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Preface

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 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 presents the summary of the second output of the evaluation, covering the period April 2014 to January 2015. The evaluation focuses 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 a previous evaluation, completed by the same team in July 2013, but is a stand-alone piece of research. It formulates research recommendations intended to contribute to learning within the partnership to support future decision making. The report also contributes to a wider understanding of partnership working. The full report is presented in the accompanying document *Evaluation of the UCLH-Macmillan Partnership to deliver improvements in the care, treatment, support and information to patients with cancer throughout their individual journeys* (RR-1446-UCLH/Mac).

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Summary

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).