PERSONALISING CARE FOR PEOPLE LIVING WITH CANCER

FINAL REPORT FOR

THE MACMILLAN LIVING WITH AND BEYOND CANCER PROGRAMME

SOUTH YORKSHIRE, BASSETLAW AND NORTH DERBYSHIRE CANCER ALLIANCE

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1 INTRODUCTION

Since April 2016 Macmillan, NHS commissioners, providers and the voluntary and community sector have been working in a programme approach to implement Living With and Beyond Cancer (LWABC) across eight CCG localities in the South Yorkshire, Bassetlaw and North Derbyshire Cancer Alliance region.

The aim of the programme is to enable every adult living with breast, colorectal or prostate cancer in each of the eight localities to have access to the LWABC model of care from diagnosis onwards. The model of care has three interdependent elements – risk stratification, recovery package and supported self-management.

Most of the programme’s work to date has focused on earlier parts of the pathway and on improving experience for patients who will be cured of their cancer. This piece of research is the start of the programme’s work to explore the needs of people living with cancer who will not be cured. Throughout this report we will refer to this group as people with advanced cancer or people living with cancer.

1.1 Exploring the needs of people living with cancer

People living with cancer, that is those people that are on a non-curative pathway, form a highly heterogeneous group which includes people living with metastatic disease for many months and even years and those approaching the end of their lives. Those in the palliative stages of care may have reached that point very quickly, through later detection or a more highly aggressive form of cancer, whilst for others it may mark the end of a much longer journey.

As for all people affected by cancer the needs of those on this pathway will vary from individual to individual. The lengths of people’s journeys can be so variable and the level of stability in their condition can be very different. An individual’s needs may vary with time, not only as their disease progresses but
also as their life circumstances change. In contrast to those on a curative pathway, who have the chance to live beyond cancer, these patients’ journeys are timebound. The period of time may be unknown and unpredictable, but its finite nature makes time even more precious, and consequently patients and carers have less tolerance for time lost or wasted.

So, identifying and meeting the needs of people living with cancer in a timely, and effective way is vital to delivering the personalised care that the living with and beyond cancer programme aims to do.

This is an ambition which reflects and supports the findings and recommendations in ‘Achieving World-Class Cancer Outcomes A Strategy For England 2015-2020’, in particular Chapter 6: ‘How should we improve experiences of care, treatment and support?’

1.2 Methodology

The purpose of the work has been to firstly understand current service models, experience and potential unmet needs, and secondly to understand what works for whom in what context and why. Finally, to bring this knowledge together to help inform the development of new service models, through innovation and through sharing what already works well; evolving current systems and processes to be even better and more wide reaching, rather than wholesale reinvention.

We have approached this work through conversations with a wide range of professionals from seven localities across the region, patient representatives, patients and carers. These conversations have taken place in groups through facilitated workshops and via one-to-one discussions.

As a framework for conversations we used the statements from the government’s commitment to end the variation in end of life care across the health care system by 2020 so that people approaching the end of their lives:

- have honest discussions with care professionals about their needs and preferences
- make informed choices about their care
- develop and document a personalised care plan
- discuss their personalised care plans with care professionals
- involve their family, carers and those important to them in all aspects of their care as much as they want
- know who to contact for help and advice at any time

We held six workshops for professionals which in total had 84 attendees, who were a mix of professionals from health, care and community and voluntary sectors, and patient representatives. Following these workshops, we conducted an intermediate analysis to identify:

- emerging themes
- areas for further exploration
- groups/organisations/individuals with which to engage further

To explore the themes further, we undertook one-to-one conversations with 19 professionals, 7 patients and 4 carers. We also met with a patient action group.

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1 We use the term professionals to describe any member of staff from health, care and community and voluntary sector, regardless of whether they are a clinical, managerial or support professional.
1.2.1 Data limitations

Whilst professionally we had strong representation from acute, community nursing, hospice, CCG and Macmillan, we spoke to fewer from primary care, the voluntary sector care, care homes and children’s and young people’s teams.

It was impossible to speak to a truly representative number of professionals and patients within the timescales and resources available. However, through broad consultation followed by intelligence-led follow-up, we believe we have been able to get a good understanding of the localities. Our findings are consistent with the messages that the programme team themselves have been hearing over the last couple of years. They are also reflective of our wider experience of working with cancer professionals and patients across the UK.

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2 Ten had not been involved in the first round of workshops, nine had attended workshops but we needed to explore key themes with them in more detail.
2 SETTING THE CONTEXT

Our brief was to understand what was working well in relation to personalising care for people living with cancer, and what needed to be improved. It’s inevitable when committed professionals come together that they focus on how to improve services, and so the workshops had a strong improvement focus, although we did encourage all workshop groups to also identify examples where things were working particularly well.

Despite the workshop outputs being predominantly about improvement, it was also evident from our conversations that the system is far from broken: overall care for people with advanced cancer is good, and professionals are committed to personalising care as much as possible. However, there are some barriers that prevent it being a consistently good experience, and points within the journey where things are more likely to go awry. We discuss these in Chapter 3, but it is important to stress that our report focuses on how to further improve a system that is already working well rather than implying that things are in poor shape.

As one professional put it:

“"We’re a good way up, but a distance to go!"”

2.1 Local variations and similarities

The starting point for this research was to understand what was happening in each of the localities, and whether and how local variation created different challenges or factors that were unique to a locality which may require specific solutions.

Of course, the system in each locality is different, as they are served by different NHS Trusts and have different services, teams and community assets in place. All link to the tertiary centre in Sheffield, but depending on the locality there may also be connections with Trusts and centres outside the programme regional footprint. This means many patients from across the region are treated in other places as well as their own local NHS trust hospitals.

The other organisations in each locality, such as hospices, social care and community and voluntary services, all make a significant contribution to cancer care. The range of these services, their capacity and connections vary between localities, but in each locality these services are providing a similar level of quality care. There are pockets of good practice and likewise there are some gaps in provision but, overall, we found that there were more similarities than variances.

Furthermore, the challenges and issues we uncovered were common across localities, and indeed are not unique to the region; they are similar across the country. Consequently, the rest of this report focuses on the common issues identified, rather than providing a locality by locality analysis.

It is important to note that the similarities in issues does not indicate that a single standardised solution is required, regionally or nationally. Each locality’s unique system, relationships and assets will require a solution that fits its context, but there is learning from how other localities and regions have addressed these same challenges, and existing solutions might in some cases be adaptable to fit.
2.2 Strengths within the system

As previously mentioned, much is working well in the region, and there are strong foundations on which to build and improve. Across the region we have identified three core strengths which will be key enabling factors for improving personalised care for people living with cancer.

Community assets
In addition to statutory bodies, there is a thriving community and voluntary sector, with a variety of organisations offering support suitable for people living with cancer in their own community. In a context of austerity and financial constraints, just keeping going is a challenge; to be thriving is a great achievement. Across all the localities, we didn’t find a lack of community-based services, but we did find that professionals’ awareness of and referral to the services was variable.

Relationships
Professionals from health, social and voluntary organisations have developed strong relationships based on respect for their respective roles, and an understanding of what each brings to the care and support for people living with cancer. Some of these have developed over many years, and not all have been easily established, but they demonstrate the value of the human connection for a strong, robust healthcare system. We found that, as well as strong locality-level relationships, there were good relationships at a regional level as a result of past regional working and strengthened by the programme.

Professional commitment
We did not meet one professional that did not want to make things better for people living with cancer. There is a will and a strong commitment to improving patient and carer experience and for that experience to be as personalised as possible. Professionals raised a variety of issues that sometimes frustrated their attempts to ‘do the right thing’, which are discussed in the following chapter, but the core commitment and will remains.
3 IMPROVING PERSONALISATION OF CARE FOR PEOPLE LIVING WITH CANCER

Our conversations have led us to a single overarching theme that underpins all of what follows. The transition points within the pathway are the points of vulnerability at which things are not only more likely to go awry, but also have greater impact because the patient is often at their most vulnerable. This is not unique to advanced cancer, but patients’ and carers’ time and patience are often less abundant, so the emotional impact can be much greater.

David said he didn’t know what was happening, “they just let it dawn on me that I was terminally ill. Eventually I asked how long, they wouldn’t say, I asked if I would see my next birthday, they said ‘you may well’.”

For patients on a curative pathway, the transition at end of active treatment is often challenging, with patients reporting feeling abandoned, as they are no longer wrapped in the protective care of regular hospital treatment. For patients with advanced cancer though, a key transition is from active treatment to palliative care, and it was at this point that we heard the risk of feeling lost and unsupported was at its highest. This is rarely due to care not being available, but it is about the patients’ perception of the transition.

James told us “I was told my Dad was being transferred to palliative care – I had to look it up I didn’t know what it meant”

In addition, those patients living with cancer as a long-term chronic condition may have very little interaction with clinicians about their cancer for long periods of time, unless they are re-entering the clinical pathway due to a sudden deterioration, and that sense of isolation from services and care can be difficult. Not knowing who to call if they have queries, not being sure when they should seek support and advice, or perceiving that health professionals are busy and others might have more pressing needs, can all act as barriers to patients getting the care and support they need.

Lucy told us “I can ring the Breast Cancer nurse – but they don’t seem to have time”

We have identified five sub-themes which contribute to the challenges of these key transition points. These are shown in the diagram below, and we examine each in more detail in the following sections, highlighting both the problems and potential solutions, which we have drawn from existing practice.
3.1 Communication

We heard from patients that a frustration for them was having to re-tell their story to professionals. There is an expectation that the patient’s history is available to all professionals involved in their care, but we know this is not the case. This is frustration shared by professionals.

Paula said “we saw a different consultant every time – got mixed messages, I’d have to go through story again.”

Locally, work is ongoing to develop systems that enable patient information to be shared more readily between organisations involved with patient care and support. However it is likely that such integration across the region will take some time to achieve. In the absence of shared systems it often falls to the patient or carer to relate to the health professional their history and treatment regime; in extreme cases patients literally carry their medical records with them to overcome the disjointed nature of communications.

For some, the retelling goes beyond frustration, and a patient or carer having to relate again what is a traumatic story can be draining and potentially emotionally damaging.

3.1.1 Possible solutions

A wholesale reinvention of health and social care IT systems is likely beyond the scope of this programme. However, there are potential local solutions, some of which are decidedly low-tech, that can help improve communications between professionals across the sector. These include:
**Electronic Palliative Care Coordination System (EPaCCS):** enables the recording and sharing of people’s care preferences and key details about their care with those delivering their care. The systems support coordination of care and the delivery of the right care, in the right place, by the right person, at the right time. Currently this system is only used for people in their last year of life but as we know palliative care can extend beyond twelve months. EPaCCS serves a broadly similar purpose to the e-HNA and care plan process; understanding and documenting what’s important to the patient, their needs and how those needs might be met. A link between these two systems could help manage the transition from active treatment to palliative care more seamlessly.

**Red book:** a simple low-tech solution where key patient information is kept in hardcopy form and retained by the patient. It can be updated by any professional that is providing care for the patient and so provides an immediately available history to other professionals that may become involved in care, whether that is a colleague from the same team or if a patient is for example subject to an emergency admission. It reduces the need to retell their story and for patients or carers to be able to recall medications etc.

**Care Home red bag:** a similar concept to the red book with patient information kept accessible to professionals treating people in care homes. This can be really important in decision making about admission to hospital as it can be used to ensure that information such as preferred place of death is readily accessible. If called to a deteriorating patient in a care home, where perhaps family are not available to contribute to decision making, health professionals with good intent may err on the side of caution if a patient’s wishes are not readily available.

**Neighbourhood teams:** In Barnsley we heard from a Community Matron that held monthly Neighbourhood Nursing meetings that were attended by a wide range of health and social care professionals including GPs, Macmillan Nurses, mental health team, Yorkshire Ambulance workers, Live Well Barnsley. In essence, these extended MDTs enable the professionals to discuss complex cases, identify the main issues and from that determine who should be the key worker and who else might need to be involved in supporting each patient.

This has not come about by accident but through a process of building relationships over time and being persistent enough to keep inviting colleagues until they come. Now that the value of these meetings can be seen they are so well attended it is often standing room only. Attendees bring their lunch so there is no doubt time for a bit of a catch up as well as getting on with finding the best way to support their patients. Despite similar structures in other parts of the region we did not hear that collaboration at this level was taking place everywhere and we therefore conclude that it is people and their behaviour that contributes strongly to this rather than just process and structure.

### 3.2 Relationships in new settings

Patients can become very connected to the team providing their care and delivering their cancer treatment. In particular, we hear of the strong relationship between patients and their CNS. When a patient is no longer receiving active treatment and is handed over to community services or the palliative care team this represents a significant change for them, and the end of a trusted relationship. Not only are they faced with the reality of there being no cure for their cancer, in this fragile state they have to establish relationships with new people in new places.
They may also find they are being supported by multiple professionals for their cancer and potentially other co-morbidities. Patients can find themselves with multiple appointments, that tie them to the house, and reduce even further any sense of a normal life.

Jane told us she appreciated support at home but having to wait in was a pain, and then when the District Nurse came they always seemed rushed. She would ring to cancel a visit but then someone would turn up anyway. She lived near her GP and wanted to go there for support but getting past the receptionist was a challenge.

### 3.2.1 Possible solutions

The solutions suggested here focus on the patient having a seamless transition and receiving joined up care, which may be delivered by different roles and organisations but to the patient is seen as a single entity.

**Support Worker/Navigator:** these roles are not new to health and care, nor cancer care, however they are being introduced specifically to support the implementation of LWABC and could be further extended to support people living with advanced cancer. They have different titles in different settings; however their functions are very similar. To ensure consistency across these roles the programme is sharing job descriptions, competency frameworks, induction plans and escalation processes.

These roles have been supporting people affected by cancer within the programme footprint since April 2017, in both community settings and acute teams. Where hosted in an acute setting they are a community-facing role, part of the clinical team but with expertise in linking people affected by cancer to information and community support based on their expressed needs.

The introduction of these roles is already having a demonstrable impact, particularly in acute settings. The programme has been able to evidence\(^3\) that the roles have created more capacity, releasing CNS time to support people with complex needs and enabling more (HNA) conversations. For example, in one Trust in the programme, the introduction of a Clinical Support Worker released 54 hours of CNS time over an 11 week period.

The current ‘Support Worker’ solutions being implemented in each of the localities are summarised in Appendix 2.

**Collaborative teams:** professionals that work well not only within their own team but across teams can make a real difference to a patient and achieve efficiencies. A simple real-life example is this: A community matron is visiting a patient to change a syringe driver, and a district nurse is due to visit the same patient on the same day to change a dressing for a leg ulcer. When a neighbourhood team is working well, those two nurses will have a conversation to recognise the multiple needs, acknowledge that the matron can deliver more general nursing duties too and combine the visit. By being person-focused rather than task-focused, the team will not only save time for themselves, importantly the patient has only one visit.

**Co-location:** brings about opportunities both formal and informal to collaborate and share information which enables professionals to gain a more holistic picture of their patients. A single telephone contact number means the patient doesn’t need to figure out who they should call, someone else can triage the call and make sure they speak to the right person. Hubs that offer both clinical support, information and advice,

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\(^3\) Using the ‘Intervention Tool’ designed by South Tees Hospitals NHSFT
perhaps access to other support services accessible in their community makes it less daunting to seek support. Any measure that presents the many professionals that may be involved as a cohesive team rather than a diverse and dispersed set of individuals has to make it easier for the patient.

3.3 Routes into support

Any person with cancer needs to be able to access timely support. People living with the disease long-term potentially have quite long periods where they feel quite well, but may still value support during that time. Support for this group is not as well-publicised as it is to those in active treatment or receiving ‘survivorship’ support. If their condition and/or circumstances change after a long period of stability, finding their way back into support, and even knowing who to call, can be challenging. And those that are approaching end of life may need significant emotional and practical support alongside their specialist care. Getting back on the care pathway can be difficult, as can finding sources or other support, especially if this has to be initiated by the patient, who most likely has no idea what is available.

Claire said “I didn’t know who I could contact. I needed equipment to help care for mum, like a toilet seat – I didn’t know how to get it.”

3.3.1 Possible solutions

**Meaningful conversations/HNAs:** Meaningful conversations about a patient’s needs (using the Holistic Needs Assessment (HNA) framework are already a fundamental part of the LWABC programme, but activity is currently focused on patients recently diagnosed and those completing curative treatment. If these conversations could be extended to key stages in the advanced cancer journey (for instance at key transition points, and every 6-12 months for patients living long-term with cancer as a chronic condition) they would provide the touch points where patients support needs could be identified and they could be funnelled into the appropriate services. Having regular conversations of this type also allows for earlier discussion of advanced care planning preferences, and makes the transition to an advanced care planning conversation much more natural when the time comes.

**Support Workers/Navigators:** This raises the question of who would have these conversations with the patient. It needs to be someone who has the time and skill to devote to the conversation and who can then tap into the necessary support. Support Workers/Navigators have already been introduced into earlier stages of the pathway, some in acute settings but others in community settings. We have already identified the value of having this role available to support patients with advanced cancer in section 3.2, and if this can be implemented then they would be well-placed to have the regular conversations with patients to help them into the support they need.

3.4 Skills, confidence and shared responsibility

Of the six commitments around which we themed our research conversations, being able to have an honest conversation with a patient, was the most commonly mentioned challenge; in terms of how vitally important it is and how it is not always done or done well. Honest conversations about prognosis, treatment options with realistic explanations of consequences, the option to stop treatment, preferred place of death, DNARs are all vital for advanced care planning and yet we heard that some professionals lack the skills and/or confidence to have those conversations. Patients’ and carers’ preferences also contribute to those conversations not always being easy to have. Being able to read a situation and a
patient’s needs, to give them the information in the way that they need and to truly involve them in shared decision-making, is not easy. But as someone moves from active treatment to palliative care or palliative to end of life, having the skills and confidence to be able to have those honest conversations is vital.

Mary told us how important it was for the oncologist to be direct and clear. To be positive but without giving false hope, to provide options for treatment but to be realistic about it.

Professionals described the challenge of working with some consultants, who are reluctant to ‘give up’ and who continue to suggest new treatment options, without necessarily giving the patient and their family sufficient opportunity to think about whether they might prefer to stop treatment in the interests of a better quality of life for their remaining time. Some professionals also expressed worry that patients might accept these options rather than speaking up about preferring to stop treatment, because they felt that they shouldn’t give up if the consultant wasn’t giving up. With the consultant being the ultimate accountable clinician for the patient’s treatment decisions, it can also be difficult for other health professionals to raise the prospect of stopping treatment. These are cultural challenges that will not be resolved overnight, although many professionals reported that they felt things were changing as medical education changed over time. They also expressed the importance of every professional being equipped and confident to talk honestly with patients about their preferences, so that they can provide the care the patient wants and needs.

We also heard from cancer specialists and non-cancer specialists alike, that non-cancer specialists and non-palliative care specialists tended to back off from conversations about care and support with patients who were palliative, even though the conversations and needs were not related to technical palliative care issues. Whether it was for fear of stepping on the palliative care specialist team’s toes or a fear of doing something wrong, they tended to step back even though the care or support required was within their skillset and professional boundaries. In short, if a patient is under the care of the palliative care team, other professionals are reluctant to get involved when they could easily deliver the care or support that’s needed, leaving the palliative team to focus on the more specialist aspects of care.

As one hospice professional described it, those involved with caring for people that are in palliative care “need to learn to feel a little uncomfortable”.

3.4.1 Possible solutions

Training and education: some organisations have already provided Difficult Conversations training for some cancer professionals, and several workshops led to suggestions of offering refreshers and expanding availability to other colleagues. A hospice in the region is currently piloting a programme of education and support for care home staff, to equip them with the skills and knowledge to be able to care for residents at the end of life. This is supplemented by a dedicated helpline at the hospice to answer care home staff queries and avoid admissions when the patient could otherwise stay at home.

3.5 Supported transition and self-management

Going from intensive regimes of active treatment to the symptom control of living long-term with cancer as a chronic condition is a major shift for the patient, in terms of their clinical interactions as well as the mental and emotional changes they will experience. They may begin to feel quite well as the effects of chemo diminish, and their immune system may rebuild leaving them less susceptible to infection, but at the same time the fear of not knowing what to expect can make it difficult to let go of the clinical support and
self-manage their condition. It is perhaps akin to the patient that is cured and then left to get on with their lives beyond cancer, but with greater fear as unexpected symptoms could be the sign of a much faster-approaching deterioration.

3.5.1 Possible solutions

Self-management support: Intensive transition support provided by community matrons in one locality we heard about provides patient support for six weeks which educates the patient to self-manage. The intent is clear from the outset, so the patient is under no illusion that this support will be ongoing, but it eases them into self-management, gives them the confidence to look after themselves, but always leaves them with a route back to support.

Empowering patients and carers: Giving patients and carers the skills and confidence to be able to lead as normal a life as possible. We heard from one patient that needed injections at home as part of her treatment. She could have had the District Nurse do them but that would tie her to the house. Her husband was trained to deliver them allowing them the flexibility to manage their own time. Another carer said she had received from the hospice team that had given her advice and support so that she felt able to take her mother away for a short break. A husband we spoke to was trained to provide quite intense care for his wife including managing her feeding system, so he could bring her home to die. Having a quick and easy route back to support is essential as a safety net, but handing responsibility to patients and carers allows them to make the most of the time they have left, no matter how short.

3.6 Barriers and enablers

The possible solutions provided above is by no means exhaustive, and certainly not innovative. So why are these solutions not already in place? This section examines some of the barriers to implementation of these simple solutions and identifies the enablers that will be needed to make progress.

3.6.1 Barriers

There are two fundamental barriers to providing integrated, personalised care.

Time

Professionals reported being under enormous time pressures, and most that we spoke to were already working longer than their contracted hours. This can make it difficult to do the additional communication, networking and relationship building that might address many of the challenges described above. In addition, there are aspects of professionals’ workload (often administrative processes) which they do not see as adding value or indeed feel like barriers to providing patient care. This is a frustration for professionals, as they know that they’re not always able to do all they would want to for every patient.

Whilst in an ideal world more resource would help free up staff time, the realities of NHS finances mean that significant resource increases are unlikely. Therefore, it may be that at least part of the solution lies in using time differently and collaborating to maximise efficiency. New roles such as support workers may also be part of the solution, to enable specialist professionals to operate at the top of their skillset whilst also increasing the overall amount of support and care available in a cost-effective way.

We also note, both here and in other parts of the UK, that patients can be reluctant to contact their CNS because of a perception that they’re very busy and so they don’t want to bother them. There is no doubt they are incredibly busy and often working far beyond their contracted hours. But somehow this message has reached patients, perhaps because they often have to return calls out of hours, and this can be a barrier to asking for help. Support Workers by contrast are also very busy but appear to give the patient
the impression that they have as much time as the patient needs. It’s not entirely clear, but seems to be a function of them being more reachable by phone than CNSs inevitably are, and also how they talk about available time with the patient; this creates a sense of spaciousness that encourages patients to ask for what they need. There may be learning in this for how other professionals communicate with patients, to encourage them to feel able to seek support when they need it.

Siloed resources
The NHS has become increasingly fragmented over recent years, with professionals who would in the past have worked for the same organisation now being employed by different organisations. As resources have become scarcer, the time available to do anything above and beyond what is commissioned has become more challenging. Collaboration across these organisational siloes is difficult, and may be actively discouraged or prevented by the employing organisations. Furthermore, because of the difficulties of moving money between different parts of the system, redesigning services to meet a patient need can be prevented because the savings end up being generated in a different part of the system.

Where we have seen collaboration across boundaries and siloes, it has usually been because professionals have long-standing relationships and trust, and there is a spirit of genuine reciprocity where people help each other out in the knowledge that everyone benefits. Having confidence that their managers will support a little blurring at the edges, for the benefit of the patient and shared organisational efficiency, obviously plays an important part too.

3.6.2 Enablers
Some of the solutions to the issues we’ve described at the start of this chapter will come from improved processes and development of new role. We’ve described these in each of the relevant sections, and there will undoubtedly be many other ideas sparked by local professionals when they reflect on the findings of this work and talk to more patients about how to improve their care.

However, it’s not all about processes – it’s also about enabling behaviours. The barriers we describe are unlikely to be going away anytime soon, but through our conversations we have identified a number of enablers that can help to overcome these barriers and to facilitate the processes needed to improve personalised care.

People
Where things are already working well, it comes down to people. Passionate and driven professionals who want to make a difference, and have the tenacity to keep knocking on doors and encouraging other professionals to work together more effectively. Professionals who will do an additional task during a home visit, if it means one less visit for a patient and frees their colleague up to do something else. Professionals who pick up the phone even though they should have clocked off an hour ago, because it might be a patient that needs help. Professionals who can see the benefit of collaborative working but sometimes have to push boundaries to make it happen. We met lots of these professionals during our research, and heard stories of many more. Having a culture that gives them permission to do the most important things with their time would unlock their resources to best effect for the patient – whether that patient has advanced cancer or is on a curative pathway.

Conversations
Personalised care depends on quality conversations at all stages of the pathway. The conversation at the start of a patient’s journey sets the foundation for all future conversations and care planning. Looking at the issues we’ve identified during transition points, a meaningful conversation would eliminate many of the
problems. Where we heard examples of personalised care working well for patients with advanced cancer, high quality conversations were always at the heart of the care.

These conversations are not the responsibility of one individual, although there is value in having a constant – a person who builds rapport with the patient through their journey. All those who support people living with cancer need to have the skills and confidence to have those conversations. Moreover, they need to be empowered to have those conversations.

Conversations behind the scenes, between professionals, are also crucial. As health and care provision has become increasingly fragmented, referral processes and forms have in many cases replaced the conversations professionals used to have with each other when seeking another professional’s involvement in a patient’s care. The paper trail is essential for safety and accountability, but the attendant conversation is the root of understanding the patient’s story and needs.

Collaboration
Providing personalised care is a team game, not pass the parcel. Where we see personalised care working well, professionals understand and respect each other’s roles but also use their judgement to blur the lines (with each other’s agreement and the support of their managers) so they can use their collective skills and time to best effect. If all organisations and managers within the system released and empowered their staff to do this, more collaboration could flourish.
4 CONCLUSIONS AND RECOMMENDATIONS

We have taken a pragmatic approach to our conclusions and recommendations, keeping them within the realm of what is possible for the programme and its partners to achieve, rather than suggesting unrealistic ideal-world solutions.

Fortunately, within the bounds of the pragmatic and feasible there is much potential for further improvement of personalised care for people living with advanced cancer.

Our findings indicate that improving personalised care will rely upon a combination of cultural and process/workforce factors, which we describe in more detail below.

4.1 Culture

Culture might be best described as ‘the way we do things around here’; the norms of behaviour that characterise an organisation’s routine ways of working. These behaviours are driven partly by the structures and systems within an organisation, but can also be influenced by management approaches and the daily practice of all the people within the organisation.

4.1.1 Collaborative behaviours

Many of the professionals who provide care to people with advanced cancer are employed by different organisations, and located in different places. This can make collaboration less easy; they’re unlikely to bump into each other by the kettle and the way money flows through the system can disincentivise organisations from encouraging collaborative working with colleagues from other organisations.

However, our findings show that collaboration across organisational and professional boundaries is fundamental to ensuring the ball doesn’t get dropped during those difficult transitions that people living with cancer experience.

Collaboration takes work – it’s easier in many respects to plough one’s own furrow – but the advantages for patient experience, resource efficiency and staff satisfaction are worth the effort.

Structures and systems may be part of the solution, for example creating regular meetings such as take place in Barnsley, or co-locating teams and services to enable cross-fertilisation, but this all needs to be underpinned by the small-scale daily behaviours of collaboration: sharing information, helping each other out in the spirit of reciprocity, finding opportunities to talk about and solve patient problems together. As NHS structures have become more fragmented, it seems to have become harder to behave collaboratively, and there is both a need and an appetite for that to be restored.

4.1.2 Permission

Which brings us to permission. We become conditioned to work in particular ways by the norms of our employing organisations, and so to have the confidence to behave differently we need to know that we won’t be punished for doing so.
There is an appetite amongst professionals to work more collaboratively, to use their time to best effect and to solve problems for patients so that care is better. This needs to be unlocked by managers and organisations giving their express permission to work differently and by managers leading by example.

4.2 Process and workforce

Whilst addressing the cultural factors above will contribute to improving personalised care for people with advanced cancer, there are also some process and workforce changes that will be necessary.

4.2.1 Meaningful conversations

As with other parts of the LWABC programme, personalised care for people with advanced cancer all starts with a conversation. As patients can be living for relatively long periods with cancer, regular conversations to explore their changing needs and direct them to appropriate support would ensure patients are not left feeling isolated or unable to get the support they need. These conversations may also lay the foundations for future conversations about advanced care planning, and may enable some of those discussions to take place earlier than they sometimes do currently. We would recommend an annual conversation with six-monthly touchpoints to check if things have changed.

As with the conversations in other parts of the pathway, using the Holistic Needs Assessment (HNA) framework will allow for a consistent and comprehensive structure to ensure all the patients’ needs are explored.

4.2.2 New roles

The Support Worker role (and similar roles such as Navigator) is already proving its value in other parts of the pathway as part of the LWABC programme, and the role and skillset also fits well with the kind of support people need when living with cancer beyond active treatment. The role is well-suited to being the constant as patients navigate the various transitions in the care, to having regular meaningful conversations with patients and helping them to find and access the support they need.

Given that most people with advanced cancer are being cared for predominantly in the community setting, it makes sense for the Support Worker role for this patient group to also be community-based.

4.2.3 Simplifying essential communication channels

Improving the extent to which all professionals have access to a patient’s information would dramatically reduce the frustration, and in some cases distress, experienced by patients having to tell their story over and over to every person they meet along their journey. In the longer term, we would all hope that single unified systems can become the norm, but that is unlikely to be achieved quickly so a shorter-term fix is also required.

We recommend each locality considers what would work best in their context, and making use of existing systems and processes where possible, to introduce a simple communication system that enables all those involved in a patient’s care to have access to the essential information without asking the patient every time.
4.3 Integration with the wider LWABC programme

Whilst this research has focused only on people living with advanced cancer, our findings show that this group’s needs align very closely with the rest of the LWABC programme. Improving personalised care for people living with cancer therefore does not need a separate programme or to be ringfenced apart from LWABC. Rather, our findings indicate that by stretching new roles and conversations from the programme further along the pathway many of people’s needs will be met.

The frustrations around communication are not unique to patients with advanced cancer, but their limited time makes it a more pressing issue for them. The systems developed in this part of the pathway could therefore be stretched backwards into the rest of the LWABC pathway in due course, with advanced cancer having been the early adopter.

4.4 Alignment with the National Cancer Strategy

The findings of this research present a local picture that very much reinforces the national strategic direction. In particular, around our key workforce finding, Recommendation 61 in ‘Achieving World-Class Cancer Outcomes: A Strategy For England 2015-2020’ states that:

**NHS England and the Trust Development Authority should encourage providers to ensure that all patients have access to a CNS or other key worker from diagnosis onwards, to guide them through treatment options and ensure they receive appropriate information and support.**

**In parallel, NHS England and Health Education England should encourage providers to work with Macmillan Cancer Support and other charities to develop and evaluate the role of support workers in enabling more patient centred care to be provided.**

The Support Worker role is already being adopted within the programme, and as we’ve already discussed, our research has shown the applicability of and appetite for the role in this later stage of the cancer pathway too. Rather than needing different interventions or roles, our findings highlight the importance of stretching the same types of roles and conversations right along the pathway.
## APPENDIX 1

### Table 1 Summary of group consultations in each locality

<table>
<thead>
<tr>
<th>Locality Group</th>
<th>Sheffield</th>
<th>Doncaster</th>
<th>North Derbyshire &amp; Hardwick</th>
<th>Barnsley</th>
<th>Rotherham</th>
<th>Bassetlaw</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>CNS/Nurse</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>5*</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Palliative</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
<td>1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Hospice</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>5*</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>CCG</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>CVS</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Care Homes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Community Care</td>
<td></td>
<td></td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Other</td>
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<td>6</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Children &amp; Young people</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Macmillan (excl. prog. team)</td>
<td>1</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Patient Representatives</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>8</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>18</strong></td>
<td><strong>17</strong></td>
<td><strong>15</strong></td>
<td><strong>18</strong></td>
<td><strong>18</strong></td>
<td><strong>9</strong></td>
<td><strong>95</strong></td>
</tr>
</tbody>
</table>

*Includes additional focus groups

**Engaged through Barnsley Patient Action Group**

### Table 2 Summary of one-to-one consultation

<table>
<thead>
<tr>
<th>Role</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>CNS/Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Hospice</td>
<td>4</td>
</tr>
<tr>
<td>CVS</td>
<td>7</td>
</tr>
<tr>
<td>GPs</td>
<td>2</td>
</tr>
<tr>
<td>Care Homes</td>
<td>1</td>
</tr>
<tr>
<td>Community Care</td>
<td>1</td>
</tr>
<tr>
<td>Children &amp; young people</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total professionals</strong></td>
<td><strong>19</strong></td>
</tr>
<tr>
<td>Patients</td>
<td>7</td>
</tr>
<tr>
<td>Carers/Family</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total non-professionals</strong></td>
<td><strong>11</strong></td>
</tr>
</tbody>
</table>
APPENDIX 2

Summary of ‘Support Worker’ roles across the programme area:

Acute-based

★ Rotherham x3 (x1) Prostate from November 2017, (x2) Colorectal & Breast agreed December 2018
★ Chesterfield x3 Prostate, Breast, Colorectal from January 2018
★ Wakefield x3 Prostate, Breast, Colorectal from May 2018
★ Doncaster x3 Prostate, Breast, Colorectal agreed December 2018
★ Barnsley x3 Prostate, Breast, Colorectal Panel in January 2019
★ Sheffield – in discussion for 2019

Multiple (existing) support worker roles have evolved in other tumour sites for different reasons.

Community-based

★ Doncaster - ‘Living well’ (existing) & additional roles through the LWABC programme
★ Bassetlaw - ‘Aurora’ (existing) & additional roles through the LWABC programme
★ North Derbyshire & Hardwick – practice nurses; aim for multiple LTC (planning) & Macmillan Information & Support Service (existing) & community-based Blythe house Hospice
★ Rotherham - volunteer care coordination role (planning) & Macmillan Information & Support Service (existing)
★ Sheffield - multiple roles in support organisations (existing)

Role titles include:

★ Cancer Support Worker
★ Cancer Care Co-ordinator
★ Key Worker
★ Advocate
★ Health & Wellbeing Practitioner
★ Navigator