainly)
 - Improved coding and use of clinical reminders (e.g., alert box) to better highlight non-responders to clinicians
 - Actively promoting the Cancer Screening Programmes within the practice (e.g., waiting room)
- GP practices identified several challenges that hindered practice change:
 - Suspension of the Bowel Screening Programme from March 23 to July 1, 2020, due to Covid-19 meant new processes were delayed or implemented over a shorter time period (<6 months)
 - Inconsistent coding practice between and within GP surgeries
 - Lack of resources to implement and sustain process for contacting non-responders to Bowel Screening
 - Negative perceptions regarding the role of primary care in health promotion including promotion of cancer screening programmes

MODULE 2 FINDINGS – PROMPT RECOGNITION AND EARLY REFERRAL

This section summarises the findings from the pre- and post- evaluation surveys as well as the document analysis of the module reflections on current practice and the impact of planned changes to processes and systems.

Of the 53 GP practices that participated, 42 completed module two (79.2%) (Table 10). Practice size varied with just under half of practices (45.2%, n=10) having a large patient list size (over 8,000 patients). Participating GP practices had on average: 3.83 GPs, 3.36 reception staff, 2.49 administration staff and 2.27 Practice nurses involved in the Toolkit. Just under half of staff within the GP practices were involved in the Toolkit (49.0%, n=532) with the most common roles being GPs, administration staff, practice nurses and reception staff.

Table 10: Participating GP practice demographics

	No.	%
GP practices within each HB that completed module 2		
ABUHB	8	19.0
BCUHB	5	11.9
CAVUHB	5	11.9
CTMUHB	5	11.9
HDUHB	9	21.4
PTHB	4	9.52
SBUHB	6	14.3
Wales	42	79.2
Practice size		
Small (up to 3,999 patients)	8	19.0
Medium (4,000 to 7,999 patients)	15	35.7
Large (over 8,000 patients)	19	45.2
GP practice staff*		
Reception staff	251	23.1
GPs	242	22.3
Administration staff	193	17.8
Practice nurses	121	11.2
Healthcare assistants	97	8.94
Practice manager	56	5.16
Pharmacists	42	3.87
Nurse practitioners	42	3.87
Physiotherapists	13	1.20
Dispensers	11	1.01
Mental health nurse	6	0.553
Paramedics	5	0.461
Frailty nurses	4	0.369
Occupational therapist	2	0.184
Total staff	1085	

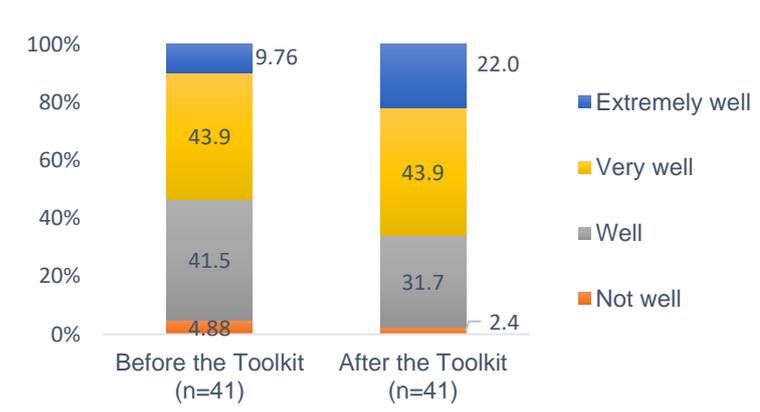
Staff involved in the Toolkit		
GPs	161	30.3
Administration staff	87	16.4
Practice nurses	75	14.1
Reception staff	74	13.9
Practice managers	42	7.89
Healthcare assistants	40	7.52
Nurse practitioners	25	4.70
Pharmacists	13	2.44
Dispensary staff	8	1.50
Physiotherapists	3	0.64
Frailty nurse	2	0.376
Occupational therapist	1	0.188
Paramedic	1	0.188
Total staff involved	532	49.0
*No. staff in GP practices at time of Toolkit participation		

IMPROVING CLINICAL PRACTICE

How well do GP practices believe they carry out the following...?

Application of the NICE Suspected Cancer: Recognition and referral guidelines

At baseline, most participants indicated that they applied the NICE Suspected Cancer guidelines 'well' (41.5%, n=17), 'very well' (43.9%, n=18) or 'extremely well' (9.76%, n=4). After the Toolkit, the proportion of GP practices reporting that they applied the NICE Suspected Cancer: Recognition and referral guidelines 'very well' or 'extremely well' increased from 53.7% (n=22) at baseline to 65.9% (n=27) after the Toolkit (increase of 12.2%).



Awareness and use of NICE guidelines summaries

Module 2 increased awareness of all NICE guidelines summaries amongst GPs. Before the Toolkit, over half of GP practices were aware of the Macmillan Rapid Referral Guidelines (57.1%, n=24) and NICE Suspected cancer recognition and referral – symptom desk easel (CRUK) (64.3%, n=27). After the Toolkit, the largest increases in awareness were: CRUK Suspected Cancer Recognition and Referral Symptom Reference Guide (from 19%, n=8 to 76.2%, n=32).

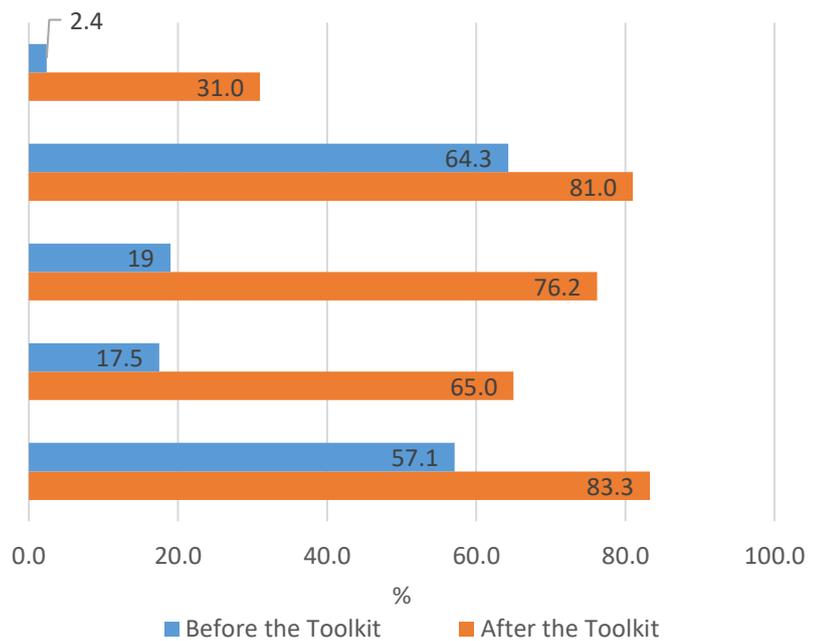
Adult Cancers Infographic - Referral pathways by presenting symptom:
increase of 28.6%

NICE Suspected cancer recognition and referral – symptom desk easel (CRUK):
increase of 16.7%

CRUK Suspected Cancer Recognition and Referral Symptom Reference Guide:
increase of 57.2%

C the Signs: **increase of 47.5%**

Macmillan Rapid Referral Guidelines:
increase of 26.2%



Module 2 also increased use of NICE guidelines summaries amongst GPs. After the Toolkit, the largest increase in awareness was the Macmillan Rapid Referral Guidelines (from 43.9%, n=18 to 85.7%, n=36).

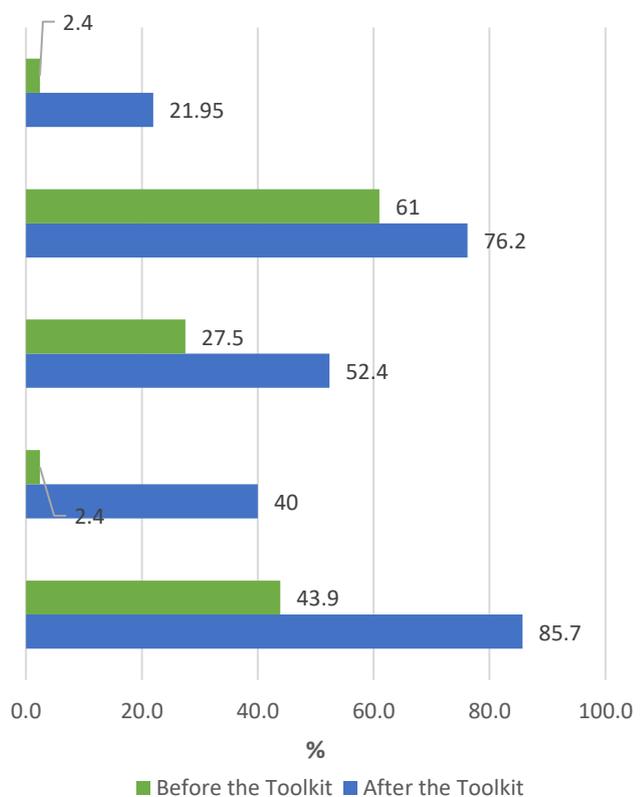
Adult Cancers Infographic - Referral pathways by presenting symptom (Will Stahl-Timmins 2017): **increase of 19.6%**

NICE Suspected cancer recognition and referral – symptom desk easel (CRUK):
increase of 15.2%

CRUK Suspected Cancer Recognition and Referral Symptom Reference Guide:
increase of 24.9%

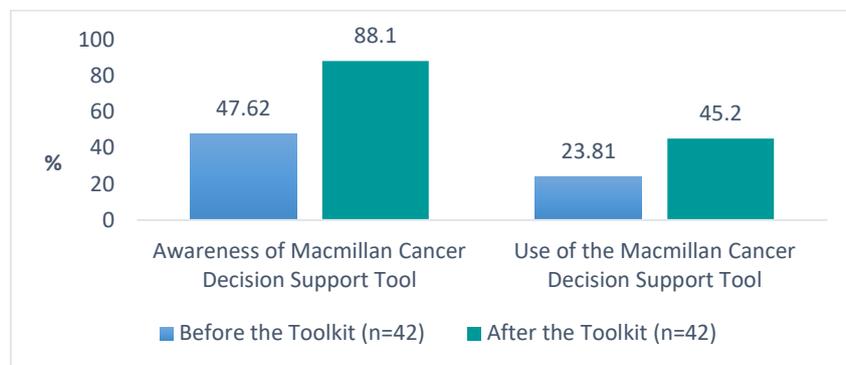
C the Signs: **increase of 37.6%**

Macmillan Rapid Referral Guidelines:
increase of 41.8%



Awareness and use of the Macmillan Cancer Decision (CDS) Tool

After the Toolkit, the proportion of GP practices that reported they were aware of the Macmillan CDS tool increased from 47.6% (n=20) to 88.1% (n=37) (increase of 40.5%). Use of the CDS tool increased from 23.8% (n=10) to 45.2% (n=19) (increase of 21.4%).



GP practices (n=16) who reported that they did not use the Macmillan CDS tool highlighted several reasons why they did not use the tool including:

- Time consuming to use during 10-minute consultation
- Not user friendly
- Not intuitive enough
- Sometimes oversensitive (e.g., pulls up older symptoms i.e., 21 years ago)
- Usability issues reported from EMIS users (e.g., difficult to download and cumbersome to navigate)
- Haven't used the tool in a clinical scenario

EVIDENCE OF PRACTICE CHANGE

This module encouraged practices to review and improve the provision of care for patients on a USC pathway including the provision of information, coding and safety netting processes. The following section describes current practice and changes made as a result of this module.

Improving the provision of information to patients on a USC pathway

Before the Toolkit

Most practices mentioned several key pieces of information that they would communicate, mainly verbally, to patients referred on a USC pathway. While some participants acknowledged that the information shared would vary depending on the clinician, patient and the clinical situation (e.g., high vs a low suspicion of cancer), others provided several key topics that would usually be discussed. The following themes emerged 'referral process information', 'explanations regarding purpose of referral', 'safety netting advice' and 'referral practicalities'.

Theme 1: Referral process information

Participants described how they would communicate the referral process, type of tests/ investigations and offer advice and support. In the main, most practices would provide this information verbally and very few reported that they provided written information to patients.

“There will also be discussion about what type of tests/ investigations they may need. Confirmation of the patient's availability will be made and any relevant dates which may affect this - e.g., holiday, are clearly stated in the referral letter.” (P12, ABUHB)

“We explain what the USC referral is and any information they feel they require. Discuss any red flag signs or symptoms and if worsening advise the best course of action for them to take.” (P23, SBUHB)

“Referral Processes help and support available, triage for any urgent questions. Macmillan local contact. Specialist nurse availability in secondary care. All the above are offered to patients.” (P26, PTHB)

“Verbal information, on-line information and sign posting to different websites. Written information and reassurance. Information re time planning of what should occur and when and if any deviation then contact numbers are given. Discussed the chance that a referral may be downgraded, talk about pathway of/for diagnosis, also that new information may be requested from department and that referral may be re-directed...” (P37, HDUHB)

In addition to explaining the referral process, some practices stated they would stress the importance of the referral to encourage patients to attend their appointment.

“Verbally express the need for USC referral. Express the importance of attendance at such appointment.” (P73, CTMUHB)

“We let them know of our concerns regarding their symptoms. We also let them know the urgency with which they are being referred.” (P28, HDUHB)

“Discuss reason for referral and advise of necessity for speed of referral.” (P41, ABUHB)

Theme 2: Explanations regarding purpose of referral

Some but not all participants described how they would clearly explain that the referral was for a cancer service. Others also expressed that they would reassure patients by explaining that most referrals do not result in a cancer diagnosis. A few participants also voiced the difficult balance between giving patients all the information and causing anxiety in patients.

“Currently patients are advised that they are being referred for investigation for a symptom/ finding that could be caused by cancer.” (P3, CTMUHB)

“All clinicians advise the patient that they are referring under the urgent suspected cancer pathway in order to rule out cancer, usually erring on the side of caution.” (P4, BCUHB)

“Currently if a USC referral is made, the clinician will usually discuss the possibility of a cancer diagnosis being made...” (P12, ABUHB)

“GPs are generally explicit during consultations that they are concerned that the patient has sinister symptoms and that cancer is one of the possible diagnoses.” (P43, PTHB)

“Difficult as balance between managing anxieties whilst awaiting review between stressing need to attend. Sometimes I avoid the word cancer, but stress that I’m referring them urgently to make sure nothing sinister going on. Tend to state that they are on the urgent suspected cancer pathway - often by way of single symptom/age and therefore will make sure they are seen urgently, but doesn’t necessarily mean cancer.” (P29, SBUHB)

“Some GPs told patients that they were worried about cancer if the patient was also concerned or if they had a very strong suspicion that it was cancer. Others did not specifically state the referral was looking for cancer if the patient was extremely anxious, did not mention cancer or if they felt cancer was not as likely.” (P74, CAVUHB)

Theme 3: Safety netting advice

Most practices conveyed that they would advise their patients on a USC pathway to contact the surgery if they did not receive an appointment within a certain time-period. There was substantial variation in the time specified by practices, which included 1 to 2 weeks, 2 weeks, 2 to 3 weeks, 3 to 4 weeks or 4 weeks.

“They are advised that if they have not heard anything from the hospital within 2-3 weeks, to get in touch with the surgery so it can be chased up.” (P3, CTMUHB)

“We advise that if the patient has not received an appointment within 2 weeks, they should contact surgery.” (P4, BCUHB)

“...and that if they do not receive correspondence from the relevant department within 4 weeks then they should inform us.” (P14, ABUHB)

“...ring us in 3-4 weeks if not heard regarding an appointment.” (P19, ABUHB)

“Routinely ask patients to contact us if not heard within 1-2 weeks.” (P32, CAVUHB)

“Patients are all told to expect a hospital appointment within two weeks and if not to contact the GP again to expedite the appointment.” (P43, PTHB)

“Routinely ask patients to contact us if not heard within 1-2 or for some 2-3 weeks.” (P70, CTMUHB)

Theme 4: Referral practicalities

Other practices discussed additional considerations for USC referrals such as ensuring patient contact details are correct, arrangement of a dedicated follow-up appointment and encouraging the patient to take a relative or friend to the hospital appointment.

“It is important to check that they have given up to date personal details such as confirming the Current Address, Contact details such as mobile phone number.” (P5, SBUHB)

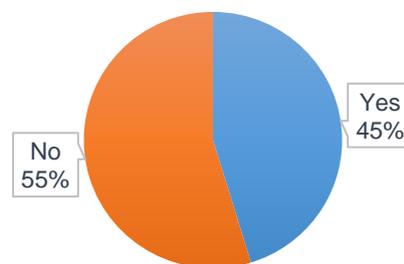
“Discuss the appointment and to take a friend/ partner/ relative with them for support.”
(P10, ABUHB)

“Confirmation of patients details e.g., telephone, address. Patient is informed of the USC referral and demographics always checked.” (P27, CAVUHB)

“Moreover, once patient has attended for their appointment(s) to book a follow-up review with their GP either Face to Face or virtual.” (P62, HDUHB)

Improving coding practice

In addition to reviewing and developing action plans to improve the provision of information to patients on an USC pathway, GP practices were also asked to assess their coding practice for USC referrals. Before the Toolkit, under half of participating GP practices had a system in place for coding USC referrals (45.0%, n=19/42).



Practices descriptions of their coding practice identified:

- Some referrals were coded by speciality and not urgency
- Use of 'Fast Track Cancer Referral' code (#8Ht), however, inconsistently applied within GP practice team
- Use of practice proformas which generate a clinical code when saved onto the patient's record

Those participants (n=23) that reported that they did not have a system in place for coding USC referrals stated they maintain a separate list/ register of USC referrals. A secretary or member of the admin staff then monitors the list to ensure that the patient attended their appointment.

After the Toolkit

This module enabled GP practices to:

- Implement the recommended Toolkit code for 'Fast Track Cancer Referrals'
- Increase practice staff awareness of the USC referral process, Read code and summaries of guidance

Theme 1: Coding improvements

Participants reported that this module encouraged GP practices to implement new processes for coding USC referrals. Many participants increased their use of the recommended USC referral code - Fast Track Cancer Referral, however, several stated that further improvements were still needed as not all clinicians are using the same code.

“After review of how referrals were coded, team now standardises USC referrals by codes using “fast track referral for suspected cancer”. Using this approach allows for easier recognition in notes and with prioritising/follow up.” (P2, ABUHB)

“The use of read codes had improved (2 vs 20), however, it appeared to be only a couple of partners using the correct read code.” (P5, SBUHB)

“As a practice we have started to use the read code “fast track urgent suspected cancer” #8HHt. This was not used previously at all so this is definitely an improvement from the first audit.” (P16, CTMUHB)

“We have been a little slow to implement our coding changes, but already we can see more easily those referred for suspected cancer, and so follow-up to check they have been seen. It is also easier to assess the number of these referrals made and the conversion rates.” (P32, CAVUHB)

“[NAME] our secretary now attaches the USC code to all USC referrals. This has already made a real difference as we have gone from 0 on baseline data, to 38 at 6 months. This was all to do with awareness of the correct code to use. Coding seems to have been one of our biggest problems...The Macmillan e-module on coding and safety netting in the context of cancer was also very useful to help make us more code aware and hence safety aware.” (P59, HDUHB)

“Over the past 6 months we have been coding any fast-track referrals to allow us to safety net more efficiently. We have been asking patients to contact us if they have not received an appointment within 2 weeks and are now able to run searches of all fast-track referrals to ensure follow-up has been arranged. When referring patients for suspected cancer we have been discussing with them that cancer is a possibility and therefore it is very important that they are seen quickly.” (P76, BCUHB)

Theme 2: Increased awareness

Many participants mentioned how the practice had greater awareness of the USC referral process within their practice and information including correct code for USC referrals and referral guidelines. In terms of the provision of information to patients, a few practices reported that they provide more information to patients during the consultation or on the practice website.

“There has been increased awareness among practice staff about USC referral criteria and how to access the referral guidelines.” (P3, CTMUHB)

“The whole practice awareness and adoption of the Macmillan rapid referral guidelines (hardcopies in everyone's room). This is likely to have led to the 20% increase in cancer diagnosis via USC referrals.” (P19, ABUHB)

“Another factor which helped support our new improved approach to patient information and support was discussing the Macmillan Toolkit at a practice meeting and making

everyone aware of the findings of the first round - and the distribution of 'packs' with important information, including correct coding.” (P59, HDUHB)

“The team are more aware of admin involvement in the following up of USC referrals. Time set aside each week to liaise with admin and follow up or delegate to follow up.” (P37, HDUHB)

“We are now using more social media and the practice website for patient information and education of symptoms.” (P4, BCUHB)

Improving the safety netting of urgent referrals for suspected cancer

Before the Toolkit

In terms of their practice before the Toolkit regarding the safety netting of patients on a USC pathway, participants conveyed various safety netting advice given and the processes for monitoring these patients. Analysis revealed two key themes: ‘*safety netting advice*’ and ‘*formal monitoring of USC referrals*’.

Theme 1: Safety netting advice

There are several recommended pieces of information to communicate to a patient in a GP consultation. In terms of safety netting, GP practices highlighted that they would ensure that the patient was aware of the time period by which they should receive an appointment from the hospital. The time period varied from ten days to two weeks.

“All the doctors present at our meeting voiced that they gave explicit instructions to each patient that if they had not heard anything by 2/52 then they should let us know. As before we reiterate the importance of checking patient address phone (in Mobile phone) contact details with each patient when making a USC referral.” (P5, SBUHB)

“All patients are told to contact the surgery if they have had no contact with secondary care after 10 days.” (P26, PTHB)

“No formal system other than safety-netting with the patient. Patients are told to contact the practice if no appointment received within 2 weeks.” (P58, HDUHB)

“Patients are advised at point of consultation to re contact the surgery post two weeks in order to alert staff to chase referral if no response at this time.” (P69, PTHB)

“All GPs give verbal safety netting along the lines of ‘If you have not received an appointment within 2 weeks, please can you call us to let us know and we can chase it for you’.” (P74, CAVUHB)

Theme 2: Formal monitoring of USC referrals

GP practices stated different processes and systems that support the safety netting of patients on a USC pathway. Participants mentioned several actions that a GP practice would use to ensure appropriate safety netting practice. Admin or secretaries, in the main, were responsible for maintaining and monitoring a list of practice USC referrals (usually a spreadsheet) to

ensure that the referral was received, prioritised, that an appointment was arranged and that the patient was seen. In some cases, this responsibility included:

- Checked WCCG to ensure referrals were received and prioritised
- Ensured that any delays or problems were highlighted to referring clinician including DNA letters and referral downgrades

“USC referrals are tracked by admin staff on a paper list. The referrals are tracked to ensure receipt by the hospital and then monitored to ensure an appointment follows. Any delays or problems in this process are highlighted promptly to a clinician and the practice manager.” (P12, ABUHB)

“All USC referrals are closely monitored by secretaries. Any DNA letters received are acted upon promptly to ensure patients do attend and are seen. Relevant letters from specialists regarding appointments and ongoing treatment plans are also monitored.” (P17, HDUHB)

“Practice secretary will chase appointments if this has not been forthcoming I.T. (WCCG) has function to view confirmation of viewing by secondary care.” (P26, PTHB)

“Spreadsheet sent by Health Board listing USC referrals from practice and their eventual destination/ action. Search for USC referrals 'in house' to ensure that outcomes have been achieved.” (P18, HDUHB)

“Admin staff check register for appointments given or planned at least twice per month and feed back to GP when necessary. Any downgraded referrals are notified via referral update email and sent to referring GP. Any DNA of appointment is notified via hospital letter and referring GP notified.” (P27, CAVUHB)

“Individual GP currently responsible for making a task for themselves when they send a USC referral. Will check the patient has been seen and look out for clinic letters/investigation etc.” (P46, SBUHB)

After the Toolkit

The Toolkit enabled practices to improve the safety netting of patients on a USC pathway by:

- Increasing awareness and use of patient information to support verbal conversations regarding a USC referral
- Increasing awareness and use of recommended codes for USC referrals
- Improving audit and follow-up processes for patients referred on a USC pathway

Patient information

Some practices established new processes to ensure information was provided to patients on a USC pathway. This included written information (e.g., letters) and improvements to the verbal information given to patients.

“Safety netting letter had initially been used widely but then when GPs ran out of copies, they stopped using the letter. Letter has been saved onto the computer system accessible by all GPs so they can print copies of it and further printed copies also given to all GPs.” (P3, CTMUHB)

“We now send all 2ww/USC referrals a letter indicating they have been referred on a cancer pathway and should be contacting us if they have not heard from the hospital at 2 weeks. This was a positive change.” (P60, HDUHB)

“Patients are given verbal advice about the referral process and advised to contact practice/ referring clinicians back if they have not heard in 2 weeks.” (P16, CTMUHB)

“We have also given the patient a contact number for first appointments and our secretary to chase up if they have not heard from secondary care within a specified time frame.” (P14, ABUHB)

Coding improvements

Most practices reported improvements to their coding and audit processes as a result of this module. Use of the recommended code improved practices’ audit system, which in turn made it easier for practices to monitor patient progress.

“Improved read coding made it easier to audit and check progress.” (P41, ABUHB)

“Read coding #8HHt (which still hasn't been fully implemented) will enable admin staff to search and monitor the progress of people referred. Currently our secretary has been searching on USC WCCG to monitor the progress and ensure the patient has been reviewed, this has helped streamline the process and acts as a safety net to fall back should a patient 'slip through the net.” (P73, CTMUHB)

“Our medical secretaries have now added an extra approach of running a search weekly of the referrals and check if patients' have been seen.” (P69, PTHB)

Several practices commented that the Fast-Track Cancer Referral code (#8HHt) was very useful. Good coding and audit processes meant that practices established better follow-up procedures. Benefits for the patient included receipt of prompt information regarding a downgraded referral (change in timeline for appointment) and engagement with patients who have delayed or declined their appointment to ensure attendance at the hospital.

“All USC referrals are now correctly coded on Vision and well as on WCCG... We have a 'USC referral tab' set up where we can click and get easy access to a patient information letter about the process of urgent referral and safety netting. Everyone is encouraged to ensure referrals are marked as USC on the lexacom dictation app and to send an alert to the secretary. [NAME] our secretary is able to now easily run a search of USC referrals to check progress each month.” (P59, HDUHB)

“Using the #8HHT fast track cancer referral read code when referring patients for suspected USC over the last 6 months and having a safety net check-up process in place has been very successful. Our secretary also performs a search to check that patients referred USC have been contacted by secondary care. Where patients have been downgraded to routine or assessment deemed unnecessary we have then been able to inform patients.” (P14, ABUHB)

“We have introduced a robust system for the coding of all USC referrals by our secretary, which are then entered onto a spread sheet. This is then checked on a monthly basis to make sure everyone is seen or understand the process of what happened next. We are able to see if patients are downgraded and review if we feel this is appropriate or not, safety net patients who have decided not to attend hospital due to COVID etc.” (P70, CTMUHB)

“Our safety netting has markedly improved with changes made over the last 6 months. All GPs now code “fast track cancer referral” for USC referrals or investigations e.g., CT/USS, and a designated member of the admin team runs a search for these patients every 2 weeks to check an appointment is in place and has not been missed. This has been very useful to chase those patients who have gone on to decline or postpone their appointment or investigation due to concerns re covid-19 pandemic, and resulted in a call and discussion with GP regarding risk of delayed diagnosis cancer vs risk of covid-19, and providing reassurance and support.” (P20, CAVUHB)

Challenges identified

Several challenges were identified that prevented GP practices from implementing new processes and systems. The following themes emerged ‘Covid pandemic’, ‘staffing issues’ and ‘coding problems’.

Covid pandemic

The Coronavirus pandemic has had a significant impact on primary care and their ability to complete the activities within the Toolkit. Some participants explained that due to the pandemic it was difficult to implement the agreed action plans, review search data and get together as a team to discuss the Toolkit.

“Due to the change in services due to COVID and how the working pattern had changed for everyone we did not manage to complete some of the pathways we had anticipated to do.” (P16, CTMUHB)

“Unfortunately, due to Covid pandemic - monthly reviews of cancer referrals were not performed.” (P29, SBUHB)

“At present we have Drs and staff isolating and / or working from home which is a hindrance to set up proper discussions although we can use applications like zoom or Microsoft teams it is not always productive and technology isn't always reliable.” (P23, SBUHB)

Participants also highlighted their concerns regarding referrals during the pandemic including delays in appointments and the impact of referral downgrades.

“Increased incidence of patients NOT getting an appointment within 2 weeks either due to downgrading referrals or lack of capacity in secondary care to meet the 2-week appointment target. This is very disappointing and extremely worrying.” (P17, HDUHB)

“Covid has made an impact on waiting times for x-rays and delaying diagnosis in patients. Clinics have been held virtually however some have been cancelled or postponed due to Covid and its restrictions.” (P23, SBUHB)

“USC pathways were generally disrupted due to Covid, especially for patients with colorectal problems as colonoscopies and gastroscopies were not being done in secondary care.” (P43, PTHB)

“There has been delays in patients being seen by secondary care due to hospital Covid restrictions, some of those patients we have referred as a USC have been downgraded or sent back e.g., gastro USC referrals, stating as they are unable to perform OGD/scopes then for GP to arrange CT scans and refer back as necessary.” (P45, SBUHB)

Staffing issues

Several practices expressed that staff turnover and capacity issues hindered their ability to implement the intended changes. Some practices explained that it was difficult to circulate the new changes to the team, including locums, which also hampered participants’ ability to establish new ways of working within their teams.

“At present clinician turnover creates challenges to the dissemination of new ways of working. The many changes in response to the Covid pandemic have had an impact on developing practice related to cancer.” (P76, BCUHB)

“...changes to system of working, and at times low staffing levels have all impacted on actioning this toolkit.” (P60, HDUHB)

“We unfortunately experienced some delay in implementing the above changes due to administrative / staff changes however this system is now in place.” (P42, ABUHB)

“There are serious capacity issues within the practice (due to lack of available clinician time) so it is difficult to arrange follow up and for patients to access a follow up appointment when needed. Practice is under a lot of pressure with lack of clinicians and frequent use of locum clinicians who may not be fully aware of what they should be doing and the importance of recording the information.” (P34, BCUHB)

Coding problems

Individual clinician choice regarding use of Read codes had an impact on the usability of the searches and audits within the Toolkit. When incorrect codes were used, the ready-made audit within the Toolkit was then inaccurate and would not pick up all patients for example, the number of patients referred on a USC pathway.

“The searches would have been easier but the choice of read code is very variable from Dr to Dr. Indeed, one of our partners still uses faxed paper referrals.” (P5, SBUHB)

“Analysis of code #8Hht shows some anomalies in how this code is being used and it isn't clear that the addition of this code is adding much benefit at the moment. Within Wales referrals can be routine, urgent or USC and the distinction between urgent and USC may

not be apparent to the person typing the letter, resulting in #8HHt being added erroneously at times.” (P12, ABUHB)

EVIDENCE OF LEARNING

Improving the safety netting of ‘low risk but not no risk’ patients

Before the Toolkit

Practices described their current practice regarding the safety netting of ‘low risk but not no risk’ patients. Descriptions focussed on the following categories: ‘red flag advice’, ‘follow-up appointments’ and ‘documentation of safety netting advice’.

Theme 1: Red flag advice

Predominantly GP practices described how they would ensure that patients were made aware of the signs and symptoms to look out for, particularly ‘red flag’ symptoms and when they should return for a follow-up appointment if symptoms persist, worsen or change.

“All staff use ‘safety netting’ with symptoms that could lead to ‘red flags’ or sinister features. As with many symptoms specifically warning patients of ‘red flags’ and the symptoms they need to monitor for is also a useful tool practiced within the team.” (P2, ABUHB)

“We all use safety netting routinely but agreed that one has to be specific rather than generic when explaining to patients what symptoms should prompt re-attendance e.g., in the case of dyspepsia, dysphagia, regurgitation, weight loss, haemetemesis or a persistent or worsening symptom of dyspepsia not resolving with whatever treatment has been given.” (P5, SBUHB)

“Also, patients are given advice on returning sooner if worsening of symptoms. Patients are given red flag symptom advice like, haemetemesis, weight loss, and dysphagia and to be reviewed as soon as possible if any.” (P16, CTMUHB)

“Explaining to the patient that although presenting short-onset symptoms (cough, hoarseness, loose stool, dyspepsia etc.), are not currently red flags, if they persist then this would be itself a red flag and would need investigating to ensure no sinister cause.” (P20, CAVUHB)

“Again, no standard approach, up to individual clinicians how they share the uncertainty with patients and give follow up advice. Ensure all clinicians are aware of sharing the uncertainty with patients and what symptoms/signs they need to be aware of and when they may need review.” (P34, BCUHB)

Theme 2: Follow-up appointments

If patients were not referred during a consultation, many practices reported that a designated follow-up would be arranged by the practice. In other instances, the onus was placed on the patient to arrange a follow-up appointment if their symptoms persisted, changed or worsened.

“We usually will arrange a follow up appoint to re-assess the patient if not referred initially e.g., dyspepsia and then refer if concern remains or patient is not improving.” (P14, ABUHB)

“Currently if a patient is seen with low-risk symptoms most clinicians tend to review them in a few weeks time to ensure resolution of symptoms.” (P16, CTMUHB)

“Importance of follow up to see how symptoms develop e.g., telephone review/face to face. Continuity of care for follow up of patient and results and investigation review.” (P32, CAVUHB)

“Patients have follow-up appointments with the GP until they are seen in hospital.” (P41, ABUHB)

“Explain the importance to patients of returning at 4 weeks for review if symptoms have not resolved and explain why we would be concerned if symptoms have failed to respond to dietary changes and trial of PPI. Review at 4 weeks and if symptoms ongoing/not resolved then arrange bloods and OGD referral.” (P73, CTMUHB)

Theme 3: Documentation of safety netting advice

GP practices explained that they record the safety netting advice given to the patient and symptoms in the patient’s records. Information recorded varied between practices and also between clinicians.

“Documentation in patients notes regarding red flag discussion, worsening symptom advice – especially important to document clinicians’ thoughts on worsening advice and management to alert clinicians who subsequently review the patient.” (P32, CAVUHB)

“We use codes in the notes such as ‘change in bowel habit’. We also use codes such as ‘worsening advice.’” (P42, ABUHB)

“There is evidence in consultations of safety netting advice, the detail of which is variable amongst GPs. This varies from worsening advice being documented as a broad term to specific details of red flag symptoms having been discussed and documented in detail.” (P43, PTHB)

“Some clinicians document very clearly what they have told the patient in terms of when to seek further help and advice but others document less.” (P74, CAVUHB)

After the Toolkit

This module enabled practices to identify key areas for improving the safety netting given to patients with ‘low risk but not no risk symptoms’ including:

- Documentation on patient records regarding safety netting advice and symptoms
- Establishing a designated follow-up appointment
- Provision of patient information

“Review appointment could be pre-booked to encourage patient engagement with follow-up.” (P73, CTMUHB)

“A proposed change the clinician could make the follow up appointment themselves to ensure a follow up takes place at an appropriate time in case the patient is unable to do this. If the patient does not attend then this should be Read coded and a re-call put in place by admin staff to contact patient for further review.” (P14, ABUHB)

“We could all ensure to document more clearly safety netting advice given e.g., ‘please try x, y, z and if this does not improve things after x weeks or your symptoms worsen, please let us know and book a review as this would be concerning...’. We will endeavour to ensure to think about safety netting and document it.” (P59, HDUHB)

“Following our final discussion of the toolkit we have agreed to set up a template to code this information specifically.” (P43, PTHB)

“We will formalise this. Red flags often on NHS conditions leaflet - definitely present for dyspepsia - hand out/text same to consolidate our verbal advice.” (P29, SBUHB)

Improving opportunistic discussions of cancer signs and symptoms

Before the Toolkit

Participants described their current practice regarding opportunistic discussions of cancer signs and symptoms with patients. Practice varied according to individual clinicians. Descriptions focussed on the following categories: ‘*patient consultations*’ and ‘*active promotion of cancer signs and symptoms*’.

Theme 1: Patient consultations

Participants provided specific examples during a routine consultation that would prompt a clinician to discuss the signs and symptoms of cancer opportunistically (when appropriate and relevant). Specific topics that would prompt clinicians to discuss signs and symptoms included smoking cessation, obesity (weight in some cases), skin lesions and menopause.

“Current practice is that signs and symptoms of cancer are discussed if the appropriate opportunity arises during a clinical contact e.g., if a patient asks about if their symptom could be related to cancer.” (P3, CTMUHB)

“We discuss cases where appropriate: Lifestyle advice – discuss smoking cessation and signs of possible lung cancer. On raising weight as an issue, we do not usually discuss cancer. If patient is consulting with a skin lesion we discuss care in the sun, signs to look out for of skin cancer. Menopause – advise patient to present if new bleeding after 12 months...” (P4, BCUHB)

“...individual consultations may lead to a discussion about cancer in general or specific cancers, depending on an individual’s risk profile or personal concerns.” (P12, ABUHB)

“Each clinician in all consultations (time permitting) will discuss any appropriate signs and symptoms dependent on patients’ lifestyle and presentation. For example, obesity.” (P26, PTHB)

Theme 2: Active promotion of cancer signs and symptoms

Some participants reported that the practice actively promotes the signs and symptoms of cancer using the waiting room and practices’ websites. Practices utilised leaflets, TV screens and posters in the waiting room to promote cancer screening programmes and NHS campaigns (e.g., Breast cancer awareness).

“We do have campaign and awareness leaflets out on a specific table in the main areas for patients to look at and request more information if required. The tables hold useful leaflets and cards etc. providing signposting and information available locally. We also do any awareness days such as wear Pink for Breast cancer etc. and promote awareness through staff participating in these events.” (P23, SBUHB)

“Posters in waiting room/toilets, red flags for cancer bowel, cancer ovary, breast awareness, testicular awareness.” (P29, SBUHB)

“The practice has an area for patients, which houses useful leaflets and cards etc. providing signposting and information available locally as well as a QR board. We try and participate in awareness days such as wear Pink for Breast cancer etc. and promote awareness through staff participating in these events and through posters in the surgery waiting areas.” (P45, SBUHB)

“Leaflets are used to provide useful information to patients and signposted to websites that can provide a raft of supporting information. Furthermore, utilizing our Community Connectors. We publish on our Practice website Cancer Awareness Information and participate with all National campaigns.” (P62, HDUHB)

Other examples where cancer signs and symptoms would be raised opportunistically with patients at risk included medication reviews, chronic disease management clinics (e.g., COPD) and screening appointments (e.g., smears).

“Other instances may be when a screening test is being discussed, e.g., bowel/cervical smear/breast/request for Prostate-specific antigen (PSA) test.” (P12, ABUHB)

“Currently discussed during chronic disease management clinic, during smears, during medication reviews when BMI alcohol and smoking history is taken.” (P16, CTMUHB)

“We discuss breast awareness and cervical screening when we see patients with breast problems or at consultations involving contraception or gynaecological issues, Hormone Replacement Therapy (HRT) requests.” (P45, SBUHB)

“Signs and symptoms are routinely discussed with patients at Healthy Lifestyle, Chronic Disease clinics as part of guidance and upon consultation if vague symptom are present at a consultation.” (P62, HDUHB)

“Mainly done during contact with HCP. Opportunistically discussing symptoms and signs of cancer with patients, particularly those at risk (such as a COPD review and patient still a smoker - reinforce what symptoms to look out for).” (P73, CTMUHB)

After the Toolkit

This module enabled GP practices to identify the following improvement actions to enhance opportunistic discussion of cancer signs and symptoms with patients:

- Actively promoting cancer signs and symptoms and screening programmes to patients using TV screens, posters and leaflets
- Increasing staff awareness of opportunities to promote cancer signs and symptoms

“To start to use noticeboard and TV to publicise common signs and symptoms and lifestyle advice. Use monthly meetings to discuss cancer risks. Encourage identification of patients who have not attended screening and encourage patient to participate.” (P4, BCUHB)

“Poster in the waiting room of symptoms and signs that could be cancer and encouraging to seek help. Continue to promote cancer awareness days.” (P74, CAVUHB)

“Link NHS signs and symptoms leaflet to our website. Practice team to have greater awareness of NHS signs and symptoms leaflet.” (P19, ABUHB)

“We can aim to try to do more to try and educate patients if the chance arises during the course of a normal consultation. Perhaps we could try to promote some of the cancer NHS campaigns and awareness days on our Facebook page.” (P59, HDUHB)

Others practices recognised the importance of staff being aware of opportunities and encouraged their team to utilise medication reviews and screening appointments to promote cancer signs and symptoms.

“We could use practice nurses and pharmacists who conduct chronic disease management to read code use of rescue packs e.g., for COPD if frequent and appropriate health promotion, smear uptake, bowel screening uptake, smoking cessation.” (P14, ABUHB)

“Reminding clinical staff to discuss at the opportunities above and to build into medication review/COPD review etc. Smear takers to discuss signs/symptoms cervical cancer at time of smear.” (P46, SBUHB)

“To improve this, we will incorporate a symptom check list into all chronic disease reviews asking about lumps, chest pain, breathlessness, cough, bleeding, unintentional weight loss, change in moles. To be used by practice nurses and GPs.” (P74, CAVUHB)

MODULE 2 SUMMARY

As a result of undertaking and completing this module GP practices (n=42) have:

- Increased awareness and use of summaries to support the application of the NICE suspected cancer referral guidelines
- Increased awareness and use of the Macmillan Cancer Decision Support (CDS) Tool
- Improved coding practice for USC referrals by
 - Establishing practice process for auditing USC referrals
 - Implementing the recommended Toolkit code for 'Fast Track Cancer Referrals'
 - Increasing practice staff awareness of the USC referral process, Read code and summaries of guidance
 - Many participants conveyed that implementation of the Fast-Track Cancer Referral code was extremely useful for their practices
- Improved safety netting of urgent referrals by
 - Increasing awareness and use of patient information to support verbal conversations regarding a USC referral
 - Increasing awareness and use of recommended codes for USC referrals
 - Improving audit and follow-up processes for patients referred on a USC pathway
 - Increased use of patient information leaflets
- Identified areas for improving the safety netting of 'low risk but not no risk' patients
 - Documenting safety netting advice and symptoms on the patient record
 - Establishing a designated follow-up appointment
 - Increasing use of patient information leaflets
- Identified areas for improving opportunistic discussions of cancer signs and symptoms
 - Actively promoted cancer signs and symptoms and screening programmes to patients using TV screens, posters and leaflets
 - Increased staff awareness of opportunities to promote cancer signs and symptoms
- Identified several challenges that hindered practice change:
 - Staffing issues including staff turnover, staff time and competing priorities
 - Coronavirus pandemic – demands on primary care and changes to the way services were offered
 - Inconsistent coding practice amongst practice teams

MODULE 3 FINDINGS – SUPPORT THROUGH TREATMENT

This section summarises the findings from the pre- and post- evaluation surveys as well as the document analysis of the module reflections on current practice and the impact of planned changes to processes and systems.

Of the 53 GP practices that participated, 18 completed module 3 (33.9%) (Table 11). Practice size varied with just over half of practices (55.6%, n=10) having a large patient list size (over 8,000 patients). Participating GP practices had on average: 3.94 GPs, 3.31 reception staff, 2.47 administration staff and 2.38 Practice nurses involved in the Toolkit. Just over half of staff within the GP practices were involved in the Toolkit (55.4%, n=255) with the most common roles being GPs, reception staff, administration staff and Practice nurses.

Table 11. Participating GP practice demographics

	No.	%
GP practices in each HB that completed module 3		
ABUHB	3	16.7
BCUHB	3	16.7
CAVUHB	4	22.2
CTMUHB	2	11.1
HDUHB	4	22.2
PTHB	2	11.1
SBUHB	0	0
Wales	18	33.9
Practice size		
Small (up to 3,999 patients)	1	5.56
Medium (4,000 to 7,999 patients)	7	38.9
Large (over 8,000 patients)	10	55.6
GP practice staff*		
GPs	105	22.8
Reception staff	92	20.0
Administration staff	81	17.6
Practice nurses	50	10.9
Healthcare assistants	45	9.78
Pharmacists	24	5.22
Practice manager	23	5.00
Nurse practitioners	21	4.57
Physiotherapists	5	1.09
Paramedics	5	1.09
Dispensers	5	1.09
Mental health nurse	2	0.435
Occupational therapist	2	0.435
Total staff	460	
Staff involved in the Toolkit		

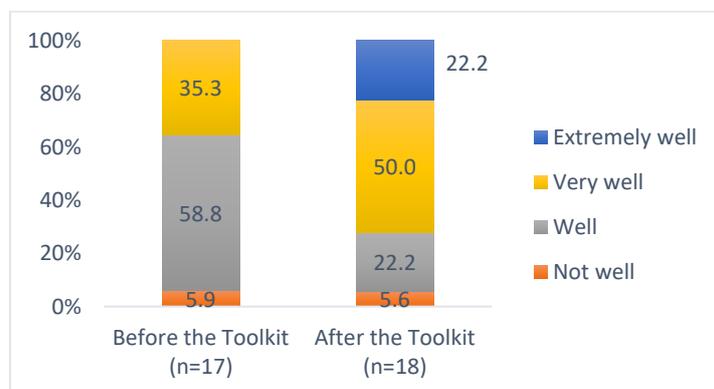
GPs	71	27.8
Reception staff	43	16.9
Administration staff	42	16.5
Healthcare assistants	24	9.41
Practice nurses	23	9.02
Practice managers	19	7.45
Pharmacists	11	4.31
Nurse practitioners	10	3.92
Dispensary staff	8	3.14
Physiotherapists	2	0.78
Occupational therapist	1	0.39
Frailty nurse	1	0.39
Total staff involved	255	
*No. staff in GP practices at time of Toolkit participation		

IMPROVING CLINICAL PRACTICE

How well do GP practices believe they carry out the following...?

Supports patients at the point of diagnosis

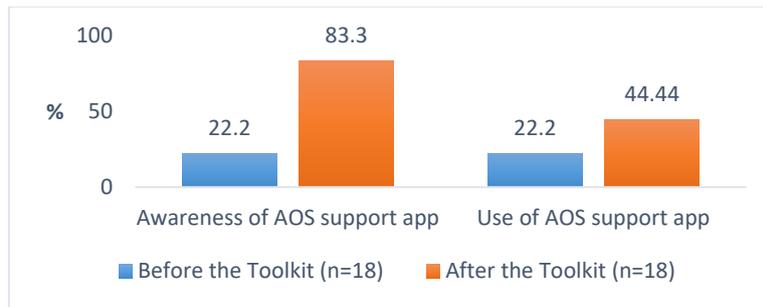
At baseline, most participants indicated that they support patients at the point of diagnosis 'well' (58.8%, n=10) or 'very well' (35.4%, n=6). After the Toolkit, the proportion of GP practices reporting that they support patients at the point of diagnosis 'very well' or 'extremely well' increased from 35.3% (n=6) to 72.2% (n=13) (increase of 36.9%).



Increasing awareness and use of tools

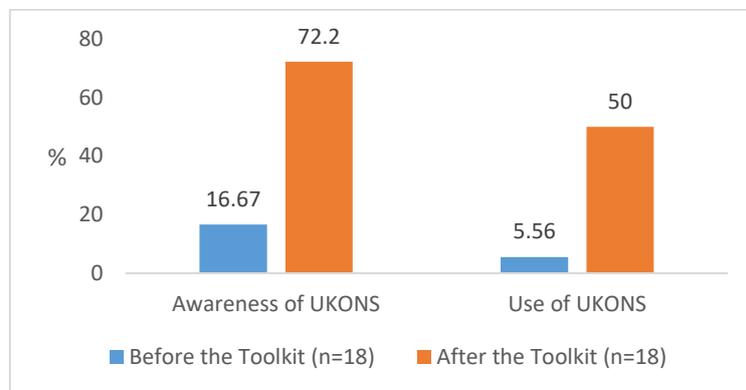
Acute Oncology Support (AOS) App

After the Toolkit, GP practices reporting they were aware of the AOS App increased from 22.2% (n=4) to 83.3% (n=15). Use of the AOS app also increased from baseline (22.2%, n=4) to 44.4% (n=8) after the Toolkit.



UK Oncology Nursing Society (UKONS) and Macmillan Cancer Support Tool

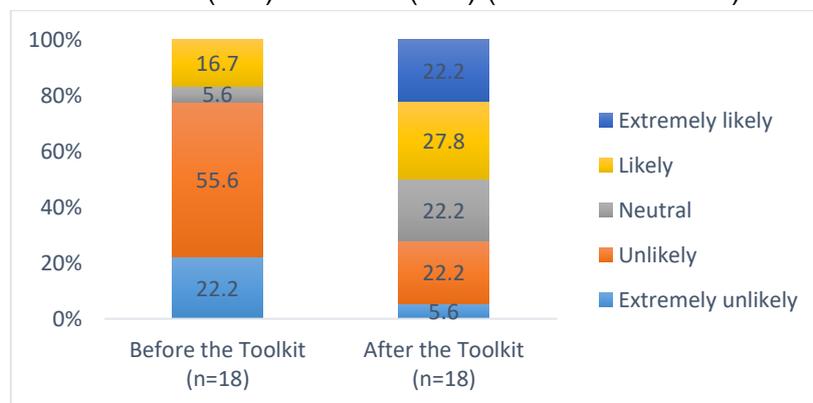
After the Toolkit, GP practices reported an increase in awareness of the UKONS and Macmillan Support tool for oncology treatment toxicity risk assessment from 16.67% (n=3) at baseline to 72.2% (n=13) after the Toolkit. Use of the UKONS and Macmillan Cancer Support Tool also increased from 5.56% (n=1) to 50.0% (n=9).



How likely are GP practices to consistently code...?

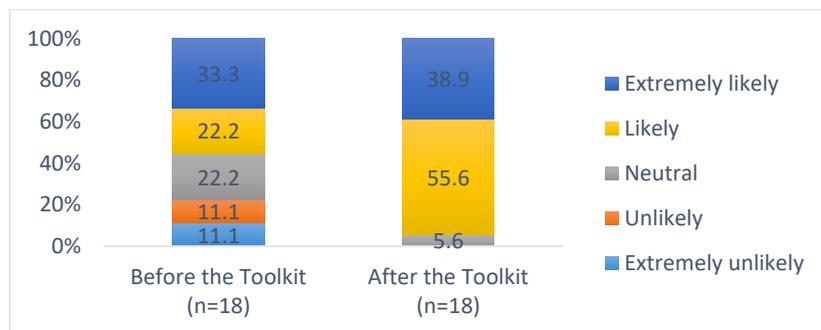
Cancer care key worker

At baseline, most participants reported that they were 'extremely unlikely' (22.2%, n=4) or 'unlikely' (55.6%, n=10) to consistently code cancer key worker. After the Toolkit, the number of GP practices that reported they were either 'extremely likely' or 'likely' to code cancer key worker increased from 16.7% (n=3) to 50.0% (n=9) (increase of 33.3%).



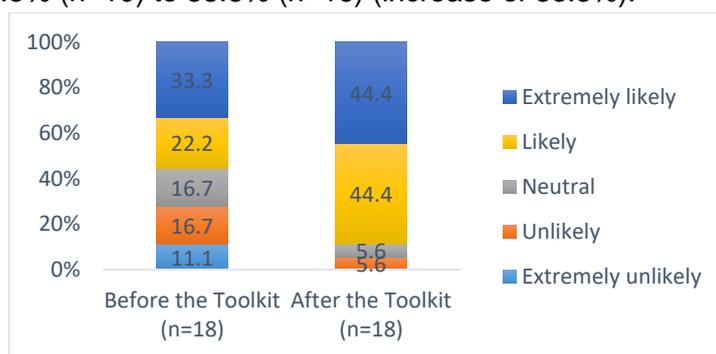
Radiotherapy treatment

At baseline, half of participants reported they were either 'likely' (22.2%, n=4) or 'extremely likely' (33.3%, n=6) to consistently code radiotherapy treatment. After the Toolkit, the proportion of GP practices reporting that they were 'likely' or 'extremely likely' to code radiotherapy increased from 55.5% (n=10) to 94.5% (n=17) (increase of 39.0%).



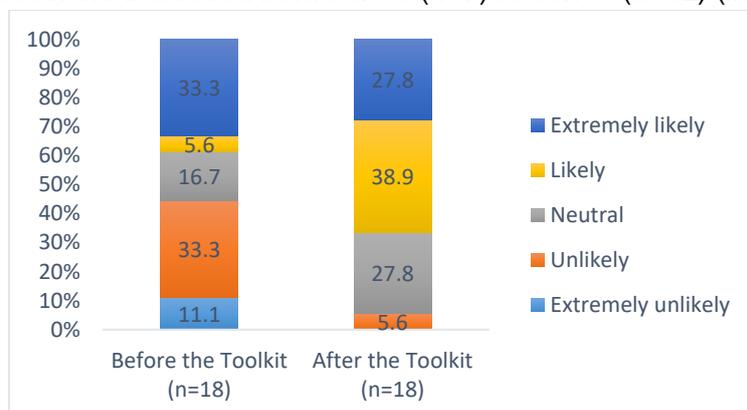
Chemotherapy treatment

At baseline, just over half of participants were 'likely' (22.2%, n=4) or 'extremely likely' (33.3%, n=6) to consistently code chemotherapy treatment. After the Toolkit, the proportion of GP practices that reported they were 'likely' or 'extremely likely' to code chemotherapy treatment increased from 55.5% (n=10) to 88.8% (n=16) (increase of 33.3%).



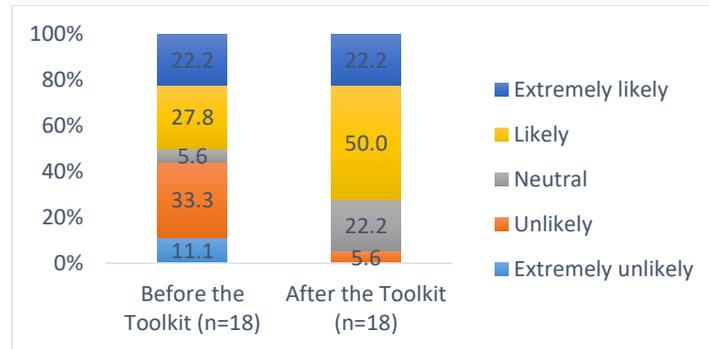
Immunotherapy treatment

At baseline, one third of participants reported that they were 'unlikely' (n=6) to consistently code immunotherapy treatment while 11.1% (n=2) were 'extremely unlikely'. After the toolkit, the proportion of GP practices reporting they were 'likely' or 'extremely likely' to code immunotherapy treatment increased from 38.9% (n=7) to 66.7% (n=12) (increase of 27.8%).

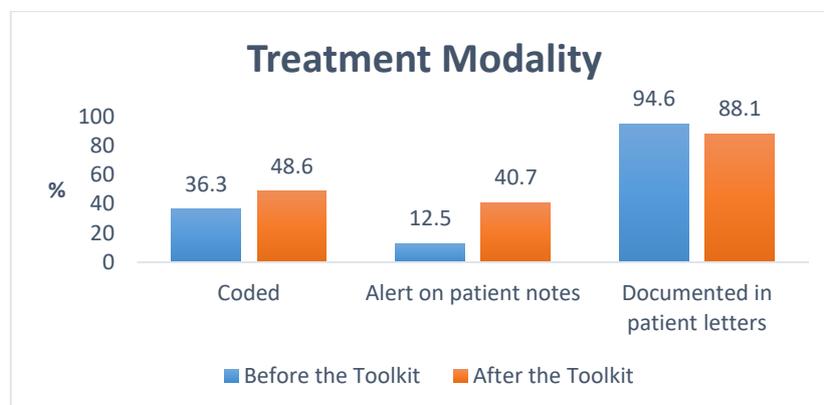


Hormone treatment

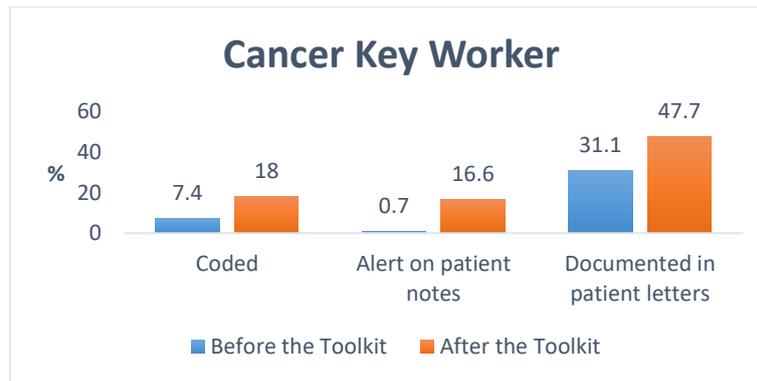
At baseline, one third of participants reported that they were 'unlikely to consistently code hormone treatment (33.3%, n=6) while 11.1% (n=2) were 'extremely unlikely'. After the Toolkit, the proportion of GP practices that reported they were 'likely' or 'extremely likely' to code hormone treatment increased from 50.0% (n=9) to 72.2% (n=13) (increase of 22.2%).



Each GP practice reviewed a sample of patient records at two time points to identify if treatment modality and cancer key worker information were being documented on GP systems. In the main, the graph below demonstrates that treatment information is documented in patient letters (94.6%, n=105/111 and 88.1%, n=104/118). This suggests the primary care is receiving this information from secondary care, but it is not likely to be coded or highlighted on the patient record as an alert. After the Toolkit, GP practices increased their use of alerts from 12.5% (n=14/112) to 40.7% (n=48/118) and coding from 36.3% (n=29/80) to 48.6% (n=51/105).



After the Toolkit, the proportion of GP practices that identified key worker information in patient letters increased from 31.1% (n=42/135) to 47.7% (n=82/172). However, this suggests that less than half of GP practices reported that key worker information was documented in the patient records. Increases were also reported improvements in coding from 7.4% (n=10/136) to 18.0% (n=31/172) and use of alerts from 0.7% (n=1/135) to 16.6% (n=27/163).



EVIDENCE OF PRACTICE CHANGE

Improving coding practice

In addition to examining patient records, GP practices reviewed educational material that prompted changes to coding practice. After six months, the practice reflected on changes made to improve the coding of treatment and cancer key worker information.

This module enabled some practices to improve coding practice by:

- Increasing awareness and use of recommended codes for treatment modality and cancer key worker (e.g., templates)
- Adding alerts to flag key information to clinical/ reception staff

“A further review was carried out of all cancer patients identified in the 6-month audit of whom 10/29 patients were undergoing immunotherapy/ chemotherapy/ radiotherapy. 7 out of the 10 had this treatment modality coded in the notes which was an improvement from the first data collection where only 1 out of 3 patients in the 10 notes reviewed had their treatment modality recorded.” (P3, CTMUHB)

“A system is now in place with a designated template to record cancer diagnosis and treatment modalities. An alert is added to patients' notes to alert staff to fast track them to a GP when they telephone with a medical problem to avoid delays in the triage system.” (P43, PTHB)

“Overall, coding relating to cancer has improved within the practice - both clinicians and administrative staff have received training on this. Coding of treatment modality has improved, and this is being coded as a high priority problem; however, the creation of an alert within the notes is less likely to be done...” (P47, CAVUHB)

“We have implemented the additional Read codes when information is available in letters provided by other agencies, moreover, added to Problem page within patient's Individual Electronic Health Record.” (P62, HDUHB)

“At present at the practice we are placing an alert with cancer diagnosis and treatment on patient alert box while you first enter the patients notes. As indicated between questions six and seven - all relevant key information is documented under cancer care review and

when discussed with patient. The Macmillan cancer care template is utilised throughout.”
(P69, PTHB)

Challenges identified

GP practices identified several factors that hindered their ability to implement changes to improve the coding of treatment and key worker information. The following themes emerged:

Theme 1: Correspondence from secondary care

After reviewing patient records and communications from secondary care (e.g., letters), several participants highlighted that information about a cancer key worker is not always shared with primary care. This means that this information cannot be coded on the GP systems.

“Regarding key worker - this is rarely shared it would seem - I have coded this where I can. I wonder how useful it is - as we need contact details as well stored, but it is certainly a positive step.” (P6, CAVUHB)

“There is variability in information from secondary care regarding treatment plans and key workers. There is more complete information from certain providers and breast and urology clinics from Hereford are especially good at providing this information. Urology and haematology at ABUHB also provide good documentation. Variability in communication from secondary care makes it difficult to record this information on the practice system and often patients are not fully informed about this information too.” (P43, PTHB)

“No clear information regularly provided in patient correspondence from secondary care [in reference to key worker information] ...” (P58, HDUHB)

“I found mention of 2 key workers only during my review of patients - both times made by clinical nurse specialists. I think generally - despite the Cancer Delivery Plan for Wales 2016-20 aiming for each health board to assign a named key worker to co-ordinate care - on the whole it's fair to say this is not happening often...” (P59, HDUHB)

Other participants stated that information specifying the start and end dates for treatment are not specified in letters to primary care. Some expressed that this information can be difficult to find, particularly when there are multiple letters from secondary care.

“We have not made any big change in our coding of treatments at present, partly due to the Covid-19 pandemic but also as clinicians we aren't always aware when a patient is starting or finishing treatments. Letters often say they are considering a particular treatment, but we rarely get informed that the treatment is going ahead or has started and often find out about the treatments after it has happened or if the patient contacts us directly.” (P33, HDUHB)

“Re: treatment plans - we note a lot of detail in the text of the letter, but it's not always coded as treatment is planned and no start date given. They are 'awaiting chemotherapy'”

and 'awaiting radiotherapy' codes but then these would need removing once treatment starts and we don't always get informed of the start date.” (P40, ABUHB)

“There has been improvement in the documentation in patient letters although this information can be hard to find...” (P34, BCUHB)

“Sometimes difficult to navigate all the information from different clinic letters. Seldom all information available in one letter...Sometimes the information isn't available in the clinic letters.” (P19, ABUHB)

Theme 2: Resource availability

A few practices suggested that the lack of resources such as time hindered the practices' ability to implement the changes set out in their action plans.

“Time constraint was the key factor in Read coding and putting alerts on the notes.” (P16, CTMUHB)

“Can be time consuming to input all the individual [Read] codes and complete alert box and flag to OOH.” (P19, ABUHB)

“On a pragmatic level we have to balance the established workload of the coders with the benefit of changing practice/ coding/ training needs for this to work.” (P58, HDUHB)

EVIDENCE OF LEARNING

Contacting patients following a cancer diagnosis

Before the Toolkit

At baseline, nine (50.0%) practices indicated that they had a process in place to contact patients following a cancer diagnosis. All GP practices reviewed a sample of patient records and reported that two thirds of patients were contacted specifically about their diagnosis (62.5%, n=155/248).

Where contact occurred, GP practices described how receipt of a letter from secondary care would usually trigger the practice to contact the patient regarding their cancer diagnosis. However, in some cases, the referring clinician/ GP would decide whether the patient needed further contact. When contact occurred, participants used various methods including letters and telephone calls. Very few practices reported using the code '#8CL0 Cancer Diagnosis discussed'.

“At point of documentation received by the practice for a new diagnosis of cancer, administration staff will code the patient notes and send task message to cancer link GP.” (P69, PTHB)

“New cancer diagnosis comes in by letter and admin team forward to referring clinician and it is up to them to make contact. I review all new cancer diagnoses in a meeting with practice once a month and again advise clinician who referred.” (P6, CAVUHB)

“All letters with a new diagnosis of cancer are forwarded to the GP. GP to then phone the patient for review.” (P19, ABUHB)

“Process is triggered by letter, Read code or sometimes 'word of mouth'. All patients diagnosed added to 'special list'. Letter sent for cancer care review if not already been seen by the time of clinical meeting.” (P24, ABUHB)

“The practice has had a system where a letter is sent to patients inviting them to see a member of the practice team if they wish, when the Practice receives confirmation of the diagnosis, and the patient has been informed. It also includes a leaflet about Macmillan in Wales.” (P34, BCUHB)

“Some GPs but not all telephone the patient when they are processing hospital letter and review them by telephone, offering a face-to-face review if the patient wishes.” (P43, PTHB)

After the Toolkit

After reviewing a sample of patient records, GP practices reported that under two thirds of patients were contacted specifically about their diagnosis (60.1%, n=230/383). While there were no improvements in the proportion of patients contacted, 12 practices indicated that they implemented a new or improved process. These improvements were categorised into the following:

- Improved coding practice including increased awareness and use of recommended codes
- Proactive patient support including establishing contact with patients following a cancer diagnosis

This module enabled practices to review and improve their processes for contacting patients following a cancer diagnosis. Some GP practices indicated that they enhanced their coding; however, others stated that the recommended code was not consistently used.

“Coding changes were implemented, and all staff made aware...appears to be working well with 17/18 patients contacted.” (P19, ABUHB)

“We have also much improved our Read coding of the above and now use a standard Read code when contacting a patient with a letter/call about their cancer diagnosis.” (P20, CAVUHB)

“We have worked hard on improving our cancer coding within the practice, ensuring that diagnosis codes rather than morphology codes are used and that all new cancers are coded as a new priority problem. Both administrative staff and clinicians have received training on this. However, use of the code 'cancer diagnosis discussed' appears to have been more poorly utilised and a reminder on this will be sent.” (P47, CAVUHB)

“Whilst carrying out work and searches through this Toolkit, it was identified and highlighted that several codes were being used and treatment codes not always able to be applied (not working). Administration staff have been contacted to look into this matter further. Each patient contacted has been relooked at and notes reviewed to clarify and rectify any coding issues.” (P69, PTHB)

Some practices implemented new processes that enabled practices to offer proactive support to patients with cancer. However, it is clear from the responses that there was some confusion regarding this initial contact following a diagnosis and completion of a cancer care review.

“In the last six months we have created a letter to be sent to patients newly diagnosed with cancer containing signposting services, support and inviting them to attend a Cancer Care Review at the surgery. We have a robust system where a designated member of the admin team will search every 2 weeks for new cancer diagnoses and send them the letter.” (P20, CAVUHB)

“GPs now print out letter with diagnosis on it and put in house call book - GPs to tick when they have seen letter. Letter to then go to secretary so she can send and invite for CCR.” (P25, CAVUHB)

“Our healthcare assistant [Name] adopts a structured and systematic approach to reviewing patients. These reviews have been mainly by telephone in Covid times, but she has seen many patients face to face too. Feedback from patients has been good with the majority valuing contact and the offer of support, even if their information needs are very few initially. Some patients have contacted her subsequently for further advice. She has linked in with [Name] our social prescriber when signposting to local resources.” (P43, PTHB)

“As we have relatively small numbers of new cancer diagnoses within our population, we have also arranged that all letters from secondary care relating to a possible new cancer are forwarded to our new 'cancer lead' to be reviewed and to ensure that the correct coding is done. A register of new cancer diagnoses from the past 6 months is being kept. We have recently created a template letter to be sent to all patients newly diagnosed with cancer inviting them to contact the surgery for a review, but this process has yet to be implemented; the current pandemic has delayed putting this into action.” (P47, CAVUHB)

Challenges identified

Reflections on action plans and improvements made, participants identified several factors, which hindered their ability to implement and sustain improvement plans. Some participants described how staffing issues and time affected the practice's ability to initiate processes to contact patients following a cancer diagnosis. Other participants stated that the Coronavirus Pandemic was also contributing factor.

“Due to ongoing issues with changes in reception and administrative staffing, we were not able to develop the planned system of these staff making initial contact with patients after a cancer diagnosis.” (P3, CTMUHB)

“Sometimes workload interferes with contact, recent constraint of Covid-19.” (P19, ABUHB)

“However, the coronavirus pandemic and the strain on our staffing levels as a small surgery has impacted on our plans to improve support to our newly diagnosed patients as much as we had hoped.” (P59, HDUHB)

“...but this process has yet to be implemented; the current pandemic has delayed putting this into action.” (P47, CAVUHB)

After conducting the audit at six months, some practices reported that their searches did not identify any patients who had a discussion following their diagnosis. Participants concluded that their practice teams were not using the code (#8CLO – Cancer Diagnosis Discussed).

“0 on search but I can’t believe this as I have used the code #8CLO. I will ask my colleague to search for this code and get back to you on it but I know that we ring the vast majority of our newly diagnosed cancer patients. Obviously not everyone is using the correct code.” (P6, CAVUHB)

“A lot of these patients were actually contacted following their cancer diagnosis but unfortunately not Read coded appropriately. When a search was conducted the results returned as 0, although quite a number of patients were contacted via telephone to have a discussion about their diagnosis and management plan.” (P16, CTMUHB)

“Although we have spoken to a lot of these patients we have not managed to use the code #8CLO - so that’s a reminder for us to be aware of using this.” (P59, HDUHB)

A few practices remarked that the sharing of information from secondary care takes time to arrive to the practice and that this can cause delayed contact with a patient following their diagnosis.

“Sometimes although seen within 2 weeks the clinic letter takes time to arrive making the process more difficult.” (P16, CTMUHB)

“Some hospital correspondence from the MDTs suggest that patients may not always be aware of the diagnosis, therefore there is a need to receive confirmation the patient is aware of the diagnosis before contact is made by the GP.” (P58, HDUHB)

Ensuring history of cancer treatment is highlighted to reception staff receiving phone call

Before the Toolkit

The majority of GP practices indicated that they did not have a formal approach in place to ensure that history of cancer treatment is highlighted to reception staff receiving a phone call (94.4%, n=16/17). A few participants conveyed that reception would rely on the patient to inform them of their cancer diagnosis and treatment or the receptionist could determine this

by opening the patient's notes. One practice indicated that they depend on 'word of mouth' to communicate information to the reception team.

"Would only have an idea if seeing a recent cancer diagnosis in the patient record or if the patient/ relative tells them." (P34, BCUHB)

"Currently this information is highlighted to a point: (1) Diagnosis is usually listed in Summaries on the patient record. (2) The patient may inform the receptionist that they have cancer/are undergoing specific treatment for cancer." (P58, HDUHB)

"Staff would be able to see if the cancer is coded as an active problem." (P33, HDUHB)

"Word of mouth currently. Small team - tend to get to know patients very well." (P25, CAVUHB)

After the Toolkit

GP practices recognised the importance and benefits of ensuring that history of cancer treatment is highlighted to reception staff receiving a phone call from a cancer patient. This module enabled practices to identify key areas for improvement:

- Awareness of cancer patients amongst the whole practice team
- Establish process to flag history of cancer treatment to reception staff

Theme 1: Whole practice team awareness of cancer patients

Action plans from practices described how participants wanted to ensure that the whole practice team were aware of cancer patients. Participants identified ways to increase awareness such as sharing list of cancer patients with all staff and holding discussions regarding cancer patients during practice meetings.

"Letters regarding new cancer diagnosis will be circulated to all clinical staff including nurses. All new cancer diagnoses are discussed at the GP partner meetings and a list of these patients will be circulated to administrative staff for information so that there is increased awareness of patients with cancer." (P3, CTMUHB)

"Potentially information sharing at morning huddle. Electronic list of patients. All new cancer diagnoses circulated to staff." (P19, ABUHB)

"...creating a list of patients currently undergoing active cancer treatment which can be circulated monthly to all practice staff (either as email or desktop folder)." (P47, CAVUHB)

Theme 2: Use of alerts

Several GP practices indicated that they would implement an alert approach to flag history of cancer treatment to reception staff. Participants described how the cancer diagnosis would be coded and an admin note with a warning would be placed on the patient's record.

"When cancer therapy is started, it will be coded as a significant diagnosis and an alert will be added to the patient record so that whenever the record is loaded, the person will be

made aware of the treatment. The alert will be removed once the treatment is completed.” (P3, CTMUHB)

“To ensure cancer treatment is Read coded and also flagged up in yellow alert box in notes, in all cases.” (P20, CAVUHB)

“Highlight active cancer as admin note and warning on journal. Lead nurse will have to ensure this is kept up to date.” (P24, ABUHB)

“We have agreed to add an alert that the patient has cancer, and this will be immediately available to all clinical and non-clinical staff who open the patient record. This will alert receptionist to prioritise and fast track patients for immediate GP call back. A note will be added for urgent call back/cancer patient to the slot note. The alert will be added at time of diagnosis when the New Cancer and treatment template is completed with a written reminder provided on the template. We cannot search for alerts and when the patient's treatment is completed, and it is deemed unnecessary to have the alert it should be removed opportunistically by a clinician.” (P43, PTHB)

“This process could be improved by presenting key information more obviously to the receptionist. The reception staff do not always need to look at the patient summaries, or even go into a patient's notes, therefore, when booking an appointment for a patient, it is possible to add notes/ link a message to their details...Otherwise, a yellow flag reminder in the notes is more obvious than entries in the summaries page. More thorough information could be added to the summary screen e.g., key worker information, current chemotherapy/ radiotherapy/ hormone therapy being given to the patient.” (P58, HDUHB)

Challenges identified

The only challenge identified during this improvement activity related to the use of alerts within the GP systems. Several participants stressed that reception staff do not always review patient notes when booking them in. Others stated that alerts could be difficult to keep up-to-date.

“We agree it is needed but unfortunately alert boxes get ignored and they are not removed so may be out of date once treatment is completed.” (P6, CTMUHB)

“We discussed adding alerts to notes but felt these would be hard to keep up to date especially once treatment is complete.” (P40, ABUHB)

“Quite often staff do not open patients' notes when booking appointments...” (P16, CTMUHB)

“The reception staff do not always need to look at the patient summaries, or even go into a patient's notes, therefore, when booking an appointment for a patient, it is possible to add notes/ link a message to their details. The main challenge with this would be ensuring such linked messages are current and updated.” (P58, HDUHB)

Prioritising patients currently receiving treatment for urgent clinical triage

Before the Toolkit

Almost two-thirds (61.1%, n=11) of GP practices indicated they were aware of the need to prioritise patients currently receiving treatment for urgent clinical triage. To facilitate prioritisation, participants stated that the practices used alerts or a triage list to flag that an urgent call back was required.

*“Patients can get access to doctor on the day, via on call if all appointments are gone. If they tell reception what the issue is, reception will prioritise on the booking list for on call, with alerts such as ****NEXT CALL PLEASE**** or ****URGENT****. We would then ring back as soon as possible.”* (P6, CAVUHB)

“Currently if there are no book on the day appointments left patients are added to a triage list for GP to call them. If reception is concerned, they phone GP/come and see GP to call the patient urgently.” (P25, CAVUHB)

“All Practice Team are aware that these patients owing to their diagnosis, history and complex needs are to receive priority and timely intervention. Furthermore, all these are flagged within each patient’s Health Record, known as patient prompts and additionally we can independently add additional warnings and prompts for safety netting.” (P62, HDUHB)

“In our experience the patient normally makes the receptionist aware at the outset of the phone call. All patients calling in are assessed same day anyway.” (P40, ABUHB)

After the Toolkit

The Toolkit enabled practices to identify key areas for improvement including:

- Use of alerts to flag key information
- Investment in training to ensure reception staff are aware of the process for prioritising oncology patients who are unwell

Theme 1: Use of alerts

Several practices reported that they would add alerts to the clinical record to flag key information to staff including cancer diagnosis and treatment modality in order to ensure prompt triaging.

“...alerts will be added to records of patients currently undergoing cancer treatments so that staff will be aware of the treatment immediately when accessing their records.” (P3, CTMUHB)

“We could try to link the radiotherapy/ chemotherapy/ immunotherapy code to an alert that pops up when the receptionist accesses the record.” (P40, ABUHB)

“...without relying on the patient to share crucial information, the simplest way would be linking a flag/ message to the patient’s name/ registration details. An action plan to inform those not currently aware of which patients have cancer and need urgent prioritisation would be as noted above: linking a note/ message to a patient’s name, considering a

yellow flag/reminder in the notes, ensuring any current diagnosis/ therapy is clear in the summaries page as well as in the yellow flag reminder.” (P58, HDUHB)

“...when placing an alert with new cancer. Diagnosis in the primary pop up alert box, a prioritisation message to be placed to initiate prompt urgent triage.” (P69, PTHB)

Theme 2: Investment in staff training

Several participants expressed the importance and need for staff training in triaging and prioritising calls from cancer patients. Some participants also highlighted the importance of making all staff aware of the need for urgent triage of cancer patients.

“Practice staff will be provided training regarding triaging and prioritising calls.” (P16, CTMUHB)

“Ensure an awareness of urgent triage for such patients is part of the training for reception.” (P34, BCUHB)

“Through training to all practice staff to provide education on the need to prioritise these patients, why this is important and how they would flag this to a clinician...” (P47, CAVUHB)

“As part of routine induction training for reception staff - this should be included along with the usual - chest pain/999/ill child/let the GP know urgently... I will raise this with our PM.” (P59, HDUHB)

PRIMARY CARE ACCESS TO URGENT ADVICE

GP practices reflected on their experiences of obtaining urgent advice regarding an unwell oncology patient. Prompts elicited responses from participants regarding what worked well (or not) and how to improve access to urgent advice by primary care. In terms of current practice, the majority of participants stated they received helpful advice when speaking to the Acute Oncology Team or other specialists (e.g., Chemotherapy nurse, Specialist Registrar and Consultants).

“Acute oncology team contacted for advice on unwell patient undergoing chemotherapy, urgent admission arranged, easy to access, good advice and patient well supported.” (P20, CAVUHB)

“Phoning to speak to the chemotherapy nurse on call has worked well when it is possible to speak to someone directly.” (P3, CTMUHB)

“Tend to ring on call specialist registrar (SPR) at Velindre. DVT Doppler clinic are very helpful.” (P6, CAVUHB)

“24hr on-call registrar, consultant or clinical nurse specialist at Velindre Hospital.” (P19, ABUHB)

“Palliative care team at hospital very helpful. Contacting palliative care nurse easy and helpful.” (P25, CAVUHB)

In terms of what has not worked well, several participants articulated that while support is great when they are speaking to an individual, it can be very difficult and time consuming to get a hold of busy clinicians. Some also expressed that delays can occur because clinicians are also busy in primary care. When attempting to contact an individual or team by phone, other participants described how it took time to access advice because they were bounced between departments and specialities.

“Sometimes it is not always possible to speak directly to the chemotherapy nurse on call. On one occasion I ended up speak to several different departments within Velindre to try to find out whether a patient could be admitted or not.” (P3, CTMUHB)

“...can be hard to get hold of via switchboard and sometimes bounced between neurosurgeons and spinal team first, which can be very frustrating and time consuming.” (P20, CAVUHB)

“Oncology doctors out of area, can take a few phone calls to trace.” (P33, HDUHB)

“It takes a lot of time to get through on the phone sometimes and there are delays with call-backs with advice when requested.” (P43, PTHB)

“Often difficult to speak to palliative care nurses. They often cannot immediately take the call, then neither can the GP clinicians when they call back! Can be difficult to know best method of getting in touch with oncology consultant.” (P47, CAVUHB)

When asked how to improve future access to urgent advice, several participants stated that more information from secondary care is needed and that treatment summaries would facilitate timely access to this information.

“It would be useful to receive treatment summaries particularly relating to beginning and ending of cancer treatments so records can be kept up to date.” (P3, CTMUHB)

“Improve communication from Velindre regarding cancer treatment plans. Communication is often delayed, and it is unclear what treatment the patient is having/has had, and any red flags or possible side effects to be aware of during this treatment. Very clear need for clear treatment summaries, which are sent out promptly (ideally prior to treatment starting) to ensure GPs are fully aware of current treatment.” (P20, CAVUHB)

“In letters information regarding possible complications/management. List of useful phone numbers.” (P25, CAVUHB)

“Better information about what treatment patients are going to receive i.e., how long it is likely to take, how it will be administered etc. Treatment summary at the end so Primary Care are aware that the treatment has been completed and what treatment the patient has had.” (P34, BCUHB)

Other participants felt that dedicated phone lines or email contacts for advice would be helpful.

“If a dedicated phone line/ email advice line could be set up for advice regarding urgent/ more routine problems for patients undergoing cancer treatments, particularly if it would be possible to leave a message if it is not possible to speak to someone immediately.” (P3, CTMUHB)

“Email between providers and direct contact for acute changes.” (P6, CAVUHB)

“Patients and GPs to have a contact detail on whom to call in case of an emergency as currently there is no system in place and although patients are given contact details, they do find it difficult to access the service. It would be prudent to have an emergency number or service which patients and clinicians can access in case of acute emergencies.” (P16, CTMUHB)

“A dedicated GP access line.” (P33, HDUHB)

“...and e-advice platform for non-urgent queries.” (P47, CAVUHB)

Others stated that having contact information for CNSs, key worker and oncology consultants would be helpful.

“To obtain all clinical specialist nurses' emails and current up to date contact numbers.” (P69, PTHB)

“Oncology consultants to provide best method of contacting them/ days they work to GP surgery. Better promotion and visibility of on call numbers in and out of hours.” (P47, CAVUHB)

“Keyworker/ emergency clinical contact number being listed in the clinic letters is always helpful.” (P40, ABUHB)

MODULE 3 SUMMARY

As a result of undertaking and completing this module GP practices (n=18) have:

- Reported improvements in how well they:
 - Support patients at the point of diagnosis
- Increased awareness of the:
 - Acute Oncology Support (AOS) App (from 22.2% to 83.3%)
 - UK Oncology Nursing Society (UKONS) and Macmillan Cancer Support Tool (from 16.7% to 72.2%)
- Increased use of the:
 - Acute Oncology Support (AOS) App (from 22.2% to 44.4%)
 - UK Oncology Nursing Society (UKONS) and Macmillan Cancer Support Tool (from 5.56% to 50.0%)
- Improved coding practice for:
 - Cancer key worker
 - Treatment modalities
- Established a formal process for contacting patients following a cancer diagnosis
- Identified areas for improvement including:

- Awareness of cancer patients amongst the whole practice team
- Process to flag history of cancer treatment to reception staff and to ensure prompt prioritisation and triage (e.g., alerts)
- Investing time in training for reception staff so they are aware of the process for prioritising cancer patients
- Reflected on their experience of gaining urgent advice regarding an unwell cancer patient
 - When possible, to speak directly to an individual for urgent advice, the Acute Oncology Team and specialists in secondary care were reported to be very helpful
 - Practices stated that it can be very time consuming to access urgent advice as clinicians can be very busy
 - Improvement ideas included a dedicated advice line or email account and increased use of treatment summaries to ensure relevant and timely information reaches primary care
- Identified several challenges that hindered practice change:
 - Keeping alerts up-to-date on the GP system and ensuring that they are not ignored by staff
 - Sharing of key information from secondary care to primary care to ensure practices can act promptly to support oncology patients
 - Staffing issues including staff turnover, staff time and competing priorities
 - Coronavirus pandemic – demands on primary care and changes to the way services were offered

MODULE 4 FINDINGS – CANCER CARE REVIEWS AND THE LONG-TERM CONSEQUENCES OF CANCER

This section summarises the findings from the pre- and post- evaluation surveys as well as the document analysis of the module reflections on current practice and the impact of planned changes to processes and systems.

Module 4 was mandatory, so all participating GP practices completed this module (n=53). Practice size varied with just under half of practices (47.2%, n=25) having a large patient list size (over 8,000 patients) (Table 12). Participating GP practices had on average: 3.81 GPs, 3.24 reception staff, 2.44 administration staff and 2.19 Practice nurses involved in the Toolkit. Half of staff within the GP practices were involved in the Toolkit (49.8%, n=658) with the most common roles being GPs, reception staff, administration staff and practice nurses.

Table 12. Participating GP practice demographics

	No.	%
GP practices in each HB that completed module 4		
ABUHB	10	12.8
BCUHB	7	6.7
CAVUHB	10	15.6
CTMUHB	5	9.1
HDUHB	11	22.4
PTHB	4	25.0
SBUHB	6	12.2
Wales	53	12.8
Practice size		
Small (up to 3,999 patients)	9	17.0
Medium (4,000 to 7,999 patients)	19	35.8
Large (over 8,000 patients)	25	47.2
GP practice staff*		
GPs	300	22.7
Nurse practitioners	46	3.48
Practice nurses	152	11.5
Healthcare assistants	114	8.62
Pharmacists	52	3.94
Physiotherapists	14	1.1
Paramedics	7	0.53
Mental health nurses	10	0.78
Occupational therapists	2	0.15
Frailty nurses	4	0.30
Practice managers	69	5.22
Administration	234	17.7
Reception	309	23.4
Dispensary	8	0.61
Total staff	1321	

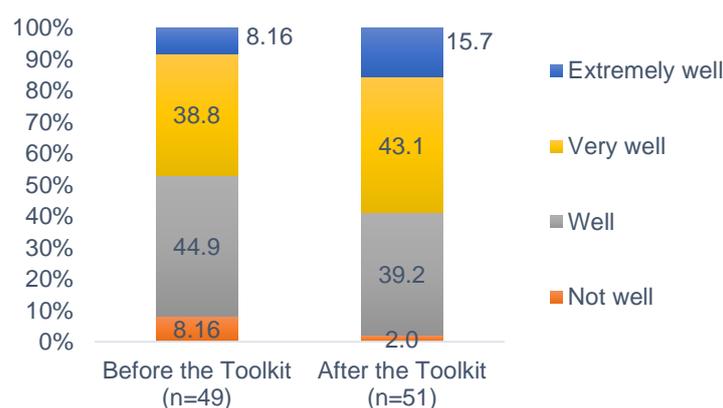
Staff involved in Toolkit		
GPs	202	30.7
Nurse practitioners	27	4.10
Practice nurses	94	14.3
Healthcare assistants	48	7.29
Pharmacists	20	3.04
Physiotherapists	3	0.45
Paramedics	1	0.15
Occupational therapists	1	0.15
Frailty nurses	3	0.46
Practice managers	52	7.90
Administration staff	105	16.0
Reception staff	94	14.3
Dispensary staff	8	1.23
Total staff	658	49.8

IMPROVING CLINICAL PRACTICE

How well do GP practices believe they carry out the following...?

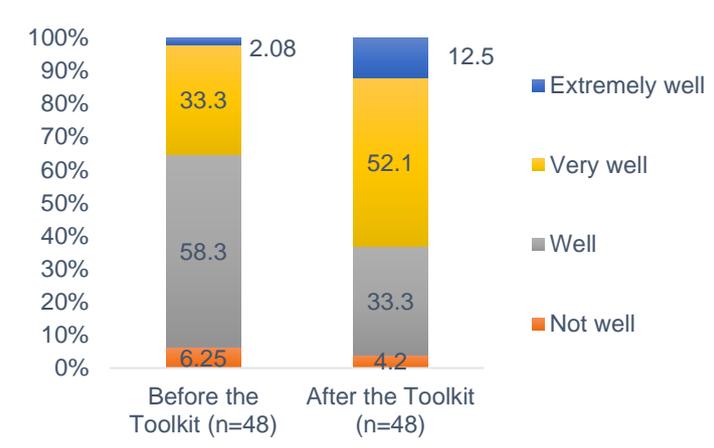
Support patients through treatment

At baseline, most participants indicated that they support patients through treatment 'well' (44.9%, n=22), 'very well' (38.8%, n=19) or 'extremely well' (8.16%, n=4). The proportion of GP practices reporting that they supported patients as they go through treatment 'very well' or 'extremely well' increased from 47.0% at baseline to 58.8% after the Toolkit (increase of 11.8%).



Support patients during recovery

At baseline, most participants indicated that they support patients during recovery 'well' (58.3%, n=28) or 'very well' (33.3%, n=16). The proportion of GP practices reporting that they supported patients during recovery 'very well' or 'extremely well' increased from 35.4% (n=17) at baseline to 64.6% (n=31) after the Toolkit (increase of 29.2%)

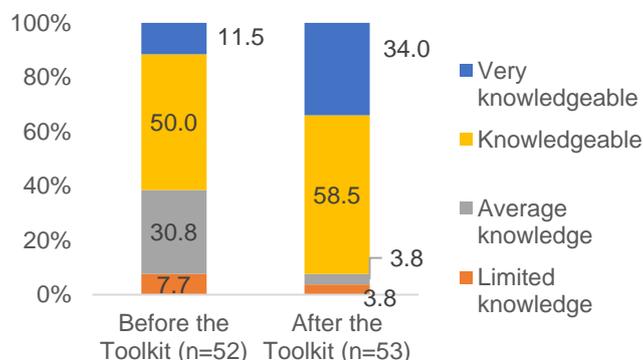


IMPROVING KNOWLEDGE

How knowledgeable are GP practices about...?

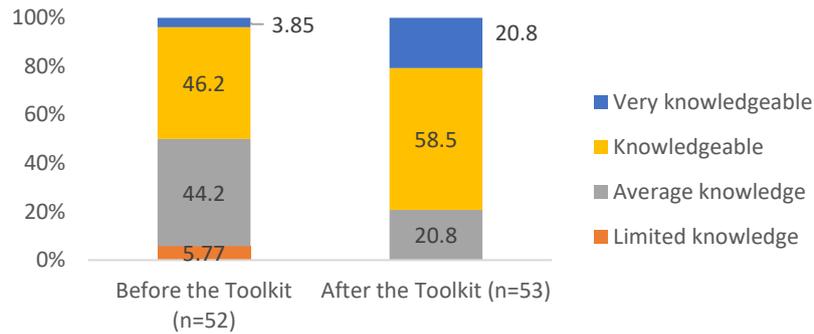
Holistic needs of people living with cancer

At baseline, most participants reported that they had 'average knowledge' (30.8%, n=16) or were 'knowledgeable' (50.0%, n=26) of the holistic needs of people living with cancer. The proportion of GP practices reporting that they were 'knowledgeable' or 'very knowledgeable' regarding the holistic needs of people living with cancer increased from 61.5% at baseline to 92.5% after the Toolkit (increase of 31.0%).



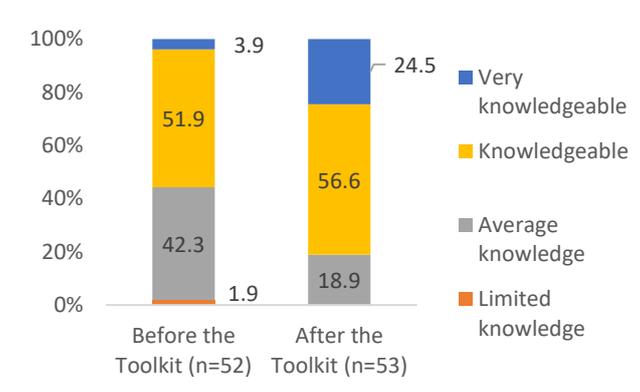
Long-term health concerns related to a cancer diagnosis

At baseline, most participants reported that they had 'average knowledge' (44.2%, n=23) or were 'knowledgeable' (46.2%, n=24) of the long-term health concerns related to a cancer diagnosis. The proportion of GP practices reporting that they were 'knowledgeable' or 'very knowledgeable' regarding the long-term health concerns of a cancer diagnosis increased from 50.1% at baseline to 79.3% after the Toolkit (increase of 29.3%).



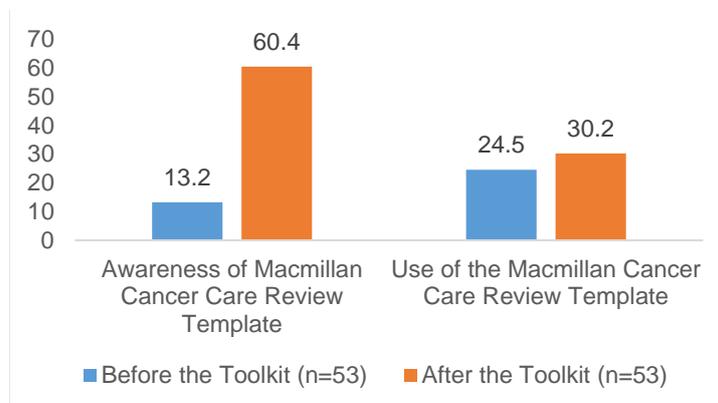
Long-term consequences of cancer

At baseline, most participants indicated that they had ‘average knowledge’ (42.3%, n=22) or were ‘knowledgeable’ (51.9%, n=27) of the long-term consequences of cancer. After the Toolkit, the proportion of GP practices that rated themselves as ‘knowledgeable’ or ‘very knowledgeable’ increased from 55.8% at baseline to 81.1% after the Toolkit (increase of 25.3%)



Increasing awareness and use of the Macmillan Cancer Care Review Template

After the Toolkit, the proportion of GP practices that indicating they were aware of the Macmillan Cancer Care Review Template increased from 13.2% (n=7) to 60.4% (n=32) (increase of 47.2%). Use of the Macmillan Cancer Care Review Template did not change significantly.



EVIDENCE OF PRACTICE CHANGE

Improving cancer care reviews

Before the Toolkit

At baseline, GP practices had varied approaches to cancer care reviews while others reported that they did not have a formalised or consistent process for carrying out CCRs.

“No structured cancer care reviews at present...” (P60, HDUHB)

“No consistency in approach and there is no structured system to provide and document reviews...” (P43, PTHB)

“Currently, we do not have a formal procedure for offering CCRs...” (P19, ABUHB)

For those that identified having some form of a process, the following themes emerged: ‘*formalised CCR approach*’, ‘*Informal CCR approach*’, ‘*CCR delivery*’ and ‘*Documenting CCR information*’.

Theme 1: Formalised CCR approach

At baseline, some GP practices reported use of a structure for identifying and inviting patients for a designated cancer care review appointment. In terms of staff involvement, both clinical and non-clinical staff actively contributed to those processes including administration staff, GPs and Practice nurses. However, overall, most practices stated CCRs were GP led.

Sub-theme: Identifying patients for a CCR

Very few practices reported that they had a structured process for identifying and/or inviting patients for a cancer care review. Those practices with an active approach for identifying patients eligible for a review described how a CCR invite was triggered during coding processes (e.g., staff coding a cancer diagnosis) or at practice meetings when new cancer diagnoses were discussed. This was often off the back of a letter received from secondary care indicating that a patient had a new cancer diagnosis.

“When a patient has a new diagnosis of cancer our admin staff read code the diagnosis and send a re-call to prompt invitation for a cancer care review within 3 months of diagnosis.” (P14, ABUHB)

“Practice will have a flagging system when a new diagnosis is made their regular GP or the referring GP will contact them and give them opportunity to visit or offer an appointment to discuss cancer care review...” (P16, CTMUHB)

“There is a weekly meeting between myself and [Name] where we pick up newly diagnosed [patients]. We then schedule in cancer care review time with each patient.” (P37, HDUHB)

“Currently I chair a practice meeting and inform clinicians of new cancer diagnosis once a month. I would ask referring clinician to review patient.” (P6, CAVUHB)

Sub-theme: Inviting patients for a CCR

GP practices described structured processes for inviting patients to a cancer care review using various methods such as telephone and letters. These practices used recall systems to invite and arrange specific appointments to deliver a cancer care review. Others reported using a mixed approach with both a structured and opportunistic element for inviting patients to a CCR.

“Cancer care reviews are currently offered to patients with a new/recent diagnosis of cancer. The patient is contacted and offered an appointment with the doctor. Depending on individual patient circumstances the doctor may initially make contact with the patient by telephone and conduct a review over the phone.” (P12, ABUHB)

“Cancer care reviews are currently being done by our 2 practice nurses. They are given a list of patients with cancer and are currently contacting them by phone or letter on an ad-hoc approach basis to arrange cancer care reviews.” (P20, CAVUHB)

“There is a weekly meeting between myself and [Name] where we pick up newly diagnosed. We then schedule in cancer care review time with each patient. If the CCR are missed for whatever reason they are flagged and picked up by the other clinicians.” (P37, HDUHB)

“Practice nurse proactively undertakes CCRs. GPs often perform these opportunistically during home visits or medication reviews.” (P73, CTMUHB)

Theme 2: Informal CCR approach

The approaches for inviting and arranged a CCR described in this section were more reactive rather than pro-active. Participants reported that they did not use a dedicated appointment and did not necessarily always have a formal structure in terms of timing and approach.

Sub-theme: Unplanned CCRs

Most practices described an ad hoc or opportunistic approach to cancer care reviews. Participants described how these unplanned reviews, in some cases, were only initiated if the clinician decided the appointment was needed.

“Due to staffing levels CCRs were undertaken on an ad hoc basis prior to commencing the toolkit...” (P77, BCUHB)

“Cancer care reviews are offered informally by some of the GPs in the practice but are not coded. We don't have a formal policy in place.” (P78, BCUHB)

“All quite ad hoc...We don't have a formal arrangement for arranging these, so it tends to be whichever clinician has a good relationship with the patient, or sometimes when specific queries are raised...” (P67, BCUHB)

“Currently done opportunistically by doctor - informal chat. Practice will have a flagging system when a new diagnosis is made their regular GP, or the referring GP will contact them and give them opportunity to visit or offer an appointment to discuss cancer care review...since QOF doesn't exist now these have not been read coded and done regularly as they used to be.” (P16, CTMUHB)

“Opportunistically. Historically all new cancers were documented by the practice cancer lead - GP and either telephone consultation or highlighted in notes 'need cancer review'...” (P10, ABUHB)

Sub-theme: Patient contact triggers CCR

Other practices explained that CCRs were instigated after patients attended the surgery for other reasons, which may or not have been related to their cancer diagnosis. In these circumstances, the contact would trigger an opportunistic discussion regarding their diagnosis and needs.

“Cancer care reviews are not currently formally or regularly offered to patients. There are no procedures in place to invite patients for a cancer care review. If patients present to the surgery for an issue related or unrelated to their cancer, ad ad-hoc review may be carried out...” (P47, CAVUHB)

“Ad hoc basis by GPs if a patient attends for an appointment about their cancer, or maybe brought up if attending on another matter...” (P34, BCUHB)

“Currently we appear to be doing these reviews opportunistically when the patient contacts the surgery for a review or medication or house call request. All the reviews are being done by GP...” (P45, SBUHB)

“Opportunistic discussion of cancer care when patients present, but not really a holistic review of patient.” (P44, CTMUHB)

“Currently CCR are done opportunistically when a patient sees a doctor. Patients are not specifically called in for them on new diagnosis of cancer. CCR are currently always with a Doctor. A lot of informal CCR take place with the nursing team, for example when patient attending to have sutures removed after surgery, etc...” (P42, ABUHB)

Theme 3: CCR delivery

Sub-theme: Unstructured approach

Some participants acknowledged that their practice did not have a formal procedure to deliver CCRs including the content that would be covered during an informal or structured cancer care review.

“No structure to them, generally patient led...” (P29, SBUHB)

“No consistency in approach and there is no structured system to provide and document reviews, other than a template regarding cancer diagnosis and treatment discussion.” (P43, PTHB)

“There is no formal content or recording process.” (P61, PTHB)

“We don't have specific topics that we cover. I suspect the doctors are less informed re benefits etc., and these are probably not discussed a lot. Also, this might be something that we feel is already being addressed by a palliative care or specialist cancer nurse and not think needs addressing.” (P67, BCUHB)

Sub-theme: CCR discussion content

There was significant variability in terms of the content that would be discussed during a CCR. Many practices highlighted that they ensure discussions cover various holistic topics such as medical, physical, financial, emotional and psychological needs. In addition, participants also reported that they would offer support and signpost patients and their carers/ family to information and resources.

“The content will include a review of the diagnosis, discussion of the patient's understanding, experience and reaction to the diagnosis. Discussion would also cover planned treatment, also emotional aspects of the diagnosis for the patient and their family. If appropriate, referral to a specialist nurse may be discussed. Practical aspects may be discussed, such as benefit entitlement.” (P12, ABUHB)

“The review usually includes discussion about diagnosis, the treatment plan and a review of medication...” (P3, CTMUHB)

“Mostly physical, little information regarding social or psychological aspects discussed or documentation of referral to St David's...” (P10, ABUHB)

“Again, during CCR options, assessment of needs, review, progress, sign posting for support services for patient/family and carers are duly considered with further follow-up options: Macmillan Cancer Support Services, Cancer UK and Marie Curie.” (P62, HDUHB)

“Offer empathy/sympathy regarding diagnosis, discussion around patient understanding of diagnosis, plan of secondary care based on patient understanding and clinic letters, explore how patient feels about diagnosis/plan and the support they have and if palliative, then longer discussion regarding patient choices, available community care/support.” (P71, BCUHB)

Theme 4: Documenting CCR information

Sub-theme: Use of CCR code

Most practices identified that cancer care reviews, both structured and informal, were completed but that it would not always be coded as such (using the CCR Read code).

“Generally, it was noted that we typically use the Vision code #8BAV then use the free text box to complete cancer care reviews.” (P5, SBUHB)

“The cancer care review is then read coded and information recorded in the patients’ record.” (P20, CAVUHB)

“Cancer care reviews are offered informally by some of the GPs in the practice but are not coded. We don’t have a formal policy in place.” (P78, BCUHB)

“In our practice, these reviews are done and coded only by the GPs. We do not currently have a trained nurse or allied health care professional who can do these for us.” (P28, HDUHB)

“Currently done opportunistically by doctor - informal chat...but since QOF doesn’t exist now these have not been read coded and done regularly as they used to be.” (P16, CTMUHB)

“Sometimes these reviews are coded as CCRs, but many are not, so this activity is not captured.” (P32, CAVUHB)

A few practices commented on how they record information that was discussed during the CCR but that this practice was not always consistent.

“...Sometimes there is documentation of carer’s details. The recording of CCR information in the patient’s record is variable...” (P3, CTMUHB)

“Information would be recorded in the patient record, usually a combination of a template entry and free text.” (P12, ABUHB)

“I also suspect the recording may be a bit hit and miss. We forget that sometimes the most important part of a consultation for the patient is a small area of reassurance etc. and might not capture this fully with free hand text.” (P67, BCUHB)

Sub-theme: Template use

Responses varied in terms of template use to support CCRs discussions with some practices reporting inconsistent use of the Macmillan Cancer Care Review Template or no use at all.

“We have a cancer care review template but it is not used widely used.” (P74, CAVUHB)

“Some clinicians...use the Macmillan Cancer Care Review Template.” (P27, CAVUHB)

“We do not currently use the Macmillan cancer care review template but this is an area that we have highlighted to improve.” (P14, ABUHB)

“The use of a cancer care review template is infrequent.” (P3, CTMUHB)

Improvement plans

To improve the quality and content of CCRs, participants identified several areas for improvement. These actions were themed into the following:

- Increasing template use
- Improving coding practice
- Increasing awareness of CCR information
- Improving CCR delivery

Theme 1: Increasing template use

Participants agreed to utilise templates, including the Macmillan CCR Template or a more locally designed template, to improve documentation of information and to ensure a more holistic and consistent approach to CCRs.

“Increase use of Holistic Needs Assessment (HNA) and cancer care review templates to ensure consistency.” (P7, ABUHB)

“GPs to formally record cancer care reviews utilising the Macmillan template.” (P17, HDUHB)

“Use the cancer care review template to ensure full holistic assessment.” (P74, CAVUHB)

“Create a practice guideline for Vision. Standardise clinician approach to this across the practice. Use Macmillan tool within Vision Plus (Cancer Care Review - Macmillan).” (P18, HDUHB)

“Will look at updating the Cancer Care Review template so it is more cancer specific - it was felt that the Macmillan one didn't include appropriate information (e.g., only treatment options are chemo/ radiotherapy, no option for surgery/ immunotherapy/ palliative).” (P4, BCUHB)

“We plan to design a cancer care review template to include all the above themes. We note the Macmillan offering but feel we can design something with more local theme. This will include embedded information to be given to patients as appropriate at the end of their cancer care review.” (P42, ABUHB)

Theme 2: Improving coding practice

Many participants acknowledged that their coding practice could be improved within their practice to ensure consistent and robust audit processes for monitoring the delivery of CCRs. Some practices indicated that they would ensure the suggested Toolkit CCR code would be used while others acknowledged the importance of coding advice given to the patient.

“Need to ensure cancer care reviews are coded as has to be picked up on searches.” (P2, ABUHB)

“As already stated, we already cover a large amount of this work. We now plan to do this more formally. Clinic letters with new cancer diagnoses will be forwarded to GP's

and CCR to be done and read-coded, including medication review and read-coding of advice given and any signposting.” (P19, ABUHB)

“We need to be more mindful of our coding of these reviews which we will try and achieve.” (P28, HDUHB)

“Our coding could be better. We agree we can incorporate more into the cancer care review especially w.r.t navigation to other support resources. Our practice has already informally started adding codes after impromptu conversations with patients.” (P40, ABUHB)

To facilitate good coding practice and audits, practices identified that they would utilise the Macmillan CCR Template or develop their own practice-based template.

“Use of the template to encourage more complete and consistent recording of information discussed with patients...” (P3, CTMUHB)

“Template will be created in clinical system this will prompt for consistent Read coding - for improved audit results.” (P60, HDUHB)

“We are hoping to have a template to ensure good documentation of CCR's as well as correct READ codes for audit purposes.” (P45, SBUHB)

“Vision + template - Macmillan cancer care review. Use this and Read Code from the template to enable more accurate auditing.” (P27, CAVUHB)

Theme 3: Increasing awareness of CCR information

Several participants agreed that awareness amongst staff of resources and tools to support holistic CCR delivery needed improvement. Actions included disseminating information on the Macmillan CCR template and 'Carrying out an effective CCR' booklet. Other participants described how they would ensure that staff would have easy access to signposting information including local services and further sources of support for their patients.

“We wanted to increase awareness amongst GPs of the CCR and how we can complete this and be more efficient at doing this. An email update regarding CCRs was compiled and sent out to all the Doctors and senior management. It was also discussed in the practice meeting. The Macmillan toolkit was highlighted and using the website to help with patient management was also encouraged. We also highlighted the importance of using services on our doorstep such as Maggie's which we believe to be an excellent resource.” (P5, SBUHB)

“We have used the resources provided in this toolkit i.e., the 'carrying out an effective cancer care review leaflet and shared this resource with all GP's.” (P28, HDUHB)

“We will make GPs aware of the information above which lists what to cover in a cancer care review and make doctors aware of the CCR template to use if they find this helpful.” (P30, CAVUHB)

“To keep a library of useful local and national services to which patients and their carers can be signposted by clinical and admin staff.” (P47, CAVUHB)

“Speak about our roles and responsibilities in the context of managing cancer patients with the aim of developing a more patient centred approach.” (P73, CTMUHB)

Theme 4: Improving CCR delivery

GP practices identified several different approaches for improving the delivery of CCRs. The actions were themed into the following:

- Utilising a whole team approach
- Need for staff training
- Use of a dedicated CCR appointment
- Implementing a structured CCR approach
- Applying a holistic approach

Sub-theme: Utilising a whole team approach

Throughout the Toolkit, GP practices were encouraged to involve the whole practice team to improve their delivery of cancer care. The role of Practice nurses in carrying out CCRs was promoted in this module and many practices scoped this within their teams. While several participants agreed to utilise Practice nurses, others went further and identified other roles that could contribute such as Healthcare assistants and pharmacists. Many also identified that this would be a collaborative approach between clinical staff to meet patients' needs.

“Practice nurse/ HCA reviews where appropriate. Patient could then be referred to GP if complex/ patient wishes.” (P39, CAVUHB)

“We hope to train up our PNs to do cancer care reviews. All nurses are keen to participate in this. We are sourcing training for this and looking at cross-cluster training.” (P42, ABUHB)

“Utilise our PNs in CCRs as part of chronic disease management.” (P46, SBUHB)

“Cancer care review to involve GP, practice nurse and/or pharmacist as appropriate...” (P47, CAVUHB)

“At a meeting we have discussed the issues raised in the audits for Cancer Care reviews and think it is appropriate and achievable for our HCA's to undertake the training and carry out the cancer care reviews as per the protocol.” (P61, PTHB)

“A dedicated nurse will be allocated one day a week to monitor observe and offer support to cancer patients in the surgery with addition to a GP link as a safety netting process.” (P69, PTHB)

Sub-theme: Need for staff training

Several participants acknowledged that before Practice nurses and Healthcare assistants could take up these new roles in the delivery of CCRs, they must undertake training.

“Further information to be provided for nurses to allow them to do cancer care reviews particularly when they are the first point of contact for patients after diagnosis e.g. patients who attend the nurse to have prostatic injections for prostate cancer.” (P3, CTMUHB)

“The nurses were interested in attending a study session if possible, and would bring this learning back to the practice.” (P12, ABUHB)

“Finding courses for our practice nurses to go on. Our practice pharmacist was also interested.” (P33, HDUHB)

“CCRs will initially be GP led but we aim to train our nurses to be able to fulfil this soon now we are back to full nursing capacity.” (P45, SBUHB)

“Feel utilisation of practice nurses for this will be positive step forward - will see how they want to progress this following specific training.” (P29, SBUHB)

Sub-theme: Use of a dedicated CCR appointment

Some participants identified that their practices' CCR approaches could be improved by allocating designated appointments with additional time to ensure that the information could be covered adequately during the consultation.

“Identify new cancer patients. Separate clinic slots/or clinics to facilitate these reviews. Longer appointment times for cancer reviews.” (P39, CAVUHB)

“We will have the nurses to do a holistic review in given appointments either face to face or by telephone.” (P44, CTMUHB)

“Team felt more dedicated time to do CCRs rather than ad-hoc/afterthought. GPs will delegate to PN where possible, and intentionally aim to make contact, especially after diagnosis or nearing end of treatment course.” (P46, SBUHB)

“To involve a longer/ specially designed appointment to which patient's carer (if applicable) is also invited.” (P47, CAVUHB)

Sub-theme: Implementing a structured CCR approach

GP practices agreed actions included improving the process for identifying and inviting patients to a CCR. Participants described how they wished to establish a structured approach by implementing administration processes to identify and invite eligible patients for a CCR either in person or over the phone with GPs or Practice nurses.

“Drawing cancer care reviews into our compassionate communities work. In time, all new cancer diagnoses should receive a phone call from a named clinician who will then offer a face-to-face CCR should the patient wish to attend.” (P7, ABUHB)

“We will have a system to offer all newly diagnosed patients a structured review which will be based on the patients’ needs and priorities. This will be documented on a locality agreed template.” (P43, PTHB)

“Administration staff will send a task/message from Emis to the CCR nurse when newly diagnosed patients and documents enter the surgery. In addition, an administration link will also be added to support CCR nurse.” (P69, PTHB)

“Practice newly designated ‘cancer lead GP’ to keep an up-to-date and easily accessible record of all patients with cancer. List to be used to invite all patients annually for a cancer care review (if deemed appropriate after review by GP).” (P47, CAVUHB)

Sub-theme: Applying a holistic approach

Other actions focused on improving the content covered during a cancer care review. GP practices recognised the importance of ensuring that their CCRs cover a broad range of topics and not just patients’ physical or medical needs.

“Explore psychological, financial and occupational issues with patients rather than just looking at physical symptoms.” (P11, ABUHB)

“Ensuring we cover diagnosis, also a medication review and look into exercise/ work and sign post them to resources such as Macmillan recovery package.” (P44, CTMUHB)

“Improve quality of CCRs, especially wellbeing, financial/work support and carers information - more signposting. Physical Activity and W/L advice - Macmillan Physical Activity Resources online information and more NERS referrals.” (P46, SBUHB)

“CCRs need to be structured and cover: discussion around diagnosis to ensure understanding of it, treatment discussion that covers the possible impact on quality of life, including: how someone might be affected physically, emotionally and financially, medication review, discussion about the information needs of the patient and their carers, physical activity advice and signposting to local support services and signposting to Macmillan Cancer Support and other appropriate organisations.” (P71, BCUHB)

“Ensure all aspects of patients’ care/ journey are addressed (include psycho-social factors).” (P73, CTMUHB)

After the Toolkit

This section provides evidence of the positive changes GP practices made as a result of this module.

Theme 1: Established structured CCR

This module facilitated practices with the adoption of a formalised approach to CCRs including establishing an invitation process and a specific review appointment for patients that was proactive instead of reactive.

“We also felt that inviting patients for review was better than waiting for them to present to us.” (P32, CAVUHB)

“The identified key person (CCR nurse) had experience in district nursing and palliative care background. This has provided support and experience with knowledge to identify key factors promptly. Initial letter from CCR nurse is sent out at point of information received in order to make patients aware of service available and support. We have received feedback from patients who are in process of receiving support and currently being reviewed by CCR nurse - effective service where they feel they have a point of contact who can sign post to other services needed...” (P69, PTHB)

“The admin process implemented on completion of the Macmillan toolkit six months ago has clearly had a very positive impact. Whenever a new cancer is coded, the admin team book that patient in for a telephone review with the most relevant GP who carries out a cancer care review. Not every GP has used the Macmillan template however, but all agree that it has been a worthwhile admin process to implement.” (P71, BCUHB)

“Coding is better. We continue to actively follow up newly diagnosed patients. One GP has reviews of new cancers on her PDP i.e., starting meetings to discuss all new cancers within the practice - this will also highlight which doctor will do the review if the correspondence has come to a GP who doesn't know the patient. This will improve continuity of care.” (P40, ABUHB)

Theme 2: Increased use of templates

Some participants reported increased use of templates, such as the Macmillan CCR Template or the HNA checklist, which enabled GP practices to improve documentation and deliver a more holistic and comprehensive CCR.

“The use of the template has also improved the holistic nature of the reviews and made us as clinicians consider other aspects, and signposting onwards.” (P70, CTMUHB)

“We improved our cancer and palliative templates for recording information. These also had helpful links to Macmillan support groups and organisations to give patients and carers.” (P14, ABUHB)

“The feeling was the CCR template was helpful in prompting a more holistic approach.” (P32, CAVUHB)

“CCR template well received - may be utilised more by PNs as they begin doing these reviews, and GPs can use if less familiar with patient's past medical history/ background and can facilitate a more holistic review.” (P46, SBUHB)

Theme 3: Increased awareness and use of patient information

GP practices reported a better understanding of information and resources to support CCR discussions including increased awareness of local services, increased use of patient information leaflets and signposting to further support available (e.g., financial services).

“Reviews which were carried out since engaging with the Macmillan toolkit have generally improved. Clearer understanding of extra services available have been highlighted and implemented into our ongoing cancer care management.” (P5, SBUHB)

“Statistically, it suggests it went well. There were some anecdotal reports of individuals being more aware of the process outlined above over the last 6 months.” (P17, HDUHB)

“More signposting and social support/ advice offered such as financial support and referrals to Macmillan psychological services.” (P73, CTMUHB)

“Cancer care reviews are being done more regularly. Two or three of the above patients [reviewed] had more than one review in the time period. New practice template is being used and leaflets and lifestyle advice being offered more regularly (5 of the patients had been offered both - 2 of the remaining were unsuitable for lifestyle advice).” (P4, BCUHB)

Theme 4: Improved coding practice/ documentation

Some practices noted an improvement in the coding of cancer care review information.

“Better read coding and documentation of CCRs...” (P16, CTMUHB)

“Far more detailed CCRs documented on second audit cycle.” (P73, CTMUHB)

“Overall, cancer care reviews have improved. Mostly doctor dependent regarding using template and read codes.” (P10, ABUHB)

“Improvement in coding system.” (P35, SBUHB)

Theme 5: Education

A few participants commented that members of staff attended the Cancer Care Review and Cancer Buddy Training delivered by the MPCCF nursing team. As a result, GP practices were better equipped to implement a structured CCR approach and had greater awareness of cancer information, resources and tools.

“Two of the GPs have attended the recent Macmillan cancer care review training and hope to implement this in the practice. One of the admin staff has completed cancer buddy training and this will also be helpful as part of CCRs.” (P16, CTMUHB)

“One of our nurses attended a Macmillan study day on cancer care reviews and shared her experience with the rest of the team in a practice meeting. She found the day very helpful and brought in some print outs of the material that was covered, which was circulated. This led to a discussion about cancer care reviews and the role of the practice nurses/doctors. We discussed that often patients with a recent diagnosis/treatment for cancer will have an appointment with the nurse as their first point of contact, perhaps for stitch removal, or for a dressing change. Both nurses agreed that they feel more confident and informed to view this as an opportunity for a cancer care review. We all agreed that cancer care reviews should be seen as an ongoing process, with different aspects being more relevant at certain times, and that different members of the team all have a part to play in the support they can offer. This also includes the wider practice team - as a small rural dispensing practice the reception and dispensary staff often have a lot of contact with these patients and are also a valuable source of support/ information and signposting.” (P12, ABUHB)

“...One GP (nominated cancer lead) and our practice nurse attended a series of modules on cancer care review training, and we have now developed a structured framework for carrying out cancer care reviews. We aim for these to be both opportunistic and to call patients on an annual basis..” (P47, CAVUHB)

“I am also very pleased to report that our practice manager, secretary and one of our HCAs did the Cancer Buddy on-line training - enjoying it and finding it useful...I think the factor that best supported our action plan for improving the quality of cancer care reviews was definitely the on-line training. Prior to this our staff were a bit uncertain about how to do it, and finding time to do it in amongst all their other duties but I think the training has really helped them see that it's not much different to a lot of the chronic disease management they are already so good at doing...” (P59, HDUHB)

Challenges identified

GP practices identified several factors that hindered their ability to implement changes to improve the quality of cancer care reviews. Some participants described how routine work was restricted (e.g., no face-to-face reviews) and changes were made to their way of working (e.g., telephone consultations). Significant work pressures in primary care meant that planned changes were unable to be implemented. For example, provision of longer appointment times for CCRs.

“Covid19 has made this more difficult - telephone calls only, although leaflets have been dropped off by staff at patients houses.” (P4, BCUHB)

“Under 50% of new cancer diagnoses in last six months have had a cancer care review. However, this number will have been impacted by the Covid-19 pandemic. Patients have been sent letters following a diagnosis of cancer but not all have responded to offer of a cancer care review, possibly due to the pandemic.” (P20, CAVUHB)

“It is something we do opportunistically, and this has somewhat been limited by Covid-19.” (P30, CAVUHB)

“Current times have been challenging given the global pandemic which has certainly impacted on the ability of our PN team to undertake these reviews - significantly less face-to-face work undertaken.” (P42, ABUHB)

“Unprecedented work/Covid pressures impacted on facilitating some changes/training etc.” (P58, HDUHB)

Other challenges included the lack of training available for Practice nurses and lack of capacity for staff to implement planned changes.

“Lack of practice nurse cancer course.” (P19, ABUHB)

“Changes in administrative and nursing staff meant that we were not able to put into place our improvement plan as originally detailed.” (P3, CTMUHB)

“The issue here is our nurse who has done cancer care review training is now working with us as a ANP so we need to increase training in our other practice nurses - now is not the time though - COVID.” (P6, CAVUHB)

“The surgery has been exceptionally busy over the past few months so allocating longer appointment times for cancer care reviews and other chronic disease reviews has been more difficult due to the increased demand for same day and emergency appointments.” (P74, CAVUHB)

Promoting the role of Practice nurse in CCR delivery

In addition to improving the quality of cancer care reviews, Toolkit participants were asked to consider the role of Practice nurses for the delivery of CCRs.

Toolkit impact

To support this, GP practices were asked to conduct an audit of their practice data over a six-month period to determine the number of completed CCRs (Table 13). At the first data collection point, 78.5% (n=754/960) of cancer patients had received a cancer care review compared to 79.5% (n=831/1045) at the second data collected point.

Table 13. Cancer care review audit data

	Before the Toolkit (n=960)		After the Toolkit (n=1045)	
	No.	%	No.	%
Completed CCRs*	754	78.5	831	79.5
Cases reviewed**	523	69.4	476	57.2
*Lower number could be due to eligible patients declining or an appointment may not have been arranged at the time of the audit				
**Each individual practice was asked to review 10 patients each				

The majority of CCRs were completed by a GP (Table 14). There was a small increase in the number of CCRs carried out by practice nurses (from 3.4% to 8.2%) and ‘other’ staff (from 4.4% to 6.9%). However, as not all completed CCRs were reviewed, it is possible that the

number of CCRs completed by Practice nurses and other healthcare professionals may be underestimated.

Table 14. Roles involved in the delivery of CCRs

	Before the Toolkit (n=523)		After the Toolkit (n=476)	
	No.	%	No.	%
CCRs completed by GP	370	70.7	351	73.7
CCRs completed by PN	18	3.4	39	8.2
CCRs completed by 'other'	23*	4.4	33**	6.9
*Roles specified: Minor illness practitioner (n=10), unspecified role (n=13)				
**Roles specified: Advanced Practitioner - Pharmacist (n=1), Healthcare assistant (n=7), Minor Illness Practitioner (n=10), Nurse Practitioner (n=2), Advanced Nurse Practitioner (n=4), unspecified role (n=9)				

In addition to the audit, participants were asked to indicate whether practice nurses carry out CCRs (Figure 11). The proportion of GP practices indicating Practice nurse involvement did not change significantly from 24.5% (n=13) at baseline to 30.2% (n=16) after the Toolkit (increase of 5.7%).

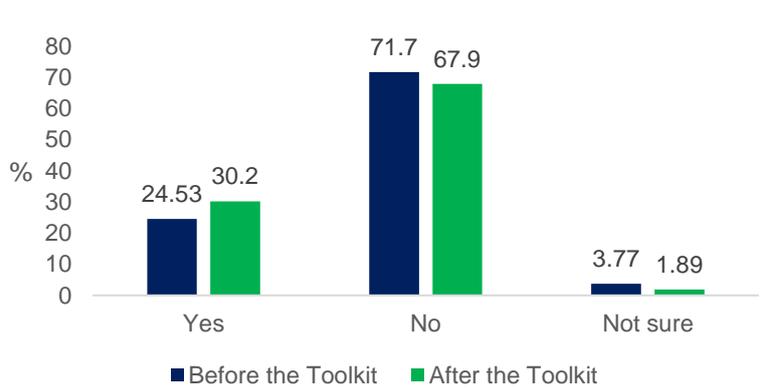


Figure 11. Practice nurse involvement in delivery of CCRs

GP practices were also asked to indicate whether their Practice nurses were interested in the Macmillan Cancer Course. 75 Practice nurses expressed an interest. This represents half of Practice nurses working in the 53 GP practices at the time of Toolkit participation. This suggests that there is an appetite for cancer education amongst Practice nurses (49.3%, n=75/152).

Challenges identified

Practices provided several reasons why practice nurses did not carry out CCRs. The following themes emerged '*availability of CCR training*', '*Competing priorities and demands*' and '*Perceived GP role*'.

Theme 1: Availability of CCR training

Initial plans for Module 4 included the provision of CCR training by the MPCCF programme nursing team. Due to the Covid-19 pandemic, these training sessions were delayed until

September 2020. As a result, many practices who were waiting for the training before moving ahead with Practice nurses delivering CCRs, were unable to do so before completing the Toolkit. The most significant factor, which prevented Practice nurses from carrying out CCRs, was the lack of training available. Several practices identified that Practice nurses needed this training to increase skills, knowledge and confidence before undertaking CCRs.

“Decreased confidence with this task without formal training.” (P18, HDUHB)

“At zero months, our two practice nurses were interested in attending the cancer care course but there was not availability to register.” (P19, ABUHB)

“They are awaiting the training, but also being such a small practice, we have very close continuity, and the GPs perform the CCR role as standard - but we are keen that it becomes part of the chronic disease remit for our nurse practitioner moving forwards.” (P32, CAVUHB)

“Training in cancer care reviews has only just completed, we do have a practice nurse interested in starting up doing the reviews now.” (P33, HDUHB)

“Lack of capacity and training. New practice nurse has started but is in the process of being trained. Other practice nurse has been on sick leave and needs training in cancer care review, she is also currently fully booked with other chronic disease reviews, smears etc.” (P34, BCUHB)

Theme 2: Competing priorities and demands

Competing priorities and demands placed on for staff had an impact on availability to attend training to be undertake CCRs and prevented Practice nurses from carrying out CCRs.

Sub-theme: Inadequate time

Several participants identified that Practice nurses did not have the capacity to take on additional work. This meant that priority areas for Practice nurses took precedence over new work to undertake CCRs.

“In addition, due to the pandemic and one of our practice nurses leaving her post, our remaining practice nurse has experienced an additional workload.” (P47, CAVUHB)

“Only one nurse - not enough time for her.” (P25, CAVUHB)

“...The nurses have been completing more acute triage work rather than routine reviews.” (P26, PTHB)

“Heavy workload and one said she didn't think she was allowed.” (P37, HDUHB)

Sub-theme: Covid-19 pandemic

Many participants also described the impact of Covid-19 on their services generally, but also how this hindered their ability to implement planned changes. Participants reported that the pandemic and its knock-on-effects such as staff availability and changes to ways of working,

meant that practices had to prioritise nursing time. This meant that Practice nurses could not attend training or deliver CCRs.

“... We were hit with pandemic and unfortunately we have been prioritising the nurses clinic times.” (P23, SBUHB)

“Covid epidemic with all its ramifications; sick leave, restructuring, clinic changes, practice roles etc.” (P58, HDUHB)

“Changes to the way we work during Covid. Team members shielding, staff shortages due to this and self-isolating/staff sickness.” (P60, HDUHB)

“We have not been able to implement this due to current Covid pandemic restrictions, increased staff sickness and change in working practice to a telephone first model. We hope to implement this in the future.” (P45, SBUHB)

“Staff shortage in nursing team, relying on locum nurses to provide primary care nursing duties so unable to train up with new skills at this time, especially as we are in a pandemic.” (P39, CAVUHB)

“Due to the current pandemic our nurses have not yet been able to attend the cancer care review course but hope to do so in the future.” (P74, CAVUHB)

Theme 3: Perceived GP role

Some participants were of the view that CCRs were the responsibility of GPs, and therefore did not see change necessary. One practice highlighted that their established, GP led delivery of CCRs was working well so in their view, it was not necessary to change their processes.

“Following clinical meetings as a practice, at present we felt doing CCRs as GPs was an appropriate method to manage patients. We are still considering future methods to improve CCRs and will review the possibility of nurse input if needed.” (P5, SBUHB)

“The Practice felt and planned that cancer care reviews are a GP task.” (P17, HDUHB)

“The GPs would rather have this responsibility.” (P71, BCUHB)

“... traditionally GPs do the cancer care review in our practice.” (P40, ABUHB)

MODULE 4 SUMMARY

As a result of undertaking and completing this module GP practices (n=53) have:

- Reported improvements in how well they:
 - Support patients through treatment and during recovery
- Increased practice knowledge of the:
 - Holistic needs of people living with cancer
 - Long-term health concerns related to a cancer diagnosis
 - Long-term consequences of cancer
- Increased awareness of the:

- Macmillan Cancer Care Review Template (from 13.2% to 60.4%)
- Identified areas needing improvement including
 - Use of templates (e.g., Macmillan Cancer Care Review Template)
 - Coding of CCR information
 - Awareness of CCR information, resources and tools
 - Ensuring a holistic and structured approach to CCR delivery
- Positive changes made as a result of this module included:
 - Established structured CCRs
 - Increased use of templates to ensure a holistic CCR
 - Increased awareness of CCR information, resources and tools
 - Improved the coding and recording of CCR information
 - Improved access to CCR training for staff
- Identified several challenges that hindered practice change for improved CCRs:
 - Increased demands on primary care during the Coronavirus pandemic and changes to the way services were offered had a significant impact on participants
 - Staffing issues including staff vacancies, turnover, staff time and competing priorities
- Promoted the role that Practice nurses can play in the delivery of CCRs
 - Small change in the number of GP practices utilising Practice nurses in the delivery of CCRs (from 24.5% to 30.5%)
 - Discussion led to wider team involvement in the delivery of CCRs including Healthcare assistants, Minor Illness Practitioners and Pharmacists
 - 75 Practice nurses expressed an interest in the Macmillan Cancer Course
 - Reflections on the challenges of Practice nurse involvement in CCR included:
 - Lack of CCR training
 - Competing priorities and demands such as staff time and the impact of Covid-19
 - Perceived GP role

MODULE 5 FINDINGS – IDENTIFYING AND SUPPORTING PEOPLE WITH ADVANCE SERIOUS DISEASE

Of the 53 GP practices that participated, 26 completed module 5 (49.1%) (Table 15). Practice size varied with over half of practices (57.7%, n=15) having a large patient list size (over 8,000 patients). Participating GP practices had on average: 3.73 GPs, 2.67 reception staff, 1.95 administration staff and 1.95 Practice nurses involved in the Toolkit. Under half of staff within the GP practices were involved in the Toolkit (40.8%, n=288) with the most common roles being GPs, administration staff, reception staff and practice nurses.

Table 15. Participating GP practice demographics

	No.	%
GP practices in each HB that completed module 5		
ABUHB	3	11.5
BCUHB	5	19.2
CAVUHB	6	23.1
CTMUHB	1	3.85
HDUHB	4	15.4
PTHB	3	11.5
SBUHB	4	15.4
Wales	26	
Practice size		
Small (up to 3,999 patients)	2	7.69
Medium (4,000 to 7,999 patients)	9	34.6
Large (over 8,000 patients)	15	57.7
GP practice staff*		
GPs	153	21.7
Reception staff	170	24.1
Administration staff	130	18.4
Practice nurses	82	11.6
Healthcare assistants	61	8.64
Practice manager	39	5.52
Pharmacists	29	4.11
Nurse practitioners	24	3.40
Physiotherapists	4	0.57
Paramedics	1	0.14
Mental health nurse	9	1.27
Minor illness practitioners	2	0.28
Frailty nurse	2	0.28
Total staff	706	
Staff involved in the Toolkit		
GPs	97	33.7
Administration staff	43	14.9
Reception staff	32	11.1

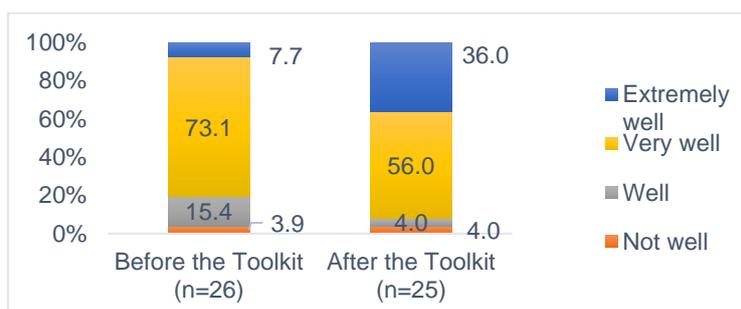
Practice nurses	43	14.9
Healthcare assistants	21	7.29
Practice managers	25	8.68
Nurse practitioners	15	5.21
Pharmacists	10	3.47
Frailty nurse	2	0.69
Total staff involved	288	
*No. staff in GP practices at time of Toolkit participation		

IMPROVING CLINICAL PRACTICE

How well do GP practices believe they carry out the following...?

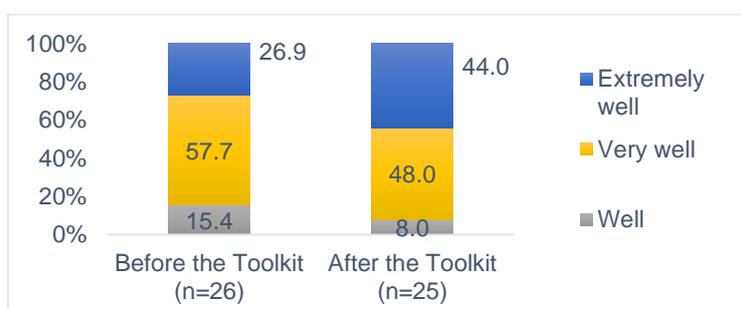
Supports patients when cancer becomes incurable but still treatable

At baseline, most participants reported that they support patients when cancer becomes incurable but still treatable 'very well' (73.1%, n=19). The proportion of GP practices reporting that they supported patients when cancer becomes incurable but is still treatable 'very well' or 'extremely well' increased from 80.8% at baseline to 92.0% after the Toolkit (increase of 11.2%).



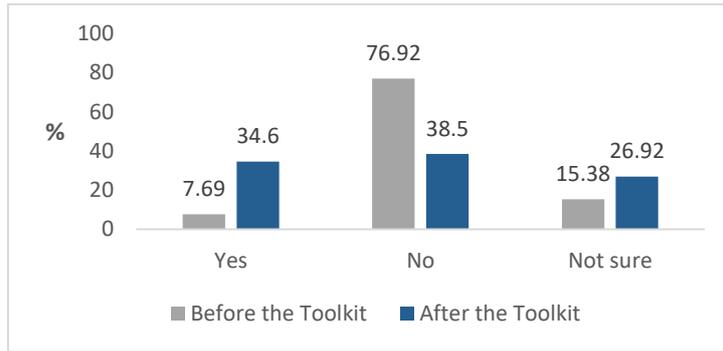
Supports patients as they move into end-of-life care

At baseline, all participants felt that they support these patients well, very well or extremely well. The proportion of GP practices reporting that they supported patients as they move into end-of-life care 'very well' or 'extremely well' increased from 84.6% at baseline to 92.0% after the Toolkit (increase of 7.4%).



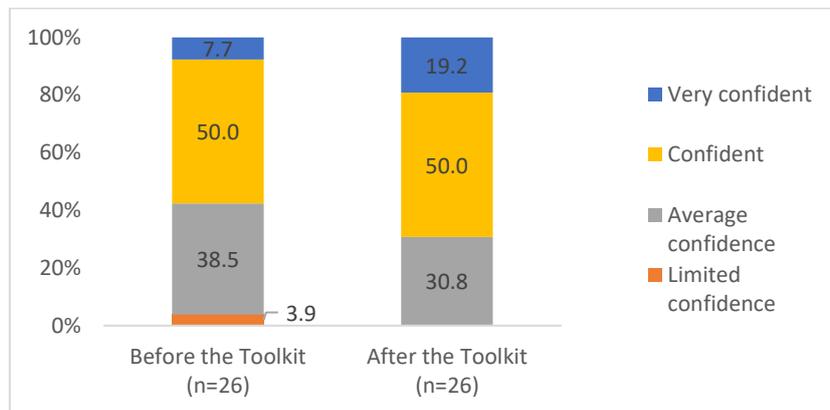
Use of the Macmillan Palliative Care Template

The proportion of GP practices that used the Macmillan Palliative Care Template increased from 7.69% (n=2) at baseline to 34.6% (n=9) after the Toolkit (increase of 26.9%).



IMPROVING CONFIDENCE

Before the Toolkit, over half of participants (57.7%, n=15) felt 'confident' or 'very confident' to initiate conversations with patients regarding Advance Care Planning compared to 69.2% (n=18) after the Toolkit (increase of 11.5%).



EVIDENCE OF PRACTICE CHANGE

Identifying patients for the palliative care register

Before the Toolkit

GP practices were asked to describe their approach for identifying patients for inclusion to the palliative care register (e.g., patients with heart disease, cancer diagnosis etc.). The following themes emerged: '*Correspondence from secondary care*', '*Palliative care meetings*' and '*Clinical judgement*'.

Theme 1: *Correspondence from secondary care*

Participants stated that any patient eligible for inclusion to the palliative care register might be identified after coding information received from hospitals.

"If we receive a clinical letter stating a poor prognosis, not for further treatment..." (P74, CAVUHB)

“All new cancer diagnoses in letters are flagged and seen by a GP.” (P61, PTHB)

“When letters come back and patient is coded as palliative, they are added to the list.” (P56, CAVUHB)

“We try and identify patients from any clinical letters or discharge summary and then proactively arrange a contact/review and discussion where appropriate.” (P45, SBUHB)

“If patient likely to die within a year from hospital letters. Consider Heart failure patients, COPS, chronic illness and nursing home patients.” (P25, CAVUHB)

Theme 2: Palliative care meetings

Participants also highlighted that palliative care meetings would be used to discuss and agree patient inclusion to the palliative care register.

“Also, from our palliative care meetings those who are known to our palliative care nurse and as patient’s health declines when GPs consider patients to be palliative. We do not use any tool for this.” (P14, ABUHB)

“During cancer register review practice meetings, patient record reviewed and placed on palliative care register if relevant.” (P46, SBUHB)

“The whole Practice team can nominate and suggest anyone who goes forward to the Palliative Care meeting to be included in the Palliative Care Register.” (P61, PTHB)

“MDT meetings patients are reviewed and added if needed.” (P72, HDUHB)

Theme 3: Clinical judgement

Many participants indicated that inclusion to the palliative care register would be based on staff knowledge and expertise.

“...are known to the community palliative care team then they will be included on the palliative care register. If a GP is seeing a patient who is clinically deteriorating quite quickly then they would also be included, as would patients who are thought to be in the last days or weeks of life.” (P74, CAVUHB)

“No formal 'system'. Identified through...GP incidental identification.” (P71, BCUHB)

“Our current approach is ad hoc, relying on individual doctors or nurses to add the patient’s name to the palliative care register.” (P58, HDUHB)

“All practice and extended team members are encouraged to suggest patients for inclusion on the palliative care team register.” (P43, PTHB)

“From our own experience with patients with long term conditions as well as information from secondary care team.” (P16, CTMUHB)

Improvement plans

This module enabled practices to identify key areas to improve the identification of patients for the palliative care register including:

- Taking a more proactive review of Gold Standards Framework list
- Increasing use of data/ information from hospital letters
- Taking a more proactive approach to identifying patients eligible for inclusion
- Increasing whole team awareness of triggers for inclusion to the palliative care register

“To go through the current GSF list and adjust as needed. To discuss at monthly practice meetings. We plan to try to proactively review the GSF list and move people up/down as needed.” (P4, BCUHB)

“When letters come back and patient is coded as palliative, they are added to the list. Ad hoc when patients seem to be deteriorating. This could be better. We could consider when discussing at clinical meeting, and when data is pulled from the hospital letters.” (P56, CAVUHB)

“We feel that we have to be more proactive in identifying patients for inclusion on the palliative care register, so that timely support can be offered and discussion around ACP can be planned. We will use the document “identifying patients for supportive, palliative and advance care planning” (adapted from SPICT). Individual doctors and nurses will consider the disease specific indicators to identify patients. We find that in general we are more aware of cancer patients, and have to work harder to identify and include patients with non-cancer chronic diseases who are approaching end of life.” (P58, HDUHB)

“We are now asking non clinicians (who also know patients well) for their thoughts on asking ‘the surprise question’...Dr X also looking at proactive searching by age bracket. We have a list of patients (known as ‘the white board’ as the patient numbers are written on a white board!) of vulnerable patients we are worried about. Proactively cross referencing these may find additional patients.” (P67, BCUHB)

“MDT meetings patients are reviewed and added if needed. Letter received are reviewed for inclusion on palliative care register (this process needs reviewing and tightening up with clearer guidance for clinical coding staff).” (P72, HDUHB)

“To be more aware of patients with increasing frailty who may be appropriate to add to the palliative care register.” (P78, BCUHB)

After the Toolkit

Evidence of positive changes made by GP practices to improve the identification of patients for the palliative care register included:

- Use of the Traffic Light system to structure palliative care register
- Improved discussions with patients
- Improved documentation and communication of key information between sectors
- Increased awareness of prognostic indicators

"We have reviewed the GSF list and grouped into blue/green/amber and red. We now discuss red and amber cases at our monthly practice meeting and discuss any who need to be changed to a different level." (P4, BCUHB)

"Our awareness of the need for ACPs increased and our readiness to discuss and we've demonstrated that we've been doing these earlier / in advance vs 6/12 ago. Handover to OOH has improved, as well as DNACPR documentation." (P46, SBUHB)

"We are identifying on a monthly search all new cancers and sending a gentle letter asking the patient to contact us to book an appointment (at present due to COVID-19 mostly we are dealing via a telephone consultation), we then do a cancer care review. We include these patients in our Palliative Care meetings and if we feel they should be anticipatory record as such on their notes we also discuss any follow ups needed and allocate a GP to do this and put on their appointment screen to remind them." (P23, SBUHB)

"During the covid-19 pandemic we have had consultations with lots of frail and vulnerable patients and we have been more mindful of the prognostic indicators and asking ourselves the surprise question." (P74, CAVUHB)

"As stated earlier in comments we have recognized that via coders/ MDT and administration from Palliative Care Meetings we are good at grading and coding. However, the GPs during their consultation despite tabs/ guidelines and help tools this is still not being undertaken. We have identified a GP who will review the whole list to get a validation position as at the 31st January 2021 so that we can go from there with the systems we have put in place. We are developing a suite of reports to try and identify patients who are not on the palliative care register and should be and these patients could be regularly reviewed. We feel that this should be weekly in the first instance to provide effective management of care in the last stages of life." (P72, HDUHB)

"Staff and especially clinician involvement has really improved palliative care list and input for these patients." (P67, BCUHB)

"There has been marginal improvement in the snapshot of the last 10 practice deaths in terms of the number on the palliative care register and those that could/ should have been included. The shift in emphasis from end of life care planning to advance care planning on the patient record guideline will hopefully prompt and earlier consideration of adding to the palliative care register... This process has provided an opportunity to improve communication between doctors, district nurses and the palliative care team." (P58, HDUHB)

"By using the new palliative care guideline, it will hopefully prompt us to read code the patients appropriately in order to ensure they don't slip under the radar." (P45, SBUHB)

"On reviewing the notes of the last 10 deaths, 5 of them died as part of acute admissions, 3 died due to frailty and were in nursing homes, 2 of them were on the palliative care list but a further 3 could have been on the register as they were in care

homes and were not added to the palliative register. Although end of life meds, DNAR and ACP were initiated. So, the practice has identified this as a learning need and will try and include more patients on the palliative register. When starting patients on JIC medications or end of life medications this will be used as a trigger to be included in the palliative register.” (P16, CTMUHB)

Challenges and opportunities

Participants highlighted significant challenges that GP practices faced as a result of the Covid-19 pandemic including an increase in sudden deaths, rapid deterioration of patients and the temporary suspension of palliative care meetings, which delayed or prevented improvement actions from being implemented.

“Current Covid 19 pandemic means that most of the last 10 deaths were due to Covid rather than terminal illness. This has resulted in more unexpected deaths than would normally be expected. Also due to suspension of palliative care meetings and temporary palliative care nurse replacements reporting and updating of our palliative care register may not be up to date.” (P14, ABUHB)

“I think we still have some work to go in terms of considering frail, elderly patients for inclusion on the register. The increased pressures on the service as a result of Covid has meant that we have not done as much in terms of identifying patients for inclusion on the register and initiating conversions about future care as we would have liked.” (P74, CAVUHB)

“It was identified following latest searches that patients are not always being coded correctly and appropriately. The CCR nurse has highlighted some of these during her reviews with patients. In addition, those patients who have been identified have not been coded palliative care however were coded cancer diagnosis.” (P69, PTHB)

“Palliative care meetings have not been happening recently, as they would have normally been due to the Covid 19 crisis. Once palliative care meetings are up and running again properly, that will allow us to have time to re-focus on ensuring the register is up to date and regular palliative care discussions and reviews are occurring.” (P30, CAVUHB)

Other participants expressed that the pandemic was an enabler for change. Some participants acknowledged the importance of palliative care and advance care planning discussions while others felt that the pandemic shone the light on palliative care and advance care planning which facilitated some GP practices with patient discussions.

“Again, working during the pandemic brought about much discussion about palliation in the community and managing the elderly/frail/chronic diseases as well as cancer patients outside of the hospital. As secondary care and the hospice became busy with COVID cases and it was even more important to assist people (and their families) in their final days to have a 'good death'.” (P46, SBUHB)

“There is still some work to do. We have been looking at ACPs as a practice, especially in the Covid situation, which has made it easier in some respects to have the discussion.” (P56, CAVUHB)

Improving palliative care meetings

Improvement plans

This module asked GP practices to review Macmillan’s Top Tips to supportive and palliative care meetings and to document actions to improve their palliative care meetings. Many practices highlighted several areas for improvement and the following main themes emerged: ‘Needs based coding’, ‘Wider team involvement’, and ‘Learning opportunities’.

Theme 1: Needs based coding

Several practices described how they planned to use colour coding categories (e.g., Traffic Light System or RAG – Red Amber Green) to prioritise patients for discussion during palliative care meetings. Patients coded as ‘green’ on the palliative care register have a prognosis of six to twelve months while ‘amber’ patients have a prognosis of weeks and ‘red’ patients have a prognosis of days.

“We have decided that we are going to have a colour coded scheme on our palliative care list, so that those who are only on green are acknowledged as being on the palliative care register, but they might not necessarily be discussed at every meeting if there is no indication. This will encourage us to put more patients on the palliative care list and to broaden our criteria slightly.” (P30, CAVUHB)

“Action plan: improve identification and inclusion on palliative care register (as previously discussed), adopt RAG approach - discuss only red and amber...” (P58, HDUHB)

“Use colour coding and see how dividing meeting by colour goes next time? We are a small practice, so we are able to discuss all patients which makes this easier...” (P67, BCUHB)

“Plan the meeting and use the agenda as a tool, e.g.: Introductions, Red patients (15 mins – include discussion of physical, social, psychological and spiritual dimensions), Amber patients (30 mins) and Green/Blue ‘changing’ patients...” (P71, BCUHB)

Theme 2: Wider team involvement

Several participants identified that they could improve these meetings by ensuring that attendance was more inclusive and included staff such as Palliative care nurses, District nurses, Practice nurses, Cancer Care Review Nurse and administration staff.

“We will invite community staff - District Nurses, palliative care nurses to join our meetings remotely to add in their perspective on housebound or frail patients whom we might not be seeing F2F.” (P46, SBUHB)

“To include the newly allocated CCR nurse.” (P69, PTHB)

“Invite the lead/administrator to ensure GP notes are up to date and accurate, and highlight key areas – especially actions and accountabilities.” (P71, BCUHB)

“Get everyone involved.” (P78, BCUHB)

Theme 3: Learning opportunities

Other GP practices stated that they would conduct Significant Event Analysis or review patient outcomes to identify good practice and areas for improvement.

“We could reflect more on deaths whereby the patients ACP has not been adhered to identify learning needs. These could be identified through the death proforma templates that we complete following all deaths. These could be discussed at the next palliative care meeting.” (P14, ABUHB)

“Discuss all deaths since last meeting - were they on the register - should they have been? Highlight good practice from 'good deaths'. Utilise significant Event Analysis. Patients who died in hospital? Was that preferred place of death? Could it have been prevented?” (P25, CAVUHB)

“After reviewing Macmillan's top tips guide to supportive and palliative care meetings we have decided to discuss recent deaths and highlight what went well and what could have been done better...” (P74, CAVUHB)

After the Toolkit

Evidence of positive changes made by GP practices to improve palliative care meetings included:

- Increased use of needs-based coding system (e.g., Traffic light system)
- Wider team involvement in palliative care meetings
- Improved internal and external communication
- Improved documentation

“The move to use the RAG system of patient prioritisation has allowed us to move meetings from bimonthly to monthly, having shorter more focused meetings. Including death reviews at the end of the meeting will also highlighted good practice, and instances where things could have been done better or differently. During our most recent palliative care meeting, we discussed ways of increasing cooperation between primary care and the specialist palliative care team, drawing on the strengths of each discipline. By its very nature the palliative meeting is a prompt for participants to consider possible palliative care patients on their caseloads, and this will trigger ACP discussions and communication across the team.” (P58, HDUHB)

“We have started having monthly palliative care meetings and triaged patients as per Macmillan traffic light system.” (P78, BCUHB)

"We are now, however, having weekly Community Resource Team meetings and patients on Red in GSF and some of those who are amber are discussed at this (DNs, OTs, social workers, GPs etc. present). These are arguably much more useful." (P4, BCUHB)

"CCR nurse now attends these meetings too. This is of benefit as some patient have only been initially seen by the nurse and not the doctor after diagnosis." (P69, PTHB)

"We have tried to amalgamate palliative care nursing information onto our vision template after palliative care meetings to ensure patient records have all relevant information. This information is also shared with out of hours." (P14, ABUHB)

"Current system works well. As above implemented some changes with regard to ACP and communication with wider team as a whole has improved efficiency." (P2, ABUHB)

"We have set a guideline (template) up on the system so all data can be easily recorded at a click of a button and we can free text any other info if needed we have discussed this in both Palliative meetings and Practice meetings." (P23, SBUHB)

"This has further helped us formalise our discussions. Adding of codes has been useful." (P67, BCUHB)

Challenges identified

While several practices were able to implement planned improvements, many participants acknowledged the impact of the Covid-19 pandemic. Some participants stated that palliative care meetings were temporarily suspended while others expressed that whilst meetings went ahead, it was difficult to get staff to attend the virtual meetings.

"Due to COVID, meetings were all delayed and only one meeting was conducted." (P16, CTMUHB)

"No meetings held as yet due to poor availability of clinical staff due to capacity issues." (P30, CAVUHB)

"Palliative care meetings have all been held virtually during Covid. This has worked but attendance is poorer than when we had face to face meetings." (P43, PTHB)

"The impact of the Covid pandemic has disrupted the normal working of the practice, but we have tried to conduct our meetings remotely. The drive to include more non cancer diagnoses on our palliative care register will be an ongoing process." (P58, HDUHB)

"The last 6 months have been dominated by the covid-19 pandemic. No palliative care meetings have taken place and the register has not been maintained. This is something we will be addressing in the New Year." (P72, HDUHB)

“The Covid-19 pandemic has really impacted on our ability to hold monthly palliative care meetings. There have been changes in rotas and staff in the community palliative care team and it has been quite difficult to organise a formal virtual palliative care meeting.” (P74, CAVUHB)

Improving ACP discussions with patients

Before the Toolkit

Theme 1: ACP triggers

Many participants highlighted various triggers that would result in ACP discussion with patients. Some described how clinical knowledge and expertise would be used during consultations and home visits to assess if a patient was deteriorating. The outcome of the assessment would then prompt placement on the palliative care register (where appropriate).

“Currently discussions about ACP tend to happen when a GP is seeing a patient who is thought to be in the last few weeks of life and the discussion has been triggered by a clinical decline. Community palliative care nurses tend to have these discussions a lot earlier.” (P74, CAVUHB)

“ACP usually done either when mentioned by patient/family or when condition deteriorates and is recognised as life limiting as part of an overall assessment. Identify at cancer care reviews if ACP is needed and relay to relevant clinician to discuss.” (P72, HDUHB)

“This is determined by the clinicians’ clinical judgement and knowledge of the patient based on frequency of visits, general deterioration, recent hospital admissions and relationship with the patient and their families. With liaison with our palliative care nurse we feel that our discussions occur in an appropriate timely fashion.” (P14, ABUHB)

“As clinicians we initiate discussion at home visits or clinical consultations as appropriate. ACP discussions are done by our lead GP for nursing home patients at admission.” (P45, SBUHB)

“...following discharge from hospital if unwell or reaching terminal phase or following clinic review where treatment completed or deemed palliative.” (P46, SBUHB)

“Depending on the specific patient scenario, possible ACP discussions can be initiated at: Medication reviews, home visits for unrelated matter, post-discharge from hospital/ acute event or move to a nursing/residential care setting.” (P39, CAVUHB)

Another trigger for some practices was placement on the palliative care register, which would then prompt a consultation to discuss ACP with the patient.

“Most of the time ACP is initiated when patient is placed on the palliative register and deemed appropriate.” (P16, CTMUHB)

“When patients are added to the palliative care register and discussed at the meeting it prompts us to discuss their ACP.” (P78, BCUHB)

Theme 2: Use of patient information

“If not ready to discuss, the practice has ACP packs which include: 5 things to do before I die, One last thing, Planning for your future care and The Practice of Health After Death Information Leaflet for patient relatives.” (P27, CAVUHB)

“We find an informal approach has always worked best - it can be introduced gently, although the pandemic has forced our hand a bit more and raised awareness in the public domain. The Respect pages on the Resus council's website has been a useful link and patients are guided to this prior to their holistic review. We will continue to use this approach.” (P40, ABUHB)

“We raised patient awareness of the importance of advanced care planning through practice information displays and campaigns on Dying Matters every six months and many patients, especially those with early dementia value the opportunity to have information. This prompts patients to discuss these issues with the loved ones and also, with healthcare professionals.” (P43, PTHB)

Improvement plans

This module enabled practices to identify key areas to improve ACP discussions with patients including:

- Arranging ACP training for staff members
- Increasing staff and patient awareness of ACP
- Increasing use of patient information ACP leaflets
- Establishing a more proactive approach
- Improving ACP documentation
- Recognition that a cancer care review is an ACP opportunity (where appropriate)
- Improving ACP initiation for non-cancer patients

“In order to improve ACP in our practice we would like to undergo some training either through Macmillan learn zone or through the health boards Macmillan ACP nurses. We would like to extend this training to our local nursing home if they have not received training recently. We would like to have more patient information on ACP visible in the surgery to prompt patients to think about it. We have considered using the surprise question at chronic disease reviews to prompt us to think about future care planning.” (P74, CAVUHB)

“Clinician awareness, prompting by other team members. Practice use of leaflets to open conversation. Need to source more leaflets - email sent.” (P67, BCUHB)

“Action plan: 1. recognition and identification of patients - this will follow on from inclusion on the palliative care register, but may also include patients who may approach us directly without being identified as having a terminal condition. 2. Act to discuss, record and share an advanced care plan. This may be done concurrently with

the DNACPR form, but not necessarily. Discussions may be held over a period of time, and involve more than one professional. Use the resources highlighted. Consider using the Macmillan document "preferred priorities of care". 3. Put ACP code on a guideline." (P58, HDUHB)

"Discuss at clinical meetings to think about ACP decisions. I will arrange training for the healthcare team for ACP in our practice CPET session." (P56, CAVUHB)

"Since our discussions we have become a lot more aware of getting ACPs done, and in formalising this process, we are ensuring that all the appropriate discussions are being had in a timely manner." (P30, CAVUHB)

"Need to ensure when a patient is added to the palliative register a review with the patient is arranged to discuss ACP." (P34, BCUHB)

"We think that it would be appropriate to initiate the ACP in Cancer Care Reviews. Palliative Care Reviews and take the opportunities when visiting Nursing and Care homes." (P23, SBUHB)

"We have identified that our non-cancer palliative patients need to be identified and ACP should be discussed and referral to palliative care considered earlier." (P14, ABUHB)

After the Toolkit

Evidence of positive changes made by GP practices to improve ACP discussions with patients included:

- Established formal process to initiate ACP discussions earlier
- Improved ACP documentation
- Increased access to patient information leaflets
- Incorporation of ACP into templates already used by practices (e.g., CCR and palliative care template)

"More awareness throughout the team and at routine palliative visits are exploring and documenting ACP. Also working with St David's to have ACP scanned to patients' notes if done by third parties." (P2, ABUHB)

"We now have a leaflet stand with various Macmillan leaflets on ACP etc. We have been ensuring that discussions are raised earlier." (P4, BCUHB)

"We have improved our palliative care template to include ACP discussions. We are proactively using the ACP forms already in nursing/ care homes." (P14, ABUHB)

"We have identified that we are still not doing as many ACPs as we had hoped too but we have got an ANP who does the nursing home ward rounds and have started ACP in all the patients. We are also starting to initiate the conversations with patients with long-term chronic diseases and hope to improve this process. Sometimes we have initiated the conversation but not documented." (P16, CTMUHB)

"We have incorporated ACP discussion in the cancer care review, and it is also in our clinician's template. We also discuss the outcomes and the necessity in our Palliative Care meetings." (P23, SBUHB)

"Since using the toolkit, as a practice we have now adopted the ACP proforma on Vision. We have therefore greatly improved our practice in terms of ensuring these discussions are held in a timely manner." (P30, CAVUHB)

"We're much better at having the discussions and documenting plans but less good at coding it as an ACP. We rarely complete an official ACP form but that's because they don't seem to be easily accessible/available. We've now found some proformas on the intranet." (P40, ABUHB)

"By having aide memoir reminders on the new palliative care guideline with easy access to download the ACP documents we hope to be more proactive in discussing these with patients." (P45, SBUHB)

"The inclusion of a tab labelled advance care plan on the practice guideline should prompt both discussion and recording of this subject. Despite having a tab labelled Advance care plan - a search has revealed that this has not been coded in the last 2 months. I have discussed this in the practice meeting with GPs and registrars, and will change its position to a more prominent position within the advance care plan guideline." (P58, HDUHB)

"The Cancer Care review nurse now carries out ACP discussions as well as GPs involved. Relationships are built and patients have trust and confidence in the CCR nurse and feel this easier to discuss sensitive matters on future plans e.g., place of death." (P69, PTHB)

"Our MDT discussion continue in the same way, though issues of GP coding recorded discussion which are in the notes remains poor." (P72, HDUHB)

"We restarted our palliative care meetings along the guidelines from Macmillan and have them more regularly (monthly) and have triaged them according to changing/progression of disease." (P78, BCUHB)

"As a practice we have undertaken some ACP training. Some of our staff attended a webinar Series run by Cardiff University on ACP. I notified our local care homes about the upcoming webinar series that had a session specifically targeted to support care home staff with end-of-life care. This included information on ACP and some access to local education and training opportunities. When talking to palliative patients we ensure that we have asked where that person wishes to be cared for and if there was anything they really didn't want to happen so that we can clearly document these decisions as a priority 1." (P74, CAVUHB)

Challenges and opportunities

Participants highlighted several challenges that hindered their ability to implement planned improvements to improve early discussion of ACP with patients including:

- Lack of time to initiate conversations appropriately and sensitively
- Covid-19 pandemic prevented face-to-face conversations which some felt was important in order to engage effectively with the patient
- Patient and clinician willingness to engage in a discussion regarding ACP

“Factors which have hindered improvements are suspension of palliative care meetings due to Covid and temporary palliative care nurse cover.” (P14, ABUHB)

“Patients are not always ready for Palliative care discussions, even when widespread disease and prognosis months. 3 patients were reviewed, and this was a consistent theme, patient factor, yet DNACPR was in place for 1 of them.” (P27, CAVUHB)

“No changes currently made due to lack of capacity within the practice to enable proactive ACP discussions. This is a problem because timely ACP discussions can be time saving in the future.” (P34, BCUHB)

“COVID has hindered us due to not being able to visit face to face and therefore have been unable to engage.” (P35, SBUHB)

“Due to the COVID19 pandemic, the timely conversations with patients have been restricted (especially as these chats should be face-to-face ideally).” (P39, CAVUHB)

“Formulating ACPs are time consuming however, especially if the GP needs to speak to numerous relatives who don't agree. We've allocated doctors to our nursing homes so that the residents get continuity of care.” (P40, ABUHB)

“Minimal changes to current practice. As a practice and as individual clinicians we didn't find the ACP discussions appropriate to the practice working.” (P71, BCUHB)

“ACP discussions are held more often with patients; we have learned that patients often don't mind being asked questions in a kind and sensitive way. Hindering is still our willingness to have these discussions more often.” (P56, CAVUHB)

Other participants acknowledged that they were in contact with patients more frequently and patients were more willing to engage in ACP discussions because of Covid-19.

“Having more difficult conversations over the phone, broaching ACPs with families and patients were certainly more challenging done remotely, but most families were responsive to support information in the community when services stretched and under strain. Lots more anticipatory care discussed within last 6 months, has been in best interest of patients and helpful for whole staff training.” (P46, SBUHB)

“It has been made more difficult in some ways, but easier in others, to do this given the Covid restrictions. We are having less contact with some patients, but those who we do have contact with are more willing to discuss EOL, on the whole.” (P67, BCUHB)

Improving ACP documentation

Just under half (46.2%, n=12) of GP practices indicated use of the code #9e2.00 (OOH service). GP practices that did not use this code provided several reasons why such as:

- Use of different code – #9e0 (OOH notified)
- Clinicians unaware of #9e2 code
- Use of free text to capture information in patient's notes instead
- Notification through online system (e.g., Aadastra)

Participants were also asked to review the last five patients on their palliative care register in order to determine if key information were coded. Generally, GP practices reported in improvements in the coding of key information as a result of completing this module (Figure 12).

- The proportion of records indicating an ACP was in place increased from 51.8% (n=57/110) to 67.0% (n=75/112) after the Toolkit (**increase of 15.2%**)
- The proportion of records indicating a DNACPR was in place increased from 79.1% (n=87, 110) to 90.9% (n=100/110) after the Toolkit (**increase of 11.8%**)
- The proportion of records containing evidence that key information was shared with OOHs increased from 60.6% (n=63/104) to 75.0% (n=81/108) after the Toolkit (**increase of 14.4%**)
- The proportion of records with evidence of anticipatory medication being prescribed increased from 69.1% (n=76/110) to 79.5% (n=89/112) after the Toolkit (**increase of 10.4%**)
- The proportion of records with preferred place of death documented increased from 63.6% (n=68/107) to 77.5% (n=86/112) after the Toolkit (**increase of 13.9%**)
- The proportion of records that indicated patients achieved their preferred place of death increased from 79.7% (n=63/79) to 86.0% (n=86/100) after the Toolkit (**increase of 6.3%**)
- The proportion of records that had next of kin contact information documented increased slightly from 79.0% (n=83/105) to 81.1% (n=90/111) after the Toolkit (**increase of 2.1%**)

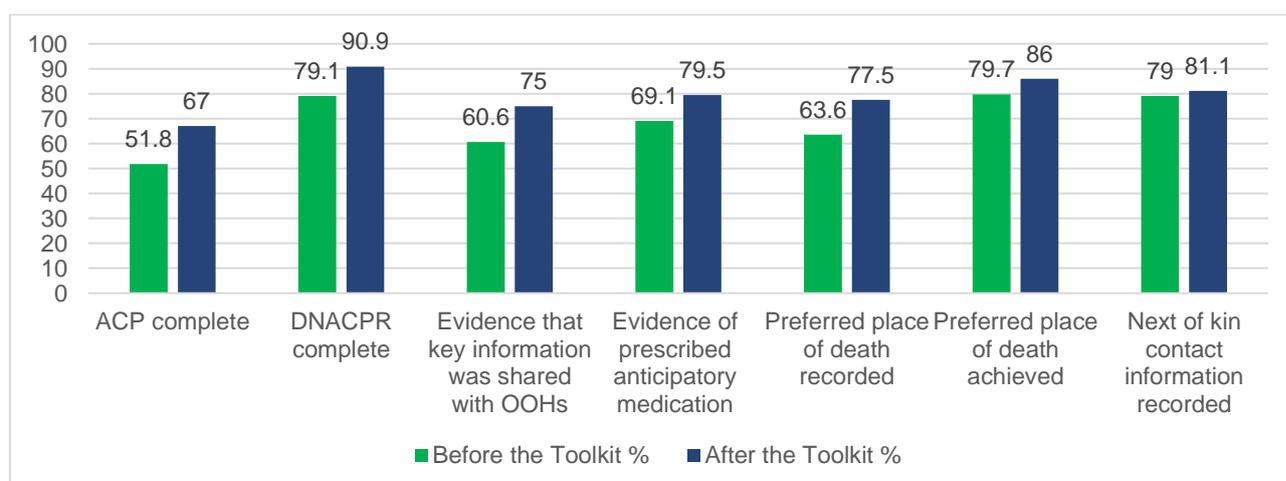


Figure 12. Coding of key ACP information

Improvement plans

In addition to examining patient records, GP practices reviewed educational material that prompted changes to coding practice and the documentation of ACP information. Improvement actions were themed into the following categories: *'Improving coding practice'*, *'Updating OOH system directly'* and *'Use of ACP templates'*.

Theme 1: Improving coding practice

Many practices identified that they could improve the consistency and accuracy of ACP documentation. Some participants identified that this could be improved by increasing awareness of the correct codes amongst practice staff using guidelines and key documents.

"Document/code ACP decisions on notes." (P2, ABUHB)

"Continue to update Adastra [OOH IT system] and ask staff member to code on EMIS." (P4, BCUHB)

"We need to ensure that the information is coded on the practice system correctly to facilitate audit." (P43, PTHB)

"Ensure consistency of coding of ACP - to be entered by doctor or nurse having the discussion." (P58, HDUHB)

"Code ACP as a priority 1 and code when information has been shared with other members of the community team." (P74, CAVUHB)

Theme 2: Updating OOH (Adastra) system directly

Other participants identified that improvements could be made to the way they share information with OOHs by ensuring staff update Adastra directly.

"We will put the ACP form as a template easily accessible from patient electronic records the patient will also have a copy and we will share with Out of Hours via Adastra." (P23, SBUHB)

"GP access to update other computer systems (i.e., OOH)." (P39, CAVUHB)

"Look at how ACP information is shared and accessed by OOH (integration into IHR or special notes/ scanned document)." (P58, HDUHB)

"Admin team to update record in Adastra when DNAR form completed or ACP discussed." (P78, BCUHB)

Theme 3: Use of ACP templates

Several practices discussed using available ACP forms or creating their template to support improvements to the documentation of ACP information.

"ACP discussions could be documented on an all-Wales ACP form which could be sent to GPs, OOH, DNs and community palliative care teams. Use standardised ACP forms to record discussions." (P74, CAVUHB)

“Create an advanced care template within clinical guidelines with pre-defined fields.” (P58, HDUHB)

“Consider using an ACP (embedded) so that this can be accessed from patient record to allow all clinical colleagues to familiarise themselves with patient's preferences/needs.” (P46, SBUHB)

“We will put the ACP form as a template easily accessible from the patient electronic records. The patient will also have a copy.” (P45, SBUHB)

“We discussed how we could better document this using the appropriate ACP form and this has since been added to our communal library on Docman.” (P30, CAVUHB)

After the Toolkit

Evidence of positive changes made by GP practices to improve the documentation of ACP information:

- Increased recognition for the importance of documenting ACP information amongst staff
- Improved process for sharing information with OOH
- Improved documentation of ACP information including next of kin details, DNACPR, preferred place of death and prescribing anticipatory medication

“More awareness and communication between the wider team and teams in the community has meant more effective documentation/ active planning.” (P2, ABUHB)

“Great improvement in having ACP discussions earlier. The only one with no preferred place of death had been admitted as an emergency and had previously been unable to decide. Covid19 has hindered anticipatory drug prescribing but in all these cases they were in place when needed. We now have more logins for Adastra enabling it to always be updated regardless of staff being on holiday etc.” (P4, BCUHB)

“We have improved on completing DNA forms and of ensuring anticipatory meds are in place. We have also improved our documentation of contact details of NOK. We still need to improve our information sharing with OOH. Completing the toolkit and using the ACP proforma has helped with these.” (P30, CAVUHB)

“There is better recording of DNACPR, preferred place of death, prescribing anticipatory medication and informing the out of hours service.” (P34, BCUHB)

“Protocol for dealing with DNACPR amended to include adding Read code #9e2 when sending DNACPR to OOH.” (P39, CAVUHB)

“During Covid we have been much more consistent in recording contact details of relatives/ friends for frail and vulnerable patients. We have also updated DNACPR forms and an escalation plan for all care home patients and have discussed more of them in palliative care meetings. Contact details for family have been added as alerts so that they are instantly available.” (P43, PTHB)

“Timing from ACP discussion to death does not seem drastically different but our documentation of important documents/ discussions and handovers has vastly improved. Likely as we’ve navigated many more palliative cases in the community, and supported people in their preference to die at home during the pandemic were dying in hospital in isolation was not in people’s best interests.” (P46, SBUHB)

“Two out of 5 patients had an ACP in place originally on question 17. Post 6 month review now show all 5 patients had ACP in place. This is highlighting that the CCR nursing role is affective within our practice. This indicates small improvements. GPs are more aware of having these discussions also now since carrying out this toolkit with Macmillan.” (P69, PTHB)

Challenges identified

Some practices highlighted challenges that prevented participants from implementing planned improvements. Participants described how the pandemic changed practice priorities, reduced capacity (e.g., lack of time) and the difficulties of improving inconsistent coding practice amongst team members.

“Our priorities this year have been somewhat diverted to dealing with Covid so that may have impacted our ability to improve some things, but it seems that our patients are generally getting very good care despite the limitations that we have encountered this year.” (P30, BCUHB)

“Lack of time tends to be an issue in making clinicians reluctant to start ACP discussions and if they clinician does not know the patient. There is a perception that everything needs to be discussed at once too. No palliative care meetings are being held in the Practice at present due to a lack of time, however when held in the past they have been found to encourage clinicians to share information and initiate ACP discussions with patients.” (P34, BCUHB)

“Covid 19 has been a major upheaval in distinguishing palliative care due to Covid rather than any other diagnosis.” (P37, HDUHB)

“Still not recording QOF code. We need to improve our coding as I think these discussions are taking place by the palliative care nurses, but they are not documented in the notes. We need to address this in our palliative care meeting.” (P78, BCUHB)

MODULE 5 SUMMARY

As a result of undertaking and completing this module some GP practices (n=26) have:

- Self-reported improvements in how well they:
 - Support patients when cancer becomes incurable but is still treatable
- Increased use of the Macmillan Palliative Care Template (from 7.69% to 34.6%)
- Improved processes for identifying patients for the palliative care register by
 - Using the Traffic Light system to structure palliative care register
 - Improving the documentation and communication of key information between sectors

- Increasing awareness of prognostic indicators amongst practice staff
- Made positive changes to palliative care meetings including
 - Increased use of needs-based coding system (e.g., Traffic light system)
 - Wider team involvement
 - Better internal and external communication (e.g., OOHs)
 - Improved documentation
- Enhanced ACP discussions with patients by
 - Establishing a formal process to initiate ACP discussions earlier
 - Increasing access to patient information leaflets within the practice
 - Incorporating ACP into templates already used by practices (e.g., CCR and palliative care template)
- Improved documentation of ACP information by
 - Increasing awareness of the importance of documenting ACP information
 - Establishing a formal process for sharing information with OOH
- Identified several challenges that hindered practice change including:
 - Coronavirus pandemic – sudden deaths, rapid deterioration of patients, completing ACP discussions over the phone instead of face-to-face and the suspension of palliative care meetings
 - Patient and clinician willingness to engage in ACP discussions
 - Competing priorities and lack of time to appropriately initiate ACP with patients

Conclusions and recommendations

Conclusions

Despite the pandemic and pressures in primary care, 53 practices participated and over 650 primary care staff engaged with the Toolkit. Overall, the evaluation findings demonstrate that a cancer quality Toolkit facilitated practices with reviewing and improving services that diagnose, care for and support their patients living with cancer.

The findings suggest that the Toolkit resulted in a significant amount of change for many GP practices including:

- Increased cancer knowledge
- Increased awareness and use of cancer specific tools and resources
- Improvements in clinical coding
- Improved access to information to support their patients living with cancer
- A shift in mentality from cancer care being an individual clinician responsibility to a whole team-based affair
- Implementation of new or improved processes, which led to more proactive cancer patient care.

The findings also shed light on how participating GP practices viewed and interacted with the Toolkit. Overall, most participants believed that the Toolkit facilitated quality improvement within the practice and was deemed a useful information resource. The process of reflection on cancer care processes and approaches led to discussion, new learning and wider team involvement. Specific elements and activities that were deemed most useful within the Toolkit included:

- The ready-made structure to review and improve systems and processes
- Team and cluster collaboration and learning
- A '*one stop shop*' of useful information and resources
- Audit and feedback exercises utilising the practices' own data.

While the Toolkit was viewed highly, many participants felt that the time required for running searches and completing activities (e.g., action planning and reflections) was burdensome for staff. Analysis of the post-survey identified that the top three factors, which hindered Toolkit completion, were staff time to undertake quality improvement, competing priorities within the practice and staff numbers to undertake quality improvement.

In terms of practice action plans and improvements, regardless of the module completed, several factors either hindered, delayed or halted GP practices from implementing changes.

Coronavirus pandemic

Participating GP practices experienced increased demands and significant changes to the way services and care were offered to patients, which had an impact on their ability to implement planned changes, including the suspension of the Bowel Screening Programmes from March 23 to July 1, 2020, increased telephone consultations and involvement in the rollout of Covid-19 Vaccination Programme.

Inconsistent coding practice

Across all modules, coding practice varied between and within GP practices. The searches relied on all clinicians within a practice being aware of and using the appropriate codes recommended in the Toolkit. Participants had trouble in changing individual clinicians' choice of code and encouraging clinicians to take the time to code key information (e.g., CCR completed).

Availability of resources

Lack of resources to implement action plans and new processes was a significant barrier for GP practices. Participants faced staffing issues such as vacancies, turnover and competing priorities, which meant that 'normal' GP practice activities took precedence over participation in the Toolkit. In addition, human (e.g., staff time) and financial implications of needed changes had an impact on the implementation and sustainability of action plans.

Attitudes to change

Many participants described difficulties with engaging other colleagues to participate in the Toolkit, in securing buy-in from colleagues for needed changes and harnessing commitment to the planned actions.

In addition, the tool for collecting and documenting information (i.e., Interactive PDF) was troublesome for some. Reported issues included difficulties in entering data, saving the data and navigating the lengthy document made it difficult to complete the Toolkit within the suggested time frame of six months. The length of the document also meant that some were overwhelmed with new information and tools, which meant that the information and actions were not easily digested by GP practices. GP practices identified several adjustments or additional features that they felt would enhance the Toolkit's usability and acceptability including changes to the layout and length of the document. Others suggested that the Toolkit could be enhanced by including different learning formats such as e-modules and videos.

The second objective of the Toolkit was to create a framework of peer support to facilitate primary care teams to provide seamlessly coordinated care and high-quality patient experiences. To facilitate this, participating GP practices were encouraged to involve their whole primary care team, including clinical and non-clinical staff, in the Toolkit and to share learning with colleagues in their cluster. The findings suggest that while GP practices were successful in involving various clinical and non-clinical roles, just under half (57.7%, n=22) of practices stated that it was easy to involve their whole team. While practices were encouraged to engage with other GP practices in their local cluster, no resources were provided to do this, and just 26.4% (n=14/53) indicated that they shared learning with colleagues in their cluster.

The final objective of the Toolkit was to provide a current picture of cancer care provision in primary care to inform future developments in Wales. At the start of the Toolkit, participants provided insight into their current approaches and processes in key areas, however due to the small sample size, caution is needed when interpreting these conclusions.

Module 1 – Detecting cancer earlier

- Awareness of local rates (cluster and health board) for all cancer screening programmes was low amongst participating GP practices

- GP practices engaged in multiple activities to promote health and wellbeing by exploiting key opportunities when patients attend the surgery such as vaccination clinics, cervical screening, blood pressure checks and chronic disease clinics
- GP practices recognised the importance of promoting the link between lifestyle and cancer risk, however, they also acknowledged the challenge of raising this information in a sensitive way with patients
- Most GP practices had an agreed approach for identifying non-responders to Bowel Screening but less than half had an established process for contacting these patients to encourage uptake
- Participating GP practices described the use of mainly ad hoc approaches and clinical reminders (e.g., alert box) to encourage clinicians to engage with patients who did not respond to their screening invite, however, some participants had established processes including telephone and letter contact and viewed these positively.

Module 2 – Prompt recognition and early referral

- Less than half of participating GP practices had a system in place for coding USC referrals. Those that did not have a system in place reported that their practice maintained a list/ register of USC referrals which would be maintained and monitored by a secretary/ administration staff
- Few GP practices indicated use of the 'Fast Track Cancer Referral' code (#8HHT) and that this was applied inconsistently within the practice
- Broadly speaking, participating GP practices followed the recommendations within the NICE Suspected Cancer: Recognition and referral on patient support and safety netting, however, while many explicitly state that the referral is for a cancer service, several discussed the difficult balance of providing this information and causing anxiety in their patients
- Many participants actively and opportunistically promoted cancer signs and symptoms to patients during consultations (where relevant), at chronic disease clinics, screening appointments and medication reviews
- Almost all GP practices were aware of at least one of the NICE guideline summaries mentioned in the Toolkit and used at least one of those resources
- Few participating GP practices were aware of and used the Macmillan CDS tool

Module 3 – Support through treatment

- Low awareness and use of the UKONS tool and AOS app amongst participating GP practices
- There was variability across participants for the coding of cancer treatment modalities and key worker. While patient letters contained treatment information, practices were not always coding that information
- Cancer key worker information was not always present in patient letters, and therefore, unlikely to be coded on the patient record
- Half of practices routinely and proactively contacted their patients following a cancer diagnosis (this is different to a cancer care review)
- Only one practice had a system in place to ensure that history of cancer treatment would be highlighted to reception staff receiving a phone call from a cancer patient

- Almost all GP practices indicated they were aware of the need to prioritise patients currently receiving cancer treatment for urgent clinical triage and used alerts or a triage list to flag that an urgent call-back was needed for a cancer patient.

Module 4 – Cancer care reviews and the long-term consequences of cancer and its treatment

- Low awareness and use of the Macmillan Cancer Care Review Template amongst participating GP practices
- Approaches to CCRs varied from practice to practice with some having a formal process for identifying and inviting patients to a CCR (e.g., dedicated CCR appointment) while others relied on an opportunistic approach when patients attended/contacted the surgery for other reasons
- Generally, CCRs were conducted in person or over the phone, however, Covid-19 increased the use of telephone contact due to government guidance and social distancing rules implemented during 2020
- Clinical and non-clinical staff, including administration staff, GPs, Minor illness practitioners, Pharmacists, Nurse practitioners and Practice Nurses contributed to the delivery of CCRs, however, most CCRs were led and completed by GPs
- Delivery of CCR content varied from practice to practice and between staff within the same practice. Many recognised the importance of a patient-led and holistic approach to discussions, however some acknowledged that a holistic approach was not always applied
- Few practices indicated that Practice nurses carry out CCRs. Significant challenges hindered participating GP practices from implementing change due to the lack of CCR training, attitudes around CCRs being a GP led role and the increased demands on Practice nurses to undertake priority responsibilities
- 75 Practice nurses expressed an interest in the Macmillan Cancer Course. This suggests that there is an appetite for cancer education amongst Practice Nurses.

Module 5 – Identifying and supporting people with advanced serious illness

- Limited use of the Macmillan Cancer Care Template by participating GP practices
- Practices varied in their inclusion criteria for the palliative care register with some using it for all patients with a life shortening illness or when a patient who is frail with other comorbidities deteriorates while others only include patients who were in the terminal phase
- For practices with an inclusive approach, the traffic light system was necessary to ensure timely palliative care meetings. Active reflection and full team participation were also essential
- Increased recognition, potentially due to Covid-19, of the importance to initiate early ACP discussions with eligible patients, particularly the non-cancer population
- Coding of key ACP information varied between and within practices due to use of different codes, lack of awareness of codes and use of free text to capture information in the patient record.

Strengths and limitations

A strength of this evaluation was the use of complimentary data (pre- and post-surveys and qualitative reflections) in order to provide in-depth information regarding current practice, improvement plans and outcomes. A further strength was the use of evaluation frameworks to guide the design of the surveys and the overall evaluation plan. This ensured that the content of the Toolkit was assessed appropriately according to the Toolkit objectives.

As with all evaluations, there were several limitations to this project. Eleven months into the launch of the Toolkit, the Coronavirus pandemic resulted in significant changes to working processes within the healthcare system, including within primary care. For many practices, this presented a huge challenge to not only participate in the Toolkit project but to plan and act on the identified areas needing improvement. However, the fact that many participants were able to make positive changes during Covid-19 is a strong indicator of the usability and effectiveness of this Toolkit.

The original evaluation plan specified a sample size of 126 GP practices. While 131 practices initially expressed an interest to participate, difficulties in recruiting and maintaining involvement resulted in a smaller sample size than expected (n=53). Therefore, the findings may not be representative of all GP practices in Wales.

Furthermore, as participants self-selected, they may represent a sub-sample of the population who had a particular interest in cancer care and quality improvement not shared with the target population at large. In addition, to not over burden primary care professionals within participating GP practices, only one clinical member within the team completed the pre- and post- evaluation surveys. It is possible that other members of the team had different experiences and perceptions of the Toolkit.

Data collected on changes in knowledge, awareness and improvements to processes for the provision of cancer care were self-reported. It was not possible to validate this data or to gather information on other variables (e.g., campaigns or educational events) that may have influenced or contributed to practice changes. In addition, the link between practice improvements and patients' outcomes is vital but this was beyond the scope of this project.

Lessons learned

Based on the information gathered in this project and the experiences of the project team the following lessons were identified:

1. MPCCF GP facilitators were utilised to promote the Toolkit and engage with colleagues in local health boards including educational events, LMC meetings and email. This approach was vital to ensure buy-in at the local level and to maintain involvement throughout the project. It is essential that future projects engage with local GP clusters before rolling out similar QI projects.
2. The MPCCF programme team structure, which included local GP leads, GP facilitators, nurse leads and support staff (project management, project support, communication officer and an evaluation officer) to design, implement and evaluate the Toolkit were vital to the success of this project. The diverse skill mix ensured the 'day-to-day' running of the project moved forward at pace and any issues (e.g., challenges faced by

participating GP practices) were dealt with in a timely manner. Future projects should ensure that adequate resources are planned for in order to design, implement and evaluate national projects like the Toolkit.

3. Multiple support processes were set-up from the outset which included one-to-one support via email and telephone from local Health Board GP facilitators and dedicated support through a Toolkit 'Help' Email covered by a project support officer, communications officer and an evaluation officer. This ensured that queries were promptly dealt with. Future projects should ensure that multiple avenues for support are established to maintain engagement with participants and encourage completion.
4. The MPCCF programme team and Macmillan Cancer Support ensured that monitoring and evaluation were considered from the outset of the project. This, combined with an adaptive management approach which addressed issues as they arose, were imperative to achieve the outcomes of this project. Future projects should consider evaluation from the outset of the project design.
5. Several editorial groups were held to design the Toolkit based on previous pieces of work published by Scotland and England. Several areas needing improvement were agreed, however, participating GP practices felt that some of the modules were difficult to complete and the amount of information contained within the Toolkit was overwhelming. Module 4 focused entirely on one topic and the layout was structured around current practice, action plan and reflections on practice changes. Future QI initiatives should adopt a simple structure, which would lead to high quality data and higher participant satisfaction.
6. The MCQT project utilised a collaborative approach to develop the Toolkit with representation from MPCCF Health Board GPs, End-of-Life GP Facilitators, MPCCF regional nurses and Macmillan Cancer Support Programme and Project managers. Whilst the collaborative approach was essential for the project, this led to long and repetitive debates about the content of the Toolkit. This resulted in limited time to adequately test the Toolkit before the national launch across Wales. Future projects need to secure a shared vision (e.g., aims and outcomes) between all stakeholders from the outset to ensure adequate time is available to develop and test the tool.
7. During the planning and testing phases, the MCQT engaged with several stakeholders, however, upon reflection, most of the clinicians involved had an interest in cancer and/or quality improvement. To improve the acceptance and success of the Toolkit, intended users, particularly those without an interest in cancer, should be included in the design and testing phases.

Recommendations

Based on the findings and conclusions of this project the following actions are recommended:

1. Macmillan Cancer Support and the WCN should revise the Macmillan Cancer Quality Toolkit to increase uptake and facilitate effective QI in cancer care provision across Wales. To address this, the following actions should be considered:
 - a. Adopt a web-based platform to ensure information is updated, saved and shared instantly between participants and the MCQT project team.
 - b. Condense and re-structure Modules two, three and five to one or two key improvement areas (like the structure of Module four) to reduce confusion,

- information overload and to ensure adoption and completion of the Toolkit within busy GP practices.
- c. Incorporate other educational strategies including training events and facilitated workshops to support and embed cancer quality improvement within GP practices across Wales.
 - d. Align the Toolkit topic areas with the Quality Statement for Cancer (Welsh Government 2021) as well as the priorities of the Strategic Programme for Primary Care (SPPC), Public Health Wales Primary Care Division, NHS Collaborative and the WCN. This has the potential to ensure targeted improvements in key priority areas as well as the opportunity to capture timely information on the processes, approaches and challenges within primary care.
 - e. Re-design the roll-out of the MCQT from a one-off activity to a staged approach whereby the QI initiative is broken down into focused topics and smaller stages over several years. This would give practices more time to plan, implement and evaluate which could in turn ensure long-term and sustainable change.
 - f. The Toolkit needs to be adequately resourced in order to encourage participation and completion. To achieve this, dedicated support (e.g., facilitators) needs to be provided with any future roll-out.
 - g. In addition to lesson learnt point 7, a structured assessment of the resources (e.g., staff time) required is needed before any future roll-out of the Toolkit or its equivalent.
 - h. Macmillan Cancer Support and the WCN should engage with a broader range of stakeholders to develop and roll-out future QI initiatives including the SPPC, Public Health Wales Primary Care Division, the Wales Cancer Alliance (WCA) and GP clusters (through the LMCs). This has the potential to ensure inclusion of a broader range of evidenced-based resources and in turn, greater acceptability and usability of a cancer quality Toolkit.
 - i. Macmillan Cancer Support and the WCN should include different learning formats within or alongside the Toolkit such as videos, e-modules and educational events, in order to meet diverse learning needs within primary care.
2. Further research is needed to determine the long-term impact of this educational tool (e.g., sustainable changes) and the effect the Toolkit has on patient outcomes.
 3. Participating GP practices faced significant challenges in undertaking quality improvement, particularly in relation to staff time and competing priorities, GP clusters should work together to share resources, ideas and knowledge when undertaking QI initiatives such as the Toolkit.
 4. The MPCCF programme, Macmillan Cancer Support and the WCN, despite the sample size, should utilise the current practice data contained within the Toolkit to inform the development of future projects and programmes.
 5. With the introduction of the Quality Assurance and Improvement Framework (QAIF) as a contract reform to the GMS contract in Wales 2019/2020 there is an opportunity for Primary Care to incorporate the MCQT to encourage cluster working across Wales.
 6. Macmillan Cancer Support and the WCN should share the good practice (action plans and outcomes) identified within the Toolkits to all GP practices and clusters across Wales.

Appendices

Appendix 1 – Module objectives

Module 1 – Detecting Cancer Earlier

1. Increase your practice's knowledge of preventable risk factors for cancer and how you can promote these to patients.
2. Increase your practice's awareness of Public Health Wales' cancer screening programmes and local uptake rates.
3. Increase your practice's knowledge of the risks and benefits of Public Health Wales' bowel screening programme.
4. Establish a whole practice process that improves the coding of and follow-up with people who do not take up bowel screening after it has been promoted to them.

Module 2 – Prompt Recognition and Early Referral

1. Improve your practice's application of NICE *Suspected cancer: Recognition and referral guidelines* (2017) and increase the awareness and use of summaries to support this.
2. Improve your practice's processes relating to when information is provided to a patient if a clinician suspects cancer and refers them urgently.
3. Improve your practice's coding and safety netting of urgent referrals for suspected cancer.
4. Improve the quality of safety netting advice your practice gives to patients with 'low risk but not no risk symptoms' who may not be referred urgently.
5. Increase your practice's awareness and use of the Macmillan Cancer Decision Support tool.

Module 3 – Support Through Treatment

1. Review and improve your practice's process for contacting people following a diagnosis of cancer.
2. Ensure the consistent coding of cancer diagnoses and treatment.
3. Improve your practice's assessment and management of people who have received cancer treatment.
4. Review and promote effective communication pathways between primary and secondary care when advice is needed during treatment or when problems occur.

Module 4 – Cancer Care Reviews and Long-term Consequences of Cancer and its Treatment

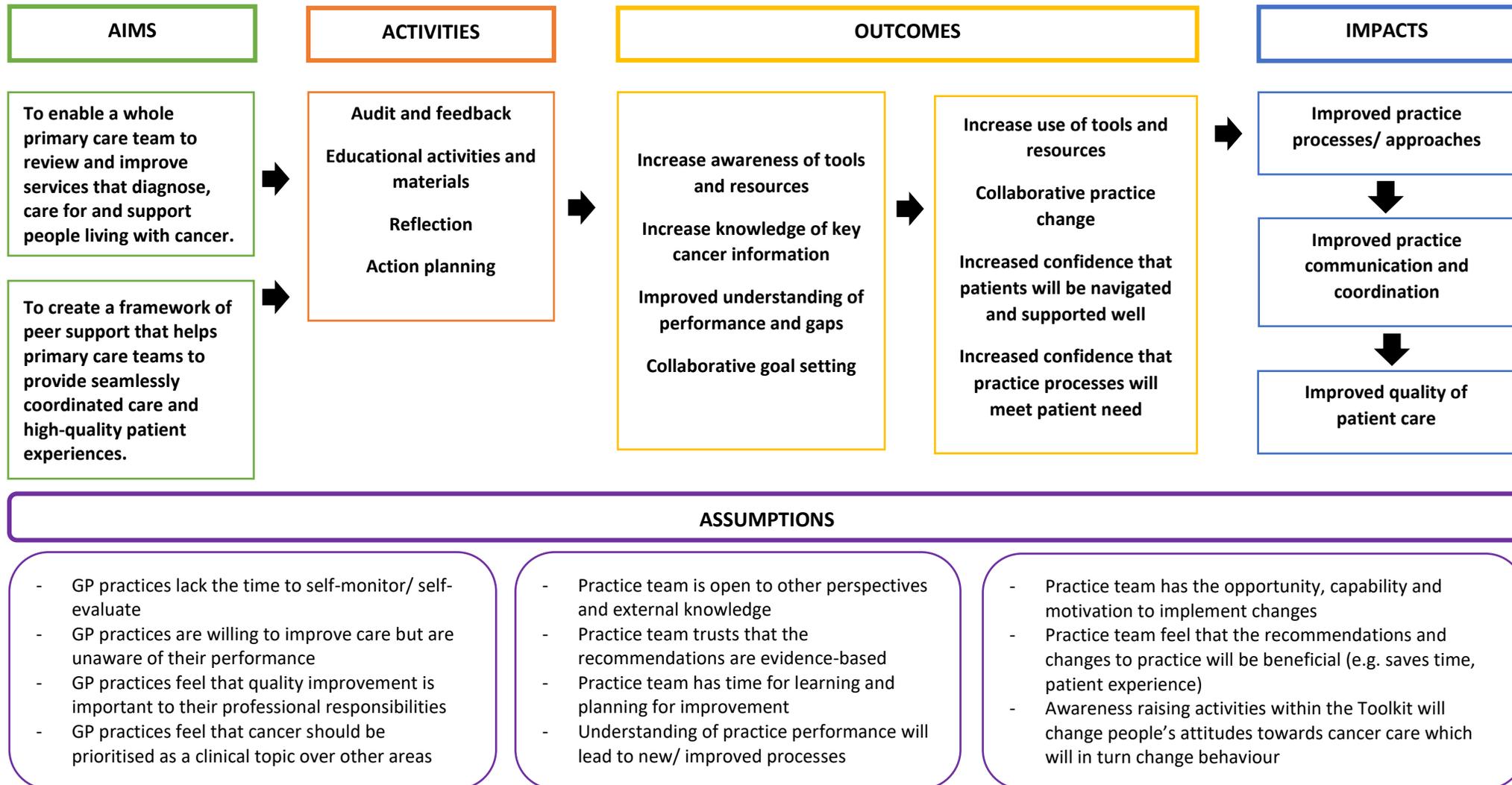
1. Increase your primary care team's knowledge of the holistic needs of people living with cancer and the support they need after treatment.
2. Ensure your practice adopts a structured, holistic approach to cancer care reviews.

3. Promote the role that practice nurses can play in carrying out holistic cancer care reviews and managing the long-term needs of people living with cancer.
4. Increase your practice's knowledge of the long-term consequences of cancer and its treatment.

Module 5 – Identifying and Supporting People with Advanced Serious Illness

1. Ensure your practice identifies at an early stage people who should be included on your practice's palliative care register.
2. Review and improve your practice's approach to palliative care meetings.
3. Promote the importance of offering timely advanced care planning discussions with patients.
4. Improve the recording and sharing of information about patients on the palliative care register.

Appendix 2 – MCQT evaluation framework



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