Evaluation of the Macmillan Local Authority Partnership Programme

Final report

November 2020

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Contents

Executive summary i

1. Introduction 1

2. The Macmillan Local Authority Partnership Programme 2

3. The evaluation 8

4. Partnerships 11

5. Model design and development 20

6. Service delivery 29

7. Outcomes 43

8. Economic assessment 55

9. Conclusions 61

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Executive summary

1. The Macmillan Local Authority Partnership (MLAP) Programme was initiated by Macmillan Cancer Support (hereafter Macmillan) in 2015. The aim was to develop an approach to improve health and wellbeing outcomes for people affected by cancer (PABC) by understanding people's holistic needs and developing personalised, community-based routes to meeting those needs. Four partnerships, Dundee, Fife, Durham and Tower Hamlets, participated in the programme to March 2020 and each received £1m funding from Macmillan to enable them to develop a local MLAP.

2. Dundee, Fife and Durham each delivered a new service for PABC that ran beyond the March 2020 programme end date. The services involved offering PABC a holistic assessment of their non-clinical needs, support with developing a care plan to respond to identified needs, and signposting/referral to other sources of support to meet those needs. Tower Hamlets took a different approach; at the time of writing, the site was finalising delivery and implementation plans based on ideas developed through a co-design process with stakeholders from the health and social care system and input from co-production volunteers.

Partnership working

3. The key aspect of MLAP programme was new partnerships between Macmillan and local authorities to meet non-clinical needs of PABC. Historically Macmillan has worked closely with the health service but less so with local authorities. Major progress was made in developing these partnerships, with certain factors facilitating more rapid progress in some sites, including: existing positive relationships between partners; existing systems to facilitate joined up working (including legally mandated integration of services and joint working, as in Scotland); effective and visible leadership; a set of effective governance arrangements; a clearly articulated rationale and aim; clarity on roles among partners; and a strong programme / partnership manager with team support.

Service design

4. The programme has generated significant learning on how to develop a service to support PABC with non-clinical needs. Good practice included allocating significant time on scoping activities to fully understand the context, being flexible to adapt to changes in the environment (such as the national introduction of social prescribing in England); and using a link worker role with a core set of skills and expertise (particularly in communication and networking). Sites reported challenges that other systems should be alert to, largely centred around difficulties in maintaining up to date knowledge of community assets, lack of clear career progression routes for link workers, and managing gradual take up of the service.

Co-production

5. Co-production was fundamental to the MLAP programme in terms of development and review of services and activities, and in providing credibility to the programme. Effective co-production was facilitated by clear terms of reference, role descriptions and expert support. It was recognised that co-production could be challenging to implement fully, and requires careful resourcing, sufficient time, and effective recruitment.

Service delivery

6. By the end of December 2019, 1,534 PABC had used the MLAP services and 2,117 HNAs had been undertaken. Lessons from the experience of service delivery included the need to balance personalisation against cost-effectiveness (in terms of location for conducting HNAs), and to ensure an appropriate staffing mix, as well as the importance of maintaining knowledge of the local support landscape for options for onward referral and signposting.

Experiences and outcomes for PABC

7. Evidence indicates that the programme's services helped to reduce non-clinical needs for PABC (in terms of number and severity of concerns), and helped people to feel more able and confident to manage their own health and care. In the absence of a control or comparator, it is not possible to assess the extent to which the changes were a result of the MLAP programme, but quantitative data from HNAs and surveys, triangulated with qualitative insights from interviews and free-text survey responses, indicates that the MLAP services were at least partly contributing to these changes.

Conclusions

8. The MLAP programme was a huge programme of work, running for several years and spanning two nations, covering a large population of PABC and operating in a variety of different contexts. The programme involved national activity, local development, influencing and delivery, and inter-site learning. The work towards realising shared visions and translating these into delivery models by local partnerships is testament to the buy in and commitment to the MLAP programme approach.

9. Without Macmillan's funding it is unlikely that the work would have progressed at the scale and pace that it has. The funding proved vital in pump priming partnership formation, service design and delivery, enabling new ways of working to be trialled and implemented in very different contexts and different ways, to explore 'what works' and the impacts for PABC.

10. Exploring how the programme models or principles can be translated to support people with other long-term conditions is already underway at programme and site level and should be pursued in order to fully realise the ambitions set out by the programme and explore its full potential for improving support and quality of life for wider groups of people in need. The programme's focus on personalised needs assessments and care plan development offers learning and models for others to consider. Ensuring alignment with other social prescribing and personalised care schemes will continue to be key, to avoid any sense of duplication or misalignment, and to avoid 'competing' for resources

Recommendations:

for Macmillan

Recommendation 1: Consider the pre-conditions needed to successfully introduce an MLAP. Examples include visible senior leadership buy in; in-kind resources to support programme team recruitment, supervision and activity; strategic alignment and political support; realistic stakeholder expectations; and a history or backdrop of strong partnership networks.

Recommendation 2: Be clear with new partners on the expectations for an MLAP. There is a clear model for an MLAP in Scotland, less so within England (nor Wales and Northern Ireland). Being clear on the type of outputs sought, potential delivery model and the respective roles of Macmillan and other partners, may also be helpful in managing expectations nationally and locally.

Recommendation 3: Provide clarity on national versus regional support offers. Support that was targeted and timely was highly valued.

Recommendation 4: Build in flexibility., recognising the complexities of partnership working. Variation in local systems and the provision of services creates unpredictability for programme delivery. Under such circumstances, it is helpful for Macmillan to be as flexible as possible about how their grants can be used (whilst ensuring focus on an agreed vision).

Recommendation 5: Be clear on how the MLAP programme and service align with other local Macmillan activities, to help local partners to avoid any (actual or perceived) duplication of offer.

Recommendation 6: Introduce standardised data recording across all sites, including separate records for each HNA. This is expected to facilitate improved analysis and comparison across areas, generate learning about how context and different models influence service usage and outcomes, and enable aggregation of data across sites to give an understanding of cumulative impact.

Recommendation 7: Continue to offer responsive, targeted support to sites. This is likely to involve drawing on support and expertise from different parts of Macmillan, at national and regional levels.

Recommendation 8: Continue to share learning across MLAPs, potentially supporting a Community of Practice for managers and/or link workers.

Recommendation 9: Introduce a portal or site to host MLAP programme tools and resources to avoid duplication of effort.

Recommendation 10: Conduct light-touch follow up evaluation, to explore longer term outcomes and learning emerging.

Recommendation 11: Consider alignment with other Macmillan offers. This may help to provide clarity around the cancer support landscape (for PABC and professionals/partners).

for local partnerships seeking to adopt the MLAP programme ways of working

Recommendation A: Undertake partnership visioning exercises to ensure the vision remains well aligned and to monitor progress towards its achievement, in order to sustain engagement and ensure progress remains on track.

Recommendation B: Develop a high-level plan and expectations, co-produced with key partners. This will help to secure buy in and manage expectations in terms of progress and outcomes realisation.

Recommendation C: Introduce robust governance arrangements to build a sense of shared ownership and help to reduce the likelihood of the partnership stalling in the absence of a key leader, manager or champion.

Recommendation D: Involve PABC in recruitment activities. This enabled effective recruitment in a couple of the MLAP sites, and was identified as good practice by Macmillan leads and local stakeholders.

Recommendation E: Carefully plan for and resource coproduction. This is likely to include procuring experienced support to deliver coproduction activities and consideration of the skills needed and experience sought from coproduction volunteers and how to access this support.

Recommendation F: Work closely with the local voluntary and community sector (VCS) to maximise potential impacts for PABC. Given the funding and capacity pressures and concerns of the VCS, Macmillan and sites will need to maintain or expand efforts to ensure they fully understand any impact of their work on the VCS and can work effectively in partnership with them to support PABC.

Recommendation G: Consider the scope of the partnership and alignment with other local social prescribing schemes to avoid duplication and to target the most vulnerable and priority individuals and communities. This should also help to to inform planning for sustainability.

Recommendation H: Balance the need for efficiency against providing personalised care. This is to ensure appropriate personalisation and responsiveness to people's needs and wishes, alongside ensuring efficiency and maximum reach. This might include, for example, considering the most appropriate setting in which to deliver HNAs.

Recommendation I: Consider (and where possible, build in) career progression routes for link workers, to reduce the risk of turnover.

Recommendation J: Consider sustainability from the outset to secure buy in and reassure potential referrers or stakeholders that the model is intended to provide longer term solutions. Capturing the 'true costs' of delivery as well as evidence of benefits emerging will ensure there is a clear 'ask and offer' for local commissioners to consider when planning for sustainability.

1. Introduction

1.1 The Macmillan Local Authority Partnership (MLAP) Programme was initiated by Macmillan Cancer Support (hereafter Macmillan) in 2015. The aim was to develop an approach to improve health and wellbeing outcomes for people affected by cancer (PABC) by understanding people's holistic needs and developing personalised, community-based routes to meeting those needs. Four partnerships, Dundee, Fife, Durham and Tower Hamlets, participated in the programme to March 2020 and each received funding from Macmillan to enable them to develop a local MLAP.

1.2 In December 2016 Macmillan commissioned SQW and the Social Care Institute for Excellence (SCIE) to undertake a three-year independent formative evaluation of the MLAP programme, with the aims of assessing: the rationale and approach taken; the partnerships; Macmillan's strategic capability; and the scalability of the model. The evaluation was also to share findings and learning with key stakeholders. The evaluation ran to March 2020, following a three-month extension to its original timescales. The final report was delayed to November 2020 due to the Covid-19 lockdown and impact on capacity within Macmillan.

1.3 The key research methods for the evaluation included: review of documents and data throughout (at site and programme levels); interviews with programme and site stakeholders; attendance at relevant site and programme meetings throughout; surveys of PABC using MLAP services; analysis of holistic needs assessment (HNA) and electronic holistic needs assessment (eHNA) data; an online survey of staff and key stakeholders in three of the MLAP sites; and collection and analysis of financial data.

1.4 This is the final report for the evaluation. It includes evidence from evaluation activities conducted to March 2020. A toolkit based on learning from the evaluation of the programme is available on the SCIE website at https://www.scie.org.uk/integrated-care/leadership/learned/mlap.

1.5 The report is structured as follows:

- Section 2 - a description of the programme
- Section 3 - a description of the evaluation
- Section 4 - findings relating to partnerships
- Section 5 – findings relating to model design and development
- Section 6 – findings relating to service delivery
- Section 7 – evidence on emerging outcomes
- Section 8 – an economic assessment overview
- Section 9 – conclusions and recommendations.

2. The Macmillan Local Authority Partnership Programme

2.1 The Macmillan Local Authority Partnership (MLAP) Programme was initiated by Macmillan in 2015 with the aim of **developing an approach to improve health and wellbeing outcomes for people affected by cancer (PABC[1]) by understanding people's holistic needs and developing personalised, community-based routes to meeting those needs**. Four partnerships (elsewhere also referred to as sites), Dundee, Fife, Durham and Tower Hamlets, participated in the programme to March 2020 and are the subject of this evaluation report[2].

Context for the programme

2.2 The MLAP programme was conceived in a context of rising incidence and prevalence of cancer, with an ageing population and increasing cancer survival rates. These developments mean there is a growing number of people affected by cancer, with associated social, emotional, financial, practical, physical and spiritual needs, in addition to medical needs[3].

2.3 The needs of PABC can vary greatly, depending on their cancer journey stage, demographic characteristics, socio-economic status and a range of other factors. One Macmillan study that looked at the social care needs of people with cancer found they required significant levels of support with their emotional needs, mobility, practical tasks, medical appointments, personal care and looking after dependents[4]. It also identified that carers for PABC have needs, which may be similar to the needs of PABC and/or specific to their caring role (such as bereavement support)[5]. The same study found that non-clinical needs of PABC have not always been met by appropriate, timely services, with some PABC receiving no support at all for their needs[6].

2.4 Those who do not receive appropriate support can end up accessing services elsewhere in the health and social care system: one in five PABC go to hospital for unplanned care or an emergency visit because of lack of support. Moreover, PABC continue to pay for a high proportion of their own care, and many receive support from informal carers and / or the voluntary and community sector (VCS)[7].

2.5 The shortfall in support for PABC's non-clinical needs is due to a range of factors[8]:

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[1] Where possible, we have tried to refer to people as people or people affected by cancer (PABC). For clarity and brevity, we sometimes use the term 'service users' to refer to people using the MLAP services.

[2] Manchester embarked on the programme but withdrew in 2019 to pursue other routes to meet PABC needs. Warwickshire also embarked on the programme but exited within a few months. Learning regarding the MLAP set up and development in Manchester has been provided separately to Macmillan and Manchester site leads. Warwickshire was not included within the evaluation due to its early exit.

[3] As elucidated in the evaluation specification.

[4] Macmillan (March 2015) 'The social care needs of people with cancer', https://www.macmillan.org.uk/_images/hidden-at-home-report_tcm9-300461.pdf (Accessed 29/04/19)

[5] Ibid.

[6] Ibid.

[7] Macmillan (2013) ''The social care needs of people with cancer', https://www.scie-socialcareonline.org.uk/the-social-care-needs-of-people-affected-by-cancer-research-insights/r/a11G00000032BtUIAU (Accessed 29/04/19)

[8] Macmillan's website contains references to multiple pieces of research providing evidence on the following factors.

- A lack of understanding from social services and cancer services of the wider needs of cancer survivors beyond their healthcare needs. In 2010, 90% of people with cancer were not referred for assessment by social services within three months of diagnosis[9]
- A lack of awareness among health, social care and VCS professionals of other existing services, eligibility criteria, what is provided and how to refer or advise PABC to access them
- A lack of awareness among PABC of existing services and criteria for receiving help
- A lack of integration within health and social care (particularly outside of Scotland), which may make it harder for PABC to navigate both systems and receive the support they need
- The context of constrained resources and growing demand, which may limit capacity to provide services for PABC.

Overview of the programme

2.6 In light of the growing number of PABC and the challenges in meeting their needs, Macmillan launched the MLAP programme. The programme was intended to maximise the value of constrained resources and work in partnership with local authorities or health and social care partnerships. The partnership with local authorities was a new step for Macmillan, which historically has worked more closely with healthcare organisations. The rationale for working directly with local authorities was that they are better positioned than healthcare organisations to support local populations with non-medical holistic needs.

2.7 The MLAP programme ran in four sites through to 2020 – Dundee, Fife, Durham and Tower Hamlets – through partnerships between Macmillan and the respective local authority or health and social care partnership (in Scotland). Macmillan invested £1m in each site. The aims were to:

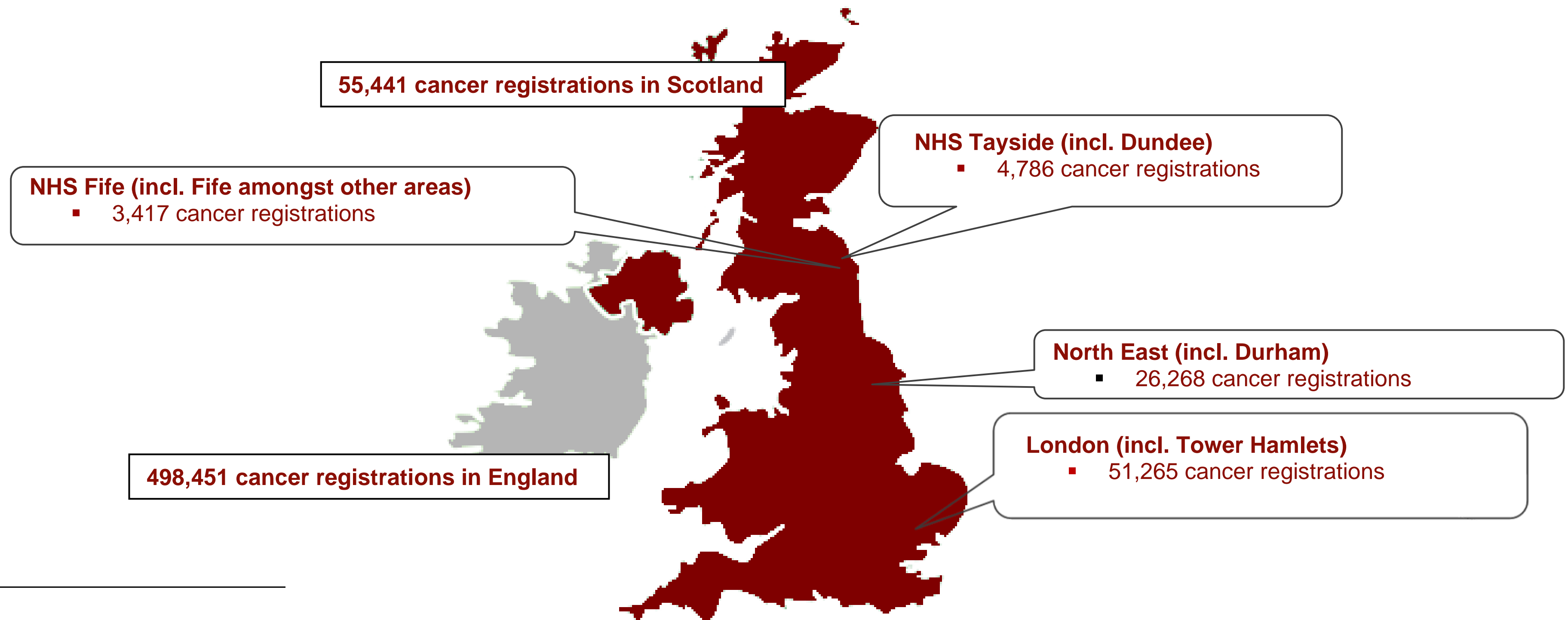
- Ensure PABC were central to the programme
- Determine the non-clinical needs of PABC
- Identify gaps in service provision
- Link existing services, and help set up appropriate new ones
- Help PABC to engage with the right services for them
- Improve outcomes for PABC.

[9] Xavier Chitnis, Adam Steventon, Adam Glaser and Martin Bardsley (May 2014) 'Use of health and social care by people with cancer' https://www.nuffieldtrust.org.uk/files/2017-01/social-care-for-cancer-survivors-full-report-web-final.pdf (Accessed 20/04/19)

Overview of the MLAP sites[10] [11]

2.8 The sites experienced different journeys through MLAP programme. A Memorandum of Understanding (MoU) was signed in November 2015 for Fife, Dundee and Durham; development of the local programmes then started immediately with the appointment of the programme managers and partnership development. These three sites each delivered a new service for PABC that is running beyond the March 2020 programme end date.

2.9 Tower Hamlets signed their MoU in 2016, although the programme did not start until staff were in post in 2018. At the time of writing, Tower Hamlets was finalising delivery and implementation plans based on ideas developed through a co-design process with stakeholders from the health and social care system and input from co-production volunteers.



[10] England cancer registrations for 2017 (latest year available). From https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland

[11] Scotland cancer registrations for 2018 (latest complete year available). From https://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry/

Table 2-1: Overview of the MLAP sites and partnerships

Dundee	Fife	Durham	Tower Hamlets
Background			
Dundee City Council applied to be an MLAP site in 2015 because: • The city has a higher than average cancer incidence and mortality rate (vs. Scotland) • There was a clear drive towards health and social care integration plus personalised care. The success and learnings from Macmillan's Improving Cancer Journey in Glasgow (ICJ) initiative were a major influence on the development of the MLAP in Dundee as well as Macmillan's Transforming Care After Treatment programme. Following a successful pilot, the service went fully live in November 2017.	The Fife Health and Social Care Partnership was committed to supporting its ageing population, in which cancer was the main cause of death. Holistic care, integrated delivery and reduction of health inequalities were key aims. The Glasgow ICJ was also a key influence on the development of the MLAP in Fife as well as Macmillan's Transforming Care After Treatment programme. The service went fully live in September 2018 with funding for three years.	Durham had higher rates of cancer incidence, early death from cancer, and deprivation, than the England average. Durham County Council wanted to identify and analyse unmet needs of PABC and seek sustainable ways to support the local population. Their ambition was a non-clinical cancer journey from prevention to survivorship/end of life, providing support to all PABC. The 'Joining the Dots' service (JtD) went fully live in January 2019 with funding to March 2021 (from Macmillan and the Northern Cancer Alliance). County Durham Clinical Commissioning Group (CCG) will fund the service beyond that date.	The locality had: • High levels of socio-economic deprivation among residents • 72% of PABC with another long-term condition • Relatively poor outcomes for cancer • Some of highest levels of mental health need in England. The partnership aim was to explore how acute, primary and community settings could work together to address these issues. The area had a complex health and social care landscape, with transformation occurring in several domains.
Pathway / approach			
Referral from clinicians or other organisations, or self-referral in response to Information Services Division (ISD) invitation letter. Person-centred conversation with a link worker (face to face or telephone) using the HNA tool to determine what matters to the person. Care plan coproduced to reflect the HNA conversation, including needs and actions such as information, sign-posting/ onward referrals. Shared with services as agreed with PABC.	Referral from clinicians or other organisations, or self-referral in response to ISD invitation letter. Person-centred conversation with a link worker (face to face or telephone) using the HNA tool to determine what matters to the person. Care plan coproduced to reflect HNA conversation, including needs and actions such as information, sign-posting/ onward referrals. Shared with services as agreed with PABC.	Referral from clinical nurse specialists (CNSs), VCS, self-referral. Person-centred face-to-face conversation with a link worker (referred to as facilitators in Durham) using the HNA tool to determine what matters to the person. Care plan (known as support plan in Durham) coproduced to reflect HNA conversation, including needs and actions such as information, sign-posting/ onward referrals. PABC can share with others as desired.	Understand current arrangements and practice to identify what changes could improve patient care and experience. Develop a holistic support pathway that spans organisations and sectors. Improve coordination and information sharing.

Dundee	Fife	Durham	Tower Hamlets
Team			
Two support facilitators to conduct HNAs, a programme manager, admin support. Located within Dundee Health & Social Care Partnership.	Three link workers to conduct HNAs (2.5 FTE), two local area coordinators (1.5 FTE) to liaise with organisations offering support and conduct HNAs, a programme manager, and data analyst. Located within Fife Health & Social Care Partnership.	Programme manager and administrator ran the programme from within the County Council. Service contracted out to existing local provider. JtD run by a service lead and six FTE facilitators to conduct HNAs, develop support plans, advocate for PABC and follow up on receipt of support.	Programme manager and programme coordinator with coproduction expertise. Located in Tower Hamlets Council within Adult Social Care, alongside Public Health.
Headline Reach and Outcomes			
• 465 service users (to end of 2019) • 5% servicer users were carers • Most common concerns raised were money, tiredness, and moving around • Average number and severity of concerns fell from first to second HNA • Health and wellbeing events led by coproduction group brought clinical and community services together • Identified a need for peer to peer support and funded a pilot with Dundee Volunteer and Voluntary Action to provide a peer support service	• 566 service users (to end of 2019) • 5% servicer users were carers • Most common concerns raised were tiredness, moving around, eating and sleep, followed by money • Average number and severity of concerns fell from first to second HNA • "*I was very pleased with the way my concerns were listened to and with the advice given regarding these concerns*" [service user] • Introduction of community venues for HNAs • Close cooperation with housing department to support PABC	• 503 service users (to end of 2019) • 16% servicer users were carers • Most common concerns raised were money, worry/fear/anxiety and housing • "*Joining the Dots is a great service and should continue to be funded…, it is so much needed*"" [service user] • Coproduction group that both identified problems for local PABC and designed the model for JtD – which had credibility as a result • Commitment (pending local evaluation) from Durham CCG to ongoing funding.	• Good links established with other transformation bodies, initiatives and professionals • A comprehensive asset map • Cancer Health Intelligence report • Insights from 48 residents affected by cancer • Facilitated delivery of training on 'cancer as a long-term condition' to cross sector workforce • Co-designed the holistic support pathway, developed a series of 'change ideas' and functions required to deliver personalised care.

Key Enablers			
CEO of Dundee City Council chaired the Project Board "*Dundee has partnership in its DNA*" [Dundee stakeholder] Local experience through involvement in Macmillan's Transforming Care after Treatment (TCAT) programme Drew on learning from Glasgow ICJ – Dundee workers shadowed peers Effective Cancer Voices co-production group involved throughout and continues to be represented on the project team and board.	Senior support from within the Health and Social Care Partnership – a commitment to the ICJ model until 2022 in the Strategic Plan Local experience through involvement in Macmillan's TCAT programme – inherited two staff from TCAT Drew on learning from Glasgow and Dundee's early experience MLAP is part of region's Social Prescribing Strategy Group – and the lead sat on the sub-group for social prescribing to represent the H&SCP.	Championed by the Cabinet member for Adult and Health Services and Chair of the local Health and Wellbeing Board Programme manager had strong experience of networking on challenging issues across different organisations Existing local provider with relevant experience of needs assessments plus structures and processes, and knowledge of the local context Significant time invested in recruiting and establishing a coproduction group and following good practice in running the process.	Good support from Public Health colleagues, particularly Healthy Adults Team, e.g. access to cancer health intelligence Member of the pan-London Living With and Beyond Cancer Partnership Board Existing transformation programmes mean period of flux in which new ideas and approaches can take hold Programme coordinator with coproduction expertise and capacity to invest in accessing hard to reach communities Lived experience on recruitment panel for programme manager.

3. The evaluation

3.1 In December 2016 Macmillan commissioned SQW and the Social Care Institute for Excellence (SCIE)[12] to undertake a three-year independent formative evaluation of the MLAP programme, with the aim of assessing the rationale and approach taken, the partnerships, Macmillan's strategic capability, and the scalability of the model. The evaluation was also expected to share findings and learning with key stakeholders. The evaluation was subsequently extended by three months to allow additional data collection, and finished in March 2020. The final report was delayed to November 2020 due to the Covid-19 lockdown and impact on capacity within Macmillan.

3.2 The evaluation involved co-production and engagement at site and programme levels to capture relevant data and insights. It was designed to provide formative insights to inform refinement of the programme, site implementation, and any future roll-out or related activities by Macmillan. As the evaluation progressed, the data provided initial insights on outcomes emerging and a preliminary economic assessment of service delivery in three sites.

3.3 There were four main strands to the evaluation:

- Co-production of a Theory of Change (ToC) for the programme and each site (undertaken by the Tavistock Institute, completed in May 2018; available separately)
- Co-production of an evaluation framework for programme and site level evaluation (completed in September 2018 for the programme)
- Collection, analysis and reporting of baseline and interim outcome, experiential, financial and service use data (during late 2018 and 2019)[13]
- Production of a toolkit on how to develop a Macmillan Local Authority Partnership, led by SCIE (in April 2019 and Autumn 2020). The MLAP toolkit is available https://www.scie.org.uk/integrated-care/leadership/learned/mlap.

3.4 The evaluation framework guided the delivery of the evaluation in terms of areas of research and methods of data collection. It mirrored the structure of the ToCs, considering outcomes:

- For PABC
- At the team and service delivery level
- In terms of the partnership and system
- From the programme as a whole.

3.5 The key research methods are shown in the table below.

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[12] SCIE led on developing the toolkit for the programme.
[13] This was additional to the work originally planned and set out in the evaluation specification, which focused on baselining outcomes and economic implications, rather than tracking emerging outcomes.

Table 3-1: MLAP programme evaluation activities and methods

Method	Detail
Document review	Including relevant documents provided by sites and Macmillan e.g. MoUs, Board and/or Steering Group papers and minutes, governance charts, process maps, scoping papers including asset mapping, case studies, local evaluation reports.
Interviews with programme and site stakeholders	Four waves including the Macmillan programme lead, Macmillan regional staff, site programme managers, Board and/or Steering Group representatives, coproduction group members, other site stakeholders, and service delivery staff.
Attendance at relevant site and programme meetings	Including MLAP Programme Steering Group meetings, Learn and Share events, cross-site calls, site Board and/or Steering Group meetings, and coproduction events.
Surveys of PABC using MLAP services[14]	Four wave anonymous online and paper survey for users of the Dundee, Durham and Fife services, distributed by sites. First wave prior to HNA, second within one month of the HNA, third within 3-6 months of the HNA, and the fourth within 9-12 months of the first HNA. The surveys were live from February 2019 to December 2019.
Analysis of eHNA and HNA data	Including anonymous data from all users of the Dundee, Fife and Durham services, from service go-live to 31 December 2019.
Survey of the wider workforce in sites	One-off online survey distributed by sites (Durham, Dundee and Fife) in November 2019, targeted at those involved in delivery, overseeing or supporting the MLAP service.
Collection and analysis of financial data	Data provided by Dundee, Durham and Fife sites during November 2019 – February 2020.

Source: SQW

Introduction to this report

3.6 This is the final report for the evaluation[15], structured according to the main areas of the ToCs and the key questions in the evaluation framework. It builds on findings presented in the two interim reports and includes evidence from evaluation activities conducted to March 2020. It is intended for review by Macmillan and key site stakeholders. The accompanying toolkit is available on the SCIE website at https://www.scie.org.uk/integrated-care/leadership/learned/mlap.

Key considerations

3.7 The initial evaluation specification described a **formative evaluation**, with data collection processes to be designed and introduced to collect baseline evidence. As the evaluation progressed, some emerging outcomes data were collected and analysed and these are presented within this report. However, partnership activities are continuing in the four sites, so further outcomes and impacts are anticipated.

[14] The MLAP services were generally referred to as the ICJ (Improving Cancer Journey) service in the Scottish sites. this report sometimes refers to the services in all three sites as the MLAP services and uses ICJ when referring to Dundee's or Fife's service alone.

[15] The first interim report presented evidence collected up to October 2018 and the second interim report covered evidence to July 2019.

3.8 Some other key considerations to bear in mind when reading this report are as follows:

- **Attribution**: In the absence of a comparator against which to measure changes in outcomes for people using the MLAP services, data have been triangulated to provide some degree of certainty that the MLAP led to positive outcomes observed. However, without a comparator it is not possible to assess the extent to which these changes would have occurred in the absence of the MLAP services, or to what degree.
- **Comparison**: In programmes such as this it can be instructive to look at differences between sites. However, comparison, particularly of outcomes, should be done with caution given the different contexts, approaches and models adopted, and variations in both the timescales for service delivery and available data. In addition, there were differences in how the sites interpreted and recorded HNA data and activity by the link workers/facilitators, meaning straight comparison is not always possible.
- **PABC surveys**: Only Fife had any respondents to the 9-12 month follow up PABC survey. Dundee and Durham had low numbers of responses to the 3-6 month post-HNA survey. Evidence on outcomes is therefore based on a small number of responses and is likely to be affected by self-selection bias, different approaches to offering the survey to service users and the length of time services were operational for. Surveys were not issued in Tower Hamlets where no new service was introduced as part of the MLAP.
- **Workforce survey**: Responses were low (34 in total across the three participating sites) and were unevenly distributed across sites. Fife and Dundee had significantly fewer responses than Durham. The survey was not issued in Tower Hamlets because the programme was not in service delivery mode and the questions would not have made sense to professionals.
- **HNA/eHNA data (hereafter referred to as 'HNA data')**: HNA data is generated by sites during HNA and care planning conversations. It includes demographic data on service users, information about their concerns, needs, actions and outcomes. Data were only available to calculate outcomes for two sites. Fife and Dundee used the electronic HNA data system to record data on each service user. These sites recorded each HNA undertaken with a PABC, providing a second (or even a third or fourth) data point for most service users (when follow up HNAs were undertaken). During the evaluation timeframe, Durham used a paper HNA, with their data recorded in a bespoke database. Each user only had one HNA record, with any updates being recorded in the same record. Therefore calculation of outcomes for service users was not possible for Durham, as it was not possible to evidence changes in individuals' HNA data over time.
- **Economic assessment**: Some of the values used in the economic calculations are based on small numbers of responses to the user and workforce surveys, and should be treated with caution. Optimism bias has been applied as appropriate.

4. Partnerships

4.1 This section presents findings and reflections regarding how partnerships were developed and evolved across the four MLAP sites (Dundee, Durham, Fife and Tower Hamlets). It is based on several waves of interviews with MLAP central programme and regional staff, site staff and key stakeholders, as well as participation in and observation of programme and site level meetings and review of site and programme documentation.

Summary - Enablers for successful partnership working

1. Partnership working can start quicker and be more effective in **established partnership systems**, where existing relationships between partners are often stronger and less early 'familiarisation' work is necessary.
2. Partnership working has been most successful where sites had existing systems in place to facilitate joined up working. It has been particularly effective where systems have **legally mandated integration of services and joint working,** notably in Scotland where the Scottish Health and Social Care Partnerships came into existence in 2016.
3. Effective and visible leadership is vital for successful partnership working. Local authorities face multiple competing priorities and tight funding pressures, so programmes such as the MLAP programme require **committed senior leadership**, within a set of effective governance arrangements, to ensure partners can agree and progress a shared vision.
4. A **clearly articulated rationale and aim** is fundamental to establishing an MLAP (and should be stated in the Partnership Agreement). Partners should be clear about their role and what they are expected to contribute, as this helps to ensure their continued engagement with the partnership.
5. To operationalise a partnership there needs to be a **strong programme / partnership manager** with team support, creativity and flexibility in developing approaches to deliver partnership aims. **Early planning for recruitment** of programme managers and other roles is important to avoid delays in mobilisation.

Barriers and challenges to successful partnership working

1. The current **climate of austerity is likely to pose funding pressures** to the programme once Macmillan funding ends. This is a risk to the sustainability of the progress made in sites. This is likely to affect not only the MLAP programme, but also those referring in and picking up referrals from the service.
2. **Engaging with clinicians can be difficult** due to different priorities, modes of operating, capacity levels and working cultures. This can be exacerbated by clinicians' experiences of multiple short-lived initiatives and change and complexity within local systems.

3. The local VCS is a vital part of the system for an MLAP, but individual **VCS organisations can feel vulnerable to changes generated by larger organisations**, in particular those which may affect their caseload numbers, even where there is not an immediate effect on them. Engagement needs to be early, frequent and approached in a spirit of partnership. There also needs to be a good understanding of the capacity of (and any impact on demand for) the local VCS, as this is likely to underpin the sustainability of MLAP programme approaches.

Macmillan's role

1. **Macmillan has invested significant resources** into the partnerships aside from the grant funding, although the scale and nature of support varied between sites. Support has involved providing tools, expertise and practical support, and has been valued by sites when it was tailored to specific issues and came at the right time.
2. This **support has come from multiple people and teams** within Macmillan. This highlights the variety of support needed at different stages of the programme, with each partnership having different local capacity, capability and need.
3. Working effectively with local stakeholders and partners relies on strong **relationships and high levels of trust**. There is evidence this has been achieved across the sites, although with some variations.

System

4.2 The sites had different health and social care systems. The differences have affected the speed at which partnership working could progress and the potential for change.

4.3 The Public Bodies (Joint Working) (Scotland) Act 2014 legislated for the creation of Health and Social Care Partnerships (HSCPs), which formally integrated health and social care with joint planning, monitoring and resourcing of some services. The partnerships had to be constituted by March 2016. Whilst at the time the MLAPs were established the HSCPs were immature, the legal basis meant that they were on a strong footing. The HSCPs aligned the aims, remit and accountability across health and social care more clearly than previously, and so Macmillan's ambition to pursue an integrated approach to the holistic needs of PABC was well aligned. Over time, the new organisational reality began to facilitate a change in culture, as staff became used to engaging with colleagues in both health and social care roles, with shared aims and responsibilities.

4.4 The England sites had their own structures in place to support partnership working but were not underpinned by the same legal basis as in Scotland. Health and Wellbeing Boards had a convening function, bringing together representatives from the NHS, public health, social care, children's services and the VCS. They assessed local needs and developed a strategy, but their role was more about encouraging integration than providing a formal basis for it.

4.5 There were local mechanisms in development in England:

- The Tower Hamlets Together (THT) Partnership was an integrated health and social care partnership which included the local authority, primary care, secondary care, NHS commissioners, and the voluntary sector. Its vision was to develop a shared culture of person-centred and coordinated care. The MLAP programme sat under the Promoting Independence Board of the THT Partnership and also reported to the Living Well Board. This governance structure also oversaw other transformation initiatives relevant to MLAP's aims. In addition, Tower Hamlets had an integrated commissioning directorate which straddled the local authority and the Clinical Commissioning Group (CCG) with a jointly appointed Director of Integrated Commissioning for Health and Adult Social Care in the Borough.
- The consequences of the different organisational structures in England were evident in the challenges faced by Durham's Joining the Dots service (JtD, as the MLAP programme was known locally). The programme was located within Public Health in the local authority, but limited public health funds meant that the MLAP had to look elsewhere for funding. The local Cancer Alliance has provided additional funds to supplement the service to March 2021.
- There remains no nationally mandated mechanism for integrated planning and distribution of resources in the England sites, unlike in the Scottish sites (although the Scottish mechanism is far from mature). However, there are nationwide moves to improve integration: Sustainability and Transformation Partnerships (STPs) between local NHS organisations and councils now cover all of England. The partnerships develop shared proposals to improve health and care in their locality. Some STPs are evolving into Integrated Care Systems, more formal collaborations between NHS organisations, local councils and others. These take collective responsibility for managing resources, delivering NHS standards, and improving the health of the populations they serve.

Leadership

4.6 Identification of leadership and support from senior stakeholders was a key indicator of site readiness for the MLAP programme. In 2015 when Macmillan approached a range of areas about the potential for an MLAP, they were seeking to establish shared values, agree a shared vision, and plan for a partnership programme amidst multiple competing priorities for local authorities. Therefore, there had to be individuals within the sites willing to explore the concept and get it mobilised.

4.7 In most cases this personal commitment came from those who subsequently continued to provide leadership and support to the programme:

- In Dundee, the CEO of the local authority chaired their Project Board
- Fife had high level support from their HSCP
- Durham's MLAP programme was championed by the Cabinet member for Adult and Health Services and Chair of the local Health and Wellbeing Board
- In Tower Hamlets, the partnership was given some impetus by the Interim Director of Adult Social Care who chaired the Board.

"I think it's been really helpful to have a Director of Adult Social Care who is really invested in the programme, who has steered his team to engage really openly, has been open to hearing about how the programme has been progressing and has made suggestions, has made appropriate links, and has connected me to individuals, people and forums." Tower Hamlets stakeholder

Relationships

4.8 Partnership working was reinforced by long-term relationships at individual and organisational levels. Some of the sites were able to draw on a long history of partnership working and capitalise on the experience and knowledge of particular individuals and their involvement in local work relating to cancer.

4.9 Dundee and Fife were able to build on a history of partnership working: in these two sites Macmillan had previously collaborated on a benefits service, a physical activity programme and palliative care. Both areas had also been involved in Macmillan's Transforming Care After Treatment programme (TCAT), which meant a host of professionals and practitioners locally had shared experience, at both a strategic and operational level. Some of the MLAP Board members had been involved in TCAT. In Fife, 1.5FTE local area coordinators who had worked in the TCAT service transferred to the Fife ICJ service.

"Dundee has partnership in its DNA -and this is meant at a deep level. They have a strong history of working together and are invested in Dundee as a city rather than just as a council." Dundee stakeholder

4.10 Sites identified that partnership working was most effective where there was **genuine openness to the perspectives and interests of others** and willingness to support each other and **compromise**. These attitudes engendered respect and trust which strengthened the partnership and allowed for concrete delivery and achievements, which in turn bolstered the partnership with a shared sense of success. Such experience was evident in Dundee, where the site reported pride in being able to mobilise their service largely according to plan. It was also evident in Durham, where genuine openness to the contributions of the co-production group delivered a model with strong buy-in and commitment across the board.

4.11 A **lack of openness and willingness to engage was reported in respect of some clinicians** in all sites, and was considered to be a consequence of multiple competing (and different) priorities, different modes of operating, experience of multiple short-lived initiatives that did not offer long-term benefits to their patients, and change fatigue. Learning from Glasgow ICJ indicated this could be a challenge. Sites tried to tackle the issue by undertaking extensive direct engagement with clinicians (e.g. holding sessions with cancer nurse specialists); they made differing levels of progress in this respect.

"Clinicians work with hard evidence so you need to provide evidence of impact and the difference that the service will make or else there will be scepticism…. There is a duty of care on professionals to make sure they do

no harm to patients, so you need to make sure it is going to work for them before they get referred." Dundee stakeholder

4.12 There was a fundamental challenge in linking a community focused programme housed in the local authority with healthcare professionals, especially given the volume and diversity of those engaged with PABC, even in sites where health and social care were formally integrated. This was because of different work cultures and priorities. It also mattered how healthcare professionals engaged with PABC: GPs for instance may only see a few patients who are diagnosed or treated each year. The challenge was recognised by programme managers and incorporated into their work plans.

Clear rationale

4.13 For partnership working to be effective, sites highlighted that a **clear rationale was needed**, namely an agreed assessment of the problem, a shared vision for the partnership (in terms of both the goal and how it might be reached), the offer and ask from different partners, and the added value for PABC. In addition, sites identified that partners were interested in an articulation of how the MLAP programme approach might be applicable to patients with other long-term conditions.

4.14 All sites shared a similar assessment of the problem (poor identification of and support for PABC holistic needs, although Tower Hamlets' problem stemmed more from poor communication and information-sharing, meaning PABC can struggle to access existing support) and **agreed a shared goal with Macmillan**, namely a desire to improve outcomes for PABC. This was fundamental to establishing partnerships and was **embedded in MoUs between each site and Macmillan.**

4.15 In Scotland, there was (and remains) a national commitment from the Scottish Government to roll out and fund a model like the ICJ model, which obviated most of the issues faced by the other sites. In the English sites, the agreed assessment of the problem was relatively uncontroversial (as was agreement of the high-level goal), but the structures were more complex and did not have the same legislative frameworks around integration as Scotland. This meant that in some cases setting up the programme was more complex.

4.16 **Challenges arose in terms of how the goal might be reached** in systems with multiple competing priorities and shifting health and social care landscapes, even where there was a shared assessment of the problem and joint vision. Part of the programme purpose was to experiment in how PABC non-clinical needs could be better met in different local contexts. Macmillan's current position is that any service that their programmes develop or support should work for both cancer and other long-term conditions. There may be a **challenge in communicating this clearly to partners**. Reconciling cancer and long-term condition priorities may not be (so) challenging where the identified problem relates more to coordination, integration and flow of people through services and the system (as identified in Tower Hamlets), than gaps in service provision or lack of service capacity.

Operationalising partnerships

4.17 All sites signed their MoUs, recruited their programme managers and began to operationalise their partnerships at different times. Tower Hamlets faced challenges in agreeing an **appropriate salary banding for the programme manager post**, whilst also having to adhere to a set of local authority administrative procedures for recruitment. Fife and Tower Hamlets both revised their banding to facilitate effective recruitment. Subsequent MLAP sites might **consider planning for recruitment earlier in the process**, mindful of the potential time lags often associated with recruiting key staff, and associated delays with mobilisation.

Critical enablers to mobilisation

4.18 Aside from the different start points, all sites took longer than they expected to progress certain aspects of their MLAP. Evidence from the sites indicated that there were some key elements to successfully operationalising a partnership:

- **Recruiting an effective programme manager**: the dedicated MLAP programme manager was required to influence a wide range of partners across multiple organisations and at different levels. In the English sites, where the system had fewer formal structures to facilitate integrated working and commissioning, the role of the programme manager in influencing partners became even more important.
  - In Durham, the programme manager came with strong experience of networking on challenging issues across different organisations, which proved useful to the early stages of bringing partners together, scoping the problem and designing a solution. When the service was up and running the site appointed a replacement postholder with experience of service delivery to manage the service (with the initial postholder taking up a new role in the local authority but maintaining strategic oversight).
  - In Tower Hamlets, the programme manager had strong negotiating and influencing skills, which helped bring a huge variety of partners to the table and endorse the MLAP.
- Recruiting **sufficient programme team capacity** was also key to making steady progress. In all sites, the **programme manager** was the first team member to be in post. Subsequently sites recruited additional posts such as **administrative/business support or coordination and co-production expertise.** This freed the programme manager from certain tasks and allowed them to focus their capacity on core partnership tasks such as relationship development and asset mapping.
- The extent of **preparatory work done by the partnership before the programme manager came into post** also influenced the rate of progress of the MLAP.
  - For example, Dundee and Fife set up a Programme Board before their programme manager started, so there was already a governance structure to build on. Previous asset-mapping completed by TCAT programmes also gave MLAPs a foundation on which to build.

- Linked to this, the **existing structures** on which a new pathway/model could be established made a difference to how rapidly an MLAP was developed.
  - Dundee and Fife were both able to set up a new service within their HSCP: this direct delivery was an accepted model of provision within Scotland, informed by learning from Glasgow ICJ.
  - Durham identified a provider who was delivering a wellbeing service locally as a candidate for delivering their MLAP service. The provider had staff familiar with undertaking HNAs (non-cancer specific) and signposting people to further support. It had structures and processes in place for recruiting, training and supporting staff, for recording data and knowledge of the local context, all of which the MLAP service could 'piggy-back' onto.

4.19 Delivering on core partnership tasks was partly influenced by the **context** in which the site was operating: for example, tasks in the scoping period such as asset mapping were more difficult where the local landscape was more complex and dynamic, and easier where there were support structures or services available. For example, the Scottish sites benefited from having a National Cancer Registry from which they could source relevant data to understand the local cancer landscape.

Challenges

4.20 In a context of limited public funds, the availability of funding from Macmillan was welcomed by many at local partnership level, but it also posed challenges. The MLAP programme funding was intended to help sites to identify issues, design solutions and pilot models, and was not meant to be used for longer-term service delivery (the intention was that following initial piloting, any sustained delivery would be funded by local partners, informed by the evidence generated through the pilot). However, among local authorities under financial pressure, **identifying sources of future funding was challenging,** even where there was positive early evidence about the effects on PABC.

4.21 VCS organisations across three sites expressed varying degrees of concern about how the **MLAP programme funding might disrupt the local landscape of referrals and provision**. While there was no concrete evidence that MLAPs drove increases in referrals at levels that presented difficulties to VCS organisations (even small and largely volunteer-staffed organisations), a perception persisted that this remained a risk. Sites tried various mechanisms to build relationships with and involve the VCS, for example by including them on their Boards, and keeping track of referrals/signposting. This continued engagement and monitoring was key to forestalling any problems.

4.22 However, there was no mechanism for funding to 'follow the person' and the local VCS also expressed some concerns that by providing funding to the local authority, Macmillan missed the opportunity to invest in small, local VCS organisations that already served their target users and populations. This was referenced in two sites.

"If local charities weren't there, Macmillan could not do this project. But local charities need support and need fundraising… There is a good local

third sector network… they [Macmillan] need to work with what is already there." Site stakeholder

Macmillan's activities and support to local partnerships

4.23 Macmillan provided a range of inputs to the MLAP sites. First and foremost, it provided the **concept, supporting evidence** to make a case to initiate discussions with potential partners, and the **funding** to get the programmes and mobilisation underway. There was also collaboration with partners to create the **Macmillan Partnership Agreement** which outlined the key principles of the partnership.

4.24 Subsequently, inputs came from three main sources: the **national programme team; the regional teams; and specialist support from within Macmillan** such as finance and system engagement. Expertise was provided to sites (to varying degrees) on topics including how to undertake co-production, how to consider financial sustainability for a service, and how to recruit service staff. This represents a considerable level of investment, made possible by the size and scale of Macmillan's remit and team and their organisational experience.

Learning regarding Macmillan's support and activities

4.25 ***Being nimble:*** Sites appreciated Macmillan's support when it came at the right time. For example, Macmillan played an important role in organising the recruitment process for the programme managers in Fife and Tower Hamlets. They helped to draft job descriptions, which helped to ensure the right person was found for the post. On the other hand, sites found working with the national communications team to be challenging, with agreement on branding of communication materials taking longer than expected locally.

4.26 ***Branding:*** Linked to the point above, it was felt that Macmillan's branding sometimes dominated to the exclusion of local groups. The role of Macmillan branding caused sensitivities in some sites. In one site there was confusion as to why the site was unable to use Macmillan branding and benefit from the charity's reputation. In other sites, it was felt Macmillan was too rigid about branding activity, with insufficient profile being given to local parties. Small local charities are sensitive to the impression that their own contributions are less well promoted. They expressed concerns that this may reduce the chances of them receiving funding to sustain the services on which MLAPs rely if their contribution was not widely recognised.

4.27 ***Tackling specific issues****:* Rather than generic support, sites valued tailored support for specific problems.

- Macmillan brokered engagement with the ICJ service in Glasgow to enable the MLAP sites to learn from that experience[16]
- **Bespoke, defined, agreed contributions** were an efficient way for Macmillan to help the partnerships to achieve the agreed goals.

[16] https://www.macmillan.org.uk/_images/Glasgow-improving-the-cancer-journey-programme-full-evaluation_tcm9-301271.pdf

4.28 From the outside, **Macmillan was reported by some to appear to be a large, complex organisation** in which different parts were not always as well coordinated as they potentially could have been. Macmillan was also perceived to fund a range of roles and programmes that were not always fully aware of each other or did not seem to share the same agenda, sometimes producing **confusion among local stakeholders**. In one site, existing services funded by Macmillan perceived the MLAP programme as competition, a perception that could perhaps have been more effectively addressed by the Macmillan regional team.

Overall reflection

4.29 Through a combination of contextual circumstances, effective leadership and governance, high quality programme managers and teams, and the momentum generated through Macmillan's funding and support, partnerships were developed that were able to introduce services that ensured the non-clinical support needs of PABC were identified and they were able to access appropriate support (more detail on outcomes for PABC is provide in Section 7). In the case of Tower Hamlets, (at the time of writing) the partnership reached the point of agreeing other changes with local partners to ensure PABC could better access support for their non-clinical needs.

5. Model design and development

Introduction

5.1 This section of the report describes the process of designing and developing the key elements of services and models introduced as part of the MLAP programme. It examines key elements of the process including co-production, wider stakeholder engagement, commissioning arrangements and resources that were used.

5.2 The section explores why these routes were taken and the associated advantages/disadvantages of the different approaches to design and development. It presents issues to consider for future development of existing or new MLAP sites. The following sections consider learning from service operation to date and findings on outcomes.

Summary of findings

5.3 Following a wealth of activity in the four sites, three sites operationalised a service model supporting PABC and capturing data, whilst one site was developing plans for the delivery of a range of ideas developed through a co-design process, focusing primarily on changing ways of working and levels of integration.

Key findings – enablers and 'what works' in MLAP service design

1. Spending significant **time on scoping activities** prior to service model design and development is important. Each site spent time scoping out the local demographics and cancer data, mapping local assets and pathways, coproduction and liaising with a wide range of stakeholders to fully understand the context and how it would affect (and be affected by) an MLAP. **The time required for this should not be underestimated**; a clear plan with milestones is key to ensuring stakeholders remain reassured regarding progress, to help sustain momentum, provide clarity, and manage expectations.

2. **Services are not static**: this includes MLAP services and other services, including other roles such as social prescribers. There was agreement in the partnerships that the services delivered under the MLAP programme must be monitored to ensure they remained appropriate within a changing local and policy context. **Services must be sufficiently flexible to adapt to emerging learning** on what is working well and what is working less well. Monitoring this at operational and strategic levels is key.

3. There are different possible service models (under local authority control, commissioned services etc.) but within them **facilitator or link worker roles appear to be key. These require a core set of skills and expertise**, centred around effective communication and networking.

4. The current **policy context is credited as being a key enabler of the MLAP work**, namely, the integration agenda, the growing understanding of cancer as

a long-term condition, the policy commitment to personalisation, and the rise of social prescribing.

Challenges and barriers

1. All sites have commented on **how challenging it is to maintain up to date knowledge of community assets**. A solution has not yet been identified although there is work in progress: the Scottish Service Directory created by NHS24 is in the process of linking with ALISS (A Local Information Service for Scotland), which provides information on health and wellbeing and VCS services for people living with long term conditions, disabled people and unpaid carers.
2. As noted above, facilitators and link workers require specific types of skills and expertise. However, these roles currently **lack clear career progression routes**. This risks staff turnover, as talented or ambitious post-holders gain experience and may wish to move on, particularly if recruited on temporary contracts. This could undermine the consistent delivery and effectiveness of the services if knowledge and/or networks are lost.
3. **Take up of the service is likely to increase gradually**: staff need to be supported through changes in service usage and demand rates, and stakeholder expectations regarding caseloads and reach during the early stages of implementation need to be managed.

Service development

5.4 Sites approached the development of their service model in different ways.

- **In Dundee and Fife, there was a strong focus on understanding the Glasgow ICJ model,** given the similarities in demographics. There was merit in this approach; identifying key principles and learning from Glasgow meant that Dundee and Fife were not starting from scratch. However, it took time to understand and account for the local context; for example, housing issues are not as significant an issue in Dundee as in Glasgow, which was only realised after the service became operational and PABC concerns were recorded. The programme teams required confidence in the emerging data to adapt the model to Dundee's/Fife's circumstances.
- In Durham, the co-production group (details are provided later in this section) was supported to analyse patient, carer and stakeholder engagement work to clarify the problems locally, and given scope to identify a solution (that had to be reasonable within the available funding and other parameters). The service specification was developed based on the vision developed by the co-production group. Although the model devised was fairly similar to the ICJ model in Scotland, because of the way it was generated it had a huge amount of credibility and commitment locally.
- **Tower Hamlets began with a scoping period** that included an asset mapping exercise, commissioning of a Cancer Health Intelligence report, hosting a series of focus groups to gather insight from local PABC, and engagement with key

professionals in services and organisations across the system. Lack of integration and information sharing between existing service provision was found to be the key issue, in contrast to the other MLAP sites. Subsequently the site identified the functions key to better integrated working across agencies and co-designed a holistic support pathway for PABC. Tower Hamlets is likely to adopt a different approach to delivery to the other sites. It will focus on better coordination of support between agencies, improving ways of working within and between teams and supplementing existing arrangements for assessment of holistic support needs, rather than setting up a new independent service.

5.5 A common message from stakeholders was **the importance of preparation prior to the design and development of the service model, with a focus on understanding local needs and responding to findings from the scoping phase.** All of the sites spent a significant amount of time scoping out the local demographics and cancer data, mapping local assets and pathways, and liaising with stakeholders to properly understand the context and how it would shape an MLAP.

5.6 Beyond the scoping period, sites tried to **maintain their awareness of relevant local and national developments**, recognising that the context is not fixed at the point at which scoping concludes. All sites commented on the **challenge in maintaining up to date knowledge of community assets** (in particular), which can quickly evolve as new services are commissioned/established, and others cease to operate or change their criteria. For the sites delivering a service, the offer is assessment of needs and referral/signposting: the site is dependent on external organisations for delivery of that support. For Tower Hamlets, supporting the local health and care system to implement changes is subject to partner agencies agreeing to share information and collaborate to bring about different ways of working.

5.7 There is an ongoing need for **review of and challenge to the services**. In Durham, some members of the co-production group will move to the Steering Group in order to take on this role and continue offering challenge to professionals. In Dundee the Cancer Voices group continues to be represented on both the project team and Board.

Team capacity and staff development

5.8 There was significant investment in team development. For example, in **Dundee and Fife**, prior to delivery the **facilitators completed Macmillan training and undertook shadowing of Glasgow ICJ workers**. These activities were considered particularly valuable. The facilitators/link workers also undertook local authority training modules, spent time with nursing teams to understand the services currently being delivered, and received support from the Macmillan Nurse Consultant (Cancer), who is a trained coach, clinical supervisor and mentor, and who provided formal clinical supervision (via peer learning sessions for facilitators) and formal evaluations. The workers received ongoing support from the programme manager and attended action learning sets. In **Fife**, in addition to the action learning sets, speakers presented at team meetings, for example those running local support organisations.

5.9 Despite some debate around the type and level of expertise needed for the facilitator or link worker roles, there was a **core set of skills** that seemed to be important, namely effective communication and networking.

- Fife understood the role and responsibilities of the TCAT workers, having inherited two (1.5 FTE) local area coordinators from the TCAT service, which gave them some confidence in understanding the skills needed for the MLAP roles.
- Similarly, in Durham the provider awarded the delivery contract was already providing a wellbeing service, and considered that many of their workers' skills were transferrable. Half of the current six JtD (MLAP) workers transferred from the wellbeing service to the MLAP service. This was identified locally as one of the benefits of awarding the contract to an existing provider, but also posed a challenge in ensuring facilitators were clear on the distinction between their old and new roles.

> *"There was debate and discussion around the level of practice needed for the role [of support facilitator]. As it has turned out, the level that the facilitators are at is effective. You don't need senior people doing the role, you need effective communicators and people who have the skills, networks and determination to keep going." Dundee stakeholder*

5.10 A key issue for staffing services (or for Tower Hamlets, supporting staff working in multiple organisations) is the maintenance and development of the skills and experience of existing staff in a context of a **lack of clear career progression.** While many clinical roles have formal career pathways, link workers, facilitators and similar staff do not have the same recognition and formal pathways with corresponding pay and benefits structures. This risks a high turnover, as talented or ambitious post-holders may move on to other organisations offering better opportunities. This could undermine the effectiveness of the services if knowledge and networks are lost. Sites had not experienced the loss of experienced frontline staff within the MLAP programme timeframe but were concerned about the risk it posed to future delivery.

Alignment with local priorities / strategy

5.11 Alongside operational delivery, sites have tried to maintain a strategic focus on how their services or models should develop within shifting contexts.

5.12 The health and social care integration agenda was growing stronger and remains a priority. The MLAP programme was already aligned with this agenda and Macmillan was able to offer insights on the evolution of this agenda at a national level. However, sites had to be alert to local developments such as the availability of funding pots and changing preferences for different types of support models, as well as shifting roles within local systems.

5.13 Cancer is being increasingly viewed as a long-term condition in both England and Scotland. For example, in Tower Hamlets, the MLAP programme team and Macmillan GP developed and co-facilitated training sessions on personalised care and cancer as a long-term condition. These sessions were funded by Health Education England and attended by multidisciplinary professionals.

5.14 At the same time, social prescribing was increasing in profile and reach. The new Primary Care Networks in England were allocated funding for social prescribing; the MLAPs will need to be alert as to how they interact with these developments. There may be a risk of duplication or confusion within local systems if alignment between MLAP services and other social prescribing is not carefully considered, at both strategic and operational levels. Tower Hamlets for example, identified a number of potential overlaps and synergies and was working with primary care partners locally to influence the role of the new social prescribers.

5.15 As opportunities arose, sites actively tried to position themselves to take advantage of them. For example, the ICJ in Fife was included in the HSCP's Strategic Plan for 2019-2022. In the context of a tight fiscal climate and associated restructuring of services, it was important for the ICJ service to be given this strategic commitment. The Plan included the goal of establishing an opt-out model, whereby every person in Fife who received a cancer diagnosis would be offered the service by NHS Fife, trying to ensure 100% coverage where even the ISD letter does not reach every person diagnosed with cancer (due to data issues).

Co-production

Key findings – enablers and barriers of co-production

Enablers of co-production

1. Co-production groups offered **insight and enthusiasm** to programmes from different perspectives to that held by local authority staff and partners. This was seen as extremely beneficial to MLAP development and refinement.
2. Elements designed by the co-production groups were **seen as having more credibility** by some partners and stakeholders, leading to greater buy-in from stakeholders.
3. Development of **clear terms of reference and role descriptions** for the group and its members was key to ensuring coproduction panel members (and others) were clear about their remit and responsibilities, as well as stating how their contributions would be utilised.
4. A workshop led by an expert in co-production, for the Durham MLAP programme team helped to firmly set the basis for understanding what genuine coproduction should look like.

Barriers and challenges to co-production

1. Co-production groups challenged aspects of the programme and asked for modifications; indeed, this was a key part of their role. While this proved effective in helping to inform improvements to the programme, it sometimes **required additional (and unexpected) time and resource** from project teams to respond to feedback and comments and make modifications. **The resourcing of co-production activities needs to be carefully planned,** with sufficient time allocated to act on feedback and report back to group members to avoid a perception that their input is not being considered or acted upon.

2. **Recruitment** of passionate and committed individuals was challenging for several reasons. **Sites tapped into a range of channels** to reach potential co-production group members. This included existing user involvement initiatives, various local communication channels and networks, and charities. Flexibility proved key to recruiting diverse and sufficient numbers to the group.

Activities

5.16 Across the sites, co-production volunteers were involved in the MLAPs in a range of ways. Dundee, Fife and Durham all formed co-production panels. Some volunteers migrated into the MLAPs via previous user involvement initiatives, but sites also recruited new members through communication activities and local networks. Durham recruited through a range of routes including early engagement events and contacting members of existing charity organisations.

5.17 Tower Hamlets initially did not establish a formal group to meet regularly but did undertake engagement with local communities through focus groups. The site reflected that formation of a formal group was not the right model for co-production in their locality at that stage, due to people's personal circumstances and competing demands. Instead, they formed a virtual co-production group, made up of a network of the forty-eight PABC who attended five engagement sessions and others who expressed a desire to be kept informed and involved virtually. Their input was sought on an ad hoc basis and they contributed to the co-design workshops that developed a 'holistic support pathway', change ideas which led to the final list of deliverables, and identified the functions required to deliver high quality integrated personalised care for PABC in the borough.

> *"Some of the people that come to the focus groups are needing to work throughout having chemotherapy treatment, because they are on low incomes and need the money in order to pay rent and bills". Tower Hamlets stakeholder*

5.18 Tower Hamlets stakeholders reported gathering rich insights from speaking to 48 PABC across five sessions from a diverse range of communities and age groups, including carers. Tower Hamlets also developed case studies showcasing the challenges faced by people and where and how these were supported or exacerbated. These case studies were used to deliver cross-sector training on integrated working and the 12 co-design workshops with stakeholders.

Contribution of coproduction panel members

5.19 There were several core types of activity or involvement with PABC, which evolved within sites according to local understanding of what co-production involved and the experience of programme teams, with some advice from Macmillan when requested. These included:

- **Design support:** co-production volunteers helped to identify and define the particular issues facing PABC locally and provided input to potential solutions.
  - This was exemplified by Durham, where a new group of co-production volunteers were sourced and multiple meetings held for them to go through a process of eliciting and identifying local issues, then exploring potential solutions.
  - All sites also involved PABC in identifying local issues and designing possible solutions to improve holistic support.
- **Delivery support:** co-production volunteers delivered activities in support of the programme, such as being involved in link worker and programme manager recruitment, delivering promotional events to raise the profile of the service, redesigning the social media offer, and helping to support link workers in the delivery of HNAs. This highlights the range of skills and interests needed amongst panel members – and those supporting co-production from the programme team.
- **Advisory:** co-production offered the programme team insights or advice on particular topics. For example, co-production groups reviewed MLAP materials such as communication materials and evaluation surveys, and set up a peer review steering group to re-purpose their role as the MLAP there shifted from design into delivery. This latter point highlights the flexibility needed in how the panels function and operate, to reflect partnership evolution locally. This requires careful negotiation with panel members, to ensure the remit continues to suit both panel members' needs and partnership requirements.

5.20 Across all sites, co-production was seen as an invaluable element by the local programme team and Macmillan. The co-production volunteers offered **experience and insight not available elsewhere**, and often brought **welcome and useful enthusiasm and honesty**.

"[I'm] pleased to have been part of something that is benefitting so many people. It makes me realise that having patients' and carers' input is invaluable when setting up a new service." Site stakeholder

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5.21 **Sometimes the co-production contributions proved challenging to manage alongside professional delivery of the programme**. Partly this was due to the emotional nature of the work and group members' own experiences: in one site, one of the co-production volunteers died during development of the MLAP, which had a significant impact on group members. Co-production, by its nature of involving people with diverse lived experience, produced demands and feedback that the programme team could not necessarily plan for. For example, the Durham co-production group disliked some of the initial branding and the team felt they had to revisit it to respect the views of the co-production panel.

5.22 The **voice of PABC was often key to generating real engagement from partners and stakeholders**. Being able to state that the Durham service model was designed by PABC provided credibility among local stakeholders such as cancer nurses. It was also critical to accessing harder to reach groups. Tower Hamlets was particularly alert to issues of diversity,

accessibility and equity among its population, and a programme team member spent a lot of time engaging local community and patient groups who could then raise awareness among the community and involve them in co-production. In one site, the inclusion of a member of a deaf charity in the co-production group meant the programme gave specific consideration to the needs of people with impaired hearing and used the learning to ensure they were sensitive to other types of needs.

5.23 Interestingly, the **volunteers themselves did not necessarily see their contribution in such a positive light.** Co-production group members were most positive about their involvement where they felt they had played an active role in shaping the programme, such as by designing the outlines of the service model in Durham. Many also appreciated the opportunity to get involved with this type of programme and develop their own skills and networks. Some of the Durham co-production group members developed genuine friendships out of the process. But in other sites (in particular where people felt they were asked to simply provide advice) they were typically less satisfied, and in some cases felt that their inputs were asked for but then ignored.

Learning regarding coproduction

5.24 **Informed support:** Expert support for co-production was welcomed by the sites, although it was provided in various guises. For example, one site had a role dedicated to co-production within their programme team and one had a team member with coproduction expertise, while the others utilised Macmillan and local support to effectively engage with co-production, such as on how to define roles, what accessibility arrangements to put in place and what tasks to involve co-production groups in. **Managing co-production requires a certain skillset and sufficient capacity**: in some cases the programme manager may be able to run this aspect of the MLAP programme, but dedicated support (such as providing co-production policy documents, recruitment strategies and workshop management) can help. Macmillan has access to these types of resources, although in Tower Hamlets the regional team's contribution was limited by their capacity. Sometimes sites may have co-production resources locally within their partnerships that they can access; understanding what skills are available, where from, how much capacity there is, and what skills are needed, is key.

5.25 **Clear role:** Given the correlation between levels of volunteer satisfaction, credibility of and buy in to the models and levels of PABC involvement in the MLAP, it is probably better to allow PABC a greater rather than a lesser role in the programme, along the lines of Durham's approach, especially given that the aim of the programme is to improve support for PABC. However, whatever approach is adopted it is vital to provide clarity on the roles that PABC are expected to play in the MLAP, and how this might develop over time. As noted previously, the MLAPs evolved and changed and the role of co-production should therefore evolve (and be expected to evolve) in tandem. Different skills and experiences of co-production group members and staff are therefore likely to matter more at different points.

5.26 **Timing:** Identifying when it is most effective to engage service users in co-production is difficult in advance; it is important people feel their contribution is meaningful and valued. Where sites are progressing slower than expected, it can be challenging to maintain engagement from some co-production volunteers. A more flexible approach to gaining contributions may therefore be appropriate. On the other hand, a well-established group may

be better able to make useful inputs. Durham's panel was considered to have been particularly effective; the site took time to establish the group before asking for concrete inputs.

5.27 **Equity:** The background evidence indicates that the PABC typically most unlikely to get additional support with their non-clinical needs are those from disadvantaged backgrounds, black and minority ethnic communities or with English as a second language[17]. Services often find it hard to access these groups, and vice-versa. Co-production volunteers can offer a significant contribution by suggesting better ways to provide services to these groups, understand their needs and raise awareness of services available to local communities.

5.28 **Capacity:** Effective management of co-production requires capacity and expertise among the MLAP programme team and/or support from partners e.g. the Macmillan team with the relevant knowledge. In Tower Hamlets, for example, co-production focus groups were convened once a dedicated member of staff with the right expertise was appointed to undertake this work. It is important to consider when capacity might be needed and what types of inputs / expertise might be required.

[17] https://www.macmillan.org.uk/_images/BME-groups_tcm9-282778.pdf

6. Service delivery

6.1 This section presents findings on the services delivered by three of the MLAP sites (Dundee, Durham and Fife), insights about their service users, and some reflections on the approach taken by and achievements of the fourth site (Tower Hamlets). It draws on qualitative evidence gathered from site and programme documents, interviews with programme and site staff and stakeholders, data from workforce and user surveys, and quantitative HNA data.

Summary of key findings – service delivery

- To ensure wide and equitable access, it is important to **generate referrals from multiple sources.** It is particularly important to build confidence amongst clinical professionals to encourage them to recommend and refer into the service, as they are in contact with (and generally trusted by) PABC.
- Sites need to **balance full personalisation against delivery of a cost-effective service**. Choice of setting for HNA is a good example of the tension between offering service users the most personalised approach and using link worker time to maximum efficiency. Whilst home-based assessments may be preferable (and the only accessible option) for some, this has travel time and cost implications, limiting caseload capacity. Use of community settings may be an appropriate compromise. Services also need to be efficiently and effectively staffed for management, frontline delivery and administration.
- **Different delivery vehicles are more or less appropriate for different contexts.** Scottish HSCPs, by nature of their organising structure, were better set up to directly deliver a service than English local authorities.
- Sites **were dependent on the wider support landscape for options for onward referral and signposting**. Services had to maintain their knowledge of local provision and maintain (and build new) links with the VCS.
- **By the end of December 2019, 1,534 PABC had used the MLAP services and 2,117 HNAs had been undertaken.** The demographics of service users are what might be expected in terms of age and gender. However, there may be a case for greater outreach to deprived populations.
- A **significant proportion of service users shared their care plan with their GP after their first HNA,** providing a way to share information across the system.
- Service users identified **non-clinical concerns**, most commonly relating to finances, tiredness, moving around (physical mobility), and housing.
- There is **scope for learning more about actions in care plans and onward referrals.** For example, if referrals are taken up, what the impact is on those organisations, and how useful the support was.

Service models

6.2 Service delivery was undertaken in three of the MLAP sites: Dundee, Fife and Durham. There were similarities and differences between the sites that can provide learning for programme stakeholders (and other potential sites or partners looking to implement a similar model).

Referrals

6.3 In **Dundee and Fife, the ISD (now part of Public Health Scotland) was commissioned by the Scottish MLAPs to send out an invitation letter** to every person receiving a cancer diagnosis who met the eligibility criteria. The sites had to pay ISD for this service. The responsibility then lay with the individual (PABC) to call the number provided and arrange a call back, which in most cases led to an appointment for an HNA. Both **Dundee and Fife also received referrals from cancer nurse specialists, other clinicians and services**, including services which are not cancer specific, plus local authority and VCS organisations.

6.1 Data on sources of referral for Dundee and Fife identified a wide range of referral sources: 27 different sources in Fife and 12 in Dundee. Overall, the most common source of referral within both Fife and Dundee was the ISD letter. In Fife other common sources were NHS Fife, self-referral and a reminder ISD letter. In Dundee the next most common referral sources were Welfare Rights, cancer nurse specialists and self-referral.

6.2 **In Durham, there was no comparable facility to the ISD letter, so the JtD service relied on people self-referring** after encountering the service's leaflets or website, **or referrals from partners** within local hospitals, primary and community care, the Macmillan Information Centre, Job Centre Plus and the VCS.

6.3 The ISD letter is likely to have helped the Scottish sites gain referrals earlier than Durham, which had to rely on its own promotion and engagement efforts to publicise the JtD service.

6.4 There were two key issues in respect of referrals:

- **Access –** while Macmillan takes a universal approach to its service offer, like all organisations it has limited resources. The principle of **proportionate universalism** is therefore relevant, i.e. ensuring that support is proportionate to people's needs and levels of disadvantage. In the case of the referrals, this means making a particular effort to publicise the service and make it accessible to more disadvantaged sections of the population, who (wider evidence suggests)[18], are typically less likely to engage with services. Referrals from healthcare professionals who have direct contact with people receiving cancer diagnoses can help to encourage those from disadvantaged backgrounds to contact the service, when they might not act on other information.

- Relatedly, to encourage referrals from professionals, it is key **to raise awareness and convince them of the value of the service**. One obstacle was the perception of duplication between clinical and community HNAs. However, where clinical services delivered HNAs, these were reported to typically have a different focus and outcome from an MLAP HNA (delivered in the community), because of the experience and skills

[18] https://www.macmillan.org.uk/_images/BME-groups_tcm9-282778.pdf

of the person conducting the HNA. For example, clinical staff are likely to have less knowledge about the financial issues faced by PABC, which reportedly may mean they are less likely to pick up on such concerns (although this may not always be the case). On the other hand, stakeholders also reported that PABC are likely to tailor their reporting of concerns to their perception of the experience of the professional they are speaking to. This differentiation needs to be clear to potential referring professionals. The evidence suggests that referrals from professionals to MLAP services build over time. Work by sites to raise awareness of professionals, particularly through sharing evidence of success, is beginning to build confidence and encourage referrals.

Pathways

6.5 In all three sites, once the team received the telephone call or written referral, **contact was made with the PABC to check eligibility for the service** (in terms of age and address) and basic information by an administrator.

6.6 Usually a home-based appointment was arranged to take place a relatively short time afterwards, but this was informed by the preferences of the PABC and varied according to site capacity. In Durham, the expectation was that the first appointment could be done within five days. In Fife the goal was to have the first appointment within ten days of a person contacting the service. The speed at which appointments could be delivered depended on the number of staff against the number of referrals. **Durham opened its service with six FTE link workers, whereas Fife opened with 1.5FTE (which increased to 2.5 FTE link workers) and Dundee with two link workers.** These numbers were based on an assessment of the numbers of people with a cancer diagnosis in the site.

6.7 Site **capacity also influenced the way in which a service user progressed through the service.** In Fife and Dundee, the first appointment was typically the only face to face appointment, so the full HNA was conducted at that meeting. Any subsequent engagement tended to be via telephone. In Durham, in the early stages of service delivery before referrals increased, link workers visited some people two or three times to do the HNA and develop a care plan. Even as the service evolved, the approach was to be service-user led and seek to meet the individual's needs in terms of the number and mode of appointments. With the small teams of link workers, it was reported that, at times, staff absence and this delivery model placed pressures on the service.

Care plans

6.8 In all three sites once the HNA was conducted a care plan was developed. The process was intended to be experienced by the PABC as a conversation rather than a checklist, and not all service users may have been conscious of having developed a 'care plan'. Nevertheless, they should have been aware of the action(s) to be undertaken to address their concerns.

6.9 Sites reported supporting their service users to take action in multiple ways - from referring them back into statutory services if they were unaware of their entitlement, to signposting them to VCS services, or, in Durham (particularly in the early stages when there were low numbers of referrals in comparison to facilitators), offering direct support such as advocacy with landlords.

Delivery vehicles

6.10 Dundee and Fife adopted the tried-and-tested ICJ model from Glasgow, also reflecting learning from TCAT programmes, and used the local HSCP to host their service.

6.11 In contrast, Durham considered several options: in-house local authority delivery; a new competitive tendering process for a private provider; or a contract extension for an existing provider. The existing provider option was selected as being lowest risk and quickest to mobilise. The contract was awarded to a partnership between a hospital trust and voluntary sector provider already delivering a wellbeing service. This allowed the MLAP service to benefit from the existing provider's infrastructure and its experience of serving the local population, facilitating quicker mobilisation and some reassurance about the expected quality of delivery.

Service evolution

6.12 **Delivery models in each of the sites evolved** as teams adapted to changing circumstances such as increasing referrals. They also adapted in response to identifying what worked well and what should be changed, for example switching the initial phone call to the user from facilitator to the administrator, and exploring new referral routes.

6.13 A key challenge all three services confronted was striking a balance between home and community locations for conducting HNAs. Travel time could be considerable, particularly in rural areas such as Durham and Fife, reducing the amount of time link workers could spend face to face or even on the telephone with service users. Home visits were seen to be beneficial for PABC in terms of making them comfortable and avoiding access issues, particularly for vulnerable individuals. However, sites also recognised the value of link workers being present at community venues, in terms of making connections with potential support options, making the service more accessible to some service users, and providing a route for promoting the service. Fife link workers began to gradually see more people in community settings; Durham piloted the use of community hubs.

> *"Probably the biggest challenge with the service design is home visits. They are travel intensive and sometimes when you are in someone's home, time goes out of the window." Fife stakeholder*

6.14 Services were actively monitoring uptake and experience of workers and users to address gaps and improve experience and outcomes. One major focus was identifying appropriate support options to meet different needs. For example, in Dundee, housing was found to be a concern for some service users. The housing department was approached and helped to identify housing champions across the teams and external providers that could support workers with individual PABC cases. Fife also worked closely with their housing department at a strategic and operational level. Of course, the ability to address needs was dependent on what support was available in a local area. For example, a small befriending service for PABC in one part of Durham did not cover the entire MLAP footprint.

6.15 Sites were contributing to local integration by highlighting the gaps between services for PABC and identifying solutions:

- In Durham the majority of acute cancer care is provided outside of the county, and hospital staff in those units tend not to know what is available locally. Similarly, Fife does not have a cancer centre and people with cancer travel to Edinburgh/Glasgow/Dundee for radiotherapy. The MLAPs supported PABC by collating local knowledge and signposting to relevant local support
- In Dundee, coproduced health and wellbeing events brought clinical and community services together.

6.16 One ongoing area for development among sites was **how to effectively deploy volunteers**. Different options had been and continue to be explored, such as peer support to provide additional emotional support for PABC. In Durham, a buddy scheme for co-production volunteers to support the JtD staff was under consideration.

What we know about service users

Key considerations and limitations in the data

6.17 The evaluation faced challenges in collecting, comparing and aggregating data for the three sites engaged in service delivery. Fife and Dundee used the eHNA data system to record data on each service user and their progress through the service. Durham used a paper HNA and recorded the data in a bespoke database which did not directly match the data fields of the eHNA system (both these systems were set up independently of the evaluation). There were also differences in how the sites interpreted and recorded HNA data and activity by the link workers/facilitators.

6.18 Below are some emerging findings based on data drawn from extracts of Dundee's eHNA data, Fife's eHNA data and Durham's database. Analysis of the data provides evidence on the demographics and circumstances of service users, and the activity undertaken by the service. Due to the differences in data recording and availability from the three sites, there is some variation in what is reported for each site. Where possible, comparable data is presented for all three sites.

6.19 Some of the findings should be interpreted with caution due to small sample size or data quality issues. The analysis and findings were tested with Dundee, Fife and Durham to clarify understanding of how data are recorded and interpretation of findings.

6.20 Fife and Dundee recorded each HNA separately (e.g. if people had more than one HNA, these were recorded separately) whereas Durham recorded a single HNA for each user (updating that original record if second or further HNAs were undertaken). This meant that analysis of changes from first to second HNA was only possible for Fife and Dundee service users[19].

[19] Durham could record progress for individual service users but it was not possible to quantitatively assess change due to the nature of data recording. Due to the nature of data extracts from Fife, some of the data are only provided for a subset of service users with two HNAs.

Service user numbers

6.21 By the end of December 2019[20], **1,534 PABC had used the MLAP services[21] and a total of 2,117 HNAs had been undertaken.**

Table 6-1: Number of service users (by the number of HNAs in each site), 2017/18 – 2019/20

Site	Service users with one HNA (%)	Service users with second HNA (%)	Service users with third HNA (%)	Service users with fourth HNA (%)	Total service users (100%)	Number of HNAs
Dundee	200 (43%)	257 (55%)	6 (1%)	2 (0%)	465	740
Fife	289 (51%)	249 (44%)	25 (4%)	3 (1%)	566	874
Durham	503 (100%)	-	-	-	503	503
All sites	**992**	**506**	**31**	**5**	**1,534**	**2,117**

Note: Categories are mutually exclusive

Source: SQW analysis of HNA data

6.22 Knowledge of service users is helpful to understand whom the service is reaching, to assess if it needs to take action to reach underrepresented groups, and to learn if there are appropriate support options for its users, for example exercise options suitable for older people.

Demographics

6.23 The demographics of service users in all sites were fairly similar to what would be expected, given what is known about the demographics of people affected by cancer in the local populations. **Service users were older, slightly more likely to be female and overwhelmingly white British.**

Table 6-2: Key demographics of people using the services

	Dundee	Fife	Durham
Median age	66	70	65
Female service users	55%	58%	58%
Service users identifying as White British	97%	98%	56% (NB. high non-response rate)
Percentage in highest deprivation area	41%	24%	30%

Source: SQW analysis of HNA data

[20] Sites provided data in early January for the period from their go-live date to end of 2019. A small number of records were dated January 2020 (3 service users in Dundee and 2 service users in Fife).
[21] The number of service users can be compared against the cancer incidence to understand the reach of the MLAP services. Cancer incidence by site is shown in Chapter 2, Overview of the MLAP sites .

Conditions and diagnosis

6.24 The top three cancer types were almost the same across all three sites: **lung, urology and breast** (although urology was the fourth most common cancer type in Fife). These are common cancers but not always the most common in the population.

6.25 The table below shows the incidence of different cancer types in Dundee and Tayside (incorporating Dundee but a wider geography)[22]. It shows urology, breast and lung cancer were over-represented in the service compared to incidence in Tayside, possibly due to the typical severity of these cancers and higher proportion of women in the MLAP service. Some skin cancers were excluded from the Dundee service due to the fact these cancers are common but not typically serious, which is why incidence is high but numbers of MLAP service users with this type of cancer are low.

Table 6-3: Incidence of cancer types in Dundee and Tayside[23]

Cancer type	Dundee service users	Tayside
Lung	21.3%	8%
Urology	18.2%	8.5%
Breast	16.7%	8.8%
Lower GI	9.6%	11.8%
Skin	1.1%	38.1%

Source: SQW analysis of ISD data

6.26 The table below shows the incidence of different cancer types in the Fife ICJ service and the local area. It shows that lung, breast and upper GI cancer were over-represented in the Fife service compared to incidence in the local area. As in Dundee, skin cancer was underrepresented in the Fife service compared to incidence in the area, but some skin cancers were excluded from the eligibility criteria.

Table 6-4: Incidence of cancer types in Fife ICJ/MLAP and Fife[24]

Cancer type	Fife service users	Fife
Lung	25.4%	9%
Breast	15.3%	7.1%
Upper GI	12.1%	4.1%
Lower GI	8.8%	10.3%
Skin	0.9%	39.7%

Source: SQW analysis of ISD data

6.27 The table below shows the incidence of different cancer types in the Durham service and the North East of England (data was only available at a wider geography than the Durham MLAP site). It shows the most common cancer type was skin (21.6%) followed by lung (18.1%), and

[22] The table only shows the highest and lowest incidence cancer types. Including all cancer types would take up considerable space.
[23] Numbers of registrations, with age-standardised incidence rates (using ESP20132), 2017. Available at: https://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2400#2400
[24] Numbers of registrations, with age-standardised incidence rates (using ESP20132), 2017. Available at: https://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2400#2400

lower GI (12.8%). Breast cancer was thus overrepresented in the Durham service compared to the local incidence, as in Dundee and Fife. Lung and urology were slightly under-represented. Skin cancer was also underrepresented in the Durham service compared to incidence in the area (possibly due to the fact people with this diagnosis may not have additional needs for which they would seek support).

Table 6-5: Incidence of cancer types in Durham MLAP service and the North East of England[25]

Cancer type	Durham service users	North East of England
Breast	17.6%	7.7%
Lung	12.3%	18.1%
Urology	8.6%	11%
Lower GI	7.5%	12.8%
Skin	2.1%	21.6%

Source: SQW analysis of ONS data

Pathway stage

6.28 The intention was for people to be able to access the service at any stage of their cancer journey, although the sites aimed to get people to access it earlier rather than later to ensure they received appropriate support as soon as required. Note, in Scotland the ISD letter was issued around six weeks post diagnosis, so people were not be alerted to the MLAP service via that route until that point.

6.29 The HNA data showed that in all sites, **service users were most commonly at the stage of receiving treatment when they had their HNA,** which is likely when most of them are made aware of the service (via ISD or professional signposting). The next biggest groups were those in palliative care and at the end of treatment. This may be due to individual choice: people approached the service when they felt ready to engage.

Carers

6.30 The programme was intended to support all those affected by cancer, not just those living with cancer. However, not unexpectedly, most service users were people with a cancer diagnosis. In Fife and Dundee about 5% of users identified themselves as a carer/relative[26]. In Durham, 16% of service users identified as carers for someone with a cancer diagnosis.

Setting

6.31 The data show that in most cases both Dundee and Fife conducted the first HNA at home, with a small minority of HNAs conducted in the community. The majority of second HNAs were

[25] Directly age-standardised registration rates per 100,000 population of newly diagnosed cases of cancer (third digit): site, sex and region of residence, England, 2017. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland. Caution should be taken if comparing rates across sites due to differences in data recording and collection between nations.

[26] Although in Dundee a significant proportion of service users are not identified as carers or people with a cancer diagnosis.

conducted remotely (by telephone) in both Dundee and Fife. A minority of second HNAs were conducted at home. The setting was not reported in the Durham data.

Timing of second HNAs

6.32 Unlike in some other situations in which HNAs are conducted, the sites expected to undertake a fairly large proportion of second HNAs. The second HNA would establish if the person had ongoing needs, whether the needs were the same as reported at the first HNA, and enable advice and support recommendations to be revised. Sites took a person-centered approach to delivering this aspect of the service, meaning service users only received a subsequent HNA if they wanted to, and although there was a service standard for offering the second HNA, it was informed by the individual's preferences.

6.33 Dundee typically had a longer period between the first and second HNA (117 days average, median 99 days) than Fife (60 days average, median 48 days) although there would also have been contact in the intervening period to discuss progress. Data were not available on timings of HNAs for Durham. Qualitative feedback indicated that link workers in Durham were responsive to their service users, returning to offer assessment, advice and support on a number of occasions for some users.

Care plans

6.34 The HNA is followed by a care plan, co-produced with the service user, which is intended to provide a plan as to how the service user can access support appropriate to their needs. **In the main, care plans were paper-based (78% in Dundee, 60% in Fife),** which was likely to be driven by the preferences of the service users. Qualitative feedback from Durham indicated that users may have a written care plan, but sometimes the care plan was simply an oral discussion between the facilitator and the service user.

6.35 The average length of time between the first HNA and first care plan was the same in both Dundee and Fife, at 1.7 days.[27] Measured another way, 50% of service users in Dundee get their care plan on the same day as their HNA; 50% of users in Fife get it on the following day – which indicates rapid development of plans by link workers.

6.36 Encouragingly, in terms of sharing information across the system and reducing the number of times a person has to repeat their story, a significant proportion of service users shared their care plan with their GP after their first HNA (72% in Fife and 49% in Dundee). Very few service users shared their reviewed care plan with their GP after the second HNA (2% Dundee, 7% Fife), reportedly because there were few or no substantive changes relevant to the GP.

Types of concern

6.37 The HNAs were intended to allow people to express any sort of concern, grouped into five categories: practical, physical, emotional, family and spiritual. The expectation was that the MLAP services would encourage people to raise non-clinical needs they tend not to bring up

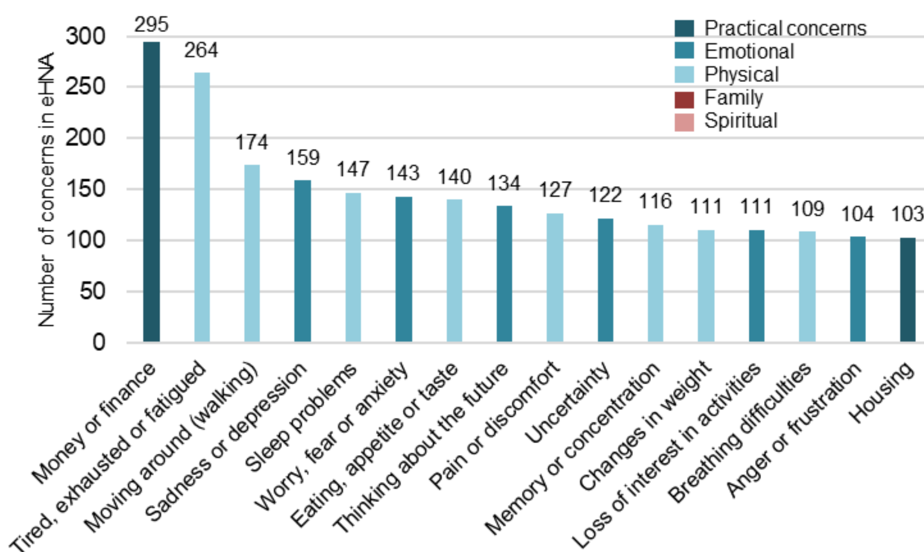
[27] For Dundee, the calculation excluded 17 "outliers" with a time difference between the first HNA and care plan > 30 days.

in secondary or primary care settings. Previous research for Macmillan[28] has shown that people tend to tailor the needs they report based on their perception of the professional they are talking to.

6.38 The three charts below (Figure 6-1, Figure 6-2 and Figure 6-3) show the most common concerns expressed by people in each of the three sites[29]. The most common concerns for PABC in Dundee were 'money or finance', 'tiredness, exhaustion or fatigue' and 'moving around (walking)'. Money was the concern reported by most service users in Durham, followed by worry/fear/anxiety and housing. 'Money or finance' was a less common concern in Fife but 'tiredness, exhaustion or fatigue' and 'moving around (walking)' were also top concerns, as in Dundee. There are likely to be a number of reasons behind the differences in common concerns across sites, including differences in the types and severity of concerns experienced, PABC willingness to discuss different issues with the link worker, and the different approaches of the link workers.

6.39 It is encouraging that service users were willing to raise concerns relating to money and housing that secondary care professionals are typically not able to explore in much detail or are not fully aware of the relevant support services. This indicates that the **MLAP programme may for some people be filling in gaps in support and helping to address needs that might otherwise go unmet.**

Figure 6-1: Most common concerns for people with two HNAs in Dundee (total concerns = 4,455, n=257)

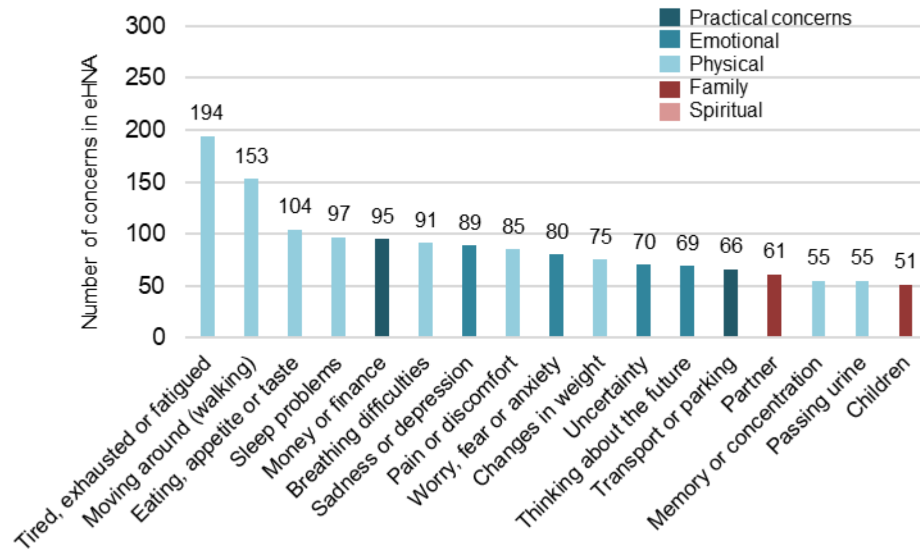


Source: SQW analysis of HNA data
Notes: Service users with two HNAs
Categories shown have a frequency higher than 100
Figures shows accumulated data from first and second HNA. At first HNA: concerns=2,495, n=257. At second HNA: concerns=1,960, n=249

[28] Edinburgh Napier University, (2018) *Improving the Cancer Journey: More than the Sum of its Parts. Second report from a five-year evaluation.* https://www.macmillan.org.uk/_images/Glasgow-improving-cancer-journey-programme-full-evaluation-2017_tcm9-324593.pdf

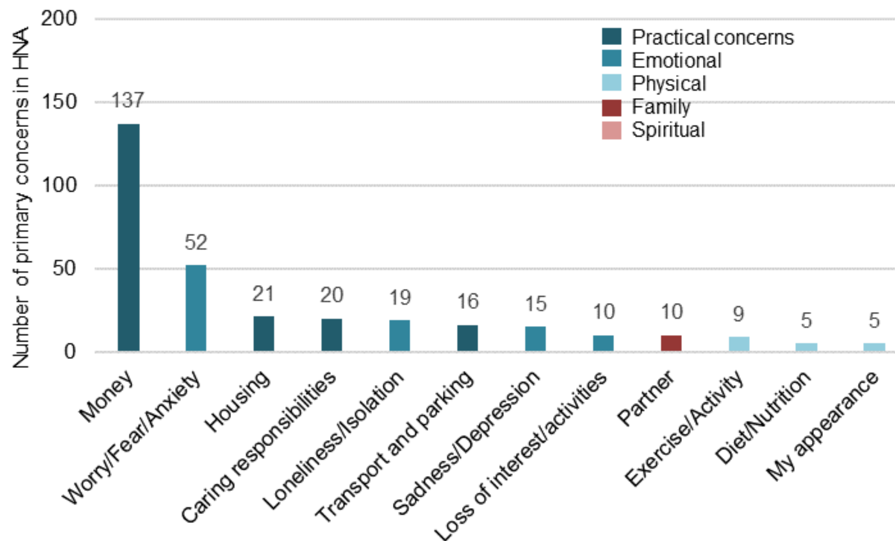
[29] Note data were recorded differently between Durham and the Scottish sites so are not directly comparable.

Figure 6-2: Most common concerns for people with two HNAs in Fife (total concerns = 2,698, n=246)



Source: SQW analysis of HNA data
Notes: Service users with two HNAs
Categories shown have a frequency higher than 50
Figures shows accumulated data from first and second HNA. At first HNA: concerns=2,246, n=246 At second HNA: concerns=452, n=155 (not all second HNA records listed concerns)

Figure 6-3: Number of service users per primary concern in Durham (n=503)



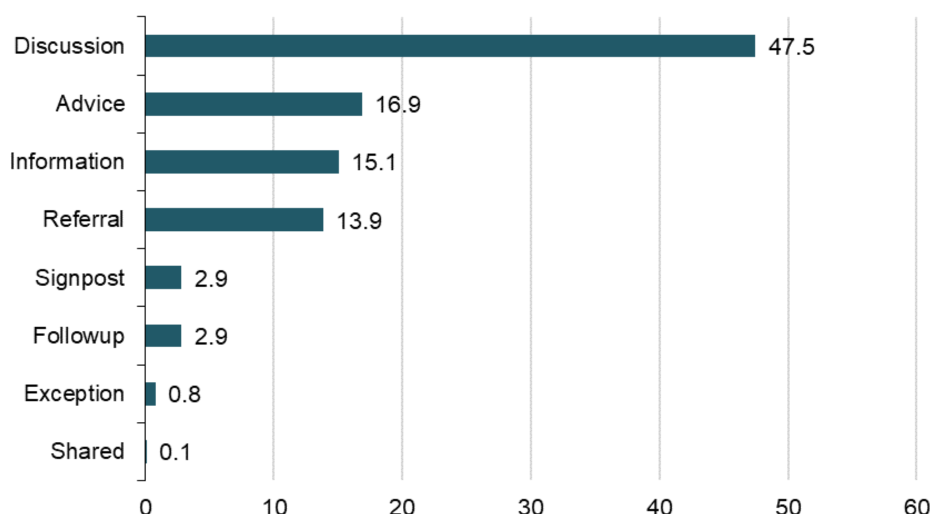
Notes: Service users with only one HNA. Data were not available on second HNAs.
Categories shown have more than 5 service users reporting a relevant concern.
Source: SQW analysis of HNA data

Actions

6.40 Data on actions is not easily tied back to the nature of concerns expressed by service users, as only the nature or type of action (rather than content) is indicated. Nevertheless, it is interesting to note that **the most common type of action in Dundee and Fife was discussion**. This could indicate that discussion is an appropriate response to many concerns rather than people requiring additional signposting and/or referral to other services (see charts below)[30]. Referrals were more common than signposting, perhaps indicating that the services send PABC to statutory services rather than informal support, but this may also be due to how data were recorded. Issues with coding may also account for why advice was much less common as an action in Fife than Dundee.

6.41 Taken together, about 15% of all actions in both sites were referrals/signposting, indicating that there are many types of support that can be offered to PABC, some of which may be relatively low-cost, e.g. provision of information.

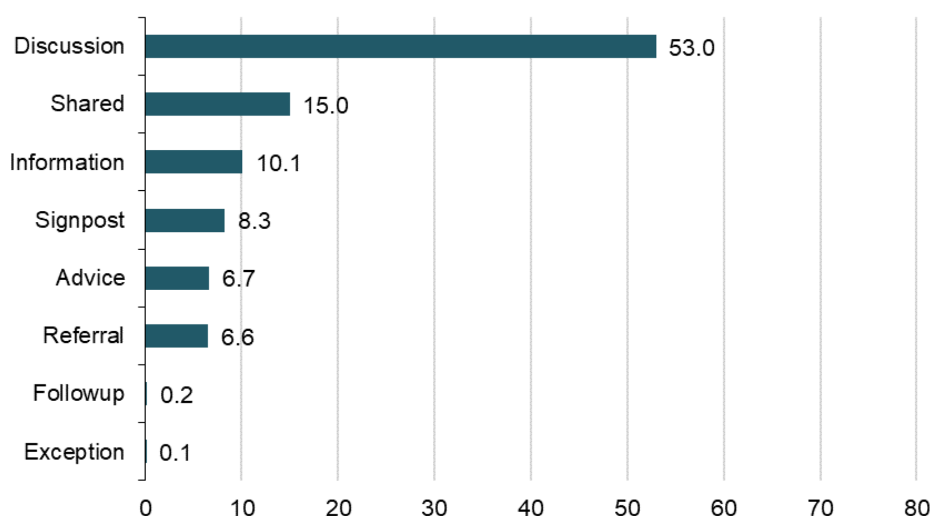
Figure 6-4: Percentage of actions reported by all service users with first HNA per action type in Dundee (n=457, total actions= 7,182)



Notes: Service users with only one HNA and an updated HNA (one and two HNAs)
Not clear what the 'Shared' category means
Source: SQW analysis of HNA data

[30] Data were not available in Durham.

Figure 6-5: Percentage of actions reported by all service users with first HNA, per action type in Fife (n=486, total actions=6,340)



Notes: Service users with only one HNA and an updated HNA (one and two HNAs)
Not clear what the 'Shared' category means
Source: SQW analysis of HNA data

6.42 The average number of actions for each service user dropped from the first to the second (updated) HNA, and the change is statistically significant. This may suggest the first HNA identified needs accurately and offered appropriate support, with fewer outstanding needs and support required at the subsequent HNA.

Table 6-6: Actions for people with two HNAs (Dundee, n=257; Fife, n=249; Overall, n=506)

	Dundee				Fife				Overall Programme: Dundee & Fife			
Actions	**n**	**Mean**	**Median**	**Min-Max**	**N**	**Mean**	**Median**	**Min-Max**	**n**	**Mean**	**Median**	**Min-Max**
At first HNA	257	15.7	12	1-88	245	13.2	11	1-47	502	14.5	12	1-88
At second HNA	140	5.2	3.5	1-32	154	3.1	2	1-25	294	4.11	3	1-32
Change: Second-First		**-10.51***				**-10.09***				**-10.38***		

*Notes: *Decrease of mean from first to second HNA is statistically significant at the 1% level. Note not all second HNAs listed action. Data were not available in Durham*
Source: SQW analysis of HNA data

Onward referrals and signposting

6.43 The rationale for the MLAP programme was that people have non-clinical needs that are best addressed by non-clinical support. Data from sites regarding onward referrals and signposting so far reveals **a significant degree of referral into public services such as council-provided welfare advice**, as well as 'internal' referrals to other Macmillan services. There have also been referrals back into the health service, as link workers encouraged service users to follow up on physical health concerns with their clinical team.

- In Dundee, the most common onward referrals related to GP/nurse, Macmillan (non-clinical support such as welfare advice), and Maggies[31]
- In Fife, the majority of onward referrals related to cancer nurse specialists (CNSs)
- In Durham, CNS and Macmillan were the most common onward referrals[32].

6.44 When the HNA data is combined with qualitative feedback (from service user survey responses and interviews with site stakeholders), it appears that there was also a significant amount of diversity in the onward referrals for support, meaning it is hard to quantify the nature of support recommended. Fundamentally however, local knowledge was considered crucial to being able to effectively refer or signpost a service user to support appropriate to their needs.

6.45 The **main reported gap in provision was access to appropriate support for service users with mental/emotional health needs**. There was feedback that there was limited provision of counselling and psychological interventions, and where these did exist there was limited capacity. Fife had access to a public portal that facilitated access to psychological interventions, which improved the options for link workers to refer to.

[31] A charity providing free cancer support and information in centres across the UK and online.
[32] In Durham data is recorded differently, as onward referrals are recorded per service user ('main onward referral'). In In contrast, in Dundee and Fife, onward referrals are reported per concern.

7. Outcomes

7.1 This section presents findings on the outcomes generated by services delivered by three of the MLAP sites (Dundee, Durham and Fife). It draws on quantitative HNA data from Dundee and Fife, responses to surveys of service users from all three sites and data from a workforce survey in all three sites.

Summary of findings

There are indications of positive outcomes for PABC in Dundee and Fife:

- From the first to the second HNA, the **average number of (all types of) concerns decreased**
  - Overall, the highest reduction in average number of concerns related to physical concerns.
- From the first to the second HNA, the **average severity of (all types of) concerns decreased**
  - Overall, the highest reduction in average severity of concerns related to practical concerns.

Survey data indicate **people using the services had a positive experience of the HNA conversation** and felt their care/support plan addressed their concerns.

The survey data present a **mixed picture on the ability of PABC to manage their own care.** There was **a small decrease in the average number of appointments with medical staff** from the pre-HNA survey to the 3-6 month follow up survey in Dundee and Durham. There was **a small increase in the average number of conversations by phone or email with health and care staff** (from the first to the third survey in Dundee).

In the absence of a comparator group, **it is not possible attribute the outcomes to the MLAP services with any certainty**. Data on outcomes from survey responses should be treated with caution due to low numbers of responses.

Respondents to the workforce survey **reported increased knowledge and understanding of the importance of non-clinical needs of PABC**. Respondents valued the service(s) as a referral option and for increasing their knowledge about support options.

There was mixed feedback from respondents to the workforce survey on whether the services had influenced the way other staff work or increased/decreased the time other staff spend supporting PABC with non-clinical issues.

Outcomes for people affected by cancer – evidence from HNAs

7.2 Data from the HNAs of PABC were available from the three sites delivering a MLAP service (Dundee, Durham and Fife)[33]. These data provided information about the concerns that PABC reported at their first appointment with the service. In Dundee and Fife, there was also data on service users' concerns at their second HNA[34].

7.3 Analysis of the change in the number and severity of concerns expressed by PABC from their first to their second HNA provides indicative evidence on the effects of the ICJ services in Dundee and Fife. However, there were no data available from a comparison group of PABC that did not receive the service, so it is not possible to determine the extent to which these effects would have happened otherwise (although see the discussion on Additionality and attribution at the end of this section for further details).

Number of concerns

7.4 Table 7-1 shows the average (by mean and median) number of concerns expressed by PABC at first and second HNAs in Dundee and Fife. In both sites, the average number of concerns decreased from the first to the second HNA. The drop in average number of concerns was larger in Fife than in Dundee, which may (at least in part) be due to different ways of conducting the HNAs and recording concerns. Without a comparator, it is not possible to be certain that the decreases were attributable to the services, but the decreases in both sites were statistically significant.

Table 7-1: Average number of concerns for people with two HNAs

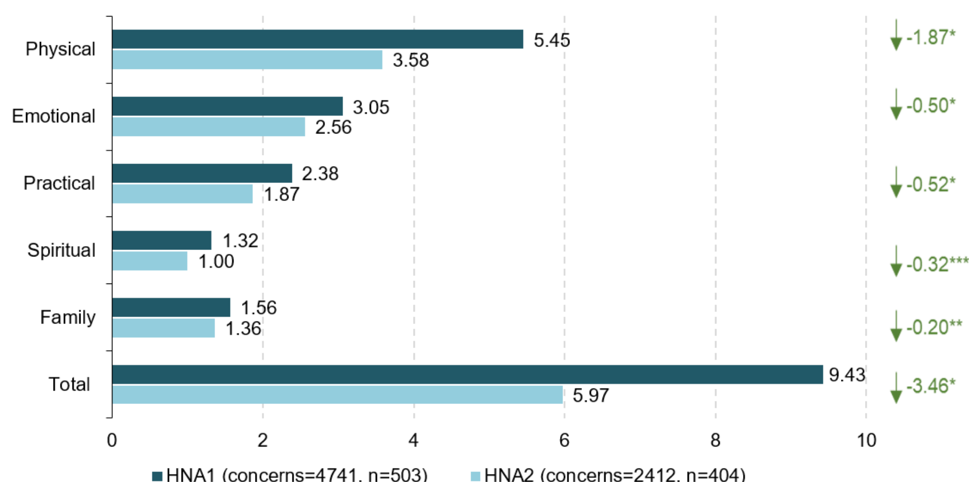
	Dundee			Fife			Overall: Dundee & Fife		
Concerns	**n**	**Mean**	**Median**	**N**	**Mean**	**Median**	**N**	**Mean**	**Median**
At first HNA	257	9.71	7	246	9.13	8	503	9.43	7
At second HNA	249	7.87	6	155	2.92	2	404	5.97	4
Change: Second-First		**-1.84***			**-6.21***			**-3.46***	

*Notes: *Decrease of mean from first to second HNA is statistically significant at the 1% level*
Source: SQW analysis of HNA data

7.5 Looking at aggregated data from Dundee and Fife, there was a reduction in the average number of all types of concerns (see Figure 7-1). The largest reduction related to physical concerns, which may (at least in part) occur as PABC learn to manage the physical aspects of their diagnosis. Practical concerns and emotional concerns had the next largest reductions. This is a positive finding, as the services were expected to be supporting PABC with non-clinical issues typically not identified or dealt with by medical staff. Family and spiritual concerns declined the least, although family concerns declined in severity (Figure 7-4).

[33] There were differences between the data provided by the three sites. Dundee and Fife used the same eHNA system and reported data in a similar way. Durham used a different system to record their HNA assessments. The Durham data are therefore not directly comparable with data from the Scottish sites.
[34] Durham's data recording did not record any second or subsequent HNAs as a separate record to the first HNA.

Figure 7-1: Average number of concerns (by type of concern) for service users with two HNAs in Dundee and Fife

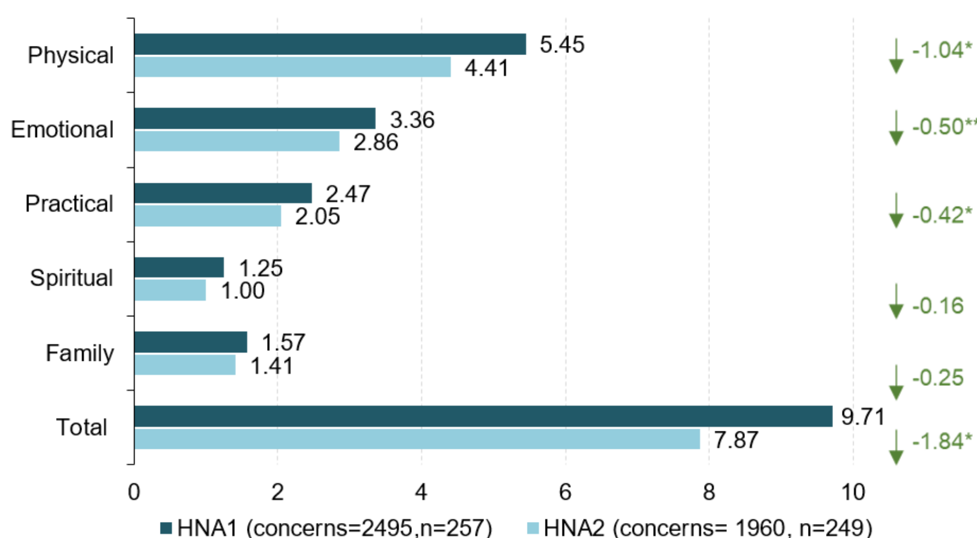


Notes: Changes in number of concerns are calculated as concerns at first HNA – concerns at second HNA. Changes may not always appear to correspond to exact difference between HNA 1 and HNA 2 due to rounding
**Statistically significant at the 1% level, **Statistically significant at the 5% level, ***Statistically significant at the 10% level*
Source: SQW analysis of HNA data

7.6 Dundee and Fife had similar patterns of reductions in the average number of concerns by type of concern: the average number of physical concerns declined the most, followed by emotional, practical, then family concerns, with spiritual concerns declining the least (Figure 7-2 and Figure 7-4).

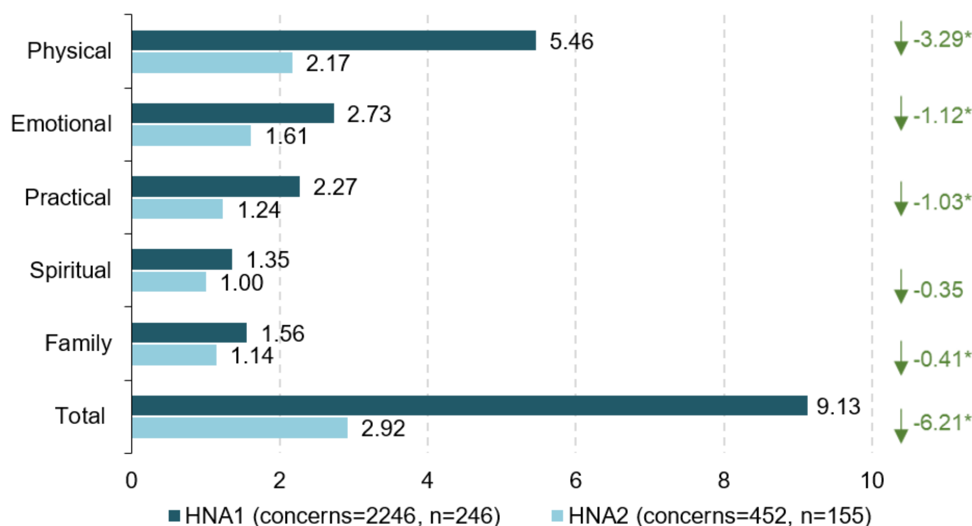
7.7 The larger drop in the average number of concerns in Fife was mainly driven by a significant drop in the average number of physical concerns. As noted above, this may be due (at least in part) to PABC learning to manage the physical aspects of their diagnosis.

Figure 7-2: Average number of concerns (by type of concern) for service users with two HNAs, in Dundee



Notes: Changes in number of concerns are calculated as concerns at first HNA – concerns at second HNA. Changes may not always appear to correspond to exact difference between HNA 1 and HNA 2 due to rounding
**Statistically significant at the 1% level, **Statistically significant at the 5% level, ***Statistically significant at the 10% level*
Source: SQW analysis of HNA data

Figure 7-3: Average number of concerns (by type of concern) for service users with two HNAs, in Fife



Notes: Changes in number of concerns are calculated as concerns at first HNA – concerns at second HNA. Changes may not always appear to correspond to exact difference between HNA 1 and HNA 2 due to rounding
**Statistically significant at the 1% level, **Statistically significant at the 5% level, ***Statistically significant at the 10% level*
Source: SQW analysis of HNA data

Severity of concerns

7.8 During an HNA, people score the severity of their concerns on a scale of 0 (no concern) to 10 (extreme concern). Table 7-2 shows the average (by mean and median) severity of concerns expressed by PABC at first and second HNAs in Dundee and Fife. The average severity of concerns decreased from the first to the second HNA in both sites. The average level of severity was similar in both sites, but the decrease in average severity was slightly greater in Dundee. Without a comparator, it is not possible to be certain that the decreases were attributable to the services, but the decreases in both sites were statistically significant, with the exception of spiritual concerns (of which only a small number were recorded).

Table 7-2: Average severity of concerns for service users with two HNAs

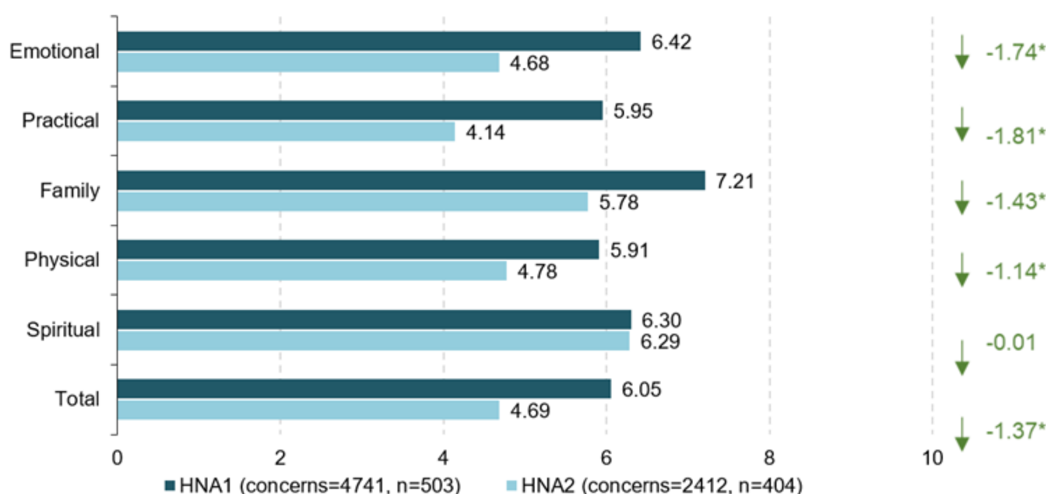
	Dundee			Fife			Overall Programme: Dundee & Fife		
Severity of Concerns	**N**	**Mean**	**Median**	**N**	**Mean**	**Median**	**N**	**Mean**	**Median**
At first HNA	257	6.19	6	246	5.91	6	503	6.05	6
At second HNA	249	4.34	4	155	5.25	5	404	4.69	4.5
Change: Second-First		**-1.85***			**-0.67***			**-1.37***	

*Notes: *Decrease of mean from first to second HNA is statistically significant at the 1% level*
Source: SQW analysis of HNA data

7.9 Practical concerns reduced the most in average severity when looking at aggregated data for both sites, followed by emotional concerns (see Figure 7-4). As discussed above, this is a positive finding for services designed to support PABC with non-clinical issues. Average severity of spiritual concerns decreased the least, but this was based on a small number of concerns being reported. The next lowest reduction in average severity occurred for physical

concerns; this is in contrast to the greater reduction in the average *number* of physical concerns. This may be explained by people becoming accustomed to or learning to manage certain aspects of their diagnosis (leading to the number of concerns reducing) but ultimately still having to cope with a serious illness (meaning that the severity of concerns does not reduce to the same extent).

Figure 7-4: Average severity of concerns for service users with two HNAs in Dundee and Fife

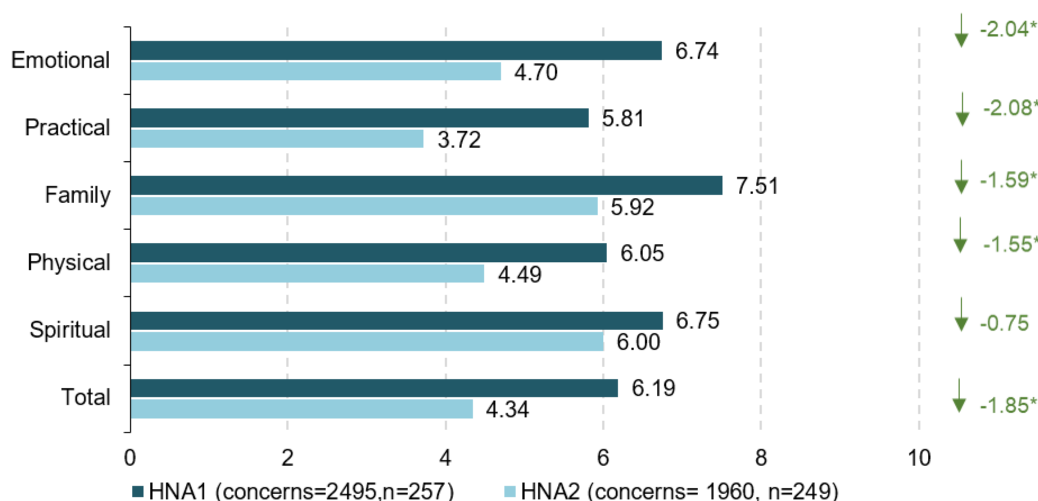


Notes: Changes in severity of concerns are calculated as severity at first HNA – severity at second HNA. Changes may not always appear to correspond to exact difference HNA 1 and HNA 2 due to rounding
**Statistically significant at the 1% level, **Statistically significant at the 5% level, ***Statistically significant at the 10% level*
Source: SQW analysis of HNA data

7.10 Dundee's greatest reduction in average severity of concerns was for practical concerns followed by emotional concerns. Fife's greatest reduction was for family concerns followed by emotional concerns (see Figure 7-5 and Figure 7-6). There was one increase in average severity, namely for spiritual concerns in Fife, but this was based on a small number of people reporting spiritual concerns.

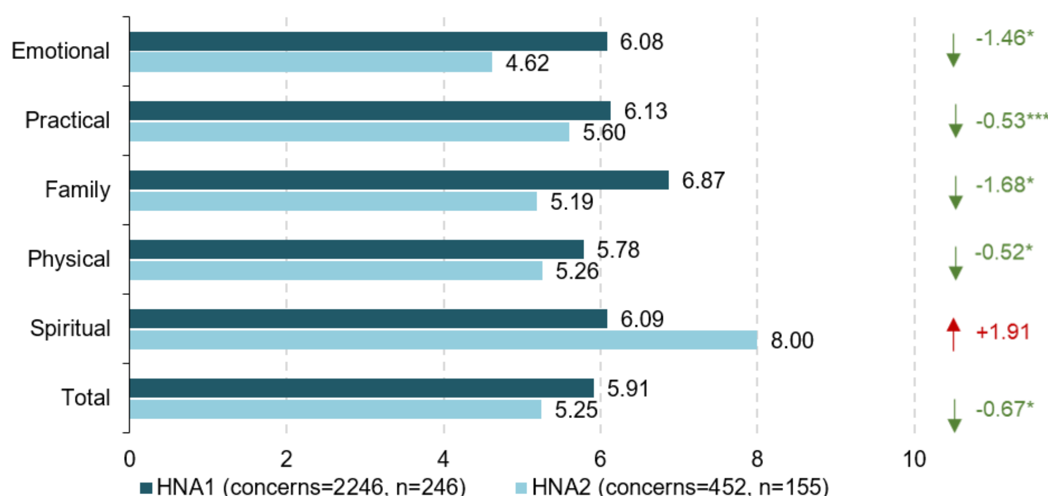
7.11 It is hard to explain these differences between sites, as they may be affected by a multitude of factors, including how staff in the respective sites interpret or manage the HNA, how concerns are reported, and the nature of the people using the service.

Figure 7-5: Average severity of concerns for service users in Dundee



Notes: Service users with two HNAs
Changes in severity of concerns are calculated as severity at first HNA – severity at second HNA. Changes may not always appear to correspond to exact difference between HNA 1 and HNA 2 due to rounding
**Statistically significant at the 1% level, **Statistically significant at the 5% level, ***Statistically significant at the 10% level*
Source: SQW analysis of HNA data

Figure 7-6: Average severity of concerns for service users in Fife



Notes: Service users with two HNAs
Changes in severity of concerns are calculated as severity at first HNA – severity at second HNA. Changes may not always appear to correspond to exact difference between HNA 1 and HNA 2 due to rounding
**Statistically significant at the 1% level, **Statistically significant at the 5% level, ***Statistically significant at the 10% level*
Source: SQW analysis of HNA data

Understanding changes in average severity of concerns

7.12 As noted above, there are many reasons as to why the number and/or severity of concerns reported might change from a first to a second HNA, apart from the role of the service in helping the person access support relevant to their needs. For example, people may be further on in their cancer journey and thus more accustomed to or better able to deal with the physical or emotional aspects of their diagnosis.

7.13 Of all the myriad variables that might have influenced the severity of concerns, data were available to test for correlation between changes in the average severity of concerns from first to second HNA and each of three variables: pathway stage, time from first to second HNA, and socio-economic deprivation. The key findings were that:

- Progression along the cancer pathway was very weakly correlated with a decrease in the overall average severity of concerns in both Dundee and Fife[35].
- A longer time period between HNAs was very weakly correlated with a decrease in the average severity of concerns in Dundee. In Fife a longer time period was correlated with an increase in average severity of concerns[36]. It is not clear why the direction of the correlation differed between sites.

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[35] The change was statistically significant at the 5% level in both Dundee and Fife.
[36] The changes were statistically significant at the 5% level in both sites.

- Greater deprivation was very weakly correlated with an overall decrease in the average severity of concerns in Fife[37] but the direction of correlation varied within Fife for different types of concerns. Deprivation data were not available for Dundee.

7.14 However, the very weak linear relationships[38] between the average severity of concerns and the explanatory variables (even where they are statistically significant) and the opposing directions of correlation, mean these findings do not explain whether these variables played a role in changes in severity of concerns.

Outcomes for people affected by cancer - from service user surveys

7.15 A survey was undertaken to gain information about the experiences and outcomes of people using the MLAP services. There were four waves of the survey[39]. As of 31 December 2019, pre-HNA data for Dundee, Durham and Fife showed that, in terms of demographics, survey respondent demographics were similar to those of service users completing an HNA.

7.16 Responses to linked questions in three of the four waves of the survey (pre-HNA survey, 3-6 month follow-up and the 9-12 month follow-up survey[40]) provided self-reported evidence on the influence of the MLAP service on outcomes for respondents[41].

Ability to self-manage

7.17 To assess how actively service users managed their own care, respondents were asked what they do when they have a non-medical problem, and about their own level of knowledge, confidence and access to information and support[42]. However, the low number of respondents to these questions means that it is not possible to draw any conclusions[43].

Use of health services

7.18 Respondents were asked to note the number of appointments they had with medical staff in the preceding three months, to assess any changes in usage of healthcare[44]. Data show there was some (statistically significant) change in appointments with various health services[45]:

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[37] The change was not statistically significant at the 5% level.
[38] A correlation between variables indicates that as one variable changes in value, the other variable tends to change in a specific direction. A correlation ranges from -1 to 0 or 0 to 1. Correlation coefficients whose magnitude are between 0.3 and 0.5 indicate variables which have a low correlation and those with magnitudes lower than 0.3 have very low/weak linear correlation.
[39] Four waves of a survey were distributed by the MLAP services to their users: a pre-HNA survey, an immediate post-HNA survey, a 3-6 month follow-up survey and a 9-12 month follow-up survey. Data from the 9-12 month follow-up survey were only available from Fife.
[40] The immediate post-HNA survey focused on respondent experience not outcomes
[41] Due to data availability, outcome analysis was undertaken by comparing: pre-HNA vs 3-6 month follow-up for respondents from all three sites; and pre-HNA vs 9-12 month follow-up for respondents only from Fife (n=19).
[42] Statements assessed are: I am well informed about what support is available to me (outside of the hospital and GP services), I am confident that I can manage my own wellbeing (or find support to do so), I know how to access support to deal with any effects cancer has on my life. Respondents were given a 5 option Likert scale for their answers.
[43] The number of respondents was too low to estimate statistically significant changes.
[44] Respondents were asked: In the last 3 months, roughly how many appointments or contacts have you had with medical staff? Please include all appointments and contacts, not just those related to cancer.
[45] Only statistically significant results are reported. All data are based on pre-HNA survey and 3-6 month follow up survey responses.

- Overall programme (three sites): there was a decrease in the average number of overnight hospital stays (2.9 to 2.1, n=42, statistically significant at 5%)
- Dundee: there was a decrease in the average number of scheduled hospital appointments (4.7 to 4.0, n=5)
- Durham: there was a decrease in the average number of appointments with respondents' GPs, nurses or other specialist at their GP surgery (7.0 to 4.4, n=13, statistically significant at 5%) and an increase in the average number of conversations by phone or email with a NHS health professional to get advice (2.1 to 3.1, n=13, statistically significant at 10%)
- Fife: there were no statistically significant changes in the average number of appointments with clinical staff (n=24)[46].

7.19 The small but statistically significant decrease in the number of health appointments in Dundee and Durham is interesting but based on a small number of responses. Moreover, in the absence of a comparator, it is not possible to attribute this decline to support from the service. There may have been other reasons for the decline, for example related to cancer treatment.

Experiences of people using the MLAP services

7.20 Data from the 3-6 month follow-up survey for Durham (as there were insufficient responses to the 9-12 month follow-up survey in these sites) and 9-12 month follow-up survey for Fife, provide some insight into how respondents perceived the HNA conversations. Overall, perceptions were positive in all sites, although figures need to be treated with caution due to low response numbers and possible response bias[47].

- In Durham, the majority of survey respondents felt listened to (25/27), able to discuss things (25/27), treated with dignity and respect (24/26) and supported as a result of the conversation (21/24)
- In Fife, over half of respondents felt listened to (13/19), able to discuss things (14/19), treated with dignity and respect (13/19) and supported as a result of the conversation (14/19)
- Most respondents felt their care/support plan addressed their concerns at all sites (based on post-HNA survey data)
- Overall, most respondents thought their care/support plan addressed their concerns (75%, 135/181), which broadly corresponds to the reduction in the number of concerns evident in aggregated and site HNA data

[46] This was also true in respect of the pre-HNA and 9-12 month follow up survey data for Fife where n=9.
[47] No data have been presented for Dundee as there were only 5 respondents.

- A higher proportion of service users in in Dundee (88%, 22/25) and Durham (83%, 40/48) thought their plan addressed their concerns when compared to Fife (68%, 73/108).

"Joining the Dots is a great service and should continue to be funded…, it is so much needed" (Durham)

"I was very pleased with the way my concerns were listened to and with the advice given regarding these concerns, I see no need for improvement" (Fife)

7.21 A few respondents had views on improvements to the service, related to the level of information provided regarding the service, and timeliness of the referral:

"Perhaps a more clear introduction to what this programme is, what it can & cannot do" (Fife)

"I should really have been made aware of this sooner as I'd have appreciated this post hospital." (Dundee)

Interactions with health and care staff

7.22 Respondents were asked how much they agreed with statements[48] regarding changes in interactions with health and care staff and in their knowledge, confidence and access to information and support. There were very few responses to these questions. Overall, Fife's respondents reported an improvement in how involved they felt in decisions about their care, whereas Dundee's respondents showed no change. Durham respondents reported a decrease in how involved they felt in decisions about their care[49]. Similarly, Fife's respondents reported a positive increase in levels of knowledge, confidence and access to information, but feedback from Durham was mixed and there was limited change for Dundee's respondents.

Outcomes for the workforce

7.23 An online survey was distributed by the Dundee, Durham and Fife site programme leads to their MLA teams and wider workforce during November and December 2019. Thirty-four people responded to the survey: seven from Dundee, nineteen from Durham[50] and seven from Fife. Four respondents were clinicians. The nature of involvement by respondents with the

[48] Statements assessed included: Staff involved in my care understand my non-medical concerns, I am able to talk about the things that matter most to me with staff involved in my care, I feel listened to by staff, I am treated with dignity and respect by staff, I feel appropriately involved in decision about my care.
[49] Dundee had 5 respondents answering relevant questions in the surveys, Durham had 13 and Fife had 13. Not all respondents answered each question in these sections of the surveys.
[50] There was one additional respondent who did not know about the service and therefore did not answer the survey. This response has been removed from the analysis.

MLAP programme varied; the most commonly mentioned roles were: supporting the delivery of the work; service design; and making referrals to the service.

7.24 Given the low response rate, particularly from the Scottish sites, and the likely self-selection bias, the results should be interpreted with caution. Nevertheless, there was some feedback that the MLAPs had positively affected staff. Four-fifths of respondents reported that their knowledge of non-clinical needs of PABC had increased as a result of the service, and nearly three quarters reported that their understanding of the importance of these needs had increased.

"The consultation events I attended meant I had the chance of meeting other cancer patients and carers, which increased my knowledge and understanding."

"Because of my involvement with the service, I have gained a more in-depth knowledge and understanding of the needs of cancer patients. Meeting with members of the Cancer Voices Group and the Macmillan Support Facilitators has proved me with a greater insight into the issues faced by cancer patients and their families."

Respondents to workforce survey

7.25 Respondents also reported positive outcomes such as improved communication with PABC, improved skills in caring for PABC, increased knowledge of support options and valuing the MLAP as a support option, and increased job satisfaction.

"I am now much more aware of the impact unsuitable housing can have on cancer patients and/or their families."

"It has certainly raised my awareness of existing support groups and the many new support groups which have started since the inception of [the service]."

"The service works with patients who have many practical aspects of support requirements and that means our service can concentrate on clinical care."

"Deeper involvement with partners has allowed our charity to support more people living with cancer due to referrals from MLAP. I feel more job satisfaction [because of] improved partnership working."

Respondents to workforce survey

7.26 Evidence from interviews with stakeholders[51] in sites tended to support the narrative that the MLAPs have been beneficial to healthcare professionals, largely through being able to provide their patients with the kind of support that they are unable to as (for example) a GP or cancer nurse.

"I feel very positive about [the service]. It's really making a different to people affected by cancer… really cutting down on the things we used to chase round trying to find and can go directly to facilitator. Life's a lot easier." Durham stakeholder

7.27 The survey data were insufficient to give a clear picture on how the MLAPs had changed the practice of healthcare professionals, aside from providing a new referral option[52]. The main concern expressed by a small number of clinical professionals was that clinical or emotional needs may be identified by HNAs without there being local services to address them. Sites were aware of these concerns and responded by providing clear information to clinicians (particularly cancer nurses and GPs) about service operation, including referral back to secondary or primary care as relevant.

Outcomes for services/systems

7.28 The clearest positive effect on other services and the system was the introduction of a new and valued referral route. Five respondents stated the MLAP service had changed the operation of their organisation by introducing a new referral route for PABC with non-clinical needs, and nearly two thirds of respondents reported improved communication, coordination and sharing of information with services regarding PABC.

7.29 However, many respondents also reported that the service had not generated any change, which may be a reflection of the scale of the services compared to acute cancer care and primary care. There was no noticeable impact reported in terms of use of statutory health or care services. It is also worth noting that two respondents felt the MLAP service had negative consequences for their organisation: not following up quickly enough so the service had to be chased about appointments for patients after referrals made; and increasing confusion about what services Macmillan provided.

7.30 Concerns that services (particularly among the VCS) receiving referrals would experience capacity issues have not been borne out. VCS organisations have reportedly been able to absorb any additional referrals to date. Impacts on other organisations were continually monitored by the MLAPs.

Additionality and attribution

7.31 No comparator group was identified for the evaluation. In lieu, attribution and additionality were explored through questioning service users about where else they would have received

[51] These were semi-structured interviews, held face-to-face or via telephone.
[52] For instance, 18 respondents reported no change in the amount of time they themselves spend supporting PABC with non-clinical issues while 6 reported a decrease and 7 reported a small increase.

the kind of support offered by the MLAP services. A small number of respondents to the PABC surveys indicated there was no alternative route to receiving this kind of support: Dundee (24%, 6/25), Durham (8%, 4/48), Fife (9%,10/108).

7.32 The workforce survey also explored the additionality of MLAP services. There was a mixed response from the small number of respondents: 19 reported some or none of the changes they had identified would have happened without the MLAP service. The qualitative feedback provided greater insight, namely that the services were additional in terms of quality (efficiency of accessing support), speed and scale.

"Services were there but [the MLAP service has] helped in bringing things together in a more efficient and effective manner."

"Some changes may have happened, however, it may have taken longer with more onus on the person to seek the information. For [some PABC] this may not have happened as some people do not ask for help. They don't want to bother their clinical teams."

"Increased referrals were already beginning to happen due to more awareness of our service but I do think [the MLAP service] has helped move number of referrals in an upward direction."

Respondents to workforce survey

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8. Economic assessment

8.1 This section presents details of the type and scale of resourcing provided for the MLAPs, including both financial and in-kind contributions, followed by reflections in the adequacy and sustainability of the resourcing.

8.2 It follows with a detailed economic assessment of the work undertaken in the three sites with an operational service (Dundee, Durham and Fife), presenting the costs incurred to date as well as monetised benefits emerging as a result of the MLAP service.

8.3 It is important to keep in mind when reviewing these findings that a series of assumptions have been made (agreed with site representatives) regarding inputs, activity levels, benefits and sustainability plans. These assumptions are informed by progress and activities delivered to date and vary across the three sites. This variation means that it is not possible to conduct an economic assessment of the MLAP programme as a whole. Instead, site level insights are presented in the text below.[53]

Summary findings

- A **range of inputs went into the programme at national and local levels from Macmillan, beyond the grant funding**. This included support from Macmillan's national programme team, other parts of Macmillan's national team, and the regional teams in the form of provision of tools and resources, as well as time and expertise.
- While some of these additional elements and inputs were not originally anticipated, stakeholders reflected that they were essential given the complexity and scale of system change sought.
- **Local partners also contributed in-kind resources** to ensure MLAPs were able to be formed and progress. The exact resources, timing of input and scale of commitment varied across each site.
- Sustaining the level of resourcing longer term (once Macmillan's funding ends) remained a key risk.
- Cost benefit analysis shows that, measured in financial terms, the sites are not expected to not re-pay the money invested in them over the analysis timeframes. However, measured in terms of public value, all three sites are expected to re-pay the investment.

[53] Sites were provided with individual documents presenting further detail regarding the assumptions taken and figures generated as a result for their own service.

Types of resources needed to deliver a MLAP

8.4 **Financial**: funding came from Macmillan in the form of grants to each of the sites, provided from commencement of partnership development in each site. This fully funded the work in Dundee, Fife and Tower Hamlets to date (excluding in-kind contributions)[54]. Durham obtained additional funding from their Cancer Alliance to extend the lifespan of the service.

8.5 **In-kind:** all sites received in-kind resources from partners. This included an organisational 'home' (e.g. an office or desk(s) for the programme staff, IT, telephone, managerial and supervisory support etc.). Durham's MLAP was housed in the Public Health department of the local authority; Tower Hamlets' MLAP sat with the Adult Social Care directorate, and the two Scottish sites were housed by their HSCP. In addition, partners contributed their time via partnership and service planning meetings, input into governance arrangements and partnership formation, recruitment support, providing venues for meetings and providing referrals into and out of the MLAP services. Much of this was essentially the time, skills, knowledge, experience and networks of stakeholders, which they provided in addition to or as part of their day job.

8.6 **Macmillan's non-financial inputs:** Macmillan provided an array of support through the national MLAP programme team and Macmillan regional teams. These teams provided advice on policies to support the programme (such as risk management), expertise on particular aspects of the MLAP programme (such as co-production) and facilitated access to the other MLAP sites and Glasgow (for learning from ICJ). There was also a range of training provided including, for instance, cancer awareness training, motivational interviewing and delivery of action learning sets for link workers.

8.7 In many cases sites were given additional support from Macmillan: Dundee, Fife and Durham welcomed support on the implementation of eHNAs for example[55]. In other cases, support offered by Macmillan was perceived by some locally as indicating a lack of confidence in the site's ability to deliver the programme according to Macmillan's requirements. For example, frequent partnership meetings to check progress felt intrusive for some stakeholders.

Levels and flexibility of resourcing

8.8 Site stakeholders reported that they did not feel constrained by the size of financial resources provided by Macmillan for their MLAP programme. Each site received £1m for the lifetime of the MLAP programme, initially planned to be four years. Some of the sites had to request a re-profile of their spend because they found themselves unable to spend what they had planned within the original timeframe. Dundee's funding was extended from 2019 to 2021 and Fife's from August 2020 to August 2021 because of underspends on the programmes. Reprofiles were necessary because the sites were unable to move from scoping to delivery as rapidly as expected. Tower Hamlets had the longest scoping period (over two years) but they operated in arguably a more complex environment than the other sites, had less direct learning to build on (compared to, for example, the TCAT programmes in Dundee and Fife), and were not seeking to introduce a new service in the same way that the other sites did.

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[54] Note Fife's funding came from the Macmillan Scotland budget rather than the MLAP programme budget.
[55] Durham received support on the eHNA system but had not implemented it during the evaluation timeframe.

8.9 Challenges related to funding were typically more about flexibility, for example how much sites were allowed to spend on programme staff for scoping and mobilisation:

- The spending of Macmillan funds is (understandably) tightly controlled in order to adhere to the charity's obligations to its donors as well as its legal obligations.
- The in-kind resources provided were generally reported to have been manageable for partners to provide. However, where partners are not able to provide additional operational support for programme development, the programme was limited in the range and extent of activities that could be undertaken and the rate of pace possible.
    - In Tower Hamlets, there was limited operational support from both the local authority and the local Macmillan engagement team due to capacity constraints and focus on other priorities. This meant tasks such as asset mapping and co-production took longer than they may otherwise have done.

8.10 For Macmillan itself, the level of input (beyond the grant funding) was more than was originally anticipated. There was however an awareness (particularly amongst the national programme team) that system change at scale is resource intensive and consequently some sites would need more support than others, at different points and in different ways.

Sustainability

8.11 Planning for sustainability has varied across sites, and continues to pose a challenge and risk, given competing demands for constrained resources. Future funding plans for MLAPs were as follows at the time of writing:

- Fife: it was anticipated that the local area coordinators (who manage the link workers) would continue to be funded by the HSCP, which had included a three-year commitment (to 2022) to the ICJ model in their strategic plan. However, funding for link workers remained uncertain
- Dundee: the service would be Macmillan funded until 2021. Further commitment would need to be negotiated, with no agreement reached to date
- Durham: the CCG committed to maintaining funding for the service at the current level on an ongoing basis
- Tower Hamlets: negotiations about funding beyond the Macmillan funding (which runs to 2022) were continuing.

Cost benefit analysis

CBA model

8.12 The evaluation undertook a cost benefit analysis for the three sites delivering an operational service (the full model and analysis is available in separate Excel workbooks). Sites provided data on financial and in-kind costs. HNA and survey data provided evidence on outcomes including changes in concerns for service users, changes in service use, and changes in staff time spent dealing with non-clinical concerns.

8.13 There are a few **caveats to the analysis**:

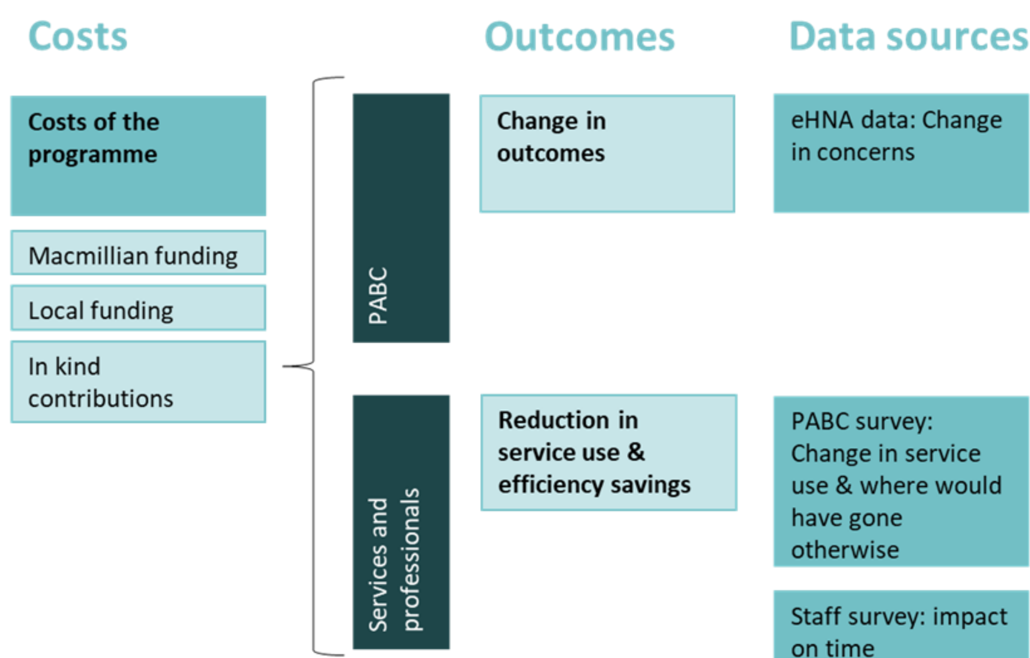
- Sites determined their own timeframes for the cost benefit analysis to fit with local priorities. This means both that **the level of saving by the sites is not comparable, nor (as outlined above) is it possible to provide an overall programme level economic assessment**
- **Sites each selected their own analysis timeframes** (based on their confirmed funding period and/or realistic timeframes for realising outcomes) which are not consistent across the three sites.
- Some of the values used in the calculations are based on small numbers of responses to the user and workforce surveys, meaning **the final savings figures should only be considered indicative**
- Sites have provided estimations of ongoing demand and likely delivery based on full staffing levels**.**

8.14 The key elements of the model are shown in Figure 8-1 below. Data on all in-kind and financial contributions were provided by sites. Outcomes were calculated based on:

- Changes in concerns reported in eHNA data for Dundee and Fife (their average was applied to Durham) and monetised using a value from New Economy's Manchester CBA tool derived from a Department of Health valuation of quality-adjusted life years
- Reductions in service use in terms of GP appointments, as reported by respondents to the user surveys, and monetised according to the standard unit costs of health and social care (2019)[56]
- Reductions in time spent by clinical staff on non-clinical issues as reported in the workforce survey, and monetised according to local data on staffing and costs.

[56] https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2019/

Figure 8-1: Cost benefit analysis model for MLAP sites



Source: SQW

Findings

8.15 Cost benefit analysis shows that, **measured in financial terms, the sites do not re-pay the money invested in them over the analysis timeframes**. However, measured **in terms of public value, all three sites do re-pay the investment**. This is shown below.

Table 8-1: Financial and public value return on investment (RoI)

	Financial RoI per £1 invested	Public value RoI per £1 invested	Period of investment
Dundee	£0.28	£4.61	6 years
Fife	£0.24	£3.39	4 years
Durham	£0.61	£2.99	3 years

Source: SQW analysis of MLAP site data

8.16 Given the variation in assumptions, analysis timeframes and parameters across the sites, it is not sensible to calculate an overall public value or financial return on investment figure.

8.17 However, it is possible to **estimate an average financial benefit per service user** by looking at the estimated average reduction in GP appointments for a year and the reduction in staff time for 2019. **This financial benefit amounts to £513 per service user**. The cost per service user is calculated for 2019/20 based on the cost for each site in 2019/20 divided by the number of service users in that year. The analysis shows that Fife's service costs an

average of £453 per service user against an average financial benefit of £513 per service user, indicating it may be possible to generate a positive financial return from an MLAP service[57].

Reflections

8.18 While an economic assessment of any programme is important, it needs to be contextualised in terms of what the programme was intending to achieve. The MLAP programme was an ambitious pilot that aimed to explore new ways to support PABC with their non-clinical needs. Financial savings were not directly targeted as an aim of the programme and were only expected to accrue over time as the new services became established, with professionals and PABC becoming more accustomed to using them for non-clinical needs, thereby reducing time spent by clinicians on dealing with non-clinical concerns. Further learning from the sites may indicate greater financial savings. The current CBA only models the savings over a few years. If the sites were able to continue running, they would be able to continue to generate benefits while only incurring ongoing rather than set-up costs, which might help them achieve a positive ROI. Alternatively, it may be that the services are addressing unmet need, and thus are not helping any existing services to make savings.

8.19 The initial funding amount appears to have been larger than required, with sites being allowed to extend the period in which they can use their funding because of underspend. However, programmes should always plan for a sustainable funding model from the earliest point to avoid introducing a service that has to be withdrawn later.

[57] Fife is used to illustrate the point. Dundee and Durham's costs were higher than the financial benefit per user in 2019/20. Fife's cost per service user was lower than Dundee's and Durham's because of the higher number of service users for 2019/20.

9. Conclusions

9.1 In this section of the report we reflect on the implications of the key findings from the programme and the work in the sites. This includes reflections on the partnership approach and development, Macmillan's role and partnership resources, the types of approaches and models adopted, the outcomes and achievements emerging, leadership and management, and sustainability.

Programme design and partnership approach

9.2 The MLAP programme has been a huge programme of work, running for several years and spanning two nations, covering a large population of PABC and operating in a variety of different contexts. The programme has involved national activity, local development, influencing and delivery, and inter-site learning: the scale, variety and complexity of activity and focus must not be underplayed.

9.3 Partners came together at site level to develop a shared vision and joint aims for their local partnership: this in itself is no small undertaking. The work towards realising this vision and translating it into delivery models is testament to the buy in and commitment to the MLAP approach. Macmillan recruited sites with both a high level of need and a willingness to engage; identifying readiness to engage is likely to remain key in any future similar programmes to mitigate the risk of sites withdrawing from the programme. The MLAP programme provides learning regarding the conditions for readiness. At a headline level, the preconditions needed relate to leadership, project management, political support, strategic alignment (with local and national aims and policies) and realistic expectations regarding the rate and scale of pace, as well as the in-kind contributions needed.

9.4 The Scotland sites were able to make progress relatively quickly, largely due to having the Glasgow ICJ model to learn from and replicate plus the learning from the TCAT programmes, as well as strategic buy in nationally. This may indicate that the conditions in Scotland, with the integration of health and social care via HSCPs and a political commitment to the ICJ model, are particularly favourable to the MLAP programme ways of working and approach, and may offer 'quick wins' if replication or wider roll out is sought. That is not to downplay the progress in England sites: Durham also made relatively quick progress with developing and implementing their model (whilst also undertaking extensive co-production activities) and managed to secure Cancer Alliance funding. This indicates that the MLAP programme is recognised as aligning with (at least some local) Cancer Alliance priorities. Tower Hamlets continues to focus on improving communication, information sharing and coordination rather than direct service delivery. This has required using the asset mapping and feedback from PABC to undertake extensive co-design work with stakeholders to develop 'change ideas' and deliverables.

9.5 This latter point is important. Macmillan left it relatively open to the local partners to determine the type of model they wanted to develop to support PABC with non-clinical needs from the point of diagnosis. Three of the sites identified a gap in provision and consequently developed a 'new' service for PABC to supplement and integrate with existing provision. Tower Hamlets approached it differently because they identified the existence of services for

PABC that were not working well together. The site is seeking to change how existing provision is delivered across the system to enable better integration (and hence access) for PABC. This is in response to the findings of their asset mapping and engagement work. They each took the time to decide what was most appropriate in their local context. Some stakeholders have argued that the Tower Hamlets approach is more ambitious with wider reaching implications for local partners and PABC. However, the scale of ambition has an impact on the rate of pace, with practical changes to services accessed by and available for PABC not yet realised in Tower Hamlets (who also commenced later than other sites, with delayed project manager recruitment) whereas the other sites are finding other sources of funding to sustain their services. Managing expectations regarding the scale of focus and timeframes for benefit realisation is likely to be important in future MLAPs, given the variation across the sites participating in this programme.

Strategic alignment, vision and positioning

9.6 The MLAP programme was a flagship programme for Macmillan, who provided millions of pounds in funding, and generated extensive in-kind contributions from a range of partners. It offered the opportunity to develop and test models with potential to positively impact on the lives of not only PABC, but also those affected by other long-term conditions.

9.7 This scale of ambition is important to note. Macmillan is a charity fundamentally focused on supporting and improving the lives of PABC. Cancer is increasingly being recognised as a long-term condition. Arguably this recognition has improved during programme timescales, and people with cancer often also experience other co-morbidities. The desire by Macmillan to generate learning relevant for other long-term conditions is to be credited, given their core focus on cancer. As might have been expected, delivery to date has focused on PABC (including carers). Exploring how the programme models or principles can be translated to support people with other long-term conditions is already underway at programme and site level and needs to be pursued in order to fully realise the ambitions set out by the programme and explore its full potential for improving support and quality of life for wider groups of people in need.

9.8 There were variations in strategic alignment and demonstrable political support for the programme, particularly when taken at a national level. In Scotland, the Government produced a Cancer Strategy in 2016 that included a commitment to "*Invest £9 million over 5 years to support access to health and social care services during and after treatment, via for example, Link Workers to provide support in the most deprived communities and initiatives such as Macmillan's Improving the Cancer Journey*"[58]. In 2019 the Scottish Government and Macmillan launched an £18m partnership to roll out the ICJ/MLAP model across the country. In England there have been drives towards introducing social prescribing in all Primary Care Networks and increasing moves towards personalisation, including the release of NHS England's Long-Term Plan, which set out that personalised care will become business as usual across the health and social care system[59]. The approach that the MLAP programme has tried and tested is well placed to help realise these national ambitions. This gives further weight to the argument that focus should increasingly be placed on how elements of the programme

[58] https://www.gov.scot/publications/beating-cancer-ambition-action/pages/8/
[59] https://www.england.nhs.uk/personalisedcare/

design and delivery can be transferred to support people with other long-term conditions. The programme's focus on personalised needs assessments and care plan development offers potential learning and models for others to consider. It is important that this learning is not lost, to avoid any need to 'reinvent the wheel' or risk of fragmentation in local offers.

9.9 This latter point is important. The policy and delivery context has arguably become more complex during programme timescales, particularly in England. Ensuring alignment with other social prescribing and personalised care schemes will continue to be key, to avoid any sense of duplication or misalignment, and to avoid 'competing' for resources when Macmillan funding ends. The point about alignment extends to other Macmillan services as well as local NHS or local authority (or HSCP) commissioned models: the running of MLAP services alongside HNAs delivered in clinical settings was not reported to pose major issues, but may be an area to monitor to avoid potential duplication and confusion going forward. Awareness raising around the differences in both (and rationale for adopting both approaches within a given locality) may also be an important area for Macmillan to consider, given the increasing complexity of local systems.

The role of Macmillan

9.10 Without Macmillan's funding, it is unlikely that the work would have progressed at the scale and pace that it has. The funding proved vital in pump priming partnership formation, service design and delivery, enabling new ways of working to be trialled and implemented in very different contexts and different ways, to explore 'what works' and the impacts for PABC.

9.11 The amount of funding was deemed sufficient in all sites. Indeed, it wasn't the amount of funding that typically posed issues in the sites, rather the level of flexibility associated with the funds. This is a tricky issue to manage: Macmillan has responsibilities to its funders as a charitable organisation, and has certain constraints it must work within. However, the exploratory nature of the MLAP programme required flexibility in funding arrangements, including flex regarding when funds were drawn down by sites, with progress not always occurring as planned. At this stage in the programme the flexibility issues appear to have been resolved, with sites having extended their funded period where needed to ensure funds are used appropriately and avoiding any potential underspends.

9.12 The funding was not the only important input from Macmillan. The programme team were credited with bringing relevant knowledge, credibility and ideas; regional teams provided additional support to sites at key points. The scale of Macmillan as an organisation proved key in enabling sites to access relevant support and expertise in a timely manner.

9.13 That said, there were challenges. There was confusion and some frustration regarding branding, support was not always as forthcoming at times as sites would like, and it wasn't always clear for sites whether national or regional leads should be approached for different types of inputs. Macmillan's scale offers strengths in terms of the variety of skills and resources available in-house; it also poses a degree of complexity however, and at times did not appear to be as joined up as some site level stakeholders had expected.

9.14 As sites embedded their service delivery, the input from Macmillan (particularly the national programme team) lessened over time. It remains to be seen what Macmillan's input might look like in future, particularly as local partners are being requested to fund the models once

Macmillan's initial investment comes to an end. Capturing learning regarding Macmillan's ongoing role is likely to be key for helping to inform Macmillan's role in other future programmes.

Service design and development

9.15 The sites have all undertaken extensive co-production activities, ensuring the voice and vision of PABC informs their plans and models. There is wide ranging learning regarding this: co-production is vital for services for PABC and was credited with adding legitimacy to the models developed, helping to refine the communication materials and delivery approach, amongst other things.

9.16 Learning from the MLAP sites highlights the resources and skills needed to ensure effective co-production. Simply tagging the responsibility onto someone's existing day job is unlikely to prove sufficient, manageable or generate the meaningful engagement and inputs required. Macmillan was able to offer specific expertise to some of the sites, which proved helpful; others recruited staff with relevant expertise to lead on this aspect. Being clear on the resources, experience and skills available is vital when planning the work, to enable additional support to be procured as needed.

9.17 The development of clear terms of reference for co-production groups or panels is also important, being clear on how and when inputs will be sought, and how the feedback will be acted upon. Co-production was particularly meaningful where sites actively engaged PABC in design, rather than merely asking for comments on outputs or plans; feedback to coproduction volunteers as to how their input was incorporated proved vital.

9.18 Within the terms of reference and recruitment of coproduction volunteers it is also vital to plan for the roles to evolve over time, as partnership needs change in line with service development and implementation. Panel members' roles will not remain static; this is likely to mean different types of skills/interests and capacity are needed.

9.19 Those running panels will also need to carefully consider recruitment, as well as what approach is most appropriate to their local circumstances. MLAPs took steps to capture diverse voices and inputs as part of their coproduction activities. Capturing this range of perspectives (and avoiding any health inequalities being exacerbated by failing to do so) will be important for others seeking to learn from or replicate the MLAP approach. This may take more time and effort in some localities than others, and highlights the importance of thorough scoping and asset mapping from the outset, to enable existing groups to be engaged and used to reach seldom heard communities, and avoiding starting from scratch wherever possible.

9.20 Sites have also had to adapt and flex their delivery models as new learning or increased demand have emerged; building in processes and time for reflection and revision will be key, for both the existing partnerships and any future similar programmes. There is a balance to be struck between delivering support in people's homes or preferred setting, against efficiency and maximising the reach of the service. MLAPs have adapted their approaches over time, with increasing focus on the use of community settings (where appropriate) and telephone follow up HNAs and engagement. This shift over time should be anticipated by any future MLAPs, reflecting demand for support and the (relatively) limited capacity of the

services. MLAPs worked hard to ensure those needing addition or in-house support received this however, highlighting the importance of flexibility.

9.21 It is also key to understand what other support is available in the locality for PABC to access or be referred to. The partnerships do not operate in isolation: effective delivery and support for PABC is dependent on other provision and capacity within the system, much of which will be provided by VCS organisations. VCS organisations are often in a precarious financial position, with uncertainty regarding sustainability, and/or constrained resources against a backdrop of increasing demand. There is a risk that this becomes exacerbated, as demand from other social prescribing schemes continues to increase. This needs to be carefully considered by both existing and any future MLAPs. Whilst current sites were not evidenced as negatively impacting on VCS capacity or overwhelming the system, this remains a risk to be monitored and managed carefully. Early, frequent and open engagement with the VCS is important to ensuring they feel genuinely included, as the MLAP programme model relies on strong local assets.

9.22 This aligns with another key conclusion: the importance of careful and detailed monitoring. The MLAP sites worked with the evaluators to introduce rigorous monitoring and data collection processes. At times this felt onerous for busy programme leads and site stakeholders, but has enabled progress and outcomes to be monitored and evidenced. It will be important for the existing sites to continue to monitor reach and outcomes longer term to evidence the outcomes and impacts emerging and any changes in this over time or for different groups. Building in local processes to reflect on the data (for example, as part of Steering Group or Board meetings) and identifying local capacity for analysis and interpretation of the data will be important, to enable refinements to be made as needed, and to provide evidence to inform future commissioning.

9.23 Partnerships are evolving, dynamic entities, the demands and outcomes of which will shift over time. They are also highly context specific, shaped by and helping to influence and inform the local context. That Macmillan built in an element of local flexibility into the programme is key; this has enabled local partners to agree and define their own local plans and models. Continuing this flexibility and reflection will remain key as the landscape continues to evolve.

Outcomes and impacts

9.24 The evidence indicates that the programme's service models are helping to reduce the non-clinical needs for PABC: people are reporting a wide range of family, emotional, practical, financial, spiritual and physical needs, for which the evidence indicates they may otherwise have sought clinical advice and support or lived with as unmet needs. Needs are decreasing (in terms of number and severity) between first and second HNAs, and the survey of service users indicates that people feel more able and confident to manage their own health and care after engaging with the service. In the absence of a control or comparator, it is not possible to assess the extent to which the changes are a result of the MLAP programme, but the quantitative data from HNAs and surveys, triangulated with qualitative insights from interviews and free-text survey responses, indicates that the MLAP services were at least partly contributing to these changes. The fact that people report non-clinical needs, which may otherwise have gone unmet, indicates that the service is filling in a gap in local provision.

9.25 The data indicate a number of referrals back into health and care services for support following the HNA. Many of these may be an indication of effective integrated care, with link workers helping people to return to health services at an appropriate time. However, it would be worthwhile monitoring trends (in terms of volume and type of referrals) to ensure the service does not increase demand on the system inappropriately.

Management and leadership

9.26 As outlined above, visible senior leadership is a key enabler and necessary pre-condition for any MLAP. All sites had this, and also benefitted from inputs from leaders from across the local health and social care system, including politicians as well as senior officers. Early engagement and shared visioning proved key for securing this buy in.

9.27 In addition, the role of the programme manager, recruited to manage day to day development, engagement and activity (under direction of the programme board) also proved vital. Ensuring this role is banded appropriately (in terms of salary and seniority) and proved key in ensuring successful recruitment. Involving coproduction panel members as part of the recruitment process was also seen to be helpful. The continuity of postholder also proved key; managers remained in post, enabling memory to be built up locally, and avoiding any resetting of relationships. This is important, but also ties into another key learning point: link workers and facilitators also bring essential skills and capacity to partnerships, and the career progression for these roles should be considered. Without clear progression paths there is a risk that postholders may leave, risking lack of continuity and momentum locally.

Planning for sustainability

9.28 There remains uncertainty regarding future sustainability of the partnerships: the degree of uncertainty varies across sites, and all have made inroads into exploring and securing future funding.

9.29 The case for the model (in existing and future MLAPs) needs to be made robustly to have local support and, importantly, to set a foundation for demonstrating success to possible future commissioners. This programme has demonstrated that a robust model should be informed not just by the number of HNAs being delivered, but evidence of how PABC needs are being met and how the model can add value to the local system. Learning from the sites shows that it can take time to get this evidence together, which in some cases has delayed delivery and proved to be a source of frustration when people want to move faster.

9.30 The cancer landscape and social prescribing arrangements continue to evolve; demonstrating the added value of the programme will be key for ensuring sustainability. Considering system and strategic alignment is also vital, as is consideration of potential future roles for Macmillan.

Recommendations

Recommendations for Macmillan

9.31 Below are a series of recommendations for Macmillan, based on findings presented throughout this report and the conclusions presented above.

9.32 **Recommendation 1: Consider the pre-conditions needed to successfully introduce an MLAP.** The MLAP sites each relied on a series of key success factors or enablers. We suggest that Macmillan seeks to explore the extent to which these are evident in any future programmes. Examples include: visible senior leadership buy in (across key partner organisations); in-kind resources to support programme team recruitment, supervision and activity; strategic alignment and political support; realistic stakeholder expectations; a history or backdrop of strong partnership networks; and plans for (or openness to considering) potential sustainability options. Exploring the existence of these with local partners is likely to help identify sites with the essential pre-conditions in place.

9.33 **Recommendation 2: Be clear with new partners on the expectations for an MLAP.** There is a clear model for an MLAP in Scotland because of the ICJ model in Glasgow and emerging model in Dundee and Fife; thus new partnerships are likely to have a good shared understanding of how PABC holistic needs can be met. However, the model is not so prominent within England (nor Wales and Northern Ireland). Macmillan should therefore invest in ensuring partners in these nations have a clear understanding of what an MLAP is intended to achieve and how that might be realised. Being clear on the type of outputs sought, potential delivery model (e.g. is the programme about system transformation or service delivery, or both), and the respective roles of Macmillan and other partners when working together, may also be helpful in managing expectations nationally and locally. Fundamentally, Macmillan needs to invest in building strong, trusting relationships with local stakeholders, starting from the point of agreeing a high-level vision with local partners and offering investment.

9.34 **Recommendation 3: Provide clarity on national versus regional support offers.** The source or best possible provider of support (from within Macmillan) was not always obvious for local partners, leading to some confusion. Support that was targeted and timely was highly valued though: we recommend that Macmillan provides clarity about the levels and type of support available for partnerships, and where this can be accessed from, as well as any capacity limitations. This will also help partners to identify where they may need to draw on support from within (or recruited to) their local system.

9.35 **Recommendation 4: Build in flexibility**. Recognising the complexities of partnership working, variation in local systems and the provision of services creates unpredictability in programme delivery. Under such circumstances, it is helpful for Macmillan to be as flexible as possible about how their grants can be used. For example, a programme that begins with scoping and is not necessarily aiming for a specific model tried and tested elsewhere, may need flexibility on how it allocates funds and time between scoping, design and delivery stages, as well as between the types of staff needed to deliver those stages. Flexibility on Macmillan's branding requirements, to accommodate local partners, may also help support the maturing of a partnership as the local partners take on increasingly prominent roles in the service delivery and Macmillan's support decreases.

9.36 **Recommendation 5: Be clear on how MLAP programme and services align with other local Macmillan activities.** This will include considering any other HNA processes as well as support and information provision available in the locality and from the wider health and care system serving the same population. Providing this clarity could help local partners to avoid any (actual or perceived) duplication of offer, and ensure PABC do not 'fall through the gaps'

in local provision. This may also serve to strengthen the case for MLAPs being introduced and developed in certain sites, and/or help to inform pathways.

9.37 **Recommendation 6: Introduce standardised data recording across all sites, including separate records for each HNA.** Providing clarity regarding data collection processes at the outset is likely to manage expectations about the type of monitoring needed and resource required to establish (and deliver against) these processes. As far as possible, it would benefit the programme, the evaluation and the partnerships to have a standardised process for recording HNA data. This would facilitate improved analysis and comparison across areas, which would generate learning about how context and different models influence service usage and outcomes, and aggregation of data across sites to give an understanding of cumulative impact. Separate HNA records also permit analysis of changes between HNAs and thus provide evidence of impact of the service on its users. Liaison between sites (with Macmillan) is likely to be key to resolving variations in recording. Macmillan may be able to usefully assist by providing some written guidance/criteria regarding the data recording, reflecting lessons learned and expectations regarding the data.

9.38 **Recommendation 7: Continue to offer responsive, targeted support to sites.** Macmillan has offered a high level of support to sites. Tower Hamlets is likely to continue needing specific inputs while exploring what support to PABC will look like locally. But as the other three sites mature, they would continue to benefit from timely, appropriate, mutually agreed support. We recommend that Macmillan continues to offer flexible support, and also builds this into its delivery model for any future similar programmes. This is likely to involve drawing on support and expertise from different parts of Macmillan, at national and regional levels.

9.39 **Recommendation 8: Continue to share learning across MLAPs, potentially supporting a Community of Practice for managers and/or link workers.** Throughout the programme Macmillan has convened learn and share meetings, events and calls. These have helped to avoid sites 'reinventing the wheel', provided a sense of peer support for programme managers, and enabled Macmillan and the evaluators to remain fully sighted on progress and learning emerging in an efficient and effective way. We recommend that these be sustained and potentially developed into a Community of Practice for both programme managers and link workers (separately).

9.40 **Recommendation 9: Introduce a portal or site for storing MLAP programme tools and resources.** Linked to the point above, to avoid duplication of effort, we recommend that a portal be developed to 'host' resources developed by Macmillan and sites, to share practice and enable local tailoring. This might include coproduction materials, recruitment materials, service level agreements or delivery models, monitoring tools and communication materials, amongst other resources. It is understood that Macmillan is developing such a portal in Scotland.

9.41 **Recommendation 10: Conduct light-touch follow up evaluation, to explore longer term outcomes and learning emerging.** The evaluation and monitoring tools are all in place and embedded within sites; we recommend that Macmillan follows up with the sites and continues to monitor progress, learning and outcomes. This will help to track any implications emerging as a result of Covid-19, as well as the longer-term outcomes emerging for PABC, local services and systems.

9.42 **Recommendation 11: Consider alignment with other Macmillan offers.** Macmillan has sought to do this throughout, but we recommend that now may be a timely point for Macmillan to consider how the MLAP programme aligns with some of its other flagship programmes and support offers. This might include schemes operating within MLAP sites as well as other offers and support arrangements. This may help to provide clarity around the cancer support landscape (for PABC and professionals/partners).

Recommendations for local partnerships seeking to adopt the MLAP programme ways of working

Partnership development and planning

9.43 **Recommendation A: Undertake partnership wide visioning exercises.** This proved key for generating buy in and providing clarity about the purpose and aims of the MLAP in each site. We recommend that any future partnerships undertake this exercise. Reconvening, perhaps on an annual or six-monthly basis, to ensure this vision remains well aligned, and to monitor progress towards its achievement, may also prove useful in sustaining engagement and ensuring progress remains on track.

9.44 **Recommendation B: Develop a high-level plan and expectations, co-produced with key partners.** This will help to secure buy in and manage expectations in terms of progress and outcomes realisation. It may also help to identify potential alignment (needed or in place) at operational and strategic levels. Consider the parameters and arrangements for working with partners to help mitigate delays or issues emerging as development progresses.

9.45 **Recommendation C: Introduce robust governance arrangements**. It is important to ensure governance and operational arrangements are in place to avoid overreliance on any one individual, and to build a sense of shared ownership. This will also help to reduce the likelihood of the partnership stalling in the absence of a key leader, manager or champion.

9.46 **Recommendation D: Involve PABC in recruitment activities.** This enabled effective recruitment in a couple of the MLAP sites, and was identified as good practice by Macmillan leads and local stakeholders. We recommendation that future sites build this into their recruitment practices, for programme managers and perhaps also for link workers/facilitators.

Service design and development

9.47 **Recommendation E: Carefully plan for and resource co-production.** This is likely to include ensuring a diverse and representative range of voices inform service and programme plans, procuring experienced support to deliver co-production activities (whether in-house, from Macmillan or drawing on local partner expertise), developing terms of reference, and building in flexibility into volunteer roles and remits. Ensure mechanisms are in place to actively respond to any volunteer feedback or inputs, with explanations provided how when and why their inputs cannot be acted upon, as well as transparency about how (and where) their contributions have made a difference. Consider the skills needed and experience sought from co-production volunteers, and consider flexible approaches to accessing this support.

This may include engagement with local VCS groups, as well as (or instead of) panel recruitment.

9.48 **Recommendation F: Work closely with the local VCS to maximise potential impacts for PABC.** MLAPs aim to help PABC to identify and express their non-medical needs and access relevant support. They do not attempt to meet needs directly (with the possible exception of facilitating peer support). Ultimately, much of the relevant support is provided locally by the VCS. Given the funding and capacity pressures and concerns of the VCS, Macmillan and the sites will need to maintain or expand efforts to ensure they fully understand any impact of their work on the VCS and can work effectively in partnership with them to support PABC. HNA and survey data is expected to provide valuable insights into PABC needs and the extent to which support is being accessed, as well as any potential barriers to this, which could usefully inform local commissioning. Ensuring mechanisms are in place to use this data for commissioning will be key.

9.49 **Recommendation G: Consider the scope of the partnership**. Is the focus on cancer or wider to encompass other long-term conditions? If the shift is to considering long-term conditions alongside cancer, it will be important to consider alignment with other local social prescribing schemes as part of this, to avoid duplication, ensure strategic alignment and to target the most vulnerable and priority individuals and communities, but also to inform planning for sustainability, by identifying potential funding streams and strategic priorities. Agreement regarding this should be undertaken in discussion with Macmillan as well as local partners.

Service delivery

9.50 **Recommendation H: Balance the need for efficiency against providing personalised care.** MLAPs evolved their models over time, largely (but not completely) shifting away from home visits to undertake HNAs towards use of community settings where deemed appropriate, and/or limiting home visits to the initial HNA conversation. We suggest that future MLAPs build this into their models, to ensure appropriate personalisation and responsiveness to people's own needs and wishes, alongside ensuring efficiency and maximum reach. Allowing for a degree of flexibility will help to ensure those with the highest needs can continue to receive their HNA at home, or their preferred setting.

9.51 **Recommendation I: Consider / build in career progression routes.** Risks were identified regarding worker attrition, potentially jeopardising established relationships and momentum in delivery. This is a particular risk for temporary funded posts (even if these are funded for three years or more). We recommend that local partners work with Macmillan to consider what the progression routes could look like for local programme team members, to mitigate this risk. This may involve looking wider across Macmillan's local portfolio of offers/services, as well as across local partners, or include routes for progression and promotion within partnership teams.

Monitoring and evaluation

9.52 **Recommendation J: Consider sustainability from the outset.** Mitigating the risk of introducing short-term unsustainable interventions will help to secure buy in and reassure potential referrers or stakeholders that the model is intended to provide longer term

solutions. Planning for sustainability – in terms of future funding and potential resource requirements – will be a key part of this. As part of this, we recommend that local partners capture the 'true costs' of delivery, as well as evidence of benefits emerging, to ensure there is a clear 'ask and offer' for local commissioners to consider when planning for sustainability.