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# Preface

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Informed by the 2010 NHS National Cancer Patient Experience Survey, which highlighted weaknesses in patient experience at University College London Hospitals (UCLH) NHS Trust, the trust and Macmillan Cancer Support entered into a partnership to deliver a programme that aims to provide ‘the best care, treatment, support, and information to patients at every stage of their individual journey’. This partnership formally launched in April 2012.

RAND Europe and the Health Services Research Group at Cambridge University, who together form the Cambridge Centre for Health Services Research, were commissioned to undertake an evaluation of the UCLH–Macmillan Cancer Support partnership. The evaluation, commenced in March 2012, aimed to take an explicit whole systems approach, with a particular focus on the ability of the partnership to enhance care coordination at transition points along the cancer care pathway.

This report represents the second output from the evaluation and covers the period April 2014 to January 2015. It focuses specifically on the workings of the partnership and aims to identify and analyse the views of stakeholders, including staff and volunteers, on how well the partnership is working, how it has changed attitudes and ways of working, and the approach of leaders within the partnership. It follows, and where appropriate builds on, a previous evaluation, completed by the same team in July 2013. However, the current evaluation – and this report – is a stand-alone piece of research. It formulates research recommendations intended to aid UCLH and Macmillan Cancer Support by contributing to learning within the partnership to support future decision making. The report also contributes to a wider understanding of partnership working.

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# Abstract

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The University College London Hospitals (UCLH) NHS Trust–Macmillan Cancer Support partnership is intended to improve the experiences of carers and of patients with cancer by improving the whole journey, from diagnosis through to palliation, and to embed this in a system that actively engages patients and carers in decision making at each step. Key changes introduced as a result of the partnership include a support and information service, a learning forum for cancer nurses, one-to-one support for patients and an extended and restructured volunteering service. Central to intended improvements was a new building with a dedicated outpatient clinic area, day care and chemotherapy services, day surgery, and on-site diagnostic services to diagnose and treat cancers and haematological disorders.

This report is the second output from a three-year evaluation of the partnership. It aimed to assess the working of the partnership and its capacity to support the partners' plans to move forward. The evaluation team aimed to approach the question of how the partnership was working from the perspectives of staff, volunteers and senior strategic and operational managers. The evaluation also aimed to understand if, even at this early stage, there were perceptible changes in patient experience compared with comparable changes in patient experience elsewhere in the NHS. This phase of the evaluation applied both quantitative and qualitative data collection methods. These were:

- In-depth **interviews** with staff and volunteers conducted between May and August 2014 (n=21)
- An online **survey** of a wide range of staff involved in the delivery of cancer services conducted between December 2014 and January 2015 (n=88)
- In-depth **interviews** with senior strategic and operational managers within the partnership conducted between April and June 2014 (n=16)
- **Analysis** of the 2012/13 and 2014 waves of National Cancer Patient Experience Surveys

Towards the end of our data collection we supported a learning event to report our findings to members of staff and to elicit their reflections on the findings. These views, along with the other data sources, also informed the final discussion and conclusions. Key findings were that: a) within broadly positive perceptions across the board, there were important variations – with senior staff being more positive and optimistic than frontline staff; b) there was a positive ambition, vision and expectation among leaders, but this was not always communicated to the whole organisation; c) staff wanted to understand what the partnership meant in specific terms for their jobs and careers; d) there was strong support for strengthening learning through partnership working; and e) there was a danger that positive changes might be undercut by growing pressures on staff. On the basis of these findings, the evaluation identifies five recommendations.

### **Evaluation's recommendations**

1. Create a learning environment to help bridge the perceived gap between high-level vision and specific working practices, to inform the future direction of the partnership and to spread the lessons learned more widely;
2. Ensure that readily available, relevant and timely data on patient experience are routinely used;
3. Optimise the wider networks of the partners;
4. Communicate specific goals to reinforce the high-level vision; and
5. Support culture change and engage with frontline staff.



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# Summary

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## Background

The UCLH–Macmillan Cancer Support partnership, which formally commenced in April 2012, has at its heart the aim to deliver better patient experience, with high-quality care coordination. The approach was influenced both by evidence from the 2010 National Cancer Patient Experience Survey, which highlighted some weaknesses in patient experience at UCLH NHS Trust, and by a belief that by carefully attending to the whole patient journey, the experiences of patients and carers can be transformed. To address this, the partners committed to improve the entire care pathway, from diagnosis through to palliation, and to embed in this a system that actively engaged patients and carers in decision making at all steps along their journey. The new system was to include providing relevant and accessible information and improving care and emotional support. Specific key changes included a support and information service, a learning forum for cancer nurses, one-to-one support for patients and an extended and restructured volunteering service. Central to the intended improvement was a new building with a dedicated outpatient clinic area, day care and chemotherapy services, day surgery, and on-site diagnostic services to diagnose and treat cancers and haematological disorders.

## Aims and methods of the evaluation

This evaluation aimed to provide a rich understanding of how staff and volunteers understood the partnership, how the partnership had changed attitudes and perceptions about ways of working, and how the approach of leadership within the partnership was developing. We also looked at patient experience through a secondary analysis of a national survey. As such, the evaluation provides a rich but specific body of evidence to inform partnership decision makers as they consider the next stage in their partnership working. Although it follows, and when appropriate builds on, an earlier evaluation, the evaluation reported here is a stand-alone piece of work. The evaluation team aimed to approach the question of how the partnership was working by analysing the perspectives of staff, volunteers and senior strategic and operational managers. The evaluation also aimed to understand if, even at this early stage, there were perceptible changes in patient experience compared with national trends.

In order to meet these objectives, we undertook both quantitative and qualitative data collection. These were:

- In-depth **interviews** with staff and volunteers providing cancer services at UCLH (n=21). Interviews focused on understanding how staff at different levels/in different roles experienced the

cultural change the partnership seeks to achieve. Interviews took place between May and August 2014.

- An online **survey** of a wide range of staff involved in the delivery of cancer services at UCLH, not only those associated with the cancer centre (n=88). The survey explored whether and how staff experienced change in the ways of working and approaches to patient care. The survey was deployed from December 2014 to January 2015.
- In-depth **interviews** with senior strategic and operational managers within the partnership (hereafter, 'the partners') (n=16). Interviews sought to explore the impact of and the value that partners place on the partnership and whether or not objectives had been met and why, and to so provide a narrative and learning about the partnership, how it has developed, what it has achieved and what the challenges have been. Interviews took place between April and June 2014.
- **Analysis** of the 2012/13 and 2014 waves of National Cancer Patient Experience Surveys (NCPES), building on the analysis of waves 2010 and 2011/12 undertaken in the first stage of the evaluation. The specific focus of the analysis was on the degree to which UCLH reported improved patient experience relative to elsewhere in the NHS over time.

At the end of the evaluation we supported a learning event to report our findings to members of staff from both Macmillan and UCLH and to elicit reflections on the findings of the evaluation from a variety of staff. These views, along with the other data sources, informed the final discussion and conclusions.

## Key Findings

### *Within broadly positive 'average' perceptions, there were important variations*

Staff and volunteers showed a broadly positive attitude towards the partnership in general and in particular towards those aspects with which they were most familiar in particular. (The Macmillan Support and Information Services [MSIS] and Clinical Nurse Specialist [CNS] forum were most frequently mentioned.) Where respondents expressed an opinion, they stated that the partnership had contributed to delivering enhanced skills and a more patient-focused approach. They valued concrete improvements to ways of working over 'high-level' claims about partnership working and wanted to see more specific and visible changes. In the survey response, staff were also concerned about some negative consequences for staff experience, and this view was repeated in the Learning Event. The anxiety was that wider drivers reducing staff satisfaction and engagement from across the healthcare system might pose a barrier to future progress of the partnership. Of direct relevance to the partnership's working is that those staff working closest to the patients ('nursing and healthcare assistant') were least likely to report increasing job satisfaction in the preceding two years and were most likely to think they had insufficient support from management. Furthermore, only just over 40% of respondents considered that senior leadership allocated adequate resources to improving care, while only just over 18% of staff agreed/strongly agreed that staff involved in the provision of cancer services were rewarded or recognised for improving cancer services. In short, 'average' positive perceptions masked some important variations with, for example, 100% of 'general management' stating they strongly agreed that patient care was UCLH's top priority, compared with just fewer than 17% among 'nurse or healthcare respondents'.



Furthermore, a small number of respondents, using the 'free text' options in the survey, which enable participants to write in their own response, expressed the view that patient experience was being privileged at the expense of patient safety. The respondents clearly felt sufficiently strongly to raise this view without prompting. Because this came from only a small number of respondents and because this question was not asked directly, it would not be appropriate to quantify this response. This should be balanced by the finding that in the survey, the majority of staff considered that the quality of care had improved over the past two years. However, a considerable minority, especially among the 'nursing or healthcare assistant' group, reported that the quality of care had actually decreased in the previous two years (58% of 'nursing or healthcare assistant' and 31% of 'nurse'). Respondents identified a number of barriers that continued to prevent them from delivering the highest quality of care, these being primarily related to a perceived lack of time to manage their workload. However, no specific evidence was presented for this concern that patient numbers are increasing without corresponding increases in staff numbers, and these comments are in tension with other reported views that the partnership supported more patient-centred care.

It should perhaps also be borne in mind, however, that the perceptions measured may be driven by secular trends, by wider anxieties about working in the NHS, or by hospital-specific concerns which are not related to the partnership. Anxieties expressed may also be associated with change in general, rather than with partnership working in particular.

*There was a positive ambition, vision and expectation among leaders but some anxieties at the front line*

In partner interviews there was a high level of optimism that taking the partnership further forward would improve patient experience and, in particular, strengthen collaborative working along the whole patient pathway. The sense of ambition and optimism is itself an important demonstration that aspects of partnership working have settled in well, raising expectations that now that the partnership is maturing, it is capable of delivering greater and better results. However, while the high-level vision that the partnership was a 'good thing' was seen to have been communicated, the communication of specific implications for what this meant for staff working close to the patients was said to have been patchy. That said, both MSIS and CNS were reported to be helpful, and staff reported that the partnership had helped with identifying better ways of working and improved mixing of skills. Therefore concerns about more specific implications for ways of working suggest that there may be something more complicated going on (a less tangible unease about change, perhaps, but also concerns about career progression and jobs that were not specifically related to the partnership) that requires further investigation.

*There was support for strengthening learning opportunities*

The theme of the partnership actively supporting learning was strongly represented at the learning event held in March 2015, which was attended by some 30 members of staff of all levels from Macmillan and UCLH. The interest in learning included: learning to adapt in a changing world, learning from others, and sharing what has been learned with others interested in achieving more patient-centred and high-quality care in London and beyond. The opportunity for small-scale experimentation and evidence-driven

learning was stressed as a practical route forward for the partnership. The participants related this to the sense that, as the partnership embarked on its next phase, it would require new approaches.

### *Positive changes already achieved will need to be nurtured*

While the new building may have reinforced patients' positive reactions to the services, it was the better ways of working and of mixing of skills more directly that made an impression on staff as being a benefit of the partnership (despite the anxieties noted above). There was a view that such better ways of working would lead to improved experiences for patients (although the evidence for this view is so far largely anecdotal). The success of MSIS and the CNS forum suggest the early partnership is in the initial stages of an underlying culture change towards more holistic patient care. What these emerging changes to culture might include is described by one stakeholder:

*I think the first thing for me would be that UCLH gets to grips and properly embeds the patient voice. Properly. And what I mean by that, I don't mean listening to complaints or having a group you don't really listen to. Having a strategic approach to really being able to hear patient and public, both in terms of when they want to change things, hearing when it's going really well so that staff can hear that properly, as well as learning from when things don't. And so it's a combination of engagement, involvement, patient leadership.*

Such change will need to be nurtured, especially in the light of the perception that increased volumes of patients may undercut the benefits of the partnership for the quality of care.

### *Looking forward in time and outward to the wider healthcare system*

Although this topic was not part of the formal evaluation, the evaluation team thought it helpful to discuss the contribution of the partnership to date to the key challenges for delivering improved care for cancer patients identified in the NHS Five Year Forward View as: how to give patients greater control over their own care; how to break down the barriers to delivering a genuinely integrated service; and how to innovate and learn from information from patients and carers. In addition, the NHS is expected to deliver annual efficiency savings of 2% across its whole funding base, and any significant reform would need to be oriented toward financial, as well as health, goals.

The partnership has already created opportunities to respond to wider challenges in a variety of ways identified below. This is not a comprehensive assessment of all the changes taking place in the wider healthcare system, but it is an effort to highlight some important challenges where the partnership could be making an effective response. Completely meeting these challenges is beyond the specific contribution of the partnership on its own.

First, the capacity to provide more person-centred care has been strengthened by involving volunteers, supporting one-to-one working and building staff capabilities through mutual learning. This potentially supports a model of giving patients greater control over their healthcare while delivering care that is more personalised, better coordinated and respectful.

Second, the partnership has helped respond to the need for better-integrated care. At the core of the partnership is the aim of improving the experiences of carers and patients by improving the whole journey, from diagnosis to palliation. This includes support and information services, along with a restructured volunteering service, providing information and guidance intended to give patients greater

control. This helps make more tangible the aim of more ‘personalised’ care. In addition, the partnership has helped lay the foundation to break down barriers between hospitals and other care providers. This is apparent in the Vanguard bid and should also help meet the needs of those patients with multiple health conditions and care needs.

Third, the Five Year Forward View anticipates an NHS that can respond to information from patients and carers about what they want and about what is working in their experience. MSIS is seen to be a success, and further efforts to provide quick feedback linked to the success (or otherwise) of changes would be needed to ensure the availability of information to support a flexible and responsive service. But the partnership could also catalyse London-wide and national networks of learning to identify new and more effective ways of working.

The partnership is therefore well placed to respond to these challenges, but it will no doubt need to be refreshed as these challenges unfold.

## Recommendations

*Recommendation 1: Create a learning environment to help bridge the perceived gap between high-level vision and specific working practices, to inform the future direction of the partnership and to spread the lessons learned more widely*

The sense of anxiety about a perceived gap between a high-level strategy and specific changes to ways of working is unlikely to be improved by relying on wholly top-down approaches. Furthermore, in a complex environment where simple and effective models of improvement are not available, there is a need for experimentation and learning to support adaptation and improvement. Therefore, there are benefits in exploiting opportunities for experimentation with rapid learning cycles, based on timely and relevant data on, for example, patient experience, delays and patient activation. Evidence-driven experiential learning would not only help frontline staff relate the aims of the partnership more clearly to their work, but also provide a stream of ideas and evidence to help decision makers adapt and improve (Pritchett et al 2012). Support from Macmillan in this, in particular in drawing on lessons from elsewhere through its other programmes delivering change along the patient pathway, would be both helpful and welcomed. Staff, especially at the front line, report that ‘good’ challenges in their work may actually improve job satisfaction, and staff report an appetite for learning. Engaging in learning and improving activities should not only support the delivery of the partnership but also improve job satisfaction and possibly help address the need for support for career progression.

*Recommendation 2: Ensure that readily available, relevant and timely data on patient experience are routinely used*

Improving the availability of current data would allow a more informed discussion, especially of patient experience. In interviews, staff and volunteers stressed the value they placed on Macmillan Support and Information Services. Staff also use patient feedback data from Meridian. Even so, perceptions of patient experience vary and are, on average, more positive than national comparisons found in the NCPES. Therefore there is an apparent need for better ways to measure, for example, patient activation, to ensure

decision making is informed by relevant and timely data of patient experience. It is less clear from this evaluation whether the underlying problem is that data are not available or that data are not used in making decisions.

*Recommendation 3: Optimise the wider networks of the partners*

The partnership is nested within a number of other sets of relationships that might be more effectively leveraged. In particular, Macmillan can draw upon a wealth of national experiences and evaluations to contribute to learning and thinking within UCLH, across London and, indeed, nationally. At the learning event it was apparent that this was not seen to be happening. Equally, care for patients diagnosed with cancer is only part of the work of the trust, and lessons learned, we were told, were not communicated more widely in the trust or across London.

*Recommendation 4: Communicate specific goals to reinforce the high-level vision*

The theme of developing and communicating a shared vision was frequently a concern of more senior management. The evidence presented here suggests a messier problem, where three related communications issues interact. The first is to communicate the high-level vision. From the evidence, we can see this has broadly been successful. The second is to show what this vision means for specific tasks, and this appears to have been less successful. The third is that many staff appear to hold on to the second view while simultaneously thinking that the partnership has provided practical support, especially through MSIS and the CNS forum. The recommendation for communications is therefore to structure messages to more effectively reconnect these three issues. The evidence collected here therefore suggests that different, rather than more, communication focused on tangible benefits for patients and staff would be helpful. Connecting the issue of communication to the themes of improved learning and engaging with wider networks (Recommendations 1 and 3) should be considered.

*Recommendation 5: Support culture change and engage with frontline staff*

Culture change is important, and leadership has a crucial role in delivering cultural change. Building a relationship of trust and mutual understanding between staff and leaders is a necessary platform for delivering culture change. Our findings suggest that sections of staff feel that they are unsupported, that their work is underappreciated, and that they have limited career opportunities. Building a visibly supportive organization would support achieving the wider ambitions of the partnership (but analysing what this might look like was beyond the scope of this evaluation).

## Acknowledgements

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## Abbreviations

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CI	Confidence interval
CNS	Clinical Nurse Specialist
MCSW	Macmillan Cancer Support Worker
MSIS	Macmillan Support and Information Services
NCPES	National Cancer Patient Experience Surveys
OR	Odds ratio
RoE	Rest of England
UCLH	University College London Hospitals





# 1. Introduction

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## 1.1. The partnership

The UCH Macmillan Cancer Centre opened in April 2012 as part of a new partnership between Macmillan Cancer Support and University College London Hospitals (UCLH) NHS Trust. The intention behind creating the partnership was to improve patient care for those with cancer by, for example, strengthening the role of volunteers, improving patients' access to relevant information and providing patients with better one-to-one support. These improvements were to be delivered through a programme (hereafter: the partnership) designed to improve the diagnosis, care, treatment, support and information available to patients with cancer throughout their individual journeys.

Patient experience and care coordination are therefore at the heart of the partnership. Key initiatives that became part of this programme are outlined in Textbox 1. Part of the background to the programme is evidence in the 2010 National Cancer Patient Experience Survey (NCPES) that highlighted some weaknesses in patient experience at UCLH NHS Trust [1]. To address these weaknesses, the partners committed to improve the entire care pathway, from diagnosis through to palliation, and to embed in this a system that actively engaged patients and carers in decision making at all steps along their journey. This was to include, in particular, providing better access to useful information, delivering improved care, and providing emotional support. Central to the intended improvement was a new building with a dedicated outpatient clinic area, day care and chemotherapy services, day surgery, and on-site diagnostic services to diagnose and treat cancers and haematological disorders.

Textbox 1 below, we outline the key initiatives which were part of the partnership at the time of completing this report. In order to appropriately interpret the findings from this evaluation, it is important for readers to understand that data collection took place before some of these initiatives were in place. Interviews took place between May and August 2014, and the online survey closed in January 2015. In consequence, more recent initiatives (including the CNS forum and the Schwartz Center Round) do not feature in the responses and were not, therefore, a focus of the analysis presented here. Our findings also reflect the fact that while some partnership elements, such as the MSIS, were widely known to the participants, others were less well known. The focus of this evaluation was also much more centred around understanding staff and patient experience and around views on the partnership itself, than on the individual work streams within the UCLH–Macmillan partnership programme.

**Textbox 1 Key initiatives which were part of the UCLH–Macmillan partnership at the time of the evaluation**

**Macmillan Support and Information Service (MSIS) – opened April 2012**

This service is aimed at anyone affected by cancer and provides access to individualised, supportive cancer care which is integrated with the experience of treatment and follow-up. The experienced team of health professionals and support staff offer a range of services in a welcoming and informal space for those affected by cancer and red cell conditions. These include a programme of sessions to support and facilitate self-management when living with cancer and red cell disease, welfare and benefit advice, a psychology and counselling service, complementary therapy sessions and a wig fitting service.

**Macmillan One-to-One Support Workers – started June 2012**

Macmillan Cancer Support and partners developed a model of one-to-one support for patients and conducted a UK-wide pilot to test out this new role. One-to-one support for people living with a diagnosis of cancer might best be understood as a service that supports their journey across the whole cancer pathway, based on the intensity and nature of their needs, to improve quality of care and patient experience and outcomes in a more cost-effective way. The Macmillan Cancer Support Worker role sits alongside the existing workforce and helps the Clinical Nurse Specialist with her or his day-to-day activities.

The pilot has since been evaluated at the trust, and the role has been implemented in other multi-disciplinary teams.

**Macmillan Volunteering Service – started June 2012**

Volunteer roles and activities were developed in conjunction with the individual staff within the UCH Macmillan Cancer Centre, thus engendering local ownership. Each volunteer has a role description. Once they have been interviewed and placed, the volunteers are supervised and managed within departmental teams. The service currently engages 65 volunteers across 19 different roles. The volunteer roles include meet and greet in the main entrance and in the pharmacy, help with patient experience feedback, and peer support. Within the support and information service, volunteers provide support on welfare rights, creative writing and art workshops, fundraising, workshops to help with appearance and support hair loss, and complementary therapies both in the Cancer Centre and on the cancer wards at UCLH.

**Sage and Thyme – started September 2012**

This Level 1 communications training is provided to staff to teach the core skills of dealing with people in distress. It aims to remind staff how to listen and how to respond in a way which empowers the patient. This programme is still being rolled out at the trust, and a total of 846 staff members have already attended this training.

**UCLH cancer Clinical Nurse Specialist (CNS) forum – first event January 2014**

The UCLH cancer CNS forum is a community of around 60 CNSs who are members of different multi-disciplinary teams at the trust. The forum was established at the beginning of 2014 with the aim to raise

the profile of CNSs by enabling them to meet as a group, in order to emphasise the value of their role and to formalise recognition of and respect for the CNS community. Six forum events have taken place since 2014, including a two-day residential event.

### **Schwartz Center Rounds® – started April 2014**

These are meetings which provide an opportunity for staff from all disciplines across the organisation to reflect on the emotional aspect of their work. Rounds were originally developed by the Schwartz Center for Compassionate Healthcare in Boston, USA. The trust runs on average about 10 rounds a year at various hospital sites. To date, about 820 staff members have attended the rounds.

### **Macmillan Values Based Standard® pilot – started September 2012**

This pilot was run at the trust for two years to improve patient-centred care within the head and neck multi-disciplinary team. Macmillan Cancer Support worked closely with cancer patients and staff for three years to develop the Macmillan Values Based Standard, eight value domains that particularly support the dignity and respect of patients. These are seen as practical things staff and patients can do on a day-to-day basis to ensure that people's rights are protected across the care pathway.

## **1.2. Aims and overarching approach of the evaluation**

This evaluation focused specifically on the working of the partnership and aims to identify and analyse stakeholders' views of how well the partnership is working and to contribute to learning within the partnership to support future decisions. It considered how well the partnership is working and how it might be improved. It follows a previous evaluation, completed in July 2013. Where appropriate (for example, to show changes in staff experiences and attitudes), we compare the current data with data collected in the earlier evaluation.

### **1.2.1. Aim of this evaluation**

The purpose of the evaluation reported here is to assess the working of the partnership and its capacity to support the partners' plans to move forward. This evaluation aimed to achieve a balance between a summative (reporting on performance) and a formative (contributing to learning) approach. The evaluation team aimed to approach the question of how the partnership was working from the perspectives of staff, volunteers, and senior strategic and operational managers. The evaluation also aimed to understand if, even at this early stage, there were perceptible changes in patient experience compared with comparable changes elsewhere in the NHS.

In order to meet these objectives, we undertook both quantitative and qualitative data collection, namely:

- In-depth **interviews** with staff and volunteers providing cancer services at UCLH (n=21). Interviews focused on understanding how staff at different levels/in different roles experienced the cultural change the partnership seeks to achieve. Interviews took place between May and August 2014.

- An online **survey** of a wide range of staff involved in the delivery of cancer services at UCLH, not only those associated with the cancer centre (n=88). The survey explored whether and how staff have experienced change in the ways of working and approaches to patient care. The survey was deployed from December 2014 to January 2015.
- In-depth **interviews** with senior strategic and operational managers within the partnership ('the partners') (n=16). Interviews sought to explore the value of and impact that partners place on the partnership and whether or not objectives had been met and why, and to so provide a narrative and learning about the partnership, how it has developed, what it has achieved and what the challenges have been. Interviews took place between April and June 2014.
- **Analysis** of the 2012/13 wave of National Cancer Patient Experience Surveys (NCPES), building on the analysis of waves 2010 and 2011/12 undertaken in the first stage of the evaluation. The specific focus of the analysis was on the degree to which UCLH improved relative to elsewhere in the NHS over time, to inform our understanding of the contribution of the partnership to observed change.

Towards the end of the process, the evaluation team supported a learning event to report its findings to members of staff from both Macmillan and UCLH and to elicit reflections on the findings of the evaluation from a variety of staff. These views, along with the other data sources, informed the discussion section of this report.

### 1.3. Structure of this report

Following this introductory chapter, the findings from the four methods are detailed individually in chapters 2 to 5: chapter 2 details the findings from the in-depth interviews with staff, chapter 3 presents an overview of the key survey results, chapter 4 reports on the interviews with key stakeholders in both organisations and chapter 5 reports on the wider evidence from the NCPES. The report does not have a standalone methods section. Instead, the methods are presented at the beginning of each chapter. These chapters also have a short summary for ease and speed of reading. The report concludes with a report on the learning event, discusses the findings and makes recommendations for future action.

## 2. Providing cancer services at UCLH: perceptions of staff and volunteers reported in interviews

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### **Textbox 2 Summary of staff and volunteers perceptions of providing cancer services at UCLH, based on interview findings**

In total 21, interviews were undertaken with staff and volunteers providing cancer services at UCLH. The staff and volunteers' responses can be summarised in the following three overarching themes:

#### Defining and understanding the partnership

Within a broadly positive perspective, the staff and volunteers' understanding of, and attitudes towards, the partnership varied. For many, Macmillan Support and Information Services (MSIS) was the most visible (and positive) consequence, and it was viewed positively along with Clinical Nurse Specialists (CNS). However, interviewees often struggled to define the partnership and instead related it to specific examples that they were familiar with (e.g. MSIS and CNS).

#### Changes in ways of working and providing services

There is a majority perception that the partnership has enhanced skills and knowledge – for example, clinical skills and approaches to patient care – and strengthened a patient-centred approach.

#### Perceived added value of the partnership

The partnership was perceived to have positive branding and symbolic value for staff, with a recognition that there is something solid to build on. Challenges for the next phase include the perception that increased throughput of patients has created pressures that may potentially limit quality of care. While the new building may have reinforced patients' positive reactions to the services, it is the ways of working and mixing of skills, as a result of the partnership, that more directly made an impression on staff. This suggests the underlying culture is starting to change (explored further in Chapter 3), which was particularly reflected in the contributions of MSIS and CNS to cancer centre staff working styles. However, we note that there are thought to be challenges in communicating the value of the partnership (including both the MSIS and CNS initiatives) and that this may be a problem not just in terms of reaching senior clinical staff in the centre, but also in terms of future fundraising purposes. The importance attached to MSIS by interviewees suggests that its continued funding will be important to its future perceived success.

## 2.1. Introduction

In this chapter we report on perceptions of staff and volunteers providing cancer services at UCLH, which were collected by means of in-depth interviews. Overall, we conducted three sets of interviews: two as part of the data collection for our first evaluation (scoping period in 2012 and a further round 1 in 2013) and one for the evaluation reported here (conducted in 2014). As we reported in section 1.1, this timing is important in relation to the specific initiatives discussed, but the emerging issues are wider and, we believe, remain relevant. The interviews reported here sought to explore the following: staff and volunteer experiences of working at UCLH, including potential changes in their experiences over the past few years; staff's perceptions of the UCLH–Macmillan partnership and its implications for their work; and the extent to which staff experienced a change in culture of working at UCLH and whether and how this might have been influenced by the UCLH–Macmillan partnership. In reporting these views, and where appropriate, we have drawn on the insights and views of staff and volunteers who were previously interviewed in earlier rounds, in order to provide a sense of change over time. The findings relate to staff and volunteers interviewed as a whole, although, where appropriate, distinctions are made if these were significant for interpreting the findings.

## 2.2. Methods

### 2.2.1. Sampling and recruitment in round 2 of interviews

With support from UCLH, we identified a sample of 49 potential interviewees, representing clinical, administrative and volunteering staff working in different units across UCLH, of whom 23 had been interviewed before in either the scoping phase or the first formal round of interviews. Within this initial sample of interviewees from each category, we initially randomly selected individuals for interview. In some cases, snowball sampling led to the recruitment of more interview participants. Where a potential interviewee declined to participate or did not respond, we repeated the process by randomly selecting a second person from the list of staff names in a given unit. This process resulted in a final sample of 21 staff and volunteers, who were invited to participate by personalised letter. This process was facilitated by UCLH staff. Table 1 provides an overview of the range of Cancer Centre staff and volunteers who agreed to participate in the second formal round of interviews (Phase 2 of the evaluation).

**Table 1 Staff and volunteer interviews: participant characteristics, Phase 2 of the evaluation**

Role	Number	Abbreviation used in this report
Consultant (medical oncologist; haematologist; clinical oncologist)	3	Consultant
Junior doctor	2	Junior doctor
Clinical Nurse Specialist	5	CNS
Macmillan Support and Information Services	5	MSIS
Cleaning and housekeeping staff	1	Maintenance staff
Volunteer service representatives	5	Volunteering staff
TOTAL	21	

As indicated above, in our analysis we include references to staff and volunteer interviews previously undertaken as part of our earlier evaluation. In total, over the course of both evaluations, 34 people were interviewed, of whom 13 were interviewed more than once, due to some staff having left and others not being available to be interviewed again.

### *2.2.2. Data collection*

The use of in-depth interviews enables a detailed understanding of the views of the individuals involved and the impacts the partnership had on them. We used a semi-structured interview guide to explore staff and volunteer experiences of working at UCLH, as summarised in section 2.1. Interviews were carried out in a private setting on the premises of the UCH Macmillan Cancer Centre. They lasted 35–45 minutes, were audio recorded with the participants' consent, transcribed verbatim and anonymised to protect confidentiality.

### *2.2.3. Data analysis*

Interview transcripts were analysed by applying codes to each meaningful section of text. Codes were then grouped into higher order themes and the transcripts were systematically analysed according to the initial coding structure. The analysis was informed by the research questions and contextual knowledge of the programme and by themes emerging from the scoping period, while it also further explored new themes emerging from the data. We used QSR Nvivo software to assist in data management and the process of coding. Two researchers (EP, SH) independently coded a subset of transcripts from the interviews and compared notes for consistency, after which one researcher completed the coding for the rest of the interviews.

In the following section, we present the main observations emerging from the interviews. Where appropriate and relevant, we use direct quotes from interview participants to support observed findings. To ensure confidentiality, study participants are identified only by their role, as shown in Table 1.

## **2.3. Findings**

We identified three overarching themes, which reflect the focus of this evaluation but which also draw on the insights gained in the previous interview rounds:

1. Defining and understanding the partnership; including the notion that staff and volunteers identify with UCLH and/or NHS strongly when working in cancer services; the strong presence of MSIS and its place in manifesting the partnership and the influence of space on ways of working;
2. Changes in ways of working and providing services, including the perceived positive influence of the partnership through changes in working style, and the knowledge and resources provided by MSIS and CNS; and

3. Perceived added value of the partnership, including the reputation of both organisations reinforcing the value of the partnership, the Macmillan brand as providing a symbol of care, and the challenges of the partnership going forward in communicating their value.

### 2.3.1. Defining and understanding the partnership

At the time we conducted this round of interviews, the cancer centre programme had existed for more than two years and the partnership between UCLH and Macmillan had been established for longer. We sought to understand how staff and volunteers understood the partnership itself and how they chose to define it. Overall, the staff and volunteers interviewed found it challenging to clearly define the partnership, but as the interview progressed, we gathered different aspects of their perspectives of it. We summarise these perspectives under three themes: (i) their perceived organisational affiliation and identity as a result of the partnership; (ii) the role of MSIS as a key component of the partnership; and (iii) the influence of infrastructure, or space, on explaining the partnership.

#### Staff and volunteers identify with UCLH and/or NHS strongly

The staff we interviewed varied in terms of their length of service working at UCLH, or for the NHS generally, although most of them had been working in the NHS in a similar role for at least two years. When prompted to talk about the partnership, staff expressed some difficulty in defining what this was, but the same staff expressed loyalty to working for UCLH (or the NHS generally) rather than Macmillan, including those employed or jointly funded by both UCLH and Macmillan (e.g. MSIS staff).

*As far as I know all the consultants and the nursing staff and everyone are paid by UCLH. It's an NHS building, an NHS-funded building with the staffing being NHS. (MSIS\_01)*

This type of response was also observed among the volunteers, who mostly had been in their post for a period of 2–6 months and had come from a variety of other roles both within and outside of healthcare services, but who still identified with the UCLH/NHS brand rather than Macmillan.

*Because people were saying 'You work for Macmillan right?' and I'm, like, well actually no it's NHS. It's confusing for family and friends. They're always saying to me 'Don't you work for Macmillan?' and then it's always interesting to people who don't even know what Macmillan is. (Volunteer\_01)*

Some of the staff alluded to two types of challenges that this division can bring: a sense of disconnect from other members of staff not associated with the partnership in the wider hospital, and, for the patients, an immediate association with cancer and 'end-of-life care' which could occur for patients who are not familiar with the full range of services that Macmillan offers.

*I think we're all employed by the NHS but for some it's a barrier to the other staff because they think we're employed by Macmillan and are not part of the team. I think it's a problem with some of the patients because we look after haematology patients as well with no malignancies. (MSIS\_02)*

*Well, I did hear that some patients at the beginning, you know, who maybe, quite rightly who didn't want their cancer diagnosis, felt a bit aggrieved by some of the green logos around the place, that didn't constantly want to be reminded of cancer and Macmillan. But that's not what I hear now for the most part from patients. (CNS\_01)*



As noted by the last participant, there may be a sense that some of these misconceptions have now subsided, as both the staff and patients become more aware of the different contributions of the partners to services.

### The partnership is seen to be manifested for many through the Macmillan Support and Information Service

Most staff, when prompted to describe the partnership and its meaning, referred to the MSIS as the embodiment of the partnership. Indeed the acronym MSIS and the word partnership were used almost interchangeably by some staff during the interviews, implying in those instances that this was seen to be the main manifestation of the partnership and indeed the main form of Macmillan presence within the Cancer Centre.

However, MSIS as a service itself was perceived differently by different staff groups. For example, most of the CNSs interviewed saw the value of the MSIS, because they reported to have seen evidence of how patients benefitted from the type of environment provided and the extra care and well-being support which they themselves could not provide due to time and space constraints within the clinics. This view was not necessarily shared by the few consultants we interviewed, who expressed concern about the lack of 'real data' in demonstrating their value added to UCLH as a whole, both in this round 2 of interviews and in previous rounds. However, one CNS noted that the value of the types of services provided by the MSIS may be more 'obvious' to CNSs as MSIS provides services that are an extension of the type of support offered by nurses, whereas consultants, according to this interviewee, primarily concerned with diagnosis and clinical treatment, may be too far removed from the extra support provided outside of the clinics. Although this particular view would have to be explored further, a common view among the small number of consultants interviewed suggests that the whole value of MSIS was not well understood at the time.

### Influence of space and environment

The physical space, from building design to branding, was also seen to be both a part and a consequence of the partnership, as the staff inevitably referred to this in the context of describing the partnership. In fact, for most of the staff, the space is a very positive manifestation of the partnership, and one that has the potential to extend to health and well-being for patients. Referring to the partnership, one staff member commented on how this is manifested through the physical space and, to some extent, branding:

*I do think it's [the partnership] worked and I think the first thing when patients come in the building is normally very impressed because it's not a load of old hospital buildings. Also I think they recognise the Macmillan brand and logo is very familiar to patients. Macmillan are very good at getting the message out publically. So coming into the building at least there's one thing they can recognise even if they've never been to this hospital before. Seeing the Macmillan name, the green colour, there's something at least they can relate to. (CNS\_01)*

One junior doctor also commented on his positive perception of such an environment for patients:

*It's a nicer environment and it actually makes the whole process of how cancer is being treated, for all of us, much better. I think if I had cancer and I needed three or four cycles of chemotherapy, I wouldn't want to be*

*stuck at the top of a hospital building anywhere. It's not that the care is probably worse but it's the environment that's much more hectic. (Junior doctor\_01)*

We noted, however, a difference between how the CNS reacted to the change in the space in the clinics in the new Cancer Centre compared with MSIS staff. Those in the clinics feel more pressure, more crowding in patient waiting areas, less time to go through the patients per day, while the MSIS space was described by interviewees as rather less pressurised, given that the MSIS as a holistic service in one location did not exist in the previous building.

### *2.3.2. Changes in ways of working and providing services*

In the process of listening to the interviewees sharing their views and understanding of the partnership, we identified a few themes that relate to the extent to which the partnership was seen to have impacted on the staff and volunteers' ways of working and providing services. We report specifically in the areas of (i) patient care and managing patient flow and (ii) the influence on staff roles as a result of knowledge and resources provided by CNS and MSIS, as these were explicitly asked about during the interview. We also comment on indications of cultural change. We take 'cultural change' to relate to customs and beliefs, but more specifically, in this instance we are looking at how tasks and roles are understood and how attitudes to patients, carers and the workplace shape 'the way things get done'. We fully recognise that culture eludes simple measurement, but never-the-less it is possible to talk to people about the drivers and consequences of cultural change.

#### Positive influence through changes in working styles has been perceived

The improvement in knowledge and resources brought by Macmillan was mainly related by interviewees to two contributions of the partnership: the MSIS and the CNS who had received Macmillan training in some form. A few nursing staff working with Macmillan-sponsored CNSs noted how they were able to learn from their ways of working and treating patients (one nurse commented on how this must be due to the many training opportunities available for Macmillan nurses), but it is unclear if this view is shared across all nurses throughout cancer services generally.

Staff also noted how communication skills, although important in many specialities, are particularly important with cancer patients, and these were seen to be encompassed in the set of skills brought by staff with exposure to Macmillan, whether through training or otherwise. In addition, a few staff commented on the Macmillan team working style and use of focus groups:

*They [Macmillan] have got a track record that's proven and they're using different skills and pulling it in. So it's resources in a way that I think we don't always get working in a hospital...and it's not just directly with the patients but help with your teams and the way you work in the teams for the benefit of other patients. For instance, running the support groups, having the focus group, things that really we didn't have the skills in our team to do. Macmillan were able to offer that so that we could run a session with Macmillan, that they all had the experience and knowledge that we didn't have, or the training. (CNS\_01)*

One nurse involved in research particularly praised Macmillan in terms of the expertise and skills they brought to their department. Staff within MSIS also commented on the (positive) challenge that they bring to their way of working – this challenging to the status quo and the potential to change ways of

working depicted the types of culture change that were more readily apparent from the handful of interviewees.

*They [Macmillan] take an interest in what we do and how we do it. I think that's helpful because speaking as someone who has worked for the NHS for a long time, it's always good to have somebody from outside to say, "Why do you do it this way?" and "What are you doing?" I think it's something we don't always understand. (MSIS\_02)*

We note, however, that the influence on ways of working from the partnership is not a view shared across all staff, especially the more senior consultants, who may have had less perceived involvement with the partnership. One consultant alluded to his perception that the quality of care that was good previously has remained good despite the new centre, due simply to the good staff and team he had available:

*The quality of care is still the same, like the chemo nurses are still amazing, they were amazing in the [old building] and they're still amazing today and the teams that I've worked with, the, like, clinicians, were amazing in the Rosenheim and they're still amazing today. I just think being in a nicer building and nicer environment just makes it all feel better. (Consultant\_01)*

### Support from the new volunteering service is welcomed

Although it was less prominent in this round of interviews, there was a universal positive reaction to the volunteering model brought about by Macmillan, which was different to that from the NHS model. Indeed, a senior consultant had previously commented in round 1 that the volunteers '*are fantastic, I don't know whose idea it was, if that was Macmillan then I take my hat off...*' The volunteers themselves also commented on how they perceived their value to patients and staff:

*Because as a volunteer, I'm not saying we have more time, but the paid staff are doing checking and everything, so we can spend, like, 10 minutes extra with the patient and that gives them a really good impression that they're being looked after. And somebody coming for the first time not knowing what result they're going to get, whether they have cancer, you are supporting them and that really benefits them – it really benefits them. I've had very good feedback, you know – thank you for looking after them. (Volunteer\_02)*

The positive influence of these volunteers therefore seems to be centred around providing more information for patients and making facilities and services available to patients (e.g. MSIS and volunteers). With the exception of the universally positive responses to the volunteering system, we note that many of these perceptions did not come through in the earlier interview rounds, reflecting the time needed for some of these changes to be perceived among some of the staff. It was noted, however, especially in comments made by both consultants and nurses, that changes in ways of working were less apparent among more senior management and consultants. Such sentiments continued to be expressed throughout the data collection, with interviewees often noting the challenges in reaching more senior staff, as discussed in the next section.

### 2.3.3. Value of the partnership

Although they were not specifically asked about this topic, many of the staff interviewed presented their ideas and perceptions of the value that the partnership brought to UCLH. It is important to note that

when they spoke of the partnership value, the comments were raised and phrased as if the staff considered themselves to be employed by UCLH, and they therefore spoke of the partnership as either ‘what Macmillan brought’ or, sometimes, ‘what the partnership brought’. We discuss three main aspects of the value as perceived by the staff: (i) the reputation of both organisations, (ii) branding as a symbol of care and (iii) indications of the challenges of communicating value in future.

### Reputation of both organisations reinforces value of partnership

As in previous rounds of interviews, the staff across roles (from nurses to consultants) recognised that both Macmillan and UCLH had strong and positive reputations. This was often identified as the reason for the ‘match’ made in this partnership, and a logical reason for why the two organisations came together. Hence this was often a starting point when discussing the value added of the partnership.

For instance, UCLH was seen as a place where good-quality service can be provided and a place that is ‘highly prestigious’, especially among the senior consultants interviewed, while the Macmillan brand was seen as a symbol of care, which, staff reported, adds value in itself from the patient perspective.

*Macmillan are a recognisable brand name with a proven track history. (CNS\_01)*

*I think the Macmillan brand is recognised and patients have confidence in it. I think they feel that it’s about them and that there are certain standards that Macmillan are going to expect, so I think they like that. (CNS\_02)*

For some interviewees, who did not have much previous experience of Macmillan services, the value of their services was understood and expanded especially by the presence of MSIS, symbolising their added value, as noted in earlier sections.

During the interview, we asked about the hypothetical scenario of having had a different donor for the Cancer Centre, and the effect they would anticipate this to have had. Most staff responded with saying that the centre would not have had the reputation that Macmillan has, nor the associations of good patient care, specifically cancer care. For instance, one staff member expressed how she/he associates Macmillan with ‘cancer, charity, support, survivorship, research, the cancer nurses that are community based’ (CNS\_03), while another noted that ‘when you think of cancer you think of Macmillan’ (CNS\_02).

The strength of the Macmillan brand was evident in the range of staff interviewed, including nurses, MSIS and maintenance, and one junior doctor:

*Yes, I had heard of them before just as, probably, as one of the most famous cancer charities in the country and so when you think about what cancer charities do, everything from research grants to supporting patients to erecting large buildings, yes, Macmillan would be probably the first name. I think everyone’s heard of Macmillan as a charity. (Junior Doctor\_01)*

### Challenges resulting from the partnership include communicating the value of the partnership and fundraising

Despite the mainly positive reflections brought out in these interviews, many of the staff interviewed noted future challenges as the partnership progresses; in the interviews these were said to mainly relate to fundraising and branding and to communication of the value of the partnership. For example, staff noted how there is no further dedicated funding for MSIS, and they noted the potential challenges in being able

to fundraise for this service alone. The main challenge is the patients' and donors' perceptions, which may conflict with the fundraising goals. For example, one interviewee shared the anecdote that a patient wished to donate to 'Macmillan' following the good care the patient had received at MSIS, not understanding that this donation will not directly reach MSIS. Another challenge, which also influences their potential to fundraise in future, lies in communicating the value of the partnership. Given the initial struggle in even recognising what the partnership means to staff, communicating it and fighting for its sustainability may prove difficult. But beyond this is the challenge of even communicating the one thing that people do see as being the partnership: the MSIS itself. The staff we interviewed recognised that communicating the value of MSIS and the impact it has to wider senior clinical staff and external stakeholders was a challenge so far, and that it will continue to be a challenge in future. Further, given our earlier note about the limited knowledge and understanding of partnership activities of the staff interviewed, we would argue that the whole value of the partnership and communicating other activities could be strengthened, if indeed this is the intention of the partnership.

## 2.4. Conclusions

Interviewees showed a broadly positive attitude to the partnership and identified positive developments in relation to ways of working with patients in particular. Unsurprisingly, there were variations within this general attitude, with more scepticism at the consultant level about the value being added. MSIS was identified as successful and as core to the partnership, and the Macmillan 'brand' was seen to fit well with, and strengthen, the existing strong brand of UCLH. Other activities relating to the partnership, or that have emerged as a result of the partnership, were not easily identified by the staff we interviewed, suggesting a lack of awareness of wider partnership working across the organisation.

In the following chapter we can locate these interview responses within the broader evidence from an online staff survey.



### 3. Providing cancer services at UCLH: perceptions of staff reported in an online survey

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#### **Textbox 3 Summary of staffs' perception of providing cancer services at UCLH, based on survey responses**

In total, 88 respondents, representing a range of staff members involved in the delivery of cancer services from across the trust, completed the survey. Visibility of the partnership among staff was low, with over a third of staff reporting that they were unaware of the partnership. However, staff reported notable changes in their experiences and the ways working at UCLH during the lifetime of the partnership. While we cannot attribute these changes directly to the partnership, they provide context for the wider environment within which the partnership operates. We classified these changes into three key themes:

#### **Staff members' opinion on the quality of cancer care provided at UCLH**

Just over 90% of respondents either agreed or strongly agreed that patient care is UCLH's top priority. The majority of staff considered that the quality of care had improved over the past two years; however, there a considerable minority, especially among the 'nursing or healthcare assistant' group, reported that the quality of care has actually decreased in the past two years (58% of 'nursing or healthcare assistant' and 31% of 'nurse'). Respondents identified a number of barriers that continued to prevent them from delivering the highest quality of care – these being primarily related to the perception that there was insufficient time to manage their workload.

#### **Staff members' opinion of patient/service users' experience of care at UCLH**

Respondents broadly perceived that UCLH is doing well/improving in the area of patient experience. Respondents stated that this was demonstrated through greater responsiveness to patient surveys and that, in general, feedback was both listened to and acted upon wherever possible. It was clear from the free text responses that a few respondents considered that patient experience was being promoted at the expense of patient safety. The majority of respondents considered that UCLH sees patient experience (measured on a five-point scale, from a priority to not seen as important at all) as either a priority or important (85/88 (96.6%)). Only one respondent did not consider that patient experience is seen as important; this respondent reasoned that this was demonstrated by the long waiting times between appointments, with patients sometimes waiting 'all day' for tests and procedures.

### Experiences of staff

There were reported to be some negative changes in staff experience. It is apparent throughout the survey from staff's free text responses that there is particular concern regarding what are perceived to be unmanageable workloads, restricted staff numbers and a lack of room for staff to meet and consult, both with patients and with each other. Almost a quarter of staff reported that they had not received enough support when working with people with cancer and their families; for clinical staff members, this figure ranged from 22% among 'registered nurse' to 36% among 'medical'. For all respondents, a debriefing after a difficult incident was considered to be the most helpful support, followed by coaching/mentoring and individual supervision.

## 3.1. Introduction

There is an ambition within the partnership to achieve an impact on organisational culture and patient experience among staff delivering cancer services across UCLH. A survey of a wide range of staff involved in delivering cancer services across UCLH was therefore undertaken to gauge staff perceptions on changes in organisational culture as well as ways of working and staff experience of working at UCLH over the preceding two years. It sought to explore what staff members believed defined cancer services at UCLH, whether and how staff had experienced change in the ways of working, and approaches to patient care. Additionally, it aimed to find out what they thought could be changed or improved to enable them to better support cancer patients in the future.

For logistical reasons, and as agreed with the funders, it was not feasible to undertake a 'before and after' staff survey. The survey was therefore designed to enable staff to include their perceptions of change over the preceding two years. This timeframe was specified to capture changes that may have occurred during the lifetime of the partnership. The survey did not ask staff to attribute changes to the partnership, as it was assumed that to most frontline staff the partnership is tangential; indeed, when asked directly if they'd heard of the partnership, over a third of staff reported that they were unaware of its existence. The results are instead intended to provide context of the environment in which the partnership is operating, and to provide learning for the partnership based on the views of staff working at UCLH.

## 3.2. Methods

The survey questionnaire, following inputs from Macmillan and UCLH, comprised a series of closed and open-ended questions, capturing the following seven themes: (i) Staff experience of working at UCLH; (ii) The environment in which staff provide cancer services; (iii) What staff think about the quality of cancer care services that are being provided at UCLH; (iv) Staff views on the cancer services improvement, and the role of different aspects in it, such as leadership; (v) Cancer patient experience; (vi) Understanding of the UCLH–Macmillan partnership and experience of it; and (vii) About them and their role.

The online survey was uploaded using the RAND in-house online survey tool 'Select Survey' (SelectSurvey.NETv4.126.000, ClassApps.com, Overland Park, USA). Potential respondents were invited by email to participate. The survey was distributed to the 17 multi-disciplinary team



(MDT) coordinators, who were asked to cascade the link to all of their team members (not only those who are associated with the cancer centre), including Clinical Nurse Specialists, ward managers, ward nurses and receptionists, consultants and allied health professionals. Data collection took place from 2 December 2014 to 26 January 2015, and one reminder was sent.

A descriptive analysis of the survey results was undertaken in Microsoft Excel. Open-ended questions were imported into NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012).

### 3.3. Findings

In total 203 respondents started the survey, of whom 88 completed it. It has not been possible to calculate an overall response rate because the total number of recipients of the survey is unknown; only one MDT coordinator responded to our request to provide data on the number of team members who had been forwarded the survey. Given these uncertainties about respondents to the survey, formal hypothesis testing was considered inappropriate.

In the following section, we present a summary of the results for the 88 respondents who completed the survey. Some respondents did not answer all of the survey questions; consequently, the total number of responses presented varies for individual questions because we present the results based on all those who answered the survey question. In this chapter, we focus on the results related to staff's perceptions of the quality of cancer services delivered, of patient experience at UCLH and of their experience of working at UCLH.

#### 3.3.1. Overview of respondents' characteristics:

Nearly three-quarters of respondents were female (65/88 (73.9%)), and the median age range was 41 to 50. Respondents represented a range of staff members, as reported in Table 2. For the 15 respondents who categorised themselves as 'other', this included those in administrative positions, an MDT coordinator, complementary therapists, a pharmacist, a clinical psychologist, a counsellor and one individual who preferred not to say.

**Table 2 Breakdown of participants by occupational group**

Occupational Group	Number
Medical	14
Registered nurse	18
Nursing or healthcare assistant	12
Wider healthcare team	3
Allied health professionals/healthcare scientist/scientific and technical	21
General management	5
Other	15
TOTAL	88

All of the respondents reported that they had some level of interaction with cancer patients; 60% on a daily basis, 19% on a regular basis and just over 20% occasionally. Additionally, all of the respondents reported that they work as part of a team, and the majority identified themselves as belonging to two or more teams (59/88 (67.0%)). Over 81% of respondents stated that they have been working at UCLH for more than two years, while only six respondents have been working at UCLH for less than a year. The majority of respondents indicated that they work full time (30 or more hours).

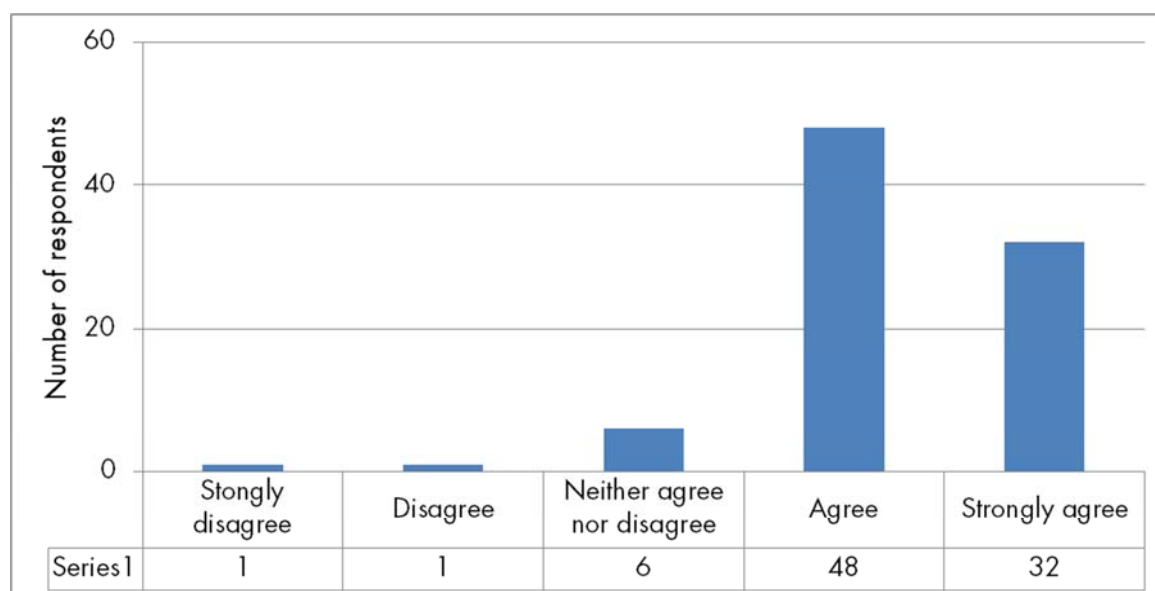
The visibility of the partnership was relatively low, with over a third of respondents reporting that they were unaware of the partnership. This was further reflected in the free text responses, because even among those who stated they had heard of the partnership, over a third commented that they had no or a limited understanding of how the partnership operates or simply commented ‘cancer centre’. The remaining respondents perceived that the partnership has contributed to patient support and experience. For example, a ‘wider healthcare team’ member commented:

*UCLH and Macmillan are pursuing goals to improve patient experience in cancer supply. Within UCLH this has included the new cancer centre, the Macmillan support worker posts and the planned/current electronic holistic needs assessment trial.*

### 3.3.2. Staff members’ opinions on the quality of cancer care provided at UCLH

Overall just over 90% of respondents either agreed or strongly agreed that patient care was UCLH’s top priority (see Figure 1). There was some variation among the occupational groups, with 100% of those in the ‘general management’ group stating they strongly agreed that patient care was UCLH’s top priority, compared with 16.7% of ‘nurse’ respondents who strongly agreed and 66.7% who agreed.

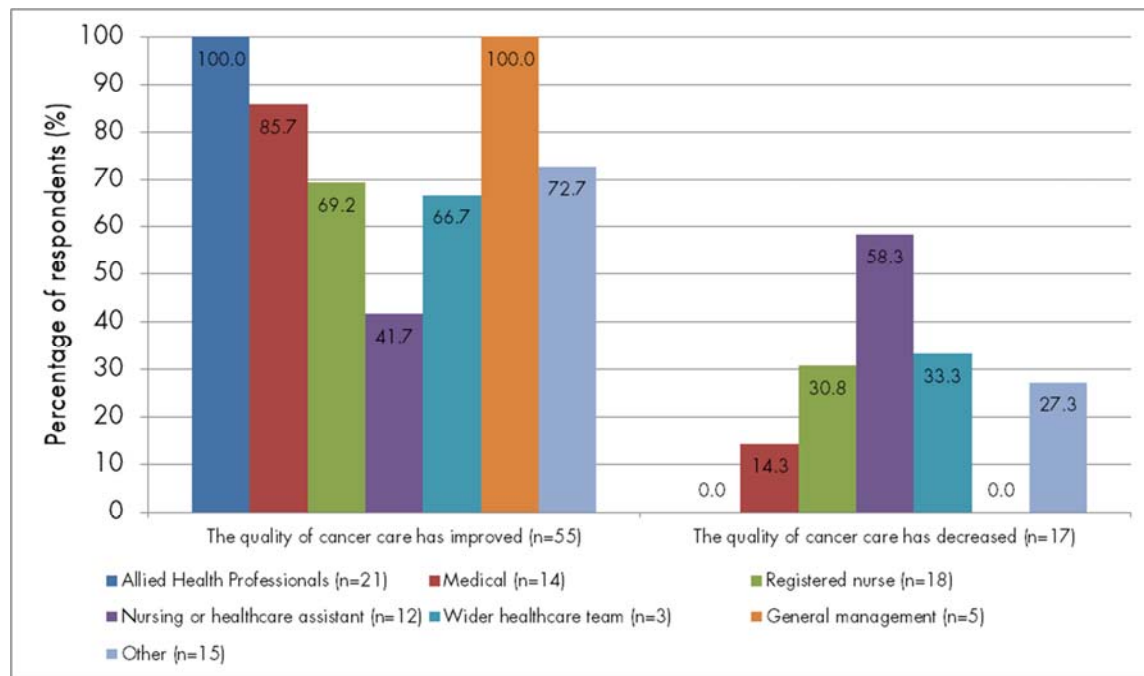
**Figure 1 Responses to the statement ‘Care of patients/service users is UCLH’s top priority’**



Overall, 55 out of 72 (76.4%) respondents considered that the quality of care has improved over time, and the majority of respondents reported that this change has occurred over the past two years (51/88 (58.0%)). However, these overall percentages mask some important variation between occupational

groups, as demonstrated in Figure 2 Response to the question ‘If you feel the quality of cancer care has changed, in what direction has the change been?’, presented as the percentage distribution of responses by occupational group. The majority of ‘nursing or healthcare assistant’ actually reported that the quality of care has decreased (7/12 (58.3%)), while almost one third of ‘registered nurse’ considered the quality of care to have decreased (4/13 (30.8%)). This is in contrast to ‘allied health professionals’ (n=21) and ‘general management’ (n=5), who universally reported care to have improved, and the majority of ‘medical’ staff who said the same (12/14 (85.7%)). These differences should be interpreted with caution given the sample sizes, particularly for some occupational groups. However, the findings warrant further investigation.

**Figure 2 Response to the question ‘If you feel the quality of cancer care has changed, in what direction has the change been?’, presented as the percentage distribution of responses by occupational group**



For the 48 respondents who considered that the quality of care has improved and who provided an example to illustrate their reasoning, the majority commented that the improvement has been brought about by the implementation of more advanced treatment techniques. For example, respondents cited the use of the complex radiotherapy treatments IMRT and RapidArc and the fact they are being used for a greater number of patients. Other respondents commented that they have been able to provide an improved standard of care as a result of changes to service delivery, including a reduction in waiting times, greater integration of services and better communication between teams. For some, quality improvements were a result of improvements in the environment in which care is delivered, while others equated the quality of care to the patient experience. They stated that there is greater support now available to patients and their families. However, it was noted by one ‘medical’ respondent that:

*It is difficult to comment without breaking down the service into its parts – a global assessment does not accurately convey the picture. Some teams have made progress, but overall this is undermined by the relentless increase in the volume of work.*

This reinforces the sense that, when asked about why the quality of care has changed, respondents answers show they conceptualise ‘quality of care’ in different ways (for example, as patient experience or patient safety). A selection of quotes illustrating the identified themes is presented in Textbox 4 by professional group.

#### **Textbox 4 Selected quotes from staff who considered the quality of care to have improved**

*‘I work within chemotherapy and the area has been slowly improving to reduce waiting times for patients. I believe there is so much more that we can be doing just by having more empathy for a patient.’ (Allied Health Professional)*

*‘General care for AHP’s for patients has improved in terms of awareness of patients’ needs and the support that is available for them.’ (Allied Health Professional)*

*‘Greater pressure and scrutiny from hospital board to improve UCLH position in national cancer survey. Staff have achieved this despite no additional resources.’ (Registered nurse)*

*‘I think we offered new ways to receive treatment such as Ambulatory Care for Teenagers and Young Adults and we are looking at patient experience and acting on patients’ feedback and recommendations more.’ (Registered nurse)*

*‘Improvements in diagnostics, therapeutics and support services.’ (Medical)*

*‘The cancer centre provides a much better environment for patients (and staff).’ (Medical)*

*‘New Cancer Centre has integrated care for the better overall.’ (Other)*

For the 16 respondents who provided illustrative answers for why they considered that quality of care had decreased, this was principally reported to be a result of the fact that the number of patients is increasing without a corresponding increase in staff numbers. Respondents identified a number of associated consequences which have negatively impacted on their ability to maintain the quality of care, including an increase in waiting times and a reduction in time staff have available to spend with individual patients. Selected quotes that are illustrative of the key themes are presented in Textbox 5 by occupational group.

#### **Textbox 5 Selected quotes from staff who considered the quality of care to have decreased**

*‘Care on the wards is not given the priority it used to be given. The nurses are very stretched and not enough senior nurses on the wards. Also the wait for outpatient treatment is too long.’ (Registered nurse)*

*‘Staffing pressure across the Inpatients and Outpatients. Number of patients has increased hugely and there is no reflection on this with staffing.’ (Registered nurse)*

*‘Growth of patient caseload not matched by growth in patient-facing staff or adequate facilities. Almost impossible to get new posts approved despite double digit growth.’ (Other)*

*'No suitable expansion in capacity.'* (Medical)

However, despite these concerns, 83.0% of respondents rated the current quality of cancer care delivered at UCLH as 4 or above on a scale of 1 to 5, where 1 was considered poor and 5 excellent. Only two out of the 88 respondents rated the quality of care delivered as 2 or below (1 'allied health professionals', 1 'nursing or healthcare assistant'). Variation in ratings was observed between occupational groups with all 'general management' rating the quality of care as 4 or above, compared with 58.3% of the 'nursing or healthcare assistant' group.

Participants were asked to provide written details of what prevents them from delivering high-quality care. The key theme arising from the 63 respondents who provided a written response was that there was not enough time to meet their workloads. Additional barriers identified include the shortage of staff, lack of consultation/meeting rooms, poor IT systems, poor communication between teams, and administrative burden. Selected quotes that are illustrative of these key themes are presented in Textbox 6 by occupational group.

#### **Textbox 6 Selected quotes from staff on what prevents them from delivering high-quality care**

*'Time. Patients need more time in clinics than we can give them. We need to promote non-medical prescribing to help this.'* (Allied health professional)

*'Infrastructure problems with e.g. lifts, theft of equipment, short term locum staff disrupt continuity, lack of adequate cover at times.'* (Allied health professional)

*'Particularly within my circumstances, within my team, management politics, which does not honour patient care consistently. Depending on the 'agenda' the team will be working on pleasing politics and very old-style management methods. Even team supervision is used as a political tool, which prevents members to fully benefit from it.'* (Allied health professional)

*'Radiotherapy: Better integration of clinicians with other professions would help. Lack of cross-cover between clinicians makes service very vulnerable when they are sick/on leave. Also, our radiotherapy machines are coming to end of life. Not all of them can provide current standard of IMRT required. – we need to upgrade them in order to technically develop our services in line with other UK RT centres.'* (Allied health professional)

*'We need to prioritise safety with respect to administration of chemo, but this involves so many checks (Dr /pharmacy/nurses etc) it causes big delays. Chemo production is slow and causes delays esp when it is made up on the same day as they attend clinic. Insufficient inpatient beds to house all the patients presenting with acute oncological emergencies in dedicated oncology wards. They all end up having their admissions delayed while beds are found or as outliers in non-oncology beds.'* (Registered nurse)

*'There are not enough inpatient beds. We cannot provide continuity of care between outpatients and inpatients. A&E is a terrible place to be if you have cancer and no bed to go to. The staff there are so overworked that unless you are dying you do not get the necessary attention.'* (Registered nurse)

*'The cancer division is very large and communication over such a wide sector is difficult. Clinical teams are quite segregated and this does not lead to a supportive working environment. There is a lack of recognition of the importance of the work of nurses who are employed at band 5 wherever possible, rather than band 6 or*

*higher to reflect the value placed on their expertise in cancer care. In contrast to this, there are an increasing number of managers paid at band 8b or above, who do not communicate as much as they should with clinical teams/frontline staff. Trying to lead on innovations/service development is very difficult due to high levels of bureaucracy/red tape within our organisation. I don't think that innovation and/or willingness to change is a strong point of ours.'* (Registered nurse)

*'Lack of staff therefore not having time to discuss psychological and social issues with patients.'* (Registered nurse)

*'I work in a privileged area where I can deliver what I think is important but the challenges faced by ward nurses is at breaking point.'* (Registered nurse)

*'When the clinics are over booked, waiting area small gets very hot patients do not want to wait down stairs to reduce overcrowding.'* (General management)

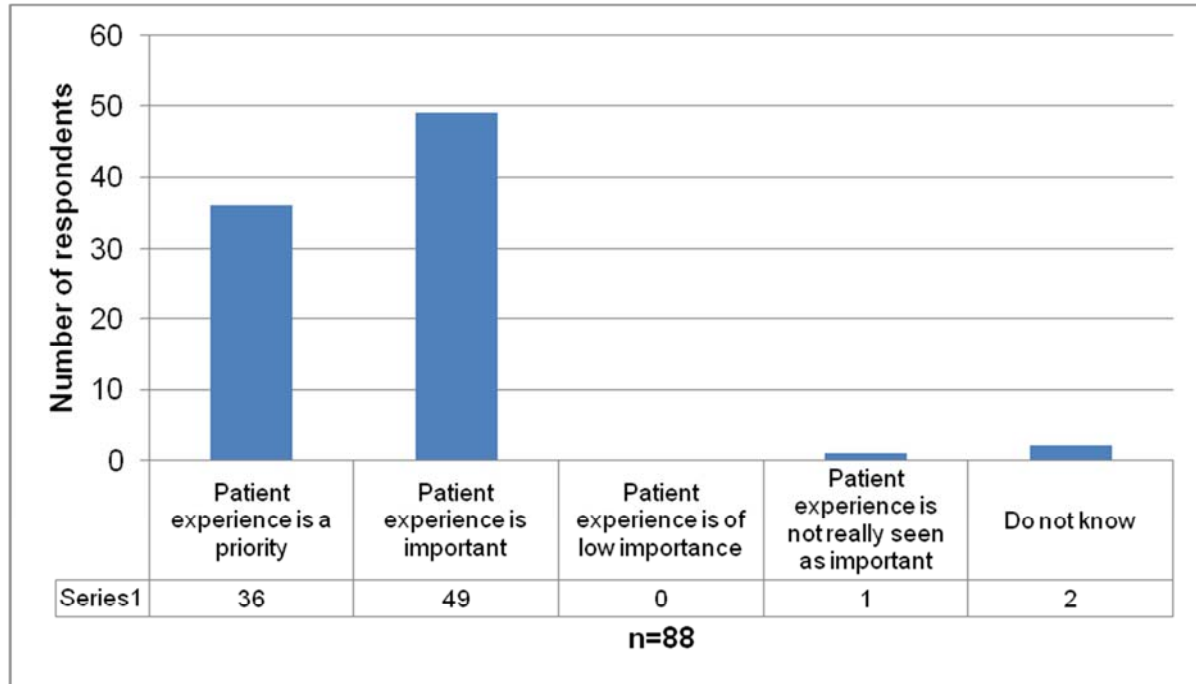
*'Too much is focused on the patient, and the staff get left behind. There is a sort of forced bonhomie, and if you don't want to be a happy-clappy team member you're suspected of not doing your job properly.'* (Other)

*'There aren't any written Standard Office Procedures, and this seems to have led to vagueness on occasion. The printer provision has been quite sporadic and this has meant a hiatus in smooth delivery of service provision. There are no regular charts published locally to show how well (or not) the Cancer Services is performing as a team.'* (Other)

### 3.3.3. Staff members' opinion of patient/service users experience of care at UCLH

It can be seen in Figure 3 that most respondents considered that UCLH sees patient experience (measured on a five-point scale, from 'seen as a priority' to 'not seen as important at all') as either a priority or important (85/55 (96.6%)). Only one respondent (who identified themselves as 'other') did not consider that patient experience is seen as important; they reasoned this was demonstrated by the long waiting times between appointments, and waiting sometimes 'all day' for tests and procedures.

**Figure 3 Response to the question ‘What importance do you think is given to cancer patient experience in UCLH?’**



For those respondents who consider that patient experience is a priority or important, the vast majority who provided supporting answers commented that this was demonstrated by the importance being given to results from patient surveys, such as the NCPES and Meridian. One ‘medical’ cited the ‘*close cooperation with the Macmillan Cancer Institute*’ as evidence. However, for a couple of members of staff prioritisation of patient experience was perceived to come at the expense of patient safety and the staff’s own experience. Selected quotes that are illustrative of the key themes emerging from respondents’ written responses are presented in Textbox 7 by occupational group.

**Textbox 7 Selected responses from staff illustrating the importance given to cancer patient experience**

*‘We are always asking the patient about their experience and act on the comments we get back – we are able to use the Meridian survey to give us real time data.’ (Allied health professional)*

*‘I think that UCLH does think patient experience is important but if it was a priority staff would be given more support on promoting ideas as a group effort. There is no facility for individual teams to collect the feedback from patients and change their practice to make it patient focused. For example – we have a clinic pharmacy system, rather than push this on patients why not try and assess the value and change it to meet a patients need. There is no resource to try and improve our system.’ (Allied health professional)*

*‘Within our team we constantly discuss how to improve cancer patients’ experience and listen to their concerns/ideas and try to incorporate them into service improvement.’ (Medical)*

*‘It is a priority, but sometimes other external pressures (increasing patient numbers etc.) put this at risk.’ (Registered nurse)*

*'I think the idea of prioritising patient experience is emphasised over the content.'* (Registered nurse)

*'The patient tends to get lost in the system. In Haem [haematology] especially, doctors often treat the blood results rather than the patient in front of them, leading to inappropriate interventions. Nursing staff who try to advocate for the patient are rarely listened to.'* (Nursing or healthcare assistant)

*'The Trust hold patient feedback in high regard.... However, the Trust often forgets front line staff and try to squeeze as much as possible out of each person. Patients continue to give good feedback which is positive.... However, this does not mean safety is maintained at all times with the entire Trust suffering with lack of staff...morale decreased when the workforce review was introduced which was poorly handled and unnecessary.'* (Nursing or healthcare assistant)

*'The outcomes of the National Cancer Experience Survey have focused the Trust into channelling improvements areas that have scored low.'* (General management)

*'A huge amount of time and resources goes into providing a positive patient experience which is distinct from providing acute medical treatment: the cancer centre is a spacious and modern building, art exhibits and musical performances take place in patient waiting areas, holistic and complimentary treatments are available, there is a roof garden for patients to relax in.'* (Other)

*'Patients are always given priority over staff. Staff accommodations in the cancer centre are negligible, staff rooms are tiny and there are no designated staff toilets.'* (Other)

The importance being placed on patient care was perceived to have increased by the vast majority of staff, across occupational groups, over the past two years (58/64 (90.6%)). Among the respondents who provided a written response to justify their answer, the majority reported that previously poor survey results were the catalyst for this change. One respondent cited *'new outpatient facilities with increased support from services such as counselling/Macmillan'* as evidence that patient experience is valued more. Selected quotes to illustrate respondents' answers are presented in Textbox 8.

#### **Textbox 8 Selected responses from staff related to change in importance placed on patient experience**

*'When something changes about a patient's treatment care is taken to make sure that the patient is advised of all the facts and reasons why things have changed.'* (Allied health professional)

*'Patient information scored low in the survey so we have actively improved on this across London Cancer.'* (Registered nurse)

In relation to the current patient experience at UCLH, 70.5% of staff ranked patient experience as 4 or above, on a scale of 1 to 5, where 1 was considered poor and 5 excellent. Only 4 respondents ranked patient experience as 2 or less (1 'registered nurse', 1 'nursing or healthcare assistant' and 2 'other').

As was the case with quality of care, there was variation among occupational groups, with a greater proportion of 'general management' rating patient experience as a 4 or above than 'nurse or healthcare assistant' (80.0% and 41.7%, respectively).

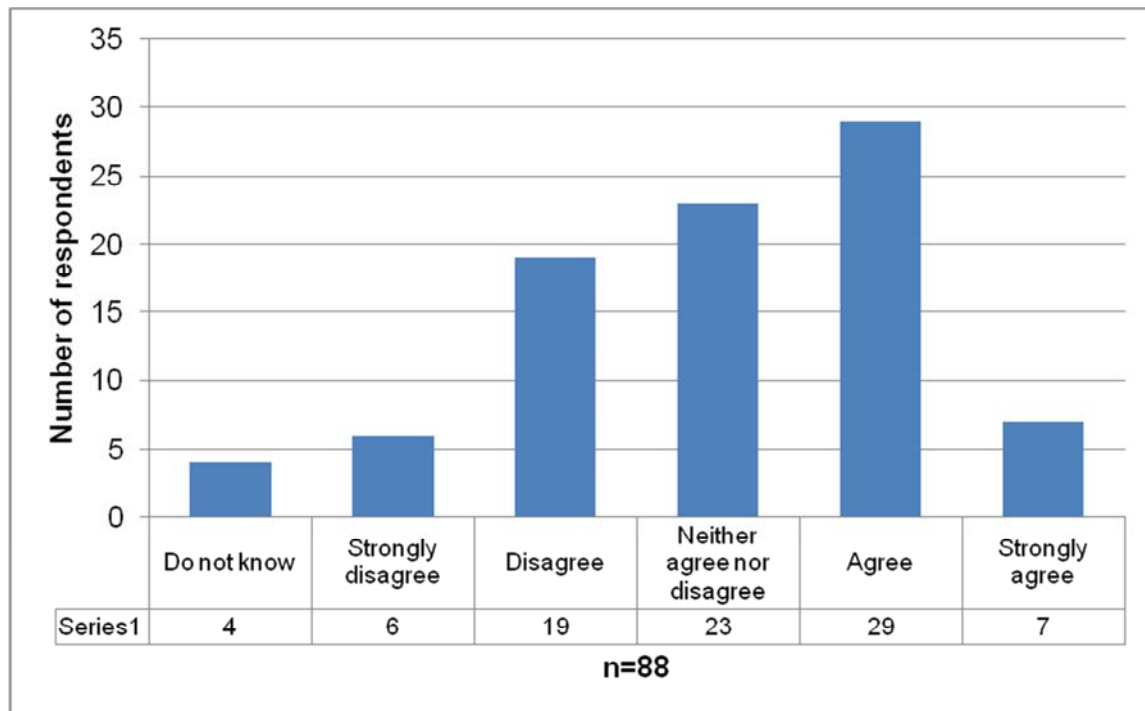


### 3.3.4. Experiences of staff

Just over 36% of staff reported that their job satisfaction had increased in the preceding two years. This ranged from 60% among ‘general management’ to 25% among ‘nursing or healthcare assistant’. For those who enjoyed their work, reasons related to the fact that their role is challenging and they feel that they have opportunities to develop their skills. Conversely, some of the 26% of respondents whose satisfaction had decreased reported that they no longer felt challenged and considered that they were not supported. Being overworked was also cited as a reason for a decrease in job satisfaction.

Almost a quarter of staff reported that they do not receive enough support when working with people with cancer and their families; for clinical staff members this figure ranged from 22% among ‘registered nurse’ to 36% among ‘medical’. For all respondents, a debriefing after a difficult incident was considered to be the most helpful support, followed by coaching/mentoring and individual supervision. It can be seen in Figure 4 that only just over 40% of respondents considered that senior leadership allocates adequate resources to improving care.

**Figure 4 Responses to the statement ‘Senior leadership allocates adequate organisational resources (e.g. finances, people, time and equipment) to improving cancer services’**



Only just over 18% of staff agreed/strongly agreed that staff involved in the provision of cancer services are rewarded or recognised for improving cancer services (see Figure 5). It can be seen in Figure 6 that, on average, respondents considered an individual’s seniority to be the key determinant of whether staff involved in the provision of cancer services are rewarded.

Figure 5 Responses to the statement 'Staff involved in the provision of cancer services are rewarded and recognised (e.g. financially and/or otherwise) for improving cancer services'

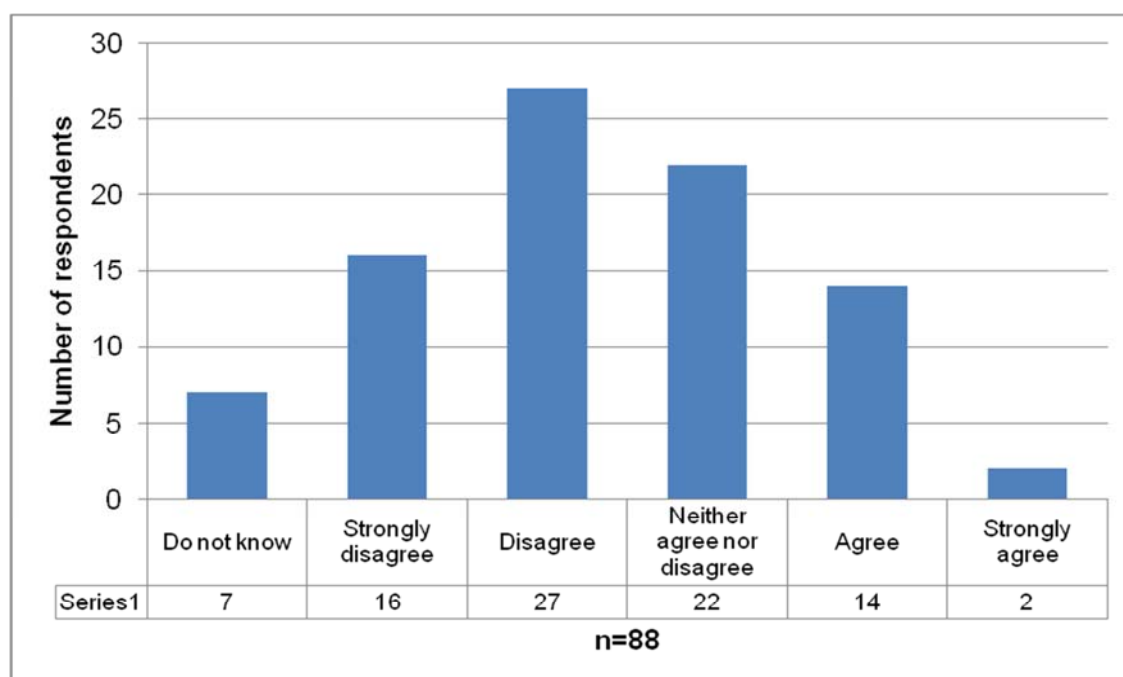
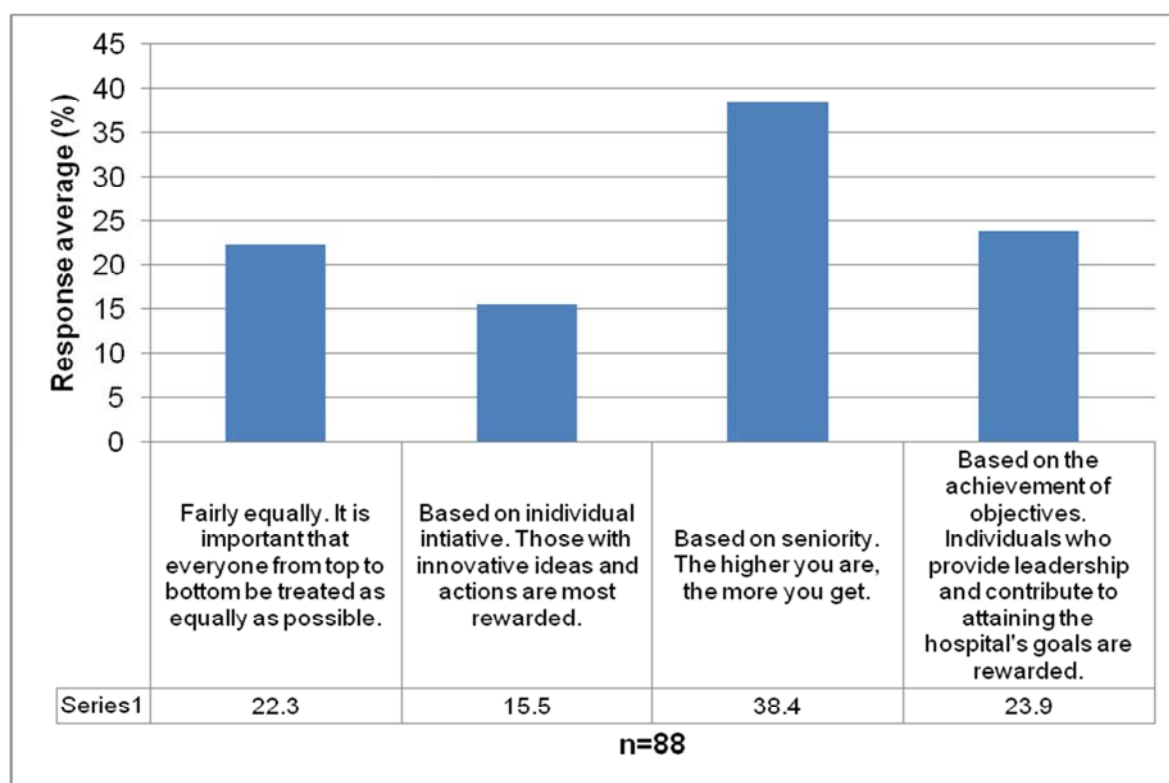


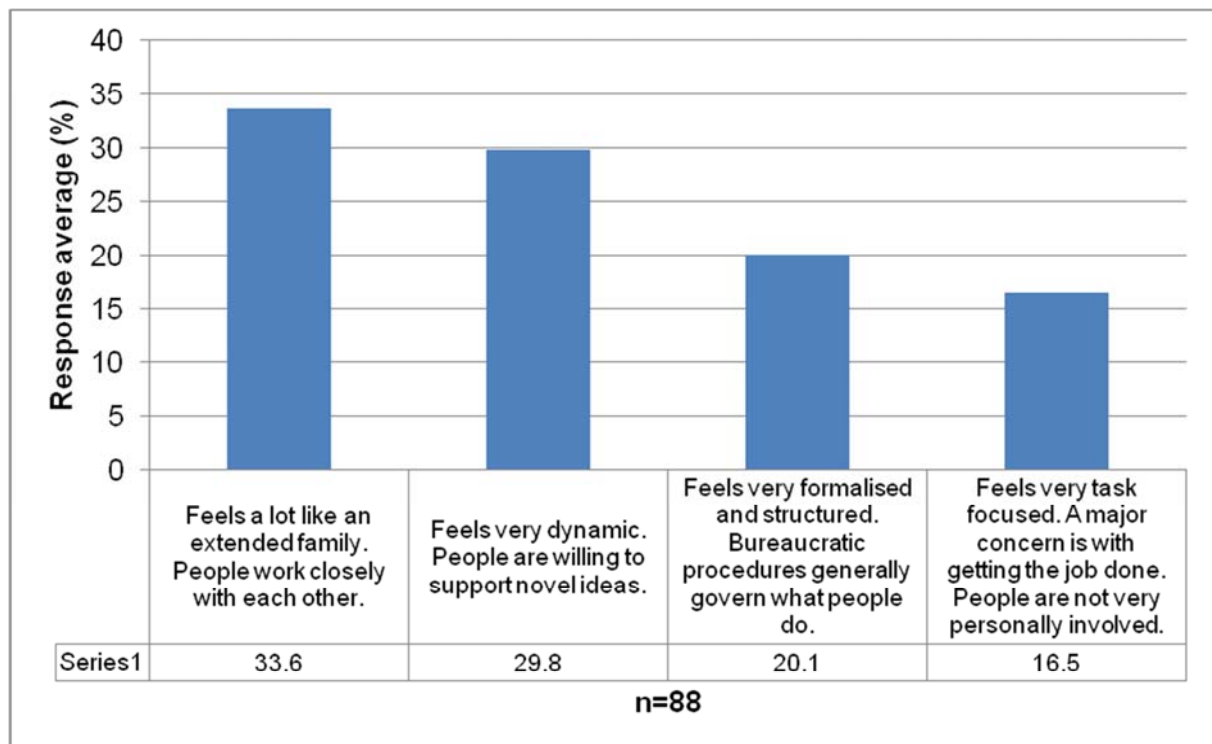
Figure 6 Average number of points assigned to the statements on rewards for providing cancer services



Note: For each series, staff had to distribute 100 points among the four statements depending on how they felt these resemble cancer services. We present the average points assigned to each statement.

However, despite these reported challenges, staff were relatively positive about the environment they worked in (see Figure 7). On average, when asked to weigh up their feelings towards the environment for cancer service, staff across all occupational groups allocated the highest number of points to the more positive perceptions. For ‘feels a lot like an extended family’, the average score ranged from 25.4 among ‘nursing or healthcare assistant’ to 49.0 among ‘general management’, while for ‘feels very dynamic’, the average score ranged from 23.3 among the ‘wider healthcare team’ to 37.5 for ‘medical’.

**Figure 7 Average number of points assigned to the statements on environment for cancer service provision**



Note: For each series staff had to distribute 100 points among the four statements depending on how they felt these resemble cancer services. We present the average points assigned to each statement.

### 3.4. Conclusion

Although it is not possible to attribute these findings solely to the partnership, and although it is likely that concurrent initiatives and other factors will also have had an impact, this chapter indicates some positive perceptions about changes in the ways of working at UCLH over the past two years. Staff members’ opinions on the quality of cancer care provided at UCLH are positive, with just over 90% of respondents either agreeing or strongly agreeing that patient care was considered to be UCLH’s top priority. Those whose role was further from the ‘front line’ were more positive about recent developments in patient care than those closest to the patient, in particular, a notable proportion of ‘nurse’ and ‘healthcare assistant’ staff actually reported the quality of care to have decreased. Clinical staff reported continuing pressures of time and workload as barriers to improved care. In addition, it is clear that a few respondents considered that patient experience was being promoted at the expense of patient safety.

However, whatever the causality, efforts to improve the quality of care and patient experience have coincided with some negative changes in staff experiences. Whatever the reason, it is apparent that there is particular concern regarding what are perceived to be unmanageable workloads, restricted staff numbers and a lack of room for staff to meet and consult, both with patients and with each other. Almost a quarter of staff reported that they had not received enough support when working with people with cancer and their families. Good practice was identified by respondents and in particular the value of a debriefing after a difficult incident, followed by coaching. These findings highlight examples where the partnership could in future focus its efforts to support staff. Helping to build a visibly more supportive organisation would support achieving the wider ambitions of the partnership.

## 4. The UCLH–Macmillan Cancer Support partnership in practice: views of key stakeholders

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### **Textbox 9 Summary of key stakeholder views on the UCLH-Macmillan partnership,**

We interviewed 16 individuals (hereafter, ‘partners’) who play key roles in leading the partnership, to understand their perceptions of how well the partnership is working. We discuss their views in the following two areas:

#### **Views on the current state of the partnership**

When asked about the achievements of the partnership to date, the majority highlighted the CNS forum and the Support and Information Services (MSIS) as two positive things that would not have been possible without the partnership. Many in both organisations felt the current partnership had reached sufficient maturity to support broadening the scope and reach of collaborative working – in particular, around patient pathways and working with primary care, expanding partnership work throughout the UCLH NHS Trust, influencing London Cancer and contributing to national agendas. Participants explained that these initiatives would improve care, experience and outcomes for patients and carers, embed the patient in everything that is done within the trust, and strengthen the reputation of both organisations. Participants also expressed a sense of personal challenge and enjoyment from engagement with the partnership.

#### **Enablers supporting future partnership development**

It was evident from the interviews that the partnership was continuously evolving. Factors that participants identified as having enabled the current success of the partnership, as described above, were: (i) personnel within key roles, (ii) moving on from Phase 1 of the partnership as a team, (iii) introduction of the Programme Board as a way of running the partnership and (iv) an underlying commitment of individuals to ‘making it work’.

## 4.1. Introduction

This chapter reports the findings of interviews with key stakeholders, which we have termed partners. These are individuals identified by the two organisations (Macmillan and UCLH) as having a leadership and senior role within the partnership. Interviews were intended to understand the partners' roles and experiences of working within the partnership. In addition, they explored the purpose and meaning of the partnership and the intended and actual impact. Partners were also asked specifically about the role of the partnership in influencing cultural change.

## 4.2. Methods

Potential participants (n=16, 8 from each organisation) were identified and invited to participate in an interview. Written information was provided to potential participants prior to them agreeing to participate. Interviews were conducted by two interviewers (EP or EN), audio recorded and transcribed verbatim. Interview transcripts were anonymised and analysed with the use of Nvivo (v10). Initially 'open codes' were applied to the data to represent the significance of sections of text. These were incrementally grouped into organising categories, or 'themes', which were modified and checked constantly in order to develop a coding frame. The coding frame, partly influenced by the research questions but particularly emerging from the data, was used to systematically assign the data to the thematic categories. Thematic categories were agreed between three researchers (EP, CM, JE) after analysis of the initial interviews and then applied.

## 4.3. Findings

Interviews were conducted with 16 partners between April and June 2014. Participants were across both organisations (Macmillan and UCLH) and varied in their length of involvement with the partnership, some had been involved from the start and others had joined relatively recently.

Throughout this chapter participant quotes are identified by the organisation the participant worked for, and identifiable data has been removed.

### 4.3.1. Views on the current state of the partnership

It was evident at the time of the interviews (April–June 2014), that the majority of participants considered the partnership to be in a healthy position. Participants spoke with enthusiasm about the partnership and expressed optimism for the future, in terms of both the immediate focus, the next three years and the longer term.

*I think there's too much for both organisations to offer each other, not just in terms of the existing expertise but, I think, in terms of the uncharted landscape that's out there in healthcare in this country.... So I think whilst the focus at the moment is on defining the next three years, which I think does make a lot of sense, I think that there should be an eye on the long-term future with how we can take steps over the next three years to make that life-cycle something which is long term. (UCLH)*

The sense of optimism stemmed from what partners considered to be the potential in terms of what the partnership could achieve and from the belief that the partnership as a relationship between the two organisations had reached a stage of maturity.

### Broadening scope and agenda

When asked about the achievements of the partnership to date, the majority highlighted the CNS forum and the Support and Information Services (MSIS) as being two things that would not have been possible without the partnership. In terms of partnership going forward, many identified the potential to broaden the scope and reach of collaborative working. Specific ambitions were most commonly raised around patient pathways and working with primary care, expanding partnership work throughout the UCLH NHS Trust, being influential with London Cancer and contributing to national agendas. Participants explained that the aims in doing this would be to improve care, experience and outcomes for patients and carers, to embed the patient much more in everything that is done within the trust, and to strengthen the reputation of both organisations.

*We need to be doing things across a much broader spectrum and we need to be doing things which go well beyond the conventional delivery of clinical services, and I think the Macmillan Support and Information Service which we have is a nice example of the kind of thing which we would see being rolled out. We would also say that there are things we would have ambitions for in terms of diagnostic centres, that kind of thing, and training and education for staff, for patients, for the public, perhaps in a much broader sense, and definitely Macmillan would bring a huge amount in terms of those agendas. (UCLH)*

*...where we are now is, is really important and is really important for the wider way we're working across the UK. So what I, I suppose what I like about this is the opportunity that we have with the UCLH as a key centre of excellence and absolutely aligned to UCLP and research, but also, you know, that we do have a massive opportunity if we get it right to use that learning to influence not only across London but more widely, and I think at times we haven't used that enough. (Macmillan)*

Several participants mentioned that the type of change that the partnership was now seeking to achieve – for example, around closer working with GPs and training of healthcare professionals across the pathway – was going to take time to develop and realise and that, although Phase 2 would concentrate on the next three years, the partnership was likely going to be longer lasting.

*...it's got the potential to be run, training programmes for healthcare professionals who deal with cancer from primary care right through. That's got, you know, years of growth in it so, and it's just around what, I don't think the partnership will end unless they have a massive row and take the name off the building. (UCLH)*

### Maturity of partnership

Several participants described a sense of optimism which had grown during the preceding year and expressed the view that the partnership had reached a stage of maturity that meant it was in a strong position to take forward the broader agendas and to tackle challenges arising. This development in the relationship was expressed broadly by participants from both organisations.

*I feel really positive about the future, I think we've got a really good working relationship...it's relaxed, it's informal and even having conversations over some of the more difficult things [is] done in a professional, non-hostile way. Whereas I think maybe a year or so ago there were real opportunities for things to escalate quite quickly and I think both organisations have shown quite significant compromises on various things and they've altered their usual style, which has gone some way. (UCLH)*

*I know that sounds terrible clichéd but I think it really is, it's nice to look back and say, 'Actually we're in a good place' and we can reach an understanding. I know that relationships take time, but it feels like we're actually in the place where people are on the same page and they know what's expected almost. (Macmillan)*

From the accounts of participants, we learned that there seemed to be a growing acceptance within the partnership that there would be times that either organisation would be doing something that the other may not like, but that, because there was greater respect now within the relationship, these would not be damaging to the partnership. The need for UCLH to fundraise, which had caused 'significant anxiety (Macmillan) from the perspective of Macmillan, and to work with other cancer charities provided tests for the partnership that they now felt would be dealt with differently.

*So things around fundraising we've managed to unpick, sort of broader principles about how organisations have worked together. So slowly, we've kind of sort of carved off some of the sensitivities and then worked out a way that we can have a bit of a gentlemen's agreement about things, but we wouldn't have been able to do that a year ago, two years ago. (UCLH)*

*...we are only about two thirds funded by the NHS... So we've set up a charity called the UCH Cancer Charity, and we need to fundraise...and we have to fundraise against the Macmillan brand, which is awkward. (UCLH)*

*...so I think that was part of that lack of understanding with the partnership before. A slight lack of, not that there wasn't trust, whereas there were three, over whether they go into partnership with a pharmacist, whether CR UK [Cancer Research UK] could film in the building and there was a third thing. And I get a phone call now and that's actually how a proper partnership should work. And we're hardly ever going to say no, but it's blooming annoying when you find out afterwards! And so for me, that is what I feel...I don't know whether it was there before, I don't see the real evidence that it was there before, but I think we've probably got into a little bit more of a 'Let's respect each other as partners and flag up stuff'. It's not easy because what we're slightly living with is the legacy and the new world and how do we manage that legacy and push the new world ahead, and that's going to grate slightly, but we'll find a way. (Macmillan)*

This was placed in contrast to previous issues that were perceived to have caused far greater sticking points within the partnerships. Several participants, from both organisations, referred to branding and the final payments in Phase 1 as being painful to resolve and hard to look back on. In general there was optimism that potential challenges would not cause the same difficulties in the future, partly because of the change in the contractual relationship and partly due to growing maturity and respect within the partnership.

*Branding. I bet I'm not the only person where that's the first word that has cropped up. Branding...branding...I don't want to think about branding ever again. Every time it gets mentioned under the guise of another organisations it's, like, 'Oh no. Not the branding thing again.' The branding thing: that's the nub of I think where I talk about where we really could have done a better job about working out whose values are what and what we both wanted out of this... That's been the bit where there's*



*just the mismatch of what each organisation wanted: was just not well managed and not well thought through in advance. So when it came to it then it becomes a really difficult conversation. I think we've got that resolved, but it's still a difficult conversation. (UCLH)*

*I think it has evolved, which is good. I think the particularly since the opening of the Cancer Centre, I think both organisations have been understanding each other more. Sometimes talking at cross purposes but always with good intent, I think. (Macmillan)*

We further explore the theme of the maturity of the partnership in chapter 6.

### The partnership as bringing challenge

It was notable in this round of interviews, compared with earlier ones, that a number of participants expressed a sense of personal challenge and enjoyment from engagement with the partnership. Several participants talked about the challenge that the partnership brought, in terms of considering alternative ways to working, and that these challenges in themselves were bringing change and optimism. It was typically regarded by participants that the changes that were needed were within UCLH.

*A very different perspective and set of skills and experiences, I think that's what I get involved with, and I think that's what the partnership is all about. People like [name] are just very different in their way of thinking to the type of people you would typically find...in the NHS, which is really stimulating. I enjoy that. (UCLH)*

*So it was great for me because actually lots of people saying different things just coming from really different perspectives...and it was great because we had UCLP [UCL Partners] in the room; we had...it was a real broad range of people. That was good because it meant it was a really different dialogue. Sometimes it's just about making sure there is a different dialogue. (UCLH)*

*But I think just the existence of the partnership forces the conversation, you know, I like to believe the conversation forces change as well. (Macmillan)*

#### 4.3.2. Enablers to partnership development

It was evident from the interviews that the partnership was thought to be continuously evolving. Factors that participants identified as having enabled the current position of the partnership, as described above, were: (i) changes in personnel, (ii) moving on from Phase 1 of the partnership, (iii) introduction of the Programme Board and (iv) an underlying commitment to making it work.

##### Changes in personnel

In the year leading up to the interviews, there had been 'significant change of turnover both within UCLH and within Macmillan' (Macmillan), some of which included individuals closely involved in the partnership. Participants reflected that they felt that some of these changes had been key to the progression of the partnership in the past year. Some of the new appointments that had been made included people who had a good understanding of the other organisation from previous employment or who had worked with others in the partnership in the past. This was thought to have enabled their smooth transition into the partnership. In the previous round of interviews, participants had expressed concern that losing key individuals may be a potential threat to the partnership. Indeed, some participants

reflected that the changes in personnel had been difficult because of a loss of knowledge and history. However, others reflected that such change held advantages for the partnership because people were joining with a fresh perspective and without preconceived ideas.

*I think it probably provides...an obvious challenge that someone you've just lost – all their knowledge and experience – because however much you write down, there are still the little quirks that you remember. But I think the opportunity is that people are coming in fresh, they're not bogged down in what has happened.... And they are coming, like, 'Great, I've picked it up, let's go forward'.... Yeah, I think that change in personnel is interesting and half the time you're, like, 'Amazing, all that knowledge', but at the same time, they bring people in who don't have any misconceptions about this. They obviously applied because they wanted the role for what the role was and so they can take that forward and make the most of it. And like you said, fresh eyes, they can see things that you might have missed. (Macmillan)*

### Moving on from Phase 1

There was a sense conveyed through the interviews that the completion of the cancer centre and the process of moving to Phase 2 of the partnership had allowed participants the space to consider what the partnership could achieve. The cancer centre had by necessity consumed the early focus of the partnership, but there was a sense of relief among several participants that this landmark had been achieved and that the partnership could now turn to consider its future ambitions in more detail.

*So the new memorandum of understanding is based on a much better understanding of what each party wants out of things. And a better understanding of the potential of the centre, you know, a real conversation of having pathways now, which probably wouldn't have happened previously.... We're now in a position where everyone's saying, 'Okay, now let's remember how marvellous this thing we've got is and how much more potential there is for it'. (Macmillan)*

*I think that it possibly hasn't really been what I would call a true partnership to now, and I don't know what I, I'm not quite sure what I mean by that, but I think it's been a little bit too much focused on money and the building and now it's time to think, 'Well, you know, what are the other things that we can work on together?' (UCLH)*

At the time of the interviews there was also a feeling that Phase 2 would be less attached to money than Phase 1 and that this had allowed better consideration of what the partnership wanted to achieve.

*actually the second stage that I've been more involved in, looking at what we're going to do going forward, actually I think it's a three-page document. It just sort of says these are the things we are kind of thinking about doing, you know, and part of the initial contract obviously has more money attached to it and had the buildings. (Macmillan)*

### Introduction of the programme board

At the time of the interviews the management of the partnership had recently been modified, the Joint Directors (initial management group with senior representation from both organisations) had been discontinued and a programme board had been introduced which maintained representation from both organisations but with broadened membership. Most participants welcomed the new model and felt it

operated in a more effective manner. The change had led to a broadening of the membership to a wider number of individuals across the two organisations and to a renewed sense of purpose.

*There's definitely bigger membership on there now, and it's slightly, there's, like, another layer down rather than it just being sort of, I think originally it was sort of six key people and now it's [more]. (UCLH)*

*Is everyone still calling it Joint Directors, and probably always will, but so we've now got whatever it is but it's chaired in a more sort of proactive way now and a little bit more kind of 'Okay, this is what we've got to do let's get on and do it'. (UCLH)*

Participants also explained that they thought the programme board was going through the process of making a clearer differentiation between strategic and operational functions. This was broadly welcomed; some had suggested that partnership meetings had tended to be transactional in nature.

*I think it's just making sure that at, say, the joint directors' meeting, ensure that people attend and the issues that need to be, that it doesn't just become the stock 'This has happened', but it's the thing that you keep the strategy there and you keep it going forward. And then having the full operational groups do the day-to-day because I think that sometimes you don't want people to be involved in every part of it, because then you lose that knowledge. (Macmillan)*

#### **An underlying commitment to making it work**

Interviewees broadly reflected that there could be optimism in the partnership moving forward because of a fundamental commitment on behalf of both organisations to making it work, in recognition of mutual benefits that could be achieved. Participants spoke of the shared values and commitment to those, but also observed that both organisations had too much of a 'vested interest', partly because of the joint naming of the centre, to allow it not to work.

*it is the success of being linked, the two organisations being linked, so for Macmillan they have to be associated, you know, they are associated with this organisation, you know, they don't want the service to fail, and likewise we've got a very strong commitment with an organisation that has been very generous. (UCLH)*

*I feel like that they [UCLH] know that they need to improve and with our experience, we want to help that. Their services are already amazing. There's something in it definitely for both sides, that you have our name allied to the clinical outcomes. I feel like they definitely share their different elements within that, which people know where their value is added. (Macmillan)*

#### **4.3.3. Continuing challenges**

While the participants in general portrayed a sense of optimism and enthusiasm around the partnership, a number of continuing challenges emerged from the interviews. The two main, ongoing challenges were around communication about the partnership and the need, perceived among some participants, to achieve a common aim around the purpose of the partnership beyond broad visionary goals.

## Communication

It was evident from the interviews that communication about and within the partnership was a challenge. There was recognition that knowledge and understanding of the partnership was not consistent or widespread in either organisation, but particularly in UCLH. Even among some 'partners' interviewed, there was a sense of frustration at a lack of information fed down from what was previously called the Joint Directors, now the Programme Board.

*I don't believe that both organisations at all levels have the same level of understanding of what the partnership w, There were pockets of great mutual understanding. (Macmillan)*

*Not much [information being fed down] and I think again that's probably because it took me six months to get round my role and other things and then by the time I was actually fully operational and understanding that, you know, that's something really important and then those meetings a few were cancelled and so here I am now in June and actually really keen to know what's been agreed. I mean [name] has been really good at keeping me in the loop yes, but there's no, like, comms... Like the meeting papers are not distributed other than to the group. (Macmillan)*

The lack of wider understanding about the partnership led to frustration for people of both organisations in their day-to-day working and was felt by some to limit the potential of the partnership.

*Yes, and the size of the trust makes it difficult for UCLH anyway internally, so even if some people are briefed and then they thoroughly understand how to work with us..., that work stream may overlap with the work that's managed by another department such as volunteering...but actually the volunteer service department is probably managed at corporate level by a team who's never heard about us, so then you've got to kind of start this conversation again, which shows that, you know, if there was a real understanding of the partnership possibly that would make life easier for everyone. (Macmillan)*

*I think that [communication] will definitely help, yeah, definitely, and the communication of that memorandum of understanding will also help in terms of how we're spreading the word about it. I'm keen that Macmillan also communicate with their donors and their staff with how it works because sometimes I find that not all their staff understand the partnership, kind of understand the funding arrangements either. So it's a problem with both sides. So staff in this building might say, 'Oh, is this building totally funded by Macmillan?' to me and I'll explain to them, 'No, it's this', but then I also hear people from Macmillan saying, 'So what's the relationship?' So there is a bit of confusion on both sides. (UCLH)*

In terms of addressing the challenges of communication and poor awareness about the partnership, joint communications from the two organisations had not been widely considered. There was a sense that a clearer memorandum of understanding may help awareness and understanding but that this had not led to a communications strategy. One partner reflected that communication would have to be targeted and that widespread, common communications about the partnership would not be effective.

*I think you do need to have multiple communications but those communications may not be articulating the partnership, they may just be articulating that aspect of the partnership which is relevant to whoever the audience is. I think you need more segmented communication because for some people it's obvious why Macmillan's there, so for the nurses that's clear, for the docs probably not, you know, for managers, you know, you need different communications for different audiences, I think. (Macmillan)*

## Shared vision and aims for the partnership

When asked what the partnership was about, participants most commonly talked about synergy: bringing together the ‘best of both worlds’ and being greater than the sum of the parts. They saw that UCLH brought specialist clinical expertise and wider influence, both across London and at a national level. Macmillan was seen as bringing expertise in patient experience, a similarly respected name with a national profile.

When asked more specifically what the partnership was about, partners tended to talk about the global aim of improving patient experience and outcomes. It was challenging for some to clearly articulate what the partnership does, but most commonly there was a sense of it being about ‘doing things differently’.

The building had previously provided something very tangible to frame the partnership around. While there was general agreement that the partnership was always intended to be about more than the cancer centre, partners found it a challenge to articulate what else it was about as they looked forward.

*There’s a difference between having a vision and having a strategy, and I think the partnership has a clear vision and aim but not a clear outcome beyond the original outcome that was the building. So it’s very much easier to describe when it’s a physical thing you’re building... Now we’re into the territory of new services, new ways of working... things that we both want are going to be harder to define. (UCLH)*

The need to be able to define the partnership differed among partners. Some felt that formalisation of the partnership aims and goals would assist in communicating more broadly about the partnership and the wider nature of the relationship beyond very specific projects.

*...but more importantly I think how it communicates what it’s involved in and what it’s doing, because it is very defined, it’s very restricted at the moment to certain key projects and certain things within cancer. So should it have it written down? It needs to have its goals and aspirations.... The two organisations need to say what is it that they want to see.... It may just be something really simple.... (UCLH)*

Others felt that there was no need to communicate a common statement about the partnership or that what you communicate about the partnership would vary depending on the audience.

*I don’t think it should, I don’t think people need to know exactly what it is. It’s interesting your question ‘What is the partnership trying to deliver?’ I don’t think actually in terms of a cultural statement I don’t think anyone has ever pinned that down; it would just be doing two things that we can’t do together. So, no, I don’t think everyone needs to do, I think it’s more a case of this is the way that we do things rather than this is why we do things, yes. (UCLH)*

*I suppose when I’m telling people about it, it depends who I’m telling. To a lot of people, it helps to have something very tangible to define that relationship, so I often do include at the outset the fact that Macmillan have invested £10 million in the Cancer Centre, so that just helps demonstrate the level of commitment there has been from Macmillan, and I think a lot of people either forget that or don’t know that. I think it’s quite a useful point of reference actually for what then follows. I then go on and say something along the lines the relationship is about how we can identify as a mutual trust, where we can draw on each other’s strengths to the benefit of patients.... (UCLH)*

#### 4.3.4. Cultural change

Since ‘culture change’ can mean different things, as part of the interviews, we asked participants what the term meant to them and what they thought was the role of the partnership in relation to culture change. Our interest was in identifying how interviewees understood changes in attitudes, values and beliefs that were relevant to patient care and ways of working, and whether these changes were related to the partnership in any way. Participants did not naturally talk about culture change within the context of the partnership until it was raised in the interviews, and for most it was a difficult concept to talk about. We got the sense that, for the participants, culture change was about ‘a different way of doing things’ or about change that would become embedded within the way of doing things to the point where it was not noticed as new. There was an understanding that the depth and permanency of change may be greater than would have been achieved through individual interventions.

*...culture change [is] not being another initiative, but something you embed and you really keep people focused on, so culture change needs an understanding, needs people to understand that this is where we're going, but not in terms of understanding that these are just the rules there, in terms of understanding the ethos and the principles behind what you're about, and that seems really either very easy or very difficult, and it's probably a journey.... It's a journey. (UCLH)*

When asked about ‘culture change’, most participants referred to culture change within UCLH, although one participant did refer to culture change within the partnership. The type of culture change that was thought to be needed in UCLH was around making patient experience the priority both across the trust and across patient pathways. This was expressed as having to become better at listening to patients and the public and having to make the patient voice central to care.

*I think the first thing for me would be that UCLH gets to grips and properly embeds the patient voice. Properly, and what I mean by that, I don't mean listening to complaints or having a group you don't really listen to. Having a strategic approach to really being able to hear patient and public, both in terms of when they want to change things, hearing when it's going really well so that staff can hear that properly as well as learning from when things don't. And so it's a combination of engagement, involvement, patient leadership. (Macmillan)*

*If you look at patient experience I think the reason that we're challenged at the moment in thinking through ‘What next?’ for the Cancer Patient Experience Programme is because all of the relatively easy things to do; we've had a good go at. We haven't fixed them all and there's a bit more to do, but we have gone as much as we can do and the other changes that are necessary are cultural. They are about changing people's behaviours. (UCLH)*

Participants most commonly identified doctors as the group of staff where culture change was most needed.

*Fundamentally for me I think that broadly means the way our clinicians behave. (UCLH)*

However, one participant stressed that it was about everyone in the organisation.

*It's everybody. It's how an individual can change it, you know. It's from Chief Exec to ward receptionist to cleaners. I mean I was a ward sister and I think we've lost an awful lot. We used to have a ward culture so you would have your cleaner who you knew. You'd have a stable ward team and that was great...it was a*

*real family. I think we've lost that, so through things like the CNS forum, strong leadership from a, you know, the cancer nurse who has executive-level confidence can help. (Macmillan)*

Participants talked about the challenges of culture change and that it would take a long time to achieve. Not all participants could talk about the role of the partnership specifically with regard to culture change, but some explained that the financial support and time provided by Macmillan enabled the consideration and introduction of new ways of working. The CNS forum was most commonly raised as an example of enabling culture change.

*I think the partnership would have a role in changing culture in that, you know, judicious use of funding and thinking through what are the important things that need to be taken forward collectively could well change culture and I guess the culture that I'm thinking about is...it's not treatment for cancer patients because we have very good treatment, it's about the care and support and the experience that patients and their families have here and really any aspect of that may need scrutiny, and I think Macmillan bring to that table a lot of experience nationally, which is very helpful, of trying different ways of doing things which we can tap into, and also the education and training side of, of what Macmillan can offer which, you know, there is a lot of work that suggests, you know, education and exposure can change people's way of working and their ways of thinking about things. (UCLH)*

Aside from the time needed to effect culture change, particular challenges were highlighted with regard to attempting to influence ways of working within a large NHS organisation. This was partly because of competing demands and incentives for clinical staff; scepticism about the partnership among staff; and a reflection that trust-wide initiatives, such as 'in their shoes', had been challenging.

*I think perhaps some of our consultant body are just more deeply sceptical not just about Macmillan but about most things...or about another thing that we're doing somewhere else in the division which is going to be a service improvement project or about the work we've done in cancer, or about London Cancer itself or about the commissioners. So I think there's just a very deep scepticism about things which are going on around them, perhaps because of the way the organisation hasn't sought to engage them in perhaps the design. (UCLH)*

*I think we are going to have challenges along the way because I think UCLH tends to look internal first. (Macmillan)*

#### 4.4. Conclusions

Interviewees reiterated the centrality of the CNS and MSIS to the partnership and projected a positive belief that the partnership was working well. In particular, participants believed these initiatives would improve care, experience and outcomes for patients and carers; embed the patient in everything that is done within the trust; and strengthen the reputation of both organisations. Participants also expressed a sense of personal challenge and enjoyment from engagement with the partnership. It was also evident that the partnership was thought to be continuously evolving. Factors that participants identified as having enabled the current success of the partnership, as described above, were: (i) personnel within key roles, (ii) moving on from Phase 1 of the partnership as a team; (iii) introduction of the Programme Board as a way of running the partnership and (iv) an underlying commitment of individuals to 'making it work'. It was

also believed that the partnership was contributing new ways of thinking and working within the trust and that behaviours are changing as a result. It was apparent that, in moving forward, there were a number of continuing challenges for the partnership, including communication about and within the partnership, reaching and formalising the shared vision of the partnership and challenges associated with trying to foster culture change. In general, however, there was confidence that the partnership had matured and that respect and common commitment would help to enable the partnership to meet these and future challenges.



## 5. Changes over time in UCLH National Cancer Patient Experience Survey scores compared with other English hospitals

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### **Textbox 10 Summary of changes over time in UCLH National Cancer Patient Experience Survey scores compared with other English hospitals**

We examined changes in the experience of cancer patients treated at UCLH from 2012/13 to 2014 using the National Cancer Patient Experience Survey (NCPES) data, building on the earlier analysis of NCPES data from 2010 and 2011/12 undertaken in the first stage of the evaluation. In addition, we compared the pace of change of cancer patient experience at UCLH to the pace of change at other English NHS hospitals to determine whether any observed changes in patient experience at UCLH were above and beyond what could have been expected based on the average NHS hospital in England, given the fact that the general policy drivers are applicable nationwide. While we cannot attribute any observed changes directly to the partnership – as the NCPES includes data from patients receiving cancer care from across UCLH – the time period of the analysis includes data from before and during the early phases of the partnership, providing insight into any changes in the pace of change in patient experience at UCLH which may have occurred after the introduction of the partnership. The analysis identified two key findings:

- Across England, modest degrees of change in cancer patient experience (typically improvement) were apparent over time (2010–2014) for most survey questions.
- There were only few aspects of experience where change over time (either improvement or deterioration) of UCLH performance was significantly different to that of other English hospitals.

These findings are both reassuring, i.e. UCLH is following national improvement trends, and a cause for potential concern, i.e. by and large, UCLH does not ‘outperform’ the pace of improvement in patient experience in the rest of NHS hospitals.

## 5.1. Introduction

This chapter provides a summary of changes over time in the experience of cancer patients treated by UCLH as measured by national survey samples (2010, 2011/12, 2012/13 and 2014 surveys) and compares these trends with those observed in other NHS hospitals. While we cannot attribute any observed changes directly to the partnership, as the NCPES includes data from patients receiving cancer care from across UCLH, the time period of the analysis includes data covering a period of 4 years and 9 months, spanning both the period before and the period after the UCLH–Macmillan partnership, thus providing a broader picture of differences in the pace of change in cancer patient experience that has occurred at UCLH since the introduction of the programme.

## 5.2. Methods

The analysis uses data from evaluative questions in the 2010, 2011/12, 2012/13 and 2014 National Cancer Patient Experience Survey (NCPES). The NCPES is a postal questionnaire survey sent to patients who were treated for cancer during a three-month sampling period. Thus far four waves of this survey have been carried out post-2010 (2010, 2011/12, 2013/14, 2014) with a large core of identical questions, allowing evaluation of trends over time. Response rates are relatively high using a postal methodology, at around 66% consistently throughout the surveys. The findings, which are publicly reported, are used by clinicians and managers to track improvement and motivate initiatives to improve cancer patient experience locally. Anonymous data are deposited at UK Data Archive for independent bona fide research, as used in this analysis.

We present data on 56 evaluative questions relating to processes of hospital care which were common (identical) to at least two of the four surveys and for which, therefore, time trend analysis was possible. Where the question number for the same question has changed between surveys, we used the 2014 question for labelling purposes. Likert-scale questions were converted to binary forms defining patient experience as good or poor, consistent with the public reporting conventions for the NCPES surveys.

We used mixed effect logistic models to explore whether UCLH time trends varied compared with time trends in other NHS hospitals. This involved using appropriate regression models, which allow different factors to be considered simultaneously. The ‘mixed effect’ component of the models means that we correctly accounted for the fact that patients within a hospital may be more similar to each other than patients between different hospitals. This means that the analysis took into account the clustering of patients with different characteristics in certain hospitals (e.g. UCLH might have a different clinical and socio-demographic case mix compared to that of other hospitals). Logistic regression was used because the measures were binary, i.e. yes or no, rather than continuous (e.g. age).

We also allowed for trends over time to be different for each hospital. This is important because high performing hospitals may be improving more slowly than average, and, conversely, low performing hospitals may be improving faster than average (or vice versa).<sup>1</sup> Patient age, sex, ethnic group and cancer

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<sup>1</sup> Technically this means that these models included a random intercept and slope for hospital and that they allowed for correlation between them.

diagnosis were included as patient-level case mix variables. Because some of the questions had non-linear trends, we treated the survey year as a categorical variable, with the baseline year being the reference category (for the majority of questions this is 2010). For the sake of simplicity, we only present the results comparing the 2014 survey to the baseline survey.

## 5.3. Results

### *5.3.1. Trends over time in NHS hospitals other than UCLH*

Across the 56 questions studied, there was evidence that hospitals other than UCLH had improved for 36 questions and deteriorated for 6 questions. There was no evidence for change over time for the remaining 14 questions (see Table 3, column 2).

### *5.3.2. Trends over time in UCLH*

Across the 56 questions studied, there was evidence that UCLH had improved for 4 questions (Table 3, column 3). These were:

- Question 11 – Patient told could bring friend when diagnosed
- Question 17 – Staff explained potential treatment side effects
- Question 47 – Patient asked about name they prefer to be called
- Question 69 – Patient did not feel treated as a set of symptoms

There was no statistically significant evidence for change (either improvement or deterioration) for the remaining 52 questions (see Table 3, column 3). An immediate comparison of the number of questions with statistical evidence of improvement over time between hospitals in the rest of England (36 questions; see 5.3.1 immediately above) against the respective number of questions for UCLH (4, see above) may be misleading. These results should not be interpreted as indicating that UCLH improvement was ‘lagging behind’ trends observed in other hospitals (as above); the small number of questions with statistical evidence of improvement in UCLH reflects the relatively small (compared with the rest of NHS hospitals) number of respondents. For this reason it is useful to note that UCLH performance improved over time for 35 questions, 27 of which were questions for which there was also evidence of improvement in hospitals other than UCLH (see above).

### *5.3.3. Differential trends over time (UCLH compared with other NHS hospitals)*

There was no evidence for differential change between UCLH and other English hospitals except for five questions, among which four have differentially improved and one has deteriorated (see Table 3, column 4). Specifically, UCLH appears to have improved over and above national trends for:

- Question 11 – Patient told could bring friend when diagnosed
- Question 23 – Clinical Nurse Specialist listened carefully
- Question 47 – Patient asked about name they prefer to be called
- Question 69 – Patient did not feel treated as a set of symptoms

But differential deterioration compared with national trends for:

- Question 63 – Information given to GP

Caution needs to be applied when interpreting these results due to the fact that many tests were performed (i.e. each of the 56 questions is being tested separately). When multiple tests are carried out, a small number of tests are likely to result in significant results simply by chance. We note that, of the 5 questions where there is evidence of differential trends over time for UCLH, the strength of evidence for 3 questions is weak (p-values between 0.03 and 0.05) and that this may well have arisen due to multiple testing. However, for 2 questions (Questions 11 and 47) the evidence is very strong and highly unlikely to have been due to chance ( $p \leq 0.001$ ).

#### *5.3.4. Supplementary analysis*

In a supplementary analysis, we found that adjustment for teaching hospital status had little impact on the results shown above.

Table 3 Case-mix adjusted odds ratios (OR), 95% confidence intervals (CI), and p-values for positive experience from patients treated by UCLH compared with hospitals elsewhere in England

Survey question		Other NHS hospitals in 2014 vs 2010 (have other hospitals improved over time)		UCLH in 2014 vs 2010 (has UCLH improved over time)		Differential change in trends over time (whether UCLH outpaces or lags behind national trends)	
		OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
6	Purpose of tests explained	1.26 (1.21-1.32)	<0.001	0.93 (0.61-1.43)	0.753	0.92 (0.82-1.03)	0.163
7	Tests explained	1.25 (1.19-1.32)	<0.001	1.09 (0.69-1.73)	0.716	0.96 (0.85-1.09)	0.550
8	Written info for tests	1.28 (1.22-1.34)	<0.001	1.26 (0.80-1.98)	0.326	0.99 (0.88-1.13)	0.936
9	Explanation of test results	1.10 (1.06-1.14)	<0.001	1.18 (0.82-1.69)	0.380	1.02 (0.92-1.13)	0.713
11	Told could bring friend when diagnosed	1.27 (1.21-1.34)	<0.001	3.23 (1.84-5.68)	<0.001	1.29 (1.11-1.51)	0.001
12	Told diagnosis sensitively	1.10 (1.05-1.15)	<0.001	1.17 (0.76-1.79)	0.478	1.02 (0.90-1.14)	0.783
13	Diagnosis explained	0.99 (0.95-1.02)	0.416	1.13 (0.82-1.55)	0.473	1.04 (0.95-1.13)	0.424
14	Written info for diagnosis	1.29 (1.24-1.34)	<0.001	1.21 (0.83-1.76)	0.330	0.98 (0.88-1.09)	0.725
16	Views taken into account	1.06 (1.02-1.10)	0.001	1.08 (0.78-1.52)	0.634	1.01 (0.85-1.20)	0.891
17	Side effects explained	1.15 (1.11-1.20)	<0.001	1.48 (1.03-2.13)	0.036	1.07 (0.97-1.18)	0.186
18	Written info about side effects	1.26 (1.20-1.32)	<0.001	1.30 (0.80-2.10)	0.284	1.01 (0.88-1.15)	0.892
20	Shared decisionmaking	0.98 (0.93-1.03)	0.363	1.13 (0.71-1.80)	0.604	1.04 (0.92-1.18)	0.544
21	Given name of CNS	1.43 (1.34-1.51)	<0.001	1.53 (0.84-2.81)	0.168	1.02 (0.86-1.20)	0.817
22	CNS easily contacted	0.97 (0.92-1.02)	0.21	0.82 (0.49-1.38)	0.451	0.96 (0.83-1.10)	0.532
23	CNS listened carefully	0.96 (0.91-1.02)	0.179	1.61 (0.98-2.65)	0.060	1.15 (1.00-1.32)	0.043
24	CNS gave understandable answers	1.00 (0.94-1.06)	0.936	1.56 (0.91-2.69)	0.110	1.13 (0.97-1.31)	0.109
25	Given info about support groups	1.30 (1.21-1.39)	<0.001	1.15 (0.58-2.25)	0.689	0.97 (0.80-1.16)	0.724
26	Given info about impact on life	1.07 (1.02-1.13)	0.01	1.05 (0.66-1.70)	0.828	0.98 (0.61-1.59)	0.944
27	Given info on financial help	1.17 (1.09-1.25)	<0.001	0.77 (0.37-1.59)	0.485	0.89 (0.73-1.09)	0.264

Survey question		Other NHS hospitals in 2014 vs 2010 (have other hospitals improved over time)		UCLH in 2014 vs 2010 (has UCLH improved over time)		Differential change in trends over time (whether UCLH outpaces or lags behind national trends)	
		OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
28	Told about free prescriptions	1.61 (1.49-1.75)	<0.001	1.19 (0.53-2.70)	0.675	0.92 (0.74-1.15)	0.470
29	Seen info about cancer research	1.06 (1.02-1.11)	0.004	0.96 (0.61-1.52)	0.864	0.90 (0.57-1.43)	0.661
30	Asked to take part in research	0.84 (0.80-0.88)	<0.001	0.88 (0.53-1.47)	0.634	1.03 (0.79-1.33)	0.850
31	Took part in research	0.95 (0.90-1.01)	0.081	1.17 (0.73-1.86)	0.522	1.23 (0.77-1.97)	0.394
33	Explanation of operation	1.31 (1.24-1.39)	<0.001	1.21 (0.69-2.14)	0.504	0.98 (0.84-1.14)	0.792
34	Written info about operation	1.49 (1.42-1.57)	<0.001	1.52 (0.91-2.53)	0.106	1.01 (0.87-1.16)	0.944
35	Explanation of operation outcome	1.29 (1.23-1.35)	<0.001	1.05 (0.65-1.70)	0.828	0.95 (0.83-1.08)	0.412
37	Doctors gave understandable answers	1.10 (1.05-1.17)	<0.001	0.86 (0.51-1.45)	0.578	0.93 (0.81-1.08)	0.355
38	Confidence & trust – doctor	1.04 (0.99-1.10)	0.1	0.96 (0.59-1.58)	0.885	0.98 (0.85-1.12)	0.752
39	Doctors did not talk as if patient was not there	1.06 (1.01-1.12)	0.022	0.99 (0.60-1.65)	0.976	0.98 (0.85-1.13)	0.790
40	Family given chance to talk to doctor	1.03 (0.99-1.07)	0.167	0.85 (0.57-1.26)	0.406	0.95 (0.85-1.06)	0.333
41	Nurses gave understandable answers	1.19 (1.13-1.25)	<0.001	1.58 (0.95-2.64)	0.080	1.08 (0.94-1.24)	0.280
42	Confidence & trust – nurse	1.23 (1.17-1.28)	<0.001	1.34 (0.87-2.07)	0.179	1.03 (0.91-1.15)	0.674
43	Nurses did not talk as if patient was not there	1.16 (1.10-1.22)	<0.001	1.31 (0.83-2.07)	0.254	1.03 (0.91-1.17)	0.620
44	Enough nurses on duty	0.96 (0.91-1.01)	0.15	0.93 (0.54-1.60)	0.796	0.99 (0.85-1.15)	0.904
45	Thought information withheld	1.17 (1.11-1.24)	<0.001	1.29 (0.79-2.09)	0.307	1.03 (0.90-1.17)	0.708
46	Not given conflicting info	1.02 (0.97-1.06)	0.463	1.07 (0.74-1.56)	0.712	1.02 (0.92-1.12)	0.775
47	Asked what preferred name	1.17 (1.13-1.21)	<0.001	2.49 (1.73-3.57)	<0.001	1.46 (1.22-1.75)	<0.001
48	Given privacy when discussing	1.17 (1.11-1.22)	<0.001	1.19 (0.74-1.92)	0.469	1.01 (0.88-1.15)	0.924
49	Given privacy when being treated	1.31 (1.22-1.40)	<0.001	1.45 (0.77-2.72)	0.251	1.03 (0.86-1.22)	0.758
50	Able to discuss fears	1.03 (1.00-1.07)	0.066	1.17 (0.84-1.64)	0.353	1.06 (0.90-1.26)	0.469
51	Staff helped control pain	1.03 (0.98-1.09)	0.242	0.83 (0.48-1.44)	0.507	0.94 (0.81-1.09)	0.436

*Evaluation of the UCLH-Macmillan Partnership to deliver improvements in the care, treatment, support and information to patients with cancer throughout their individual journeys*

Survey question		Other NHS hospitals in 2014 vs 2010 (have other hospitals improved over time)		UCLH in 2014 vs 2010 (has UCLH improved over time)		Differential change in trends over time (whether UCLH outpaces or lags behind national trends)	
		OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
52	Treated with respect	1.17 (1.11-1.23)	<0.001	1.23 (0.79-1.92)	0.357	1.01 (0.90-1.15)	0.813
53	Written info post-discharge	1.24 (1.18-1.31)	<0.001	0.78 (0.46-1.33)	0.360	0.88 (0.76-1.02)	0.088
54	Given contact post-discharge	1.46 (1.35-1.57)	<0.001	0.99 (0.51-1.93)	0.981	0.90 (0.75-1.08)	0.260
55	Family given info post-discharge	1.10 (1.05-1.15)	<0.001	0.84 (0.55-1.28)	0.414	0.93 (0.83-1.04)	0.212
56	Given care post-discharge	0.96 (0.91-1.01)	0.138	0.75 (0.43-1.31)	0.316	0.94 (0.81-1.09)	0.395
57	Staff helped control side effects – radiotherapy	0.78 (0.73-0.84)	<0.001	1.48 (0.75-2.93)	0.258	1.19 (0.99-1.44)	0.067
58	Staff helped control side effects –chemotherapy	0.74 (0.70-0.79)	<0.001	0.96 (0.54-1.69)	0.879	1.07 (0.92-1.25)	0.387
59	Staff helped control pain – outpatient	0.93 (0.87-0.98)	0.012	0.86 (0.49-1.51)	0.601	0.98 (0.84-1.14)	0.798
60	Given emotional support	0.93 (0.89-0.98)	0.005	0.96 (0.61-1.51)	0.858	1.01 (0.89-1.14)	0.911
62	Doctor had documents	1.22 (1.13-1.33)	<0.001	1.70 (0.83-3.48)	0.147	1.09 (0.90-1.33)	0.371
63	Information given to GP	1.31 (1.20-1.42)	<0.001	0.53 (0.21-1.30)	0.164	0.78 (0.61-1.00)	0.049
67	Given right amount of information	1.00 (0.95-1.05)	0.963	0.84 (0.52-1.35)	0.470	0.95 (0.84-1.09)	0.475
68	Offered a written care plan	0.82 (0.78-0.85)	<0.001	0.71 (0.48-1.05)	0.089	0.93 (0.76-1.14)	0.491
69	Did not feel treated as a set of symptoms	1.06 (1.02-1.10)	0.004	1.55 (1.08-2.22)	0.016	1.11 (1.01-1.22)	0.038
70	Overall care satisfaction	1.10 (1.05-1.16)	<0.001	1.37 (0.84-2.23)	0.205	1.11 (0.87-1.42)	0.384

NOTE: Please note in particular column 4 (right-hand side), where evidence for differential improvement / deterioration is explored. Across the table, where estimates are significant they are 'coloured' in green (where improvement) or red (where deterioration).

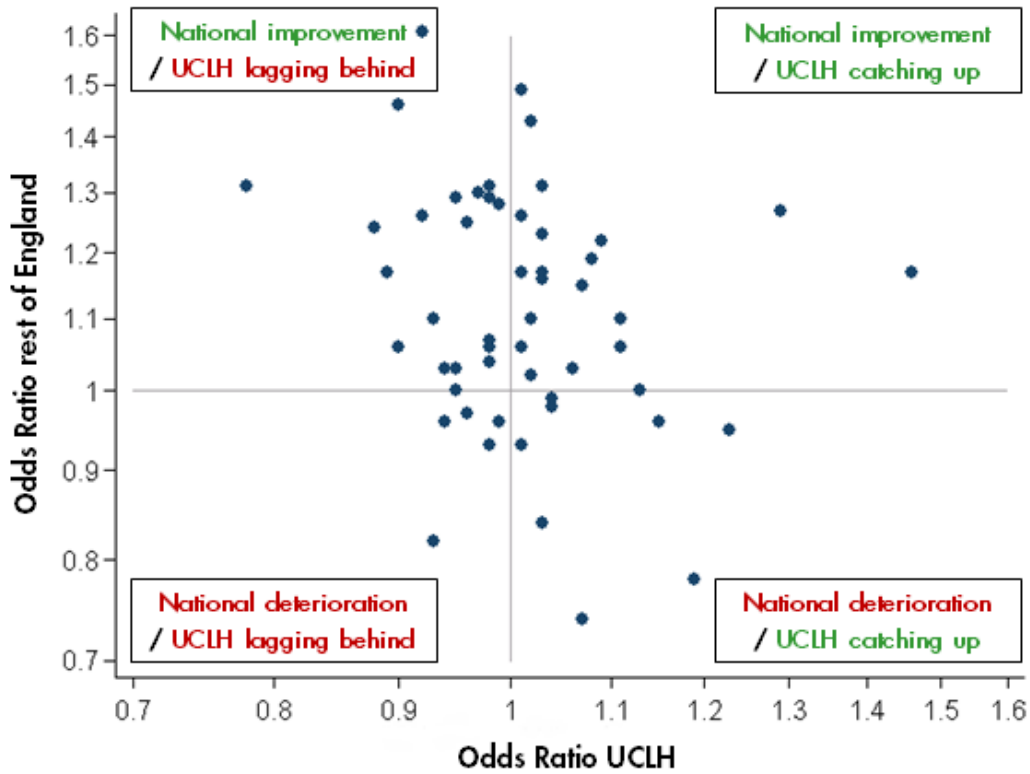
### 5.3.5. Visual summary of comparative time trends

Because of the risk of type II errors, whereby we fail to find differential change when it exists due to a lack of statistical power, we will consider all questions together in this section (independently of statistical significance). Figure 8 provides a visual depiction of our findings. Each dot in the graph represents one of the studied survey questions. We distinguish four quadrants, considering nationwide trends between 2010 and 2014 for each question together with UCLH's performance relative to these trends for these same questions. The vertical axis presents the odds of NHS hospitals other than UCLH ('Rest of England' [RoE]) improving over time (if Odds Ratio [OR] greater than 1) or deteriorating over time (if OR less than 1). The horizontal axis displays UCLH's improvement change above and beyond the national average for each of the 56 questions of the National Cancer Patient Experience Surveys (represented as dots) – with OR greater than 1 on the horizontal axis indicating that UCLH improved faster than average and OR less than 1 indicating that UCLH lagged behind. If we were to see, in general, more dots on one side of the line than the other, this might be suggestive of differential improvement/deterioration overall, even though for any one question we cannot say with certainty whether or not differential trends exist.

It can be seen that most questions (dots) are represented in the upper half of the figure – indicating nationwide improvement in experience. It can also be seen that there is a nearly even split between the number of questions on the left-hand side (UCLH lagging behind) and the right-hand side (UCLH catching up) of the graph. This provides no indication of overall differential trends for UCLH. These findings summarise the facts that: (i) there is overall nationwide improvement and (ii) UCLH is an overall 'follower' of national improvement trends, without evidence of either over- or under-performance in trends.



Figure 8 Quadrant diagram considering change over time in nationwide ('Rest of England') trends in cancer patient experience 2014 vs 2010 (OR>1 indicating improvement and OR<1 indicating deterioration over time), combined with trends over time in UCLH performance above and beyond national trends (OR>1 indicating differential improvement and OR<1 differential deterioration of UCLH trends vs national trends)



#### 5.4. Broader reflections on measuring and using patient experience

It is important to identify some broader lessons with regard to the measurement and use of patient experience data:

- Expectations of measurable improvement at the hospital level through the NCPES need to be realistic both in terms of effect size and expected follow-up period during which these improvements are likely to occur. It has been reported (although only anecdotally) that at the outset of the partnership it had been agreed that UCLH should ‘aim to move from the bottom 20% to the top 20% of English hospitals ranked for cancer patient experience’. In reality, as has been shown by nationally reported NCPES data, UCLH’s performance (rank) typically remains in the bottom fifth of the distribution of hospital scores for most questions. It may be better to recognise the timescales that are a feature of delivering such complex improvements. It is likely that large improvements measurable at the hospital level are much slower and require more time than the typically annual/bi-annual interval between NCPESs.
- There are many more ways to measure patient experience than the NCPES – which are infrequent events providing high-level intelligence at the organisational level. National survey measurement

should be complemented and amplified by the real-time patient experience measurement collection to pace and monitor improvement efforts during the intervals between the national surveys. Such real-time surveys can be supported and embedded within ‘measure-do-re-measure’ improvement cycles; the Meridian patient survey platform available to UCLH provides the infrastructure for such surveys, which will need to be designed, customised and ‘owned’ by improvement communities. We return to this theme in our discussion in chapter 7.

## 5.5. Conclusions

The findings from the NCPES scores show modest degrees of change (typically improvement) in cancer patient experience across English NHS hospitals, including UCLH. In terms of UCLH’s relative performance, the analysis found relatively few cases in which change over time (either improvement or deterioration) in cancer patient experience performance at UCLH significantly differed from other English NHS hospitals. These findings are both reassuring, i.e. UCLH is following national improvement trends, and a cause for potential concern, i.e. by and large, UCLH does not ‘outperform’ the pace of improvement in patient experience in the rest of NHS hospitals. Given that the NCPES includes data from patients receiving cancer care from across UCLH, it is not possible to equate this apparent lack of impact to a failure of the programme and, as stated above, it is potentially too early to expect that the programme would have had a measurable impact at the hospital level.

## 6. Learning event and next steps

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### 6.1. The UCLH–Macmillan learning event

On 11 March 2015, the partners held a learning event, attended by some 30 members of staff of all levels from Macmillan and UCLH. The evaluation team were invited to present the emerging evaluation findings. This provided an opportunity to further explore staff's understanding and opinions of the partnership and to share and reflect on our emerging findings. The discussions at this event informed the final conclusions and recommendations. During the session, participants were specifically asked to reflect on the following questions:

- What findings resonated for you?
- What did you like?
- What was different from your personal experience?
- What are some lessons for the next phase?

We followed this with small-group discussions (five participants per table) which were facilitated by members of the evaluation team. Key reflections included the following:

A successful partnership requires good morale.

All tables recognised anxieties about staff feeling overworked and not being recognised. One table asked, if *'happy staff lead to happy patients'*, why does the partnership not focus on staff satisfaction? Others suggested low staff morale may be more linked to wider issues in the NHS. Improved career progression was one of a number of specific issues identified as being important for staff. It was not argued that the purpose of the partnership should be to improve morale but, rather, that without good morale the partnership would be less successful.

There has been a strong and growing patient focus.

The perceived increase in patient focus also resonated. Both staff and volunteers were seen to have contributed to this improvement. Volunteers were seen to *'have been set up well by Macmillan'*, and Macmillan's name was seen to have helped with promoting the volunteer services. MSIS was also perceived to be strongly supportive:

*MSIS/Volunteering service was so new to us, so it shone a torch for the rest of the services.*

The CNS forum was widely seen to have benefits by creating a forum for supporting improving practice. It was assumed that patient experience had indeed improved, and for some participants this spread

beyond cancer patients to the whole trust. One group observed that healthcare did not always have the patient at the centre but that the partnership had encouraged a shift and that priorities had changed to focus more on the patient.

Moving forward to the next phase will require an evolving emphasis.

There was agreement with the evaluation's observations that change was needed if the partnership was to evolve as planned into the next phase. The recent more operational focus from senior management was welcomed but it was felt management should drive the aims of the partnership forward more firmly. It was said that staff would *'quite like them to put more pressure in some areas to set objectives and make sure that they are met'*. It was also felt that success could be more celebrated and that Macmillan was well placed to highlight good practice in this respect. In general the view was that the partnership needs to work on delivering more specific benefits within the broad vision already articulated:

*What resonated for me was that there was disconnect between [the original] vision and idea for it, and what then got communicated and described to everyone else.... Take home message for me is to look at practical deliverables as much as vision.*

Learning should be at the heart of the partnership.

A strong theme from each table was the importance of supporting learning and exploiting the opportunity for learning that has been created by the partnership. For example, there was a discussion about how useful real-time feedback was as part of strengthening the cycle of doing, learning and improving. There was also a view that there was a need to collect less, but smarter, data. This included better and quicker data on patient experience and outcomes made available to those best placed to act on the information. There was a belief that the partnership should better promote what it does and set up a learning program, which would be good for staff morale and benefit patients. The existing situation did not meet universal approval, and the need for a greater emphasis on learning was also expressed as a negative comment on the existing situation:

*We are not drawing enough from the experience of Macmillan, and Macmillan are not drawing enough from the partnership.*

However, Macmillan was seen to be a great potential source of national ideas, supporting innovation within the trust and a test bed for innovation, Textbox 11.

#### **Textbox 11 Specific comments related to innovation**

*'How much national knowledge from Macmillan's 10 initiatives (of which UCLH is one) is being fed back into the partnership?'*

*'Can we encourage more experimentation and learning?'*

*'Bring more learning into UCLH!'*

*'Become better at identifying problems; access best evidence on how to deal with these both from the partnership and other sources/experiences!'*

*'The partnership could also support learning across London more widely'*

The building remains important.

We did not specifically ask, or report on, the building, but it emerged spontaneously in many groups. The partnership was seen by some to have come into being due to the building. One participant said, *'the partnership gelled automatically when we built the Macmillan cancer centre'*. Someone else said, *'[You] feel a sense of pride when you go into the building'*. However, others reflected evidence reported in previous chapters, expressing concern about the availability of space with patients, confidentiality and places for staff to share knowledge. One person said, *'the real value is in the interactions between people'*.

Fairness across the whole trust is important.

There was also a concern that the success of the partnership should not lead to inequity of services across the trust. For example, there was a plea to make all wards within UCLH aware of the services at the cancer centre so that all patients with cancer across the trust could benefit from them. At times the cancer centre *'can feel very separate from the rest of the trust'*. It was felt that cancer patients within the wider trust do not necessarily get the best care, as staff on the wards do not know of the services in the cancer centre, which are there for all UCLH patients with cancer.

There is interest in, and commitment to, taking the partnership forward.

Throughout the discussions there was a clear commitment from across participants to take the partnership forward and make it work. There was less clarity about what steps could and should be taken to achieve this.

## 6.2. Conclusions

Key observations from the learning event are as follows: First, the conclusions from our data collection broadly resonated with staff who attended the event. This gave the evaluation team greater confidence in arriving at the conclusions listed in the final chapter of this report. While the feedback from the learning event provided important nuance, it did not substantially alter the conclusions in most respects. Second, the importance of learning and experimentation came across more strongly in the learning event than in our data collection. And, third, staff across the organisations did not see the partnership as working separately from other, wider operational issues (staff morale, building, fairness across the whole trust) or as having a set of solutions that were in some sense different from delivering quality improvement as it is more generally understood in healthcare.

The learning event took place in the presence of a number of influential and senior managers whose commitment to the partnership was recognised. Furthermore, the event was also framed as a 'celebration' of the partnership. It is therefore important to interpret what was said in this context in mind. However, views (including criticisms) appeared to be expressed honestly. We therefore gained added confidence in our findings given the broad agreement from a highly informed group. The emphasis on learning, which added an interesting dimension, was multi-faceted. It included: (i) recognising that Macmillan could support learning within the trust because of their wider experiences; (ii) arguing that the programme experience could support learning elsewhere in London but also support Macmillan's learning elsewhere

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in the country; and (iii) recognising the importance of learning at the heart of a dynamic and developing partnership.

## 7. Discussion, conclusions and recommendations

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### 7.1. Discussion and data limitations

Achieving high-quality and safe healthcare, and simultaneously delivering patient satisfaction, have been key goals of government policy across the world, especially in recent decades. Results might be summed up as ‘unmistakable progress, troubling gaps’ [2 3]. In the UK (for example, Ling et al., 2010 [4]), efforts to improve quality and patient experience have had ‘patchy’ outcomes. Achieving sustained improvement is not easy, and there is no available blueprint that guarantees success. In this context, the evaluation aimed to provide a rich understanding of how staff and volunteers understood the UCLH–Macmillan partnership, how the partnership had changed attitudes and ways of working and how the approach of leadership within the partnership was developing. We also looked at patient experience through the secondary analysis of a national survey.

The evidence produced for this report provides the insights of those involved in leading, managing and delivering patient care. However, before applying these insights, it is important to understand limitations in the data. Four in particular should be taken into account:

- The perceptions measured may be driven by secular trends, by wider anxieties about working in the NHS or by hospital-specific concerns which are not related to the partnership. Anxieties expressed may also be associated with change in general rather than partnership working in particular.
- The timescales involved would not necessarily allow changes in practice and behaviour to have measurable benefits for patients and carers.
- The data is focused on the stakeholders’ perspective on the partnership. While this delivers insights that should be helpful for decision makers within the partnership, they should be triangulated with other data that has not been part of this study, for example, tracking how well partnership meetings function and are followed up. More widely, decisions about the future of the partnership need to be taken in the light of whether or not partnership working is having the desired results for patients.
- The data sources are largely internal to the partnership. A measure of fitness for the partnership is how well it functions within wider changes in the health and care system; to address this, it would be helpful to understand more about how well the partnership supports actions in primary care, social care and other parts of acute care.

## 7.2. Looking backward, forward and outward to the wider healthcare system

In this conclusion it may be helpful to step back from data collected specifically for this evaluation, which has primarily focused on the partnership itself, and discuss the partnership in the wider context of changes in the NHS. The question here, therefore, is not what the partnership has done, but, rather, how well the partnership might be enabling and catalysing a more effective response to emerging challenges and, similarly, how the partnership might be shaped going forward to strengthen and improve this response. Although not part of the formal evaluation, this brief section highlights the relationship between the work of the partnership as outlined in this report and wider challenges in the NHS.

The challenges which face the NHS organisation are outlined in, among other places, the NHS Five Year Forward View [5]. For services aiming to meet the needs of cancer patients and their carers, significant challenges include: how best to give patients greater control over their own care, how to break down the barriers in how care is delivered to provide an integrated service, and how to innovate and learn to keep adapting to new information from patients and carers. In addition, the NHS is expected to deliver annual efficiency savings of 2% across its whole funding base, and any significant reform would need to be oriented toward financial, as well as health, goals. The partnership has already created opportunities to respond positively to these challenges in a variety of ways identified under the subheadings below. Completely meeting these challenges is beyond the specific contribution of the partnership on its own; a relevant question is whether or not the partnership has strengthened the capacity of the partners to meet these challenges.

### *7.2.1. Giving patients greater control over their own care*

First, the capacity to provide more person-centred care has been strengthened by involving volunteers, supporting one-to-one working and building staff capabilities through mutual learning. This potentially supports a model of giving patients greater control over their healthcare, while delivering care that is more personalised, better coordinated and respectful. From the responses of frontline staff in particular, it is clear that this is still a work in progress. But it should not be expected that this sort of transformation would be fully delivered at this stage in the partnership.

### *7.2.2. Delivering a more integrated service*

Second, the partnership has helped provide a basis for better integrated care. At the core of the partnership is the aim of improving the experiences of carers and patients by improving the whole journey, from diagnosis to palliation. This includes the support and information services, along with a restructured volunteer service, providing information and guidance intended to give patients greater control. In addition, the partnership has helped lay the foundation to break down barriers between hospitals and other care providers. This is apparent in the Vanguard bid and should also help meet the needs of those patients with multiple health conditions and care needs. The partnership could further enable better integration of primary and acute care systems.



### **7.2.3. Innovating and adapting in the light of new information from patients and carers**

Third, the Five Year Forward View anticipates an NHS that can innovate and respond to information from patients and carers about what they want and what is working. MSIS is seen to be a success, and further efforts to provide quick feedback linked to the success (or otherwise) of changes would be needed to ensure the availability of information to support a flexible and responsive service. But the partnership could also catalyse London-wide and national networks of learning to identify new and more effective ways of working. This will include creating opportunities for building relationships and strengthening trust across different providers. It will also include developing further efforts to define cancer outcomes more holistically and to collect the data needed to ensure that holistic outcomes are identified in a timely fashion. As well as ensuring that learning from elsewhere is used, the experiences of the UCLH–Macmillan partnership should also influence practice elsewhere and inform wider networks.

Meeting these three most relevant challenges from the Five Year Forward Review would require a consolidation and transformation of existing services. Because this would place new demands on partnership working, it is likely that the partnership itself will need to be refreshed in the context of current challenges if it is to support new ways of working needed to meet both the changing demands of patients and their carers and the changing needs of the health and social care system as articulated in the Five Year Forward Review.

## **7.3. Conclusions**

### **7.3.1. Within positive ‘average’ perceptions, there were important variations**

Staff and volunteers showed a broadly positive attitude towards the partnership in general and towards those aspects with which they were most familiar in particular (MSIS and CNS forum were most frequently mentioned). Where respondents expressed an opinion, they stated that the partnership had contributed to delivering enhanced skills and a more patient-focused approach. They valued concrete improvements to ways of working over ‘high-level’ claims about partnership working and wanted to see more specific and visible changes. In the survey response, staff also expressed concerns about some negative consequences for staff experience, and the view was repeated in the Learning Event that unhappy staff would pose a barrier to future progress of the partnership. It is unclear whether or not these concerns related to morale are a result of the partnership, but they are almost certainly relevant to its future success. Staff working closest to patients (‘nursing and healthcare assistant’) were least likely to report increasing job satisfaction in the preceding two years and most likely to think they had insufficient support from management. Furthermore, only just over 40% of respondents considered that senior leadership allocated adequate resources to improving care, while only just over 18% of staff agreed/strongly agreed that staff involved in the provision of cancer services were rewarded or recognised for improving cancer services. In short, ‘average’ positive perceptions masked some important variations, with 100% of ‘general management’ stating they strongly agreed that patient care was UCLH’s top priority, compared with just under 17% among ‘nurse or healthcare assistant’ respondents. Furthermore, a small number of respondents, using the ‘free text’ options in the survey, expressed the view that patient experience was

being privileged at the expense of patient safety. The respondents clearly felt sufficiently strongly to raise this without prompting. Since this question was not asked directly, it would not be appropriate to quantify this response. In the survey, the majority of staff considered that the quality of care had improved over the past two years; however, there was a considerable minority, especially among the 'nursing or healthcare assistant' group, who reported that the quality of care has actually decreased in the past two years (58% of 'nursing or healthcare assistant' and 31% of 'nurse'). Respondents identified a number of barriers that continued to prevent them from delivering the highest quality of care, these being primarily related to a perceived lack of time to manage their workload. However, no specific supporting evidence was presented for this concern that patient numbers are increasing without corresponding increases in staff numbers, and these comments are in tension with other reported views that the partnership supported more patient-centred care.

Overall, understanding what lies behind these variations should be a priority. Alongside concerns, however, there was a widespread belief that patient experience was improving. (Unfortunately, this was not supported by the National Survey of Cancer Patient Experience in England, but it is entirely possible that staff identify changes in their patients' experiences more precisely than is revealed through annual, national hospital-wide surveys.) In interpreting these findings, it should be noted that not all stakeholders share the same views and not all opinions align with each other. It is also important to recognise that more general trends are likely to be relevant, in particular concerning recognition, salaries and working conditions in the NHS. This reinforces our warning above that perceptions should be interpreted in context, and with caution.

### *7.3.2. There was a positive ambition, vision and expectation among leaders but some anxieties at the front line*

In partner interviews there was a high level of optimism that taking the partnership forward would improve patient experience and, in particular, strengthen collaborative working along the whole patient pathway. The sense of ambition and optimism is itself an important demonstration that aspects of partnership working have settled in well, raising expectations that now that the partnership is maturing, it is capable of delivering greater and better results. However, while the high-level vision that the partnership was a 'good thing' was seen to have been communicated, the communication of specific implications for what this meant for staff working close to the patients was seen to have been patchy. That said, both MSIS and the CNS forum were reported to be helpful, and staff also reported that the partnership had helped with identifying better ways of working and improved mixing of skills. Therefore concerns about more specific implications for ways of working suggest that there may be something more complicated going on (a less tangible unease about change, perhaps, but also concerns about career progression and jobs that were not specifically related to the partnership) that requires further investigation.

### *7.3.3. There was support for strengthening learning opportunities*

The theme of the partnership actively supporting learning was strongly represented at the learning event held in March 2015, which was attended by some 30 members of staff of all levels from Macmillan and UCLH. The interest in learning included: learning to adapt in a changing world, learning from others, and sharing what has been learned with others interested in achieving more patient-centred and high-

quality care in London and beyond. The opportunity for small-scale experimentation and evidence-driven learning was stressed as a practical route forward for the partnership. The participants related this to the sense that, as the partnership embarked on its next phase, it would require new approaches.

#### *7.3.4. Positive changes already achieved will need to be nurtured*

While the new building may have reinforced patients' positive reactions to the services, it was the better ways of working and of mixing of skills more directly that made an impression on staff as being a benefit of the partnership (despite the anxieties noted above). There was a view that such better ways of working would lead to improved experiences for patients (although the evidence for this view is largely anecdotal). The success of MSIS and the CNS forum suggest the early partnership is in the early stages of an underlying culture change towards more holistic patient care. What these emerging changes to culture might include is described by one stakeholder:

*I think the first thing for me would be that UCLH gets to grips and properly embeds the patient voice. Properly. And what I mean by that, I don't mean listening to complaints or having a group you don't really listen to. Having a strategic approach to really being able to hear patient and public, both in terms of when they want to change things, hearing when it's going really well so that staff can hear that properly, as well as learning from when things don't. And so it's a combination of engagement, involvement, patient leadership.*

Such change will need to be nurtured, especially in the light of the perception that increased volumes of patients may undercut the benefits of the partnership for the quality of care.

## 7.4. Recommendations

*Recommendation 1: Create a learning environment to help bridge the perceived gap between high-level vision and specific working practices, to inform the future direction of the partnership and to spread the lessons learned more widely*

The sense of anxiety about a perceived gap between a high-level strategy and specific changes to ways of working is unlikely to be improved by relying on wholly top-down approaches. Furthermore, in a complex environment where simple models of improvement are not available, there is a need for experimentation and learning to support adaptation and improvement. Therefore, there are benefits in exploiting opportunities for experimentation with rapid learning cycles, based on timely and relevant data on, for example, patient experience, delays and patient activation. Evidence-driven experiential learning would not only help frontline staff relate the aims of the partnership more clearly to their work, but also provide a stream of ideas and evidence to help decision makers adapt and improve [6]. Support from Macmillan in this, in particular in drawing on lessons from elsewhere through its other programmes delivering change along the patient pathway, would be both helpful and welcomed. Staff, especially at the front line, report that 'good' challenges in their work may actually improve job satisfaction, and staff report an appetite for learning. Engaging in learning and improving activities should not only support the delivery of the partnership but also improve job satisfaction and possibly help address the need for support for career progression.

*Recommendation 2: Ensure that readily available, relevant and timely data on patient experience are routinely used*

Improving the availability of current data would allow for a more informed discussion, especially of patient experience. In interviews, staff and volunteers stressed the value they placed on Macmillan Support and Information Services (MSIS). Staff also use patient feedback data from Meridian. Even so, perceptions of patient experience vary and are on average more positive than national comparisons found in the NCPES. Therefore there is an apparent need for better ways to measure, for example, patient activation, to ensure that decision making is informed by relevant and timely data on patient experience. It is less clear from this evaluation whether the underlying problem is that data are not available or that data are not used in making decisions.

*Recommendation 3: Optimise the wider networks of the partners*

The partnership is nested within a number of other sets of relationships that might be more effectively leveraged. In particular, Macmillan can draw upon a wealth of national experiences and evaluations to contribute to learning and thinking within UCLH, across London and, indeed, nationally. At the learning event it was apparent that this was not seen to be happening. Equally, care for patients diagnosed with cancer is only part of the work of the trust, and lessons learned, we were told, were not communicated more widely in the trust or across London.

*Recommendation 4: Communicate specific goals to reinforce the high-level vision*

The theme of developing and communicating a shared vision was frequently a concern of more senior management. The evidence presented here suggests a messier problem, where three related communications issues interact. The first is to communicate the high-level vision. From the evidence, we can see this has broadly been successful. The second is to show what this vision means for specific tasks, and this appears to have been less successful. The third is that many staff appear to hold on to the second view while simultaneously thinking that the partnership has provided practical support, especially through MSIS and the CNS forum. The recommendation for communications is therefore to structure messages to more effectively reconnect these three issues. The evidence collected here therefore suggests that different, rather than more, communication focused on tangible benefits for patients and staff would be helpful. Connecting the issue of communication to the themes of improved learning and engaging with wider networks (Recommendations 1 and 3) should be considered.

*Recommendation 5: Support culture change and engage with frontline staff*

Culture change is important, and leadership has a crucial role in delivering cultural change. Building a relationship of trust and mutual understanding between staff and leaders is a necessary platform for delivering culture change. Our findings suggest that sections of staff feel that they are unsupported, that their work is underappreciated, and that they have limited career opportunities. Building a visibly supportive organization would support achieving the wider ambitions of the partnership.

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