Evaluation of the Macmillan Integrated Cancer Care Programme

Summary Report of the Evaluation Findings

October 2018

SQW

Our way for cancercare

Cambridge University Hospitals NHS Foundation Trust

MACMILLAN CANCER SUPPORT

The Macmillan Integrated Cancer Care Programme

The Macmillan Integrated Cancer Care Programme (MICCP) at Cambridge University Hospitals Foundation Trust (CUHFT) is funded by Macmillan Cancer Support (Macmillan) and delivered primarily at Addenbrooke's Hospital. The programme began in 2015 and Macmillan funding ends in December 2018. The programme aims to change and improve cancer care by risk stratifying pathways of care for people affected by cancer (PABC) and embedding elements of the Recovery Package within Addenbrooke's – specifically, electronic Holistic Needs Assessments (eHNA) and Care Plans, Treatment Summaries, Exercise Referrals and Health and Wellbeing (HWB) events.

The MICCP has been delivered across four main programme workstreams, specifically: the Patient (Recovery Package and risk stratification); Staff (culture change); Infrastructure; and Integration.

The MICCP evaluation

This study was commissioned to provide an independent formative, summative and economic evaluation of the MICCP, generating context-specific insights and learning to inform future sustainability as well as any potential roll-out and scaling of the programme.

The study involved the design and development of a programme level and three cancer site-specific theory of change (ToC) models; developing an evaluation framework; and capturing primary and secondary data in order to generate key insights. The evaluation ran from May 2017 to June 2018, concurrent with MICCP implementation during this period.

Why integrate cancer care?

The MICCP was a direct response to the rising demand for cancer care and the wider policy context.

Rising demand for cancer care: The population projections for people living in the locality are increasing year on year[1]. Over the past 20 years, the number of registrations for newly diagnosed cases of cancer in England increased by approximately 70%, from 288,000 in 1995 to 490,000 in 2015[2]. Patient numbers within CUHFT continue to increase, with a predicted increase in cancer patients of 7% per year moving forwards. The number of PABC receiving follow up care also continues to grow, with over 8000 patients attending follow up appointments in 2016[3].

The policy context: The NHS Five Year Forward View[4] (2014) identified new models of integrated care, whilst acknowledging that services needed to be designed locally to meet local needs. The national cancer strategy, Achieving World-Class Cancer Outcomes[5] (2015) was published in response to the NHS Five Year Forward View. In 2013 the National Cancer Survivorship Initiative published their report, Living with and Beyond Cancer: taking action to improve outcomes[6]. This report was designed to inform the direction of survivorship work in England until 2015. It provided evidence to encourage

[1] Population Statistics Division, Office for National Statistics (2014)
[2] Cancer Registrations Statistics, Office for National Statistics (2015)
[3] Taken from CUHFT's report, Division B – B4: Living with and Beyond Cancer Service: to deliver risk stratified care and the Recovery Package
[4] The NHS Five Year Forward View (2014) and other documents can be downloaded from the NHS website.
[5] Achieving World-Class Cancer Outcomes: A strategy for England 2015-2020
[6] Living With and Beyond Cancer: Taking Action to Improve Initiatives (2013) National Cancer Survivorship Initiative

commissioners and providers to consider the type of services required for cancer survivors in order to deliver improved outcomes.

The MICCP vision

The MICCP is an ambitious programme of work, particularly given the size of Addenbrooke's and the role of CUHFT as a tertiary referral centre, not to mention the general pressures facing the NHS with a growing and ageing population. As the MICCP began, the complexity of delivering a transformation programme consistently across all 23 cancer sites in Addenbrooke's became apparent. The MICCP team re-assessed the programme vision and scope to reflect this operating context.

The early implementation phase required intensive engagement from a wide range of stakeholders across the cancer workforce. Between 2015 and 2018 the programme team targeted their support at specific cancer pathways, in a pragmatic approach to integrate cancer care effectively in pockets of activity. They built the tools, capabilities, understanding and best practice to engage new cancer sites and enable integrated cancer care to become business as usual in future.

Evaluation findings – progress and implementation

Integrating cancer care across the four MICCP workstreams was not a linear process. Implementation of MICCP activities varied between and within cancer sites. Staff and volunteer involvement and IT infrastructure builds happened in fits and spurts, depending on competing demands. A planned and pragmatic approach was taken, to maintain momentum with implementing the MICCP in the fast paced and complex operating environment of Addenbrooke's Hospital.

Workstream 1 – Patient: Risk stratification

The MICCP team's initial aim was to risk stratify all 23 cancer sites, but a strategic decision was taken to prioritise early implementation of risk stratification in sites with existing engagement and the most potential to realise quick wins. **By March 2018, a total of 20 pathways were mapped and risk stratified across all cancer sites**. Risk stratification involved moving patients from a consultant led clinic to a nurse led clinic. Low Grade Prostate clinics were led by both Nurses and Allied Health Professionals (AHPs). Clinics were undertaken via a mixture of telephone-based, face to face and holistic approaches, depending on where they occurred within the pathway.

Risk stratification requires relevant clinicians at the sites to collaborate to make shared-decisions around patient care. As a result, maintaining momentum was often a challenge, particularly when a key member of staff left and their replacement brought different expertise and experience to the whole process. At these points the MICCP team intervened to help identify a shared solution. To help engagement at site level, the Cancer Nurse Specialist (CNS) and AHP workforce were key. The MICCP team supported Senior CNS team leads who acted as clinical 'champions' at site level, encouraging colleagues to engage and maintain momentum.

At each point, the progress with risk stratification and setting up new clinics was affected by capacity issues at Addenbrooke's. Additionally, every cancer pathway is different, with different staff, capacity and cultures, so there was no 'one size fits all' approach.

Workstream 1 – Patient: The Recovery Package

The electronic Holistic Needs Assessment (eHNA): The most widely-delivered element of the Recovery Package was the eHNA, with 843 eHNAs taking place. There was a significant increase in the number of eHNA consultations that took place between 2015 and 2016. This was partly due to aligning eHNA completion with staff development objectives to motivate their engagement. PABC agreed that the eHNA was a valuable tool supporting different conversations with clinicians. Divergent views persist regarding the best timing for the intervention however.

Care Plans: There were 666 Care Plans generated between November 2015 and November 2017. Stakeholders agreed that Care Plans were useful for PABC, particularly in providing contact details for assisting with different queries or concerns; and detailing symptoms to look for. As such, they were welcomed as a highly beneficial tool in supporting PABC to self-manage and take control over their care. Interviewees however pointed out a number of ways in which the usability of the Care Plans could be improved, particularly in terms of functions to speed up their completion.

Treatment Summaries: Treatment Summary activity was trialled in one case study site – Colorectal – which worked to design and test a tailored template for that site. This site was strategically selected due senior stakeholder support at this site. Stakeholders agreed that Treatment Summaries could be useful in supporting self-management during recovery.

Exercise Referrals: Referrals to two exercise schemes were seen as key successes of the MICCP. This included the REACT programme delivered by a CUHFT Senior Physiotherapist, and a scheme delivered through a partnership established with Cambridgeshire County Council. The MICCP team created and streamlined processes to enable the cancer workforce to make Exercise Referrals for PABC. PABC feedback regarding the schemes was extremely positive.

Health and Wellbeing Events: Two events took place, one in 2015 and one in 2016. The events were deemed to be successful, but the preparation and delivery was resource intensive. Additionally, the multiple partners involved had different priorities for the events, which didn't always align.

Workstream 2: Workforce and culture change

The second MICCP workstream focused on workforce development, with the longer-term objective of achieving culture change. **The MICCP team designed a Learning and Development programme** to be delivered to the workforce within the CUHFT Cancer Directorate. The content of the training was evidence based and focussed on empowering the individual. It aligned with a wider drive towards person-centred approaches within the NHS Five Year Forward View and CUHFT's Learning & Development Strategy.

The training was advertised to all staff groups (qualified and non-qualified, including medics) across all cancer sites. The majority of participants were from nursing and AHP roles; no medics attended. Three one-day training courses were held in 2017, and a total of 21 people attended.

Workstream 3: IT systems

Workstream 3 was designed to encompass a range of changes to the IT infrastructure, to facilitate the flow of information across cancer services. Whilst the CUHFT EPIC team did support a number of builds for the MICCP, **securing EPIC team time emerged as a persistent barrier to delivery of the MICCP**. Changes to IT took significant time to be approved, followed by a secondary lag before implementation. There remain several outstanding requests logged but not yet approved, for example

the functionality to extract data on the use of Treatment Summaries. This led to staff frustrations. However, there were multiple reasons for the delays to EPIC builds. Work to tailor EPIC was an ongoing exercise, and the bi-annual EPIC upgrade meant that the new functionality and technology was constantly being adapted to the needs of the Trust. Systemic delays to implementing EPIC IT builds had a significant knock-on impact on the MICCP team's ability to progress certain aspects of the Recovery Package, such as uploading Treatment Summary templates or being able to extract data to monitor and analyse implementation progress.

Workstream 4: Partner engagement

Workstream 4 was set up in recognition that **whole-system change cannot happen within secondary care alone**. As such, the MICCP included a workstream to engage wider partners across the cancer workforce, including GPs, the voluntary and community sector, Cambridgeshire County Council and other strategic stakeholders including the Cancer Alliance and CCG. Workstream 4 was primarily intended to drive wider GP engagement.

The impact of the MICCP

For people affected by cancer

The MICCP sought to increase the number of opportunities for PABC to express their needs, improve the quality of conversations, provide tailored information and improve the overall experience of care. The MICCP:

- **Gave PABC the opportunity to express their needs:** the Recovery Package toolkit was reported to provide PABC with the opportunity to express their holistic needs.
- **Supported PABC to have new and different conversations through use of the eHNA:** PABC interviewees described how the thematic topics explored via the eHNA – from spiritual, financial, to mental health and fitness – prompted them to think about and express different concerns that they might not have otherwise felt were relevant to mention. Even those PABC who considered themselves particularly capable of finding their own information and were well-supported by family and friends described ways in which the eHNA gave the opportunity to access different information.
- **Supplied information to help PABC to self-manage:** stakeholders were broadly positive that the Recovery Package toolkit supported PABC to self-manage by giving them relevant information, including information around diet and nutrition, sleeping issues, worries over the genetic properties of cancer and side effects of treatment.
- **Improved the overall PABC experience:** PABC appreciated the opportunity to discuss non-clinical concerns in the hospital setting. This was best summarised by one PABC who otherwise felt that she needed little additional support but who felt that the eHNA helped 'validate her as a person, beyond being part of the machine of oncology', shifting the focus away from cancer and back to the individual as a whole person.
- **Provided follow up care which PABC found to be more convenient and less stressful:** PABC interviewees who experienced telephone, Nurse-led follow up appointments identified several benefits to the risk-stratified clinics, including saving time and money by reducing the number of hospital visits, and reducing the emotional burden associated with attending the

hospital. PABC surveys after follow-up clinics show highly positive responses to all key indicators of patient experience.

For the cancer workforce

By supporting staff and volunteers (primarily through tailored training courses), the MICCP worked to equip a core of the cancer workforce with the tools and competencies needed to deliver new models of care. Training evaluation forms asked the workforce to reflect on whether (and the extent to which) the training had altered their attitudes and beliefs when delivering cancer care. The responses were overwhelmingly positive, with attendees reporting the training to be 'mind altering.' The MICCP:

- Encouraged training attendees to re-evaluate their relationships with PABC, so that the PABC set the agenda and took ownership of their own plans: training participants also described the specific skills required to have new conversations, for example how to phrase questions and being self-reflective, considering the situation from the PABC's point of view.
- Built the knowledge, skills and confidence of the workforce: pre- and post-training questionnaires explored impact across 13 indicators. All indicators showed a notable increase in workforce self-assessment of confidence, skills and knowledge after the training.
- Encouraged the new skills to be put into practice: Trainees described the different ways they anticipated the training to impact upon practice, for example how it would shape the way they set the agenda for consultations, encouraging greater use of open questions.

Whilst stakeholders were broadly positive about their abilities to put the training into practice, they did outline some barriers to doing so. These included workloads, constrained staffing levels and entrenched ways of working.

For cancer services

Measuring the impact of the MICCP upon cancer services is challenging given the complexity of the system and other factors affecting service operation. Nonetheless, the MICCP led to:

- **Improved coordination of patient pathways:** Nurse-led clinics meant that low-risk cohorts of PABC received more appropriate follow-up care; Exercise Referrals followed a streamlined process; Recovery Package elements such as eHNA and Care Plans on EPIC built cancer workforce awareness of PABC journeys; and eHNA conversations enabled effective signposting to information to meet PABC needs.
- **Improved relationships between PABC and healthcare and support services:** PABC were positive about the impact of the eHNA on their relationships with Addenbrooke's staff, and how this differed to their previous experiences of cancer care. PABC on five-year check-ups reported how the eHNA was their first opportunity to speak to a member of the cancer workforce about other concerns and welcomed these conversations.
- **Improved capacity across the system:** Risk stratification of PABC 'freed up' senior clinician time, which was critical for accommodating newly diagnosed PABC. Risk stratified follow-up care, whilst time consuming for everyone involved in pathway mapping, was well received and valued by healthcare professionals and PABC.

For the cancer system

Specific areas of successful engagement include:

- The Exercise Referral process, which encouraged neighbouring local authorities to employ exercise referral instructors, supporting greater numbers of PABC.
- The MICCP team influenced strategic partners, leading to greater clarity amongst key stakeholders about MICCP activities.
- The Macmillan GP was involved in designing and trialling the Treatment Summary at the Colorectal site, which informed a template for wider roll out to other cancer sites

Key learning: maintaining momentum

The evaluation identified five ways in which the MICCP team maintained momentum in the complex and ever-changing operating context of a busy tertiary hospital:

1. **Prioritisation of quick wins:** By prioritising who to work with, where to work and the specific areas of focus, the MICCP trialled and tested activity, generating learning to inform wider roll out.
2. **Adopting a fluid approach:** The MICCP team was able to quickly re-prioritise and change focus, depending on momentum and capacity at that particular moment.
3. **A project team with a 'can do' approach:** Recognising the pressures and competing priorities facing key stakeholders, the MICCP team took on a variety of tasks to support implementation, from basic administration through to high level influencing.
4. **Influencing:** The MICCP team networked through formal channels within Addenbrooke's, whilst also networking externally, attending meetings with the Cancer Alliance, Macmillan GP and CCG. The dedicated MICCP team effectively encouraged engaged stakeholders, such as CNSs, to champion the work within and across cancer sites.
5. **Be realistic about the pace of change:** The wider delivery context meant that the MICCP team revised their expectations of what was possible to achieve within the 3-year programme. Being realistic about the pace of change – and recognising the scale of the challenge – was vital in managing wider stakeholder expectations.

Other key learning

As well as the behaviours and broader approach outlined above, the evaluation reveals other learning to consider when integrating cancer care. These include:

- The importance of **engaged clinicians with the authority, capacity and skills needed** to unite and enthuse colleagues around a shared vision and new ways of working.
- The role that **volunteers** can play in providing low level non-complex support.
- The importance of a **Macmillan GP champion** to trial and test specific elements and to disseminate information in an appropriate way to other GPs, providing peer credibility and understanding of the context in which they operate.

- Ensuring a **fully resourced programme team** across the whole period of delivery, able to pick up different levels of activity across multiple cancer sites and stakeholder groups.
- **Prioritising and trialling new ways of working on a site by site** basis can prove key, rather than attempting to drive through all activities at the same time.
- **Collect meaningful PABC experience data at every opportunity** where appropriate e.g. risk stratified clinic feedback and use this to inform revisions and refinement to the model.
- **Consider IT implications and build these into the work plan,** specifically in terms of prioritising activities or workstreams that will help to generate 'quick wins'.

Building the business case: the economic evaluation

The economic assessment uses information from the risk stratification and re-design process as recorded in Change of Methodology Recordings (CMRs), along with programme budget data provided by Macmillan. This includes costs to be picked up after the end of Macmillan funding to continue implementing the Recovery Package, deliver HWB events and sustain the new pathways.

As the MICCP is still in delivery, the economic assessment includes an estimate of the, as yet, un-identified (unrealised but anticipated) savings, for example, clinics commissioned during the remaining programme and beyond. The assessment includes scenarios to explore potential variations in the scale of the un-identified savings, with optimism bias set at 5%[7] in CMR estimates[8].

In all scenarios except the low (without any assumed efficiency savings) the return on investment (ROI) is over 1.0, with payback period of 5 years to 6 years. For the low scenario with no efficiency savings there is a small budget impact of £30,804, which is the additional budget required to finance the programme under this scenario.

[7] Optimism bias provides a correction for the uncertainty around the available evidence, through increasing the programme costs and decreasing the financial value of identified benefits.
[8] Data on risk stratification and attendances where the CMRs have been implemented has been used.

Table 1: Economic assessment of the three scenarios

Metric	Low	Medium	High
With no efficiency savings			
Net Present Budget Impact	£30,804	-£210,719	-£452,242
Overall Financial Return on Investment	0.99	1.08	1.16
Payback period	-	6 years	5 years
With efficiency savings of 5% p/a[9]			
Net Present Budget Impact	-£453,850	-£745,866	-£1,037,882
Overall Financial Return on Investment	1.16	1.27	1.37
Payback period	6 years	5 years	5 years

Source: – SQW economic assessment calculations.

The number of patients attending CUHFT for cancer care increases year on year, and the modelling includes an assumed 7% growth in activity per annum. **If the MICCP was not implemented the current costs would continue to grow year-on-year in line with patient numbers**. As such, by risk stratifying new patient pathways through the MICCP, the Trust is helping to meet rising demand and mitigate against the associated cost and resource implications of caring for a growing population of PABC. However, the full extent of the benefits and costs associated with the MICCP will not emerge for several years, and these calculations do not include wider potential benefits and costs, for example those for PABC or the wider cancer care system.

Conclusions

The MICCP is a key part of the wider strategy to improve cancer care and coordinate pathways, but there remains work to do at cancer site, service and system levels. The funding provided to sustain the programme post-December 2018 following the end of Macmillan's funding indicates the value placed on the new ways of working by local commissioners. Embedding the model as 'business as usual' offers potential for further benefits to emerge as the ways of working are sustained and further rolled out.

Whilst the pace of change has at times proved frustratingly slow, the risk stratified pathways continue to become live and momentum grows. The MICCP provides the foundation by which the programme can build under 'business as usual' delivery moving forwards.

Recommendations for local commissioners and the Cancer Alliance

Recommendation 1: Adopt a whole-system perspective to cancer care commissioning to maximise impacts, for example considering financial implications across partners. This can help to generate their buy in and maintain programme momentum.

Recommendation 2: Recognise risk stratification and Recovery Package activity not as a means to generate immediate savings, but as a means to meet the challenges of increasing demand for cancer care. This evaluation has shown that the model does offer potential to help meet rising demand.

[9] It is anticipated that once clinicians and PABC feel comfortable with pathways and the new ways of working become embedded, efficiency savings can be realised. We have estimated these at 5% per annum, but these have yet to be realised.

Recommendation 3: Be realistic about the expected scale and pace of change, given the system-wide focus of MICCP. Understand that every pathway is different and that it takes time to build the necessary clinical and workforce engagement to maintain momentum around risk stratification.

Recommendations for CUHFT

Recommendation 4: Consider recruiting a formal clinical 'champion' to act as a high-level influencer across sites to unblock barriers and maintain momentum. Additionally, use existing 'champions' to share the benefits and encourage other sites to engage with integrating cancer care.

Recommendation 5: Hold a strategic meeting with senior executives to discuss and prioritise the IT infrastructure required to support risk stratification and Recovery Package implementation.

Recommendation 6: Consider how best to engage local GPs so they are ready for Treatment Summaries and are sufficiently knowledgeable about the Recovery Package, utilising the Macmillan GP's networks and expertise for support.

Recommendation 7: Engage internal and external commissioners to explore ways to minimise internal commissioning delays. A schedule for anticipated CMRs to agree with the relevant director may help to minimise delays and mitigate against issues if delays do occur.

Recommendation 8: Continue with the training for the workforce. Given the need to generate culture change at site level, consider delivering team based or 'train the trainer' programmes, and target medics who play important roles in setting the department culture, flexing timing to suit them.

Recommendation 9: Use Care Plans to support continuity of care for patients when they are transferred between departments, i.e. Oncology and Urology. Supporting practitioners in the sites to correctly use the IT system that underpins the Care Plan process will be key to this.

Recommendation 10: Continue the roll out of risk stratification within high priority sites, which can be selected either for their national strategic importance (e.g. particular focus of the Cancer Alliance) or for MICCP strategic importance (e.g. to trial a new form of clinic or risk stratify remaining pathways at engaged sites).

Recommendation 11: Consider which elements of the Recovery Package implementation should be standardised, and which can be flexed. For example, whether you might offer flexibility for PABC to complete the eHNA at home, or flexing the timing of the eHNA on a site-by-site basis.

Recommendations for Macmillan

Recommendation 12: Consider how best to engage local GPs to help ensure they are ready for Treatment Summaries to be introduced more widely, and are sufficiently knowledgeable about the Recovery Package. This may be through a phased implementation via the Macmillan GP's networks.

Recommendation 13: Continue to maintain and strengthen relationships with the CCG and STP to help to build their understanding of (and inform) their priorities for future commissioning.

Recommendation 14: Continue to share learning emerging from elsewhere regarding the Recovery Package or components of the MICCP (e.g. eHNA, Treatment Summaries etc.) to inform refinement of the model in Addenbrooke's, and/or inform the roll-out to other sites.

Recommendation 15: Consider delivering Health and Wellbeing events at a regional level. There may be economies of scale through a regional approach, which Macmillan could usefully play a key role in.

Recommendation 16: The administration of eHNA was complicated by the introduction of new administration steps. In future it may be useful for Macmillan to work with Trusts before introducing IT changes which affect day to day operational activities, possibly trialling new ways of working.

Recommendations for others seeking to replicate the MICCP model

Recommendation A: Ensure resource requirements have been thought through e.g. a dedicated programme team with the necessary capacity and capability to undertake a wide range of activities.

Recommendation B: Explore IT and information governance requirements at an early stage, and secure buy-in from the IT support team (and others). In addition, agree at the outset, as far as possible, exactly what monitoring data is required to meet commissioner needs.

Recommendation C: Focus early activity on achievable sites and activities. These are likely to be those cancer sites with the capacity, capability and physical space to conduct risk stratification activities and embed the Recovery Package. Starting small and achieving quick wins can help to generate enthusiasm, momentum and learning to support wider roll out.

Recommendation D: Be mindful that risk stratification can be a long process and that external factors may adversely affect progress or momentum. It is vital to manage expectations and be realistic about the anticipated pace of change, building in contingencies where needed.

Recommendation E: Build in evaluation and PABC engagement at the outset. Collect meaningful qualitative and quantitative PABC experience data where appropriate e.g. gathering risk stratified clinic feedback, and use this in a structured way to inform revisions and refinement of the model.

Recommendation F: Align integration with local and national strategies; strategic alignment will be key to securing funding and buy in.

Recommendation G: Gain broader 'on the ground' awareness by identifying and supporting clinical champions who can influence and persuade colleagues to engage.

Recommendation H: Plan for sustainability at the outset. This is vital to avoid the new ways of working being seen as 'just another initiative' and to help overcome any change fatigue. Engaging with commissioners will be vital to supporting sustainability.

Recommendation I: Link Recovery Package and risk stratification activities into staff development plans e.g., the use of eHNA or Care Plans, and/or attending training. This can all contribute towards culture change and sustaining the impacts of the model in future.

Recommendation J: Implement a tailored learning and development programme alongside the new care pathways to embed the new ways of working, focusing on building a trusting, open relationship between PABC and the cancer workforce, encouraging culture change. Targeting the early implementers of the model for the first waves of training may help to ensure that ways of working align with the new pathways.